

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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PolicyLab Leads

Team

Sophia Jan MD, MSHP

Faculty Scholar

Sophia Jan is a faculty scholar at PolicyLab, the division chief of general pediatrics at Cohen Children's Medical Center, medical director of Northwell Health's Health Homes Serving Children and a health services researcher. Dr. Jan is an instrumental part of ensuring that the hospital delivers state-of-the-art pediatric care, provides a family-centric atmosphere and continues to maintain the medical center's status as one of the nation's top children's hospitals.

Prior to joining Northwell Health, Dr. Jan spent eight years at Children's Hospital of Philadelphia (CHOP), where she founded and became medical director of a multidisciplinary intervention team helping pediatric patients navigate and transition to adult care. She was also a faculty member at PolicyLab and associate program director of the combined internal medicine and pediatrics residency program at CHOP and the University of Pennsylvania (UPenn), and a general internist at UPenn. Dr. Jan earned her bachelor's degree from the City University of New York at Brooklyn College and her medical degree from the State University of New York Downstate Medical Center. She continued her fellowship training as a Robert Wood Johnson Foundation Clinical Scholar at the Perelman School of Medicine at UPenn, earning a Master's in Health Policy Research.



Sophia Jan
MD, MSHP
Email: sjan1@northwell.edu

Tanisha Belton DrPH, MPH

Senior Manager of Research Initiatives

Tanisha Belton (she/her) is the senior manager of research initiatives at PolicyLab at Children's Hospital of Philadelphia. She also serves as the program director for PolicyLab's Community Partnerships in Research Program as well as the staff lead for PolicyLab's Health Equity Portfolio.

Dr. Belton supports the development and execution of programs within the PolicyLab research infrastructure in alignment with the center's strategic plan, including pilot grant programs, institution and community partnerships, and methods-focused resource and training initiatives for faculty and staff. Dr. Belton has over a decade of experience managing quantitative research projects, including currently serving as co-PI for a multi-site PCORI-funded project focused on transitioning young adults with sickle cell disease (SCD) to the adult health care system. Her previous work at PolicyLab focused on identifying causes of disparities with the goal of reducing racial and ethnic disparities in underserved children.

Dr. Belton previously worked in cancer research where she managed a multi-site study testing the effectiveness of a mobile health application for prostate cancer survivors and a smoking cessation study for moms receiving WIC benefits. She also has a background in maternal and child health, which includes public health program implementation and education. She completed her Doctor of Public Health and her Master of Public Health at Walden University. Her research interests include program evaluation, health disparities, adolescent health, and maternal and child health.



Tanisha Belton

DrPH, MPH

Email: BeltonT@chop.edu

Caren Steinway, MSW, MPH

Related Tools & Publications

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[Transitioning Adolescents and Young Adults With Sickle Cell Disease From Pediatric to Adult Health Care: Provider Perspectives](#)

[Article](#)

Nov 2015

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[Transitioning to Adult Care: Supporting Youth With Special Health Care Needs Evidence to Action Briefs](#)

May 2017

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[Transitioning to Adulthood: Unique Health Care Challenges for Youth with Intellectual/Developmental Disabilities](#)

[Policy Briefs](#)

May 2017

- [Transitioning From “Sick Kid” to Community Health Worker: Building Better Bridges to Adult Care Article](#)
Jun 2018

- [A Multidisciplinary Transition Consult Service: Patient Referral Characteristics Article](#)
May 2019

- [Increasing Pediatric to Adult Health Care Transition Services through Clinical Decision Supports Article](#)
Aug 2021