

February 15, 2019

NICHD Strategic Planning Group
Eunice Kennedy Shriver National Institute of Child Health and Human Development
National Institutes of Health

Re: Request for Information on NICHD Strategic Plan for Fiscal Years 2020-2024

Dear Strategic Planning Group:

Thank you for the opportunity to comment on National Institute of Child Health and Human Development's (NICHD's) Strategic Plan for Fiscal Years 2020-2024. We commend NICHD for including a research theme aimed at improving health during the transition from adolescence to adulthood. This represents an enormous opportunity for researchers to expand the knowledge base.

As the Maternal and Child Health Bureau's (MCHB) national resource center on health care transition, called Got Transition, The National Alliance to Advance Adolescent Health works closely with many of the organizations that have signed on to this letter, all of whom are involved in ensuring that adolescents and young adults with and without special health care needs receive the recommended transition supports called for by the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP).¹

We recommend that NICHD consider the following additions to Research Theme #5:

1. The transition goal should be expanded to read: Improve the transition from adolescence to adulthood by identifying behavioral, social, **family**, environmental, and biological factors that enhance health, **including but not limited to** adolescents with disabilities or other chronic conditions.
2. The list of research opportunities should be expanded to include the following:
 - a. Develop predictive methods or strategies to identify adolescents and young adults at risk for dropping out of care and advance novel, exploratory projects to retain and re-engage this population in their care.
 - b. Develop outcome measures for transition to adulthood/adult care that pertain to population health, patient/family/caregiver experience with care, provider experience, and utilization and costs.
 - c. Conduct longitudinal research that examines the impact of the transition from pediatric to adult care, aligned with professional recommendations, for adolescents and young adults with chronic or disabling conditions. Outcomes should consider not only improved clinical processes for a planned transition but also changes in clinical outcomes, self-care skills/health literacy, adherence to care, self-reported outcome measures, experience of care, and appropriate health care utilization.
 - d. Develop methods for health care providers to increase health literacy among adolescents and young adults with and without special health care needs during the transition years.
 - e. Develop effective strategies for use by family caregivers to promote child and adolescent independence and resilience as they mature into adulthood and transfer to adult care, including but not limited to young adults with developmental disabilities.
 - f. Create transitional care pathways for adolescents and young adults with chronic or disabling conditions requiring multiple and sequenced transitions involving primary care, specialty care, and/or behavioral care.

Thank you for considering our comments. Should you like to discuss our recommendations further, please don't hesitate to email Peggy McManus at mmcmanus@thenationalalliance.org.

The National Alliance to Advance Adolescent Health
Adolescent & Young Adult Health National Resource Center, University of California, San Francisco
Adolescent and Young Adult Health Research Network
Children's Mercy Hospital Kansas City
Comprehensive Transition Program, Ann & Robert H. Lurie Children's Hospital of Chicago
CYSHCNet National Research Network
Department of Pediatrics, Henry Ford Health System
Department of Pediatrics, University of Utah School of Medicine
Departments of Pediatrics and Internal Medicine, University of California, San Francisco
Division of Adolescent/Young Adult Medicine, Boston Children's Hospital
Division of Adolescent and Young Adult Medicine, UCSF Benioff Children's Hospital
Healthcare Transition Research Consortium
Kaiser Permanente Colorado
Leadership Education in Adolescent Health Programs at:
 Boston Children's Hospital
 Children's Hospital Los Angeles
 Children's Hospital of Philadelphia
 University of Alabama at Birmingham
 University of California, San Francisco
 University of Minnesota
 University of Washington
Lucile Packard Foundation for Children's Health
Pediatric Primary Care, WakeMed Health & Hospitals
Ravenswood Family Health Center (California)
Susan B. Meister Child Health Evaluation and Research Center, Michigan Medicine

¹ White PH, Cooley WC, Transitions Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5): e20182587.