New Project to Strengthen the Capacity of Primary Care Providers to Care for Young Adults with Intellectual and Developmental Disabilities During Pandemic and Emergency Situations

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The National Alliance to Advance Adolescent Health has received funding from the <u>WITH Foundation</u> to assist primary care providers (PCPs) to care for young adults with intellectual and developmental disabilities (IDD) during pandemic and emergency situations. With this one-year grant, The National Alliance will form a multi-stakeholder advisory panel to develop practical educational materials for PCPs to strengthen their capacity to support this underserved population during pandemics and emergency situations.

The current COVID-19 pandemic and past emergency situations have illuminated the many health disparities faced by individuals with IDD. These include reduced access to in-person care, problems obtaining prescriptions, and challenges using telehealth and personal protective equipment. Many individuals with IDD have experienced reductions or loss of their direct support professionals and services for residential, employment, transportation, recreational, and other supports. At the same time, many clinicians have reported they felt less prepared on how best to assist young adults with IDD and their caregivers to prepare for and cope with emergency situations and, most recently, with the COVID-19 pandemic.

PCPs play a key role in helping young adults with IDD and their caregivers maintain their safety, health, and well-being during such emergencies. With an advisory panel of self-advocates, caregivers, and PCPs, The National Alliance will develop and widely disseminate a practical tip sheet with corresponding resources for PCPs to help this population.

"My daughter, Sarah, and I know firsthand how much the pandemic has affected access to health care and health-related services," said W. Carl Cooley, MD, of Concord, NH. "Sarah is an independent adult with an intellectual disability with complex health care needs. She has needed to leave her job, leave her apartment, and shelter with us for the past ten months. Health care services have been mostly virtual, which has been a learning experience for her providers and well as for us. As a retired developmental pediatrician, I look forward to teaming up with my daughter as advisors to this important effort by the National Alliance and the WITH Foundation."

For more information about this project, please visit The National Alliance at <a href="mailto:TheNationalAlliance.org">TheNationalAlliance.org</a> or contact Annie Schmidt at <a href="mailto:aschmidt@thenationalalliance.org">aschmidt@thenationalalliance.org</a>.

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## About The National Alliance to Advance Adolescent Health

The National Alliance to Advance Adolescent Health is a nonprofit organization whose mission is to achieve long-term, systemic improvements in comprehensive health care and insurance coverage for adolescents. Through policy analysis, technical assistance, quality improvement, and advocacy, The National Alliance works to promote effective transitions from pediatric to adult health care as part of its Got Transition™ program. In collaboration with others, The National Alliance also works to expand the availability of adolescent-centered care, access to mental health services, and improvements in health insurance coverage for adolescents and young adults. For more information, visit TheNationalAlliance.org.

## **About the WITH Foundation**

Established in 2002, WITH Foundation is a private foundation. The Foundation's initial grantmaking benefited the disability community. In 2011, the Foundation began to focus its support on organizations and projects that promote the establishment of comprehensive and accessible healthcare for adults with intellectual and developmental disabilities. The mission of WITH Foundation is to promote the establishment of comprehensive healthcare for adults with developmental disabilities that is designed to address their unique and fundamental needs. For more information, visit withfoundation.org.



