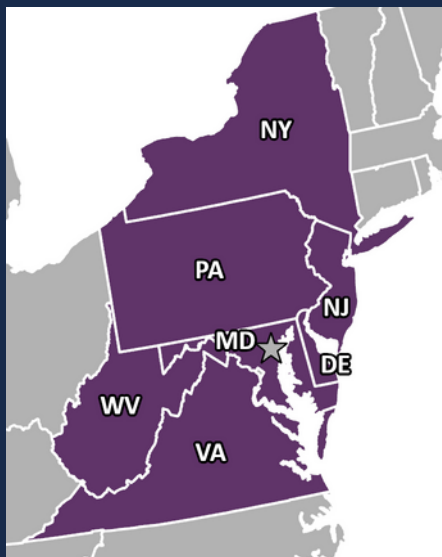


AHRQ Long COVID Care Network

Mid-Atlantic Pediatric Long COVID Network: Implementing Patient-Centered and Multidisciplinary Practices to Improve Pediatric Long COVID



Institution

Hugo W. Moser Research Institute at Kennedy Krieger

Geographic Service Area

Maryland and Greater Mid-Atlantic Region

Priority Population

Children with physical, intellectual, or developmental disabilities, children in resource-limited settings (such as rural areas), and children who are uninsured or underinsured.

Project Period

2023–2028

Contact

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Principal Investigator
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Project Overview

The Kennedy Krieger Institute's Pediatric Post-COVID-19 Rehabilitation Clinic was established in 2020 in Baltimore, Maryland, for children and adolescents who experience persistent, worsening, or new symptoms as a result of COVID-19 illness. The clinic uses a multidisciplinary, person-centered approach that focuses on both the patient's physical and emotional wellbeing. The team comprises 13 clinicians and staff, including a pediatric neurologist, physical therapist, behavioral psychologist, neuropsychologists, and education specialists, among others.

As part of the AHRQ Long COVID Care Network, the clinic seeks to strengthen its services by better understanding cultural and lifestyle factors impacting the recovery process for children experiencing Long COVID, including the role of schools. As an integrative healthcare model, the clinic incorporates conventional care, drugless approaches, complementary alternative medicine, and behavioral-lifestyle medicine in an effective model of whole-person care that also takes in account the cultural context of health. In order to broaden access to care for children across Maryland and the Mid-Atlantic region, the clinic plans to educate community providers about Long COVID assessment, care, and management through virtual programming.

Notable Features

- The Kennedy Krieger Institute has well-established expertise in treating children with physical, intellectual, or developmental disabilities (IDD), a vulnerable population that is particularly prone to poorer health and increased mortality from COVID-19.
- The clinic is expanding its Specialized Transition Program, a multidisciplinary outpatient rehabilitation program for children with Long COVID.
- The Kennedy Krieger Institute's Pediatric Long COVID Teen Online Problem Solving (TOPS) program is a novel pilot program to provide cognitive rehabilitation and mental health strategies to improve functioning and symptom management.

Project Goal: A Patient-Centered Multidisciplinary Approach to Improve Capacity and Care Delivery for Children With Long COVID

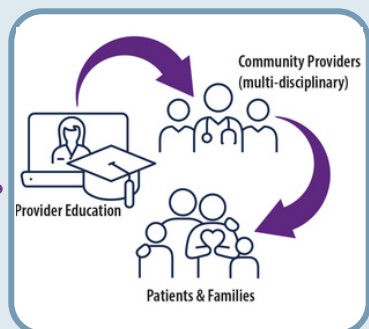
Specific Aims

The Kennedy Krieger Institute's approach to patient-centered, comprehensive care includes (1) incorporating conventional care, complementary alternative medicine, and behavioral-lifestyle medicine into an integrative healthcare model; and (2) novel telementoring efforts to improve multidisciplinary provider education and patients' access to locally available care.

Tele mentoring to Increase Access and Support Community Providers

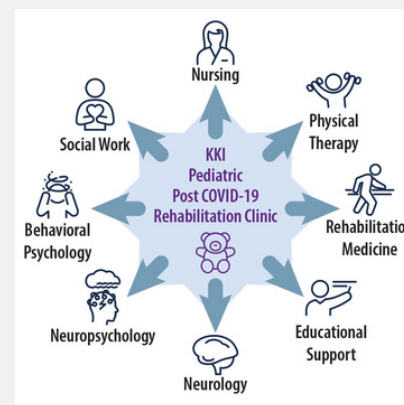
The Kennedy Krieger Institute has developed a 10-week novel Pediatric Long COVID Telementoring

Extension for Community Healthcare Outcomes (ECHO) program designed to improve medical education and knowledge dissemination to healthcare providers. The team will conduct this ECHO program twice a year. To assess improved competence among pediatric Long COVID providers, the research team at Kennedy Krieger will collect and assess ECHO participants' satisfaction, knowledge, and confidence data. The goal of this ECHO program is to build a network of providers in the Mid-Atlantic region who are prepared to provide Long COVID care to families with children from vulnerable and underrepresented populations, including children with intellectual and developmental disabilities. This will allow children to receive care locally and with less delay, which should improve health outcomes.



Extending and Strengthening the Integrative Healthcare Model Into School Settings

Kennedy Krieger's Pediatric Post-COVID-19 Rehabilitation Clinic aims to expand and strengthen the Clinic's services by integrating school-related factors into its integrative healthcare model. Currently, the Clinic has the Specialized Transition Program (STP) to prepare children for school and daily activities with a



personalized rehabilitation protocol aimed at improving daily functioning and reducing symptoms. In addition, the Clinic offers a novel virtual rehabilitation program designed to complement STP, which focuses on cognitive rehabilitation and symptom management. Recognizing the numerous challenges children with Long COVID face upon returning to school, Kennedy Krieger is committed to identifying and addressing these barriers. To achieve this, the Clinic has an educational specialist who works with patients and families to secure necessary learning accommodations recommended by the medical team. This specialist also participates in school meetings for Individualized Education Programs (IEP) or 504 plans. As part of its ongoing efforts, the Kennedy Krieger team plans to conduct surveys, focus groups, and stakeholder interviews to inform the development of resources to navigate schooling for children with Long COVID. Specifically, the team is developing a "roadmap" to guide families in navigating schooling during the diagnosis and recovery process of Long COVID. Once finalized, the roadmap will be shared with healthcare providers, particularly those in underserved areas, to ensure broader access for pediatric patients with Long COVID.

By the Numbers

- 13 physicians and staff treat patients aged 2 to 21 years
- 49% of Kennedy Krieger patients with Long COVID reside in states other than Maryland
- 32% of Kennedy Krieger patients with Long COVID have pre-existing IDD
- 72% of children with Long COVID surveyed by Kennedy Krieger reported new school-related concerns

"These efforts will make unique and significant contributions to the AHRQ broader initiative, through active participation and collaboration in the peer-to-peer learning community, mixed methods evaluation, and dissemination of findings relevant to children and adolescents with Long COVID."

- Laura Malone, Principal Investigator



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