



Children and Youth with Special Health Care Needs National Research Network

Research Project Brief

PROJECT | PANDEMIC IS DECLARED: Early Experience from Families of Children with Medical Complexity during SARS-COV-2 Lockdown: Information to Drive System Change

- *Term:* May 2020 to January 2021
- *Grantee:* CYSHCNet
- *Funding Agency:* Health Research Services Administration, MCH Research Networks Program
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Background | In spring 2020, family reports on COVID pandemic-prompted challenges in caring for their child/ren with medical complexity emerged through Family Voices leadership and interactions with health systems. We identified recurrent motifs among reported challenges and one family provided serial narratives over time around several of these obstacles. Sadly, some of the challenges exposed long-standing care gaps which families have endured. Early challenges included interruptions of home care nursing, medication, formula and supply/equipment shortages, and tight infection control restrictions. Persistence of the pandemic and “lockdown” for months prompted other concerns about family mental and physical health, postponed education and therapies, deferred preventive care, financial crisis and insurance and advocacy challenges. In many cases, families managed these threats with limited help and became the experts in mitigating such risks. We believe that family input around these care gaps and struggles will inform future crisis and emergency planning and permit policies and processes adapted for this specialized and growing population of children.

Potential Impact | We hope to learn about care challenges during the SARS-COV-2 pandemic from a wide array of CMC families with unique conditions. Knowing what occurred in diverse home settings can inform preemptive crisis planning and solutions to mitigate risks. Ultimately, such collated information from many families can contribute to research, policy development and partnerships with the wide community of people who support our children with medical complexity.



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Publication
Complex Care Journal

Organizations Involved
Boston University COIIN,
AAP, Family Voices



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