

The Effects of the COVID-19 Pandemic on Children and Youth With Special Health Care Needs

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As pediatric health care providers navigate the immediate and long-term consequences of COVID-19, and emerging or future threats to health, we must consider the unique impacts of the pandemic and societal response to it on the most vulnerable in society. Children and youth with special health care needs (CYSHCN) “have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions. They also require health and related services of a type or amount beyond that required by children generally” (McPherson et al., 1998). According to the National Survey of Children’s Health (Maternal and Child Health Bureau, 2022), 14.1 million children, nearly one in five or about 19.4%, have a special health care need. More than a quarter of all U.S. households are home to at least one CYSHCN. These children and youth are more likely to live in poverty, be non-Hispanic Black, rely more on public insurance than non-CYSHCN, and are more likely to experience unmet health care needs. Notably, 36.3% of children with multiple adverse childhood experiences have a special health care need (Maternal and Child Health Bureau, 2022). Although definitions differ on the basis of health care needs and disability across the globe, the most comprehensive analysis provided by United Nations Children’s Fund estimates that worldwide there are

nearly 240 million children with disabilities. They face substantial barriers to well-being, including poor nutrition and health, limited access to water and sanitation, inadequate protection from violence and exploitation, and poor education, resulting in negative health and social outcomes (United Nations Children’s Fund, 2021). Historically, society has fallen short in meeting the needs of CYSHCN and their families, and although many thought children would be initially spared from the effects of COVID-19, we know this to be untrue (Fry-Bowers, 2020). Across the United States and worldwide, the pandemic has substantially impacted children and youth, with the effects being felt most by those in vulnerable or disadvantaged situations, including CYSHCN. According to United Nations Children’s Fund, the pandemic “is a universal crisis and, for some children, the impact will be lifelong” (United Nations Children’s Fund n.d.). Furthermore, subgroups of CYSHCN, such as children with medical complexity with or without dependence on technology and chronic conditions (e.g., prematurity, neurodevelopmental disability, type 1 diabetes, and obesity), remain particularly vulnerable to severe acute respiratory coronavirus 2 infection and other communicable respiratory conditions. It is imperative that we understand the impact of the pandemic on CYSHCN to mitigate existing harm, prevent future risks, capitalize on opportunities to innovate, improve the delivery of care, and create more responsive systems.

This Special Issue compiles papers that address the impact of COVID-19 on specific patient populations, caregivers and clinicians, and systems of care. Cohen et al. address the challenges and opportunities that the COVID-19 pandemic presented for providing and coordinating care for CYSHCN, who rely on a diverse array of systems, including health care, education, family, and community, to promote their well-being. Each of these systems has been disrupted through the pandemic resulting in negative impacts on this population. The authors assert that despite longstanding gaps and fragmentation in services and care

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for CYSHCN, COVID-19 offers an opportunity to embrace innovation. Gigli et al. provide evidence to suggest that policy innovation may have mitigated negative impacts for this vulnerable population, whereas Enneking and colleagues demonstrate that telehealth, a widely adopted service throughout the pandemic, may be a promising strategy for improving access to neurodevelopmental consultation. Furthermore, Theall et al. add to knowledge regarding the use of virtual services by examining the perspective of both caregiver and clinician when using this service model. Their findings guide when in-person, blended or virtual services should be used in caring for children and youth with developmental disabilities, autism, and severe behavioral and emotional challenges.

The Special Issue also addresses the direct impact of the pandemic on CYSHCN, especially its impact on daily activities and behavior. Kronk et al. offer an integrative review of studies addressing sleep in children with neurodevelopmental disabilities during COVID-19. The authors noted worsening sleep disturbances for this population during shelter-in-place restrictions but noted a dearth of resources available to assist families during times of marked disruptions in routine. Pizzo and colleagues also confirm that parents of many children with neurodevelopmental disabilities reported worsening sleep habits because of changes in routines, screen use and anxiety and that interventions to mitigate the consequences were needed. Rice et al. address the behavioral health needs of children with preexisting psychiatric disorders in the aftermath of COVID-19. Finally, the unique perspective of a school nurse (Macyko) and Case Report, Health Policy, and Research Methods Department papers are provided.

This Special Issue of the *Journal of Pediatric Health Care* offers an initial collection of efforts to understand the impact of the COVID-19 pandemic on CYSHCN. The global pandemic has disrupted health care, education, commerce, and governance, across multiple levels, including individuals, families, and communities. In addition to the physical effects and implications of infection, children, youth, and families, especially those with special health care needs, have been impacted in both short- and potentially long-term biopsychosocial and educational ways that we are only beginning to acknowledge. An improved understanding of the full impact of the pandemic on this unique population should serve as a catalyst to transform systems of care to better support the well-being of all, especially CYSHCN and their families.

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