

# The Impact of COVID-19 on Systems of Care for Children and Youth With Special Health Care Needs

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**Introduction:** This manuscript describes the challenges and opportunities that the COVID-19 pandemic presented for providing and coordinating care for children and youth with special health care needs (CYSHCN) who rely on a diverse array of systems to promote their health, education, and well-being.

**Method:** Peer-reviewed published literature and reports from the national government and nonprofit organizations that advocate for CYSHCN were examined, particularly concerning systems that impacted CYSHCN during COVID-19.

**Results:** Pre-COVID-19, CYSHCN and their families faced challenges accessing and coordinating care across diverse systems. COVID-19 exacerbated these challenges because of disruptions in

care and services that negatively impacted CYSHCN. COVID-19 also highlighted opportunities for positive change and care innovations.

**Discussion:** Understanding the systems of care that CYSHCN rely on and the effects of COVID-19 on these systems can enhance access to and quality of care. Recommendations are made for practice, leadership, research, and policy. *J Pediatr Health Care.* (2022) XX, 1–11

## KEY WORDS

Children, chronic illness, mental health, family, COVID-19

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## INTRODUCTION

The COVID-19 pandemic brought unprecedented challenges for children and youth with special health care needs (CYSHCN) and their families. The unpredictable nature of the virus constantly changed the playing field that spanned health care, education, family, and community systems. For decades, CYSHCN and their families and caregivers have relied on all four of these systems to meet their myriad and often complex needs. Before COVID-19, children and families faced gaps in these systems and challenges coordinating care between individuals and professionals. The emergence of COVID-19 revealed the longstanding stress points and gaps in these systems while presenting new opportunities for change and improved care.

The COVID-19 pandemic disrupted care for CYSHCN differently than it affected other children. CYSHCN often rely on more systems of care for their health, development, and well-being and have more needs for in-person direct care and coordination than typically developing children. Although many CYSHCNs have resumed activities that

halted during the pandemic, such as attending school or day-care, the consequences of prolonged disruptions to many systems of care continue to reverberate and pose challenges for all involved.

In addition to COVID-19, this paper is timely because of other recent events and trends: (1) the 2022 release of two seminal reports from the federal government about CYSHCN, (2) sharp increases in the prevalence of mental/behavioral health mental health conditions among the nation’s youth, and (3) mounting evidence of disparities in health and health between CYSHCN and their peers.

In this article we describe the challenges and opportunities that COVID-19 presented in providing and coordinating care for CYSHCN, who rely on diverse systems to promote their health, education, and well-being. We start with a background section on the demographics of CYSHCN and an overview of the major frameworks that guided our work. Next, we discuss the four major systems (health care, education, family, and community) that these children and their families depend on. We address the cross-cutting systems issues and challenges with coordination and collaboration among systems. Finally, we conclude with recommendations for practice, leadership, research, and policy, especially in anticipation of any major disruptions to public health and the well-being of CYSHCN.

**BACKGROUND ON CYSHCN**

The U.S. Maternal and Child Health Bureau (MCHB) defines CYSHCN as “children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions; they require health and related services of a type or amount beyond that required by children generally” (Health Resources and Services Administration, Maternal & Child Health Bureau, 2022; Table 1). In 2019–20, nearly one in five children (19.4%; 14.1 million children) in the

United States had a special health care need. More than one in four households with children (28.6%) had at least one CYSHCN. Rates of CYSHCN are particularly high (36.3%) among children with two or more adverse childhood experiences (ACEs), non-Hispanic Black children (23.3%), and children living in poverty (22.8%; HRSA & MCHB, 2022).

CYSHCN are nearly four times more likely than children and youth without special health care needs to have unmet health care needs. The most frequently reported reasons for unmet health care needs among CYSHCN were cost (48.9%) and lack of appointment availability (53.9%; HRSA & MCHB, 2022).

For purposes of this paper, we identify the following groups of CYSHCN: (1) children and youth with chronic health conditions, (2) children and youth with developmental disabilities, (3) children and youth with medical complexity, (4) children and youth who depend on medical technology, and (5) children and youth who are medically fragile (Table 1).

**Conceptual Frameworks**

A single framework was insufficient to guide our analysis of systems of care. Instead, we identified five relevant frameworks: (1) Complex Care Ecosystems (Humowiecki et al., 2018), (2) Whole School, Whole Community, and Whole Child (WSCC; Centers for Disease Control and Prevention [CDC], 2022), (3) Bronfenbrenner’s Ecologic Systems Model (Bronfenbrenner, 1992; Guy-Evans, 2020), (4) the Consensus Statement on the Core Tenets of Chronic Disease Management in School (2021), and (5) the Blueprint for Change (McLellan et al., 2022).

The Complex Care Ecosystem from the National Center for Complex Health and Social Needs (Humowiecki et al., 2018; Figure 1) encompasses 10 systems for individuals of all ages with complex health and social needs. The

**TABLE 1. Definitions of children and youth with special health care needs**

Term	Definition	Source
Children/youth with Special Health Care Needs	Children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions; require health and related services of a type or amount beyond that required by children generally	Health Resources and Services Administration, Maternal & Child Health Bureau (2022)
Children/youth with chronic health conditions	<i>Chronic</i> refers to a health condition that lasts anywhere from 3 months to a lifetime	American Academy of Pediatrics (2022)
Children/youth with developmental disabilities	“Developmental disabilities are a group of lifelong conditions because of an impairment in physical, learning, language, or behavior areas”	Zablotsky et al. (2019, p. 2).
Children/youth with medical complexity	A subset of children with special health care needs who are the “most medically fragile and have the most intensive health care needs”. . . (extra time, expertise, and resources) “to achieve optimal health outcomes”	Cohen et al. (2011, p. 259)
Children/youth who depend on medical technology	<ul style="list-style-type: none"> <li>• A subset of children/youth with medical complexity</li> <li>• “Technology dependency refers to the use of (technological) medical devices without which—if they were to fail or be discontinued—adverse health consequences and hospitalization would likely follow”</li> <li>• Examples of medical technology are mechanical ventilators &amp; enteral feeding devices</li> </ul>	Elias and Murphy (2012, p. 997)

**FIGURE 1. The complex care ecosystem.**

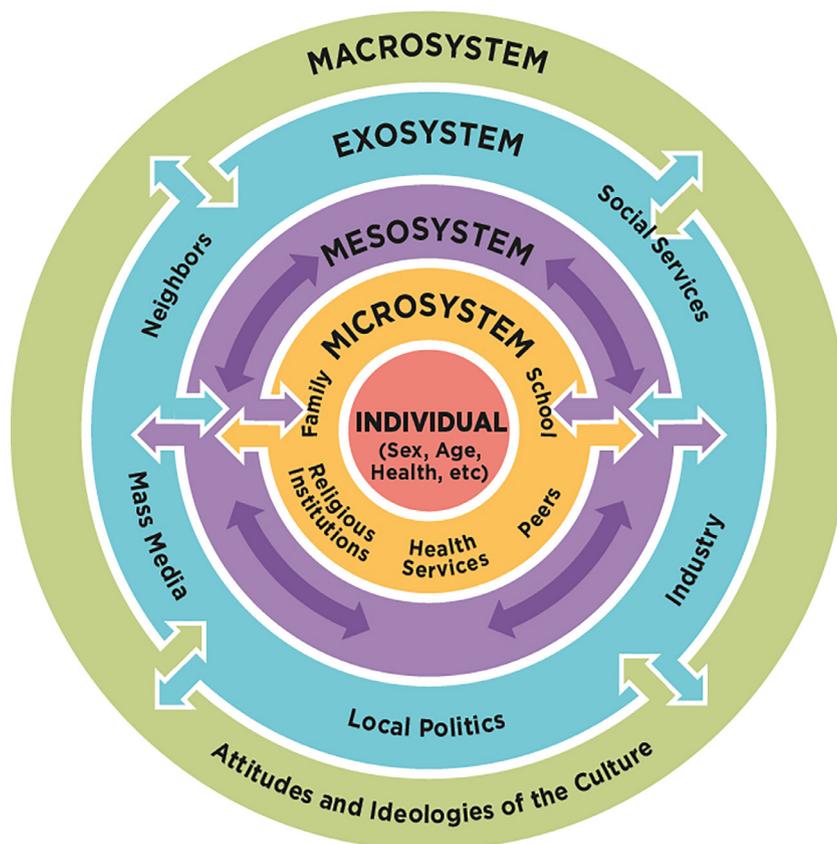
From Humowiecki et al. (2018). This figure appears in color online at [www.jpmedhc.org](http://www.jpmedhc.org).

framework builds on a shared vision of a transformed complex care ecosystem that “seamlessly integrate[s]” health and social services in local communities (p. 18). It is based on these premises: (1) current systems insufficiently address social determinants of health, (2) services and data are separated by system, (3) payment for care emphasizes volume over outcomes, and (4) the needs of individuals with complex needs are often unmet in health care systems that lack sufficient focus on person-centered care (Humowiecki et al., 2018).

Under the complex care ecosystems framework, education falls under “other social services” and employment. However, for CYSHCN, education is a major system that should not be merged with other issues. To address this shortfall, we added a second model, the WSCC framework from the Centers for Disease Control and Prevention (CDC, 2022; Figure 2). This framework is based on the (1) inextricable link between education and health for children’s well-being, (2) the importance of communities and families in supporting children’s health and education, and (3) growing emphasis on children’s physical and psychosocial environments (CDC, 2022; Figure 2).

**FIGURE 2. Whole School, Whole Community, Whole Child.**

From Centers for Disease Control and Prevention (2022). This figure appears in color online at [www.jpmedhc.org](http://www.jpmedhc.org).

**FIGURE 3. Bronfenbrenner’s Ecological Systems Theory.**

National Academies of Sciences, Engineering, and Medicine (2016). This figure appears in color online at [www.jpeds.org](http://www.jpeds.org).

Although the WSCC features schools and education more than the complex care systems model, it lacks an essential component: strong coordination among individuals and organizations within and across these systems. To address this shortfall, we introduce Bronfenbrenner’s ecologic systems theory (Bronfenbrenner, 1992; Guy-Evans, 2020; Figure 3). Bronfenbrenner identified concentric systems of a child’s life. For example, the “microsystem” includes home, family, and school. As another example, the “mesosystem” in Bronfenbrenner’s framework links two or more microsystems. It is a “system of microsystems” (Bronfenbrenner, 1992, p. 227). Examples of linkages in the mesosystem include the connection between the child’s teacher and family, health care clinicians and school personnel, and individuals and organizations in the communities and schools.

COVID-19 has drawn attention to the importance of services provided in schools for CYSHCN, especially those with chronic physical or mental health conditions. COVID-19 also raised awareness of the importance of partnerships among health care, public health, and social-service organizations to meet the needs of students with chronic health care conditions. To address these issues, seven national organizations “develop[ed] a common framework to guide an integrated, collective approach to

chronic condition management in schools” (Consensus Statement on the Core Tenets of Chronic Disease Management in School, 2021, p. 3). The collaborating organizations identified seven key components of the core tenets: accessible, comprehensive, coordinated, culturally effective, equitable, evidence-based, and child -and family-centered. Under “comprehensive,” the stakeholders specified that students with chronic conditions should be supported “during emergencies and disasters (e.g., pandemics, natural disasters, lockdowns)” (p. 4).

Many CYSHCNs, particularly those with increased medical complexity, have increased social needs necessitating nonclinical supports such as food assistance, supportive housing, and special education to thrive (McLellan et al., 2022). Parents frequently serve as caregivers and care coordinators for CYSHCN. Navigating a fragmented system is frustrating and exhausting, particularly for families with low financial resources, food insecurity, housing, or transportation challenges (McLellan et al., 2022).

The MCHB’s Blueprint for Change addresses these issues by identifying four critical areas: health equity, family/child quality of life, access to services, and finance for services (Brown et al., 2022). The Blueprint for Change calls for a holistic, coordinated, and integrated approach to health

care to help CYSHCN enjoy a full quality of life throughout their life span (McLellan et al., 2022, p. S722).

Each framework, model, and tenet described above provide ways of conceptualizing the many systems of care that CYSHCNs rely on more than non-CYSHCNs and their families. The complexities, fragilities, and vulnerabilities of the systems were accentuated during COVID-19.

## HEALTH, EDUCATION, FAMILY, AND COMMUNITY SYSTEMS FOR CYSHCN DURING COVID-19

To understand the depth and breadth of COVID-19's impact on CYSHCN and their families, we discuss four systems—health care, education, family, and community. The connections between these systems vary across geographic locales. They depend on the political will and leadership of local and state child advocates both inside of government and in the community.

### Health Care Systems

CYSHCNs are high pediatric health care service users and have been disproportionately impacted during the COVID-19 pandemic (Baumbusch et al., 2022). Health care services such as primary care, specialty care, therapies (physical, occupational, speech), and mental health are the foundation of growth and development for CYSHCN. During the pandemic, many of these services were paused or curtailed. Public health measures, especially in the early months of the pandemic, limited access to in-person health care for CYSHCN, including preventive services (Baumbusch et al., 2022; Lebrun-Harris et al., 2022). Families of CYSHCN lost opportunities for developmental screening and monitoring and anticipatory guidance for safety (e.g., toddler safety, adolescent high-risk behaviors). In addition, many families avoided taking their child to the hospital or emergency department (ED) to evaluate health-related complications (Baumbusch et al., 2022).

When primary care clinics closed, many specialty clinics provided well-child care and COVID-19 prevention advice to families of these vulnerable children. Specialty clinic providers often became the medical home or primary care providers. CYSHCN, with high acuity or medically complex needs, require ongoing medical management to optimize health and minimize the risk of health-related complications. Provision of therapies (e.g., physical, occupational, speech, and/or respiratory) that maintain or restore function for many CYSHCNs increased in specialty clinic settings because in-school and in-home services were unavailable (Coller et al., 2018).

Telehealth visits surged as an alternative to in-person visits during the pandemic (Garfan et al., 2021). Although telehealth may not be optimal for CYSHCN because a physical examination is needed for a complete and accurate assessment, it has certain advantages. An integrative review by Ferro and colleagues (2021) identified telemedicine reduced unplanned hospitalizations, health care costs, financial burdens for families, and increased caregiver satisfaction with

health care for medically complex children (Ferro et al., 2021).

Seeking health care was often influenced by family factors. For example, families with two parents had lower odds of avoiding the ED for situations in which they would have brought the child in pre-COVID-19. This suggests that families without dual parent support could not easily manage the logistics of an ED visit during pandemic isolation (Baumbusch et al., 2022). In addition, some parents (36.5%) avoided taking their children to the ED because of fear that they or their child might contract COVID-19 (Baumbusch et al., 2022; Radhakrishnan et al., 2022).

Another family factor for CYSHCN during the pandemic was that typically only one parent was permitted at the bedside in hospital units or EDs. The parent at the bedside lacked the support of other family members as they dealt with the stress of caring for and monitoring a hospitalized child. In addition, extended family and community support were often restricted.

### Behavioral and mental health

For children and youth, mental health is the overall wellness or how one thinks and regulates feelings and behaviors (or emotional, social, and behavioral functioning). “A mental illness, or mental health disorder, is defined as patterns or changes in thinking, feeling or behaving that cause distress or disrupt a person’s ability to function” (Mayo Clinic Staff, n.d., para. 2). Mental health disorders in children are “delays or disruptions in developing age-appropriate thinking, behaviors, social skills, or regulation of emotions” (Mayo Clinic Staff, n.d., para. 3).

The disruption of health care services and families’ daily lives in the pandemic has intensified the risk of ACEs for CYSHCN (HRSA & MCHB, 2022; National Governors Association, 2020). ACEs are potentially traumatic events that can affect a person’s health, well-being, and success into adulthood. The pandemic has also accentuated a previously existing mental health crisis and the lack of resources available to patients and families (CDC, 2022).

The needs of CYSHCN with existing behavioral and/or mental health diagnoses were confounded by the pandemic (Racine et al., 2021; Zijlmans et al., 2021), with many experiencing an increase in emotional distress, behavioral health concerns, and deterioration in mental health (Brik et al., 2022; Bussi eres et al., 2021; Radhakrishnan et al., 2022). Some children became more socially isolated, mainly because of the disruption of school life. Other children suffer because of the loss of a primary or secondary caregiver due to COVID-19 illness or death, further impacting their mental health (Heard, 2022). In addition, comparison studies before and during the pandemic indicate poorer mental well-being for CYSHCN following the pandemic, highlighting the moderating relationship of COVID-19 lockdown procedures on CYSHCN mental health (Hoefnagels et al., 2022). In particular, between 2019 and 2021, there were increases in mental health ED visits in the United States for eating disorders, tic disorders, and obsessive-compulsive

disorders. Moreover, there was a rise in psychiatric boarding (stays in the ED or medical-surgical units awaiting psychiatric unit admission) for children and youth during the pandemic, with 50.4% requiring more than 2 days of boarding, indicating the dire lack of inpatient psychiatric beds for this population (Ibeziako, Kaufman, Scheer, & Sideridis, 2022).

Complicating this crisis was the mental health of parents with CYSHCN—a vulnerable group. Parental COVID stressors, often from burnout and parenting experiences of CYSHCN, were associated with increased anxiety levels and sleep problems (Wauters et al., 2022).

Another factor that exacerbated the crisis in mental health care for children pre-COVID-19 was the shortage of mental health providers; this left pediatric primary care and specialty care providers filling the service gap. Chien et al. (2022) found that more than 85% of the 1,410 multiphysician primary and multispecialty pediatric practices surveyed had difficulty obtaining advice or services regarding pediatric behavioral health care, such as medication advice or evidence-based psychotherapy.

Some organizations developed innovative solutions to support patients and families of CYSHCN who require mental health support (Cutler et al., 2022). One Children's Hospital integrated mental and behavioral health clinicians into the primary care setting and offered walk-in mental health care to allow for early detection and increased access to these services (Children's Wisconsin, 2022).

School-based health centers are another innovative solution for mental health care delivery for CYSHCN. Most of these centers found the lack of staff and in-person access challenging during the pandemic, prompting them to implement telehealth to sustain service provision (Sullivan et al., 2022). Future options for expanding access to mental health for CYSHCN include offering mental/behavioral health services in specialty clinics.

## Education Systems

COVID-19 amplified the hurdles that CYSHCN and their parents faced in navigating federal, state, and local policies to ensure their children received an education that enabled them to develop to the best of their potential. It also provided a window of opportunity for local and state education policymakers to provide resources for a student population that the education system had often failed to adequately address.

Before COVID-19, CYSHCN faced challenges as they strived to learn in schools, at home, and in other educational settings (Rosenkranz, 2021). For example, some children require medication or treatments while they attend school. Others have fragile medical conditions, placing them at risk for infections and exacerbations of their conditions in-school settings, prompting parents to prefer that their children receive education at home.

Approximately 17% of all children aged 3–17 years have one or more developmental disabilities (Cogswell et al., 2022), such as attention deficit hyperactivity disorder or autism spectrum disorder. These disabilities are often associated with

physical, cognitive, sensory, or intellectual difficulties and mental and behavioral health challenges.

## Federal education policies

Two major federal laws address special education for children: (1) the [Individuals with Disabilities Education Act \(IDEA\)](#) and (2) [Section 504 of the Rehabilitation Act](#). The IDEA (P.L.94-120), enacted in 1975, requires all eligible children with disabilities to receive a free appropriate public education (FAPE) that “meets their unique needs and prepares them for further education, employment, and independent living” (Department of Education, 2017). Infants and toddlers from birth through age 2 with disabilities and their families receive early intervention services under Part C of the IDEA. Children and youth aged 3 to 21 years receive special education and related services under Part B of the law. As of 2018–19, 7.5 million infants, toddlers, and youth with disabilities received special education services. Under the IDEA, each child is required to have an individualized education program (IEP), which is a written statement of how the child's disability affects their involvement and progress in the general education curriculum and includes measurable annual academic and functional goals.

The [Rehabilitation Act of 1973](#), section 504, protects the rights of individuals with disabilities in programs that receive federal financial assistance under the Department of Education (DOE). In contrast to the IDEA, which focuses on special education for children with disabilities, the Rehabilitation Act, section 504, is a federal civil-rights law to protect all individuals with disabilities in DOE programs. Recipients of section 504 funds include public school districts, institutions of higher education, and other state and local education agencies.

Although both 504 plans and IEPs provide guidance to school personnel and parents regarding education for children with disabilities, they differ in several ways. First, the IDEA limits disabilities to specific conditions, whereas section 504 has a broader definition of a disability. Second, the IDEA focuses on students' special education needs, whereas section 504 addresses how school personnel must modify the student's environment to help the student with specific learning needs. Examples include installing handrails on steps, moving inaccessible classrooms to another location, and seating students with attention deficit hyperactivity disorder in the front and center of the classroom to minimize distractions. Third, both laws require schools to provide a FAPE to eligible students, but the IDEA requirements are more detailed than section 504 (The Understood Team, 2022).

As schools reopened in 2021, diverse stakeholders raised important questions about how to interpret and implement the IDEA, given the interruptions and lapses in implementing IEPs. Many CYSHCN experienced setbacks in their cognitive, social, emotional, and physical abilities during the pandemic and/or faced new challenges with their health care or family situations. In response, the DOE issued guidance documents “to clarify that regardless of the COVID-

19 pandemic, or the mode of instruction, children with disabilities are entitled to FAPE, and infants and toddlers with disabilities and their families to appropriate IDEA Part C services” (Department of Education & Office of Special Education and Rehabilitative Services, 2021, p. 10). The DOE documents included guidance on “social, emotional, behavioral and mental health needs of children with a disability” (p. 15) and “school-related health needs of children with disabilities with underlying medical conditions” (p. 19).

Regarding state or local jurisdictions that had instituted policies that were “inconsistent with CDC’s COVID-19 prevention and risk reduction strategies,” the DOE reiterated the IDEA’s requirements that IEP teams identify services needed to provide a child with a disability a FAPE in the least restrictive environment. The DOE also confirmed that school personnel were required to propose an appropriate educational placement that “meets the child’s school-related health needs” (Department of Education & Office of Special Education and Rehabilitative Services, 2021, p. 19–20). The DOE guidance documents are useful for all health care and education personnel who work with children and youth with disabilities and other special health care needs during and after any disruptions to a child’s education, including and not limited to COVID-19. They also are useful for understanding the rights and responsibilities of children, families, and school personnel in implementing the IDEA.

The American Rescue Plan (P.L.117–2), enacted on March 11, 2021, provided almost \$125 billion for education, most of it going to local school districts with a focus on advancing education equity (The White House, 2022). These funds can support activities that help students with disabilities and other special health care needs.

### Other school service disruptions because of COVID-19

In addition to education services provided to eligible children under the IDEA and section 504, millions of students rely on school-based services for health care, nutrition, and social services. For example, school-based health centers provide primary and preventive care for six million students, many of whom are from low-income and rural families (Sullivan et al., 2022). Approximately 35 million students live in low-income families and receive daily nutritional breakfasts and/or lunches through school or child care programs. Eighty percent of children with mental and behavioral health needs receive needed services in schools. School closures created disruptions in these and other services (Masonbrink & Hurley, 2020) and pointed to the need for system leaders to prepare for future closures and interruptions with school-based services.

In education settings nationwide, school nurses have had a longstanding and crucial role in caring for CYSHCN. COVID-19 required school nurses to change their priorities and assume additional responsibilities, such as conducting contact tracing, enforcing general COVID protocols, and providing COVID-19 education to students, staff, and families (Barbee-Lee et al., 2021). With only 39% of schools

having a full-time school nurse, COVID exacerbated the existing school health personnel crisis, which resulted in the lack of optimal health services for many children, especially CYSHCN (Vestal, 2021).

### Family Systems

Family members’ perspectives are essential because they are partners in health care system development and care delivery for CYSHCN (Allshouse et al., 2018; Coleman et al., 2022). Their pivotal roles and challenges were made glaringly clear during the COVID-19 pandemic when families of CYSHCN faced the monumental task of navigating the turbulent waters of closed health care and therapy clinics. Initially, access to services was prohibited or curtailed (Baumbusch et al., 2022). Over time, care shifted to virtual telehealth video-chat visits (Jeste et al., 2020; Lieneck et al., 2021). Although 72% of families reported a preference for these new modes of care (Baumbusch et al., 2022), the reliance on telehealth exposed a digital divide that further widened care inequities and spotlighted the importance of examining social determinants of health concomitantly with care delivery for CYSHCN (Curfman et al., 2022).

Parents of CYSHCN had to make tough decisions regarding accessing services for their CYSHCN. Consequently, there were missed or postponed outpatient visits (Lieneck et al., 2021). Jeste et al. (2020) found that at the start of the pandemic, 30% of children with a genetic diagnosis, autism, epilepsy, or neurodevelopmental disorder, including developmental delay or intellectual disability, lost all therapy services (i.e., occupational therapy, physical therapy, speech). Seventy-four percent lost access to at least some educational services or one therapy (Jeste et al., 2020). Families of CYSHCN missed preventive health care visits because of structural barriers, such as the inability to find child care, their fear of contracting COVID-19 or needing to care for other family members diagnosed with the virus (Liu et al., 2022).

Families also faced disruptions related to homecare services, such as delays in obtaining durable medical and personal protective equipment (Agoratus, 2022; Liu et al., 2022). In addition, many CYSHCNs experienced delayed hospital discharges because of home health care staff shortages (Agoratus, 2022). The pandemic worsened the prepandemic home health care nursing shortages in which 68.5% of new patients and 9.2% of existing patients experienced discharge delays because of a lack of home nursing support (Maynard et al., 2019). These discharge delays increased hospital length of stay, inpatient costs, exposure to infections, and patient and family stress.

Social determinants of health (SDOH) “conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks” (Centers for Disease Control and Prevention, 2021, para. 1), played a major role in families’ navigation through the pandemic. CYSHCN are more negatively impacted by the adverse effects of SDOH (McLellan et al., 2022) than non-

CYSHCN. Food is a key social determinant of health (Ullmann et al., 2022). In 2019–20, more families with CYSHCN lived in food insecure households than those without CYSHCN (19.3% vs. 9.8%); rates were particularly high in Black, non-Hispanic (18.8%), and Hispanic children (15.7%) than in White children (6.5%; Ullmann et al., 2022). Although there are no specific data related to job loss in parents of CYSHCN, the *American Academy of Pediatrics* (2021) reported that more parents of CYSHCN (61%) had a change in employment (laid off, furloughed, decreased work hours) than parents without CYSHCN (46%). This is consistent with past studies that reported higher levels of unemployment and decreased work hours in parents of CYSHCN because of the needed coordination and necessary time for outpatient clinic and therapy appointments (Liu et al., 2022).

In addition to SDOH, family stress experienced during the pandemic increased the risk for ACEs (Heard, 2022; HRSA & MCHB, 2022). For example, public health measures such as social distancing and restricted travel increased the risk of family violence (Campbell, 2020). Those children living in a household with domestic violence have 60 times the risk for neglect or abuse than the general U.S. child population. In particular, the pandemic increased child abuse risk factors such as decreased social support, unemployment, and limited resources (Campbell, 2020).

An American Academy of Pediatrics Survey of 9,000 parents of CYSHCN during COVID indicated that while the physical and emotional interpersonal violence increased during the pandemic, it was higher in families of CYSHCN (30% vs. 17%). Furthermore, although about half of parents reported being stressed most of the time, 60% of families reported that they grew closer (*American Academy of Pediatrics*, 2021). An additional ACE experienced by CYSHCN was the loss of a parent or caregiver because of a COVID-19 infection or complication. Ahmann (2021) found that one in four COVID deaths is a loss of a caregiver for a child, with higher rates in racial/ethnic minority groups.

### Community Systems

All the models and frameworks described in the background section of this manuscript include the community as an important factor in ensuring health and well-being for CYSHCN. Neighborhood safety, transportation, food and nutrition services, and social services are among the many community systems that support CYSHCN and their families. We focus on two community services—recreation and child care—to illustrate how COVID affects community systems that CYSHCN rely on.

### Recreation

Neighborhood context is an important supporting component for CYSHCN (Abdi et al., 2020; Coleman et al., 2022). In particular, access to parks, recreation centers, sidewalks, and libraries promotes the health and well-being of CYSHCN. Access to fresh air and outdoor green space is important for child development and promotes mental well-being for all children. A systematic review of 300 studies

revealed that green space improved children's physical activity, which concomitantly improved emotional well-being (Fyfe-Johnson et al., 2021). Socialization with friends and participation in accessible activities at playgrounds and recreation centers are protective factors that support the flourishing of CYSHCN.

At the beginning of COVID-19, all parks, gyms, and recreational facilities were closed. This reduced access to an important resource for building resilience in children, especially CYSHCN and others at risk for ACEs. Acknowledging the traumatic effects of the COVID-19 pandemic on many young children, the National Governors Association mounted multiple initiatives to prevent and address trauma and build resilience in children (Heard, 2022).

### Child Care

Good quality child care offers developmental, educational, and health benefits to children from infancy to 13 years old. Child care also enables parents to work and/or pursue education. It is provided in different settings, such as child care centers, family child care homes, public schools, faith-based organizations, or a child's home.

The main source of federal child care funding is the Child Care and Development Block Grant. In FY2022, it was funded at \$6.165 billion, covering an average of 1.5 million children per month (*Administration for Children and Families, Office of Child Care*, 2022), which is far below the estimated number of eligible children based on family income (Chien, 2019). Other federal early learning programs include the IDEA infant and toddler (Part C) and preschool programs (Part B; Guarino, 2022).

During the pandemic, the federal government provided COVID-19 relief funding to child care providers to cover the costs of maintaining and resuming child care. This included costs of cleaning, sanitation, paying personnel, and other necessary activities, even if providers were not previously receiving Child Care and Development Block Grant assistance (*First Five Years Fund*, 2021). However, even with this funding, COVID-19 revealed the enduring gaps in the availability of good quality and affordable child care, including child care for CYSHCN.

Many child care providers accept CYSHCN (e.g., children with asthma, allergies, or diabetes) and obtain medical guidance on how to meet their needs. However, some care providers hesitate to accept children with physical, emotional, sensory, cognitive, or other disabilities or those with complex health care needs. Furthermore, some parents are often reluctant to trust strangers with the special health care needs of their children.

With the pandemic, many child care facilities shut their doors, especially given the health and safety concerns of COVID-19 and the importance of keeping children, parents, and childcare staff safe. This added to the disruption many families with CYSHCN faced during the pandemic. They were often on their own to arrange care even if they were infected with COVID-19 or had to care for other ill family members. There were not many viable alternatives. On a

positive note, the pandemic broadened the constituencies and organizations to advocate for increases in federal and state funding and to call attention to the nation's child care crisis, especially its high costs to families (Fillon, 2022). This has the potential to harness support for child care for all children, including those with special health care needs.

## DISCUSSION

In this paper, we outlined the challenges to providing care across systems of health, education, family, and community for CYSHCN during the pandemic and its aftermath. We described conceptual frameworks of the systems that CYSHCN and their families rely on. Each system presents challenges because of public and private sector policies and the characteristics of the children served. We did not address the challenges of coordinating care across systems. That requires knowledge of complex systems theories, which is beyond the scope of this paper.

COVID-19 disrupted care for CYSHCN across systems for health care, education, families, and communities. Through the turbulence, we noted longstanding gaps and fragmentation in services and care for CYSHCN, offering a window of opportunity to define the problems and advocate for change. We also captured innovations, especially in telehealth, for advancing care.

## Limitations

Our scholarship has several limitations. First, evidence and policies for COVID-19 generally and specifically for CYSHCN were constantly changing. Our goal was to write a paper that would be meaningful now and in the future. However, we had a moving target as we encountered new issues and evidence. Moreover, we only had 2 years, and 2 unusual years, of evidence to base our writing on. Finally, despite the plethora of evidence on COVID-19, evidence about coordination of care within and across systems for CYSHCN and their families was lacking, especially from the perspective of CYSHCN and their families or professionals in each system.

## Recommendations for Practice, Leadership, Research, and Policy

Based on our scholarship, we offer the following recommendations for nurses, advanced practice registered nurses, and other professionals working with CYSHCN and their families:

1. Incorporate shared decision-making between CYSHCN and their families and all components of the health care systems to promote child and family well-being.
2. Implement objective measurements of child and family well-being, quality of life (e.g., family stress, social connection/social support), and physical/mental health in CYSHCN and their families.
3. Be knowledgeable about federal and state special education policies regarding the IDEA, IEPs, 504 plans,

and the rights of children with disabilities to a free and appropriate public education.

4. Advise parents about communication with education personnel regarding lapses in education progress or other concerns related to COVID-19 or other unexpected health issues.
5. Establish relationships with individuals in other systems so that if there are future disruptions in care, trusted channels of communication and coordination are in place.
6. Apply the complex care ecosystems model, WSCC model, Bronfenbrenner's ecologic systems theory, the American Academy of Pediatrics Consensus Statement on the Core Tenets of Chronic Condition Management in Schools, and HRSA's Blueprint for Change when working with CYSHCN and their families.
7. Prioritize mental/behavioral health for CYSHCN; advocate for appropriate mental/behavioral resources in health, education, and community settings, including integration of mental/behavioral health for CYSHCN.
8. Advocate for state and federal initiatives that have the potential to expand access to and coverage for child health services. This includes addressing disparities in access to broadband in remote areas and enhancing clinician and patient skills in use of telehealth.
9. Conduct research on the health and social needs of CYSHCN and their families as they interact with diverse systems.
10. Engage with stakeholders for community policies to raise the voice of nursing expertise in diverse settings that have the potential to improve child health outcomes.

## CONCLUSIONS

Prepandemic, CYSHCN and their families faced challenges in managing and coordinating care across health care, education, family, and community systems. COVID-19 highlighted the importance of these systems and their fragility. Conceptualizing the characteristics of these systems and explaining how they were affected by COVID-19 can enhance the ability of child health clinicians to care for CYSHCN so that they grow and develop to the best of their potential.

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