



Caring for Children and Youth With Special Health Care Needs During the COVID-19 Pandemic

Children and youth with special health care needs (CYSHCN) are defined as *those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.*

- CYSHCN are more likely to have **disruption** to health care, education, and community life as a result of the coronavirus disease 2019 (COVID-19) pandemic with consequences such as delayed development, reduced learning, and mental health challenges. Interruptions to services affect subpopulations of CYSHCN, such as those of younger age, those with medical complexity, and those with behavioral health conditions, in different ways. Inequities attributable to [poverty](#), [racism](#), [immigration status](#), [ableism](#), health conditions, geography, health care access, educational access, child care access, and other factors make these disruptions particularly dangerous for some CYSHCN.
- A **subgroup** of CYSHCN, yet to be precisely defined, of children with [certain chronic conditions](#) are more likely to have a diagnosis of [severe acute biological effects](#) of severe acute respiratory syndrome-coronavirus 2 (SARS-CoV-2) infection [requiring admission to the hospital or intensive care unit](#). Black and Latinx children with chronic conditions experience a disproportionate burden of hospitalization thus far. Data on the risk of infection, as well as detection of its acute and chronic effects, continue to evolve as the pandemic spreads, affecting different locations with different demographic characteristics at different times. *Given data limitations, it is essential to use precaution in the extrapolation of early pandemic epidemiologic data to the circumstances of the upcoming fall and winter period and specific patient contexts.*

What is the overall approach to minimizing the risk of infection while meeting the ongoing needs of CYSHCN during the pandemic?

Combine the following 3 strategies:

1) **Multi-layer risk reduction**, conceptualized as an application of the [Swiss Cheese Model](#) to provide extra protection for CYSHCN from SARS-CoV-2 infection through multiple layers of protection (ie, slices), because each layer has limitations (ie, holes), the size of which depend on policy and human behavior. Potential layers of risk reduction include:

- **Minimize environmental exposure risk** by avoiding *unnecessary* closed spaces, crowded places, and close contact (the **3 C's**) and spread through hands and surfaces. **Avoid closed spaces** and especially those with poor ventilation where physical distancing guidelines (ie, 6-foot rule) may be insufficient. Guidance from the Centers for Disease Control and Prevention (CDC) on improving indoor environments in a variety of settings can be found [here](#). **Avoid crowded places**, inside and outside. **Avoid close-contact settings**, such as close-range conversations, singing, exercising, and other activities that promote respiratory spread. Practice [surface cleaning](#), especially in shared spaces and with shared objects, and [hand hygiene](#), including before and after face covering use.
- **Use personal protective equipment (PPE)**, especially when the risk of exposure is higher. Nearly all CYSHCN, 2 years and older, can successfully use cloth face coverings that securely cover the nose and mouth. Practice and modeling will increase success. There are few valid medical exceptions. Close contacts of CYSHCN must also use PPE appropriately to limit spread. *Use PPE with particularly heightened consistency and vigilance in situations in which spread is more likely, such as close contact, closed spaces, and crowded locations (see PPE section for details).*
- **Test, trace, and isolate** those who are exposed, symptomatic, or infected. Screening of asymptomatic close contacts of CYSHCN with a higher risk of severe biological effects of SARS-CoV-2 infection adds additional protection limited by the availability of necessary tests (**see testing section for details**).
- **Address inequities and optimize health coverage**. Housing, income, and other supports reduce the structural risk of infection spread. Health coverage should support multiple ongoing CYSHCN needs across the continuum of care, including testing for

SARS-CoV-2 infection, counseling on risk reduction, and coordination of accommodations to safely meet the needs of CYSHCN during the pandemic. Equitable policy in both the short- and long-term will reduce disparities in the health of CYSHCN related to the pandemic and beyond (**see case management and health coverage sections for details**).

2) Creative, flexible, and responsive accommodation to *safely* achieve inclusion by overcoming the barriers introduced by the multi-layer risk reduction strategies in meeting the ongoing needs of CYSHCN in health care, education, child care, and community life (**see respective sections for details**). For example, moving activities outdoors with context-specific physical distancing and PPE can substantially reduce, but not eliminate, risk.

3) [Shared Decision Making](#) to resolve difficult decisions in health care, education, child care, and community life, balancing risk reduction with other ongoing needs, specific to the needs of the child and caregivers (especially, but not limited to, families), respecting and valuing the concerns of multiple stakeholders (health care providers, educators, school nurses, and others) to achieve consensus for needed accommodations. Practical steps include:

- Develop shared goals and objectives.
- Identify personal and cultural preferences, priorities, and concerns of all parties actively involved.
- Collaboratively review risk reduction strategies and creative, flexible, and responsive accommodations under consideration, specific to the needs and risks of the child and contacts.
- Determine which individual(s) are responsible for carrying out the actions required to achieve the shared goals.
- Acknowledge that evidence to inform these decisions during the pandemic is limited, evolving, and often subject to multiple interpretations.
- Continue to re-evaluate decisions as new data become available.

Specific Considerations

How should CYSHCN use PPE, such as cloth face coverings?

Interim guidance from the American Academy of Pediatrics (AAP) on [PPE in ambulatory care settings](#) and [cloth face coverings](#) is available for more information.

CYSHCN, 2 years and older, can safely wear face coverings that securely cover the nose and mouth, with rare exceptions. These cloth face coverings should be used in public spaces indoors at all times and outside when physical distancing cannot be maintained. Home use of face coverings also may be particularly valuable in households that include adults and CYSHCN known to be [at risk for severe biological effects](#) of SARS-CoV-2 infection. The cognitive vigilance required to use face coverings consistently over a long period is challenging. The appropriate use of face coverings should be prioritized 1) when environmental exposure risk is elevated with crowds, closed spaces, and close contacts, and 2) in homes and especially in the same room with other household members or visitors when intrahousehold spread is an increased concern. Families can promote the practice of face covering use at home to enable CYSHCN to become accustomed to situations where face coverings are more necessary.

Caregivers, CYSHCN, child care center personnel, education workers, therapists, and other individuals may require additional counseling on the use and selection of face coverings to promote inclusion and ensure the safety of all contacts in a variety of situations. It is essential to ensure that the child and all contacts use face coverings appropriately. Education resources are available from the [CDC](#) and [World Health Organization](#). Face coverings with exhalation valves should not be used, because these do not protect contacts. Attention to fitting and seal is necessary for all but may require particular attention for some CYSHCN, such as those with craniofacial conditions.

In cases in which lip reading is essential, contacts should use face coverings with transparent windows and/or use augmentative communication strategies, such as voice-to-text mobile applications. Face shields are not a substitute for cloth face coverings but may provide some additional protection to contacts (ie, source control), especially when they cover more of the front and sides of the face and neck.

The subgroups of CYSHCN known to have a [higher risk for severe biological effects of SARS-CoV-2 infection](#), as well as their caregivers and close contacts, may require similar access to the types of PPE used by health care workers. The PPE should be appropriate to the medical condition of the child and the needs of caregivers and close contacts. Close contacts should have access to appropriately fitted N95 respirators and eye protection for [aerosol-generating procedures](#) (eg, airway suctioning, airway clearance procedures, tracheostomy changes, noninvasive ventilation, mechanical ventilation, and nebulizer treatments). In some situations, child use of an appropriately sized face shield may help protect contacts.

When should CYSHCN be tested for SARS-CoV-2 infection?

AAP interim guidance on [testing](#) is available for more information, including information on use of molecular (e.g. RT-PCR) and [rapid antigen testing](#).

The AAP supports the implementation of public health surveillance that tests at a population level to identify local outbreaks of COVID-19, in partnership with health care providers and local public health departments. Among CYSHCN at higher risk for severe biological effects of SARS-CoV-2 infection who require close contact services, regularly screen for symptoms among contacts and test if there is exposure or if symptoms arise. Consider [periodically screening](#) their asymptomatic caregivers, home care personnel, child care personnel, education workers, therapists, and other close contacts in locations with sufficient testing capacity.

How should health and related service providers support CYSHCN during the pandemic?

Guidance for coding services in the pandemic is available [here](#).

Outpatient Settings

During the pandemic, health care providers should proactively reach out to CYSHCN, especially those who have not recently engaged with the health care system, to ensure child and caregiver well-being. It is optimal for the [medical home](#) to partner with the family in managing and coordinating the multiple ongoing health needs of CYSHCN during the pandemic.

- Use telehealth whenever possible, recognizing and [taking steps](#) to address the inequities in internet connectivity and devices as well as digital fluency. Collaborate with visiting and private duty home care personnel for assessments through telehealth, including weights, vital signs, physical examination findings, and home assessments. Provide equal access to translation services, including non-English languages and American Sign Language.
- Use home-based laboratory draws and diagnostic imaging whenever possible.
- Schedule interdisciplinary care planning and health maintenance visits, primarily through telehealth. Depending on the needs of individual patients, multiple visits may be necessary to:
 - Counsel about SARS-CoV-2 and multi-layer risk reduction (eg, [3 C's](#), PPE, hand hygiene, surface cleaning, screening) – **see respective sections for details**, and

needed accommodations in health care, education, child care, and community life. Use [Shared Decision Making](#) framework for difficult decisions.

- Develop emergency and [advanced care](#) plans for situations in which a child or household member is exposed, infected, or hospitalized. Regularly update schools of relevant plans to ensure continuity of care.
 - Address ongoing health care needs for health maintenance, chronic condition care plans (eg, asthma, seizures, dysautonomia), prescription refills, home care, rehabilitation/habilitation, durable medical equipment, medical supplies, and other needed care.
 - Address care typically provided during the school day for CYSHCN not receiving in-person services in school.
 - Plan for optimal timing of specific in-person visits, including vaccinations.
 - Refer to supports and resources (**see case management and health coverage sections**).
- Specific considerations for when in-person encounters are necessary and/or desired:
 - Ensure safe transportation options to facilitate in-person encounters, especially for CYSHCN whose public transit options are limited by the pandemic.
 - Make creative, flexible, and responsive accommodations in workflow and other practices for complex needs (eg, examinations in vehicles, early appointment times, immediate rooming).
 - Arrange separate areas (ideally with negative pressure flow) for [aerosol-generating procedures](#) (eg, airway suctioning, airway clearance procedures, tracheostomy changes, noninvasive ventilation, mechanical ventilation, and nebulizer treatments).

Mental Health

Both CYSHCN and their caregivers may have substantial mental health needs during the pandemic, economic decline, and social unrest.

- Assess for mental health needs in CYSHCN and caregivers and make appropriate referrals.

- Support mental health/wellness of [CYSHCN](#) and their [caregivers](#) with proactive guidance to plan safe, inclusive social/recreational opportunities.
- Connect families to peer supports such as [Family-to-Family Information Centers](#).
- Assess the need, safety, and availability of respite services, such as in short-term stay units, if available.

Inpatient/Long-term Care/Post-acute Care Settings

- Ensure adherence to [CDC guidance](#) on infection control in health care settings.
- Adopt [family presence](#) policies that balance safety and PPE conservation with the unique needs of CYSHCN, who may require a caregiver to stay with them at all times. Young adults (older than 18 years) with disabilities or other special health care needs may need a family member/caregiver present in the inpatient setting as part of reasonable accommodations in alignment with the Americans with Disabilities Act.
- Pay careful attention to interfacility transfer and discharge processes to ensure children and caregivers avoid exposure during transitions in care.

Home Care Settings

- Explore the feasibility of [home modifications specifically to improve ventilation](#).
- Adopt procedures and accommodations to prevent SARS-CoV-2 transmission into the household (ie, testing procedures, personnel scheduling).
- As needed, refer families to resources for [housing support](#) and [internet service and electronic devices](#).

Rehabilitation/Habilitation Therapies

Systems of health care and/or education (ie, Early Intervention, schools) may provide services such as physical, occupational, speech, and other therapies. Such therapies are critical for early childhood development and school-age education and must continue during the pandemic. Such services are both medically necessary and dictated by the requirements of the Individualized Family Service Plan or Individualized Education Plan (IEP). In some cases, Medicaid [finances](#) school-based therapies.

- Continue therapies regardless of in-person school attendance during the pandemic.

- Use virtual therapy services as an alternative or adjunct to in-person therapy services.
- Use appropriate PPE for in-person therapy services and give preference to larger, better-ventilated spaces.

Durable Medical Equipment (DME)/Medical Supplies/Pharmacy

- Adopt streamlined processes for approval and home delivery of DME, medical supplies, and pharmaceuticals.
- Make accommodations to move equipment from the school to home as needed for home-based instruction or services.
- Give allowances for extra supplies.

Transportation

- Prioritize and advocate for single patient/family transportation options such as vans for education needs and accessible taxis or ambulances for medical encounters. Private transport is especially important for children who have challenges using face coverings or in settings where other people will not be physically distanced or use face coverings.
- Encourage the use of a child's own car seat or assigned seat with distancing.
- Promote opening windows when possible. If using transportation with multiple individuals in an enclosed space (eg, buses to support education, medical, or community life), use strict capacity limits and universal use of face coverings.

Care Coordination and Case Management

During the pandemic, care coordinators and case managers should proactively reach out to CYSHCN, especially those who have not recently engaged with the health care system, to review needs and make appropriate referrals for supports. Families of CYSHCN have increased financial burdens generally and, thus, may need additional supports during the pandemic, including [unemployment benefits](#), [Administration for Children and Families](#) resources (including [Temporary Assistance for Needy Families](#)), and [Supplemental Security Insurance](#), which provides cash assistance to many families of children with disabilities and chronic illnesses. CYSHCN are at [higher risk for malnutrition](#) and may be at elevated risk of food insecurity from the pandemic, so families should be connected to [programs to address food](#)

[insecurity](#), such as the [Supplemental Nutrition Assistance Program \(SNAP\)](#) and [Special Supplemental Nutrition Program for Women, Infants, and Children \(WIC\)](#). Insurance coverage for medical foods may help in specific clinical circumstances. Some CYSHCN are at [higher risk for child abuse and maltreatment](#) generally and may be at even greater risk during the pandemic. [These resources](#) may support families and other stakeholders. [Family support organizations](#) are critical partners in systems navigation and connecting families to appropriate services and support during the pandemic.

How should payers of health care support CYSHCN during the pandemic?

The AAP policy statement “[Principles of Financing the Medical Home for Children](#)” should be the starting point for health coverage for CYSHCN during the pandemic. Enhanced payment for care delivery based on the complexity of care and payment for coordination of that care is essential to support substantially increased needs during the pandemic (**see Health Care Needs Section**). A pandemic may also lead to disruptions in coverage because of income reductions and job loss, resulting in loss of employer-sponsored health insurance. Coverage options are available [here](#).

- Public coverage options, such as Medicaid, should streamline the process of enrollment with policies such as presumptive eligibility.
- Medicaid programs should provide all necessary services to children as mandated by the [Early and Periodic Screening, Diagnostic, and Treatment](#) provisions of Medicaid law. Payment for all services must be sufficient to ensure the provision of all required services during the pandemic.
- States should use [health insurance premium payment programs](#) to support and maintain employer-sponsored health insurance for children eligible for Medicaid (including those who receive Medicaid through home and community-based service programs like waivers). These programs can help families afford current options and, in some cases, pay for COBRA coverage in the event of job loss.
- All payers should [cover telehealth](#) for all health providers, including primary care, complex care teams, rehabilitative and habilitative therapists, subspecialty providers, behavioral health specialists, home care providers, and others with coverage at parity for in-person services. Cross-state licensing reciprocity is necessary to help children who cross state lines for care. Given the multiple stakeholders involved in the care of many CYSHCN, payers should pay for group telehealth encounters.

- All payers should provide enhanced payment to providers across the continuum of care to account for substantially increased expenses such as PPE and increased need for typically unpaid non–face-to-face care coordination and planning during the pandemic.
- Payer case management and utilization review entities should maximize the access of CYSHCN to services needed during the pandemic and grant flexibility in meeting unique family needs across the continuum of care.
- Payers should presumptively cover habilitative and rehabilitative services for CYSHCN without formal diagnoses, because the pandemic limits the ability to perform the necessary diagnostic assessments.
- Home care during a pandemic is essential for many CYSHCN, and the AAP policy statement “[Financing of Pediatric Home Health Care](#)” should be a starting point for home care coverage.
 - Cover home-based laboratory draws and diagnostic imaging.
 - Pay for PPE, rehabilitation/habilitation therapies, and telehealth/telemonitoring. To minimize the number of providers coming into the home, use flexible staffing policies such as overtime allowance.
 - Use [home and community-based services](#) such as waivers and other options to provide targeted services and Medicaid coverage for eligible populations. Such programs should provide home modifications to improve ventilation in-home care settings, payment for PPE, telehealth devices, and internet connectivity. Provide services to all who need them without waiting lists. Use streamlined approval processes.
 - Expand options to [compensate family caregiving](#) to provide in-home supportive services.

How should school reopening decisions accommodate CYSHCN during the pandemic?

Information on school reopening is available via the [AAP interim guidance](#). Education is particularly critical for the development and well-being of CYSHCN, and communities must prioritize CYSHCN by taking all steps necessary to suppress community transmission of SARS-CoV-2 and giving school districts the resources needed to conduct education safely during the

pandemic. Inequities are particularly salient in education. Virtual learning is more difficult to access for younger CYSHCN, who may begin special education at age 3, and those with a variety of disabilities. CYSHCN from racial/ethnic minority groups and lower-income families have more barriers to virtual learning, and those with certain health conditions have higher risks for SARS-CoV-2 infection and consequences of the infection. Decisions at the community and individual level must take into account the level of community transmission and the risk of transmission to household members who may be at [higher risk](#) for severe acute biological effects of SARS-CoV-2 infection, such as older individuals and individuals with certain chronic conditions, as well as reasonable assessments of the resources required to implement plans.

[Shared decision making](#) among families, health care providers, and educators is the likeliest pathway to come to a joint decision about the best options for the individual child or adolescent as to the optimal educational environment and needed accommodations.

The [CDC School Decision-Making Tool](#) can be a useful starting point for discussions by encouraging a comprehensive review of current risks and school-based plans. Pediatricians can support patients/families by facilitating a thorough and balanced understanding of the known benefits and risks of in-person attendance, virtual learning, and hybrid models. Based on the student/family's priorities, the team (including student/family, school nurse, school administrator, teacher, and pediatrician) should work to develop creative, flexible, and responsive accommodations to allow those priorities to be met safely. [Parent training and information centers](#) can provide support regarding education issues, including IEPs and 504 Plans.

With virtual instruction (hybrid or full), schools should:

- Arrange access to adequate internet bandwidth, connection speeds, and individual devices for instruction and training for families on use, particularly those with less digital fluency.
- Update IEPs and 504 Plans to accommodate virtual and hybrid instruction methods, update and prioritize goals, and find creative and flexible approaches to achieve such goals. Revisit as circumstances warrant.
- Provide options for aides (in person at home or virtual) or home nursing to assist CYSHCN with virtual learning.
- Allow siblings of CYSHCN more likely to have severe biological effects of SARS-CoV-2 infection to complete virtual learning if desired by families.

- Develop plans for CYSHCN to get compensatory services once in-person instruction is resumed.
- Offer virtual therapy sessions and make arrangements for home-based therapies.
- Allow those choosing virtual learning to participate in some in-person activities (ie, therapy, outdoor events) on an individualized basis.
- Offer flexibility in the scheduling of remote learning options for children whose primary caregiver may have other responsibilities such as work.
- Provide options for food delivery and refer to supports to address food insecurity and other needs (see case management section).
- Support additional mental and behavioral health needs of students and staff.

With in-person instruction, schools should:

- Review IEPs and 504 Plans before the beginning of the year and update them with creative, flexible, and responsive accommodations for safe in-person school attendance while maintaining overall goals.
- Ensure updating of the IEP based on the student's current needs as well as staffing capacity and changes in the use of physical spaces at the school.
- Give children and adolescents more likely to have severe biological effects of SARS-CoV-2 infection preference to receive instruction and participate in inclusive activities in larger, better ventilated, and less crowded indoor spaces or outdoor spaces, with heightened attention to PPE, surface cleaning, and hand hygiene practices.
- Educate staff on the proper use of PPE, with particular attention to close contact situations such as therapies, diapering, feeding, and medical procedures (**see PPE section for details**).
- Support additional mental and behavioral health needs of students and staff.

How should early childhood care decisions accommodate CYSHCN during the pandemic?

Information on child care is available via the [AAP interim guidance](#). CYSHCN may receive child care in a variety of settings, including general daycare, special needs daycare programs,

medical day care programs, and in-home caregiving. As with school reopening decisions, [Shared Decision Making](#) is essential to make child-specific decisions about the risks and benefits of various child care options. CYSHCN may need updated [Individualized Health Plans](#) in the pandemic. Resources for childcare options are available [here](#).

How should communities accommodate CYSHCN during the pandemic?

Appropriate accommodations from all levels of communities and institutions may be required to achieve the safety and well-being of CYSHCN. Examples of these accommodations may include:

- Employers
 - Give parents and other family members of CYSHCN flexibility in working from home and leave policies, because these families may have added barriers to child care.
 - Advocate for families to get needed coverage across the continuum of care for CYSHCN from employer-sponsored health insurance plans. Benefits exceptions facilitated by human resource professionals can help families with needed supports.
- Community businesses
 - Comply with the Americans with Disabilities Act in outdoor dining to allow wheelchairs to pass through.
 - Set priority hours for grocery shopping and food pantry retrieval as well as prioritization for delivery programs.
- Utilities and internet providers
 - Assist with maintenance of service in the event of family financial difficulty to maintain electricity for medical equipment, appropriate climate control for medical needs, and remote connection to health care and education services.
 - Provide extra allowances for bandwidth usage because of telehealth and remote learning, especially for low-income families.
- Housing owners/landlords

- Consider [accommodations to improve ventilation](#), especially when home care providers are coming and going to meet the needs of CYSHCN.
- Use payment plans and other methods to avoid evictions that compromise home care.
- Transportation entities
 - Accommodate CYSHCN and their families who rely on public transit with accessible, capacity-limited options and enhanced access to programs that allow individual/family transportation for people with disabilities.
- Park districts
 - Help families reserve *accessible*, physically distant outdoor space for safe recreation.
- Community organizations and faith communities
 - Help CYSHCN and their caregivers through accommodations that promote safe inclusion in recreation and worship. Families can often benefit from help with errands and financial assistance as well.

Additional Information

- [Caring for Children With Acute Illness in the Ambulatory Care Setting During the Public Health Emergency](#)
- [Guidance on Providing Pediatric Well-Care During COVID-19](#)
- [Frequently Asked Questions: Interfacility Transport of the Critically Ill Neonatal or Pediatric Patient with Suspected or Confirmed COVID-19](#)
- [Newborn Screening During the COVID-19 Pandemic](#)
- [AAP News COVID-19 Collection](#)

Interim Guidance Disclaimer: The COVID-19 clinical interim guidance provided here has been updated based on current evidence and information available at the time of publishing. Guidance will be regularly reviewed with regards to the evolving nature of the pandemic and

emerging evidence. All interim guidance will be presumed to expire in December 2020 unless otherwise specified.

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