

# Supporting Students with Chronic Health Conditions in School-Based Out of School Time Programs

Accessible link: [https://www.cdc.gov/healthyschools/managing\\_CHC\\_OST.htm](https://www.cdc.gov/healthyschools/managing_CHC_OST.htm)

This issue brief presents policy and programmatic considerations for students with chronic health conditions who attend public school-based before- and after-school programs (OST programs). The brief highlights the importance of communication and coordination between students and caregivers, school administration and staff, and school-based OST programs. Each setting serves students but may have different approaches and personnel for helping students manage chronic health conditions.

## Background

For many students, time in school does not begin or end with the bell. Parents place trust in Out of School Time (OST) programs to support their children and address their health and safety. In 2020, 7.8 million children (14%) participated in an after-school program.<sup>1</sup> This includes students participating in programs offered on school grounds. Students who participate in OST programs often need support beyond learning and academics. For example, students may have chronic health conditions (e.g., diabetes, asthma) and need support to manage such conditions. In the United States, **more than 40% of school-aged children and adolescents have at least one chronic health condition.**<sup>2</sup> The health care needs of children with chronic health conditions can be complex—involving both daily management and preparing for potential emergencies. It is important that staff in settings where students spend time, such as schools and OST programs, have the skills and resources needed to support students with chronic health conditions.



OST programs vary in

- operation hours,
- staffing,
- leadership,
- resources (e.g., equipment, funding, space, training), and
- the types of regulations they must follow, such as licensing regulations and local joint use agreements.

Given the diversity of OST program operations, the approach to addressing chronic health conditions may differ at the local level.

Key policy and program considerations for children with chronic health conditions and areas where improved communication and coordination have the potential to enhance the youth experience. Recognizing that specific considerations will vary across programs, this brief provides an overview of relevant federal policies and identifies action steps that apply to a wide range of programs that are delivered on school grounds.

## Legal Issues

Districts and schools often sponsor organizations that have OST programs located on their properties. A formal exchange of information may be necessary for students with chronic health conditions that require either emergency or ongoing management in the OST setting. State and local policies and practices may vary, as no federal legislation exists that mandates information sharing between schools and OST programs. Federal laws governing health information and privacy include the Family Educational Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and can help guide considerations for schools, OST staff, and families about confidentiality.



*Various OST programs are available for school-aged children, including child-care, youth development, and special interest activities (i.e., science clubs, art programs, and sports clubs).*





*Different organizations can run these programs, including schools, local and national organizations, universities, community organizations, and parent volunteers.*



Some state laws may include provisions that explicitly permit school or OST program staff to assist students with managing their chronic diseases (e.g., administration of medication), while others might contain certain requirements to prepare for a health-related emergency. For example, many states have regulations related to the availability of medicines, such as “stock epinephrine” in schools for any student having a severe allergic reaction, with some states requiring stocking in schools. Access to medicines, such as epinephrine, or other supplies to help monitor chronic conditions, may vary outside of normal school hours. In addition, OST staff may have different training, certifications, and responsibilities than school staff for addressing students with chronic health conditions.



Federal, state, and local laws may affect the responsibilities and challenges associated with coordinating care between a school and OST program for a student with chronic health conditions. State and local laws vary by jurisdiction and may impose different responsibilities on staff or programs. Several federal laws may also need to be considered with regard to information sharing and providing appropriate accommodations for students with chronic conditions, including, but not limited to The Rehabilitation Act of 1973 (Section 504), Americans with Disabilities Act (ADA), and Individuals with Disabilities Education Act (IDEA).

The Rehabilitation Act of 1973 (Section 504)	Americans with Disabilities Act (ADA)	Individuals with Disabilities Education Act (IDEA)
<ul style="list-style-type: none"> <li>• <b>Prohibits discrimination</b> against individuals with disabilities.</li> <li>• <b>Prohibits excluding</b> an individual with a disability from participating in any program or activity that receives federal financial assistance.</li> <li>• <b>Mandates schools to provide</b> free appropriate public education to all qualified students with a disability to meet the student’s individual educational needs as adequately as the school meets nondisabled students.</li> </ul> 	<ul style="list-style-type: none"> <li>• <b>Prohibits discrimination</b> against individuals with a disability by any state or local government services, programs, or activities.</li> <li>• <b>Makes reasonable accommodations</b> available for students with protected disabilities to participate in school activities and makes their facilities and other services accessible to disabled students.</li> </ul> 	<ul style="list-style-type: none"> <li>• <b>Makes available</b> free and appropriate public education to students with disabilities that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.</li> <li>• <b>Provides funding</b> to support special education and related services—there may be additional requirements imposed on a school or program as a funding condition.</li> </ul>

If a district lacks direct involvement in or oversight of outside organizations providing OST or recreation programs on their property, the district is not relieved of its Section 504 obligations. For example,

- Daycare centers, camps, and other recreational programs covered by the ADA or Section 504 cannot refuse to admit a child because he or she has a chronic health condition and may require services (i.e., accommodations) to enable the child to participate in the program or benefit from the services available to children without such health conditions; and
- If a public-school district sponsors or contracts with an organization that discriminates against a student with a disability, the school district may be held accountable for such discrimination.



## Considerations

### School Administrators

- Create model policies, practices, and protocols using current federal, state, and local regulations.
- Involve health services staff, particularly school nurses or other health services staff, to coordinate and transition care to OST activities, including delegating tasks, such as medicine administration, if applicable, and information sharing with appropriate parties.
- Review how students with chronic health conditions are identified (e.g., on registration forms) and if students who need medicines are expected to self-carry and administer medicine (e.g., epi-pen, asthma inhaler).
- Develop communications strategies between districts or schools, OST programs, parents, and caregivers.
- Consider audience-specific staff trainings and professional development to support students who participate in OST activities.

### OST Providers

- Establish a system to identify students with chronic health conditions (e.g., collect relevant information on registration or enrollment forms), and understand program needs to better support a child's health and active participation in OST programs and activities.
- Coordinate with school administrators and school nurses or other health services staff to understand protocols and practices for students with chronic health conditions.
- Provide staff training to promote awareness of potential challenges and appropriate responses for routine and urgent matters for students with chronic health conditions. Identify ways to make these trainings readily available to new staff (e.g., as part of onboarding) to address potential loss of knowledge and skills with staff turnover.
- Communicate with parents about protocols and practices for students with chronic health conditions—especially if they differ from those during school hours.
- Encourage staff to learn about individual needs of students with chronic health conditions as part of family engagement activities.

### Parents and Caregivers

- Advocate for your child if he or she has a chronic health condition and will participate in OST activities. Share with staff how you would like to see your child's health needs addressed.
- Complete all necessary information forms and understand state and local regulations concerning medicine administration, if required for your child. Make sure that program staff are aware of any known health emergency triggers for your child.
- Ask who is responsible and what services may be available in case your child has an emergency or needs routine medical attention.
- Find out if policies or protocols are different during OST activities versus during the school day.

When students move between school-day classes and OST programs, their health needs travel with them. Coordination and communication across home, school, and OST settings provides for continuity of care. To best serve students with chronic health conditions, a multi-faceted approach involves supportive adults, including family caregivers, school staff, and OST program staff. Understanding legal considerations and local context can show how programs support the safe and active participation of the students they serve. Schools, organizations, and agencies that work with schools and OST programs can explore the [Whole School, Whole Community, Whole Child](#) framework promoted by CDC for best practices, strategies, and awareness to advance the care of all students during OST activities.

## ► Resources

[Health Information and Privacy](#) — Centers for Disease Control and Prevention

[Commonly Asked Questions About Child Care Centers and the Americans with Disabilities Act](#) — US Department of Justice

[Healthy Out-of-School Time Roadmap](#) — National Association of School Nurses and Healthier Generation

[Shared Use Playbook](#) — ChangeLab Solutions

## References

1. Afterschool Alliance, Edge Research, Burness. America After 3PM 2020: Demand Grows, Opportunity Shrinks. Washington, DC: Afterschool Alliance; 2020.
2. National Survey of Children's Health. NSCH 2018 19: Number of Current or Lifelong Health Conditions, Nationwide, Age in 3 Groups website. [childhealthdata.org](http://childhealthdata.org). Accessed February 24, 2021.

