

# Consensus Statement on the Core Tenets of Chronic Condition Management in Schools

August 2021

*As a result of the COVID-19 pandemic, the need for effective chronic condition management is greater than ever. Due to missed and deferred health care, financial and social strains on families that affect children's health, and increased incidence and severity of mental health concerns, many children with chronic conditions are returning to school with higher acuity and support needs.*

*Due to the pandemic, there is now increased recognition of the link between health and education and heightened awareness of the range of essential services provided by schools, including health services and chronic condition management. Schools have come to realize the critical importance of collaborating with health care, public health, and social service organizations and have expanded their partnerships to meet student needs. As school districts reimagine how they will operate in the coming years, the core tenets outlined in this statement can serve as a framework for leveraging new partnerships and funding to develop an educational model that fully embeds and supports the health and well-being of all children, including those with chronic conditions.*

## Organizational Sign-On



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## BACKGROUND

Approximately 25% of children have a chronic condition such as asthma, diabetes, dental disease, epilepsy, food allergy, or a mental health disorder,<sup>1</sup> and over 6% have multiple chronic conditions<sup>2</sup> (see Appendix A for definitions of key terms). Effectively managing these conditions is critically important in order for these children to lead healthy, thriving, productive lives—both now and in adulthood.

Condition	Prevalence in children
Asthma	8.5% <sup>3</sup>
Diabetes	0.4% <sup>3</sup>
Epilepsy and seizure disorders	0.7% <sup>3</sup>
Food allergy	7.6% <sup>4</sup>
Mental health concerns	13-20% <sup>5</sup>
Obesity	18.5% <sup>6</sup>
Oral health: Untreated tooth decay	13% <sup>7</sup>
Multiple chronic conditions	6% <sup>2</sup>

Schools are responsible for fostering academic growth and ensuring that all students have equitable access to educational opportunities. Effective chronic condition management is essential to schools fulfilling this mission. Poorly-controlled chronic conditions impact a range of educationally-relevant factors, including attention, behavior, dropout, academic achievement, and attendance,<sup>8-14</sup> with nearly 14 million missed school days per year from asthma alone.<sup>15</sup> Therefore, chronic conditions must be addressed in order to support student success. In addition, in order to protect

students' safety while in school, staff must be prepared to recognize and respond to life-threatening emergencies caused by chronic conditions such as asthma, food allergies, seizure disorders, and diabetes.<sup>3,4</sup>

Chronic condition management is especially needed in schools with large numbers of students impacted by health disparities. Children living at or below the poverty level have a 30% increased risk of having a chronic health care need, with higher rates of asthma, obesity, mental health conditions, and poor oral health.<sup>7,16</sup> Black children are significantly more likely to have asthma than white children, with rates upwards of 14%, and are 5 times more likely to be admitted to the hospital for asthma.<sup>17</sup> Rates of obesity and untreated tooth decay are also significantly higher in Latinx and Black children compared to white children.<sup>7,16,18,19</sup> Given that these students are also likely to face other inequities that impact educational outcomes (such as food and housing insecurity, under-funded schools, reduced access to technology, and fewer academic enrichment and extracurricular opportunities), providing effective chronic condition management is crucial for reducing barriers to academic achievement. Students living in health care shortage areas also have an increased need for school-based chronic condition management.

High-quality school health services can improve health and academic outcomes for children with chronic conditions and should be accessible to all students.<sup>20,21</sup> However, schools cannot effectively manage chronic conditions on their own. Optimizing the short- and long-term outcomes for children with chronic conditions requires an integrated, intentional, and interdisciplinary approach that engages multiple sectors. Schools provide mental health and nursing services to address children's daily health needs and support long-term chronic condition management through care planning and coordination, self-management education, counseling, and other services. Health care providers, school-based health centers, health care systems, and public health agencies work to prevent, diagnose, and treat chronic conditions in children. Mental health and

social service providers attend to emotional and behavioral factors related to chronic conditions and address social determinants of health that influence chronic disease outcomes. Families identify, support, and advocate for their children’s needs across settings. Policymakers, government agencies, and insurers develop policies, systems, funding mechanisms, and payment structures that provide access to necessary services and supports. Unfortunately, while supporting children’s health requires coordination and collaboration amongst all of these sectors, they typically operate in silos, each following discipline-specific models and frameworks. The structure of funding and financing mechanisms and a lack of inter-operable information systems further contribute to fragmentation.

## RATIONALE

In response to these concerns, representatives from the American Academy of Pediatrics Council on School Health, the Center for Health and Health Care in Schools, the Children’s Hospital Association, Healthy Schools Campaign, the National Association of School Nurses, the National Association of State School Nurse Consultants, and the School-Based Health Alliance collaborated to develop a common framework that can be used by schools and partners from across disciplines to guide an integrated, collective approach to chronic condition management in schools.

The purpose of this framework, which consists of a set of 7 core tenets and 3 foundational supports, is to promote and optimize health and academic outcomes for children by:

- Establishing shared principles on the management of chronic health conditions that can be used by stakeholders from diverse disciplines, and
- Setting a universal standard for high-quality chronic condition management in schools that establishes accountability and promotes equity.

The core tenets and foundational supports are intended to be addressed collaboratively by school stakeholders, defined as those working directly with children in schools as well as community partners that are invested in children’s health and academic success. Rather than setting forth an entirely new model, the tenets are drawn from models already in use by school stakeholders, including medical home and medical neighborhood models, the dental home model, the Chronic Care Model, the Framework for 21<sup>st</sup> Century School Nursing Practice™, care coordination frameworks, the principles of an effective system of care for children and youth with special health care needs, and the Whole School, Whole Community, Whole Child model (Appendix B). This allows for easy integration into practice while establishing a common language and shared standards that stakeholders can collectively strive for.

### **School stakeholders**

#### ***Those working directly with children in schools, such as:***

- School nurses and health services staff
- Mental health providers
- Teachers
- Administrators
- Support staff
- Volunteers
- Families
- Contracted or co-located providers

#### ***Community partners, such as:***

- Health providers (primary and specialty care, dental, mental health)
- Hospitals and health systems
- State and local public health and education agencies
- Community/social service organizations
- Insurers

## THE CORE TENETS

Effective, high-quality care for children with chronic conditions is accessible, comprehensive, coordinated, culturally effective, equitable, evidence-based, and child- and family-centered. The key elements of these tenets are further described below.

### Accessible

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School stakeholders:

- Work to ensure that children with chronic conditions are able to receive the care they need, when and where they need it, including access to school nursing services, a primary care medical home, and specialty and dental care.
- Assist children with chronic conditions in navigating barriers to care such as cost, transportation, appointment times, language and literacy, technology, and physical accessibility.
- Minimize barriers to care within schools and partner organizations.

### Comprehensive

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School stakeholders:

- Advance a comprehensive system of care to meet the needs of children with chronic conditions.
- Apply a whole-child orientation with consideration of physical, emotional, social, cultural, and academic needs.
- Support children with chronic conditions across all school settings (including field trips, before and after school care, virtual learning, homebound, etc.) and during emergencies and disasters (e.g., pandemics, natural disasters, lockdowns).
- Provide care that follows children with chronic conditions seamlessly from pre-K through high school and from school to community-based care.

### Coordinated

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School stakeholders:

- Implement team-based care for children with chronic conditions, with roles defined according to local circumstances.
- Actively share responsibility and decision-making across the team.
- Establish mechanisms and agreements for sharing information among members of the child's care team.
- Support transitions in care for children with chronic conditions.
- Provide case management and care planning for children with chronic conditions when appropriate.

### Culturally effective

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School stakeholders:

- Understand the cultures represented in their school and community.
- Consider and respect the beliefs, values, customs, and needs of all cultures.
- Develop and maintain awareness of how their own cultural framework impacts their interactions with children and families with chronic conditions.
- Use strategies such as motivational interviewing and active listening as a vehicle to understand and respond to the cultural beliefs and practices of the children and families they serve.

## **Equitable**

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School stakeholders:

- Provide individualized care and resources for all children with chronic conditions according to their needs.
- Work to eliminate bias, discrimination, and inequity within their organizations and community.

## **Evidence-based**

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School stakeholders:

- Implement evidence-based best practices and clinical guidelines for chronic condition management.
- Actively engage in performance and quality improvement activities to ensure the provision of high-quality, safe care for children with chronic conditions.
- Ensure that all children with life-threatening chronic conditions have an emergency action/care plan and access to life-saving medications and equipment at school.

## **Child- and family-centered**

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School stakeholders:

- Collaborate with children with chronic conditions and their families to identify needs and goals and engage in shared decision-making.
- Use a strengths-based approach to develop a partnership with children and their families based on trust and respect.
- Provide self-management education and support that builds independence and confidence.
- Advocate for policies, programs, and services to meet the needs of children with chronic conditions and their families.
- Include children with chronic conditions and/or their families on advisory and decision-making bodies.

## **FOUNDATIONAL SUPPORTS**

Implementing the core tenets requires supportive leadership and culture across all sectors involved, strong information and communication systems, and sustainable and equitable funding mechanisms. While progress can be made in the absence of these factors, the foundational supports provide the infrastructure needed to fully operationalize the core tenets. Long-term efforts to build and sustain these supports can be advanced through the actions outlined below.

### **Supportive leadership and organizational culture**

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School leaders:

- Prioritize and integrate health in all school policies and practices.
- Provide adequate resources and support for school health services, including a school nurse in every school.
- Recognize the leadership role of the school nurse in implementing the core tenets.

School and community leaders:

- Build partnerships and foster cross-sector collaboration both internally and externally.
- Advance improvement efforts within their organizations.
- Provide robust professional development opportunities to strengthen evidence-based care for children with chronic conditions and provide strategies for supporting those with complex medical and/or social needs.

- Leverage policies, systems, and resources to promote implementation of the core tenets of chronic condition management.
- Invest in leadership development, with a focus on supporting diverse, representative leaders.

### Information and communication systems

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School and community leaders implement systems within their organizations that support:

- Communication and care coordination across institutions and sectors.
- Individual and population tracking and management.
- Community health surveillance.
- Implementation of clinical guidelines.
- Evaluation and performance improvement.
- Adherence to privacy and patient/student protection regulations where applicable.

### Sustainable and equitable funding

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- Reliable funding is available to sustain long-term, community-wide programs and systems to optimize child health and academic outcomes, including a school nurse in every school.
- Resources to support the provision of care and services are distributed equitably among and within communities.
- Insurance payment for health services delivered by qualified providers is equivalent regardless of service location.

## GETTING STARTED

Implementing the core tenets and foundational supports begins with the three steps below:

1. **Convene stakeholders** to collaborate on implementing the core tenets. Each stakeholder has unique contributions to make to this process and can educate others on the needs and opportunities within their system. For example,
  - **Schools** provide perspective on the relationship between children’s chronic conditions and their academic performance, social-emotional functioning, and overall health. Schools can serve as the convener for other stakeholders and may function as a hub for service coordination and delivery. Ideally, districts can integrate this work within existing initiatives related to school health (e.g., under school health advisory committee or Every Student Succeeds Act planning activities).
  - **Health care and mental health providers** from both inside and outside the school can offer insight into evidence-based strategies and supports for management of chronic conditions in schools and partner in providing medical and dental care. They often have communications and information systems and other resources to support the implementation of the core tenets and are a key partner in ensuring the delivery of accessible, comprehensive, coordinated, and evidence-based care.
  - The collaboration of **children and families** is essential for advancing equitable, culturally effective, child- and family-centered care. Families know what their children need and can ensure that the core tenets are implemented in a way that meets those needs.

- **Public health partners** bring expertise in developing systems of care that are aligned with the core tenets, a knowledge of the health and social services available in a community, and a prevention orientation that can assist in building a whole-child approach.
  - **Social/community service providers** play an important role in identifying and addressing social determinants of health that impact chronic condition management and in providing supports for families and other stakeholders in meeting the needs of children.
  - **State and federal agencies** are critical to advancing the foundational supports and aligning policies, systems, and infrastructure with the core tenets.
  - **Insurers** can help identify or develop payment mechanisms to support school-based services and cross-institutional, collaborative care models.
2. **Identify strengths and gaps** in implementing the tenets within and across institutions. Stakeholders can examine the degree to which the core tenets are enacted within their respective institutions as well as exploring how application of the tenets can be strengthened through collaboration and coordination. Tools such as the [Health services Assessment Tool for Schools](#) (HATS), [School Health Index](#) (SHI), and [School Health Assessment and Performance Evaluation System](#) (SHAPE) can help schools assess their services; there are multiple [medical home evaluation tools](#) available for primary care practices that can provide a starting point.
3. **Develop collective goals and strategies** to address gaps that are affecting optimal care for children with chronic conditions. Stakeholders can work together to prioritize areas for improvement, learn from each other's successes, and leverage their strengths and resources to improve implementation of the core tenets and foundational supports across sectors.

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## Appendix A: Definitions

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**Best practice:** Practices informed by available evidence, expert opinion, and professional standards of care

**Care coordination:** “The oversight and alignment of multiple evidence-based components and interventions that support the health and well-being of students with chronic health conditions,” advance agreed-upon student- and family-centered outcomes, and support academic success. Typically led by the school nurse, ideally in coordination with the student’s health care provider(s)<sup>22</sup>

**Chronic conditions:** Conditions persisting over a period of time that require health care and/or limit activities of daily living. Includes the following:

-Allergy/anaphylaxis	-Mental health	-Seizure disorder/epilepsy
-Asthma	-Obesity	
-Diabetes	-Oral health	

**Community leaders:** Leaders of organizations and agencies that are invested in children’s health and academic success, including leaders of health care institutions, public health and education agencies, insurers, community/social service organizations, and local businesses

**Community partners:** Organizations and agencies that are invested in children’s health and academic success, including primary, specialty, and dental care providers; hospitals and health care systems; public health and education agencies; insurers; and community/social service organizations

**Comprehensive system of care:** A system or group of coordinated systems that are equipped to meet all care needs for children from birth to adulthood in a timely, accessible manner, including providing high-quality preventive, primary, and tertiary care to address physical, emotional, behavioral, and social needs

**Evidence-based practice:** Practices with evidence of effective results and/or improved outcomes from well-designed research studies

**Family:** The individuals responsible for and involved with a child’s care. Includes biological, adoptive, and foster parents and siblings; legal guardians; and other caregivers that are bonded to the child through ties of blood, marriage, love, and/or common residence.

**Policymaker:** Individual charged with making rules, regulations, and/or policies at any level, from state and federal legislators to local school board members

**School:** PreK-12 United States educational institution. Chronic condition management in schools applies to the full span of time during which school-sponsored activities and programs occur, including before- and after-school care, summer school, school-sponsored extracurriculars, and school-sponsored trips



**School health services:** Services provided by school district employees and/or contracted providers to assess, protect, and promote student health, with a primary focus on removing health-related barriers to education. Typically led by school nurse(s). May include other health and surveillance activities conducted in collaboration with outside providers such as oral health programs and school-based health centers

**School health team:** Individuals within a school responsible for collaboratively managing and supporting children's physical, emotional, and social health needs, including a school nurse

**School leaders:** School administrators (e.g., superintendents, principals, vice principals), school board members, and disciplinary leads (e.g., lead school nurse, department heads)

**School nurse:** Nurse who provides school health services available to all students in a school setting and, if applicable, is licensed and qualified as a school nurse under state regulations. Recommended to be a registered professional nurse with at least a baccalaureate degree in nursing

**School stakeholders:** Those working directly with children in schools (e.g., school staff, leaders, volunteers, parents, and contracted or co-located providers) as well as community partners that are invested in children's health and academic success (e.g., health providers, public health and education agencies, community and social service organizations, and insurers)

Appendix B: Connections with other models

The table below shows how the core tenets and foundational supports for chronic condition management in schools connect with other models used by school stakeholders.

	<a href="#">Medical Home</a> 23–27	<a href="#">Dental Home</a> 28	<a href="#">Medical Neighborhood</a> 29–31	<a href="#">Chronic Care Model</a> 32,33	<a href="#">Framework for 21<sup>st</sup> Century School Nursing Practice</a> <sup>34</sup>	<a href="#">Care Coordination</a> 22,35	<a href="#">Effective Systems of Care for Children and Youth with Special Health Care Needs</a> <sup>36</sup>	<a href="#">Whole School, Whole Community, Whole Child</a> <sup>37–39</sup>
<b>CORE TENETS</b>								
Accessible	x	x	x		x		x	
Comprehensive	x	x	x	x	x	x		
Coordinated	x	x	x	x	x	x	x	
Culturally effective	x			x	x			
Equitable	x	x			x		x	
Evidence-based	x	x	x	x	x		x	
Child- and family-centered	x	x	x	x	x	x	x	x
<b>FOUNDATIONAL SUPPORTS</b>								
Leadership support and culture				x	x			x
Information and communication systems			x	x	x			
Sustainable and equitable funding	x	x					x	

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## Appendix C: Acknowledgements

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The following individuals collaborated in developing this statement. Their affiliations were current as of their most recent involvement. This statement does not necessarily represent the official views of these individuals.

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