Safeguarding Health and Education Services to

# Children during Public Health Emergencies A STATEMENT OF PRINCIPLES

These guiding principles are designed to give states a starting point and to set standard expectations – drawing upon the best available data and research and the lived experiences of children, their families, and the practitioners that care for them.





# Introduction

The COVID-19 pandemic has had far-reaching implications on children's health and particularly for children with disabilities and/or special health care needs (hereafter 'children with disabilities'). Most notably, the pandemic has amplified existing racial inequities, through heightened levels of ethnic discrimination and increased racial disparities in accessing care and using health services<sup>1</sup>. Schools provide a myriad of services and supports - beyond education - to children and youth. As such, they are a particularly critical source of health services for children, especially those with disabilities. Parents and families of children with disabilities have made clear that the COVID-19 pandemic has disrupted this support dramatically, creating significant challenges to well-being and development beyond teaching and learning. Practitioners have also struggled to connect with and provide robust services during this challenging time.

State and territorial public health and education programs play a critical role in improving the health and well-being of those experiencing poor outcomes due to structural racism and systemic inequities. In partnership, health and education can and must improve outcomes and promote stronger, more equitable systems. However, COVID-19 has more broadly exposed the flaws in Federal statutes and regulations, which have not been designed for our current context and must be addressed now and in the future as they provide insufficient quidance for decision making at the agency level and insufficient support for families forced to navigate complicated, often conflicting processes to ensure their children receive the care they need. Not addressing the gaps in policy that can and should drive critical public health and education practices, particularly during emergencies, these systems increase the likelihood of racism and ableism impacting decision making and implementation processes<sup>2</sup>.







#### About the guiding principles

In this document, we describe a series of guiding principles around systems-level capacity building; placement and services; and educational staff support. Although there is no one-size-fitsall model for coordination, these guiding principles are designed to give states a starting point and to set standard expectations drawing upon the best available data and research and the lived experiences of children, their families, and the practitioners that serve them - for state-level coordination and system resilience that persevere through both this crisis and those that follow. Throughout the process of developing these principles (see methods section), we have placed equity and Universal Design at the center and utilized a "Health in all Policies"<sup>3</sup> approach. We firmly believe that building stronger systems to support children with special health care needs and disabilities will not only improve their circumstances but will also benefit the entire community. In other words, we are focusing policy on those most underserved to create better, more coordinated systems for all.

## C The reality of our lives has been education delivery plans that are bureaucratic and confusing to navigate.

- Participant in the family focus groups

At the state and territorial level, both health and education agencies – with particularly strong roles for Title V Maternal and Child Health (MCH) Services Block Grant ("Title V") and state special education agencies – hold responsibility for serving these children and youth and elevating the voices of those with lived experience.

We do not provide legal guidance to states or assert whether current disability rights laws are adequate to safeguard children with disabilities and special health care needs in this context. Also, we do not address the very difficult choice to keep school buildings open for in-person services or to close them in favor of virtual support. We do provide a set of best practices that aim to improve the health and well-being of those experiencing poor outcomes due to structural racism and systemic inequities, through fostering partnership between state and territorial public health and education programs.

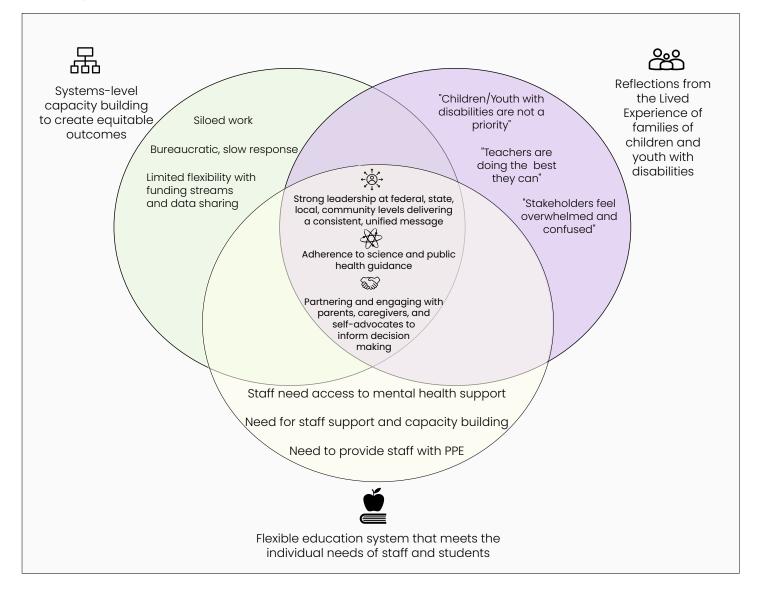




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In developing these principles, we placed the voices of families at the center of our work and are grateful for their willingness to share their experiences and ideas. In the section below and throughout this document, we strive to elevate those voices and ideas. We also relied heavily on the good work that has been done in the field already and the perspectives of public health professionals, education practitioners, and the national organizations that support these groups (see Methods). Each principle also includes an example of powerful existing work and ideas around what systems can look like if the principles are implemented intentionally and successfully. Although the COVID-19 crisis created the impetus for this work, we have designed these principles to be a resource to schools and health systems far into the future.

**Figure 2.** Experiences of Children with Disabilities and Special Health Care Needs and their Families Amid the COVID-19 Pandemic: This figure offers an illustration of the unique perspectives provided during a series of focus groups in Fall 2020.



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## Methods

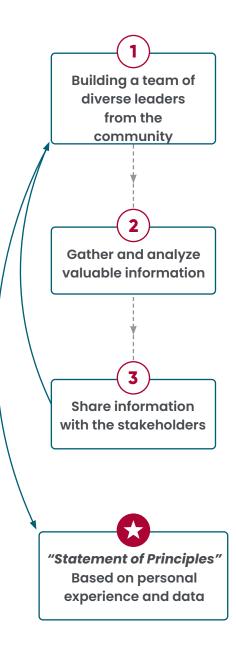
Coordination between education, health, and families themselves, is essential during any public health emergency. However, it is clear from many discussions amongst parents, practitioners, and state leaders about the need for common priorities, consistent language, and stronger alignment in funding and direction create major obstacles in providing comprehensive and aligned services that meet the needs of children and youth with disabilities.

### 66 We already have to navigate so many obstacles. We don't need yet another to navigate."

- Participant in the family focus groups

AMCHP and Child Trends wanted to ensure that the resource was grounded in equitable approaches, thus we sought to bring together a diverse group of stakeholders and to lift up leaders of/within/from communities directly impacted by racism, COVID-19, and/or educational social injustices. Specifically, we did not feel that we could adequately create this resource without basing our work off the support needs of those family, self, and community leaders and advocates, and others most impacted by this double pandemic of COVID-19 and racism.

Therefore, before we met with public health and education leaders to understand their needs, we gathered a small group of 14 family, self, and community leaders and advocates who identified as being personally impacted by these growing inequities due to a lack of coordination from state and federal leaders. These individuals hailed from 13 different states and U.S. territories and were recruited through Title V Family Delegates and Family-to-Family Health Information Centers. In our recruitment, we asked for intentional recommendations of those most impacted by multiple aspects of this pandemic, especially racism, ableism, and poverty. Our convening of this group consisted of exploring challenges and sources of help and support through reflecting on experiences in accessing health services during COVID-19 as well as breaking into small groups to discuss what supports are needed to support positive learning outcomes and quality of life for children with disabilities in remote, hybrid, and safe in-person learning environments.





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AMCHP and Child Trends took the valuable information collected from those with lived experience and analyzed patterns and themes to sketch out a visual (see Figure 2). AMCHP and Child Trends proceeded to convene four groups of health and education stakeholders (described below) and used this visual to ground those conversations in what we had heard from our group of individuals with lived experience. We collected information from these stakeholder groups in an iterative fashion to help us determine the necessary scope of this statement and to shape the content of the principles. The goal of this iterative process was to take the information from all groups and sketch out this "Statement of Principles" to set standard expectations - drawing upon the best available data and research and the lived experiences of children, their families, and the practitioners that serve them - for state-level coordination and system resilience that persevere through both the COVID-19 crisis and those that may follow.

## **Everyone learns differently.** Our kids still need an education even though they have special needs."

- Participant in the family focus groups



#### Title V CYSHCN Directors & key staff,

as well as Title V family professionals

# Educational practitioners from 8 different states.

Identifying as special education teachers, professionals, educational psychologists, and more.

#### Public Health & Disability Policy organizations:

- National Assoc. of County and City Health Officials (NACCHO)
- Assoc. of State & Territorial Health Officials (ASTHO)
- Assoc. of Univ. Centers on Disability (AUCD)
- Early Childhood Personnel Center (ECPCTA)
- American Assoc. of People with Disabilities (AAPD)
- Council for Exceptional Children (CEC)
- School-Based Health Alliance (SBHA)
- Administration for Community Living (ACL)
- CDC Foundation

#### Educational Associations & Policy organizations:

- National Assoc. of State Boards of Education (NASBE)
- Council of Chief State School Officers (CCSSO)
- National Assoc. of State Directors of Special Education (NASDSE)
- The School Superintendents Association (AASA)
- National Assoc. of School Nurses (NASN)
- National Assoc. of School Psychologists (NASP)
- American Federation of Teachers (AFT)
- National Education Association (NEA)
- National Assoc. of State School Nurse Consultants (NASSNC)



## **Foundational Themes**

The *Principles to Guide State Action to Safeguard School-Provided Services to Children with Disabilities* are guided by the following foundational themes that should exist across all principles:

## 1. Collaboration efforts should be centered around goals to create equity and disability justice.

A central goal of collaboration should be around **understanding and prioritizing the unique needs** of students living in poverty and/or students of color, who make up a disproportionate number of children with disabilities. Together, health and education must leverage collaborative efforts to improve access to services by **identifying and committing to a series of measures and outcomes to monitor and track** over time that **centers the needs of all** students, families, and professionals.

## 2. Coordination exists when families, communities, and practitioners are central partners during every step of the process.

Families, practitioners, and systems leaders all elevated the need for **regular partnership** with education and public health agencies to ensure **seamless and comprehensive services** before, during, and beyond a public health emergency. Both parents and practitioners need unique things from both systems and can **elevate challenges and share successes** that are imperative when making decisions that directly or indirectly impact learning outcomes and/or quality of life of students with disabilities.

#### **RECOMMENDATION:**

Students with disabilities, their families, and the staff that support them must be invited to the table to build and/or adapt plans *from the beginning rather than retrofitted into reopening plans*. Parents and caregivers and practitioners are important partners to both education and health entities and should be deeply engaged in decision-making around when and how to bring the two systems together. Public health emergencies, such as COVID-19, create a specific set of challenges that need **community-based solutions**, such as plans for reopening schools, supporting transitions when reopening plans shift, and supporting virtual learning.

## 3. Strong collaboration will promote resource sharing, funding coordination, and informed/supported staff.

Historically, collaboration between health and education has been on an asneeded or incidental basis, thus state departments of education may be unaware of initiatives occurring at state departments of public health, and viceversa. **Consistent and intentional collaboration and alignment on goals** and activities is *essential* for agencies to work together and share resources, and this is of even greater importance during a public health emergency.





#### 4. Existing networks should be leveraged to bridge gaps in coordination.

Both health and education have individual networks, such as through teachers and nurses. By connecting the existing networks to each other – to share priorities, challenges, and resources – states can **leverage infrastructure that already exists** to promote better cross-system coordination.

#### **RECOMMENDATION:**

Every state has a state school nurse <u>consultant</u> and state-affiliate school nurse <u>associations</u>. Robust coordination efforts would ensure that leaders from state public health and education agencies **share information directly with those networks** and promote **transparent communication with families**. This type of collaboration would be essential to building a cohesive response to a crisis such as a public health emergency but would also support ongoing efforts from both systems outside of crises.

#### 5. Develop a common language to support better coordination and data sharing.

Building on the need to identify collaborative goals and strategies across education and health, a **common language** is essential for the two systems to use or share data to understand their collective progress. One major barrier to coordination is a <u>lack of consistent language between education and health</u>. Terms may have different definitions or carry different weight across the two systems. They may also describe or evaluate the needs of children and families through a different lens. This can be exacerbated for children and youth of color, as different systems may use different techniques for gathering and reporting data on race and ethnicity. In addition to helping identify collaborative goals and strategies across education and health, **a common language is essential for the two systems to use or share data to understand their collective progress**.



# Systems-level capacity building

Beyond coordination, each system plays an important role in ensuring that children with disabilities have the educational and health services that they need to thrive. The COVID-19 pandemic has exacerbated existing gaps in the education and health systems that must be filled to expand their capacity to serve and create equitable outcomes for children.

#### **PRINCIPLE 1.**

School nurses and state school nurse consultants, where applicable, should be **present at every table** where school reopening decisions are being discussed at both the state and local levels.

#### WHY.

Health-related concerns—including PPE, sanitation, distancing protocols, and staffing needs—are prioritized when school nurses and other health staff are included in state and local conversations about school reopening. Nurses are also experts in care coordination and case management for students with special healthcare needs. Additionally, states and districts should leverage the expertise of their **state school nurse consultant**, *who acts as a liaison to state boards of education and nursing*, among other state agencies, on behalf of local school health programs. The state school nurse consultant also has influence to develop policies that ensure quality school nurse services across the state.

#### IMPLEMENTING THIS PRINCIPLE MAY LOOK LIKE:

Minnesota's Title V team, including the State School Nurse Consultant (SSNC), served on the Minnesota COVID-19 School and Child Care Response team and provided important feedback and subject matter expertise to Infectious Disease Epidemiology, Prevention, and Control Division as they developed guidance on COVID mitigation efforts for schools, child care facilities, youth programming, and youth-serving organizations. The SSNC was then recruited to support the management of supplemental funding awarded to the Minnesota Department of Health, specifically a \$8.4 million school workforce grant to increase onsite frontline health workforce personnel to address COVID-19.

• **Source:** Minnesota Title V MCH Block Grant FY21 Report on Emergency Planning and Preparedness



#### **PRINCIPLE 2.**

State health and education agencies should collaborate to make **data-informed decisions** about school closures and reopening that are clearly guided by **public health recommendations**.

#### WHY.

When families and practitioners are at the table during planning and decision making, state-level agencies may be able to better understand how to supply families with concrete risk assessments for sending their children back to school. **Providing concrete measures** for education delivery modalities to all stakeholders *takes equity into account by ensuring that all students' health risks are accounted for.* District decisions about how to safely deliver education can be politicized and forced because of public pressure *rather than adherence to health standards*. Families of students with disabilities, school staff, and students need a set of metrics that allows them to comprehensively assess the safest option for receiving educational instruction and other needed services. State education and health agencies should collaborate to define evidence-based metrics that districts can rely on when making decisions about service delivery for historically underserved youth.

#### IMPLEMENTING THIS PRINCIPLE MAY LOOK LIKE:

The *Washington State Department of Health (DOH)* developed a decision tree for the provision of in-person learning based on the risk of transmission of COVID-19 in school environments and community spread. The evidence-based metrics include considerations for who to prioritize for in-person learning and how to implement all required DOH health and safety recommendations to ensure safe learning conditions for students and staff.

#### **IMPLEMENTING THIS PRINCIPLE MAY LOOK LIKE:**

The University of Miami's Mailman Center for Child Development together with the Florida Chapter of the American Academy of Pediatrics and the Family Network on Disabilities developed a **checklist**—available in both **English** and **Spanish**—to help **families discuss the best school option with their family provider**.





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## Placement and Services

Both education and health systems are tasked with ensuring children are connected to the placements and services they need. Meeting the unique needs of students, families, and staff – during the COVID-19 public health emergency and moving forward – requires careful **coordination**, sufficient **funding**, and on-going **conversations** with various stakeholder groups including parents, public health leaders, educators, and subject matter experts. Schools need **detailed plans and clear guidance** on how instruction can be adapted to meet the needs of the family and learning environment, how to access funding required to safely support students and staff, and how sectors can work collaboratively while engaging key partners like parents, caregivers, and school staff.

#### **PRINCIPLE 3.**

Education and public health systems should be **flexible and adaptable** to meet the *needs of students with disabilities, families, and educators.* 

#### WHY.

Successful planning and implementation by education and public health agencies will account for the unique needs and flexibilities that students with disabilities and their families require. By focusing on meeting the needs of those most underserved by both systems, placements and services will better serve all by striking a balance between community safety and individual/ family choice, thus creating equity. Through developing guidelines to allow for adaptability, districts can begin to understand the flexibilities that both families and practitioners alike would benefit from and can allow for adjustments to be made prior to implementation.

#### **IMPLEMENTING THIS PRINCIPLE MAY LOOK LIKE:**

New Hampshire's School Transition Reopening and Redesign Taskforce

provided recommendations to the Governor, Department of Education, and local school districts related to the safety, risks, and needs of individual students during the pandemic, with particular concern for students with economic disadvantage and students with IEPs. Working groups were comprised of parents, students, district administrators and school staff, and education and health membership associations. If maintained in the long-term, inter-agency teams such as these are not only critical to understanding and meeting the needs of students during public health emergencies, but can help build the infrastructure to support students year-round.



#### **PRINCIPLE 4.**

Align credentialing (e.g., licensing) and allowable uses of funding to **streamline and simplify** the process for hiring new staff, particularly school nurses, counselors, and psychologists.

#### WHY.

If education and health agencies at the state and local levels connect more effectively, the result will be **more efficient methods of sharing resources**, **funding, and personnel among the two agencies**. When states are <u>proactive</u> about coordinating funding streams, it makes it easier to make quick staffing shifts, new hires, etc. on the ground in districts and schools. During a public health emergency, quick hiring decisions require simple procedures to sustain adequate school health staff to meet health protocols. **Coordination of funding and understanding of administrative barriers** *prior to a public health emergency* are essential to ensuring staff can continue to successfully do their jobs and have the ability to adapt their practices to the demands of the environment.

#### **IMPLEMENTING THIS PRINCIPLE MAY LOOK LIKE:**

Louisiana amended their state plan to allow school-based direct/therapy and nursing services to be reimbursed by Medicaid. Licensing requirements specified in state Medicaid plans often present an obstacle to using Medicaid dollars to hire and support additional school nurses and other health staff during COVID-19.





# A Call to Action

Inequities in both public health and education systems existed far before COVID-19 and will continue to exist in the context of future public health emergencies. Public Health and Education agencies at the federal, state, local, and community levels must examine their history and current context and create a plan to address these inequities, before we are faced with another public health emergency. National organizations, such as AMCHP and Child Trends, are committed to supporting public health and education agencies with the necessary resources for understanding the impacts of public health emergencies on students' academic and developmental experiences and the resources and tools to develop roadmaps for recovery.

## **Endnotes**

- 1. Abdi, F.M., Seok, D., & Murphey, D. (2020). Children with special health care needs face challenges accessing information, support, and services. Child Trends. Link to resource
- 2. Temkin, D., Harper, K., & Guros, C. (2023). Healthy schools can mitigate ongoing racial inequities in education. Child Trends and Kaiser Permanente Thriving Schools. Link to resource
- 3. Rudolph, L., Caplan, J., Ben-Moshe, K., & Dillon, L. (2013). Health in All Policies: A Guide for State and Local Governments. Washington, DC and Oakland, CA: American Public Health Association and Public Health Institute. Link to resource

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