


The Intersection of Education and Healthcare: Supporting Children with Chronic Health Conditions

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Objective: Chronic health conditions in childhood have been negatively associated with linguistic, academic, and occupational outcomes. Traditionally, categorical diagnostic approaches relying on exclusionary criteria are used in healthcare services. **Methods:** This literature review examines research from various fields to evaluate the effects of chronic illness in cognitive-linguistic development in children. We explore the implications for different conceptualizations of the term “chronic illness.” We compare categorical and non-categorical diagnostic approaches, specifically in relation to children’s academic performance. **Results:** We provide recommendations for bridging the gap between healthcare and education to provide children with chronic conditions the best chance of thriving medically and academically. Definitions of chronic illness that rely on inclusive criteria and acknowledge individual variability seem best suited for clinical practice and research. **Conclusions:** Effective supports for children with chronic illness require evidence-based treatment approaches that are tailored to the unique needs of each individual child. Educators, healthcare providers, families, and related service providers must have open lines of communication to serve children with chronic health conditions. Early identification and intervention is crucial.

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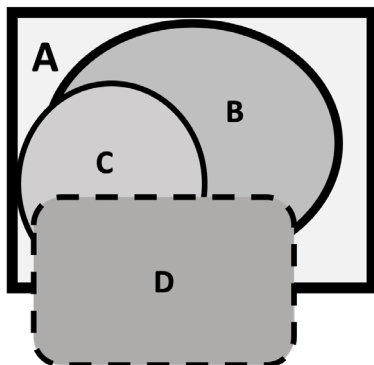
Childhood chronic illness is associated with negative educational and occupational outcomes in adolescence and adulthood.¹ Even prior to school entry, children with chronic health conditions are more likely than their healthy peers to demonstrate delays in cognitive, linguistic, social-emotional, physical, and behavioral skills.² Nevertheless, there is limited research on the underlying causes of these delays, and as a result, this population is regularly overlooked in the intervention literature. Given that an estimated 7%-30% of children are diagnosed with some type of chronic health condition,³ it is imperative that we understand the relationship between chronic illness and learning in formal and informal settings. However, available research is limited by conceptual and methodological barriers, thereby limiting

the ability to provide adequate support to children with chronic illness. As advances in the medical field continue to improve the physical prognoses for these children, educators and clinicians have an obligation to support all children at risk of falling behind their peers.

Although previous research has explored the cognitive, linguistic, and academic outcomes of children with chronic illness, these studies are scattered throughout various fields (eg, medicine, nursing, psychology, education, and others). At present, no published synthesis of this research exists that ties educational implications to childhood chronic illness. The term chronic illness is inconsistently defined in the research literature, and as a result, leads to variability in the care provided to children. Most definitions of chronic illness include a categorical

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Figure 1
Comprehensive Framework for Chronic Health Conditions – Categorical Approach
 (Adapted from Van Der Lee et al⁴)



Note.

Group A: Represents ALL children with chronic health conditions as determined from the diagnoses outlined in the International Statistical Classification of Diseases, with a duration of at least 3 months or a cure is implausible.

Group B: Represents children with chronic health conditions and challenges with daily life. The exact percentage of children from Group A who fit in this category is currently unknown.

Group C: Represents children with chronic health conditions who are in groups A and B and who require more medical care than what is typically required.

Group D: This group is a heterogeneous group of children that are at risk for developing chronic health conditions but who are not represented in Group A of the framework-yet likely overlap or should be included.

framework in which children with any of the listed conditions meet a standard definition. However, non-categorical definitions of chronic illness emphasize functional and social outcomes for children with disease. In this review, we explore the limitations of a categorical approach for diagnosing chronic illness. Furthermore, we discuss how categorical diagnostic models limit the ability to provide transdisciplinary services addressing both medicine and functional developmental outcomes in children.

METHODS

Defining Chronic Illness

The term “chronic illness” across the research literature is ambiguous.⁴ Definitions are divided

into comprehensive frameworks that use categorical versus non-categorical approaches (Figures 1-2). Categorical approaches, in general, are lists of conditions, often aligned with the International Classification of Diseases (ICD), that are considered chronic or long-lasting (generally longer than 1 year). Categorical approaches (Figure 1) include overlapping but unique groups of children. Non-categorical approaches (Figure 2), on the other hand, include criteria that an individual case will meet to be considered chronic.^{5,6} That is, non-categorical approaches rely on inclusionary criteria and generally focus on functional outcomes or quality of life measures to determine classification.

Categorical Approaches. Categorical classifications include recognized diagnoses that are recurring or long-lasting. These diagnoses are often based on professional standards and last at least 3 months, or those that have no established cure. In their review of chronic illness literature, Van der Lee et al⁴ proposed a multi-level framework for defining chronic illness. In their framework, Level 1 consists of children who have a diagnosed chronic health condition recognized by the ICD. Level 2 includes children whose diagnoses result in disability or limitations of activity. Level 3 includes children who seek medical care or services beyond what is typical of children their age. This level includes some children from Levels 1 and 2. Level 4, which the authors dub “children with special healthcare needs,” includes children who either have or are at risk for a medical, developmental, behavioral, or emotional disability and who seek additional medical care.

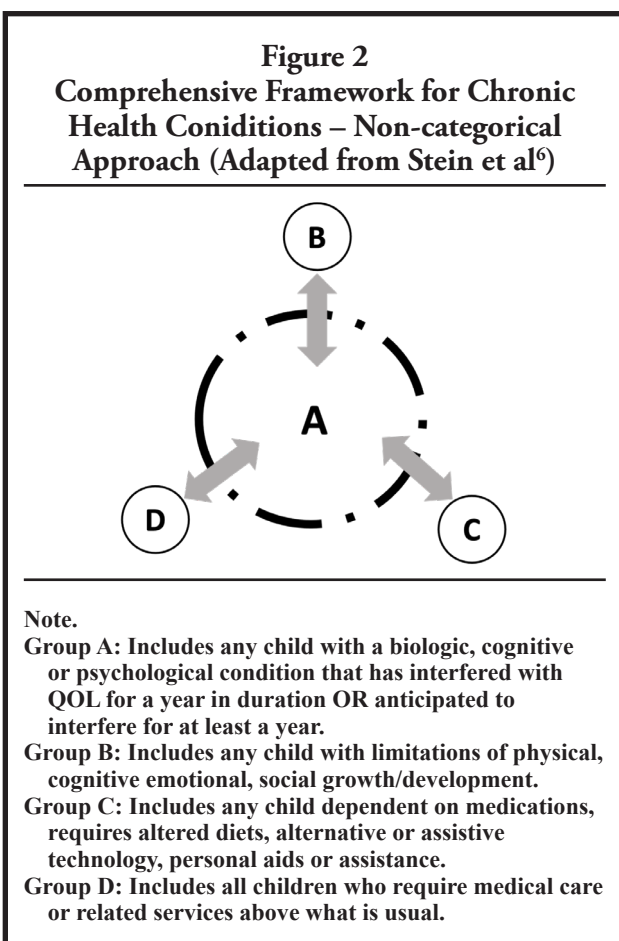
One benefit of categorical models is that much of the previous research has used this type of classification system. For example, in a study of Australian preschoolers, children were identified based on diagnosis.² From an overall sample of 22,890 children, 12.6% were identified as having some type of chronic illness. The most common, by far, was recurrent otitis media (8.9%). Other reported illnesses, in order from most to least frequently reported include chronic respiratory disease/asthma (3.3%), epilepsy/seizure disorder (0.4%), anemia (0.3%), musculoskeletal disorders, cardiovascular diseases, cancer, diabetes, malnutrition, obesity, chronic renal disease, cystic fibrosis, and chronic liver disease.

Another benefit of the categorical model is that

service delivery tends to rely on diagnostic categories. For example, the National Institute for Health and Care Excellence in the United Kingdom publishes care guidelines based on diagnostic category.⁷ The psychology literature also tells us that categorization helps us to make rapid judgments; therefore, students in health training programs may benefit initially from a categorical model.⁸ Finally, for documentation, insurance, and billing purposes, specific diagnostic categories are often required by organizations.

Non-categorical approach. Non-categorical approaches stand in contrast to categorical classification models. Within non-categorical approaches, chronic illness is not determined by a set of chosen diagnoses; it is determined by functional severity, medical interventions necessary, and prognosis. Although this definition is similar to “Level 4” of the van der Lee et al⁴ framework, it relies on functional limitations rather than a specific diagnosis.

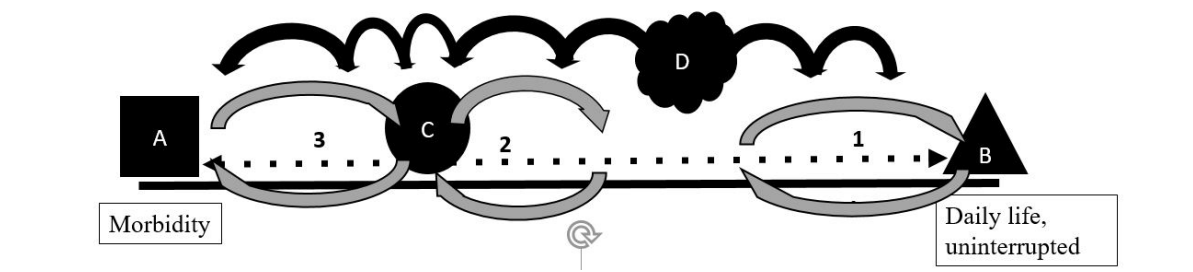
A non-categorical approach presents many advantages compared to a categorical approach.^{5,6} First, there can be wide variability within specific diagnostic categories. For example, one child with Type 2 diabetes may completely manage the disease through diet, whereas another child may require daily insulin injections and frequent hospital visits. Furthermore, when exploring the impact of health conditions on developmental outcomes, evidence suggests that severity and management of the health condition are better predictors than diagnosis alone. For example, young children with asthma that limits activities of daily living demonstrate deficits in school readiness skills, whereas children with asthma that does not limit functioning do not differ from healthy peers.⁹ In addition to variability in severity, individuals also respond to treatment differently. Therefore, there is a danger in relying solely upon diagnosis when making evidence-based judgments on treatment. A significant proportion of children with chronic illness are diagnosed with comorbid conditions, thus influencing their response to treatment. In a 2006 survey, 41% of children hospitalized for critical conditions had a comorbid condition.¹⁰ Another advantage of a non-categorical approach is that this approach does not rely upon lists that may exclude rare diseases. Although, as the name suggests, “rare diseases” are those that affect a relatively small number of people, the number of rare diseases is



large and an estimated 6%-10% of the population is diagnosed with a rare disease.¹¹ For example, the National Institutes of Health estimates that 25-30 million Americans are living with a rare disease.⁷ Therefore, a categorical classification model may exclude children with rare conditions who have exceptional healthcare needs. Furthermore, these rare diseases often take time to diagnose, with some patients waiting up to 30 years between the onset of symptoms and correct diagnosis.¹² Finally, at least in the United States, there are legal implications for relying strictly upon diagnostic categories. In a landmark case, *Sullivan v Zebley*,¹³ the United States Supreme Court ruled that in making determinations for federal disability benefits, functional outcomes must be measured rather than simply relying upon diagnostic category.

In Figure 3, we demonstrate how the impact of a disease may vary over a protracted period. Children with a chronic illness may, at times, experience few symptoms. At other times, they may experience severe symptoms and require intensive medical care.

Figure 3
Continuum of Quality of Life for Children with Chronic Health Conditions
 (Adapted from Stein et al⁶)



Note.

A - One end of the spectrum which represents a child with a chronic health condition who has an overall very poor QOL and survival is the primary focus for the medical teams/families.

B - The other end of the spectrum. **B** represents a child who has fully recovered from a chronic medical condition whose QOL is comparable to healthy peers.

C - A child with a single chronic health condition in which their baseline QOL is reduced.

D - A child with co-morbidities, each which interact and combine to influence QOL in either direction, and for potentially different reasons. Thus their baseline is inconsistent and these children may bounce on the continuum.

Situation 1: Child with a chronic health condition who may have periods of QOL comparable with their peers and other times in which QOL is impacted.

Situation 2: Child with a chronic health conditions whose QOL baseline is reduced, but have periods of improved QOL and who returns to baseline or an improved baseline.

Situation 3: Child with a chronic health condition whose QOL baseline is reduced and have periods of decline QOL and morbidity is a concern and/or their baseline moves closer to morbidity with each exacerbation.

Furthermore, extrinsic factors and comorbidities may influence a child's overall wellbeing throughout the lifespan to varying extents. Therefore, a child will move up and down this continuum of quality of life (QOL) (Figure 3). Using a functional model of chronic illness, we take this further by considering the impact on development. For many children with chronic illness, the primary goal is to avoid mortality. Nevertheless, medicine is continually advancing and most children with chronic illness living in developed nations will survive. We argue that survival should not be the end goal. Through a combination of medical and educational intervention, the goal should be to provide the child an opportunity to thrive physically, academically, and socially.

Although there are many advantages to using non-categorical approaches for identification, they have not been adopted readily by healthcare providers. One core reason is likely due to a fundamental component of human nature to categorize objects in our environment.¹⁴ In the context of medicine, not only does categorization help healthcare providers to conceptualize diagnoses, but also it can ameliorate

the discussion with parents and caregivers of a child. In fact, in healthcare, categorization is so engrained that providers must document interactions using the International Classification of Diseases codes, which inherently promote a categorical approach to diagnosis. These codes become crucial for billing and insurance purposes, which further perpetuates the categorization of diagnoses. Therefore, because it would take a monumental and collective agreement of all stakeholders to broaden the current classification system, it is unsurprising that non-categorical approaches have struggled to take hold.

RESULTS

Academic Outcomes for Children with Chronic Illness

Chronic health conditions in childhood can have lasting academic and occupational impacts,¹ with deficits noted as early as preschool. For example, in an Australian sample, preschool-age children with chronic health conditions demonstrated significant deficits in social and pre-academic areas including social competence, emotional maturity, communi-

cation skills, general knowledge, and cognitive-linguistic skills.² A latent profile analysis of children's learning profiles found that school-age children with chronic illness often fall into low-average academic trajectories, as compared to their healthy same-age peers.¹⁵ In fact, children with a chronic illness are 1.3 times more likely than their healthy peers to fall below academic benchmarks.¹⁶ Poverty plays a role in these results; children born into poverty are at higher risk for chronic health conditions. Nevertheless, chronic illness is correlated with academic performance even when controlling for socioeconomic status.¹⁷ Poverty and chronic illness combined have a cumulative effect for increasing the risk of academic failure.¹⁵

Previous research also has identified academic outcomes associated with specific diagnoses. In one meta-analysis of studies examining cognitive-linguistic skills in children with a variety of health conditions, children with chronic illness, as a group, scored lower on verbal and nonverbal intelligence measures.¹⁸ However, effect sizes varied based on diagnosis. The largest effect sizes on verbal measures, not surprisingly, were noted for children with moderate to severe traumatic brain injuries and brain tumors. Moderate effect sizes were noted for children with leukemia and congenital heart defects. Small effects were noted for children with diabetes. Another example of disease-specific effects includes findings that sickle-cell disease is associated with significant deficits in semantic, syntactic, and phonological processing skills, with medium effect sizes.¹⁹ Although there is evidence for associations between specific diagnoses and academic deficits, the underlying mechanisms contributing to these deficits are not well understood. At the present time, we cannot be sure whether these deficits are caused by specific neurological factors associated with disease (eg, hypoxia in children with asthma) or whether academic outcomes are moderated by other psychosocial elements associated with disease such as school absences, stress, poverty, medications, or other factors.^{20,21}

DISCUSSION

Intersection of Healthcare and Education

Traditionally, academic difficulties of children with chronic illness have been attributed to decreased school attendance. Children with chronic

illness are at increased risk for absenteeism, and in general, miss more school days than their healthy peers.²² Nevertheless, even when controlling for school attendance, chronic illness predicts lower English/language arts and math scores in school-age children.^{23,24} Therefore, whereas attendance is a concern for children with chronic illness, it is only one piece of the puzzle.

Chronic illness at school entry is associated with a variety of negative outcomes by age eleven.²⁴ Teachers are more likely to rate children with chronic health conditions as having more problem behaviors and lower literacy and mathematics abilities as compared to healthy peers.²⁵ Teachers also report that children with chronic health conditions have a more negative approach to learning and the teacher-child relationship is more likely to be strained. These results are predictable given that other studies have found that teachers report feeling underprepared to support both academic and physical health needs of children with chronic illness.^{3,26} Teachers and parents of children with chronic illness also report concerns regarding children's academic performance in school.²⁷ In some cases, parents and educators have attempted to collaborate with healthcare providers to improve health and academic outcomes for children with chronic illness. However, healthcare providers report barriers to collaboration, including coordinating multidisciplinary treatment approaches and the feasibility of distributing information to educators.²⁸

Little research has examined the effects of early intervention on reducing academic deficits associated with chronic illness. Nevertheless, there is strong evidence that early intervention improves outcomes for children with, or at risk for, disabilities. Early intervention supports can decrease risk and improve protective factors for children across 3 planes – child social and cognitive competence, family patterns of interaction, and family resources.²⁹ For families of children with chronic health conditions, family trainings in early intervention settings may reduce the number of emergency room visits.³⁰ In the United States, Part C of the Individuals with Disabilities Education Act provides early intervention services to children with "...other health impairments, or specific learning disabilities; and who, by reason thereof, needs special education and related services."³¹ Nevertheless,

differences in educational models across states result in inconsistent eligibility criteria and lack of specificity as to which professionals provide early intervention services.³² Therefore, although early intervention would likely benefit many children with chronic illness, inconsistent eligibility criteria may disadvantage many children.

IMPLICATIONS FOR HEALTH BEHAVIOR OR POLICY

The Science of Medicine and the Art of Delivery

Adopt holistic, individualized approaches to diagnosis and treatment. The majority of children with chronic illness do not have a single diagnostic label. These children often have co-occurring diagnoses and other psychological, social, economic, and behavioral conditions that contribute to their academic performance.²¹ Nevertheless, healthcare delivery seems to be structured around an outdated model (Figure 1) that prioritizes specific diagnostic categories rather than individualized treatment approaches based on the unique needs of a child. Healthcare should balance the science of medicine with the art of tailoring interventions to help children not just survive, but thrive both medically and academically.

One proposed mechanism to bridge this gap is to encourage a shift in the way researchers conceptualize chronic illness in childhood. Traditionally, researchers have been trained to isolate independent variables while keeping all other variables constant for clean data. However, children with chronic conditions are a heterogeneous group. Extrinsic factors and comorbid conditions may all influence academic outcomes for children with chronic illness, but these factors are typically not accounted for in the research literature. Given advances in multi-level statistical modeling, we propose that researchers work to build inclusionary rather than exclusionary models that look at the influence of chronic illness on academic outcomes in relation to other variables.

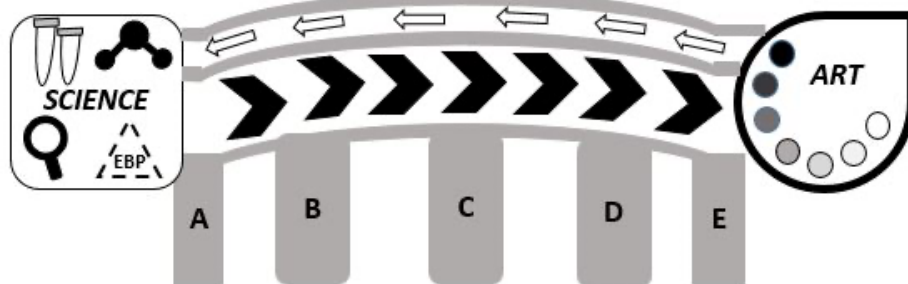
Research that operationalizes chronic illnesses using a categorical approach produces results that are not necessarily generalizable to the broad group of children with chronic health conditions. This is a problem for clinicians delivering evidence-based practices. A predominant aspect of the evidence-based practice triad requires practitioners to implement research-backed intervention approaches that

have been chosen or tailored specifically to match the unique needs of their patients.³³ Yet, when delivering services to children with chronic health conditions, 2 key challenges exist with this approach. First, it is often impossible to find research that includes participants who match the specific etiologies and demographics of the patients served in clinical settings. Second, research and training tend to value research more than clinical judgment or shared decision-making with caregivers/families (the other sides of the EBP triad). That is, we often view treatment as black or white, right or wrong, appropriate or inappropriate. However, when the research literature is lacking, practitioners are forced to wander into the world of “gray.” To help support clinicians and researchers in navigating this “gray,” we propose Figure 4, which we dub “the bridge of gray.” Figure 4 demonstrates the bridge between the science of research and the art of service delivery.

Clinically, the best way to support children with chronic illness is to balance the science and the art. Even the best informed clinicians may be ineffective if they struggle to utilize the information appropriately. For an analogous example, think of a chef preparing ingredients for a meal. The best meal will be the result of the finest ingredients and the best technique for preparing those ingredients. With the best ingredients, an unskilled chef may not mix or cook the ingredients properly. At the same time, even the best chef will be unable to salvage a recipe if the ingredients are spoiled or not available. In this analogy, the ingredients represent the science and the chef represents the practitioner. High quality service delivery is the result of clinicians using evidence-based practices in a way that matches the unique needs of their patients.

Holistic approaches to treatment may best serve children with, or at risk for, disabilities. A recommendation to balance the advantages of categorical and non-categorical approaches to identification is to adopt descriptive diagnostic approaches. Therefore, instead of eliminating diagnostic categories altogether, we adopt broader categories with an emphasis on description of the specific symptoms and risks exhibited by the individual. Although specific diagnostic categories using exclusionary criteria may benefit researchers, clinicians and children may be disadvantaged by these strict criteria.³⁴ Holistic diagnostic approaches that rely on inclu-

Figure 4
Bridge of Gray



Note.

Visual representation of the complexity of medical care for children with chronic health conditions as depicted by a bridge between the science and the art for best patient outcomes. The left hand box represents the science behind the care which includes guidelines driven by evidence based-practice (EBP). The right side represents the art of service delivery, which involves individualizing care to support both the medical, developmental, and educational needs of the child. As shown in the Figure, although the bridge has communication between the science of medicine and the art of medicine, science traditionally has been the primary driver within the decision making process (see arrows above). The complexity of care is represented by the pillars of the “bridge of gray” and include such aspects as, (A) Health-care providers, (B) Educators; (C) Caregivers/families; (D) Environments care must cross; (E) Interventions.

sionary criteria and place emphasis on the child using multiple assessments may best advantage the children we serve, particularly those with co-morbid conditions.³⁵

Increase collaboration among healthcare providers, educators, and families. Another recommendation for improving care to children with chronic illness is to increase collaboration between healthcare providers and educators. In the United States, there is no formal mechanism for sharing information between educators and healthcare providers, likely due to the legal and ethical issues of sharing protected health information. Educators typically rely upon family members to provide information regarding children’s health history and treatment plan. Nevertheless, parent report is an inefficient means of relaying important health information that may impact children’s academic success and places an extra burden on parents. Given technological advances that make sharing electronic records easier, we advocate for a formal system of direct communication between clinicians, educators/counselors, and caregivers/families. This communication should be ongoing in conjunction with the QOL continuum (Figure 3) with healthcare providers and educators providing transdisciplinary care to move children further

to the right of the continuum. Healthcare providers should be prepared to support children beyond avoiding mortality and educators should be prepared to serve children who may “appear” typical.

For children with acute medical conditions, families, healthcare providers, and educators tend to work together to develop transition plans (from school to the hospital and from the hospital to the school) to decrease the academic gaps that they could potentially experience due to missing school.³⁶ In these acute situations, collaboration among healthcare providers and educators ensure that when children are absent from school for long periods of time, they are given opportunities for cognitive-linguistic stimulation. Nevertheless, there are many children with chronic illness who miss school sporadically and experience dramatic and sudden shifts along the QOL continuum (Figure 3). For example, children may experience “flare-ups” that do not require hospitalization, but may impact their learning on a day to day basis. Ongoing collaboration and monitoring among clinicians and educators will be necessary to help these children succeed academically. When children with chronic illnesses miss school, educators can take advantage of modern technologies to support learning outside the physical classroom. For

example, many school districts already have moved to electronic textbooks and papers. Face-to-face videoconferencing software allows children to virtually attend school from a remote location (such as home or the hospital).

The World Health Organization (WHO) identified Health Promoting Schools as a priority health topic.³⁷ Key features of Health Promoting Schools include healthy school policies, physical school environment, social school environment, health skills and education, links with parents and community, and access to health services. We support this recommendation, while acknowledging systemic barriers to integration of healthcare and education including, but not limited to, lack of policies or policy implementation, insufficient advocacy for school health activities, budget insufficiencies and lack of other resources including trained staff, and cultural barriers.³⁷ Therefore, we encourage healthcare providers and educators to advocate for increased collaboration resulting in Health Promoting Schools. We further encourage policymakers to consider these systemic barriers and modify existing policies to promote further integration of education and healthcare.

Involve related service providers. Children who are absent from school also may be excluded inadvertently from support services they otherwise would receive through the school district (such as speech-language services, psychological services, occupational therapy, or others). Utilizing teletherapy as a mode for therapy services can decrease any missed sessions due to symptoms or management of care, such as medication adjustments, side effects, or appointments.³⁸ Although a somewhat emerging area, initial research on teletherapy for speech-language pathology services indicates favorable outcomes for both preschool and school-age children with limited access to traditional face-to-face therapy; furthermore, parents responded favorably to the teletherapy modality.³⁹ Although there is still much research to be done on teletherapy and it may not always be feasible for each individual situation, it is a consideration for children who physically are unable to attend school.

The *Healthy People 2030* initiative identifies schools as a priority setting for healthcare, and discusses the importance of integrating education with healthcare related service providers.⁴⁰ Objec-

tives include increased education in prevention and population health for physicians (ECBP-D09), nurses (ECBP-D10), physician assistants (ECBP-D11), pharmacists (ECBP-D12), and dentists (ECBP-D13). *Healthy People 2030* also has an objective to increase the proportion of public schools with a counselor, social worker, and psychologist (AH-R09). We agree with these recommendations and further stress that these integrated services may result in more holistic identification and management of chronic conditions in children.

Improve early identification and intervention for children with chronic illness. One of the most important clinical implications that needs to be considered when working with children with chronic illnesses is early identification. Any child with a chronic illness should receive ongoing screening and monitoring to ensure that they are developing academic skills at the same rate of their peers. If academic difficulties are detected, interventions can be started immediately to decrease large language gaps that could, in turn, affect academic, social, and emotional growth of the child. This aligns with the WHO guidelines for improving early childhood development, which emphasizes the importance of promoting early learning through responsive caregiving.⁴¹ Long term deficiencies may be avoided through effective early intervention supports.

In summary, the current model of service delivery for children with chronic health conditions is lacking; there is no systematic method to address the unique social, emotional, behavioral, or academic needs of this population at this time. Children in this group require support that can be achieved best by bridging academics and healthcare. Nevertheless, no established method for bridging this gap exists. Therefore, we provide several recommendations for supporting these children. First, we advocate for an inclusive operationalization of chronic illness that acknowledges the complexity of children's development of academic skills. Second, we call for further research addressing extraneous variables such as comorbid conditions contributing to deficits in children with chronic conditions. Third, we advocate for a formal mechanism for bridging communication between healthcare and academics to provide transdisciplinary supports for children's academic development. Fourth, we call

for early identification and progress monitoring of academic skills for children with chronic (or undiagnosed) health conditions. We believe that these recommendations will allow the fields of healthcare and education to best serve children with chronic health conditions the best long-term medical and academic outcomes.

Additional Recommendations

- Adopt holistic, individualized approaches to diagnosis and treatment for children with chronic illness.
- Increase collaboration among healthcare providers, educators, and families.
- Involve related service providers when providing education supports to children with chronic health conditions.
- Improve early identification and intervention for children with chronic illness.
- Support policies that promote integration of healthcare and education, such as Health Promoting Schools.

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Human Subjects Approval Statement

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Conflict of Interest Disclosure Statement

All authors of this article declare they have no conflicts of interest.

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