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Article

SCHOOL SUCCESS FOR CHILDREN EXPERIENCING CHRONIC ILLNESS: NATIONAL RECOMMENDATIONS FOR ADDRESSING GLOBAL BARRIERS

Legislative Alliance for Students with Health Conditions

Abstract: Advances in medicine and medical technologies over the past several decades have extended the lives of many individuals who have chronic illnesses that were once considered terminal. Likewise, these advances have enabled more students to participate in school than ever before. As such, their short-term and long-term academic outcomes must be considered when determining the types of educational supports and services that will be provided to this unique population of students. Existing legislation and policies intend to ensure access to education for all children in the United States, but there continue to be several barriers incurred by students who are ill due to vacancies in legislation, as well as state and district policies. Modifications to current legislation and policies can improve educational outcomes for these students. This paper aims to draw attention to several areas in need of modification, while also providing possible solutions for these issues.

Keywords: *chronic illness; legislation; teacher preparation; home instruction; nursing*

Introduction

Intentionally addressing the educational needs of students with chronic illnesses and other special health care needs is a relatively new concept, as it was only in the recent past that education and future planning were often not relevant considerations amidst extremely poor disease and survival outcomes. Fortunately, given advances in medicine and technology, this is a new and growing population of students who are increasingly participating in school, and for whom short-term and long-term academic outcomes must be considered. Bethell et al. (2011) reported the incidence of children in the United States with either a chronic health condition (approximately 32 million, or up to 43%, of children) and/or a special health care need (approximately 14.2 million, or 19.2%, of children). Unfortunately, these students experience a myriad of school-related problems and literature evidences the sub-optimal education outcomes experienced by this unique student population (Thies, 1999).

Fifty-eight percent (58%) of students with chronic conditions routinely miss school and 10% miss more than 25% of the year (Thies, 1999). Analyses of data across multiple states and school districts, conducted in partnership between the Everyone Graduates Center at Johns Hopkins University and the National Governors Association (Balfanz & Byrnes, 2012), have consistently found chronic absenteeism to be among the strongest predictors of dropping out of high school. This was shown to be stronger even than suspensions, test scores, and being over-age for grade, after having controlled for student demographics and backgrounds (Byrnes & Reyna, 2012). Existing legislation and policies, such as the Individuals with Disabilities Education Act (IDEA, 2004), intend to ensure access to education for all children in the United States. Yet, there continue to be several barriers incurred by students who are ill due to vacancies in legislation and well-intended yet restrictive state and district policies.

The Legislative Alliance for Students with Health Conditions (LASHC), with the support of the Council for Exceptional Children Division of Physical, Health and Multiple Disabilities; the Association of Pediatric Hematology Oncology Education Specialists; and the Association for the Education of Children with Medical Needs, proposes that this specific student population be considered in district, state, and federal education policies. Several legislative modifications can improve educational outcomes for these students. These recommendations are based on both anecdotal and empirical evidence from professionals working directly with school-age pediatric patients in a variety of settings across the country.

Education Success: Issues and Solutions

Special Education Eligibility

Problem statement. It is not surprising that students experiencing chronicity benefit from tailored, individualized support at school to address their unique learning needs. Our nation's special education legislation (IDEA, 2004) attempts to be inclusive of children with illness through the Other Health Impairment (OHI) eligibility category (Irwin & Elam, 2011). However, the IDEA definition of a health impairment is restrictive. It requires a child to be actively experiencing "...limited strength, vitality, or alertness due to a chronic or acute health problem," and this lack of vigor must adversely affect that child's educational performance (Grice, 2002).

“This definition is not comprehensive in that children who are chronically ill can experience multiple issues related to their illness that interfere with school that may or may not be rooted in vivacity” (Irwin & Elam, 2011, p. 69). Furthermore, eligibility for services is often undermined by a “missed education opportunities” caveat. This may disqualify a student from receiving special education services should the child’s school difficulties be attributed to incurred absences (even when those absences were a result of the illness). Consequently, while many children with an illness benefit from a formal and individualized plan under the OHI disability category, they are often deemed ineligible for this type of support (Grice, 2002).

Proposed solution(s). Existing legislation encompasses special education qualifications for students experiencing adverse educational performance as a result of their disease or condition under the OHI disability category. While well-intended, loopholes and *gray areas* in the legislation allow districts to limit programming for students with health conditions. Historically, the United States Department of Education (US DOE) and the Office of Special Education Programming (OSEP) have issued national memorandums to clarify misinterpreted or misapplied education laws. Such a memorandum clearly outlining the purpose and intent of the OHI category would aid in closing gaps in this otherwise effective and well-intended approach.

Teacher Preparation

Problem statement. Limited training and teacher preparation regarding best practices for students with a chronic illness also compromises students’ successful inclusion in a school setting. According to some theories, “educators either minimize or underestimate the effects of [...] serious illness and its lengthy and often invasive treatments on the child’s education, or [...] teachers simply do not know what they do not know” (Elam, 2012, p. 40). Consequently, classroom teachers frequently fail to implement interventions mitigating known negative education implications associated with pediatric disease and treatments.

Proposed solution(s). According to an informal survey sent to members of LASHC in 2015, 50% of respondents prioritized pre-service teacher education as a high-need area relative to reform, suggesting that teacher preparation programs should include specific training on supporting the needs of students with chronic medical conditions in the classroom setting. The growing number of students with chronic medical conditions in classrooms across the United States warrants a concerted effort by teacher preparation programs to include curricula supporting the unique needs of students with special health care sequelae. Content experts in the field of education for individuals with chronic medical conditions should guide instructional curriculum development to reflect evidence-based best practices. This parallels the curriculum development and verification that teacher preparation programs use to prepare school personnel supporting students with special education needs or language instruction for English Language Learners, for example.

Access to School Nurses or Health Aides in the School Setting

Problem statement. While students with a chronic illness may be permitted to attend school, disease and treatment effects may warrant special medical attention from trained professionals to ensure safety and access in school facilities. Though these needs may range from very minor and

non-invasive to more intensive, the traditional school setting may still be the least restrictive environment (LRE) for the student. When qualified professionals are not available to facilitate such support, these students are sometimes forced to receive instruction in the home, contrary to LRE mandates. Despite the increasing number and acuity of students with health conditions, the availability of qualified, reliable school nursing care is decreasing. This alarming dichotomy is causing school nurses to delegate increasingly complex care to non-licensed school personnel (Fleming, 2011), further compromising the educational experience and safety of these students.

Proposed solution(s). LASHC (2015) survey results indicated that roughly two-thirds of respondents believed “legislative mandates should include requirements for school nurses or other health care providers to be present in school buildings to ensure the safety of students with chronic medical conditions.” The growing population of students with health care needs combined with the increasing medical complexity of these students warrants a re-evaluation of school nursing status and ratios (Fleming, 2011; NASN, 2015). It is unsafe, and perhaps negligent, to consider school nurses as ancillary staff. This status suggests an optional addition to the team caring for a given student body. A thoughtful review of the valuable contributions and extensive need for school nursing care must be conducted. This review should generate enforceable policies to guide school districts in the placement of these critical team members.

Home Instruction Hours

Problem statement. It is not surprising that students with a chronic medical condition incur frequent absences from school. When hospitalized, these youth may receive instruction from a hospital teacher, should the child be well enough to participate in instruction and should such a service be available. When the child is not hospitalized, yet also not able to attend school, home instruction support from the student’s home district is an essential component in ensuring academic progress. Unfortunately, due to the lack of federal guidelines defining minimum requirements for home instruction policies at the state level (e.g., qualification requirements, number of hours provided, opportunity to accrue hours when too ill to participate in scheduled sessions), there is significant inconsistency and variability across states and districts regarding home instruction support for students with a chronic medical condition. While some states allot as few as two hours of home instruction per missed week of school for students receiving homebound instruction, others provide 10 or more hours of instruction. Sixty-six percent (66.67%) of LASHC (2015) survey respondents identified homebound instruction as the area in most need of reform. In fact, nearly 70% of respondents felt “there is a need to legislatively establish an expectation for minimum number of hours allotted for home instruction nationwide” Seventy-five percent (75%) of respondents believed “clear guidelines are needed to ensure that school services (such as homebound instruction) are guaranteed for students with chronic medical conditions during intermittent and extended absences when school participation is not feasible.”

Proposed solution(s). To ensure these students are given equal access to instruction, both quantitatively and qualitatively speaking, it is essential that guidelines for home instruction be mandated to rectify current discrepancies. Ideally, federal guidelines will be adopted; however, given the time constraints associated with passing changes in federal legislation, proposing state-level changes and mandates may be more prudent and timely. Subsequently, advocacy can be

initiated immediately by champions in each state. To guarantee educational equality for students with a chronic medical condition, the following guidelines should be considered:

1. Any student with a documented chronic medical condition experiencing frequent absences should be eligible for home instruction services without needing an Individualized Education Plan.
2. If a student with chronicity is expected to incur frequent absences, implementation of services should begin immediately (i.e., states and districts should not require that a student be absent for a specified amount of days before the initiation of home instruction services).
3. A minimum of one hour per school day missed should be allotted.
4. When students are too ill to participate, or have a medical appointment that conflicts with the scheduled home instruction session:
 - a. The school district should allow for students to accrue home instruction hours for later use, even in instances in which the patient was hospitalized outside of the child's district of record.
 - b. If the student is unable to use the hours accrued within a school year, those hours should be carried over into the summer or following school year, as needed.

Withdrawal from School

Problem statement. Exacerbating the limited hours of home instruction provided to students who cannot attend school are issues related to withdrawal of students from their home district during periods of hospitalization. State and federal funding for schools are often contingent on district performance. These performance metrics include attendance rates, standardized test performance, and participation. Given the frequent absenteeism associated with chronicity, these students are sometimes perceived as *attendance anchors*. These students can have significant impact on the school's performance metrics due to waxes and wanes in attendance, inability to participate in standardized measures, and poor performance on high stakes assessments due to low school participation.

School absences for pediatric patients revealed median initial absences for several diseases/conditions. Charlton et al. (1991) indicated pediatric cancer patients at 91 days absent, students with chronic illness at 29.5 days absent, and orthopedic patients at 15 days absent. Borgioli and Kennedy (2003) indicated that pediatric patients with multiple disabilities had a mean initial absence of 28.9 days per hospitalization. To circumvent this problem, schools will sometimes withdraw students with a chronic illness who have attendance problems to avoid having that student's erratic, yet substantiated, absenteeism count against the school's performance. When withdrawn from their home district, students are not able to accrue home instruction hours, nor are they able to receive assignments and materials to continue their studies outside of the classroom. This results in a vicious cycle of missed education opportunities. Finally, withdrawing students during periods of absence sends a strong message of rejection to patients wishing for nothing more than to attend the very school that has withdrawn them.

Proposed solution(s). Legislation allowing for districts to withdraw students during periods of absence (particularly during periods of hospitalization outside of the child's district of residence) should be re-evaluated and revised. States and districts must be permitted flexibility in denoting appropriate and substantiated absences (including absences that result in inability for the student to participate in standardized assessments or high stakes tests) incurred by students experiencing chronicity without penalization to the district. When funding and other performance measures are no longer impacted by legitimate student absences, districts will no longer be incentivized to withdraw students with a chronic medical condition from the district. Schools demonstrate their obligation and commitment to educating a child, regardless of any inherent challenges resulting from the child's illness or condition, by maintaining enrollment.

Access to Certified or Qualified Teachers

Problem statement. While instruction is often provided by a certified or licensed teacher in both the home and hospital settings, it is not uncommon for teacher quality standards to be overlooked. Due to the spectrum of patients receiving instruction in home and hospital settings, it is often difficult for a single teacher to be certified in all subject areas or for all ages assigned to a single caseload. Consequently, the instructor may provide instructional content beyond his/her scope of certification. While teachers in the home and hospital settings work hard to fulfill each student's needs, the notion that students receiving home or hospital instruction do not require highly qualified teachers negates the very principles intended to ensure the highest quality of instruction for all students. Nearly one third of LASHC (2015) survey respondents prioritized teacher qualification requirements as an area in need of clearer mandates relative to home instruction services, suggesting that provisions should be made to ensure that students who are unable to attend school due to medical conditions are provided with the same high-quality instruction offered to students in traditional settings.

Proposed solution(s). Schools and programs responsible for educating students beyond the context of the traditional classroom, particularly home-hospital programs and hospital-school programs, should be required to adhere to the same standards for providing well-qualified and appropriately certified instructors for students dependent on non-traditional settings for academic participation and progress. States and districts may consider unique or creative solutions such as job-shares across districts or programs to ensure economic feasibility and resource maximization for what may otherwise be a significant burden for small districts or programs.

Conclusion

The sector of students with a chronic condition represents a growing population. Increasing attention must be directed toward clarifying or amending policies and mandates, otherwise well-intended, which are restricting access to the highest quality of education for these students. Advances in medicine and technology have not only extended the lives of students with a chronic illness, they have made participation in life and school increasingly possible. This must be celebrated! Students with a chronic medical condition are entitled to equitable access to education, despite the severity or acuity of their condition and despite the inherent challenges or burdens – actual or perceived – associated with providing them a quality education. To provide long-term sustainability for this ever-growing student population, districts, states, and federal

education policymakers must consider how to best address the ill-defined mandates that allow for marginalization of these students.

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