

# Advocating for Immunocompromised Children in the Time of COVID-19: Learning from Children with Cancer

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Students with medically complex needs, such as immunodeficiency, may qualify for special education and related services through the disability category of other health impairment (IDEA, Sec. 300.8 c 9.) [1]. Many children with complex medical needs require specialized instruction and/or related services due to the cognitive impacts of their health conditions. School teams, however, often struggle to meet the educational needs of this group of students due to the complexity of their medical conditions and confusion regarding the cognitive impacts of acute or chronic illnesses [2].

In the spring of 2020 the COVID19 pandemic necessitated an abrupt, novel, emergency switch to remote learning in K-12 schools across the United States (US) [3]. For students with immunodeficiency and complex medical needs, transitioning to remote learning created a new set of barriers to equitable opportunities to learn. At this time of instructional shifts, we asked, what can the remote learning experiences of children with cancer tell us about advocacy best practices for students with complex medical needs? While collected at the time of COVID, the principles are relevant to advocacy needs of such students more broadly.

## BACKGROUND

Immunodeficiency is a broad term used to describe limitations in the infection-fighting abilities of the body. The types of immunocompromising conditions fall into two categories. Primary immunodeficiency is the result of genetic anomalies that impact critical components of the body's immune system; this type occurs most frequently in children and has a prevalence rate of 1/1200 people in the United States (US) [4]. Secondary immunodeficiency occurs when factors outside the immune system suppress its normal function. Examples of these factors include HIV/AIDS, cancer and cancer treatments, organ and bone marrow transplantation, diabetes, and malnutrition [5]. The number of children impacted by secondary immunodeficiency far exceed those of primary immunodeficiency [6].

The COVID19 pandemic has had a major impact for schooling for all children, but for those with complex medical needs brought about by immunodeficiency, the impacts may be even greater. The first concern has been risk of COVID19 illness in children with immunodeficiency. Early evidence indicates that, similar to the pattern seen in children in general, children with immunosuppression do not typically have increased morbidity or mortality due to COVID19 [7, 8]. Conversely, children with co-morbid health conditions may be at increased risk of severe COVID19 disease course and mortality [9]. For example, cardiac complications are common in children with cancer [10] and may have a negative impact on COVID19 disease course; relatedly, COVID19 may further exacerbate cardiac co-morbidities [11].

Beyond the infectious disease risk is the impact that immunodeficiency and associated treatment has on neurocognitive function. It is not uncommon for disease and treatment toxicity to have lasting impacts on brain development and neurocognitive function in children

with immunodeficiency including cancer, diabetes, and HIV/AIDS [12, 13]. For example, the two most common forms of childhood cancer, Acute Lymphoblastic Leukemia (ALL) and Central Nervous System (CNS) tumors, require therapy targeting the CNS, resulting in high probability of neurocognitive impairment. The etiology of these impairments in ALL is due primarily to intrathecal administration of chemotherapy, or delivering the chemotherapy agents directly into the CNS via lumbar puncture, which means that the brain is more directly affected than by peripheral delivery methods such as oral or intravenous chemotherapy. Intrathecal chemotherapy is associated with white matter impacts including demyelination, or loss of white matter surrounding the portions of neurons that facilitate communication of activity; reduced white matter tract integrity and volume, or changes in the amount and quality of the communication pathways in the brain and central nervous system; and/or leukoencephalopathy, or direct white matter injury and tissue death [14-16]. For CNS tumors, the size/location of the tumor and extent of surgical procedures, shunting to address hydrocephalus, and treatment with radiation all impact neurocognitive outcomes [17], with the extent and complications of these procedures associated with type and degree of neurocognitive impairments [18]. Radiation to CNS tumors in the developing brain results in DNA damage and creates an oxidative stress environment which is associated with impaired neurogenesis and synaptic plasticity as well as damage to the microvascular endothelium [19]. All of these contribute to downstream developmental impacts on cognition and availability for learning.

This paper will focus on the neurocognitive impacts of childhood cancer, describe ways in which children with cancer have been impacted by the changes in schooling during the COVID19 pandemic, and highlight ways in which school-related advocacy can benefit children with complex medical needs. We have used children with cancer to illustrate aspects of school transition needs during COVID19 and anticipate these findings can be extended to other populations with complex medical needs. Further, barriers experienced during COVID19 may not be exclusively unique to this time and therefore these findings may be relevant even after

the pandemic. For example, the technological infrastructure that allows students to participate virtually during COVID19 may be cited as a reason that children with complex medical needs can still participate fully and therefore do not need access to Home & Hospital once COVID19 is behind us. A case study approach will be utilized to aid student advocates in understanding the educational and related service needs of students with complex medical conditions and to highlight ways in which special education advocacy can benefit students with complex medical needs during periods of distance education and beyond.

## CASE 1: ELEMENTARY SCHOOL STUDENT, CURRENTLY IN TREATMENT

### Background

JJ is a 7-year-old female recently diagnosed with acute lymphocytic leukemia (ALL).

She is receiving chemotherapy that requires intermittent hospital admissions and at least weekly visits to the outpatient clinic. Due to her treatment, JJ is often anemic and requires blood transfusions. Both the chemotherapy and anemia mean that JJ has significant fatigue; her parent reports that she gets very tired after just one hour of remote schooling. Her medical team has recommended she have frequent rest breaks which are not compatible with her remote schooling schedule. Between her medical visits and fatigue, JJ has missed significant amounts of school work and her grades have suffered. Her parents report that she always made good grades before treatment, and the current grade drops have made her very anxious. She often cries about not doing well in school. In pre-COVID19 conditions, JJ could be receiving Home and Hospital Teaching (HHT; i.e., Homebound) services that would include modifications to schedules and work load. However, the school team determined that HHT services were not necessary because all students were currently learning remotely.

Neuropsychological evaluation of JJ shortly after initiation of her maintenance chemotherapy revealed average reasoning (e.g., IQ) and learning abilities. In contrast, and consistent with the profile seen in many children treated with intrathecal chemotherapy, JJ exhibited weaknesses in her attention, processing speed, and executive function (e.g., working memory, inhibitory control, flexibility/set-shifting, efficient problem-solving). Furthermore, fine motor speed and dexterity were also reduced, relative to others her age, and her level of fatigue substantively limited her endurance. Taken together, findings suggested that sustaining her attention to online learning, navigating multiple online systems and screens to find and complete assignments, and keeping up with and completing work on time will be much harder for JJ than her peers. Recommendations made by the neuropsychologist included schedule accommodations to address fatigue and attention (e.g., limit the number and duration of distance education sessions, offer extended time for completion

of assignments and tests, reduce the length of assignments as much as possible, permit home and hospital instruction to facilitate engagement and support missed instruction for medical needs), as well as suggestions to support executive function (e.g., simplify procedures for accessing remote assignments and instruction, provide clear checklists and rubrics for activities and assignments, provide instructions that include no more than 2 steps at a time, chunk and repeat instructions to support comprehension as needed) and fine motor skills (e.g., ensure that JJ has access to and is able to effectively use speech-to text/dictation software or can respond orally, offer alternatives to tasks requiring drawing, writing or scissor use).

### Advocacy

The school team did not fully understand the need for HHT. They mistakenly assumed that the need for HHT was based on the location of the student and not upon their physical and cognitive needs during treatment. Supporting the school team in understanding the cognitive and physical effects of treatment assisted the team in acknowledging that HHT would allow the student to continue instruction during fewer hours of the day and at times that best met her treatment schedule/periods of missed instruction due to hospitalization.

The education advocate was able to work with the school team and family to develop a 504 plan that could incorporate the accommodations recommended by the neuropsychological report. This plan was shared with the HHT teacher assigned to JJ. Given virtual schooling delivery, the advocate encouraged the HHT teacher to collaborate with the general educator to establish times that JJ could join her class for short periods in order to maintain relationships and a sense of social belonging.



## CASE 2: MIDDLE SCHOOL STUDENT, CANCER SURVIVOR

### Background

KP is a 12-year-old male with an optic pathway glioma diagnosed at age 6. Optic pathway tumors are central nervous system lesions that affect the cranial nerves critical for vision, resulting in a range of impact from blindness to partial visual field defects, such as loss of a portion of the visual field, to minimal functional impact. The location of KP's tumor has led to a significant visual deficit, including the loss of both left and right peripheral fields and reduced visual acuity, and requires classroom accommodations such as preferential seating and adaptive physical education. More recently, KP had regrowth of his tumor causing dysfunction of the hormone center of his brain requiring hormone replacement therapy, including growth hormone and thyroid replacement. KP has numerous clinic appointments to manage his hormone replacement and has been depressed about the addition of new medications, one of which must be administered by injection by the family. To treat the tumor regrowth, KP underwent 6 months of chemotherapy which unfortunately did not shrink the tumor; he went on to receive radiation therapy. KP began middle school last year and has struggled to keep up despite having an IEP. Given the additional therapies and complications of his disease, his treatment team recommended an updated neuropsychological exam.

Currently, just as schooling has been switched to remote methods for safety, neuropsychological evaluations are likewise being administered via telemedicine [20, 21]. Findings of KP's evaluation show new or progressing deficits including reduced processing speed, a need for enlarged materials, rapid onset of fatigue—particularly for visually demanding tasks, and reduced visual search efficiency (e.g., ability to find relevant information in an array). He also showed new onset difficulty with learning and retaining new information (e.g., memory). Not surprisingly, he reported difficulties coping with his complex medical needs and the impacts of his tumor on his day-to-day functioning, which result in poor sleep and appetite, exacerbating his fatigue and worsening his attention regulation. Given his neurobehavioral presentation, KP and his family reported increasing academic difficulty in the context of remote schooling.

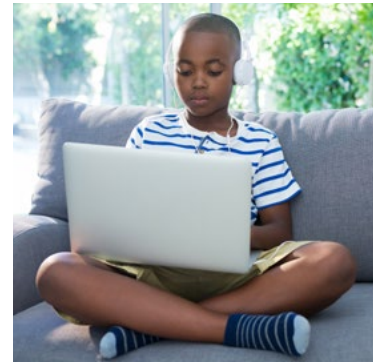
The neuropsychological evaluation report included the following recommendations with regard to vision: a consultation was suggested with both assistive technology and vision specialist team members to help determine the degree of his needs for assistive technology, particularly with regard to demands of remote schooling; careful consideration of instructional strategies to minimize time spent online and the need for rapid visual search; extended time and access to speech-to-text/text-to-speech functionality for all “written” products; access to audio recorded textbooks and any other written instructional materials; once back to school in-person, adaptive physical education to ensure his safety from projectiles or unexpected movements of his peers in his “blind spots.” With regard

to KP's memory, recommendations included clear rubrics for critical (need to know) versus “extra” information, pre-teaching/advance access to and repetition of key material, testing in a recognition (i.e., limited multiple choice options) rather than free recall (open written response) format, and access to teacher notes/slides. Similar recommendations to those in the prior case were made to address KP's fatigue and attentional dysregulation, with adjustments for age and middle school placement (e.g., reducing instructional time to core academic courses, limiting time spent online as well as the length of assignments to be completed, limiting homework to critical tasks or assigning odd/even numbered items only, utilizing alternative methods of demonstrating and assessing his knowledge). Finally, the report encouraged the school team to consider the increases in feelings of grief, loss, and anxiety felt by KP during the pandemic and recommended an increase in counseling services. However, the IEP team rejected the neuropsychological evaluation report due to the fact that the evaluation was conducted remotely.

### Advocacy

The special education advocate met with the neuropsychologist to ensure that they understood and were able to convey the findings and recommendations in the report. The advocate and neuropsychologists also collaborated to determine the best ways to present existing evidence for the validity of remote testing using best practices in telehealth. State, federal, and national professional guidance regarding assessment were consulted and summarized for the IEP team to review prior to the next meeting. The advocate also encouraged the school team to contact the neuropsychologist with questions or concerns prior to meeting.

Given that the local school system was not conducted special education assessments remotely and that it was unsafe for KP to be tested in-person during COVID19, having the school team recognize the validity of the virtual neuropsychological assessment was a key factor in helping KP to access special education and related services. Assisting the school team in understanding the validity of measures administered via telehealth assisted in moving the IEP process forward.



## IMPLICATIONS

What do these cases tell us about COVID-related distance education needs for children with cancer and other medically complex conditions? Prior to the COVID19 pandemic, these children could access supports varying from Home and Hospital teaching to accommodations via 504 Plans to specialized instruction via IEPs. Their frequency of missed school, or even avoidance of school due to immunocompromise, meant that specific plans needed to be put in place to ensure continuity of learning and availability for instruction. Although in some cases, these needs may have been met in the past via remote instruction, the current COVID-related virtual schooling delivery methods cannot be assumed to automatically address the needs of medically complex children. Many of the needs remain the same, but delivery mechanisms must be carefully thought through in terms of digital accessibility, digital organization, timing, and potential issues like photosensitivity and seizure risk.

## ADVOCATING FOR CHILDREN WITH IMMUNODEFICIENCY DURING COVID19 AND BEYOND

The cases presented above highlight some key practices in advocating for children with complex medical needs: 1) the importance of medical-school team communication, 2) the importance of shared knowledge, 3) the importance of supporting families, and 4) the importance of flexibility.

## COMMUNICATION

Children with medically complex needs have two very important teams of professionals providing recommendations and dictating daily activities – the medical team and the school team. However, these two groups of professionals do not often communicate with each other directly, and doing so requires specific procedures (i.e., written release of information), recognition of knowledge gaps, and extra time and effort on the part of multiple team members. Advocates do a great service for medically complex children and adolescents when they encourage and facilitate three-way communication between the medical team, school team, and family.

## SHARING KNOWLEDGE

As stated above, communication between the medical team, school team, and family is critical. So too, is shared knowledge. For example, the school team may be unaware of the cognitive impacts of various diseases and treatments and may incorrectly assume that once a student is “better,” there are no long-lasting impacts relevant to schooling. The medical team, while well-versed in the medical needs of their patient, is often in need of support in understanding schooling demands, special education and related services, and

home and hospital services. This lack of knowledge restricts their ability to assist the school team in educational planning. In addition to facilitating communication, advocates can encourage medical-educational knowledge sharing.

## SUPPORTING FAMILIES OF VULNERABLE CHILDREN

Care of medically vulnerable children very often requires ongoing medical visits and repeated contacts with various specialists, if not also periodic hospitalizations. All of these are not only financially burdensome, but also disruptive to the family routines and can complicate navigating further procedures such as the complexities of the IEP eligibility process. This means that advocacy is especially important to support such students and families in accessing needed services or accommodations.

## FLEXIBILITY

Medical conditions which cause immunodeficiency can cause cognitive and physical health to fluctuate. As was seen in the second case, the child’s tumor had begun to grow again, causing a plethora of changes to his physical and cognitive state. Given the potentially variable status of children with complex medical needs, it is best if the school team adopts a flexible response to instructional delivery and supports. Advocates can help the school team develop flexible plans and make sudden changes when necessary.

## CONCLUSION

Using children treated for cancer as an example, we have highlighted ways in which medically-involved and immunocompromised children have been uniquely impacted by the changes in schooling during the COVID19 pandemic, considered how those issues may continue beyond COVID19, and identified a variety of ways in which school-related advocacy can benefit children with complex medical needs. Notably, the current virtual schooling methods cannot be assumed to automatically address the needs of medically complex children, and delivery mechanisms must be carefully thought through in terms of digital accessibility, digital organization, timing, and other potential issues placing unique demands on vulnerable students.

The cases presented above highlight the importance of key practices in advocating for children with complex medical needs, including 1) medical-school team communication, 2) shared knowledge, 3) supporting families, and 4) team flexibility. Using these strategies as a guide can help equip teams to best meet the needs of a variety of students, both during the COVID19 pandemic and afterward.

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