Improving Assistive Technology Access for Students With Chronic and Complex Medical Conditions

Lessons Learned From Young Cancer Survivors

Lisa B. Carey, Kennedy Krieger Institute and Johns Hopkins University School of Education;
Andrea Harkins-Brown, Johns Hopkins University School of Education;
Kathy Ruble, Johns Hopkins University School of Medicine; E. Juliana Paré-Blagoev,
Johns Hopkins University School of Education;
Kimberly Milla, Hillary Goldthwait-Fowles, Kennedy Krieger Institute;
Clifton P. Thornton, Sydney Henegan, Johns Hopkins University School of Nursing; and
Lisa A. Jacobson, Kennedy Krieger Institute and Johns Hopkins University School of Medicine

TEACHING Exceptional Children, Vol. 55, No. 4, pp. 238–243. DOI: 10.1177/00400599221117824

Kelsey is a high school junior with a history of brain cancer. Like many young people who have been treated for cancer, she has cognitive late effects from both disease and associated treatment. Several years ago, she was found eligible for an Individualized Education Program (IEP) under other health impairment, which addresses her difficulties with working memory, attention, processing speed, and reading comprehension. Additionally, Kelsey's brain tumor resulted in blindness in her left eye and low vision in her right eye; thus, for the past few years, Kelsey's teachers have enlarged instructional documents for her. Although enlarged documents are a recognized form of low-tech assistive technology (AT), the IEP team did not recognize it as such and missed an opportunity to discuss AT options and collaborate with an AT specialist. Instead, the team documented the enlargement of documents as an accommodation.

When schooling was forced to switch to an online format in spring 2020, however, Kelsey's school staff didn't know how to continue her accommodations remotely. As a result, Kelsey started experiencing headaches from the fatigue of trying to read small fonts on her laptop. She became stressed about falling behind in her classes, and her parents began to report increases in her anxiety. When Kelsey and her mother spoke with their medical team, the hospital school liaison inquired about the use of AT. The family reported they had not heard of AT before and that the school team never mentioned it as an option.

Although enlarged documents are a recognized form of low-tech assistive technology (AT), the IEP team did not recognize it as such and missed an opportunity to discuss AT options and collaborate with an AT specialist. Instead, the team documented the enlargement of documents as an accommodation.

Health Impairment and AT

The Individuals with Disabilities Education Act (IDEA, 2004) defines AT as "any item, piece of equipment, or product system, whether acquired commercially or off-the-shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of a child with a disability." Since 1997, IDEA has required the IEP team to consider the AT needs of every student receiving special education services on an annual basis (IDEA, 2004). Assistive technology can be low-tech (e.g., a cane), midtech (e.g., a basic calculator), or high-tech (e.g., a screen reader, augmented keyboard, or speech-to-text program). Approaches to training teachers to integrate AT have changed over time, based on the ways that mainstream technologies have evolved. Today, many of the needs of students with disabilities can be addressed through instructional technology tools and devices. Smaller and more universal devices contribute to decreased stigma for persons with disabilities, increased portability allows for ease of use in the natural environment, and universal features in smartphones and laptops include options for alerts, reminders, scheduling, and behavioral prompts (Boser et al., 2014). Digital accessibility features, such as the inclusion of Voiceover as an out-of-the-box feature in the 2009 iPhone (Christopherson, 2019), have been embedded into common devices, such as tablets, laptops, and smartphones, making assistive software readily available—if users know how to enable and use those features. However, even when teachers receive training on the effective integration of instruction and AT, this may not be sufficient to prepare them to meet the needs of all students. Specifically, teachers lack adequate training to support the needs of students with chronic and complex health conditions (Irwin et al., 2018).

As Kelsey's story illustrates, although accessibility features are available on many modern devices, students, families, and their teachers may not know to enable them and may not know when additional AT is warranted. In Kelsey's case, although her IEP included an accommodation of enlarged documents—a form of low-tech AT (INDEX, 2022)—her IEP team had not considered this a form of AT and therefore other assistive devices were not discussed despite an existing IEP, documented vision loss, and difficulty with reading and processing speed. There is over a decade of evidence in the field that suggests school teams should consider AT even when the team believes they are making adequate accommodations for students (Atanga et al., 2020; Bouck et al., 2011).

Use of AT impacts students' ability to access the general education curriculum and gain academic and social independence (Atanga et al., 2020). Additionally, Bouck et al. (2011) found students who received AT showed improved postsecondary outcomes, including jobs, wages, and participation in postsecondary education. AT use results in more robust and independent accessibility to instruction, employment, and community access, which in turn better prepares students with disabilities to transition from high school (Atanga et al., 2020; Bouck et al., 2011). Thus, identifying students who would benefit from AT, correctly matching devices and/or software to their needs, and providing support as students develop independence is critical to education attainment.

A mixed-methods study by Carey et al. (2022) found survivors of childhood cancer who were receiving special education services due to the late effects of cancer and its treatment were very infrequently supported with AT. These students were not taught how to use the accessibility features on the personal devices assigned to them for remote instruction during COVID-19. Qualitative interviews and survey responses highlighted that parents were searching on their own for educational supports and were unsure of how or if they could ask the school about technology solutions for accessibility barriers. Over 75% of parents and guardians surveyed reported their child's school had not discussed options

with them. An additional 10% were unsure if AT had been discussed. Despite most of their instruction occurring in the virtual learning environment at the time of the study (due to COVID-19 school building closures), only 4% of parents surveyed and none of the parents interviewed reported their children had access to AT features as ubiquitous as speech-to-text software (Carey et al., 2022).

It is important to note that parents of childhood cancer survivors are often in a position of having to learn both the medical and educational policies and procedures necessary to support and care for their medically complex child. Ruble et al. (2019) found most parents felt unprepared to advocate for needed school supports for their child with cancer. Furthermore, the ways in which neurocognitive late effects of cancer are communicated to parents can exacerbate difficulties parents experience in advocating for special education and related services for their children. Thus, parents of childhood cancer survivors may be heavily reliant on the school team to guide them and suggest appropriate accommodations, modifications, and related services, such as AT.

Gaining Access to AT

Kelsey's family followed up with the school team to inquire about AT. The school team was unsure of the options they could offer and inquired with the school district special education office, who connected the family to a statewide AT network. An AT specialist met with Kelsey and her family and communicated with the school and medical teams to gain a clearer picture of Kelsey's needs. The AT specialist walked the school team through the Student, Environments, Tasks, and Tools (SETT) framework, a decision-making framework designed to assist school teams in considering student AT needs. After considering Kelsey's needs, her learning environment, and the types of academic tasks she must complete, the team and AT specialist brainstormed the types of AT tools from which she might benefit. Following the SETT process, the school provided a laptop with a larger screen and taught Kelsey how to use her laptop's embedded text-to-speech and speech-to-text software. Kelsey was also given access to screen reading software to trial. Additional speech-to-text mathematical notation software was downloaded to her laptop. Kelsey and her teachers were shown how to enlarge documents digitally and given access to a library of audiobooks.

In addition to the services provided directly to Kelsey, the AT specialist met with the school team to assist the team in developing a deeper familiarity with the SETT framework and to provide an overview of the AT options available to all students within the district. The school team and AT specialist set guidelines for student needs that should trigger conversations about AT during future IEP team meetings and outlined when to invite an AT specialist to meetings. Critically, the AT specialist asked that in the future, any student with a visual impairment be considered for AT supports.

Although very excited to use her new AT tools, Kelsey expressed frustration that she could have been using mid- to high-tech AT for years and was only now gaining access to these helpful supports. Kelsey was also frustrated that she'd remained reliant on others to enlarge documents for her for so long when higher tech AT could have allowed her more independence. Kelsey's parents were frustrated that although the medical team assisted in communicating her needs to the IEP team to help qualify her for special education, they did not recommend AT. Kelsey's parents had assumed the medical and school teams would have recognized their daughter's needs and addressed them appropriately. They decided to work with the hospital school liaison to request the pediatric oncology team be given updated trainings regarding AT and the needs of childhood cancer survivors.

Kelsey and her parents were right to question why, after years of special education, she only gained access to AT after the transition to virtual instruction. There are many reasons why AT may not be considered for students with chronic and complex medical conditions. First, the school team may be unfamiliar with current AT options. Second, the IEP team may be unfamiliar with the school's or district's policies and procedures regarding assessing students' AT needs. Third, teachers may lack self-efficacy in adopting AT in instruction. Finally, the school team may assume that the medical team would have suggested AT if it were necessary.

As Kelsey's story illustrates, the IEP team was unsure of what AT options they could offer to meet Kelsey's needs. Additionally, the school team had little previous experience or training in supporting students with cancer. They also appeared unsure of what actions to take; thus, they reached out to the district office for assistance. Although the school had issued Kelsey a laptop, no one had enabled the accessibility features or taught Kelsey how to use them, suggesting a lack of teacher knowledge and self-efficacy with these tools. Additionally, it seems that while the school team and medical teams communicated regarding Kelsey's eligibility for special education services, the communication did not continue, and each team may have assumed that the other would reach out if there were issues.

The IDEA (2004) indicates public schools are required to provide a free and appropriate public education, or FAPE, to eligible students with disabilities. "FAPE" is a relative term, and what constitutes FAPE is specific to the unique and individualized needs of a student, as determined by the IEP Team. When determining FAPE, an IEP team is required to consider all the resources a student may need to access the general education curriculum and special education and/or related services, including AT. The IDEA requires every IEP team revisit the appropriateness of AT each year as part of the child's annual review, even if that student has not utilized AT in the past. If it is determined a student requires AT as part of FAPE, school-purchased AT devices must be made available to the student in their home or in other settings so they can access instruction (IDEA, 2004). However, to consider AT options, school teams must have knowledge of the potential AT options that are available and appropriate.

Eliminating Barriers to AT Use

Build Teacher Knowledge and Self-Efficacy

Kelsey's story illustrates that teacher knowledge of AT is critical for students' access to hardware and software that can increase their access to the general education curriculum and build independence. Because Kelsey's school team was unfamiliar with AT, no one recommended additional or higher tech options. Teacher knowledge and self-efficacy surrounding the use of AT has been shown to impact uptake and use of AT among students (Atanga et al., 2020; Connor et al., 2010; Judge & Simms, 2009; Zapf et al., 2016).

> **Kelsey's story illustrates that teacher knowledge of AT is critical for students' access to hardware and software that can increase their access to the general education curriculum and build independence.**

AT literature from the past decade has demonstrated consistent findings regarding the minimal exposure preservice and inservice teachers receive on AT during standard teacher education programs (Atanga et al., 2020; Judge & Simms, 2009; Zapf et al., 2016). Because technologies change rapidly, it is critical teachers receive frequent, updated trainings regarding assistive technology options. Teachers do not need to become AT specialists, but they do need to be knowledgeable enough to make AT recommendations, connect students and their families to AT specialists within their school district, and support the implementation and use of AT in the learning environment (Bugaj, 2018).

Schools and districts should partner with AT specialists to provide ongoing reviews of AT available and demonstrations of their use. Additionally, educators, schools, and districts can leverage free digital resources such as the IRIS Center from Vanderbilt University, the mATch-Up Tool from Johns Hopkins University, and the National Center on Accessible Educational Materials from CAST to learn more about AT and their applications in the learning environment.

Create and Communicate an AT Assessment Protocol

When Kelsey's family asked the IEP team about AT options, there was no transparent protocol in place for assessing student AT needs. A consistent protocol would have helped the IEP team identify Kelsey's needs earlier. Some schools and school districts rely on related service providers (e.g., speech language pathologists and occupational therapists) to make AT recommendations. Although related service providers offer a wealth of knowledge and should be consulted in this process, relying on these individuals to serve as the sole source of AT referrals may overlook special education students who do not utilize these services currently or who have needs outside of the defined areas generally served by these professionals. Having a shared process for the IEP team to use when discussing AT helps to ensure that students' comprehensive needs are appropriately identified. One such tool that may be adopted by IEP teams is the SETT framework.

The SETT framework is a student-centered tool that allows teams to collect and organize information to make collaborative decisions that support positive educational outcomes for students with disabilities (Zabala, 2005). The framework is based on the principle that selecting the right tools for any student begins with an understanding of that student's unique needs, the environments where that student spends time, and the typical tasks expected of that student in those environments (Zabala, 2005). The framework is ideal for selecting an appropriate system of tools for students with chronic and complex medical condition, such as the AT devices, services, strategies, accommodations, and modifications that may benefit a student's unique learning profile. More information about the SETT framework, including downloadable resources, are available at www.joyzabala.com. The infographic in ***Figure 1*** addresses the key factors inherent in the SETT framework, with additional considerations for applying this model to students with chronic and complex medical conditions.

Communicate With and Train Students and Their Families

After Kelsey's family asked the IEP team about AT options, they were eventually connected with an AT specialist. This relationship was crucial for effectively communicating with Kelsey's family and training her to use the technology. Kelsey needed to develop independence in using her AT to navigate schoolwork. The emergency shift to remote instruction during the COVID-19 pandemic demonstrated that students and their families need to be able to use instructional technologies and AT with independence across multiple environments. This requires that students and their families be given tailored guidance, training, and supporting materials. For example, school teams should create guides with screenshots to provide to students and their families and, if possible, tutorials that explain how to use these embedded features.

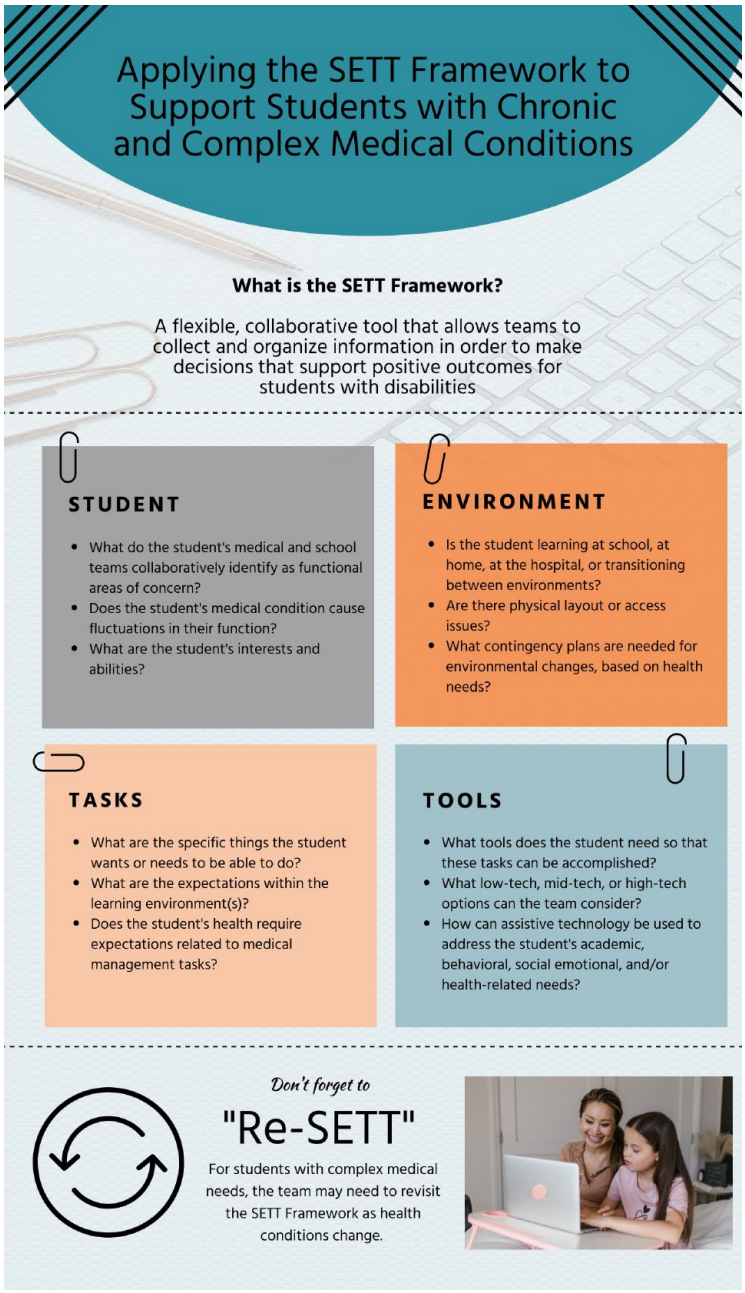
Communicate With Medical Providers

The AT specialist who oversaw Kelsey's case reopened the lines of communication with her medical team, a critical step for students who have chronic and complex medical conditions. Students who are eligible for special education and related services due to a health impairment often have interdisciplinary medical teams that are invested in supporting a patient's academic success. The medical team may have additional insights into the AT needs of the student and additional resources for assessment and/or device acquisition, if necessary. In Kelsey's case, although her medical team hadn't initially recommended AT to her school team, they were able to offer clarity regarding her vision loss and the cognitive impacts of her cancer and treatment. Together, the medical team, the school team, the AT specialist, Kelsey, and her family were able to offer their respective expertise and insight to ensure that Kelsey was matched with the best AT to meet her needs and utilize this technology effectively.

Final Thoughts

The COVID-19 pandemic exposed weaknesses in the field of special education. The emergency shifts to remote instruction highlighted many digital accessibility problems and revealed an underutilization of AT. Investing in devices and software is not enough. School teams must be supported

Figure 1 **Applying the Student, Environments, Tasks and Tools (SETT) framework to students with chronic and complex health conditions**



through ongoing professional learning activities and structures and procedures to assist in decision-making around AT. School teams who invest in learning more about AT and communicating with students' families and medical teams contribute to greater access and independence in the lives of students who have chronic and complex medical conditions.

DECLARATION OF CONFLICTING INTERESTS

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

FUNDING

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: funded by PCORI.

ORCID ID

Lisa B. Carey https://orcid.org/0000-0002-4200-5139

Lisa B. Carey, *Kennedy Krieger Institute and Johns Hopkins University, Baltimore;* **Andrea Harkins-Brown**, **Kathy Ruble**, **E. Juliana Paré-Blagoev**, *Johns Hopkins University, Baltimore;* **Kimberly Milla**, **Hillary Goldthwait-Fowles**, *Kennedy Krieger Institute, Baltimore;* **Clifton P. Thornton**, **Sydney Henegan**, *Johns Hopkins University, Baltimore; and* **Lisa A. Jacobson**, *Kennedy Krieger Institute and Johns Hopkins University School of Medicine, Baltimore.*

Address correspondence concerning this article to Lisa B. Carey, Department of Neuropsychology, Kennedy Krieger Institute, 1750 E. Fairmount, Baltimore, MD 21205-1832, USA (email: carey@kennedykrieger.org).

REFERENCES

Atanga, C., Jones, B. A., Krueger, L. E., & Lu, S. (2020). Teachers of students with learning disabilities: Assistive technology knowledge, perceptions, interests, and barriers. *Journal of Special Education Technology*, *35*(4), 236–248.

Boser, K. I., Goodwin, M. S., & Wayland, S. C. (2014). *Technology tools for students with autism: Innovations that enhance independence and learning*. Brookes.

Bouck, E. C., Maeda, Y., & Flanagan, S. M. (2011). Assistive technology and students with high-incidence disabilities: Understanding the relationship through the NLTS2. *Remedial and Special Education*, *33*, 298–308. https://doi.org/10.1177/0741932511401037

Bugaj, C. R. (2018). *The new assistive tech: Make learning awesome for all!* International Soceity for Technology in Education.

Carey, L. B., Ruble, K., Paré-Blagoev, J., Milla, K., Thornton, C. P., Henegan, S., & Jacobson, L. A. (2022). Childhood cancer survivors and distance education challenges: Lessons learned from the COVID-19 pandemic. *Journal of Pediatric Psychology*, *47*(1), 15–24. https://doi.org/10.1093/jpepsy/jsab103

Christopherson, R. (2019, June 20). *VoiceOver on the iphone turns 10- and turns blind access up to 11*. Ability Net. https://abilitynet.org.uk/news-blogs/voiceover-iphone-turns-10-and-

Connor, C., Snell, M., Gansneder, B., & Dexter, S. (2010). Special education teachers' use of assistive technology with students who have severe disabilities. *Journal of Technology and Teacher Education*, *18*, 369–386.

INDEX. (2022, March 3). *Alternative reading formats*. https://disabilityinfo.org/fact-sheet-library/assistive-technology/alternative-reading-formats/

Individuals With Disabilities Education Act, 20 U.S.C. §1400 (2004).

Irwin, M. K., Elam, M., Merianos, A., Nabors, L., & Murphy, C. (2018). Training and preparedness to meet the needs of students with a chronic health condition in the school setting:

An examination of teacher preparation programming in the United States. *Physical Disabilities: Education and Related Services*, *37*(2), 34–59.

Judge, S., & Simms, K. A. (2009). Assistive technology training at the pre-service level: A national snapshot of teacher preparation programs. *Teacher Education and Special Education*, *32*(1), 33–44.

Ruble, K., Paré-Blagoev, J., Cooper, S., Martin, A., & Jacobson, L. A. (2019). Parent perspectives on oncology team communication regarding neurocognitive impacts of cancer therapy and school reentry. *Pediatric Blood & Cancer*, *66*(1), e27427. https://doi.org/10.1002/pbc.27427

Zabala, J. S. (2005). *Using the SETT framework to level the playing field for students with disabilities*. https://assistedtechnology.weebly.com/uploads/3/4/1/9/3419723/sett_intro_article_2005_revision-1.pdf

Zapf, S. A., Scherer, M. J., Baxter, M. F., & Rintala, D. H. (2016). Validating a measure to assess factors that affect assistive technology use by students with disabilities in elementary and secondary education. *Disability and Rehabilitation: Assistive Technology*, *11*, 38–49.

TEACHING Exceptional Children, Vol. 55, No. 4, pp. 238–243.