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A Descriptive Analysis of Access to Assistive Technology in Children With Acquired Brain Injury: The Right to Assistive Devices

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Objective: Pediatric clinicians caring for children with acquired brain injury have noted that many individuals requiring assistive technology (AT) go unserved or face delays until devices are obtained, with potential adverse implications for recovery and development. In this article we map the pathways by which AT is prescribed and assess delays and barriers to access. **Methods:** We conducted a retrospective chart review of patients with moderate to severe brain injury admitted to Blythedale Children's Hospital over a 2-year period using a database drawn from the medical record. **Results:** We identified 72 children diagnosed with brain injury requiring at least 1 device. Devices were used to improve mobility and positioning, self-care, safety, and communication, and enable access to other technologies and foster social integration. We found that 55% of devices were delivered, with most deliveries to home or the hospital's outpatient department for fitting, training, and instruction. Time to delivery ranged from 12 to 250 days with an average of 69.4 days. Twenty percent of nondeliveries were attributable to change in medical status, transfer to a skilled nursing facility, or continued inpatient status, while 31% were canceled by the family. Other nondeliveries were attributed to insurance coverage. We also found that the medical record is not designed for the longitudinal tracking of devices, indicating the need for a prospective process to document the AT trajectory. **Conclusion:** Instead of tolerating delays and denials, there should be a normative expectation that children have a right to medically necessary devices, consistent with disability law. This analysis was undertaken as a step toward formulating a prospective means of tracking AT recommendations, approvals, denials, and/or deliveries. Our findings should be understood as a promissory note toward structural reforms that are reflective of society's responsibility to better meet the needs of vulnerable children and their families. **Key words:** *Americans with Disabilities Act*, *assistive technology*, *disability rights*, *neurodevelopment*, *neuroethics*, *pediatric brain injury*, *rehabilitation*

RATIONALE

Anecdotally, providers of assistive devices for children with acquired brain injury (ABI) have noted that many individuals go unserved or have inordinate delays until devices are obtained. This potentially has implications

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for recovery and/or longitudinal development. Given the importance of these devices, one would think that barriers to access would be well categorized. But a close examination of the literature indicates the lack of systematic knowledge about this key component of pediatric brain injury rehabilitation medicine.

Rehabilitative services for children with ABIs are often dependent upon assistive technologies (ATs). If we understand neither the scope of the need nor the complex ecosystem that transforms a clinician's prescription into a therapeutic reality, it is impossible to ensure proper care. This is a multistep process, each of which is a potential barrier to access.

In this descriptive study, we tracked recommendations for assistive devices at Blythedale Children's Hospital (BCH), a specialty pediatric rehabilitation hospital. We sought to better understand the provision of care and map out how, when, and whether AT devices were delivered.

This analysis was undertaken as a first step toward formulating a prospective means to track AT recommendations, approvals, denials, and/or delivery to patients. With this tool, we hope to better apprehend the impact of denials and delays on childhood development and use these data to promote systematic reform.

BACKGROUND

Children are notably affected by severe brain injury. The mean estimate of annual childhood brain injury is 691 per 100 000 population,[1] with variable incidence from infancy through adolescence.[2] An estimated 145 000 children live with the lingering effects of brain injury.[3,4] Given their early onset, these conditions have a life-long impact on health, well-being,[4] and neurodevelopment.[5] However, these adverse outcomes can be mitigated by timely and comprehensive rehabilitation often dependent on AT.[6,7]

Assistive technology allows children to interact and engage with their environment and assists their recovery and language development.[8] But AT is more than a communication support. Assistive technology encompasses any item, piece of equipment, or product system, acquired commercially, modified, or customized, that is used to enable, increase, or improve the functional capabilities of individuals with disabilities.[9] In the context of brain injury, these technologies primarily focus on augmentative and alternative communication,[10,11] positioning and mobility,[12] and computer access that provides educational support and scaffolding. During the COVID-19 pandemic, interactive software platforms enabled access to therapists and school *in abstentia.* Contemporary AT device classification may range from low-tech devices (picture boards, adaptive switches) to high-tech interventions (computerized systems, adaptive iPads, and eye gaze technology).[13] Some children's mobility and autonomy will depend on high-tech interventions such as customized wheelchairs. For others, AT will allow interactions with their families and friends.[14–16] Otherwise, they are isolated,[17] which has been shown itself to delay development as in the notorious Romanian Orphan Study.[18–20]

As critical as AT is, it can be difficult to access. It takes expertise and persistence to find the correct devices and funding.[21] Items may be funded through medical insurance, private pay, school systems, or charity. Errors can result from a mischaracterization of the diagnosis or condition.[22] It can be onerous to identify a reliable and timely funding source. Even when resources are available, the process is complex and bureaucratic. In the aggregate, this can lead to delays and denials.[23] It requires the expertise of educators, therapists, parents, and support staff capable of translating the technology into care.[24] In sum, children are in critical need of AT to sustain their rehabilitation and maximize their social integration. Securing access to AT is a clinical, ethical, and policy imperative in need of data to support practice reform.

Brain injury research is notably different in children because they have developing brains.[25] When this naturally unfolding process is harnessed in tandem with neurorehabilitation, outcomes may be improved.[15,26] When rehabilitation falters and developmental milestones are missed, the lack of AT can have a compounding negative effect.

Access to AT has been identified as a critical health need of children with ABI and enduring disabilities.[27] Yet little aggregate data exist about AT access as children transition from acute care to the community. Without these assistive devices, children are at risk of social isolation, developmental delay, and a reversal of progress made during inpatient rehabilitation. When available, AT helps restore communication and community[28] thereby exchanging the deleterious effects of social isolation with the therapeutic benefits of social integration.

Children with access to AT develop a better sense of self, self-confidence, and competence. They are perceived differently by others, and they can engage with their peers. Without AT children can be perceived as having more impairments than exist, such as an inattentive child in a classroom who is nearsighted or has hearing loss. These needs are routinely remediated with glasses and hearing aids. More significant challenges may be addressed with AT. So empowered children are set up for more independent living. Without AT they are at risk of social segregation, isolation, and even abandonment by society.[29]

The benefits of AT are not limited to children but extend to the family unit. Access to functioning AT can limit caregiver burnout and enhance relationships,

interactions that themselves are essential for developmental progress and the happiness and welfare of children. AT can also enable children to interact more equally with their siblings. Thus, the benefits of AT transcend the individual child and affect the locus of care and their broader ecosystem of support.[30]

Finally, access to AT among children with ABI may differ on the basis of sociodemographic factors. Understanding the impact of health disparities in the provision of AT is an essential contextual factor that transcends the clinical and implicates broader questions of diversity, equity, and inclusion. These disparities may have a legal bearing on equal care under prevailing disability law.[31,32]

In this article, we describe and characterize the provision and timeliness of AT access for pediatric patients with ABI following inpatient rehabilitation. We seek to understand when and whether access to AT is denied or delayed and the etiology of these barriers to care.

METHODS

We conducted a retrospective chart review of patients with moderate to severe brain injury admitted to BCH over a 2-year time frame (2017-2018) using a comprehensive database maintained by BCH drawn from the medical record. We documented basic demographic information, diagnosis, insurance status, and whether AT was recommended and if so, the types and uses of the AT.

As noted, we defined AT as any item, piece of equipment, or product system whether acquired commercially, modified, or customized that is used to enable, increase, or improve the functional capabilities of individuals with disabilities. We first identified all *International Classification of Diseases, Tenth Revision* (*ICD-10*) diagnostic codes for all patients admitted to one of BCH's inpatient or outpatient programs for the first time from January 1, 2017, to December 31, 2018. We identified 2993 unique *ICD-10* codes in this initial query. Study personnel and experienced clinicians with expertise in pediatric brain injury and physical, occupational, and speech therapy reviewed the list of *ICD-10* codes and found 93 unique *ICD-10* codes indicative of brain injury in the study population.

Examples of selected diagnoses include encephalitis, meningitis, neurodegenerative disorders, anoxic injuries, traumatic brain injury, stroke, cerebral palsy, and brain neoplasms. The data repository was queried to find all patients admitted during the study period with at least one of the 93 *ICD-10* codes. Each of the identified patients' charts was reviewed by at least 2 independent clinical study personnel to assess whether the patient had a moderate to severe brain injury.

Children were excluded if they did not have moderate to severe brain injury or if they had not been evaluated by an occupational, physical, or speech therapist during the study period. From each of the included patients' charts, the following information was retrieved: medical record number, date of birth, brain injury diagnoses, date of initial brain injury, hospitalization dates, whether AT was recommended for the patient, number of AT devices prescribed, device types, documented device receipt, delivery venue, funding, use of loaner devices, functional goal of devices, and insurance denials.

Data were obtained from the BCH electronic medical record, which utilized Meditech 6.0.8 and was stored on an institutional data repository. Additional information was obtained from records of the assistive technology service. Data were entered into a Microsoft Excel for Microsoft 365 spreadsheet and managed using secure REDCap electronic data capture tools hosted by BCH. Demographic and clinical data were reported as *n* (%) for categorical variables and as median (interquartile range or mean [SD]) for continuous variables.

Our research protocol was approved by the BRAINY Institutional Review Board utilized by BCH as well as the institutional review board at Weill Cornell Medical College.

RESULTS

Seventy-two patients were identified as having an *ICD-10* Code indicative of brain injury for whom AT was prescribed. Their diagnostic codes were cerebral palsy ($n = 21$); stroke ($n = 17$); traumatic brain injury ($n = 9$); anoxic brain injury ($n = 8$); brain tumor ($n = 6$); infection ($n = 5$); congenital malformation ($n = 4$); and encephalopathy ($n = 2$). There were 28 females (average age: 10.9 years, range: 0.8-19.3 years) and 44 males (average age: 7.6 years, range: 0.9-18.6 years). Of the 72 children, approximately 33% ($N = 24$) were White, 26% ($N = 19$) were Black, 24% ($N = 17$) were Latinx, 10% ($N = 7$) were Asian, and 7% ($N = 5$) were not categorized.

Twenty-one different types of devices were prescribed for a total of 156 devices (see Table 1). Therapeutic goals included improved mobility and positioning (82), improved self-care (50), promoted safety (14), improved communication (6), and improved access to other technology (1). There was no documentation for 3 devices.

The number of devices per child were 1 (27), 2 (22), 3 (13), 4 (5), 5 (4), and 6 (1). Of these 156 prescriptions, 143 were ordered while children were inpatient with the remainder attending BCH outpatient programs.

Of the 156 prescribed devices, there were 86 documented deliveries (55%). Devices were delivered to home (47); BCH for outpatient fitting, training, and instruction (39). Data for nondelivery of devices were available for 31 devices and were attributed to the following: change in medical status (7); not a covered benefit (6); transfer to skilled nursing facility (5);

TABLE 1 *Device types and number of devices prescribed*

Device type	Number prescribed
Adjustable bath support	21
Tilt in space manual wheelchair	18
Manual wheelchair	17
Adapted stroller	14
Tub transfer bench	14
Walker	11
Other	8
Commode	7
Hospital bed	7
Stander	6
Patient lift	6
Specialized bed	5
Slider bath support	5
Speech-generating device	5
Shower chair	4
Rehab shower chair	3
Activity chair	1
Power wheelchair	1
Cane	1
Special needs car seat	1
Transport manual wheelchair	1
Grand total	**156**

family cancelled (4); cost of device exceeded insurance-allowable reimbursement (4); out-of-network vendor (3); and child remained inpatient at BCH (2). Data were not available regarding delivery status for 39 devices.

Time to delivery was available for documented deliveries with an average delivery time of 69.4 days. There was great variability in delivery times for a hospital bed (12 days); basic commode (14 days); stander (150 days); and a special needs car seat (250 days) (see Table 2). The documented need for AT loaner devices was identified for 40 devices and 37 of these devices were provided.

Of the 156 devices, 147 were submitted to primary or secondary insurance. Of the 147 devices submitted to insurance, 85 were funded the first time, 18 were not, and data were not available for the remaining items. Importantly, approximately 42% of nondelivered devices were attributed to difficulties with insurance coverage; 46% of these devices were not considered a covered benefit, 31% exceeded the insurance-allowable reimbursement, and 23% were from an out-of-network vendor, sometimes due to a change in funding source during submission. Only 54% of all devices had documented insurance approval after the first submission; 60% of devices were unknown or ineligible for insurance coverage, and 12% of devices were rejected at first attempt at insurance coverage.

Given the small sample, and smaller subset of patients with TBI, we cannot make meaningful comparisons between patients with TBI and other brain injuries from this study.

TABLE 2 *Device type and average delivery time (days)*

Device type	Average delivery time, d
Special needs car seat	254
Stander	152
Adapted stroller	128
Tilt in space manual wheelchair	110
Manual wheelchair	82
Speech-generating device	69
Rehab shower chair	68
Other	67
Specialized bed	54
Walker	41
Adjustable bath support	40
Shower chair	29
Tub transfer bench	21
Commode	14
Patient lift	13
Hospital bed	12

DISCUSSION

It is rather astounding that this is the first article to track the sequence of events that lead to the provision of AT for children with brain injury. These data are important if we want to take seriously the role of AT in childhood development and rehabilitation. This absence of data is a scholarly omission that needs correction. In this study, we sought to map out a process from needs assessment to device delivery and utilization *using the available medical record*.

We identified 72 children over a 2-year period with a diagnosis of brain injury who required at least 1 AT device. Devices were used to improve mobility and positioning (53%), self-care (32%), safety (9%), communication (4%), and access to other technologies (0.6%). We found documentary evidence that just more than half of the devices (55%) were delivered to children, with most of these being delivered to home (55%) or BCH outpatient department for fitting, training, and instruction (45%). Ninety-five percent of the delivered devices had documented time to delivery, with delivery time ranging from 12 days to 250 days, or approximately 8.3 months. The longest recorded delivery time was for a special needs car seat.

That the average time to delivery was 69.4 days needs to be understood in a developmental context, as the loss of more than 2 months may prove especially detrimental to a child's recovery. When developmental milestones are missed or delayed because needed AT is not provided, there may be a domino effect of cascading

complications for the recovering brain of a young child. There may also be a compounding or intersectional effect as well when the developmental and restorative benefits of schooling and other social engagements are made inaccessible due to a lack of mobility, which might have been addressed with AT.

Approximately 20% of devices that were not delivered were due to the patients' change in medical status (22%), their transfer to a skilled nursing facility (16%), or because they remained inpatient at BCH (6%). Other nondelivered devices were attributed to difficulties with insurance coverage, such as the device being deemed as a noncovered benefit exceeding the insurance benefit reimbursement allowance, or an out-of-network vendor further complicating the payment stream. Our data highlight the complex process by which a prescription is translated into device delivery. Interestingly, 31% of nondelivered devices were canceled by the family; one can only imagine the frustration that would prompt a cancelation. Finally, while we cannot draw comparisons between TBI and other brain injury patients given the small sample, we would stress that multiple etiologies can lead to dependence on AT.

One of the pragmatic lessons gleaned from our retrospective review was that as good as the medical record is, it was not designed for the longitudinal tracking of devices. Although medical and rehabilitative expertise can identify and document patients' needs in the medical record, there is a device diaspora after a prescription is written, making children vulnerable to nondelivery or unconscionable delays.

It is naïve to assume that a physician's order leads to timely device delivery, like a simple antibiotic from the local pharmacy. Instead, there is a complicated approval process that must be navigated. For devices, a prescription includes a letter of medical necessity, submitted to a supplier, who then prices out the device and its components or customization. The supplier then submits the prescription and the cost to the insurance company for review. Each step engenders a delay.

When the device is medically approved by the insurance company, the parents and the supplier are informed, though the prescriber may or may not be notified. Although the family is happy to receive this news, the insurance company also informs the supplier how much they will pay for the approved device. Contractually, the supplier can either accept or refuse this amount. If refused, the prescriber can attempt a rejustification and the process is extended. This cycle can be repeated, each time further delaying the process. Despite their desire to provide patients with AT devices, some institutions limit the number of times that prescribers may undertake the rejustification and appeal process. This is a nonbillable activity, which can stress resources and staffing.

Families may learn from the supplier that, although the requested device was approved, the amount of coverage is insufficient to order the device for their child. This can lead to mistrust, frustration, and further delay. Insurers generally do not inform families because they approved the device and will pay for it, albeit at a price that may be below cost or unacceptable to the supplier. Families without insurance can negotiate with the supplier, often calling upon charitable sources for support. Some families with means will work directly with suppliers to minimize delays. All families expend an inordinate amount of time and energy to negotiate the system and procure devices that their children need. These costs are unaccounted for and are fiscally and emotionally draining for families.

When a device is approved and the price is consistent with "allowables" for coded items, the supplier submits a purchase order to the manufacturer. Not all devices are created equally. For routine devices that are in stock, delivery will occur soon thereafter. However, for expensive or customized devices, there may be additional delays while the product is manufactured to specifications.

If one were to imagine a metaphor for this process, a labyrinth comes to mind. There are pathways, alleyways, and dead ends that conspire to prolong, delay, and complicate the process. The stakeholders—patients, families, and concerned clinicians—in this journey are often left uninformed about the status of a child's AT prescription, which can be delayed, denied, or lost somewhere in a bureaucratic maze.

This initial study revealed that the process by which AT is prescribed, provisioned, and provided is complex and difficult to track. In future efforts, BCH plans to redesign the process by which device prescriptions are documented and tracked and work more collaboratively with suppliers and insurers to follow the progression of these needed services. Once implemented, we expect to share these results more broadly and undertake a multicenter study to establish an industry-wide standard that can lead to the responsible and responsive provision of AT to children in need. In tandem, we hope to test the hypothesis that delays in the provision of AT have an adverse effect on recovery following pediatric brain injury. Building on our preliminary work and the construction of a prospective tool, we hope to create a database that tracks children's prescribed AT and apprehends how denials and delays of devices impede functional status, rehabilitation, social integration, and quality of life.

LIMITATIONS

Our study is limited as a single-institution retrospective descriptive study with local characteristics, which may not be representative of other communities. More devices may have been delivered than documented

because our patient-centered medical record was not designed to track devices. This study was undertaken to identify the limitations of a conventional medical record to assess the provision, delivery, and utilization of AT and rectify these challenges by improving documentation to better track the barriers, delays, and challenges related to device delivery.

DISABILITY LAW AND THE RIGHT TO ASSISTIVE DEVICES

There are many reforms that come to mind after this initial analysis of access to assistive devices in pediatric brain injury. There needs to be better tracking of what happens after a prescription is written; enhanced collaboration and communication between clinicians, suppliers, insurance companies, and manufacturers; and more transparency with families who wait expectantly for devices that they hope can make a difference in their child's life. This could be accomplished through modifications to the electronic medical record and better tracking of insurance claims, reimbursement, and the eventual delivery of devices. But as effective as these documentation efforts may be, it is more critical that we improve access to assistive devices.

Instead of tolerating long delays, denials, and a disorganized supply chain that must come together to ensure access, the expectation should be that children have a right to devices that their clinicians believe are medically necessary. Instead of being pleasantly surprised when a prescribed device arrives, timely and accurate delivery should be seen as a norm *required by law*.[33,34]

The Americans with Disabilities Act (ADA)[35] calls for the maximal integration of people with disabilities into civil society and the nexus of their homes and families. Assistive devices are especially instrumental in the pursuit of disability justice in children because they become the means for overcoming the segregation wrought by injury or disability.[36] When the ADA was signed into law by President George Herbert Walker Bush with strong bipartisan support, the Act made special mention of AT devices in Title IV. Although Title IV speaks to technologies like TTY (teletypewriter) extant in 1990, the intent of this section of the ADA was to provide a means for societal integration using technology. This provision should not be limited to technologies that were available 30 years ago but to the suite of technologies that can help people with disabilities better integrate into society today.[37]

The availability of AT is especially important to the developing brain so dependent upon social interactions. A child with disability, deprived of a device that helps him or her to go to school, is denied the right to socialize with friends, playmates, and classmates. They are removed from an environment which fosters development and maturation. Without a wheelchair they may be unable to get to school and be in the "room where it happens."[38] Without a communication device, they may not be able to communicate with instructors or peers. These deprivations all have consequences that foster societal segregation and undermine critical developmental processes. Without access to AT children with disabilities are further disadvantaged and deprived of remediation that might allow for the maturation and societal integration.

We contend that the status quo constitutes a violation of the ADA[39] and could be subject to an *Olmstead* enforcement.[40] In *Olmstead v L.C*, the Supreme Court found that Georgia violated the ADA because it did not allow for 2 plaintiffs–with mental health conditions and intellectual disabilities–to be deinstitutionalized from the state's mental health system to live in the community, a setting that maximally integrated them into civil society.[41] Writing for the majority, Justice Ruth Bader Ginsburg reflected upon unwarranted institutionalization, stating that in writing the ADA, "Congress explicitly identified unjustified 'segregation' of persons with disabilities as a 'form of discrimination.'" Justice Ginsburg asserted that "unjustified institutional isolation of persons with disabilities" was discriminatory because, "... it perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." Furthermore, "... confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."[42] If the denial of AT leads to de facto confinement, then denials of devices could constitute an *Olmstead* violation.

If we take disability law seriously–and the dignity of children with disabilities–we have an ethical responsibility to better apprehend where the provision of AT falls short. In this article, we have attempted to map the challenging pathways by which AT is prescribed and delivered and document barriers to access. Our results should be understood as a promissory note to needed reforms to better meet the needs of children and their families.

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