Barriers to Assistive Technology Access in the Virginia Medicaid Program

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Introduction

It is estimated that, as of 2019, there were 7.39 million individuals with intellectual and developmental disabilities (IDDs) in the US (Residential Information Systems Project, 2019). According to the National Institutes of Health, IDDs are conditions "that are usually present at birth and that uniquely affect the trajectory of the individual's physical, intellectual, and/or emotional development" (National Institutes of Health, 2021). As a result, individuals with IDDs face a unique set of difficulties in everyday life compared to the general population. One way individuals with IDDs address these difficulties is through the use of assistive technology (AT), which are, according to the Assistive Technology Industry Association, "products, equipment, and systems that enhance learning, working, and daily living for persons with disabilities" (Assistive Technology Industry Association, 2015).

AT serves as a crucial tool for enabling people with IDDs to perform everyday tasks and participate fully in community life. From speech generating devices to mobility aids, countless studies have demonstrated the benefits afforded by AT to individuals with IDDs. In fact, the importance of these technologies is such that the UN Convention on the Rights of Persons with Disabilities stipulates access to AT as essential for all individuals (UN Convention on the Rights of Persons with Disabilities, 2006). Given this information, I was rather alarmed to learn that access to AT is one of the most commonly reported unmet needs among individuals receiving Medicaid Home and Community Based Services (HCBS), the most common source of services for individuals with IDDs in the US (Chong et al., 2022).

One of the biggest reasons for this disparity is cost. The high cost of these technologies, many of which can be in the thousands of dollars, is often prohibitive to individuals wishing to implement such interventions. To help cover these costs, individuals with IDDs in Virginia can apply for funding through one of Virginia's Medicaid Developmental Disabilities (DD) Waiver programs. Under Virginia law, qualifying individuals can receive coverage worth up to $5,000 per calendar year.

However, accessing funding for AT in Virginia through this program has been a historically difficult process. As of December 2022, there were more than 14,000 individuals on the waitlist for support services through the DD waiver (DeFusco, 2022). This issue is important to me personally because my mother is an occupational therapist who serves individuals on the DD waiver in Virginia, and listening to her stories about the struggles she has faced in helping her clients get the funding they need for AT services was a large part of what drove me to study this topic in the first place.

In this paper, I argue that invisible administrative work and conflicting narratives in the professional evaluation and service authorization processes, stemming largely from institutional and medical biases embedded in the federal Medicaid program, serve as the primary factors limiting access to AT funding through the DD Waiver program in Virginia. In the literature review, I will establish the importance of the issue through a discussion of the importance of AT in the lives of individuals with IDDs, the role of cost as a limiting factor in AT access, and the prevalence of unmet need for AT in the US. The subsequent analysis will utilize the framework outlined by Dr. Susan Leigh Star's in her 1999 paper "The Ethnography of Infrastructure" to examine the Medicaid program as a large-scale infrastructure system using information gathered through historical analysis and interviews with relevant stakeholders. I will first demonstrate how institutional and medical biases embedded in the federal Medicaid system's IDD services from the program's inception created barriers to accessing AT services across the country. Then, I will examine how federal efforts to address these barriers failed to facilitate AT adoption through the Virginia DD Waiver system. Finally, I will show how unrecognized administrative work and conflicting narratives in the Virginia DD Waiver program restrict public funding for AT today.

Literature Review

Research has demonstrated the wide range of benefits access to AT affords individuals with IDDs. AT has been found to foster independence, autonomy, and overall improvements in quality of life. For example, a 2021 study by researchers at Georgia Tech's Center for Inclusive Design and Innovation found that the implementation of AT systems resulted in statistically significant performance gains involving personal goals as well as an increase in quality of life survey scores and "an elevated sense of agency and personal empowerment" among participants with IDDs (Satterfield et al., 2021, p. 56-58). AT can also increase communication skills and build self-determination in adults with IDDs (Söderström et al., 2021, p. 8-10; Walker & Snell, 2013). Finally, AT improves education and employment outcomes (Morash-Macneil et al., 2018; United Nations Secretariat, 2019).

While the benefits of AT are widely accepted, the cost of implementing such solutions serves as a significant impediment for many individuals. A 2012 survey of 180 individuals with IDDs identified cost as the most commonly reported barrier to AT adoption among participants (Tanis et al., 2012, p. 58). In fact, device cost is one of the most commonly cited obstacles to AT use in surveys of family members of individuals with IDDs (Palmer et al., 2012, p. 408; Wehmeyer, 1998, p. 48). To make matters worse, those who have the greatest need for AT services are often least able to afford it. In Virginia for example, as of 2019, 25.7% of residents with a cognitive disability were living below the poverty line, compared to 8.2% of residents with no disability (Winsor et al., 2022, p. 140). As a result, for many individuals with IDDs in Virginia, access to AT services are often facilitated through the state's Medicaid waiver program

However, even among individuals on Medicaid, a program designed to offer affordable healthcare to low income families, children, and adults, there is a significant unmet need for AT services in the US. An analysis of data from the 2017-2018 National Core Indicators-Aging and Disability (NCI-AD) survey, a survey of individuals receiving Medicaid HCBS in 13 states, identified AT (54% of respondents) and home modifications (52%) as the most common unmet needs among participants (Chong et al., 2022, p. 3). Assistive technology funding through Medicaid is especially underutilized in Virginia. In a 2008 analysis of 47 states with AT waivers from 1999-2002, Virginia ranked 41st in AT waiver participation as a percentage of the total population and 40th in the ratio of AT waiver participants to the population of Medicaid-eligible individuals with disabilities (Kitchener et al., 2008, p. 187). More recently, a study of Medicaid HCBS waivers across the US found that just 3.5% of Virginians with IDDs receiving funding through Medicaid HCBS were projected to receive AT services in 2021 (Friedman, 2023, p. 4). While studies such as these have brought attention to the issue of AT access through Medicaid for Virginians with IDDs, there has been little public inquiry into the origins of this disparity. Given the potentially transformative nature of assistive devices in the lives of individuals with IDDs, a systemic examination of the Virginia Medicaid DD waiver program seems to me to be an important step towards improving the lives of such individuals going forward.

The nature of the Medicaid DD waiver program in Virginia lends itself well to historical and ethnographic analysis as an infrastructure system. This approach emphasizes the fact that a society's practices, culture, and norms are embedded in every level of the design of infrastructure systems. The ideas, processes, and assumptions embedded into the Virginia Medicaid program were analyzed using this framework, identifying the “master narratives” and “invisible work” at the heart of the program and the role they play in limiting access to AT in the state (Star, 1999, p. 384-385).

Methods

The primary methodological approaches upon which my research is based are historical analysis of research, statutes, and administrative records pertaining to the Virginia DD Waiver program and interviews with stakeholders from various facets of the program. First, to get a sense of the federal basis of the state’s Medicaid program, I analyzed documents regarding the creation of Medicaid in 1965 and of HCBS waivers in 1981. Then, I examined the federal actions taken in the late 20th century to better understand how federal priorities shifted towards community integration and provision of AT services for Americans with IDDs. Next, I delved into how these federal directives trickled down to the Virginia state level by analyzing state reports and guidelines on the DD waiver system and funding for AT services through the system. Finally, to paint a picture of the current state of AT access through the Virginia DD waiver program, I conducted interviews with stakeholders throughout the program. To gain insight on the issue from the perspective of those providing AT services in the state, I interviewed a manager at a private provider of AT operating in Virginia as well as an occupational therapist who provides AT evaluations through the Virginia DD waivers. Moreover, to examine this issue from the perspective of those applying for funding for these services, I interviewed two members of a regional advocacy organization serving individuals with IDDs in Virginia. Because I was unable to sit down with any employees at the Virginia Department of Medical Assistance Services (DMAS) or the Department of Behavioral Health and Developmental Services (DBHDS), the state agencies responsible for administering the DD waiver program, I reviewed the websites and other official content published by these agencies to gain a sense of the state's viewpoint on the issue.

Analysis

In the context of the Virginia Medicaid program, many of the barriers to accessing AT services stem from what Star refers to as the "inertia of the installed base," originating with the passage of the Social Security Amendments of 1965 by Congress (Star, 1999, p. 382). This law, known as Title XIX of the Social Security Act, created Medicaid, a healthcare program for eligible needy families and individuals jointly funded by the federal and state governments (Social Security Administration, 2015). However, the stringent federal requirements for reimbursement established under Title XIX heavily favored institution-based care for individuals with IDDs rather than community-based alternatives. This meant that states such as Virginia, which had over 5,000 individuals with IDDs residing in state-run facilities by the 1970s, had little financial incentive to transition those individuals into the community (Virginia Department of Behavioral Health and Developmental Services, 2012). Recognizing this, Congress added section 1915(c) to the Social Security Act in 1981, which allowed states to provide home and community based services (HCBS), including AT, to individuals who would otherwise require institutional care without needing federal approval (O'Keeffe et al., 2010). Nonetheless, in order to offer HCBS under section 1915(c), federal guidelines required states to demonstrate the capacity to serve recipients in an institutional setting and show that services offered under the waiver were no more expensive than institutional care (Miller et al., 1999). These conditions resulted in the entrenchment of a significant institutional bias in the "installed base" of the Medicaid system at the federal level, constituting a form of inertia that Star identifies as characteristic of almost all large-scale infrastructure systems . By placing the burden of proof on states to show that HCBS was at least as cost-effective as institutional care, rather than the other way around, these requirements created state programs in which institutional care was seen as the "default" setting for individuals with IDDs and efforts to provide community-based services were carefully scrutinized on the basis of medical necessity and cost. In fact, Medicaid expenditures on HCBS did not surpass spending on institutional care until 2013, almost 50 years after the establishment of the program (Watts et al., 2020, p. 2). Although the addition of section 1915(c) was a necessary step in addressing the program's institutional bias, efforts to facilitate community integration did not truly gain traction until the late 20th century.

This inertia in federal administration of the Medicaid program began to shift away from the institutionalization of individuals with IDDs with the passage of the Americans with Disabilities Act (ADA) in 1990. Under the ADA, the federal government enacted what is known as the "integration mandate", which requires public entities to accommodate individuals with disabilities "in the most integrated setting appropriate to the needs of the individual" (Americans with Disabilities Act of 1990, 1990). This mandate served as the legal basis for an even greater disruption to the institutional momentum of the Medicaid program in 1999 with the Supreme Court's decision in Olmstead v. LC. In the Olmstead decision, the court ruled that "[u]ndue institutionalization qualifies as discrimination 'by reason of . . . disability'" under the ADA and that, consequently, states are required to provide individuals with IDDs with community-based supports and services, rather than institutional care, if certain criteria are met (*Olmstead v. L.C.*, 1999). The Supreme Court's decision in Olmstead v. LC had serious implications for the provision of community-based services at the state level, AT being among the most important, because it paved the way for federal enforcement of deinstitutionalization through legal action. In early 2001, President George W. Bush issued Executive Order 13217 ordering the Department of Justice (DOJ) to “fully enforce” the Olmstead decision by “investigating and resolving complaints filed on behalf of individuals who allege that they have been the victims of unjustified institutionalization” (Executive Order No. 13217, 2001, p. 775).

Under this directive, the DOJ commenced an investigation into the Central Virginia Training Center (CVTC), a state-run institution for individuals with IDDs, in 2008 and expanded the review to examine the state’s compliance more broadly with the integration mandate in 2010. Upon completion of the investigation, the DOJ notified the state that it was violating the ADA by “unnecessarily institutionalizing, and placing at risk of unnecessary institutionalization, individuals with ID/DD throughout Virginia” (US Department of Justice, 2012, p. 4). In their settlement with the DOJ, state officials agreed to dramatically restructure and expand the DD waiver system. This litigious state-by-state approach to Medicaid reform is an example of Star’s description of how infrastructure systems are “fixed in modular increments, not globally or all at once,” (Star, 1999, p. 382). She asserts that “[b]ecause infrastructure is big, layered, and complex, and because it means different things locally, it is never changed from above” (Star, 1999, p. 382). This is especially true for Medicaid, wherein each individual state is given a significant degree of autonomy in administering broad federal statutes. As such, sweeping proclamations at the federal level were never going to overcome the inertia of institutional bias embedded in state Medicaid programs by the original passage of Title XIX without more concrete reforms at the state level. Even these efforts, however, came up short in addressing the primary barriers to funding AT through the Virginia DD Waiver program.

Despite drastic reforms to Virginia DD waivers following the federal investigation into the program, the excessive administrative burden limiting access to AT funding in the state has remained largely unaddressed. Access to services facilitating community integration for

Virginians with IDDs emerged as a priority in the wake of the state's settlement with the DOJ in 2012. In the settlement, the state agreed, among other items, to collect and analyze data about the provision of such supports, including access to AT (United States V. Commonwealth Of Virginia, 2012). Furthermore, Virginia's Olmstead Plan, published in 2014, identified "inadequate access to assistive technology" as a barrier to community integration for individuals with IDDs in the state (Community Integration Implementation Team, 2014, p. 20). In spite of this notable shift in attitudes at the state level toward AT services, the first three subsequent reviews found the state to be out of compliance with the settlement. In 2015, for example, just 40% of individuals selected for review with assistive technology services identified in their Individual Support Plans were not receiving those services (Fletcher, 2015). While some may assert that this disparity in AT access can be attributed to a lack of funds appropriated to HCBS, this is likely not the case for several reasons. First of all, the state reported a 167% increase in funding for waiver services from 2012 to 2020 (Department of Behavioral Health Services, 2022). Despite this surge in funding, access to AT services proportional to the number of recipients of DD waiver services has remained largely unchanged (Department of Medical Assistance Services, n.d.). Additionally, the state reported spending an average of $1,723 per recipient on AT services through the DD waiver program in 2020, significantly less than the $5000 cap (Department of Medical Assistance Services, n.d.). This points to a significant underutilization of AT services through the DD waiver rather than a shortage of funds. Instead, the evidence suggests an excessive administrative burden as the primary barrier to AT adoption by individuals on the state DD waiver. For example, the Sixteenth Independent Reviewer report, published in June 2020, found that caregivers and/or individuals on the DD waiver were largely satisfied with the services provided but raised issues " … with the complexities, which were at times obstacles to getting individuals' needs met timely, including the assistive technology authorization process" (Fletcher, 2020, p. 127). Furthermore, a 2020 survey of nurses with experience supporting individuals with IDDs, several reported that their patients had experienced unmet needs for assistive technology services due to a lack of professional evaluations (Fletcher, 2021). These difficulties in completing necessary evaluations for AT use and gaining approval for funding through the service authorization process represent significant administrative hurdles restricting access to AT funding in Virginia.

The first major obstacle to AT services through the DD waivers in Virginia is the requirement that individuals receive a professional evaluation prior to requesting reimbursement for AT services. Due to the federalist structure of Medicaid, provision of AT services varies significantly across states. In Virginia, an individual's support coordinator must first identify a need for assistive technology services. Then, the individuals AT needs must be assessed by a qualified professional. Once the assessment has been completed, the support coordinator must request a service authorization for the identified equipment (Department of Medical Assistance Services, 2022). As I learned in my conversations with several stakeholders in the process, the first step, conducting a professional assessment, poses a considerable barrier to AT services through the waiver. One manager at a regional vendor of AT services operating in Virginia pointed out in our interview that state law explicitly prohibits AT vendors such as their company from performing the assessment. Instead, assessments must be conducted by "independent professional consultants," including "speech-language therapists, physical therapists, occupational therapists, physicians, behavioral therapists, certified rehabilitation specialists, or rehabilitation engineers" (Assistive Technology Service., n.d.). Further complicating the process is the fact that third-party assessments for AT are not covered under AT services on the DD waivers in Virginia, so individuals must either pay for the service out-of-pocket or seek therapeutic consultation through the waiver, which requires a separate service authorization. Given the fact that individuals on the Medicaid waivers must meet certain income limits in order to be eligible, most cannot afford to pay out of pocket for an evaluation. Additionally, neither therapeutic consultation nor assistive technology are standalone services under the Virginia Medicaid program, meaning recipients must be receiving at least one other service to qualify (Department of Medical Assistance Services, 2022). As a result, they must go through the entire approval process for two separate Medicaid waiver services before being eligible for AT services. These lengthy administrative proceedings are an example of what Star refers to as "invisible work" (Star, 1999). Hidden beneath the waiver applications and visible procedures facilitating AT access through Medicaid in Virginia are the crucial tasks of finding qualified therapists to perform these evaluations, actually conducting the evaluations, and, for the evaluators, receiving compensation for their work. Based on my conversations with caregivers and evaluators alike, the hidden nature of this work is particularly prohibitive to AT access in the state because providers of both evaluations and the technology itself cannot be compensated through Medicaid for it. As a result, providers have little financial incentive to undergo the lengthy certification process to operate through Medicaid in Virginia, especially when they can receive compensation for this "behind-the-scenes" work in other states, leading to a shortage of providers in many regions across Virginia. The impact of these shortages on AT adoption in the state can be seen in the correlation between access to qualified therapeutic consultation and AT utilization rates. In 2023, for example, DBHDS Region 2, which serves Northern Virginia, had over twice the number of authorized therapeutic consultation providers as Region 3, which serves Southwest Virginia (Department of Behavioral Health Services, 2024). Not coincidentally, Region 2 also had a service authorization rate for assistive technology service nearly four times higher than that of Region 3. Furthermore, looking outside Virginia, states that either cover professional assessment for AT under the same waiver service (New Jersey) or do not require evaluation for AT approval (Ohio) have significantly higher rates of AT adoption (*Assistive Technology | Department of Developmental Disabilities*, n.d.; Friedman, 2023; New Jersey Department of Human Services & Division of Developmental Disabilities, 2023). While there are almost certainly other factors contributing to these regional and statewide differences, the evidence points to the "invisible work" required to complete required professional evaluations as a significant barrier to AT access through the Virginia Medicaid system.

In addition to required professional evaluations, the service authorization process for AT in Virginia poses a considerable barrier to AT adoption. Once a professional evaluation has been completed and the appropriate AT device(s) to suit an individual's needs has been identified, a service authorization request must be submitted to DMAS to approve coverage of the device(s). This process is not unique to AT services; service criteria and authorization are tools commonly used to manage utilization and control costs in healthcare settings. Until the state's DD waivers were redesigned following the DOJ settlement in 2013, Virginia code limited coverage of AT devices to those which were "medically necessary" (Department of Medical Assistance Services, 2013). DMAS has since adopted "needs-based" service criteria for AT approval, requiring individuals requesting AT to "have a demonstrated need for equipment for remedial or direct medical benefit" (Assistive Technology Service., n.d.). Even so, many of the people I interviewed expressed frustration at the lack of transparency regarding how DMAS defines "demonstrated need" and felt that the current service authorization process was still biased toward "medically necessary" devices. One therapist from a Medicaid-certified provider of therapeutic consultation services in the state recounted a time a client's request to fund AT services delivered via an iPad was rejected on the grounds that the device would be useful to anyone without an IDD. Employees from a regional advocacy group echoed this sentiment, insisting that DBHDS largely remained focused on a narrow definition of medical necessity when reviewing AT service authorization applications without considering the improved independent living outcomes afforded by the equipment. Although I was unable to interview any employees at DMAS and DBHDS for this paper, one can understand the state's motives for doing so. Because Medicaid is a publicly funded program, DMAS is obligated to ensure that taxpayer dollars are used prudently, which means preventing fraud and abuse of state and federal funds. Given the fact that financial abuse as defined by the Centers for Medicare & Medicaid Services includes "reimbursement for services that are not medically necessary or that fail to meet professionally recognized standards for health care," it is unsurprising that state agencies would place such strong weight on medical necessity in the service authorization process to attempt to prevent fraudulent use of public funds (Centers for Medicare & Medicaid Services, 2019, p. 313). The limitations of this approach stem not from the use of medical necessity criteria – most people would generally agree that unnecessary spending of public funds constitutes financial abuse – but rather in how the term has historically been defined. A 2000 report from the National Council on Disability, found that the original definition of medical necessity, developed in the 1960s when "medical care was viewed primarily as curative and palliative, with little or no consideration given to increasing an individual's functional status," imposed severe restrictions on public funding for AT (National Council on Disability, 2000, p. 15). While Virginia has since undergone efforts to expand this definition to account for individuals' functional needs, as I have argued above, no single policy directive is sufficient to overcome the inertia of a federal Medicaid program embedded with institutional and medical bias since its inception. At its core, the barrier to AT access posed by the service authorization process originates from fundamental differences in what Star refers to as “master narratives,” or voices that “[speak] unconsciously from the presumed center of things” (Star, 1999, p. 384). For DMAS and DBHDS, the state agencies responsible for administering Medicaid in Virginia, this voice has long emphasized the importance of cost effectiveness and curative treatment above all else in the provision of AT services. For individuals with IDDs and their parents, caregivers, and support staff, on the other hand, this voice underscores a desire to foster individual empowerment and functional independence through AT use, with less attention paid to the cost and/or remedial value of such services. This is not to suggest that employees reviewing service authorization requests at DBHDS do not value the functional needs of these individuals, but rather that they are operating within the parameters of a system centered around fundamentally different assumptions. These basic differences in the underlying narratives guiding each party appear to generate a friction in the service authorization process that stifles funding for AT devices.

Conclusion

Since its inception, institutional and medical biases in the Medicaid system have limited access to much needed funding for AT for individuals with IDDs across the country. Today, in Virginia, these limitations present themselves as administrative challenges to applying and receiving approval for AT funding, specifically in the professional evaluation and service authorization stages. The difficulties in these steps largely arise from a lack of recognition of “invisible work” in the application process as well as conflicting “master narratives” between the state agencies responsible for providing reimbursement for AT services and the parties applying for reimbursement.

The scope of this study was limited to some extent by the time available to complete it. With more time, future research could gain a more nuanced understanding of the issue by interviewing employees at DMAS and DBHDS. Additionally, more interviews could be conducted with AT waiver participants and their caregivers as well as therapeutic consultation and technology providers to cross-validate findings from the interviews I completed. In general, hearing from a wider audience would allow the research to reflect a more balanced, comprehensive perspective on the problem of access to AT funding through Medicaid in Virginia.

AT is an essential tool in improving community-based, independent living outcomes for individuals with IDDs in Virginia. The findings from this research have the potential to help Virginia policymakers enact changes to the state Medicaid system that aim to remove the administrative barriers to accessing funding for AT services. Furthermore, this information can help Medicaid administrators, applicants, and providers alike better understand the difficulties faced by other stakeholders in the system and, hopefully, help alleviate some of the misconceptions and conflicting narratives currently hindering the system. Overall, I hope that my research will help improve access to AT and enhance the quality of life of the thousands of individuals with IDDs living in Virginia.

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