# PRODUCTION FORECASTING AND ONLINE STOREFRONT REDESIGN FOR THE VIA CENTERS FOR NEURODEVELOPMENT

# BARRIERS TO ASSISTIVE TECHNOLOGY ACCESS IN THE VIRGINIA IDD WAIVER PROGRAM

A Thesis Prospectus In STS 4500 Presented to The Faculty of the School of Engineering and Applied Science University of Virginia In Partial Fulfillment of the Requirements for the Degree Bachelor of Science in Systems Engineering

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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. Through my sociotechnical research and technical capstone project, I will address two of the biggest such challenges facing these individuals: unemployment and lack of access to assistive technology.

My technical project will focus on another obstacle faced by many individuals with IDDs: unemployment. A 2022 survey by the National Core Indicators found that just 16% of individuals enrolled in state IDD services were employed in the community, almost four times lower than the national average labor force participation rate in 2022 (Bureau of Labor Statistics, 2023; National Core Indicators, 2023). My capstone team has partnered with VIAble Ventures, a local microbusiness run by the VIA Centers for Neurodevelopment, to increase employment opportunities for adults with autism in the community by developing a set of strategies to increase sales through the company's website.

Given the fact that the UN Convention on the Rights of Persons with Disabilities stipulates access to assistive technology (AT) as essential for all individuals, 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; UN Convention on the Rights of Persons with Disabilities, 2006). My sociotechnical research project aims to further examine

this issue using the Virginia Medicaid IDD waiver process as a case study. While many studies have aimed to identify barriers to AT access on a national scale, little has been done to better understand the issue at the state level in Virginia. Through my STS research, I hope to bring to light the elements of the state's Medicaid system that make it so difficult for individuals with IDDs to access the AT services they need.

## **Technical Project**

There are a number of factors, including challenges with social communication, sensory sensitivities, and stereotypes and stigmas, that make finding and maintaining stable employment difficult for adults with developmental disabilities. One emerging solution to this problem is the adoption of microenterprise models. Microenterprises (or microbusinesses) are small businesses that employ few people and have relatively low startup costs. Their small size and low costs afford these organizations the flexibility to set schedules and assign tasks to match the unique needs of individuals with IDDs, making this model both an attractive alternative to traditional employment for individuals requiring higher levels of support and a useful source of vocational training for higher-functioning individuals aiming to transition into the workforce.

The latter is the model adopted by VIAble Ventures, a local microbusiness run by the VIA Centers for Neurodevelopment. Through the production and sale of candles and other home products, VIAble Ventures provides work training and meaningful employment to adults with autism in the Charlottesville community. My group's technical capstone work is centered around addressing the issues of unemployment among individuals with IDDs by increasing VIAble Ventures' capacity to employ adults on the autism spectrum. As a self-sustaining business, all of the funds VIAble Ventures uses to pay their employees come directly from the sale of their products. Therefore, in order to meet its goal of expanding employment opportunities for adults

with autism in the area, the company must increase its gross profits through higher revenue and/or decreased costs. My capstone group will apply a systems thinking approach to boost online sales on the company's website, <u>https://shopviable.org/</u>, with three main areas of focus: online traffic, transactions, and website design. We will analyze website traffic and online transaction data to classify the factors that bring users to the website and result in successful transactions. We will also leverage historical sales data to determine the company's best selling and most profitable products as well as user interviews to identify areas of improvement within the website's user experience. Ultimately, the insights from these analyses will inform a set of actionable sales, marketing, and design strategies, which we will test to observe their impact on the company's sales and, therefore, capacity to employ more community members. Depending on the findings of our initial analysis, these strategies may range from promoting certain products on the front page of the website to increasing the prices of others. Rather than designing and implementing a new employment program from scratch, this project will build on VIA's existing model to increase the number of autistic individuals they are able to serve. Together with my STS research on barriers to accessing AT among individuals with IDD in Virginia, these projects aim to improve the lives of individuals with IDDs by addressing two of the biggest challenges they face in navigating everyday life.

#### **STS Project**

The question I will examine for my sociotechnical research project is: Why is it so difficult for individuals with IDDs in Virginia to access assistive technology services through the state's Medicaid Intellectual/Developmental Disabilities (IDD) Waiver process? The Assistive Technology Industry Association defines assistive technology (AT) as "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. However, 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. A 2012 study identified cost as the most commonly reported barrier to AT adoption among individuals with IDDs (Tanis et al., 2012). To help cover these costs, individuals with developmental disabilities in Virginia can apply for an Intellectual/Developmental Disabilities (IDD) Waiver through Medicaid. Under Virginia law, qualifying individuals can receive coverage worth up to \$5,000 per calendar year through this program (Assistive Technology Service., n.d.).

However, accessing AT in Virginia through this program has been a historically difficult process. 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). These ongoing issues are perhaps best illustrated by the fact that just 3.5% of Virginians with IDDs receiving funding through Medicaid HCBS were projected to receive AT services in 2021 (Friedman, 2023). In fact, as of December 2022, there were more than 14,000 individuals on the waitlist for support services through IDD waiver (DeFusco, 2022). It is important to investigate this issue because numerous studies have demonstrated the positive impact assistive technology can have on the lives of individuals with IDDs, with one such study linking the use of AT to an "elevated sense of agency and personal empowerment," and, for many of these individuals, the Medicaid IDD waiver is the only way they can afford to access AT services (Satterfield et al., 2021). In fact, as of 2019, 25.7% of Virginia residents with a cognitive disability were living below the poverty line, compared to 8.2% of residents with no disability

(Winsor et al., 2022). This issue is also important to me personally because my mother is an occupational therapist who serves individuals on the IDD 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 my paper, I will examine the reasons why funding assistive technology services through the Medicaid IDD waiver program is such a difficult process to navigate in Virginia.

To conduct this study, I will utilize the framework outlined by renowned STS scholar Dr. Susan Leigh Star in her 1999 article "The Ethnography of Infrastructure." In it, Star demonstrates how ethnographic studies can be applied to large-scale infrastructure systems. She defines infrastructure across nine distinct properties: "embeddedness", "transparency", "reach or scope", "learned as part of membership", "links with conventions of practice", "embodiment of standards", "built on an installed based, becomes visible upon breakdown", and "is fixed in modular increments" (Star, 1999). Star then goes on to describe ethnographic methods by which scholars can analyze these systems, emphasizing the importance of uncovering "master narratives", "invisible work", and "paradoxes of infrastructure" (Star, 1999). I will apply Star's research in my own project to frame the Virginia Medicaid IDD waiver program as a large-scale infrastructure system and investigate the features of this system that make it so difficult to receive funding for assistive technology services.

The primary methodological approach I will use in my research is interviews with stakeholders from various facets of the Virginia IDD Waiver Program. To better understand this issue from the perspective of those administering the program, I will interview employees at the Virginia Department of Medical Assistance Services (DMAS) as well as members of Community Service Boards (CSBs) throughout the state. In Virginia, DMAS is responsible for managing the

statewide Medicaid program, while CSBs are tasked with processing applications for services under the IDD Waiver Program. Moreover, to examine this issue from the perspective of those applying for funding for assistive technology services, I will interview members of statewide advocacy organizations, such as the Virginia Assistive Technology System (VATS) Advisory Board and the Arc of Virginia, as well as assistive technology services providers operating in the state.

## Conclusion

Access to assistive technology and securing stable employment are just two of the many hurdles faced by individuals with IDDs in the US. My technical project work will help build on the success of VIAble Ventures' existing model and expand employment opportunities for adults with autism in the Charlottesville community, potentially serving as an example for other microenterprises in the region hoping to adopt a similar strategy. Furthermore, I anticipate that the findings of my sociotechnical research on the barriers to accessing AT through the Medicaid IDD waiver program in Virginia could help state and county administrators enact meaningful reforms to better facilitate access to AT for Virginians with IDDs. Taken together, my work will contribute to the overall body of research aimed at studying and designing solutions to the challenges faced by individuals with IDDs in Virginia in an effort to improve their quality of life and personal well-being.

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