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Critical Theories of Disability Studies

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6 March 2019

**The High Price of an Autonomous Life: A Discussion on the Financial Factors that Affect  
Full Autonomy within the Deaf-Blind Community**

Any choice, no matter how unimportant other members of society deem it, needs to be accessible to members in the disability community in order for them to have a fully autonomous life. However, through research on new technology and personal accounts of individuals who use it, one will see that currently not all individuals in the disability community have full autonomy because of how society is structured—with basic choices and experiences denied from them because of a lack of accessibility in certain spaces. Of course, these accessibility gaps can be bridged through special circumstances, but they come at a hefty price. Throughout this paper I will be focusing specifically on ways of improving autonomy within the deaf-blind community because, through research, it has shown to be one of the more underrepresented disability communities in existence and deserves to be given the kind of careful recognition and attention in higher academia that it is currently lacking. Like the incredibly high cost of assistive devices and services within other disability communities, (hearing aids, motorized wheelchairs, etc...), assistive devices and services unique to the deaf-blind community come with their own high-price. Throughout this paper I will be using the term, “deaf-blind individuals”. However, to show the importance of recognizing each individual’s own right for self-identification within any part of the disability community, one should note I am only speaking of those in the deaf-blind community who self-identify as such. In the following personal accounts of deaf-blind

individuals, one will see that the level of autonomy a deaf-blind individual has is directly related to their financial status, allowing only the most financially secure and/or lucky deafblind individuals to acquire the resources necessary to secure a fully autonomous life.

When one thinks about autonomy, what is the first thing that comes to mind? Perhaps, nothing, as it is a term not often used in everyday, social conversation. Similarly, perhaps one thinks of a very simple definition, like, being able to do things for oneself. The formal definition of autonomy is, “the quality or state of being self-governing”, and “self-directing freedom and especially moral independence”.<sup>1</sup> According to this definition, autonomy is more than just being able to do things for oneself, it is being able to have a claim of self-governance over one’s life. That means making all important decisions about one’s life— important being defined as decisions that would create a lasting change or impact on one’s life. This could mean everything from what college one goes to, what house one decides to buy, and/or what doctors one chooses to trust with their health. However, what decisions make a lasting change or impact in one’s life depends on what each individual values as important. This means choices like what clothes to wear on a certain day, where one decides to shop for groceries (and what groceries they decide to buy), what kind of food one chooses to eat, whether or not to engage in conversation with a certain person in a room full of people, and countless other choices, may be just as, (if not more), important to some individuals than others.

To JennyLynn Dietrich, a young woman identifying as deaf-blind, autonomy means “to make fully informed decisions without any interference or anyone taking over that decision”.<sup>2</sup>

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<sup>1</sup> Merriam Webster Dictionary, “Definition of AUTONOMY.”  
<https://www.merriam-webster.com/dictionary/autonomy>.

<sup>2</sup> “DeafBlind: Blind But Not Blind | JennyLynn Dietrich | TEDxSalem - YouTube.”  
<https://www.youtube.com/watch?v=6uxZ4u6nses>.

She discusses the idea that it is not possible to be completely independent because we are all interdependent, and that what we should all strive for is this kind of autonomy. She explains how she does not have complete autonomy in situations even as simple as picking out a specific flavor of peanut butter unless she has a support service provider, (SSP), with her. An SSP is a “any person, volunteer or professional, trained to act as a link between persons who are deaf-blind and their environment”.<sup>3</sup> SSPs are extremely important for deaf-blind individuals because they fill all the autonomy gaps that current technology does not provide to deaf-blind individuals. SSPs often cost around \$12-\$17 per hour to employ, yet because a deaf-blind individual has to have them around 24/7 during the day if they want to live as autonomously as possible, this is not always an affordable option.<sup>4</sup> Sometimes, SSPs are provided on a volunteer basis, but that is normally for a short term, or one time, basis for specific events. As a result, many deaf-blind individuals only hire SSPs for specific outings, appointments, and transportation needs they cannot fulfill on their own. Many low-income neurotypical individuals often have to make difficult decisions regarding their finances, however, the choice of whether or not to have an SSP at any given time— someone who can give a deaf-blind individual almost complete autonomy— is a level of financial and emotional frustration a neurotypical individual will never fully understand. Another option for full autonomy within the deaf-blind community is found in recent developments in assistive technology; however, while they may not have to be paid for on a regular basis like an SSP, the one-time price of acquiring a new piece of assistive technology is much higher than many can afford.

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<sup>3</sup> “AADB -- White Paper on the Roles and Responsibilities of the Support Service Providers (SSPs).”

<sup>4</sup> Deaf Blind Ssp Jobs | Glassdoor.” Accessed March 10, 2020.

[https://www.glassdoor.com/Job/deaf-blind-ssp-jobs-SRCH\\_KE0,14.htm](https://www.glassdoor.com/Job/deaf-blind-ssp-jobs-SRCH_KE0,14.htm).

One type of technology that has recently been extremely useful for deaf-blind individuals is a refreshable braille display. They can be used to communicate with friends and family through text messaging, social media platforms, e-mail, and more.<sup>5</sup> There are even kinds that a neurotypical individual can type on while those words are converted into braille in real-time, allowing the neurotypical individual to engage in conversation with the deaf-blind individual with absolutely zero training or teaching necessary. Refreshable braille displays have even been used lately through connection with devices that convert information on T.V.s to data that the braille displays can interpret. This allows for a whole new level of autonomy for individuals who identify as deaf-blind because they now have more options for what kind of entertainment they can choose to partake in, *and* they can enjoy it without the help of an interpreter.<sup>6</sup> Refreshable braille displays use braille keys that “change continuously as the user moves the cursor around on the [computer] screen, using either the command keys, cursor routing keys, or Windows and screen reader commands”.<sup>7</sup> This allows for increased autonomy because in the same way the brain of a neurotypical individual processes the information on a computer screen through the use of their eyes and ears, a deaf-blind individual processes the information through the use of touch. Little information is missed as the deaf-blind individual runs their fingers across the refreshable braille display, taking in all the choices of websites when completing research, fonts when writing a paper, and many other things. A device like this is extremely helpful for those who can afford them, but they often cost between \$3,500-15,000.<sup>8</sup> While there are some

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<sup>5</sup> Program Helps Deaf-Blind Access Technology. <https://www.youtube.com/watch?v=pav9knVPb68>.

<sup>6</sup> Science News for Students. “New Tech Helps Deaf-Blind People ‘Watch’ TV,” August 17, 2018. <https://www.sciencenewsforstudents.org/article/new-tech-helps-deaf-blind-people-watch-tv>.

<sup>7</sup> “Refreshable Braille Displays | American Foundation for the Blind.”

<https://www.afb.org/node/16207/refreshable-braille-displays>.

<sup>8</sup> Ibid

companies like The National Deaf-Blind Equipment Distribution Program (NDBEDP), also known as iCanConnect, that provide low-income deaf, blind, and deaf-blind individuals with access to assistive technology, companies like this are few and far between, have strict application processes that may be confusing and/or inaccessible for deaf-blind individuals, and do not always provide the kind of technology that would be the most helpful in providing a fully autonomous life.<sup>9</sup> Therefore, the last form of communication that is increasing autonomy within the deafblind community, (which is also the most affordable option), is the creation and use of a new language that is quickly forming a new culture and philosophy within the deaf-blind community, Pro-Tactile American Sign Language.

Pro-Tactile American Sign-Language, (PTASL), is one of the most recent developments in the field of Deaf-Blind communication, having only been developed in the early 2000s. PTASL is a form of sign language that recognizes the value of touch to deaf-blind individuals, as it is normally one of their strongest senses, and combines traditional ASL signs with touch signals specific to PTASL to create a style of communication that encourages autonomy and inclusion.<sup>10</sup> However, it has only been introduced and accepted as its own language in 2010 by AJ Granda and Jelica Nuccio (self-identified as deaf-blind), and Dr. Terra Edwards (neurotypical/hearing & sighted).<sup>11</sup> It was thought up in the early 2000s when a group of deafblind individuals in Washington realized they had no way to sufficiently communicate with each other in meetings without the help of an interpreter. It took years of creating the language,

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<sup>9</sup> Federal Communications Commission. “National Deaf-Blind Equipment Distribution Program,” July 13, 2012

<sup>10</sup> Perkins School for the Blind. “Q&A: How Pro-Tactile American Sign Language — PTASL — Is Changing the Conversation.”

<sup>11</sup> “What Is ProTactile and What Are Its Benefits?”

<https://www.tsbvi.edu/tools-items/573-tx-senseabilities/fall-2017/5651-what-is-protactile-and>

submitting it to the government, and ultimately acquiring proof that it was different enough from ASL and English to qualify as its own language before it was recognized more officially and openly in the deaf-blind community.<sup>12</sup> It is extremely important that this mode of communication many deaf-blind individuals now use is officially recognized as a language for two reasons. The first reason is that it gives the same level of respect and recognition to deaf-blind individuals using PTASL that is given to neurotypical individuals using more commonly recognized languages like English, Spanish, Japanese, etc. . . . The second reason, and the most important one for the sake of this discussion, is that it gives a new way of communication through which deaf-blind and neurotypical individuals can use to interact with one another, as easily as two neurotypical individuals would using one of the above mentioned languages. In this case, autonomy increases for both individuals— the deaf-blind and neurotypical— as each now has a way of communicating with the other through a common language without the use of an interpreter. In fact, according to sign-language interpreter Christine Dwyer at Perkins school for the Blind,

“[PTASL] fosters autonomy. By providing people who are deafblind with information, they in turn can make the decisions for themselves — rather than relying on my vision and my ability to determine what’s going on. Let me tell you what the environment is, and you tell me how you want to proceed.”<sup>13</sup>

When an individual is given as much information as possible about their given surroundings and are able to participate in conversation at the same level of a neurotypical individual, an autonomous lifestyle is being promoted— which is exactly what PTASL accomplishes.

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<sup>12</sup> Perkins School for the Blind. “Q&A: How Pro-Tactile American Sign Language — PTASL — Is Changing the Conversation.”

<sup>13</sup> Ibid

SSPs increase autonomy within deaf-blind individuals by filling the gaps that normal society creates through its inaccessible world. Through the use of assistive devices such as refreshable braille displays, deaf-blind individuals can engage with a wider variety of their surroundings, access new information quicker, and communicate with family members easier. PTASL functions as an official language that is becoming more widely recognized and used within the deaf-blind community every day—bridging an accessibility gap between neurotypical and deaf-blind individuals that fosters increased autonomy through every conversation. While these are only three examples of ways of communication that help foster autonomy within the deaf-blind community, they are some of the most popular, and many come with a high price that make them unaffordable to many individuals. This is a problem that needs to be recognized, talked about, and taken seriously if one every wishes to create a fully accessible world for not only deaf blind individuals, but individuals of all identities.

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