

Dear State House of Representatives:

My name is Ulysses Harmony Garcia, KJ7ERC. I am twenty-five years of age, and, while I am blind and severely hard-of-hearing, I am not the only person born with this condition that would cause my hearing loss to deteriorate over time. My parents are divorced, and have been for quite some time. They are both Spanish-speaking, and my brother and I live with my mother. I am the only person in the household fluent in both languages.

I have an older brother, 27, born profoundly deaf and totally blind from an inherited condition. He has no verbal communication, and he learned basic tactile ASL (American Sign Language) for a year or two in middle school, and in his last year of high school. Because of some behavioural issues due largely to his inability to communicate, he did not receive adequate ASL training, and his teachers were frustrated that he wasn't learning anything. He didn't learn anything because he couldn't hear them. He has been traumatised to no end because he was constantly being yelled at for not paying attention.

In 2012, an intense effort was made to diagnose Adrian with Autism Spectrum Disorder and ADD and ADHD, but because he couldn't see, hear or speak, it was impossible to perform the tests needed to give him a proper diagnosis.

Adrian spent eight years, from the time he graduated high school and a three-year day programme at ARC to the present without learning anything new.

My mother has always said that because my brother hasn't been doing anything since 2010, he has gotten harder and harder to manage, especially when we were out in public. Now, he often spends all of his time being naked at home as a way to say, 'If I make them not put clothes or shoes on me, I won't be able to go out. And if I don't go out, I won't have to worry about where the bathroom is.' We can't put clothes on him because he would think that we're going out and "going out" is not something he understands. Nor does he understand the concept that he needs to wear clothes at home. He is often combative when he tries to communicate his preferences, no doubt due to the frustration of nobody understanding him, and because this is his easiest and most efficient form of communication. Our family has reached out to all available agencies to help my brother. There have been many caregivers who didn't know sign language and because he has gone so long without being able to communicate none of them have stayed long enough to make a difference.

As luck would have it, we found a caregiver last year who was able to get us in touch with a professional behaviour strategist who, unfortunately, only had experience working with sighted hearing individuals with developmental and intellectual disabilities. Sadly, however, this is not too uncommon. My brother has been cast aside by many bureaucratic systems because they couldn't place him in a box of sorts. The good news is that we have a positive behaviour support plan put in place. It has to be the first step in saving my brother's life, or I am certain he will eventually be institutionalized. He deserves a chance to lead a meaningful life, just like everyone else.

So, where does that leave me? Well, I can tell you that having to live like this for nearly all of my life has placed me inside a vicious circle that I cannot seem to find a way out. It is clearly evident that when one family member needs supplementary support, not much attention is given to the others. This is how I felt for most of my life, but it took me several years to fathom the situation. I resorted to journaling because I couldn't just walk up to my brother and have a meaningful conversation.

When I was seven or eight, I asked my brother's case manager why I couldn't get services, as well. She informed my mother and I that although I was but in second grade, I was really smart, with the combined intelligence of my mother and the case manager, so she said that I really didn't need it.

I feel that because of what this situation has done to me and my family, nobody ought not be excluded and be forced to miss out on journeying through the adventures of life.

How many times have I asked myself, 'Where were those people who said they were going to take me to the grocery store? Where were those people who promised to take me to the county fare? Where were those people who told me they looked forward to accompanying me to my classes and learn the layout of the campus? Where were those people who were going to read my mail, assist me in filling out inaccessible forms, or help me with complicated banking transactions?' Nowhere. All my relatives were too busy with their own thing to be bothered with such matters that they didn't feel qualified to do. My mother can't leave the house any more unless somebody stayed at home to look after my brother, which is currently once a week for four hours at a time. This is not enough.

Also, the sad thing is that everybody expects to get paid, and I can't afford to pay out of pocket for an SSP. Yes, I could probably afford ten or twenty dollars for one or two hours, but I'd also have to consider the logistics of gas mileage, meals, and other unexpected costs that might arise.

Becoming a support service provider shouldn't require a lot of training.

They simply need to be motivated and have a willingness to learn, and be knowledgeable about Deaf-blind culture. They would unmistakably need to be capable of communicating visual and environmental concepts clearly and be well-detailed using sign language, voice, or writing, to name a few.

Having said all that, I sincerely hope that you, as a team, can sit down, discuss this amongst yourselves, and bring this bill to the next level. I sincerely hope that people like myself will never have to deal with a similar situation in the future. This is not just for myself, obviously. It is for my fellow deaf-blind friends, too. Having a strong support system that I can lean on will allow me to do a lot more than I am, at present, able to do. Having a reliable support service provider will build my confidence and bring back my independence, though I usually like to call it interdependence, since we would be working as a team.

Please, give this a lot of thought. Thank you!

Very truly yours,

-Ulysses H. Garcia

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