

# Invisible Disabilities are Still Difficult | CPD

**Beth Schill**

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*Note from Gordon: For those of you who know me you clearly understand my disability is not invisible. I am a C-4 quadriplegic and use a power wheelchair for mobility. My power wheelchair actually liberates me and allows me to go pretty much wherever I want to go. On occasion I will run into a facility that is not accessible for me and my wheelchair. But it does not happen nearly as often as it once did. In our local community I know where I can go and where I am welcome and that's where I spend my time and money. But enough about me and my physical disability. Which is clearly not Invisible.*

*The blog below is written by a young women with an invisible disability. This is a very informative perspective from her and how she is treated with her invisible disability. I will let you read it and come to your own conclusions. But from my perspective people with an invisible disability have a harder time qualifying or receiving services then an individual like myself who clearly has a visible disability.*

**By Guest Blogger Beth Schill**

Ahhh... Invisibility. It's one of those superpowers we dream about as kids and, let's face it, as adults too. How often do we wish we could be a fly on the wall, to listen in on conversations, to see what people are like when nobody's looking? "To be invisible," we think, "now that would be cool!"

Well, for those of us with invisible disabilities, being invisible is not always as great as one may think. On the one hand, no one can tell if we have a disability just by looking at us. And for those who face visible disabilities, I can only imagine how difficult that must be. Yet for those faced with an invisible disability, it can be difficult for us in

school or the workplace to not feel understood as we deal with our own health issues. Many people see us as able-bodied adults, and wonder why we can't work an extra few hours, why we take so long doing problems or taking an exam or why we can't pull our own weight. In short, it can be a very confusing and lonely experience.

According to the American's with Disabilities Act, enacted in 1990, a disability qualifies as "a person who has a physical or mental impairment that substantially limits major life activities; has a record of such an impairment; or is regarded as having such an impairment." Some of the major life activities include:

- Caring for one's self
- Performing manual tasks
- Walking
- Seeing
- Hearing
- Speaking
- Breathing
- Learning
- Working

In the case of invisible disabilities, some of these major activities may be compromised occasionally, or intermittently depending on the nature of the disability. Thus, the distinction of having, "a record of such impairment," is key. In this case, the law helps people who, while they may not be impaired at a given moment, their condition may have, or could result in their inability to perform major life activities. These may include learning disabilities, mental disabilities, and whole slew of chronic conditions that can strike anyone, anywhere, at any time.

For me, having epilepsy qualifies as a disability under the ADA. Although most days I look and am able to act without an impairment, when I have a seizure major life activities are definitely in jeopardy, as I lose consciousness, stop breathing and lose control of my body. Even after my seizure ends, I physically look fine, though my mind is in a haze and I have difficulty with memory, vocabulary or other cognitive symptoms – often impacting my ability to learn and work. It wasn't until my last seizure I realized how frustrating it was. During my most recent seizure I fell on a hard, tiled floor. After my ER visit my arm was in a sling, my face was bruised and I had a nice batch of stitches. And in an odd way, I was glad because for once I felt like my physical appearance mirrored just how battered my brain felt.

The thing is, it shouldn't have to be this way – to be glad that one's invisible disability is visible in order to get the help one needs. So what can be done then? What do

we do when we are faced with the “gift” of invisibility? How can we as students or workers get the help we need without putting ourselves at risk of discrimination? I believe the only way is to be more public about our invisible disabilities, and to take steps on educating the public exactly what that means, and how others can help. Below are a few steps I have found to be helpful in my own journey:

### **Tell your employer about your disability**

In my own life, I have had to deal with the question of whether or not to tell my employers about my epilepsy. When I was diagnosed I was working at a major consulting firm, and after a grueling few months of burning the candle at both ends, I had a seizure. I was told by my doctor that there was no way I could continue the hours I had without putting myself at risk for more seizures. But I was loathe to seem like I couldn't do my job like everyone else. So what did I do? I used every resource that I had in hand, including a few friends who work within the disability world. They helped me recognize that epilepsy was covered by the ADA and that I had the right to “reasonable accommodations” to do my job.

In going in to talk to my bosses and my HR representative, I requested “reasonable accommodations” in the form of a regular (i.e. 40 hour) workweek and minimal travel. And due to the protections afforded by the ADA, my work was more than happy to comply. I also decided to tell the people I worked with, so that they knew how to help me if I had a seizure. But before I did any of this, I had to do my homework, understand the law, understand my job and ultimately become my own advocate.

### **Manage your life to have the balance you need and recognize your very real (though occasionally frustrating) limitations**

At my job, I mentioned that they were able to provide me reasonable accommodations in the form of reasonable hours, limited travel and so on. However, as I moved on and up in the firm, more came to be expected of me. The firm kept waiting for me to get “back to normal” and I was having a more difficult time explaining why I could not buy into the corporate culture. Ultimately, I recognized that while I could do my job well, given my very real limitations, I could not be as successful as I, or the firm, wanted me to be in the future. I decided to leave my job for one that was still challenging, but not nearly as stressful. It was one of the toughest choices I made to leave a lucrative career... but it was worth it!

Thus, finding the right job that will work with you, and not expect you to “return to normal,” is hard to find, but very much worthwhile. The world rewards workaholics, super moms and super dads and people who “stand up in the face of adversity.” And I am one of those type-A people who want to be the best. But I've had to learn to respect my body, and not just respect it, but embrace it. And though it is not easy to roll against the tide, I feel much more grounded and content than many people I meet.

### **Educating the broader public about your disability and how to help accommodate**

And that brings me to my last point – that having good work-life balance necessary to manage invisible disabilities, and knowing how to \*gasp\* ask for help, makes us superheroes of a different kind. Those of us struggling with invisible disabilities (really any kind of disability) can do a lot to promote dialogue about what it means to be healthy. Whether we have epilepsy, MS, mental disorders, a learning disability, we all have something valuable to teach in a world that is becoming increasingly fixated on “how much a person is worth.” We have innate value in understanding ourselves, our minds, our bodies, and can teach others how to respect not just us, but themselves as well. But it takes courage. For me, it means no work email after hours, not being able to be as social after work as I would like, getting a solid 8 hours of sleep, eating well and giving myself plenty of down time to decompress. Not courageous in a big way, but I'd like to think in my own way I'm helping to change the conversation

In truth, being invisible isn't really all it's cracked up to be, and to that end, I am not afraid to stand up for myself and what I believe. There are many options out there, but you have to be willing to be patient with yourself and others, understand the law and what it does, or does not cover, as well as being willing to be courageous and stand up for what you believe. And part of me telling my story, I hope, helps others to feel comfortable telling theirs.

*Beth is a Research Manager at the Partnership for Public Service. She was diagnosed with epilepsy in 2008, and has spent much time counteracting today's workaholic culture to be better accommodating to people with disabilities. Find her @beth\_schill.*

*This blog first appeared at <https://usodep.blogs.govdelivery.com/2015/09/10/what-its-like-to-be-invisible/>*