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Uniquely My Own: One Woman's Experience of Living with a Physical Disability

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Introduction

Living With the Label “Disability”: Personal Narrative as a Resource for Responsive and Informed Practice in Biomedicine and Bioethics

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Abstract. *What is it like to live with the label “Disability?”* NIB editorial staff and narrative symposium editors, Jeffery Bishop and Naomi Sunderland developed a call for stories, which was sent to several list serves, shared with the 1000 Voices Project community and posted on *Narrative Inquiry in Bioethics’* website. The request for personal stories from people who identify with the label “disabled” asked them to: consider how the label “disability” interacts with other aspects of their life in health care settings; does the term “disability” reflect their actual embodied experiences of impairment or does it fail to do justice to their particular experience of impairment; describe the kind of experiences that are possible because of the impairment(s); discuss how the label has affected their “authentic voice”; and many other concepts about what effects the label has on their lives. These authors share deeply personal experiences that will help readers understand their world, challenges, and joys. Thirteen stories are found in the print version of the journal and an additional five supplemental stories are published online only through Project MUSE. The stories are complemented by four commentary articles by Elizabeth R. Schiltz; Lorna Hallahan; Nicole Matthews, Kathleen Ellem, and Lesley Chenoweth; and Jeffery Bishop, Rachelle Barina, and Devan Stahl. These scholars come from the disciplines of law, social work, media studies, medicine, and bioethics from Australia and the United States. Together, the symposium’s storytellers and commentators offer striking and informative insights into the everydayness of living with disabilities.

Key Words. Acceptance, Accommodate, Affliction, Ambivalence, Autonomy, Bioethics, Disability, Disability Culture, Ethics, Identity, Marginalization, Narrative, Negative Emotions, Stigmatize, Valued Difference

This narrative symposium presents 13 people’s stories in the print version (another five supplemental stories are available in the online version) of living with the label of disability. The stories are complemented by four commentaries by scholars across the disciplines of law, social work, media studies, medicine, and bioethics from Australia and the United States. Together,

the symposium’s storytellers and commentators offer striking and informative insights into the everydayness of living with disabilities—insights that may confront the abstractions of both modern biomedicine and bioethics.

Mainstream biomedicine—i.e., medicine that uses knowledge of biological and physical systems as a basis for clinical practice—has for a long time

understood disability to be a “problem” anchored in the bodies of people with impairments. As such biomedical practitioners, researchers, and governments have invested much in seeking to alleviate, fix, or eliminate the causes and sources of disabled bodies. While this approach to disabled or “impaired” bodies has had differing outcomes for many individuals and families, it has also focused our collective attention on disability as being primarily a physical “affliction.” This biomedical approach to disability has also contributed to negative social stereotypes surrounding people’s personal capacities and lives that can have little to do with the daily realities of living with a disability.

In biomedical contexts, the practice of “bioethics”—i.e., the practice of exploring the moral and ethical aspects of medical research and interventions—has often been concerned with mediating between what *can* be done medically and scientifically with what *should* be done according to other—sometimes contending—values, perspectives, and concerns. Bioethicists for example have argued successfully that medical and related practitioners must obtain “informed consent” before manipulating bodies and strive to uphold patients’ autonomy, dignity, and privacy. Bioethicists have also, on occasion, actively supported attempts to prevent differently embodied persons from coming into being at all through genetic screening and abortion (see for example Savulescu, 2001; 2002; 2007). As this symposium’s commentators Matthews, Ellem, and Chenoweth point out though, the issues that many bioethicists have focused on rate little to no attention from people with disabilities themselves when they are discussing the key issues that affect their interactions with health and medical practitioners and their broader lives. Hence, while valuable ground has been made toward alternative approaches to bioethics by feminist and narrative ethicists such as Margaret Urban-Walker (2007) and Jayne Clapton (2009), many prominent bioethicists still appear to have misunderstood or ignored the lived and embodied realities of disability (Scully 2008).

In response to this disconnect, this Narrative Inquiry in Bioethics symposium explores what it is like for people to live with, alongside, and at times in opposition to the label “disability.” We have focused

on the disability label in the symposium as a shared social phenomenon that is familiar both to people who identify as having a disability and people who do not. While both groups simultaneously experience shades of both ability and disability on a daily basis (i.e., we are all abled and disabled in some way), only one experiences the social, political, and moral phenomenon of being self or otherwise *labeled* as a person with a disability. The other group, while perhaps not privy to the inner lived experience of being labeled as a person with a disability, may learn much by *listening to* and reimagining his or her own life and practices through the stories of the other. The narratives included in the symposium hence depict the everydayness of impairment in health and medical related settings and, as such, offer critical resources for reframing how we might respond to disability.

The symposium editors distributed a call for stories via several international networks including the online 1000 Voices Project, which “aims to collect, display, and analyse 1000+ life stories from people with disability from around the world” (www.1000voices.edu.au). The editors also sent the call for stories directly to groups that work with and advocate for persons living with disability in Chicago, Philadelphia, St. Louis, and Atlanta. We took a deliberately broad conception of “disability” to acknowledge that, for many, disability is simply a form of difference—albeit a potentially highly politicized one. This moved the symposium away from a biomedical conception of disability as a form of physical illness or impairment toward what is generally referred to as the “social model” of disability (Hughes and Patterson, 1997). Responding storytellers were hence able to self-define whether they experience disability or not based on their own criteria and experiences.

The Australian component of the symposium was strongly supported by the existing 1000 Voices disability life stories project team and existing storytellers. The editors circulated a draft call for papers to existing members of the 1000 Voices disability life stories project (i.e., people who self-identified as having a disability and who had previously participated in a public disability storytelling project) and sought their input on what topics should be covered in the symposium prior to releasing the

call for stories. The resulting call for stories invited storytellers to consider the following questions as stimuli for their story:

1. How does the label "disability" interact with other aspects of your life in health care settings, for example your gender, culture, and geographical location?
2. How does the term "disability" reflect your actual embodied experiences of impairment?
3. When does the label "disability" not do justice to your particular experience of impairment?
4. Have you accepted the label "disability" in your life? If yes, what effects has this had for you and others e.g., family, friends, health care providers, and co-workers?
5. Describe the kind of experiences you might have that are possible because of your impairment.
6. How have labels of disability affected the degree to which you feel that your "authentic voice" has been heard by others e.g., family, friends, health care providers?
7. How has the impact of the label disability changed for you over time e.g., as you have aged or as societal expectations and standards have changed?
8. How has the label "disability" been a hindrance in your life?
9. Has the label been beneficial?
10. What else might you want people to know?

The editors then selected stories to reflect a range of issues, writing styles, and self-identified types of impairment ranging from congenital conditions that people were born with through to mental and physical impairments acquired through illness, injury, or disabling social contexts and experiences. The resulting stories provide a rich and probing exploration of what it is like to strive for and find one's own identity, independence, and personhood within sometimes disabling and sometimes supportive social systems and institutions. The stories also depict in a rare and detailed way the minute bodily (e.g., the touch of a hand) and broader institutionalized (e.g., rules and regulations) ways that other people can enable or disable differently abled people without necessarily realizing that they have done so.

The invited academic commentators on the symposium come from a variety of backgrounds. Elizabeth Schlitz is a professor of law at the University of St. Thomas in St. Paul, Minnesota, and has first-hand knowledge of the struggles of caring

for a child with Down Syndrome. Jeffrey Bishop (a physician), Rachelle Barina, and Devan Stahl are at Saint Louis University in St. Louis, Missouri, and work in the area of bioethics. Lorna Hallahan is a professor of social work at Flinders University in Adelaide, South Australia. Finally, Nicole Matthews (Cultural and Media Studies, Macquarie University) Kathleen Ellem (Human Services and Social Work, Griffith University) and Lesley Chenoweth (Human Services and Social Work, Griffith University) are part of the interdisciplinary Australian research team that facilitates the 1000 Voices Project.

Along with the storytellers, the commentators explore the space of disability as a space between bodily impairment experienced by the disabled person and the social structures that both enable and constrain the flourishing of those living with the label of disability. Matthews, Ellem, and Chenoweth suggest that these stories might challenge both bioethics and the society and provide insight into the power imbalances experienced by those living with the label of disability. Schlitz describes an ambivalence that exists in the way the authors of the stories want both to embrace and reject the label of disability, and how that ambivalence manifests itself in the laws meant to assist them. She suggests that if we destigmatize the ambivalence about disability we share both in law and society we might "open the way for more satisfactory laws, and more satisfactory support for parents negotiating the challenges of parenting children with disabilities" (Schlitz). Hallahan concludes that these stories demonstrate something important about narratives, namely that "a narrative approach to exploring ethical questions privileges the person's telling over the abstractions so attractive (and useful) in a more conventional approaches" (Hallahan). Likewise, Bishop, Barina, and Stahl focus on the everydayness of these stories and emphasize the way in which these everyday expressions of experience of disability challenge both biomedicine and bioethics, and at the same time contribute to the identity construction of the storyteller—an identity that emerges from the embodied experience of impairment and the social structures that both enable and constrain flourishing.

Our purpose with this symposium is not to offer readers a checklist of what they should and should

not “do” in the presence of differently abled people. Rather, we are seeking to offer real, contextualized information about what it is like to live/interact on a daily basis with the label of disability. In so doing, we aim to enhance people’s sensibilities toward disability and provide professionals with relatable and practical resources upon which to draw in their daily work. Moreover, in moving toward a social model of disability, something interesting happens in our understanding of social labels, embodied disability, and personal identity. These stories show us that disability and identity are part of a fluid movement shaped by bodily finitude, surrounding social practices and contexts, and the telling and listening of one’s own and each other’s stories. Each author and commentator in this symposium tells a story of movement. Sometimes the stories are about moving from a state of health to a new state of impairment. Sometimes the narratives are stories of oscillating between a desire to claim the label disability and a desire to reject it. Sometimes they are about moving toward a new way of working and seeing. In all cases though, we can find both the desire and the resource to move ourselves toward social practices and institutions that more fully and humanely responsive to the lived realities of ability and disability.

Reference

- 1000 Voices Project. <http://1000voices.edu.au/> Accessed 09–21–2013.
- Bishop, J. P. (2011). *The anticipatory corpse: Medicine, power, and the care of the dying*. Notre Dame, IN: University of Notre Dame Press.
- Birmingham, S. (2013) Uniquely My Own: One Woman’s Experience of Living with a Physical Disability. *Narrative Inquiry in Bioethics*, 3(3) this issue.
- Chambers, T. (2013). Taking bioethics personally, *Narrative Inquiry in Bioethics*, 3(1), 1–3.
- Clapton, J. R. (2009). A transformatory ethic of inclusion: Rupturing concepts of disability and inclusion. *Studies in Inclusive Educations*, 1. Retrieved from <https://www.sensepublishers.com/>
- Hallahan, L. (2013). Down the rabbit hole: Reflections on thirteen narratives of living with the “disabled” label. *Narrative Inquiry in Bioethics*, 3(3), this issue.
- Hughes, B., & Paterson, K. (1997). The social model of disability and the disappearing body: Towards a sociology of impairment. *Disability & Society*, 12(3), 325–340.
- Introna, L. D. (2002). The (im)possibility of ethics in the information age. *Information and Organisation*, 12(2), 71–84.
- Isaacs, P. (1998). Medicine, social practices, and the nature of medical ethics. Proceedings from: The Society for Health and Human Values Spring Regional Meeting, Youngstown State University. Youngstown, OH: Higher Education Community Engagement Social Responsibility.
- Isaacs, P., & Massey, D. (Feb 24–26, 1994). Mapping the applied ethics agenda. Proceedings from: Third Annual Meeting of the Association for Practical and Professional Ethics. Cleveland, OH.
- Matthews, N., Ellem, K., & Chenoweth, L. (2013). Crafting and retelling everyday lives—Disabled people’s contribution to bioethical concerns. *Narrative Inquiry in Bioethics*, 3(3), this issue.
- Savalescu, J. (2001). Procreative beneficence: Why we should select the best children. *Bioethics*, 15, 413–26.
- Savalescu, J. (2002). Deaf lesbians, ‘designer disability,’ and the future of medicine. *British Medical Journal*, 325, 771–773.
- Savalescu, J. (2007). In defense of procreative beneficence. *Journal of Medical Ethics* 33, 284–288.
- Schlitz, E. (2013). Navigating ambivalence. *Narrative Inquiry in Bioethics*, 3(3), this issue.
- Scully, J. L. (2008). *Disability bioethics: moral bodies, moral difference*. New York, NY: Rowan & Littlefield Publishers.
- Walker, M. U. (2007). *Moral understandings: A feminist study in ethics*. New York, NY: Oxford University Press.

Personal Narratives

Uniquely My Own: One Woman’s Experience of Living with a Physical Disability

Stephanie Birmingham

“I don’t know. You’ll have to ask her. After all, it is *her* wheelchair.” These were the words my friend said in reply to the airline employee who continued a stream of questions as if I didn’t

* Name changed to protect privacy.

even exist. Maria* and I had just completed the first leg of our return trip home after a week of volunteer service in Washington, D.C. with fellow classmates when we were surprised to learn that, despite advanced confirmation with the airlines, my wheelchair could not be accommodated on the connecting flight.

As a co-leader for the service trip, it was extremely frustrating to be told that I couldn't finish the trip with everyone and that if I were going to continue on, then I'd have to make the decision to leave my wheelchair behind. I felt that leaving my wheelchair behind was comparable to leaving my independence behind. Perhaps though, what was most frustrating was the fact that once again, assumptions were made based on my appearance about what I could and couldn't do. It was figured that because I used a wheelchair and was of short stature, I was somehow less able to make a decision about how to proceed with the rest of the trip. I was considered "disabled" and the negative stereotypes associated with such label became evident.

Thankfully, I ended up making it home to my final destination after being separated from the rest of the group and booked on a later flight. It was inconvenient and annoying to have been treated the way I was by the airline employee, however it's just one example of the ignorance that seems to surround what I term "disability etiquette."

I've lived with my physical disability, Osteogenesis Imperfecta (O.I.), for my entire life. At the age of 25 I would say I've come to the point of embracing my physical limitations for what they are and rarely do I ever wish that I wasn't a person with a disability. In my personal opinion, my disability gives me a unique outlook on life and my short stature allows me to see things from a different vantage point (figuratively and literally).

Even though I've come to accept my disability and have worked to integrate it into every aspect of my life, it doesn't mean that I don't feel a bit of hurt and shock when I have awkward encounters with people who, because of a lack of experience or education, only see me for my physical nature. It's still a painful experience when I'm reminded that some people only see me for "my label."

Approximately three years ago I lived just outside Washington, D.C. for a year. Shortly after moving I decided to establish a connection with a primary care physician. My first visit with the doctor was strange and after he said, "I thought only boys got O.I." I knew this wasn't going to be a good fit. Thinking that perhaps it would make more sense to visit a female doctor, I made an appointment with a female internal medicine physician.

Getting into the office was an interesting feat in and of itself. The so-called "accessible" entrance wasn't very wheelchair-friendly and consisted of an uneven, steep ramp. Getting in required not only my calling to tell them I was outside, but also the assistance of a fellow patient to lift my wheelchair inside. During my first (and only) visit with the doctor she proceeded to complete a basic physical exam. She asked me questions about my health history, current social history and it seemed like things were going just fine. Until, much to my dismay, after having shared with her that I graduated from a private liberal arts college with a degree in Political Science, she proceeded to ask me, "Did you go to a special school as a child?"

I couldn't believe it! Did she really just say that? With as much composure as I could muster I replied, "No. You do realize that my disability has nothing to do with my intellectual abilities, right? I went to a mainstream school just like my friends. My disability means that I am short, can't walk and my bones break easily."

At this point all I wanted to do was get out of the office. I knew I'd never make another appointment with her again and this was confirmed as she tried to "push" my wheelchair as I exited the exam room. What exactly she was thinking as she tried to maneuver my wheelchair out the door I am not quite sure. All I can say is that it felt like the doctor only saw me as a medical diagnosis. Assumptions were made about my intellect based on my size, even despite having been given a bit of background on me as a person. On a brighter note, I did end up finding a female physician's assistant who was absolutely wonderful. She got a gold star in my book!

To the doctors and to the world, my disability is visible and rare. And thus, it leads people to attend

to me in bizarre ways. Take for example, the man at the train station who decided to randomly inform me that the upcoming movie, *"The Hobbit"* has a lot of "midgets" in it. Or the person who makes the offhand remark, "I believe" as he stares and walks past me. I still am amazed at one strange encounter I had with a man who saw me riding in my wheelchair on the sidewalk and pulled over in his truck. At first I freaked out thinking, "Oh gosh! What does this guy want? Who the heck is he?" He gave me a \$20 bill and said, "God wanted me to pull over and give this to you. Have dinner on me tonight!" I explained that I didn't need the money but he insisted. These examples are minor in the grand scheme of it all. Although, I believe they illustrate what I consider an additional layer of complexity that comes with being a person of short stature.

I am reminded of my short stature when I am navigating different places like the grocery store, checkout lanes, store aisles and service counters. Or when the waitress sets my glass of water too far out of my reach. Getting the can of bean soup five shelves above my head is one of those things that I dare not attempt by myself because the likelihood of me taking down the entire shelf is quite high (no pun intended). I've knocked down my fair share of display units in my best attempt at navigating store aisles. While on the one hand I'm laughing inside, on the other I am outwardly blushing a red of embarrassment at the attention that's aimed towards me. I have also managed to tangle a good number of shirts and pants in my tires and yank down tops from higher racks when I'm out clothes shopping. The strength and height that is required to heave groceries onto the checkout conveyer belt is remarkable and I've learned to no longer struggle by myself, but just ask for help from the person ahead of me if they haven't already offered (which actually happens quite a bit).

Often times I ignore the challenges my height presents to me on a daily basis partly because I'm used to them, and also because if I held on to each one I might just go completely insane or sink into a hole of self-pity and depression. Instead, I've accepted what is my current reality and done my

absolute best to embrace it and find the humor in it all. For me, a day without laughter is like a day without air—unlivable.

However, if I had to pick one aspect of my identity that my short stature and disability collides with I would have to say it rubs up against my gender—being short, disabled and female is a tricky combination. Giving hugs to friends is an interesting thing because my arms never wrap around someone's torso and instead I end up hugging one's chest, which is awkward. Same goes for when others are hugging me, my face ends up getting smooshed into their chest and that's sort of awkward. On top of it, my glasses get crunched. Being a significantly short woman has elicited interesting descriptors from others when they feel the need to "label" my presence. I've been called, "Precious," "Cutie," "Honey" and "Awww, well aren't you just cute!" These are words we use to describe kids, not women in their mid-twenties. I would rather be called "Beautiful" and seen as a mature woman and not be referred to with childlike adjectives. But, the size of my body leads people to characterize me as a child.

I am well aware that I have multiple scars spanning across my body and that I am not a supermodel (nor do I really want to be). I know that I don't have long skinny legs or voluptuous curves and I know my feet will never fit into a pair of red high heels (although, I do have an adorable pair of red ballet flats), and that's okay. I know that when it comes to disclosing my disability, I have no real choice in the matter because my wheelchair is pretty obvious. Sometimes that's frustrating but in general, I think it serves as a great "pre-screening" tool when it comes to potential relationships.

I've come to realize that there are probably a lot of assumptions made about my body and my sexuality as a woman with a disability. I can't be sure of what goes on inside the male mind, but my guess is that there's an uncertainty as to whether I can be intimate, have sex and have children. These are totally legitimate questions and are undoubtedly issues that are bound to come up eventually in a relationship. In fact, if these topics were never talked about I would question the health of the

relationship. Being short and having a disability does not negate the needs and desires I have as a woman. I would much rather have someone ask me about these things than assume what's in the realm of possibility.

Setting aside the challenges, frustrations, embarrassments, pain and fleeting moments of disliking my disability, overall I consider it to be a great blessing in my life. I like to believe that it has allowed me to be in solidarity with certain segments of our population who are often times ignored or looked down upon. I consider myself belonging to a minority group—persons with a disability. I spent a year and a half working with a diverse group of men, women and juveniles who were incarcerated in a Wisconsin jail. My disability gave me a way to connect with inmates. I could empathize with them about what it feels like to be a minority and have people assign labels to you, as is often the case with people who are incarcerated. While I could never say I knew what it was like to be dealing with an addiction or what it felt like to be away from my children, I did know what it was like to have people look at you and make automatic assumptions. I did understand the challenge of having to advocate for your rights and get past initial judgments others make. These similarities provided me a foot in the door in establishing a sense of trust when interacting with the men and women.

I can still remember one encounter I had with a kid who was being held in the juvenile detention wing of the jail. She was a 14-year-old girl who was facing transfer to a long-term facility for female juvenile offenders. Initially, she seemed a bit suspect of who I was and apprehensive to open up about what was going on in her life. However, it was after I asked her questions that honored her reality of having a cleft palate, which left her slightly disfigured, and sharing a bit about what it's been like for me growing up with a disability, I made a connection with her. I didn't get to meet her for very long afterwards due to her being transferred, but I like to believe that during those limited encounters, she felt like she wasn't alone. I hope she felt like someone was in solidarity with her despite our individual differences.

One time after meeting with a middle-aged man who was facing an extensive period of time for armed robbery and numerous drug charges, he ended our conversation explaining that even though he was looking at a lot of time and life was hard in the jail, he felt a sense of hope and inspiration by my presence. He explained that when he felt like he was caught in his anger and felt sad for himself, he said he thought about my disability and the way in which I have faced and embraced my challenges. It was then that he no longer felt such self-pity. My disability reminded him that he wasn't alone in the world and he wasn't the only person who faced challenges. And so, it was my disability that enabled me to make a difference for this inmate.

My disability has particular meaning and value in and of itself. It is an inseparable part of the experiences I have in the world. My relationships, my actions, my ways of making the world a better place are all expressions of me, but in being unique to me, they are ultimately expressed through my body and thus, my disability. And increasingly, I have embraced my physical limitations for what they are because they make me the woman I am in relation to the world.

Life is Good

Annette Chacos

I live in Hervey Bay. I'm a member of several social groups. I have adult children and grandchildren, and many lovely friends. I love to write. Most importantly I love The Lord Jesus Who has been my strength, bringing me through the good times, the not so good times, and the, 'I'm throwing in the towel' times.

I was first diagnosed with a brain tumour in 1997. Prior to knowing about the tumour and for some time after its removal I had little or no memory of events. The tumour was a left Frontal Meningioma (benign). For some time afterward I was partially

paralyzed. Now there is only some weakness on the right side of my body. Epilepsy too became part of my life. There are different types of seizures, which are rarely, if ever, amusing.

Humour is very important. If you can't laugh at the things that happen life would be a constant tale of woe. I'm very blessed. There are so many people who are much worse off than myself.

My story

In July 1997 my husband went to see if everything was okay because I wasn't up out of bed yet. I was lying across the bed in a disheveled state. After being cleaned up I was taken to the local hospital. The duty doctor, who hadn't even seen me, told my son that he didn't think there was much wrong and to take me home. My sons refused and insisted that the doctor admit me. He did.

I was diagnosed with a urinary tract infection. My memories of this are scattered. I learned some time later that I had had a Tonic Clonic seizure (formerly known as "grand mal" seizures which are commonly associated with epilepsy). After I came out of hospital I saw my general practitioner (GP). She sent me for an x-ray, and then to see a Neurosurgeon. An MRI was taken and there was a large tumour in my brain.

My memory of this time is poor. I do recall a friend phoning and I told her I was going into hospital to have a brain tumour removed. After fifteen years she is still saying I was so matter of fact about it. I now know that my emotions, like my memory, was at a very low ebb due to the tumour. There was no caring or worrying. If there was, in the next minute, probably second, it was forgotten.

Before going into hospital my late husband said to the kids "better take a photograph of your mother in case she dies." I was told about that comment some time later. What a comfort! Then one day the photo turned up. It was so ugly I tore it up. You'll note I said the *photo* was ugly!

The operation took place in Canberra hospital, at the end of August. It was to be earlier but they deferred it because an emergency came in. They were going to defer it again, by which time I was

mute and non-responsive. My daughter Maria arrived from Melbourne and my daughter Katrina and her husband Kevin came from America with their 3-month-old baby. My son Libe arrived from Sydney. Marcus, my youngest, lived locally, as did my daughter Tania. On hearing the operation was to be deferred again they took action informing hospital staff they were going to the local MP and the *A Current Affair* television show. So I had the operation—it was much easier to put me under the scalpel than battle the bureaucracy!

I have only one film from that MRI. Where the others are I don't know. According to Dr C, the tumour was very large. But to me, what does size matter—it was no longer there. Most importantly, I survived. The ten days I was in hospital are mostly forgotten. The few people I remember are like snapshots. No one moved, or so it seemed to me.

In 2006, the second tumour was removed. It was discovered by the same lovely GP, who found the first one. I was getting dizzy, off balance. She ordered an MRI, and sent me to the same neurosurgeon. Then I came up to Hervey Bay to live—I couldn't tolerate the noise, I found the grandchildren too much for me. My husband was a heavy smoker and smoke made me ill.

When I arrived I saw the local doctor—I wanted to see a neurosurgeon, and neurologist up here. He looked at the scans and said, "No big deal, it's only small. It'll be there for years." I insisted on a referral and I saw a lady specialist in Brisbane. She listened, looked at the MRI, and made an appointment for me to have the operation. The tumour was not quite 3 cm. The type of operation required that the tumour be no more than 3 cms.

One good thing though, I got my own room—I was so fortunate. But I was told if a private patient came in I would be moved. None did. Another type of seizure called De Ja Vu happened while in hospital. I was totally convinced the nurse had already been and completed what she had to do. I asked her why she was doing them again when she had already done them. She assured me she most certainly had not been before.

When I was discharged my daughter picked me up and I stayed with her until my other daughter

arrived from New South Wales, hired a car, and drove me home.

I now have short term memory loss, and I get easily distracted, have trouble processing information, my ears are extremely sensitive to noise and chill, a weakness on the right side and also balance issues—these are the things that cause me the most nuisance.

I did radio for a couple of years but I couldn't use the panel or console. My son in law and one of the elders from church did that, while I concentrated on what I do best—speaking.

The epilepsy seems to have increased seizure activity. I am having my medication adjusted. Life has it's own clock. One of the fearful aspects of it—and I don't use that word lightly—I can have a great day, and on the way to bed, half way down the corridor, it always happened in the corridor, I would get a panic attack, and be in abject fear, get into bed, be unable to sleep, get my walking stick (which I no longer need) put it on the bed, get up and lock the bedroom door, get my medi-alarm fob around my neck and bedside lamp on—and be like that most of the night, imagination playing havoc. I'm not brave, like the stars in the movies, I don't go out and investigate, the only place I go is under the covers.

And now déjà vu again. This time it often happens. It's not frightening but it is concerning. You find yourself thinking "did that happen" or "did I already do that?"

Once someone on television was eating fish and chips and I could smell the chips. As for the eyes; there's peripheral vision, spatial vision, and if that isn't enough you become cross-eyed. At the computer the curser looks like an insect or fly—until you realize what it is. Food doesn't taste good, my appetite is poor, as for sleep, it's not Sleepless in Seattle, it's sleepless in bed . . .

People think you're either forgetful or stupid. Even your family. The operation takes place, you get better, no walking frame, no walking stick. They're all gone. And they forget. They don't understand why you're not able to deal with grandchildren running around doing the things that grandchildren do—making a lot of noise. My daughter got a dog and the only way I could stop its continual barking

was to take a packet of treats and feed it, and feed it, and feed it! Clever dog. It barked in a whisper!

Although I feel very sad, it's easier to be on my own. You have your own place. You know what's going on and have your own routine.

Even friends forget.

I avoid noise and chill as much as I can. In church I sit in a secluded spot where I can hear but not find it too loud. Times like this I think about people with hearing aids. They can be switched off.

People don't know.

We MUST have more regional workshops. People need to be made aware of Brain Tumour Injury and Epilepsy trauma. But money is the be all and end all to make these things happen. Epilepsy and Brain Injury organizations need our support. With the first tumour, my family didn't know.

We had a guest speaker at our Young at Heart group (50+). She was talking about dementia. I couldn't help myself—I said to her afterward—"I have short term memory loss—brain tumour injury, short term memory loss—epilepsy, forgetfulness that often happens with ageing. How is anyone going to know if I get dementia?" She didn't quite know what to say!

I spoke to the bus drivers—there are three—I told them briefly about the tumour and epilepsy. I also mentioned the short-term memory loss, but I think that had become quite apparent to them. It is wise also to tell coordinators of any groups you attend. If anything happens they know what to do.

How have things changed for you?

I have become more tolerant of people and their shortcomings and more tolerant of my own. I must say, though, if I wasn't me I wouldn't want to live with me. I have become more grateful for what I have, and of the goodness of people.

There's no point in me saying to someone who's having a bad day, "me too." It's comfort they need. If people have a problem—if they're upset or depressed, you can't tell them about the woe is me day you've had.

I've had a lot of loss in the past few years. One of my daughters died just over three years ago. My husband, died eighteen months ago. My Mum died shortly before my daughter and my dearest friend who visited me every day for a long time after I arrived home from hospital. She came to church with me. I guess my family asked her to.

Grief is a difficult time. Like feeling a bit sad that you didn't say or do all the things you wanted to.

I have another tumour growing at present. The neurosurgeon suggested because of my age I have radiation. I returned home and began to search the internet, articles, and forums. Next, I made telephone calls to every medical association and radiologist clinic and HelpLine I could think of. I spoke to a friend who had received radio-therapy. She was pleased with the procedure and result. For the most part every one (all medical providers) was positive. But there was one crucial factor! Radiation didn't have instant tumour removal like operations did. Instead the tumour grew smaller with the passing of time and there was still the possibility of re-growth. We all have to make choices. I have made mine.

But there is a lovely end to this story. The Epileptologist I had seen in Brisbane arranged our next consultation to be on Skype. This saved me hours of travel. Awesome! The way of the future is here now.

Life is good. I don't need a "Life's Good" television advertisement to tell me that! I am constantly amazed at the people with disabilities who are out there doing activities that able people can but don't. No doubt they have reasons so I wish them well, but for all who do despite medical challenges, you are the best.

God's grace be with you, Shalom.

Tackling Adversity

John Hermanek

As a very active and athletic 21-year-old I was involved in an accident that would change my life forever, but not necessarily for the worse. I was hit by a drunk driver in a

pick-up truck while riding my motorcycle. Ironically, I was on my way to sell the motorcycle but never made it that far. I suffered a broken hand, femur, multiple lacerations and the most severe injury of them all, the loss of my right leg just below the knee. I kept the fact that I owned a motorcycle from my parents by storing it at a friend's house so I knew the news of my injury would be twice as surreal to them. I remember telling the ER nurse that I needed to be the one that called them to tell them what happened. She said she could not do that, but I told her that she did not know my mother and I was able to talk her into accommodating me.

It was the summer between my junior and senior year of college and I had just made Indiana University's football team as a walk-on linebacker (without having played HS football) so life was good and there was pretty much nothing holding me back or anything I felt I could not do.

In an instant the life I once knew would never be the same and I truly wanted to die but little did I know that life would get better, not worse. After keeping my lower leg attached with surgical tape for a week, the inevitable could not be avoided. It was devastating news. At first I refused to sign any papers authorizing the amputation surgery but I was told if I did not, I would surely die as gangrene had set in. I remember scribbling my signature and then throwing the pen—a doctor's dream I'm sure but I have to believe they've seen it all before. I was in traction for the first six weeks and had lost 60 pounds. Two weeks after being removed from traction I was able to get upright but was extremely weak. The emaciated and ghostly white image of me was tough to look at in the mirror, especially with half my right leg missing. That really took some getting used to. At that point, it was like a bad dream and I wasn't sure what to make of all of it but one thing for certain was that reality had sunk in. Surprisingly, it was at that point that I quit feeling sorry for myself and instantly knew what had to be done.

I knew I needed help and I could not do it alone so with the help of my family and friends, I started to put goals in place for myself. First on the list was to gain some weight back so I resumed working out (mostly weightlifting) and turned to my mother's

great cooking. There were some highs and lows during that process particularly with my first prosthetist (also an amputee) who told me my days of any type of sports activities “were over.” That was pretty devastating news to me but it didn’t take me long to realize he was only telling me things that he himself was never able to accomplish as an amputee and that just created more of an incentive for me because I knew deep down it was possible because I already had the drive and determination. Just under a year later I was back to a regular exercise program, my “pre-accident” weight and feeling healthy and in shape again.

I have since become more appreciative of what I have. I used to box in college and in 1991, entered the Chicago Golden Gloves Super heavy-weight (senior novice) division. Senior novice means you’ve had five or less fights at that time and that you were at least 21. I lost my first fight in 1991 on a controversial decision and came back in 1992 and had three fights. Just shy of 35 years old, my first opponent was 31, the next one was 28 and in the finals, my opponent was 21. I won all three bouts by unanimous decision and made the front page of the Chicago Tribune’s Sports page the next morning complete with a color photo. I went on to fight again in 1998 ironically against the same opponent I beat in college in the finals. It was an amateur fight on a pro card so they did not declare a winner so the final outcome is still up for debate.

I have been an amputee for most of my life now. Losing a limb can be devastating and I miss having it every single day. As a matter of fact, with something called “phantom sensation,” I can still wiggle and cross my toes and my foot still falls asleep . . . 34 years later. When wearing shorts. I get asked daily, “What happened to your knee?” I tell them that there’s absolutely nothing wrong with my knee in an effort for them to reconsider what they just asked me. If it does not hit them like a ton of bricks, and they are still waiting for answer, it is then that I lay it on them and usually they feel exceptionally embarrassed but I believe in always giving people the benefit of the doubt. That is a testimonial to the many professionals who have provided me with limbs over the years. Every time I get asked about “my knee” I look at it as a compliment.

I feel I have benefitted as a person because of this so-called “disability” even though I have never considered it to be one. It has made me stronger and has taught me how to deal better with all the other life altering curve balls that get thrown our way. Not to mention, it has secured me dates, prime seating at sporting events, always shot-gun when riding as a passenger in a car and front row parking almost everywhere I go (although I opt for the hanging placard rather than the plates—still in denial).

This was only a brief setback in my life, not an obstacle. It forced me to focus on what I “have” and not what I “lost” which was a real eye-opener for me. I thank the ingenuity and technology of the many prosthetic outlets I have been involved with and all the modern technological enhancements for playing a major role in enabling me to live a better life despite what seemed at the time to be such a devastating setback. I am married with three wonderful children and lead a normal and productive life.

How Deafness May Emerge as a Disability as Social Interactions Unfold

Gabrielle Hodge

My hearing loss ranges from moderate to profound in both ears. I use spoken English, written English and Auslan (Australian sign language) to communicate, and rely heavily on two hearing aids, speech reading skills and my vision to interact with other people. Here I demonstrate how my deafness tends to emerge as a disability through interactions with other people within the health and wellbeing context of group yoga practice. I compare two experiences from practicing yoga in group classes (which involves physical interaction and requires attendance to non-spoken tasks), and use these experiences to explore what the label ‘disability’ does not capture, how this term reflects my lived experience of deafness, and what this might mean for health and wellbeing

professionals engaging with clients who experience types of deafness.

All human interactions are uniquely and intersubjectively shaped by the actors, how they communicate, and what they are doing while interacting. In my case, if someone is simultaneously attending to some task while talking with me, this may mean that I cannot see their face and therefore cannot access their spoken utterances. During group conversations, others may overlap their spoken turns at a pace faster than I can visually track and therefore I cannot access the dynamic content of the group conversation. In these situations, my deafness may manifest as disability. This contrasts with interactions where I engage with other signers using Auslan, where my deafness does not manifest as disability at all. For me, deafness as disability tends to be an emergent characteristic of my interactions with other people, rather than a constant feature of all interactions, or all moments of a single interaction. It emerges most prominently through interactions with strangers, and less during interactions with social intimates. This characterisation contradicts the concept of disability as a fixed feature of an individual that impacts uniformly on all aspects of their experience.

I regularly practice yoga and have done so for many years. I enjoy participating in classes with other students, as we jointly learn and develop practices that challenge and illuminate different aspects of our lives. "At the heart of all yogas lies the manipulation of visible, accessible means to reach invisible, intangible ends" (Givón 2005, p. 23). How one manipulates their visible, accessible means depends on one's personal physiology, psychology and sociality. Over the years I have developed various strategies that enable me to participate in group practice and engage with other students and teachers without over-reliance on teachers or mediation from Auslan interpreters. I have mostly come to depend on observing how the teacher and other participants move (or even how shadows on the wall infer that they move) and interpreting their movements in context of the group practice.

For example, by placing myself at the front or the middle of the class, I can observe the movements

of others from several viewpoints in order to synchronise my own with theirs as the practice unfolds. Through experience, I can distinguish when these movements are intentional and when they may be accidental. By combining these strategies with one-on-one discussions with teachers before or after class, as well as doing my own research, I can subsequently learn about teachings that may be verbally expressed during classes and later match these with various teachers and practices over time. These strategies enable me to adapt to a situation where it is impossible to experience consistent face-to-face interaction and where it is difficult to access spoken instruction.

Group yoga classes usually begin with the teacher sharing some comments or a story to prompt the theme of the class. This helps us to integrate our exploration of action with the exploration of "invisible and intangible" goals. As a class, we observe our teacher's intentional movements and mirror these both mentally and physically. As the class progresses, the teacher migrates around the class observing and attending to individual students with adjustments and other assistance. Throughout the class, the teacher alternates between observing, demonstrating and assisting, while simultaneously instructing the class verbally.

Most of the students in these group classes can draw upon both spoken and visual aspects of instruction, while I primarily rely on the visual aspects. Regardless of our different accessible means, we gradually synchronise our movements as a group, thus creating one collaborative and social organism. It is this synchronisation that enables me to participate and enjoy the group practice. Sometimes I catch the eye of someone and we assist each other using speech, gesture and/or movement. If I partner up with someone during the class, we first discuss what each of us would like to achieve before attempting a pose, rather than waiting to direct each other verbally during the course of a pose in which face-to-face communication is difficult to maintain, such as during inversions. In this way, through synchronised movements and joint interactions within the group, yoga for me is both a physical and social practice. I learn through other students

as well as with them. All of these adaptations allow me to negotiate my own learning with that of other students, albeit in a different way to other students and over many classes. The extent to which other students share my experience of yoga is probably dependent on their own personal idiosyncrasies, including visual and auditory access as well as experience with the group practice.

A few months ago I returned to a class that I had previously attended on a regular basis. The teacher remembered me and we had a conversation where I reminded her how I function in group classes. The class proceeded in the usual way, until the teacher directed us to rise into a headstand without using the wall as a psychological or physical support. I believe the point of this exercise was to explore and challenge the extent of our individual vulnerabilities. I observed the students opposite me place themselves on their mats so that they would rise from the mat with their backs facing into the class and away from the wall. I decided to adapt the instruction so that I could see my fellow students as they were guided by the teacher's spoken instructions and therefore synchronise my movements on the basis of my observations. I placed myself on the mat so I could rise from the mat with my back facing into the wall and away from the class, which meant I could see the students opposite me when I was upside down. My concession to this adaptation in terms of challenging vulnerability was to place myself far enough from the wall that I could not balance upon it during the pose.

After some time, I felt ready to come down from this headstand. As I relaxed into a resting pose with my face to the ground, I felt the teacher tapping my leg, and turned around to see her chastising me for using the wall. Flustered, I explained that I felt it was better and safer for me to adapt her direction so that I could see the other students, because I could not follow her spoken instructions. I am not privy to what this teacher thought or felt upon hearing this explanation (which the entire class must have heard too), but from her facial expression it seemed to me that she realised she had not perceived this aspect of my participation and she quickly apologised.

Unfortunately, the trust implicit between teacher and student in yogic practice (i.e. that both attend and adapt to each other mindfully, rather than delivering or acting upon *carte blanche* instructions) was already broken for me. I felt humiliated, upset and overly vulnerable. I felt that my own understanding of my body was unfairly questioned and that the teacher had expected me to participate in the group class on her terms alone. I felt that there was no room for me to adapt comfortably. As our interaction unfolded, I perceived this teacher's approach to group practice as rigid and non-negotiable, which in turn contributed to the emergence of my deafness as a disability within our interaction. Since then, I have not returned to her class because I feel I am unable to safely participate in her group practice. Future adaptations on my part would need to be undertaken with an uncomfortable risk that they may be misinterpreted and result in getting told off, which I would prefer to avoid if possible.

This contrasts starkly with an experience from another class that I attend on a much more regular basis. The teacher of this particular class has developed an expert practice in non-spoken and somatic interaction. To me, it seems that her strong training in movement manifests partly as a general sensitivity to the non-spoken aspects of all kinds of human interaction. This sensitivity became particularly evident to me during one class when she enlisted me to partner with her in a demonstration of a handstand for the group.

Partner work in group practice is a supportive way for participants to develop advanced poses and their understanding of these poses. It generally involves two or more people. One person undertakes the pose while the others provide additional strength and balance support. Depending on the experience and physiology of participants, partner work may involve a range of spoken and non-spoken interaction. However, it always entails a mutual yet implicit trust that all participants attend and adapt to each other mindfully (and not, say, get distracted or become half-hearted about the interaction when one's partner is upside down in a potentially dangerous position). While partner

work may seem like a scary situation, it is usually very giving, intimate and rewarding.

Despite this, I initially felt alarmed when my teacher asked me to assist in the demonstration. However, she reassured me that all I had to do was to do what she had seen me do minutes earlier. In place, I rose into a handstand. My teacher balanced my hips. I sensed her talking to the class. She then gently ran her hand along the bottom of my left ribcage, slowly, and then repeated this movement. I interpreted this as an intentional communication for me to inhale and pull my ribcage in, thus rising higher, lengthening my spine, and moving my body into a stronger pose. After some time, I felt ready to come down from this handstand. The teacher assured me we had achieved what she intended, and commented how great it is to be able to communicate bodily through touch in such a situation. It is great. I felt she had trusted that I would understand my own body and “listen” to what she was suggesting. As our interaction unfolded, I perceived this teacher’s approach to group practice and partner work as dynamic and negotiable, which in turn contributed to the non-emergence of my deafness as a disability during our interaction. Since then, I have returned to her class many times because I feel I am able to safely participate in her group practice. All accessible means are open and available to be recruited for the exploration of action towards “invisible and intangible ends.”

By comparing these two experiences, I hope to have demonstrated that the concept of disability as a fixed feature of an individual that impacts uniformly on all aspects of their experience does not capture the graduated, contingent, and dynamic manifestation of disability according to individual experiences and interactions.

Given my exploration of what the label ‘disability’ does not capture, what does this mean for health and wellbeing professionals engaging with clients who experience types of deafness? In my case, it is a term that only partly reflects my lived experience of deafness. The degree to which deafness manifests as disability tends to be shaped by all of the individuals engaging in an interaction. I have experienced interactions where deafness results in

inaccessibility and interactions where it does not. In yoga practice at least, I have found that it is possible to negotiate and adapt my accessible means to enable me to participate and enjoy group practice in both a personal and a social way. As I build up relationships with teachers and students over time, we grow to accommodate each other. We work out how to facilitate interaction between ourselves, such as by alternating between attending to movement and attending to spoken or signed communication, rather than insisting that these things are achieved simultaneously, and by consciously expanding the context of interaction to include bodily movement and appropriate touch. Health and wellbeing professionals expect to work with their clients, as well as for them. I think this collaboration is easier if all participants are open to accommodating each other during their interactions. I believe this kind of negotiation is valued and enjoyed by all humans regardless of their subjectively shaped experience. When it comes to human interactions, it is negotiation that builds our relations more so than any rigid insistence of how they should unfold.

Reference

- Givón, T. (2005). *Context as other minds: The pragmatics of sociality, cognition and communication*. Amsterdam/Philadelphia: John Benjamins.

A Note on Being Ability-different, Atypically-bodied . . . Criptastic?

Emily Hutcheon

In being prompted to write about my experiences with disability [alternatively written: (dis)ability, dis/ability, “disability,” disAbility], I am confronted with more questions than I have answers. Am I to reflect on that small window of time, one so small that I don’t actually remember it, when I did not know that I was different? My mom

has recounted vivid moments where I seem to come to this realization—for example, at the age of three, when I see my twin sister and friends scrambling on a playground and I process that I am unable to join them. Realization of my differentness (my different body, my different way of moving, my different abilities) continued into my youth and adulthood (Can't skate—check. Can't ride a two-wheeled bike—check. Usually walk behind others, destined to be the last in a group—check. Was the smart kid in class, aka smartass-in-training—check).

Eventually, I realized that my differentness was not contained to my body or my abilities. Were my mind, my self, and my relationships different as well? I seemed to empathize when others didn't or couldn't. I saw that certain things were just *wrong*, and was confused when others didn't share my concern. I seemed to see, feel, and experience things that others did not. For instance, I had two invasive operations before the age of eleven, a handful of minor procedures and countless physiotherapy sessions. Some memories of these times are horrific. Some I cherish, including the genuine care of the health care staff. Some are hilarious, like being doped-up before invasive surgery at the age of ten and calling my favorite surgeon "*So cute!!*" But always, there was physical pain, pain, pain. At times, I was completely dependent on others to help me to the bathroom, the shower, to move around, and to recover. I received such tender and exquisite care from my mom during these times. The dependency, which I had no choice but to experience, the dependency that is feared by almost everyone I know ("If I am ever a burden to my family, shoot me") is something that my mom and I constantly joke about ("Em, I will take care of you now, *only* if you change my diapers when I'm old, kay?"). I have come to learn that this dependency, along with those other shades of vulnerability, are an inevitable consequence of being human, and to deny this is to relinquish our capacity to connect with others.

I had, and continue to have, relationships with strangers, friends and family, which are, in my best estimation, atypical. I am the recipient of staring, laughing, pointing, sympathy, disgust, empathy, tender care, curiosity, hostility, resentment, and

ambivalence. While in the gym, complete strangers approach me to say, with all the kindness, enthusiasm, and obliviousness in the world: "Glad to see you out and about. Good for *you!*" For some, I am to be protected; for others, I am to be tiptoed around; and for others, I am to be congratulated for "overcoming my circumstance" and for being oh-so-valuable to society because of my smarts and productivity.

It is a rare few who accept what Cerebral Palsy and epilepsy offer to my life and to their own, with all of their accompanying complexities, possibilities, and contradictions.

It is ironic that the excellent health care and services I have received, which have probably changed my life for the better, are only made possible because of the "disability" label, which I have come to heartily dislike. I have always felt ill-at-ease with this word and concept. In my mind, it just does not describe me or others around me. Perhaps more accurately, the definitions and associations that stubbornly accompany the term (e.g., the disabled person as asexual, passive and in need of protection, the disabled person as the conquering hero) would never accurately describe me. Undoubtedly, the term is negative in its connotations. And, of course, the concept of disability relies on certain notions of "normal." By most accounts in Disability Studies, "disability" and "normalcy" are inconstant, fuzzily bound, amorphous categories. Many, all, individuals have their feet in both categories—not only do we age, creeping slowly toward the so-called category of "impairment," but we all engage in bodily enhancements of some kind (e.g. makeup, eyeglasses, stimulants like caffeine, or prostheses which enable "superhuman" performance). And, as I and other researchers have argued, the category of disability is really a way to neatly manage the notion of vulnerability—to label others "disabled" is to render one's own body, mind, and even social location, stable and invulnerable.

So, the unconcerned use of the term disability by the public, by health professionals, and by scholars, does the following: it belies the inconstancy of disability/normalcy categories; it denies the universal vulnerabilities that we all experience; and, it shapes

these vulnerabilities as wholly negative as opposed to positive or generative experiences. And, most important to me: the use of this term *requires* me, and others, to agree that these bodies and minds we describe are in fact impaired. In an act of self-love, I would rather *not* describe myself as a defective human being. Instead, I would argue that we all occupy positions on an ability–body–mind spectrum, and we ought not to privilege one position over another. So, while the language of impairment and disability is bandied about by well-intentioned people, including doctors, nurses, my family, my neighbors, and friends, I find it oppressive to people with undervalued bodies and abilities.

As I have been re-visiting my own assumptions, frameworks, and language in the last few years, I have been confronted with some stark realities. I had a tonic–clonic (grand mal) seizure almost two years ago, with many smaller episodes after that. These episodes were frightening to me, and were preventing me from working on my graduate research. I spent many days exhausted from tremors and auras, and in emotional distress because I had no idea what was going on. In a state of desperation, I accepted the standard psychotropic medications used for epilepsy. I still protested loudly. My protest was based on past experiences with these medications—I was sure that I would fall into the unbearable insomnia and zombie-like state that I’d entered after first being diagnosed and medicated. I also couldn’t bear to put something so toxic and unknown into my body again. I tried the medications, and experienced the predicted side effects, but the episodes worsened. Enter my neurologist and his team of fellows, students, nurses, and other staff. As I had on previous occasions, I safely discontinued the drugs against my doctor’s advice. I was then placed on a waiting list for a seven-day diagnostic test and was magically ushered in several weeks later.

In those seven days, I was constantly restricted by EEG wires and hookups, which read my brain-waves 24/7. I could not step six feet outside of my room, except to a bathroom. This meant no showers, no exercise, and worst of all, three meals of hospital food per day. Ouch. (This is awful for

someone like me, who values health, fitness, and strength so highly. Luckily, family and friends came to the rescue with some good food.) When it came time for the doctors’ grand rounds, they spoke about me as if I was not there. Still, the doctors and nurses were vigilant and kind. Then they delivered their conclusions based on the information they’d gathered from this testing: “Everything you’ve been experiencing is not epileptic in the traditional sense.” (What?! What does that mean?) “We call it non-epileptiform, or psychogenic.” (What does *that* mean?) “It means that your episodes are not caused by abnormal electrical activity in the brain. They are likely caused by stress or anxiety, but the exact pathway is not known.” (Oh. My. Gosh. They’re saying this is all in my head. They must think so terribly of me. I don’t deserve the care and attention I’ve been given by this medical staff, by my family, friends, professors, or my partner. This can’t be right . . . they feel so *real*). “Um . . . we do know that this occurs in about 30% of people with epilepsy.” (So you’re saying I’m not the only freaky–deek out there then? Comforting.)

As the doctors formed these words, I couldn’t help from crying. For over a year, answers had eluded me, and this was now explained. Kind of. These seizure-like episodes are still mysterious to doctors and myself—to me, they feel like complex partial seizures. I have definitely been wrestling with some increased anxiety, it’s true . . . and this still plagues me daily. I may never know what exactly was going on. The good news is that these psychogenic episodes have now decreased to more manageable levels, and my epileptiform seizures are rare.

So, on one hand, I have benefitted from medical care. On the other hand, I tend to resist medicine’s prescriptive tendencies, its paternalism, its labels, and its language. I no longer use the terms “disability” or “disabled” when referring to myself or others. Instead, I use other descriptors if I have to, like: a group with *diverse abilities*. Someone with a *diverseability* who might be *atypically-bodied*. I might also be *criptastic*.

Not everyone in this ability–diverse and body–diverse community would agree with my

rejection of existing terms. These terms, especially the diagnoses, which come with it, ensure that our needs are met (albeit within frustrating, oppressive, bureaucratic service systems). Countless people engage in “disability pride” workshops, presentations, gatherings, and so forth. According to some, without these words, which differentiate us from others, the platform from which we express our identities and our needs may be lost. I am sensitive to this, but I want to hold true to my intuitions. I have to ask: As opposed to being *something*, can I not just *be*? Seriously.

If we pigeonhole people into certain categories (including “vulnerable,” “disabled,” even “resilient” categories of people) we potentially deny an individual’s own agency, their understanding of their life as fulfilled and whole, and the challenges, navigations, and transformations that accompany “being different” in a world that does not accept difference. Being ability-different and bodily-different has been . . . complex. In many ways the environments and institutions I navigate are oppressive, and I have been both uplifted and downcast. But there are many experiences, which coalesce to make up *me*. I can share these experiences with others. I can embrace different ways of being, different vulnerabilities, more freely and with no agenda. And, perhaps most important for me currently—as I develop my sensibilities as a feminist and activist—without these experiences and challenges I might never have discovered my capacity to resist.

Disability Embodied: Narrative Exploration of the Lives of Two Brothers Living with Traumatic Brain Injury

Douglas E. Kidd

Any discussion of personal experiences with disability, inevitably lead me to recall the experiences of my brother, Richard Kidd. An examination of our journeys clearly illustrates

the term disability. More so, our stories reveal the outcome of severe physical impairment dictates the limits of personal agency and autonomy. Perhaps an obvious conclusion, but exploration of our experience is useful as we provide living testimony to eventualities that could similarly occur to others. In order to provide context for discussion of our disabilities, I will briefly recall how we acquired our traumatic brain injuries (TBI), as well as how our brain injuries are expressed. The article will demonstrate that due to the severity of the brain damage he acquired, Richard is entirely subject to the whim of the society he encounters, and thus disabled. The article will also discuss how the disabling attitudes I have encountered sought to diminish my humanity.

Richard Kidd

Richard’s descent into impairment began in the early evening hours of December 31, 1987. As a pedestrian, Richard attempted to cross a street in Indianapolis, when a car without using headlights, slammed into him. In addition, the driver fled the scene of the accident. After stabilizing from the initial trauma—multiple compound fractures to both legs and severe brain injury—Richard spent approximately ten months in coma. After emerging from coma, Richard underwent months of therapy. Albeit with consistent direction from others, therapy enhanced Richard’s ability to hold a cup and use a spoon. These were significant victories for Richard and signaled the beginning of his recovery. However, within two years of his accident, monies ended for rehabilitation and Richard entered into custodial care at his first nursing facility. As time passed, his daily interactions with poorly supervised, unskilled, and underpaid nursing facility employees with little time to work with Richard meant it was more cost efficient for staff to simply spoon-feed Richard. Consequently, Richard lost the ability to participate in an aspect of his self-care. Richard’s humanity took years to gradually erode, but due to the severity of his impairments, he became viewed by those he encountered as an object of treatment, or reservoir of pain and pity, rather than an individual worthy of respect. Accordingly,

Richard became viewed as other. Thus began Richard's descent into disability.

A complete lack of dental care for decades provides a good example of Richard's treatment as other. Richard's experience also demonstrates that desensitized members of the medical, dental, and long-term care professions sometimes precipitate grave circumstances. The combination of an inattention to his needs and his limited ability to participate with his self-care meant that Richard typically went without dental treatment. His quality of life diminished further when aides at a nursing facility dropped him. During the fall, Richard's face smashed into the floor and several teeth were shattered. More than a decade passed before Richard finally received follow-up dental treatment—that day nearly cost him his life. Due to prolonged neglect, all of Richard's teeth required extraction. I do not question the dental surgeon's assessment of Richard's teeth. I am certain that all of his teeth needed to be removed; but Richard's sedentary lifestyle meant that he had limited ability to cope with the trauma associated with having 24 teeth removed in one session. I feel certain the dental surgeon assumed Richard was like most other patients and could handle the stress associated with the procedures. However, Richard could not cope with trauma and blood loss the extractions produced. What is worse than the dental surgeon's assessment of Richard's ability to withstand surgery is the post-op personnel decision to discharge him to home, shortly after surgery. The nursing facility was ill-equipped to cope with the extent of the blood loss that ensued and soon Richard began to aspirate on his own blood. Accordingly, Richard was sent to the hospital where he proceeded to slip into coma. Richard remained in a coma for approximately four days and in hospital for a further week. I assert that Richard is regarded as other because he is unlike most people as they face the prospect of dental surgery and this difference nearly cost him his life.

Another example of people disabling Richard came when nursing facility staff decided to restrict Richard's movements by placing a large mitt on his right hand. Staff did this out of concern that Richard

would seek to make adjustments in his groin area. Aside from being able to move his neck, eyes, and mouth, his right hand and arm are the only aspects of his body Richard can control. As soon as I witnessed the staff's decision, I insisted on removal of the mitt. At first staff resisted my suggestion but, when I mentioned I would seek to involve an ombudsman to mediate the matter, they realized that it is against the law to restrict residents in this fashion, so they relented and removed the mitt.

Yet, another example of the nursing facility disabling Richard came during the once weekly recreation sessions at the nursing facility. An aspect of the difference Richard presents is characterized by his voice growing louder as he becomes agitated. In keeping with the intent of these sessions, Richard would attempt to participate. However, staff thought Richard became too loud and disruptive so he was removed from the room. In an effort to make me feel better about Richard's exclusion from activities, staff indicated they positioned him just outside the room, so he might listen. The above are clear indications of efforts made by nursing facility staff to exclude impaired individuals from engaging in behaviors or activities. Disability Studies scholars and activists contend that when society limits impaired individuals in this manner, disability occurs.

Another example that some people consider Richard to be other occurred when I introduced him to an acquaintance at a social occasion. Given his slowed brain processing speed, Richard has limited ability to engage with the world around him. Accordingly, Richard does not make eye contact with people and often does not respond verbally. Therefore, his presentation to others is often vague. It is human nature to look for a response after an introduction and as Richard did not acknowledge the other person, this produced a puzzled look on the acquaintance's face. A look in the acquaintance's face that suggested the question: What are you? Of course, this is a subjective interpretation of the interaction, but Richard's blank expression produced an incredulous look from the acquaintance. The incident passed in a few moments and it may seem difficult to connect the concepts of otherness

and disability to the event, but make no mistake, the lack of any response from the nondisabled acquaintance, ended the possibility of any acceptance of Richard. This reflects the concept that for many, the humanity of profoundly impaired individuals is an open question.

Douglas Kidd

The event that marks the beginning of my journey of disability occurred, May 17, 2005. The woman driving her SUV at approximately 50 mph had no chance to brake as I halted my car briefly at the stop sign, and then preceded into the intersection, where she collided with me. The accident caused me to spend nearly a month in coma, followed by five weeks of amnesia. I then underwent two months of physical, speech and occupational therapies where I reacquired the ability to think, speak, and began to reconnect with the world. Outpatient physical therapy continued for a time, and 18 months after the accident, I could walk unsupported. My major injuries included, bilateral acetabular fractures, compartment syndrome injury to my lower right leg, and a diffuse intraparenchymal brain hemorrhage. While the brain injury I acquired is categorized as severe, somehow, I emerged from accident and injury and I have recovered all aspects of my life. The next section of the article will explore disabling interactions I have had with others.

An example where the actions of others in effect disabled me occurred during the sub-acute phase of my recovery. Periodically, during the weeks and months that passed since my accident, an orthopedic surgeon would evaluate my need for inevitable hip replacement surgery. As both hips were fractured in the accident, the ideal time for the surgery—while I was unconscious—was delayed when I contracted and nearly died from staph infection. During the first few consultations with the orthopedic surgeon, I was either unconscious or disoriented; however, during the last two appointments I had with the surgeon, I was conscious and clearly engaging the world at a high level. As the evaluations occurred at a teaching hospital, typically many residents, students, and the

doctor appeared in the room to evaluate my case. So many individuals appeared that I was uncertain as to my actual doctor. In the two consultations I had with the orthopedic surgeon, the extent of his verbal interaction with me was precisely one word. I am certain the images of my hips revealed to the doctor the course of future interventions, and I am not questioning the integrity of the doctor; but as I reflect back on these appointments, I cannot escape from the idea that because the doctor did not seek to engage me in conversation, he in effect diminished my humanity. Other than disquiet derived from relating the experience here, what I describe above, does not affect my life. However, I have learned that one of the hallmarks of a disabling society is when the humanity of individuals is negated.

An example of medical personnel's attempt to disable me occurred during a consultation with a physical therapist. The therapist observed my gait, and then made various measurements. At the end of the initial consultation, she provided a list of home-therapy exercises and instructions for me to my fiancé. Understand, I sat right next to my fiancé and the therapist looked directly past me and did not engage me in the conversation. As I stayed in the hospital's ICU, the therapist knew about my medical history. I can only assume that when she evaluated the severity of my brain injury, she considered me to be incompetent. The reason I suggest the therapist attempted to disable me is that she failed to recognize my mental competence and thereby she negated my humanity. I use the word "attempt" above, because I insisted and the therapist finally engaged me directly. We went on to have a good therapeutic relationship as I greatly refined my ability to walk with her help, but clearly, my ability to self-advocate meant that the therapist would recognize my humanity and help me deal with my impairment.

Similar to the way fingerprints uniquely identify individuals, my way of walking and the physical disfigurements I possess, signal to others that I am disabled. This is evidenced by the fact that sometimes strangers ask me questions about my appearance. For example, as I waited outside the Metropolitan Museum of Art in New York, a young

woman stood staring at the foot long scar on my right leg for about ten minutes. She made me very uncomfortable and then she broke the usual barrier of silence and asked if I was in pain. An aspect of my brain injury is to seek after the acceptance of others, even strangers, so I obliged her by saying, "No, I am not in pain, just waiting for a friend."

An example of my pronounced limp evoking comment from a stranger occurred as I approached a man as I walked down a hallway. He stopped me in full stride and asked, "Man, it look like it hurts you when you walk. Are you okay?" Again, I felt obliged to reassure the stranger by saying, "I am alright, just in a hurry!"

Probably the most bizarre experience of being stopped and asked about my disability occurred when a young man came alongside me as I walked towards my car. The young man recounted times when he knelt down with others, they prayed to Jesus, and this removed the person's limp. The young man asked me if I wished to kneel and pray with him. I thanked the man for his concern, but politely declined his request.

My encounters outlined above underscore the idea that people require an explanation when they encounter the unknown. I believe when some non-disabled people encounter disabled individuals, they respond from a subconscious sense of superiority that sometimes overrides the autonomy and rights of those who are physically different. Knowledge of Disability Studies scholarship informs me, that from ancient times, the humanity of those that present difference is often viewed as a threat that demands an explanation. Both, my presentation and nondisabled expectations for understanding are hallmarks of a disability interchange. More, they in part describe what it is like to live with the label "disability."

The above article describes the lived experiences of two disabled people. Throughout the article, I provided anecdotal evidence that illustrates disability is a social construct. To expand on this idea, it is not our physical issues that limit our social lives, but rather it is the perceptions of us that sometimes lead others to act in ways that work against us. In my case, while others have disabled me, I possess

the ability to resist, or mute, the impact of the intentions of others. Whereas, Richard is largely viewed as a nonperson and is therefore unable to resist the expressed will of others. It is ironic that in the one example I described where Richard nearly died because he was deemed similar to most people, yet in spite of this, his difference largely separates him from humanity, thereby producing his social death. The principal difference I see between us is the fact that I am largely able to resist the hegemonic forces that exist to determine our realities. Whereas, the extent of the brain damage Richard acquired in his accident stripped away his ability to insist on his autonomy and the respect that flows from it. The course of Richard's life since his accident instructs us that we are incredibly resilient yet fragile creatures, and his treatment by society is a measure of the quality of our humanity.

Growing Up: Seeing Myself for Who I Am and Loving It

Kerry Magro

Last weekend, I traveled to see my cousin. He had graduated from St Mary's Seminary in Baltimore and was being ordained as a Roman Catholic priest. The event was attended by many of my family members. Several of the littlest attendees struggled with all the commotion, some were said to be shy, some didn't want to be crowded, and parents and caregivers did what they could to make it easier on them. Watching those kids trying to cope with a family event, which was different and a bit confusing, brought back a flood of memories of my own childhood. Nothing was simple about my childhood.

My life has been "interesting" for sure. As a young child I faced many challenges. Until the age of two and a half I was nonverbal. Even though later I would gain speech, my developmental delays and sensory integration dysfunction issues caused great

difficulty for myself and my parents. I was evaluated by professionals and was diagnosed with an autism spectrum disorder—pervasive developmental disorder not otherwise specified (PDD-NOS) at the age of four.

Thoughts of that difficult time filled my head when watching the children at this family function. My uncles, aunts and cousins couldn't possibly know my struggles in those years. They weren't present for all the interventions and therapy sessions I endured. Today, they don't see me as someone different or disabled. I still have some obstacles to overcome in my development but rather than bemoan where I am or where I have been I have chosen to accept myself as I am. Although some may say I have a disability I choose to embrace my *abilities* and to celebrate them. I'm glad I've stayed on a path that has led me to become an independent adult. I am now a national motivational speaker, a Master's graduate, owner of a non-profit corporation and soon to be an author.

But what about this word "disabled"? Since I was six years old I seemed to have been tagged with this word by those around me. They all considered autism as a disability. I didn't even know I had autism until I was 11. But I was very aware of people defining me as being disabled. It had to be the reason I was being placed in Special Ed classes, for the hours I had to travel to doctors and therapies: occupational therapy, physical therapy, speech therapy. I was being called disabled and I didn't know why. Of course the signs were there for me that I had a problem. In daycare many things confused and frightened me: loud noises, wind, water, transitions. I cried constantly, a lot more than everyone else. I had terrible tantrums (lying on the floor kicking and screaming) to the confusion and consternation of the adults and caregivers around me. I attended two different daycare centers and was asked to leave both of them. I couldn't even make the transition from the door of a daycare center to my parent's car without fighting, screaming and crying uncontrollably.

It's now hard to believe that my difficulty with sensory integration dysfunction, transitions and social interactions lasted for almost 15 years of my

life. During those years there were many confusing, frightening and painful episodes for me, my parents and others around us.

Like most kids with these types of deficits, we tried to find splinter skills to help me compensate. I have hyper-mobility of the joints making buttoning and fine motor tasks almost impossible. I also have dysgraphia, which makes it difficult for me to hold a pen or pencil to write. Even with therapy I never learned to ride a bicycle. One bright side to the hyper-mobility was being able to learn to type 100 words per minute.

My sensitivity to water, wind and loud sounds was extreme. I fought my parents each time they tried to get me into the bathtub. I hated going on the swings because I couldn't feel my feet on the ground. My mom loved the beach, but the sensation of sand under my feet was impossible for me to deal with. We simply didn't go anymore.

Escalators and elevators were also a problem. They scared me to death. Stairs were the only way for my family and I to move between floors. Another mistake was when I went to The Liberty Science Center in my hometown. They stamped my hand, which sent me screaming and crying until someone would take it off. Darting was also severe. I would dart away without any cognition of where I was going and my parents following.

So what happened? How did I get to where I am today? To start, once I displayed these problems as a young child, early intervention in terms of occupational therapy, physical therapy and speech therapy was the key. A child pediatric therapist came to our home. We played with things to address my sensory issues. We used gak (silly putty) every week and he brushed my arms with a soft brush to sensitize me. We then went for vestibular planning exercises at Hackensack Hospital. These interventions with many hours of physical and occupational therapy were one step for me. Then it was time to address my behavior issues, centering on transitions and social interactions

Going to school was difficult. I hated public school. It was very hard to handle the interactions with other children and teachers as well as handling transitions during the school day. I was

in “multi-handicapped” special education classes where I had trouble assimilating. Later when, I went to bigger schools I was often bullied by the so-called “normal” kids for being in the “retarded class.”

Looking back, I often wonder how I managed to get through the public school experience. Fortunately for me, my parents found a way for me to be schooled at a private school out of our public school district. That school, the Community School in Teaneck, NJ, possessed the expertise, understanding and patience that I needed. At Community School we were indeed a community of students with special needs but we felt protected and nurtured by the environment we were in. We all had something, which normalized us and put us on a level playing field. There I could calm down long enough and realize I was seen as someone who had challenges to overcome but was also someone who had amazing abilities. This doesn’t mean I forgot about the tag of “disabled” but I no longer felt stigmatized or threatened by it. I no longer had to hide or feel different, a person with less value. This sense of security and safety was liberating.

So Community School was another path for me to travel to continue to work on my issues. When I was younger, I was unable to communicate. That inability was extremely frustrating and caused me to act out in very emotional ways. Community School gave me the tools and training to communicate. The negative feelings I had about my “disability” soon became manageable and less a burden.

Not only were my verbal issues addressed but my motor skill issues as well. Activities in and outside of school helped me progress. I can remember as a kid struggling so hard to do as well as the other kids. No matter how much I practiced and wanted to be good I failed. But my school and my parents continued to encourage me not to give up. Slowly but surely I made progress. I was soon playing basketball, bowling and soccer.

I think what got me through in the end was the recognition of my efforts by the people around me. No matter what happened and no matter how much my “disability” hindered me those around me, my parents, teachers and coaches always acknowledged my hard work, my skills in certain

areas and rewarded me for trying. Getting that type of recognition at an early age would help me grow out of many of my tantrums and dispel my negative energy. It would encourage me to stick to things I enjoyed, no matter how difficult or impossible they seemed.

I can say today it was worth it to be part of the ride that I took because it made me face the reality of my situation. Was I ever going to be rid of my “disability”? No! But I would still persevere and work hard to define myself in everything I do.

Given my personal journey, I would like to speak to parents about when a specific situation arises . . .

During my time in national speaking I have gained many followers via email and social sites like Facebook and Twitter. One question, which I’ve received from parents several times, is whether to wait to get their son or daughter diagnosed. I am often stunned by this question. Given the importance of early intervention for any child with a learning disability parents must not be fearful of learning the truth about their children. If you have concerns and see something then you need to act. Whether its fear about the stigma of having a child with a disability or hoping to see if they might “grow out” of their situation, inaction is *not* an option. Parents can only make the right decisions for their children when they have all the information they need and the advice of professionals. Early intervention is the key for those with disabilities to succeed.

A continued conversation about disabilities and how one approaches them is a very healthy thing. The days where hiding someone with a disability or denying it exists need to end. A future where the negative stigma about those with disabilities ceases to exist is what we all strive for. We need to be mindful that some of the most iconic people ever either had or were thought to have some type of disability—everyone from Albert Einstein showing some signs of Asperger’s to Michael Jordan who had Attention Deficit Hyperactivity Disorder.

People ask why anyone would celebrate being disabled. I say, we are not celebrating someone with a disability, we are celebrating unique individuals; each individual with their own special abilities and character. And for this I ask . . . why not?

When I was in college one of my big initiatives was to help promote this awareness effort through starting the first ever student organization focused on disability awareness. I called the group "Student Disability Awareness" which started during my sophomore year to help break barriers of intolerance towards our 1% disabled student community.

I can go on and on about the things I've done to help spread awareness on disabilities but in the end I hope our society pushes it's self towards education and awareness on this issue. This education can lead to a future of acceptance and tolerance.

So this past weekend I went to Manchester NH to my cousin's ordination and first mass. I felt love and acceptance from all the family around me; no longer afraid to be a part of the group; no longer stigmatized as being different. The journey has thankfully been a successful one for me. I can only hope that other "disabled" people can have a similar experience and a future where acceptance, tolerance and respect are the rule. What a great society that would be to live in for all our families.

The Juggling Act

Samantha René Merriwether

Depressed. Anxious. Insomniac. Learning Disabled. Physically impaired. Sufferer of Post-Traumatic Stress Disorder. Would you choose any of these labels? How about taking two or three? Sound manageable? Probably not. But why? All across our society are plastered expectations of perfection, normalcy and "acceptable" images.

I am 27-years-old and, despite the years of education I have received, the communication skills I have gained in English and American Sign Language (ASL), the countless hours spent with doctors consulting about how to "get better," I have lost my sense of identity. And, the more I think about it, the more I realize that my "authentic voice" has not yet

been born. This is the reality for me and, I suspect, for anyone else who has been labeled disabled.

When I sat down to write this, I did not struggle coming up with a story to share nor the words to intrigue readers. Instead, I grappled over using my real name and not using a "pen name." Despite my long and varied history with disability, it took me a long time to advocate my issues enough to receive services. Because labels are embarrassing. Because disability is embarrassing. And, so, now I have labels . . . many labels. However, it is still accepting them that I am left with. Unfortunately, I am just one of millions who are also fighting to find some sense of balance between honesty with myself and the societal labels that are at the forefront of our communities.

It has been a year since I took Disability Studies, a cultural pluralism course requirement for my Liberal Studies Degree at California State University. On the surface choosing this sub topic could have been perceived as an easy A, given that I am disabled. Yes, having a disability enabled the language used to be less of a shock in my overall comprehension. In reality, however, the struggle to achieve success academically is continuously challenged by my own disabilities. However, despite succeeding in the course, "easy" is not an adjective that appropriately represents my experience. The knowledge I grasped in the classroom helps me to understand what happens when I walk outside on any given day; but therein lies the glitch . . . the class is over, but my disabilities never will be.

Did I enjoy the topic of Disability Studies? Yes, immensely. Because it was something I could relate to. Did enjoying the subject matter take the struggle for comprehension away? No. Did my dyslexia absolve into thin air? No. Being disabled does not admit me, nor anyone else for that matter, into the disabled world with a "*free pass from suffering*" as if we are all in a club. Having a diagnosis helps to identify why I may not be able to do things in the way others may perceive as "normal." But, it is the label of being "normal" that is detrimental to achieving success. It represents why our society has a stilted perspective towards those who wear glasses, use walking aides, or need assistance to get

something from a grocery store shelf. Additionally, implying that any one way of completing a task is “normal” is wrong and further accents those differences, which are just that . . . differences.

One component of this course was a Panel Discussion with those living in the TAB (temporarily-abled bodied) community. Approaching this event, I was possibly more nervous to ask questions than for the four members having to answer questions. The paradox of wanting to gain more understanding from those most qualified individuals who live with these struggles everyday and intellectually knowing that respect needed to come first was immense. Oddly, once the panel opened up, asking questions was not hard. Within the first ten minutes my fears subsided; the entire experience was like speaking to old friends, only I had just met them. These individuals were, yes, dealing with impairments, but were just as relatable to me as I was to them. And, to my surprise, they were inquisitive and curious towards each other as well. This reinforced that fact that when information is lacking our society we still rely on stereotypes about topics we are not educated on; those who are disabled are not excluded from this category. It lit a fire in me to look not only at the misconceptions of how disabilities are represented in our society but also to question why my own shortcomings cause me so much anguish. I did not choose to any of my disabilities, nor do I think anyone else does. So why is there so much shame?

In the months that followed after the Panel Discussion, my interest in exploring the current research and initiatives that indicate movement towards a more supportive society increased. What I found was not only a lack of information but a very stilted perspective on how individuals needing assistance were expected to participate in society. When looking worldwide at disabilities, the only way to get information is through the United States websites. When trying to find out how many disabilities affect Americans, it makes sense that the U.S. would have that information. But, when it came to finding out about disabilities in Haiti or Dominican Republic, it is the U.S. that published this information.

Western society pushes us to be the best in medicine, technology, education, politics, athletics—everything. The misconception that, upon diagnosis of a disability, that a cure—whether it be drug therapy or surgery, will eliminate the problem or “disability” is wrong. It fosters a false sense of pride and security; and monopolizes an entire group of people because they are afraid of not being able to fit in. This is definitely true for me and more so since I have tried to take ownership of the label of being “disabled.”

The medical community, for example, pushes a prescription that works for one individual, markets it to “fix” everyone with that same problem. For those that are not helped or experience side effects are tagged with being difficult or non-compliant. The need for “fixing” only gives the power to those who are prescribing the treatment. It leads those to believe problems, whether big or small, can be solved. Despite the fact that individual choices are meant to empower a patient to take control of their situation, this is not universally achieved. You followed the rules and did what was expected of you and you are still in need. Still suffering. Still frustrated. Still in pain. You may still need help, but you try to convince yourself that nothing is wrong because you do not want to burden others more. You convince yourself that you are just not good enough to have the “Happily Ever After,” that you grew up watching in fantasy and animated movies.

The Disability Movement is one that needs to expand and students in college communities can have a massive impact on how future political and social changes are achieved. Segregating those who are different only increases the problem in our country of creating a nurturing and successful society. The more information that is put out into our daily lives’ the more success for everyone can be possible. Do I wish I had never experienced trauma? Yes. Do I wish that my body worked efficiently? Yes. Do I wish that I could read a paragraph once and understand it? Yes. Do I wish that I could chew and swallow without pain? Yes. Do I wish I could sleep without nightmares? Yes. Could these aspects of my life still change in the future? Yes, of course. The human condition is always changing. It

is frustrating, trying to keep up with developments because as soon as a book is published, a case study is completed, or piece of technology marketed; they become obsolete. Do I have all of the answers? No, I am not even close. I still hide. Cover my face and keep ear buds playing music to drown the outside world that surrounds me. This is my current method to cope. Do I want to live the rest of my life afraid, embarrassed, and exhausted? No. Is it perfect? No. But there is no such thing as perfection.

Returning to the Panel Discussion the following semester, I intended only to listen and gain more insight; however, I actually spoke as a panel member. Despite being nervous and scared, having an arena to express my experiences enabled a type of relief that I had not expected. Having a young group of college students listening to first hand accounts of what society is like for those who do not perfectly fit in the world is invaluable. It is an experience I wish I had when I first began college. Showing that I have disabilities, but still have goals, still participate in my community, still help others, and still live my life day to day proves that being "disabled" is not an invitation for others to dismiss me. It is not an opportunity to push me aside because I take up more time or energy from support services. I hope that by showing the similarities between those who share homes, streets, stores, and businesses, regardless of physical, developmental or psychological abilities helps to decrease the stereotypes of being incompetent. I seek answers and still to this day, in embarrassment, seek approval from others.

For me, finding my "authentic voice" began with this course and, of course I wanted immediate results. This is what I have been conditioned to expect. If I study, then I will get an A. If I take this pill, I will not be in pain. I believed that learning about disabilities from an academic perspective would help me gain understanding, accept and move on from the need to please and succeed. Nothing could be farther from the truth; I still struggle everyday.

But, with each study I read, each panel I attend or participate in, the closer I (and millions of others like me) am to achieving a sense of success and developing my own "authentic voice." Until those

with disabilities are able to stand up and speak freely, labels will continue to take precedence over our true identities. Not being good enough is inadvertently projected. The expected standards are represented in our everyday lives; in magazines, in television, in the media; it is unavoidable. When we see these things from an early age, we grow up with reinforced beliefs of inadequacies. Although I may not be able to change the healthcare system or housing and building codes by writing this, I do know that it is helping to open the minds of those who need our help the most . . . each other.

Surprised by Disability

Emily K. Michael

Today I am meeting Diana, one of my young blind students, for coffee. Soon she will enroll in our summer program that teaches blind teenagers independent living skills and self-advocacy. Her teachers explain that she has prepared questions for me.

"So," Diana begins, as we follow the uneven sidewalk toward the restaurant. "What would you do if you wanted to go outside without your sunglasses?"

I can guess why she poses this question, but I conceal my theory for now. Instead, I smile and adjust the large, dark sunglasses that fit over my regular glasses. "Why would I want to do that?"

"I don't know . . . Just say, you wanted to," she finishes diffidently. She walks slightly in front of me, the familiar sound of her white cane scraping and tapping against the bricks laid in the sidewalk. I rarely travel with other blind people, so the sound of her cane comforts me.

"I'm so sensitive to light that I'd be miserable without my shades," I explain. I'm careful with my tone here. Like me, Diana is unable to read facial expressions—she listens attentively to vocal cues. She is a smart 13-year-old, and she will notice if I start to sound preachy.

"Okay, so what if you wanted to go out without your cane?"

I'm ready for this one: "Diana, my cane keeps me safe. I'm happy to have it with me." The cane alerts me to vital environmental changes, like the textural difference between sidewalks and streets. Unexpected curbs, sudden stairs, perilous signposts, and wayward children become apparent to me through the white cane. It is as if the cane helps sketch the boundaries around me; its contact with objects creates a vivid spatial awareness.

I sense that my responses fill Diana with a mixture of defeat and frustration. I have not validated her reticence to use the shades or cane. Nor have I handed her a rhetorical placebo, a catchy phrase she can pull out whenever she feels uncomfortable with her disability. Resisting her white cane and dark glasses, she loathes the idea of looking different. Though neither of us can see others staring, we feel the judgment and pity—and the occasional sense of wonder from those for whom we're still a novelty, the ones who want to point and exclaim, "Look Ma, a real blind girl!"

Both Diana and I carry emblems of blindness that are easily recognized from a distance—visible signs of disability. Other disabled people can "pass" as nondisabled. If they don't use wheelchairs, crutches, canes, dogs, or braces, no one will know that they have disabilities. Hence, the disabilities that don't require visible accessories are called "invisible disabilities"—a term that strengthens the connection between disability and appearance.

Diana doesn't want to "look" blind. She wants me to give her an out, to divulge the strategies I've devised for leaving the house without my cane and shades. Underneath her casual questions lies the prevailing obsession, "What's the secret to looking normal?" As a successful blind woman, I must have it figured out. The secret, Diana, is easy to articulate and difficult to enforce. I can write it more readily than I can live it.

The secret begins with a very broad spectrum of acceptance. First, I must accept myself as a blind woman who needs a cane and dark glasses to travel in safety and confidence. Then I must accept that these mobility aids are uncommon and highly

visible—which means that, almost every time I go out, people will approach me. And lastly, I must accept that the attitudes of others do not determine who I am, that their idea of blindness does not define my experience of it.

The white cane was not always easy for me to carry. Though I have been legally blind from birth, I did not use the white cane in my daily life until high school. Before my freshman year, I could pass as nondisabled. At high school, I found myself on a large, crowded campus with only six minutes to travel to and from classes. The cane supplemented my limited visual fields, letting me know about approaching stairs, curbs, potted plants, and people. In a blink, I was visibly disabled, consistently referred to as "blind" or "legally blind" instead of the mild and familiar "visually impaired." With the cane, this new "blindness" brought me braille and the dark glasses. As I picked up the cane, put on the shades, and placed braille labels on all my textbooks, I began to learn that everyone saw my blindness differently.

When I became visibly blind, strangers started to approach me with more regularity. I received unsolicited comments that revealed the discrepancy between who I was and who everyone thought I should be. Unable to mask their disbelief, people said, "You don't look blind!" or "If you hadn't used the cane, I'd never have known you were blind." I wondered what it meant to "look blind"—did they expect me to stumble, to spill food or drinks all over myself, to grope for the objects around me? Absolutely they did. Some exclaimed, "Wow, you dress so well for a blind person!" while others consoled, "Don't worry, I run into walls all the time too!" (For the record, I rarely run into walls. That's what the cane is for.)

To outsiders observing the blind experience, blindness is signified by shuffling feet, stained clothing, wild hair, and a general lack of confidence. A blind woman should look lost, frail, and naive. No wonder Diana and my other students are afraid to look blind; they know the stereotypes and dread fulfilling them.

The prevailing attitude is that blindness, and any other physical (visible) disability, indicates an

eternal deficit—a life clouded by insurmountable tragedy in which the disabled person can never accomplish her goals and ambitions. It's not difficult to imagine the heart-wrenching scenes created by sympathetic ableism: the wheelchair user who dreams of being a ballerina, the blind man who wants to be a neurosurgeon, the deaf person who longs to hear music. Often, popular ideas about disability create images of disabled people whose genetic lottery pits them against impossible desires. And the righteous sympathy that nondisabled people are supposed to feel for these tortured "innocents with disabilities" emerges when real nondisabled people encounter real disabled people.

Called slippage, this attitude insists that the disabled person should be inept at all tasks. Slippage is the idea that an impairment in one area, such as blindness, causes all other abilities to deteriorate. Perhaps this is why some people choose to speak to me in loud voices, slowing their words, while others seem amazed when I move without encumbrance. Because I carry the cane, the performance of routine tasks—swiping my debit card at the grocery store, tying a scarf around my neck, or walking down a hallway—wins me the most effusive praise. This problematic attitude moves indiscriminately among disabled and nondisabled people. Even disabled people can believe in their own incompetence.

My experience with blind teenagers shows me how easily they internalize the cultural attitudes about disability. On the first day of our summer program for blind teens, I stood in front of the class and introduced myself. I said that my name was Miss Emily, that I had my Master's in English, and that I enjoyed singing and cooking. I added, "I'm also blind. I have some vision, but I use a cane." On nearly every day of the six-week program, I walked to students' desks, using my cane, and sat down, folding the cane. Every blind person recognizes the familiar clicks of a cane folding or unfolding and the subtle pull of the bungee cord as the user slips the loop over the folded segments. So, imagine my surprise, when in the following weeks, my students exclaimed, "Hey, you use a cane?!"

Their disbelief communicated many things to me. They couldn't believe I was blind; they were

surprised by my disability. I wanted to know what they expected from a blind person and what made me so unexpected. Did they expect never to find a blind woman in the teacher's role, speaking authoritatively? Did they never expect a blind person to sound confident, to reprimand their bad posture, to know when they were working or slacking off—as I did?

Like my students, Diana acknowledges that the label of blindness conveys a more-than-visual deficit. Many have accepted the message broadcast by the sighted world: impaired vision means impaired judgment. My students are in the process of learning the power they can exert over their own labels. I want Diana to understand this power: the white cane does not represent one idea of blindness—it signifies all ideas of blindness. Diana has the unique power to embody blindness for others, and she can decide what kind of blindness it will be. I want her to know that she can use her cane and shades in innumerable ways—as implements of independence, as shortcuts to the assistance she needs. I decide to tell her the following story.

On Friday afternoon, the tutoring center is noisy and crowded. Since our official tutoring hours have finished, the peer tutors gather for our monthly training, queuing by the sign-in computer. I thread through the lobby, my white cane catching between the thin chair and table legs, and walk toward the computer. I'll ask for help signing in as I do every time I clock on and off; unlike my personal computer, the sign-in computer isn't equipped with assistive technology. I stand near the computer, waiting as the tutors in line ahead of me sign in. I begin listening for familiar voices.

"Hey, do you need some help signing in?"

The voice belongs to a dark looming shape that has just appeared on my right. I look up to see a broad-shouldered guy in a dark shirt. His facial hair, contrasting with his skin, makes it easier for me to find his face. The friendly voice and the eagerness to assist make him familiar to me. "Hi, Patrick! Sure, could you type in my ID?"

He obliges, holding my cane and purse while I enter my password. He walks with me into the meeting room, where he helps me find a seat among

the indistinguishable tables and chairs. Unable to identify colors by sight, I can only attest that the low-contrast hues of tables, chairs, and carpet make the room a challenging place to navigate. After helping me find a seat, Patrick retreats to his customary place at the front of the room, where he interprets for our deaf tutors. When I stand up to avail myself of the refreshments, Patrick meets me at the snack table. "What would you like?" he asks, offering me a plate. He narrates the contents of the refreshment table and puts the requested items on my plate. Again, I haven't asked for his help, but I appreciate it.

As he leaves, I marvel at two things: how quickly he spotted me and how readily he assisted me. Technically, Patrick isn't at the meeting for me—and that makes his attentions seem especially considerate. Unable to ignore the graceful and unexpected help he gave, I begin to analyze the circumstances that brought Patrick to my aid.

I reason that Patrick must have seen me come in. Among the tutors, I am the only one using a white cane and wearing dark glasses. Because of my extreme sensitivity to light, I am also wearing a gray cloche hat with a bow. Add that to my dark purple coat, and I suppose I become pretty visible. So, Patrick spotted me readily, and, because of our long acquaintance or his own personal merits, he came over to see if I needed help.

Patrick doesn't see the cane and dark glasses as signifiers of eternal deficit. His offers of assistance are kind, even-keeled, and respectful. He doesn't patronize, snatch items out of my hands, or insist on helping after I've refused assistance. He respects my agency, my ability to know what I want and need. In essence, Patrick lets me define myself. Perhaps because of his work with disabled people, Patrick has come to understand the absurdity of the stereotypes. Patrick responds to the needs I voice, rather than the issues he perceives. Through these interactions, I remember that I experience disability on my own terms.

To navigate the language of disability, a disabled person must develop a resilience to the commonplace reading of the terms. Instead, she must advocate for the signification she desires. Accepting the

labels of disability and blindness signifies my commitment to expanding the space around such labels.

Let Me Pay Taxes!

Alessia Minicozzi

The first memory I have of knowing that I was *different* was when I was five years old and a caseworker entered my house to verify that I *existed*.

At the age of one and a half, I was diagnosed with a chronic disease called Spinal Muscular Atrophy, Type II (SMA). This left me in need of constant care and, at times, hospitalizations. My whole life, I've been confined to a wheelchair, and the disease has always affected me profoundly, on a physical and mental level. I have limited range of motion and strength in my arms, muscle weakness affects my speech and breathing, and, like a monkey on my back, SMA has been a constant reminder of my fragility and mortality.

In order to comply with Pennsylvania's disability requirements, a state-appointed caseworker had to make regular home visits to make sure my needs were being met under my parents' care and that my parents were not lying about my medical needs. These visits would leave me confused and annoyed. I still remember the events that took place the first time a caseworker entered my house and the emotional impact it had on me.

The time read 8:09 a.m. on my white clock radio. I wore my favorite pink satin nightgown. My mother came to lift me out of bed and enclose me in my robe. She whispered in my ear that a gentleman was here to meet me—he'd arrived early—and he wanted to ask me some questions. As my mother carried me down the flight of stairs and sat me in my wheelchair, I felt the man's eyes on our every move. This strange man sat with a scrutinizing look and asked me if I live in this house and do I normally wake up so late? I quickly turned to my

mother and gave her a perplexed stare. Why was this person here at all, and what right did he have to inquire about me like this?

Later, my mother would explain that the man was there to make sure that she was not lying when she asked the government for money to care for me. I endured countless visits from that caseworker over many years. Finally, I asked my mother, "When is this man going to stop visiting me and asking me the same questions?" She looked at me and tenderly replied that when my father finished his residency program, then we would have enough money to pay for all my care. I accepted this response and continued playing with my Barbie. Two years later, my father completed his residency program and the visits from the caseworker stopped.

In eighth grade, I left an all disabled school and enrolled in a mainstream public school, which seemed odd to me. I asked my parents why the change in schools? My parents explained that they will not live forever and in order for me to live outside an institution, I will need a salary that is above average to pay for personal care. They went on to explain that the only way to accomplish this goal is to succeed in school and to perform better than everyone else. They informed me that because I use a wheelchair, prospective employers will view me as daunting and they may be less likely to hire me. They stressed that the only way to stand out above other non-disabled candidates is to excel in an academic environment. Mom and Dad have always ended the conversation by reassuring me that as long as they are alive, they will make sure I accomplish everything I set out to achieve and that I never feel alone.

Since that conversation over twenty years ago, I had only one goal in mind: employment. The possibility of being institutionalized has always been my motivation for persevering through late nights of writing papers and studying for exams. As promised, my parents were the ones who proofread my papers and stayed up with me in order to help me to bed once I was done. When I graduated from the University of Pennsylvania, as I was heading towards the dais to receive my diploma, my mother ran towards me before I reached the stage to give

me an unprecedented hug. She does not normally display such emotion in public, and much less in front of such a large crowd of people. I honestly felt that my degree was a group effort.

A consistent jest in my family is the way I was taught about the human reproductive system. My father owned a coloring book on human anatomy where he and I would color together at night. When I started asking questions about how babies are born, my parents retrieved the book and began explaining the reproductive process in great scientific detail. This introduction to the function of body was the beginning of my life-long fascination with the field of medicine. Originally, I wanted to attend medical school, but due to the arduous physical requirements necessary to be the sort of doctor I envisioned, I decided to study a theoretical approach to medicine. I thought that by choosing a career that was less physically demanding, my professional journey would be smoother. My assumption was misguided by a colored, romantic notion of medicine where physicians are trained to care and protect patients, plain and simple.

What I failed to realize was that because physicians tend to see disabled persons only in a patient role, rather than recognizing the multiple facets of a human being, which includes the professional aspect, it is challenging for them to alter their perspective. Once I completed my undergraduate degree, I went on to earn a master's degree in bioethics with the hope of becoming a clinical ethicist. During my two years in my master's program, I worked at the hospital where I was also a patient, serving on their ethics committee as the only formally trained ethicist. Again, I thought this appointment a great accomplishment and expected my colleagues to value me and my perspective. This did not turn out to be the case.

Some of the committee members were uncomfortable having a patient as a member, despite my status as an ethicist, stating that I did not have the requisite formal clinical training. It was true that I did not have extensive clinical training (I was not a physician or nurse), but my master's program allowed me to do rotations and gain some clinical experience. The truth was they were just

uncomfortable relating to me as an ethicist and appreciating my expertise in the field because they could not look past my disease and my affiliation with the hospital as a patient. Since my parents always encouraged me to be forthright (while maintaining decorum, of course), I simply pointed out that they might question my lack of clinical experience, yet one could also point out their lack of formal ethical training.

I continued to tirelessly prepare myself for the future, when I would need to fully support myself. I completed my master's in bioethics and obtained a doctorate in sociology, both from the University of Pennsylvania. Once I received my Ph.D., I opened a consulting firm where I managed and operated the company for five years. My hope was to set my own hours, be financially independent, and avoid the prejudice of employers. Unfortunately, that dream was thwarted. With the economic downturn and widespread unemployment across the country, I was forced to close my firm. During that time, my parents faced several health issues that left my father unable to continue to practice medicine. I could no longer depend on him financially. I knew I had to quickly secure outside employment.

The day after I signed papers to close my company, I began contacting colleagues and mentors from Penn and various other prestigious institutions. I explained my circumstances and asked for assistance and guidance. Some were extremely receptive, and I was encouraged by the support and kindness I received, even from peers I'd never actually met in person. Regardless of the country's soaring unemployment rate, I was optimistic that I was going to be hired.

However, for the last two and a half years, none of the many recommendations from highly esteemed and influential colleagues, none of the hard-earned interviews, none of my tireless networking has paid off, and I remain unemployed. My most recent interview was for an academic advising position in a nursing department assisting Master of Science in Nursing (MSN) and Ph.D. students. The job description clearly stated that no nursing degree was required, but a doctorate was a plus. The morning of the interview, I woke up excited and ready for any

question they might fire at me. I left early to relax before the meeting and enjoy a cup of coffee. At the cafe, I ran into my mother's cardiologist, who has been one of the supportive colleagues helping me in my job search. I thought this must be a positive sign and the interview would go well. I arrived ten minutes early and waited in the conference room for the human resources person and hiring manager. Once they took their seats, a strange silence filled the room. It seemed they had nothing to say, nothing to ask me. Maybe this was just a courtesy interview. Even as they started to review my resume in front of me, and I saw them realize that I had the credentials to do the job, they asked me only innocuous questions and listened half-heartedly to my answers. I later found out that a colleague of mine had put in a call to procure that interview for me. The nursing department was doing my colleague a favor, but they had no intention of hiring me. This insincere effort on the part of an employer was one in a long line of disappointing job search experiences.

Sadly, I have come to fear that despite all my accomplishments and education, I still might live in an institution. In the United States, if I am forced to receive disability funding, I will again have to endure degrading visits from the caseworker and I will have failed to live the life I choose. Our country goes to great lengths to acknowledge and make accommodations for persons with disabilities, such as the passing of the 1990 Americans with Disabilities Act. However, there is a clear distinction between including persons with disabilities in theory and taking the leap of faith by hiring a person with a disability. The field of bioethics has so many professional organizations where they demand equality and ethical behavior from our healthcare providers. Why then don't we apply the same standards to hiring decisions on who enters the field? Why do we apathetically accept the tremendous number of unemployed disabled people in our society? The hypocritical way we, as Americans, treat persons with disabilities is oppressive and insulting. There are countless disabled professionals that would make excellent employees, who have tremendous intellectual capacity and eagerness to contribute to society in a meaningful way. Many politicians urge

Congress not to cut budgets for the disabled and the elderly, but how many of these disabled individuals would rather earn their own money and gain a sense of pride by not relying solely on government assistance to live? Ideologically, by continuing to treat disabled persons as victims, and reinforcing the notion that disabled people are a financial strain on society, employers feel no inclination or responsibility to hire them.

Currently, my younger sister is financially supporting me while my parents are still physically caring for me. The constant threat of institutionalization looms over me on daily basis. As a child, I did not believe that charting a successful and rewarding career path would be an unattainable goal. All my colleagues are gainfully employed and get to enjoy seeing their careers develop as the result of hard work. I worked just as hard, if not harder, than my peers and colleagues in school and at my various positions in the past. Why the disparity? What am I suppose to say when an aspiring disabled colleague asks me about my career path and employment opinions? I will never take away a dream and hope from someone younger who might face different circumstances than I. But the truth is that I fear employers don't view me or, dare I say, disabled job applicants in general, as viable professionals. I'm eager to change their perceptions, to be treated as all other professional adults are, and to pay *into* the system rather than relying on it to support me.

Every child and young adult, regardless of their physical limitations, should feel that the whole world is available to them and the possibilities are endless. My parents instilled this in me early on, and I'd like to be able to spread this ideal to other young people with disabilities. At times, I still feel a glimmer of excitement when I read a job description and start to imagine myself as a contributing member of my chosen profession. My greatest hope still is that when the time comes for my parents to leave me, I will be in a career I love and able to support myself.

A Medical Mishap

Angela Moore

In western society we live in an environment where image is valued and sought after. Acquiring Spastic Cerebral Palsy through no fault of one's own directly challenges and contradicts this. We tend to base our judgments of other people on the way they "look" before we even speak to them or get to know them. For many centuries western society has valued and aspired to having the "perfect" image and body shape. The children's nursery rhyme "Humpty Dumpty" illustrates that as far back as the 1600's when something was broken people felt there was a "need" to correct the damage and fix the problem. Maybe "Humpty Dumpty" was an obese person who fell off the wall, maybe he was an intoxicated soldier, maybe it was a name of a large cannon that was sitting on the wall of Colchester (Wright, 2008) which was set up to protect the city. No matter what the situation, the reader is left with a feeling that whenever there was something wrong with Humpty Dumpty, there was a need to correct the error and fix what was broken. Because he was "different" or "not normal" in one way or another he was not valued for his role by members of his local community. The reader is left to form his or her own opinion. Society continues to hold those views to this very day.

I am a secondary emergency teacher, have completed a Masters in Special Needs along with having a permanent acquired physical disability, Spastic Cerebral Palsy, affecting my four limbs. This was caused after an initial medical examination was "botched" by an unsupervised intern—the specialist left the theatre during the procedure when I was 14 weeks of age, over forty years ago. Further medical testing was arranged because there was a belief that I may have had hydrocephalus—swelling and excess fluid buildup around my brain causing it to be unnecessarily enlarge for my age. In my family's case this seems to be an hereditary trait that has passed from my father who has a large head. It's interesting to note that an obstetrician made a comment to my sister on the size of her toddler's head.

Since 1970 I have had a range of both positive and negative medical experiences. As a child who wasn't able to comprehend what and why things were happening I was very frightened and often very upset. As an adult I am able to understand what and why something is going on and I ask questions when needed.

"Normal" has always been completing the same things but in a different way to other people while intending to reach the same outcome of "success." There are many ways to skin a cat and "normal" is a term that has a very broad definition which is dependent upon the individual and the situation at hand. What is "normal" for me will be "different" for someone else. What is "normal" for another person will be "different" for me. It's the differences between individuals that we come to value later on in life. That I cope in a different manner from others has clearly been aided by being able to make use of information technology—laptop, mobile phones, printers, etc.—along with a feeling that the acquired physical disability that I have is a small part of the overall person that I am. Before I became a person with an acquired disability I was a normal, happy, healthy baby and even now although I will always have a disability I have excellent health and choose not to be defined by having acquired a disability. Unlike some other people I consider myself to be a person who "acquired" a disability instead of being a "disabled" person. Having an acquired physical disability is a small part of the person I am. The manner in which I acquired a severe physical disability is what I have come to value along with the fact that I have done well in many areas of life while having such a severe condition.

Unlike people who had disabilities in the 19th Century who were not given such an opportunity, I have the opportunity to participate freely in society. Traditionally people who had disabilities in Europe during early 20th century (1930's) Germany were considered along with those who were Jews, gypsies or homosexuals to be "pseudo humans" (Roberston, 2006) who were considered to be the "deserving poor" who were "appropriate objects for pity, protection and charity" (Williams, 1992) who were deliberately excluded. They were seen as "victims"

who were different and were segregated from their local communities because the view was held that they had nothing to offer and were feared as they were often controlled by copious amounts of medication. The Medical Model of Disability, which operated until the mid 1970's in Australia maintained the view that people who had a disability needed to be "cured and cared for" (ETTAD, n.d.), which automatically disempowered and disengaged them within their own communities. The Medical Model of Disability defined an individual by his or her disability and sought to control the person's access to medical care, education, employment, housing and leisure. At no stage did this Model of Disability provide families with any notion of "hope" for their member who had the disability and usually painted a very black and bleak picture for their future outlook. Medicine still doesn't offer a lot of hope for people with conditions as serious as Spastic Cerebral Palsy. Traditionally on medical advice individuals with severe physical disabilities were admitted to fully serviced institutions where all of their physical needs were met within the one facility away from their families and the general community, which reinforced the "stigma" of fear and difference. Once admitted to such institutions it was uncommon for people to leave them. It wasn't until after the days of deinstitutionalisation that people with disabilities formed self help groups, started to seek and exercise their rights to equal opportunities and commenced making a contribution to the local communities in which they lived. In Australia, this took place during the late 1960's and 1970's and was supported through the choice that my parents and others in similar situations made when they chose to keep their disabled children within the family unit even though they were advised to "leave the baby" in a hospital as it would be likely to die a natural death sooner rather than later.

As a small child I can clearly recall not a lot of "hope" offered from medical professionals for my own lifelong outcomes and now it's interesting to think that no one has ever really taken a look back to see what I have accomplished. From a medical point of view as a young child I am able to recall there were many appointments, a few operations

and very intense physiotherapy performed by my mother up until the time of puberty when my family was told that there was not a lot more that could be done to improve my situation. At one stage later on I did make inquiries into having my hands straightened but didn't follow it through when I was told they "would look better but wouldn't function any better." There was not much point in going through major surgery for little or no improvement. Apart from that I have never been the type of person who has sought to "doctor shop" to try and find a way of improving my physical being.

Nine months ago after walking in off the street for a mammogram one afternoon it was found that I had early stage breast cancer. As a result of this diagnosis I had a mastectomy and am about to complete my 6th and final round of optional chemotherapy as a preventative measure. I had all the necessary tests completed which included a cat scan which came back clear, a bone scan which was clear, my heart checked, many blood tests, a port put in my arm to prevent my veins from deteriorating under a local anesthetic in addition to any other necessary treatment. Radiation therapy was very quickly ruled out as an option because I am unable to raise my left arm above my head. This rather suited me because I would not be at all comfortable being on a bed that needed to move in and out of the radiotherapy machine. Having these tests completed reinforced to me that the disability I acquired was exactly that—*acquired*—through an unnecessary chain of events. My health has been excellent for over forty years and having Spastic Cerebral Palsy hasn't affected it. With no history of cancer in my family it has been like dealing with the great "unknown" on so many levels but as an adult I am determined to exhaust all of my options in order to overcome this.

At the time when the initial diagnosis was made I was extremely concerned about the effect surgery and treatment would have on my disability. Fortunately I needn't have worried because there has been no effect at all. In addition the surgery took place on the same date 42 years later. The surgery went well and I was discharged within two days of the procedure and made a good recovery before starting chemotherapy. I did smile when both the

surgeon and anaesthetist were quick to inform me separately that "... there was a product available now called Botox ..." that may get my left arm to be able to form a fist. Quietly and confidently I reminded them both that I was there to be treated for breast cancer and although I appreciated their thoughts I had accepted my disability many years ago. The surgeon the following day commented on my "constructiveness." I smiled and thought why fix what isn't broken. It would have been different if I had gone seeking treatment to fix the disability.

While I was extremely shocked at being diagnosed with a serious health condition at a young age I feel very fortunate that this was able to be picked up and treated quickly. While what has taken place in one sense seems extreme, as a preventative measure I feel it was the way to go. In a country like Australia I had gone from being outside the health system to front and centre within eight days. In some other parts of the world such diagnostic testing is simply not available let alone treatable. One would simply die and the cause would not become known until an autopsy was completed.

There were many falls, many tears and major fears as a young child. However, as an adult, while there are still some occasional falls I consider myself to be in a good position because I understand what event took place on a particular date and the reason why it happened. Presently having no hair my scalp bears testament to the number and severity of falls that I had as a child by the scarring that is clearly visible. I know where the incident happened and understand that no one in their right mind would wish to inflict this type of disability onto a small and innocent baby. While it's visual and one can clearly see that there is a problem I consider it to be but a small part of the overall person that I am and how I perceive it determines how other people in turn perceive it to be.

Over forty years I really haven't had a lot to do with the health care system as a result of acquiring Spastic Cerebral Palsy because I chose to accept it and not fight it. I haven't sought to be cured or fixed. I am still a daughter, sister, aunt, sister-in-law, teacher, cousin, niece, friend and neighbour regardless of what state of health my body is in.

As long as I am relatively healthy I will always be happy and contented with life.

References

- ETTAD. (n.d). *Models of Disability*. Retrieved from <http://uk.ettad.eu/understanding-disability/models-of-disability>
- Robertson, G. (2006). *Crimes against humanity: The struggle for global justice* (3rd ed.). Camberwell, Australia: Penguin Books.
- Williams, C. (1992). *Beyond industrial sociology: The work of men and women* (p. 110). Sydney, Australia: Allen & Unwin.
- Wright, J. (2008, July 15). Humpty Dumpty: The Origin of This Nursery Rhyme. Retrieved from <http://voices.yahoo.com/humpty-dumpty-origin-nursery-rhyme-1631589.html>

Living with Blindness and Fibromyalgia while Occupying Aging

Katherine Schneider

I'm blind from birth and in middle age developed fibromyalgia. I've retired from a thirty year career as a clinical psychologist and am working on my third book tentatively titled "Occupying Aging: Delights, Disabilities and Daily Life." My relationship with medical professionals includes gratitude (without good care I would not be alive) and also frustration for assumptions often made about my abilities. I write from the perspectives of an impatient patient, woman living in the United States, former provider of mental health services, person with both invisible and visible disabilities, and boomer moving into the world of the aged. My stories are mine of course, but when I swap medical stories with blind friends, similar happenings abound.

When my mom fell down the stairs at a friend's house, five months pregnant with me, she was told to go to bed for the next four months to save the pregnancy. Thus began the impact of health care

professionals on me. I was born a month premature and spent my first month in an incubator. In 1949 it wasn't known that the enriched oxygen atmosphere in an incubator would cause blindness. At least one lawsuit was filed against physicians and a hospital by a person blinded in this way. A large out-of-court settlement was received. The way I look at it, the health care community did the best they knew and without enough oxygen, I would have died.

Early in my life, my parents took me to several ophthalmologists to see what could be done for my vision. Family folklore has it that I could smell a hospital as we entered and would begin howling. These early traumatic experiences may have led to my current healthy lifestyle so I don't have to go to doctors much now. By about age five, it was clear that nothing could be done about my vision. For the next twenty years my forays into the health care system were for tonsillitis, sprains, and the usual childhood ills.

In my early twenties, I developed acute glaucoma in one eye—caused, I'm convinced, by birth control pills. In seeking treatment for this condition, I encountered the first truly insensitive physician I'd met, who said, "Your eyes aren't doing you any good; let's take them out." I was horrified! They were my eyes. I was attached to them, psychologically as well as physically. It turned out that a simple operation relieved the pressure and allowed me to keep my eyes. True, they are not the best looking big brown eyes around, but they did come with the package.

Life with blindness seemed quite straightforward until my early forties, when I developed extreme fatigue and pain all over. I was worried. I knew a blind woman who had developed multiple sclerosis and I admired her, but I did not want to walk in her brave footsteps. Then a college student came to see me with the same symptoms and said that she had recently been diagnosed with fibromyalgia. I am often very empathetic with people's concerns, but this time she complimented me by saying, "You're great! You seem to know just how I feel." I sagely counseled her about portioning out her energy carefully, prioritizing, using short cuts, and taking elevators when possible. Being an adult

student used to overachieving, she did not like what I was saying, but said she'd try to follow my advice because she could no longer do it all.

What finally broke through my own denial was the day coiling up a hose and dragging it to the basement for the winter took me an hour. It left me totally exhausted and I figured that even being middle aged couldn't account for feeling that awful.

After a thorough physical and plenty of blood work to rule out Lyme disease and multiple sclerosis, I was diagnosed with fibromyalgia and placed on low doses of antidepressants to help me sleep through the night. The medication worked and I began to feel like myself again. My battle to accept that I had another disability in addition to blindness began.

The first issue I had to deal with was fairness. Wasn't one disability my fair share? Why two? I had comebacks ready for comments like, "This will make you a better person." If that was true, I'd be better already! "God will walk beside you in this." What about when I'm too tired to walk? "You will learn from this." Can't I learn some other way?

The second issue was a practical one. One of the ways I'd always coped with the limits of blindness was to overachieve. For example, if most people read twenty books a year, I'd read twenty books a week. I was worried I would no longer have the energy to do this. I thought I had overcome the need to overachieve in order to prove myself, but fibromyalgia was going to test that assumption.

I also began to personally discover the disadvantages of an invisible disability. If people can't see it, they often assume that you're crazy, lazy, or whining for sympathy. After hearing, "Well, I get tired too," and "That's not really a disability, is it?" I began to be very selective about the people I told.

I also began to deal with fibromyalgia the academic way: by becoming an expert on it. I joined the Fibromyalgia Association, participated in the internet discussion group about it, went to a local support group, and organized an on-campus support group in addition to reading everything I could about it. I learned that fibromyalgia is a chronic condition caused by lack of stage IV sleep, manifesting itself in symptoms like pain and fatigue. Fibromyalgia often

runs in families and can sometimes be triggered by injury, illness, or extremely stressful situations. Treatments include medication, exercise, and stress management. Most people feel much better if they can re-establish deep sleep. Remissions and relapses occur for unknown reasons.

Armed with these bits of information, I began working out my own treatment plan. During summer vacations when I can nap and exercise at will, I rarely take medication. During the school year, I end up taking medicine about half the time and somewhat limiting my schedule. I fade fast after dinner, so I try to avoid giving presentations in the dorms late at night. Most students may be awake then, but at that hour, I'm about as exciting as a piece of furniture. There are still times when I do not do well at conserving my energy and I'm too tired even to brush my teeth before going to bed, let alone floss.

So what can well-intentioned friends of someone with an invisible disability do? First of all, believe them. They know what they are experiencing and what they should and should not be doing. Second, honest offers of help are welcome, even if not always accepted. A friend once asked, "How about if I come over and help you clean the fridge?" We had a nice visit and I got something done that I did not have the energy to do. Then we had a few good laughs about the green refrigerator objects we found.

What can those of us with invisible disabilities do? We can be honest about our limitations even if saying "no" is very hard sometimes. We'd better get used to the fact that explaining our limits to others and asking for help again and again will become a way of life. Although others can't read our minds, they will usually be accepting and helpful if we help them understand.

We need to accept our own feelings. Living with a disability is hard, especially when the disability is not visible. It will make you angry, sad, and frightened at times. The uncertainty factor with a disability that can change hourly adds frustration, too. Walk, swim, journal, join support groups, cry, scream! Do what it takes to get your feelings out so that you don't end up stewing over them. Prunes should be stewed; emotions shouldn't. Learn all

about your disability. Become an expert on listening to your body as well as listening to what the experts say. Even if you've been recently diagnosed, you probably have more personal experience with the illness or disability than your doctor has. While they may know what typically works, you know what is right for you.

Find the pearls in this experience of disability if and when you can. While dealing with fibromyalgia, I've found more empathy with others' suffering and gained second-hand courage watching people struggle with it and achieve great things. One member of our campus group graduated with honors. I've also developed a little more patience with myself. I'm still diving for more pearls from it, sometimes by lying flat on my back!

As I've grown older, my "only go when you have to" approach to health care included a few colonoscopies and occasional physicals before getting new Seeing Eye dogs. As I lay groggy but awake at the end of my first colonoscopy, the doc told me about possible complications requiring further attention including blood in the stool. I asked how would I know? He hemmed and hawed, so I asked (always trying to help) if it would smell different. He said it would but I probably wouldn't recognize it. Then he asked in a surprised tone: "Do you live alone?" I assured him I did except for my Seeing Eye dog. He then said: "Well you could ask a neighbor to come check your stool." Even in my groggy state I didn't think that was a good idea, so just concluded to myself "I guess I'll just die."

Then there was the recent physical where the physician's assistant was entering lots of data into the record and said after entering it: "Of course you need help dressing, bathing and cooking, right?" I was surprised enough that all I said was "no," followed by a long pause where I gathered my thoughts about how best to educate.

As a partial repayment for all the good care I have received, I'd like to offer a few suggestions to those of you working in medical settings. *Business and Social Etiquette with Disabled People* by Chalda Maloff has wonderful coverage for medical people working with each disability, so I'll confine myself to a few suggestions that would really help.

Greet me and introduce yourself when I enter your area. It makes me feel a lot more reassured to know that you are Nancy, a med tech who is going to draw blood, rather than just some wandering vampire. Saying "hi" when you're entering my room in a hospital or if I approach your reception desk alerts me to the fact that someone is there. You know you're there, but I don't . . . unless you had a lot of garlic for lunch!

Read me instructions. If they're at all complicated, give me a Braille or tape-recorded copy to take home, because I may not have someone at home to read printed instructions to me. Please give me instructions I can follow. Imagine the frustration I experience from the following directives:

"Take the pink pills twice a day and the blue ones four times a day."

"Cut small pills in half."

"Read the instructions above the toilet to prepare your urine sample."

When I arrive, have office staff offer to help me fill out patient information and consent forms in a private place, so I'm not shouting personal information in a crowded waiting room.

Remember that when I'm on your turf I'm out of my familiar territory. Something that you do five times a day is strange and scary to me. At least every few years I believe each of us should spend a day being a consumer of the type of services we provide. Sensitivity training is often given to nurses and physicians in training, but I think all of us can forget how it feels to be a patient. In my own field when I've sought counseling, I've been reminded of how much the little things mean. A friendly receptionist, help with insurance forms, asking if my panting seeing eye dog would like some water before we trot home on a hot August day: these gestures go beyond the "do no harm" of the Hippocratic Oath to make a healing interaction.

When all else fails, ask, "May I help?" If I say "Yes" follow up with "How?" Together we will figure it out.

Imaginary Interview*

Jillian Weise

Q: Are you disabled?

A: It depends. I need context.

Q: Are you rendered incapable?

A: I am awake and sober.

Q: Are you limited by parts of the body?

A: My arms are not wings.

Q: Are you entitled to certain rights?

A: Yes, I am disabled.

Q: The U.S. Government disagrees.

A: You read the letter?

Q: "Due to the subject's advanced education, the subject is no longer disabled."¹

A: It was a love letter. They could have written it better. I would've preferred something with a little more feeling, such as: "Dear Jillian: We are breaking up. We saw you outside the building with the statue of the lion. We saw you trespass through the halls and take from the shelves a number of hardbacks and take from the woman with glasses her suggestions. You have been made too erudite, too learned. If you want to protest, if you want to continue our relationship, then un-educate yourself. It would be helpful if you worked at a factory or could not find work. It would be helpful for something inside you to hurt."

Q: You seem bothered by the letter from the government.

A: No more bothered, I guess, than if the government sent a letter rescinding my name.

* I certify that this interview is true to my life experience. While the interview itself is imaginary, the questions and answers are true.

1. I received this letter in regards to Social Security Income, which I applied for while in graduate school.

Q: The name *disability* is important to you then?

A: It is important. It is very, very important. No, it is not important. I hardly think of it. It vexes me and I need it and I should not say it that often. Today, for example, I said: You must not use the word *disability* too much in this interview. After all, you do not like the word, and you have named yourself *cyborg*, so there is no reason to use the word you already rejected. After that thought came the voice of the Director, who said, "When you use the word *disability*, people think *accommodations*, people think *favours*. Best not to use it." And after that came the voice of a writing mentor: "I just don't like the word *disabled* in this piece. Is there a way to write the piece without using the word?"

Q: What is disability like?

A: It is like crowding under an umbrella, except your head sticks out, and your hair gets wet, and there are no cabs. Plus, this is somebody else's umbrella.

Q: Respond to this symbol.

A: That is where I park my car.

Q: What do you have?

A: I do not know. The doctors named the condition. They gave it a three-word, nine syllable Latin name. Now I go to other doctors and they say, "What do you have?" and I say the Latin name, and they say, "What?" and I repeat the name, and they say, "How do you spell it?" Also—and I think this is important—the prognosis for the condition reads, "No reported cases have survived past the age of two." Therefore, I am either dead with the condition. Or I am alive with a different one. Or the medical dictionary is fiction.

Q: What is the condition?

A: I am a cyborg.

Q: When did you begin calling yourself a cyborg?

A: Rephrase the question.

Q: When did you become a cyborg?

A: 2007.

Q: Where?

A: I cannot say the name of the office. The prosthetist posted a photo of me online, and in the photo I am not wearing any pants. I am wearing the cyborg leg for the first time and without any pants. I am so embarrassed. I do not want you to find the photo online. This is before we knew each other. This is before we knew what we meant to each other.

Q: I have to tell you: when I first saw you, I thought, "She looks like a woman who could be taken advantage of online."

A: Yes, that is the problem with having it physical. When it is physical, people make all kinds of assumptions. She needs help. She is lop-sided. She must be so, so sad. I thought of another definition: looked at, done to, and dissed by language. I really think, in hospitals, they should camcorder every moment from the time anesthesia knocks you out until you are awake again. Then they should give you the tape as surveillance of their behavior, and as souvenir.

Q: Explain, if you will, how you came to wear a prosthetic, and why this leg differs from others, and the ontology of the word cyborg.

A: Of course. The event. Everyone is always interested in the event. It is like a birthday party we all get to attend. The event happened when I was eleven. There was the standard preparation attendant to the event: gown, bed, alcohol, anesthesia (grape), knife, balloons. The event occurred. As far as events go, it was a breeze. I have had several events in my life, and this one does not even rank. Everyone was pleased. I forgot: Not everyone was pleased. The surgeon was crying. He wanted to save the leg. He had been working on the leg for eleven years. He was Pygmalion. He wanted to try his bone lengthening procedure on the leg. I said no. I said: Cut it out. And so. Fifteen years later, the event happened again. Same leg.

Q: The same leg can't be amputated twice.

A: Yes, I knew it would be difficult to explain. It was the same leg, the one you call *artificial* and

fake and *prosthetic*. The one I call *my leg*. I had been wearing a series of hinge-style, basic knees. I knew the mechanics of my legs. All legs fit under the umbrella of Wittgenstein's *family of resemblances*. Then, age twenty-six, I got a new leg that required an oppositional mechanics. It required electricity. It was interactive, like *beep, beep*. It had a green light and a yellow light. It came with software. I chose a name descriptive and rebellious: Cyborg. English. Two syllables.

Q: How have labels of disability affected the degree to which you feel that your authentic voice has been heard by others e.g. family, friends, health care providers?

A: "You are not." "You are, but you don't look it." "You are not enough." "I never think of you as that." "You are and you must tell us how and in what way and through a story we have heard before." "We would prefer a car accident."

Q: Respond to this symbol.

A: That is my tribe. I had to go away for a while. I wrote to them, and they wrote back: "The author does not understand the definition." I visited them, and they said, "Cyborg is a phase." I slept with one of their members and he said: "I am not official. It is only my eyeball. But I will be your Huck Finn."

Q: What do you want to say to people in the audience?

A: Hello, Bioethicists. Nice to meet you. Please may I—if it is not asking too much—have the permission to change the settings in my own leg? Just this one favor: I need someone with authority to grant me this bioethical right.

Q: That is a little confusing. Some clarity?

A: Sure. This is my leg. It is an Otto Bock C-Leg. But I bought it. So it belongs to me. I think I should have the right to change the settings in my software. For example, if I want my knee to flex slower on the step, I have to drive to the prosthetist's office, take off my pants, and hook up with his computer.

He has the special software for the leg. Since it is my leg, it is my software. Does this make sense? How can I bring you closer to me? Let's say you purchase a BMW convertible, which costs the same as an Otto Bock C-Leg. Let's say you want to put the top down. But to do that, you have to drive to the shop, talk to the mechanic, take off your pants, and then he, with his key fob, puts the top down. It is still a sunny day outside. Are you happy?