

## Seeing Through the Veil: Auto-Ethnographic Reflections on Disabilities

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**Abstract:** This article is an auto-ethnography reflecting the interactions among society, my family and my brother who has Cerebral Palsy. The experiences of me and my family show the visible and invisible veils that segregate people with disabilities and their families from mainstream Taiwanese society.

**Key Words:** Auto-ethnography, family, disability

For sociologists, personal biography can be an important entry to an unfamiliar social context that is usually invisible or misunderstood within certain cultures or ideologies. Sociologists try to be “objective” in their research projects, but it is difficult to be alienated from sociological research projects that deal with social processes in which sociologists are also situated. Thus, an ethnographer in the field of sociology has to be self-reflective and aware of the boundaries and distance between her/his own experiences and her/his research. The process of researching and writing my dissertation, “The Disability Rights Movement in Taiwan: Modernity, Civil Society and Politics of Difference,” has been a journey of self-discovery. It has given me a chance to rethink and give new meaning to my experience with disability.

I grew up in a middle-class family in Taipei. My dad was a successful businessman before he retired from a big corporation as a manager in charge of the export department. My mom is a housewife. She quit her job and committed herself to raising the family after she got married and had my sister. My sister (one year older than me) and I were considered good kids: we did well in school and attended elite public high schools and national universities. In mainstream Taiwanese people’s eyes, we were an ideal family and my mom was considered a fortunate woman—having a hard-working middle class husband and well-educated kids.

My brother, seven years younger than me, was born when my mother was thirty-nine. Unexpected news changed the “fortunate” life of my mom and had a dramatic impact on my family—my brother has a disability.

I can still remember that my family was excited and happy to have this new family member. However, after we had celebrated his first birthday, we found that he could still not sit up by himself. My parents decided to take him to see a doctor for close examination. He was diagnosed with Cerebral Palsy (CP). According to the doctor, CP could not be cured, but with proper rehabilitation, the condition could be improved. It was an unfamiliar “illness” that we had never heard of. The doctor’s diagnosis and short explanations just left us with more questions and uncertainty. My family simply did not know how to deal with it.

Can he can be “cured?” How does CP affect his life? What can we do to help him? We kept asking these questions of ourselves and all the friends and professionals we could reach.

Among my childhood memories are frequent family visits to the “Children’s Psychological Development Center” in the teaching hospital of National Taiwan University (*Taiwan da-syue Er-tong sin-li-fa-jhan jhong-sin*) and *Jheng-Sing* Rehabilitation Center. It was always my mom who took my brother for different visits. My father would give them a ride in

the car on the weekends and my sister or I sometimes accompanied the family after school or on weekends. Visiting the rehabilitation center was a family routine.

At that time, early intervention and rehabilitation for children with disabilities were still underdeveloped. To some extent, they still are in Taiwan. There was always a long waiting list at different centers. My parents were always anxious to try to use different “channels,” giving “*Hong-Bao*” (red envelopes with cash in them, that is, bribes) to get better doctors or physical therapists or more appointments. We even ended up paying a physical therapist who worked for the rehabilitation center to conduct private therapy at home for 1000 NT dollars (around \$30 dollars) per hour, which was considered extremely expensive at that time. Although my brother’s condition improved, there was no medical miracle.

When my family recognized that these “Western” treatments did not seem to work, we turned to traditional medical treatment. I suddenly discovered how many types of folk medical knowledge there are, such as acupuncture, Chinese herbal medicine, alternative healing, Chi-kung, and so on. We ended up visiting many parts of Taiwan, including Taichung, Tainan, Hsin-chu, and Kaohsiung. I can still remember one of the most difficult treatments. We had to drive for five to six hours to the southern part of Taiwan every week for six months to get a special herbal treatment.

Leaving aside the long wait for different treatments, we actually had great times together as a family. However, all these traditional treatments were the same; they did not work as the “doctors” claimed they should. After spending a lot of money and countless hours, my brother was not “cured.” We gradually realized that disability is not only a medical issue, but a social and political issue as well. We had to accept his disability and look for a support system.

When my brother got older and his disability became more visible, my family members were forced into unexpected life journeys. Not surprisingly, besides my brother, my mom was the one who suffered the most. According to traditional cultural beliefs, my mom had been considered a fortunate woman, with a hardworking and successful husband, and two “good” kids, my sister and me. It was an ideal life for a Taiwanese woman at her age. As part of traditional cultural practice, she was frequently invited to many weddings to share her fortune with newly wedded couples. But all of a sudden, when my brother’s disability became more noticeable, she realized that she was no longer invited to weddings. Nor was she welcomed to gatherings among our relatives, such as New Years’ dinners and birthday parties.

Not until the wedding of my cousin, when I was in college, did I see the invisible veil which separated my mother’s and brother’s lives from ordinary social life. She was the youngest daughter of my father’s older brother. The two families used to live next door to each other. My cousin was six years older and babysat my sister and me when we were in kindergarten. However, when the time came for her wedding, we suddenly realized that only my father, my sister, and I were invited; my brother and my mom were not on the invitation list. My uncle and aunt apologized but did not give any explanation although my cousin desperately wanted my mom and my brother to be part of the wedding. Later, I found out that it was because they believed that the appearance of my mom and brother would embarrass them and make the wedding banquet look bad. My mom felt sad, but did not say much. What I noticed was that my mom and my brother gradually withdrew from the social life of our extended family. At many other family events, although the invitation lists might not specify the guests, my mom knew that she and my brother were not welcomed. She knew that their presence would be considered disruptive to the harmony of the family gathering.

The relationship between my family and my uncle's family was broken after we leased our apartment to a community home for the independent living of four intellectually-disabled residents. The apartment was right next to where my uncle's family lived. At that time, most people refused to lease their places to people with disabilities and there was no law preventing discrimination in housing. My mom was a member of the disability rights NGO that had initiated the de-institutionalization movement in Taiwan. My family happened to have an extra apartment for rent. The deal went through, but my uncle could not understand why we leased the apartment to a group of "crazy people" and argued that his grandson and granddaughter would learn "bad examples" from people with disabilities. The two families stopped talking to each other thereafter.

The invisible lines dividing people with disabilities and their families from mainstream society not only exist in Taiwan but also in other countries. Like many middle-class Taiwanese men who experienced the regime transition from Japanese colonial rule to the Nationalist Regime, my dad always felt insecure about the future of Taiwan and began contemplating emigration to another country. He finally took action and applied for "investment immigration" to Canada. However, after years of waiting, investing, and spending a lot of money on a lawyer, my family's application was denied. At the same time, my father's close friend, who went through the same process with the same lawyer and put the same amount of money in, gained Canadian citizenship. The reason was simple: there was one disabled child in my family. We were not qualified to be Canadians, although in its immigration law, every foreigner and his/her family should be granted Canadian citizenship, if she/he makes a certain amount of investment. My family had put most of our savings into "buying" citizenship. We just did not recognize the hidden rules separating people with disabilities and their families from the rest of society.

The immigration lawyer suggested that we could give it a second try by temporarily "removing" my brother from our family registration. We could "re-adopt" him after we gained citizenship. My father brought this message home. My mom, my sister, and I all said, "No!" We told my father that "if the Canadian government denied our brother, at least we should not exclude him as part of our family." He was somewhat disappointed but certainly agreed with us. My family used to believe that Western industrialized countries have better welfare systems for marginalized groups and are more protective of human rights. I guess we realized that these "developed" societies only want money; rich able-bodied people can be part of their nation, not people with disabilities. There was a hidden rule that prohibited people with disabilities and their families from moving freely.

There was also a veil that segregated people with disabilities from mainstream schooling in Taiwan. Ironically, I was also a student in the special education system during my high school years. In Taiwan, under the "special education law," students who had IQ tests below or above two standard deviations would be categorized as "special education" students. Not surprisingly, students at the two ends of the normal distribution received very different and actually contrasting attentions and resources. Being labeled as a "special talented" student in high school meant endless schooling to prepare you to be a great scientist who would contribute to the development of the nation in the future.

This kind of "special education" was out of reach of most students, but because I passed some insipid tests in junior high school, I became a student in the special education category. I attended elite mathematics and science classes, each with fewer than ten students in the classroom. The high school even invited a professor from National Taiwan University to teach a weekly math class. In senior high school, we had our own lab and a small budget for a scientific

experimental project. During the summer, we attended science and technology summer science camp and took classes at the National Taiwan University for free. Despite the advantages, and maybe because I was not talented enough, I quit the special education lab class and transferred to a regular one in my final year of senior high school.

In contrast, my brother was not even allowed to get into a special education class for students at the other end of the normal distribution. I can still remember the tears of my mom after she received the result of my brother's IQ test. My brother was diagnosed as "mentally retarded," because of his CP diagnosis although all of my family members know that my brother does not have intellectual disabilities. There was no proper accommodation to allow him to voice for himself. According to the educational system at that time, his disability was "too severe to be educated." In other words, statistics divide people into different categories. The power and ideology behind the statistics—the ideology of development, promoting science and technology and able-bodyism—decided the distribution of resources and excluded people with disabilities from school.

As far as I know, more than half of my senior high school classmates from the "special education" classes moved to the United States, obtained graduate degrees, and became American citizens. None of them became a scientist working for the Taiwanese people. Many people question, "Why do we waste money on intellectually disabled children?" But nobody has asked, "Why do we waste money educating people who eventually become American citizens?" Is not education a fundamental right in modern society?

I thought that accepting my brother's disability had never been a problem for me. Until junior high school, I did not realize the invisible line I had drawn within myself between him and my social life. I can still remember an occasion during a break from a "voluntary self-study" evening section in junior high school. I was chatting with a close friend and we were complaining about the high expectations from home, school, and society. I mentioned how my sister, who had entered the best senior high school, pressured me to do well in the senior high school entrance examination. He then asked me, "Do you have other siblings?" I was silent for a while and then told him that I have a brother who has CP. He suddenly laughed at me and said, "You must feel ashamed of your brother. I usually hear you talking a lot about how successful your sister is, but never hear you saying anything about your brother. I didn't even know that you had a brother."

I was suddenly speechless. He was right. I always mentioned my over-achiever sister to my classmates and friends and complained about the pressure I felt in her shadow. I almost never mentioned anything about my brother. I suddenly realized that I also had drawn a line in my heart that separated my brother from my social world.

From 1987 to 1996, my high school and college years, Taiwan experienced a rapid democratic transition. Martial law was lifted and people in Taiwan suddenly had the rights of assembly and freedom of speech to make demands on the state. I can still remember my mom coming back from demonstrations and petitions, one after another. She always showed a mixed feeling of anxiety and excitement because she was not quite sure it was safe to speak up in public, but was thrilled to be expressing herself and voicing her concerns regarding disability rights to the government.

Like many college students at that time, I could not resist the temptation to be part of the burgeoning student movements. With no special commitment to particular issues, I participated in several "studies groups" and protests—Taiwanese sovereignty, labor, environmentalism, feminism, gay rights, and so on. Like many students at that time, I enjoyed the label of "student

activist” and relished the idea of “going against the state.” The freedom to walk in the middle of the streets was actually a lot of fun. If my memory is correct, I never participated in any disability rights demonstrations in college, even though my mom was there. I guess that, in a way, it was fashionable for college students at that time to obtain the label of “activists for whatever” except “disability.” My mom was usually supportive of my little student activism, while my dad was more uncertain and warned me to keep some distance from politics.

To a large extent, people do not realize that disability is everywhere. I have become more aware of the veil of disability around myself in the process of taking disability studies seminars and doing research on the disability rights movement in Taiwan. I am not quite sure why I ended up choosing to do my dissertation on the disability rights movement, but I am glad to have rediscovered my experiences with disability in the process of writing. My personal experience has constituted my entrance to disability studies and social movements. Writing about it has been an invaluable process of lifting the veil. The problem of the twenty-first century is the problem of how society defines the “normal” and treats the “different.”

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