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# **CULTURE, DISABILITY, AND DISABILITY COMMUNITY: NOTES ON DIFFERENCES AND SIMILARITIES BETWEEN JAPAN AND THE UNITED STATES**

*Miho Iwakuma*

## **I. Introduction**

As a disabled person who often travels cross-culturally, I prepare myself to adjust to the differences when the airplane lands in Narita International Airport, Japan. My first realization of “I’m home” starts immediately after I leave the airplane, accompanied by an airport attendant. An attendant navigates me, since the airport building provides a different route, a backstage path, for people with disabilities (PWDs) to use. The airport facility is wheelchair usable, but not inclusive of other passengers without disabilities. This subtle, unconscious divide between the disabled and non-disabled is one of many cultural differences that can be noticed between Japan and the U.S. This article outlines several cultural differences as well as universal aspects of disability across cultures.

## **II: “Shogaisha:” People with Disabilities in Japanese**

An invention and change of terminology is not isolated from cultural and historical perceptions of the natives toward a phenomenon, including a category of people (Devlieger 52, Iwakuma 247). One striking difference between English and Japanese concerning disability lies in the terminology ascribed to the disabled. A noun in Japanese referring to people who have disabilities is “Sho-gai-sha.” It must be recalled that each Chinese character chosen signifies a specific meaning. For example, “sha” means a person or people. The first character, *sho*, refers to something such as an obstacle or hardship, while the second one, *gai*, means “a harm, disaster, or pollution.”

Therefore, it can be speculated that “shogaisha” signifies, at least etymologically, and unveils how the non-disabled have viewed those with disabilities, that is, “people with obstacles or hardships, or the polluted.” Moreover, in the United States, whenever a term becomes too old-fashioned or stigmatizing, it has constantly changed, for instance, from “the muted,” to “the handicapped,” to “the disabled,” then to “people with disabilities, and now to “the differently able-bodied.” Conversely, it is interesting to note that in Japan this reference of “shogaisha” has not changed for at least fifty years.

### **III. Two Disability Discourses: “Try Harder” and “Don’t Be a Burden on Others”**

When returning to Japan, I always become conscious of Japanese expectations for PWDs that are different from those in the U.S. people, and I adjust my mind along with the language I speak. According to Phillips, in the U.S. the philosophy of “try harder” prevails. People in the U.S. are not supposed to be satisfied with what they have accomplished or who they are—they are expected to better themselves in any given circumstance. “Sky is the limit” or “push the envelope” is a mantra for people in the U.S. When this “try harder” philosophy is applied to PWDs (especially to those who acquired disabilities later in their lives), however, it perpetuates the achievement of normalization and the idealization of “normal” (Phillips 257-60). Individuals with disabilities are pressured to “try harder” in order to lessen their disabilities, restore independence, and most of all, to become one of “the normal” again. In this notion, one’s disability is thought of as something that is an entity isolated from the self. To become one of “the cured” is the most desirable outcome and the highest accomplishment for PWDs. Accordingly, accepting one’s disability is somewhat synonymous with “giving up;” thus, coming to terms with one’s disability is considered to be second best to finding the cure. (This mindset may be correlated with rehabilitation’s lower status in the medical industry, in general.)

This “try harder” theme powerfully operates in Japan, too. One of the participants in my dissertation project was a woman who wore prosthesis for her amputated leg below the knee. The elderly at hospital once told her that because the woman could walk like the able-bodied, she should wear a pair of long pants to hide the prosthesis, which is the only reminder of her disability. My participant felt puzzled by the fact that she was no longer seen as who she was, but rather she was labeled as “disabled” by the society. Additionally, she was reminded of an implicit social manner expected for the disabled.

That is, if the cure is not feasible, PWDs should put their effort into looking, behaving, and assimilating as the able-bodied.

However, in Japan, another rhetoric is often used in dealing with PWDs. That is, “do not be a burden on others,” or “don’t burden others.” Although they may appear similar, the “don’t be a burden” theme differs from the “trying harder” ethos. The “try harder” ethos encourages people to be independent and self-reliant. On the other hand, “don’t be a burden” comes from a Japanese group-oriented, collective tendency which harshly criticizes disturbing the group harmony and not following cultural scripts. More precisely, a “burden” (*meiwaku*) refers to being different from others, or doing something that violates cultural norms and expectations. The “don’t be a burden” philosophy has been a powerful gravitational force dictating the lives of PWDs and their environment, the dimension of this essay explored hereafter.

#### **IV: A History of the Japanese Disability Community and Independent Living Movement:**

Hayashi details a history of PWDs in Japan from the 19<sup>th</sup> century to today. For a long time, PWDs had been restricted to either living with their relatives, mostly parents, or they were confined in institutions. Regardless of differences in these living conditions, individuals with disabilities were commonly viewed as subordinates to the authority figures (parents or institutional staff) and child-like people who could not look after themselves. Since PWDs were not considered productive members of society, they were repeatedly told that the least they could do was to try not to burden others.

Before the 1970s, prior to the dawn of the Japanese disability movement, the nation’s approach toward PWDs had been oriented to protecting, patronizing, segregating, and rehabilitating (Hayashi 855-59). The long road to Japan’s disability movements, which emerged in the 1970s, was punctuated with several important turns of event, such as the Fuchu Ryoiku Center case and the incident of a counter-petition against a mother who killed her disabled child. The Fuchu Ryoiku Center incident made public how—for the sake of medical research—disabled individuals were kept under inhumane conditions at an institution where residents were abused by staff, prohibited to go out for months, and/or received lobotomies or autopsies without consent, just to name a few such abuses. The dreaded and loathed residents’ hunger strikes followed by sit-ins caught some media attention. Another turning point, the counter-petition against the child

killing, was initiated by a radical disability group called Aoi Shiba, mainly comprised of people with cerebral palsy (CP), that disdained the disabled's parents group that asked for a petition against the mother. Members of Aoi Shiba harshly criticized the underlying connotation of the petition that the lives of the disabled are not worth living; thus, killing them, although out of desperation, is understandable (Hayashi 861). An early period of Japan's disability movement, along with other social movements in the '60s and '70s, was depicted as aggressive, radical, and anti-social (Hayashi 859-62). Exposed to the humiliating living conditions, people with disabilities, either in institutions or at home, started to look for an alternative way of life: living independently in community.

The next era, the 1980s, was meaningful in many ways for Japan's disability movement. Under the slogan of "Full Participation and Equality," the 1981 International Year of Disabled Persons started and the Japanese disability movement turned another corner (Hayashi 865, Tateiwa 205). In order to meet the United Nations mandate, the Japanese government followed through by establishing several agencies, and some disabled persons were invited to join (Tateiwa 206). During the national Diet in 1980, the term "normalization" was used for the first time by a disabled congressperson, Eita Yashiro (Tateiwa 206-207). Most notably, that international year prompted dialogue between the government and disability groups, which previously had been antagonistic (Tateiwa 208).

In addition to the aforementioned domestic changes in the 1980s, Japan's disability movement met the west (Hayashi 865-866, Asaka 37-47). Many well-known U.S. activists such as Ed Roberts and Judy Heumann were invited to Japan to hold symposia and conferences in many cities. In turn, some disabled individuals from Japan went to the U.S. and worked as interns at CIL (Center for Independent Living) offices to embody the philosophy of the independent living movement. Today's many disability leaders in Japan were those returnees, and Asaka is one of them. Born with osteogenesis imperfecta, Asaka lived in the U.S. for six months in Berkeley, CA. During her stay, she seems to have experienced fundamental differences on disability between the two countries (Asaka 37-48). She was stunned by the "business-like" attitudes of CIL workers who closed the office and went home at five o'clock. In Japan, disability activism was Asaka's life itself for 24/7; there was also no distinction between her private life and public life as an activist (Asaka 46-47). Her identity embodied the activism and vice versa. In addition, she observed the harsh reality of the full-measured meritocracy of U.S. society in which there were many young homeless women and people with mental disorders living and

sleeping on the U.C. Berkeley campus.

When she tried to apply what she had learned from living in the U.S., Asaka experienced friction with local activists in Japan (Asaka 47). The difficulties she met came from cross-cultural differences regarding disability that exist between the U.S. and Japan. Such concepts as self-determination, assertiveness, human rights, or community living—all central doctrines of the U.S. disability movements—sounded foreign in a Japanese cultural context. For example, in the United States, a grown child's independent living is considered a sign of adulthood and maturity; thus, it is socially accepted. Contrarily, a group-orientation, modesty, and respect for the social structure and authority dictate people's courses of action in Japan. In such a cultural milieu, even college seniors, especially female students, are encouraged to commute from home to work until their marriage. Therefore, it was even harder to fully comprehend what the human rights, independence, and so on should be for PWDs who were always told not to burden others and to be thankful and apologetic for benevolence from the non-disabled. Knowing these fundamental differences, the disabled returnees who were pioneers of Japanese CILs had to start by laying the ground work of making foreign notions less frightening and more culturally appropriate to Japan (Heyer 18). Indeed, the current situation of the U.S. and Iraq points out that transferring a culturally ingrained notion like democracy to another soil requires patience, modification, compromise, and creativity.

Heyer points out that the disability indices of Japan and the U.S. are deeply rooted in cultural, social, and political norms of equality and disability (2). According to her research, the U.S. disability doctrine adheres to a premise of equality of opportunity, while the Japanese approach traditionally is concerned with equality of results.<sup>1</sup>

The American disability rights movement very clearly and self-consciously builds on [the] rights tradition developed by its own civil rights movement... The ADA's interpretation of equality is one that emphasizes sameness and non-discrimination. The emphasis is on the removal of barriers that prevent equality of opportunities.... Japanese registration has emphasized different needs over equal rights...the right to be different is well protected and supported in Japan. Especially in the areas of education and employment policy, the emphasis on different and special needs has resulted in well equipped but nonetheless separate facilities. (Heyer 23)

This cultural, philosophical difference reminds me of my own experiences at the airports. In the U.S., no matter how small or rural,

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<sup>1</sup> Similar to the Americans with Disabilities Act, Affirmative Action is also based on a premise of equal opportunity, rather than equal result.

I can expect an airport to be accessible so that everyone, including a person with a wheelchair, can use the same facility (equal opportunity). Beyond this guaranteed equal opportunity, however, I rarely receive special consideration in the U.S. Therefore, anything else, such as finding the nearest elevator or a gate for the flight or making it on time to board the plane, becomes a lesser issue: I'm fully responsible for these matters. On the other hand, as I mentioned earlier, in any Japanese airport an attendant always escorts me while I am using the facility. That is because the airport authorities acknowledge my difference and special needs so that everything is arranged before my arrival. They strive for an equal *result* in my use of the facility by giving me special treatment. In Japan, therefore, I never have to look for an elevator or gate or miss my plane. The airport staff does everything in the least painful and most efficient way, which compensates for my having to use a different, segregated route from everyone else in the same airport.

#### **V: "Independence" for People with Disabilities**

One might think that being put in an institution and treated like a caged animal must surely be humiliating, and thus it makes sense that the disabled rebelled against it. But why would someone with a disability wish to leave his or her home where parents would do anything with unconditional love? Indeed, the parents love their children and would fight to the end for them. The parents of children with disabilities may even have a stronger determination to protect them from any outside harm.

Harris and Long point out that in a caregiving context, while "intimacy, but [with] a distance" (243) is a primary virtue in the U.S., Japanese caregivers tend to idealize what is called "totalizing care" (249). In the notion of totalizing care, there is no such concept as "secondary caregiver"; thus, a caregiver takes on all of the responsibilities and is thereby at risk of burnout. Such totalizing care is framed from within the Japanese family unit, which is called "*ie*." This family unit identifies the mother (or wife) as a primary caregiver and is bolstered firmly by a culture of shame. Shame is an instrument of the group-identity of self in Japan, and anything or anybody who brings shame to an in-group is subject to sanction by its members (Ishi *et al.* 30). For a family with a disabled child, sometimes parents withdraw and alienate themselves from others due to a strong sense of shame that they brought the disabled child into the world. Particularly, the mother often becomes a target of shame to the immediate and extended family as someone who could not bear a healthy,

“normal” child. Isolated from the outside world and overwhelmed by the pressure of totalizing care for the disabled child, a mother-child relationship becomes extremely introverted and closed. In an extreme case, this spiraled, closed relation pushes parent(s) to the edge and triggers the unthinkable, the killing of a child by the parent of which Aoi Shiba was violently accused in the 1960s.

Two decades have passed since their protest, yet in the ‘80s (and even today) the same tragedy is reproduced. In 1984, a child with autism was killed by his mother (Okahara 78). The mother tried to purge her emotions in the following statement: “I used to wish that you (the child) would never grow and stay as a child so that I could’ve taken care of you forever. Since you’ve gotten older, gone beyond my protection, I started thinking about terminating your life.... You had your own right to live.... I became emotionally disturbed. I was in a state of insanity” (Okahara 79). Many people with disabilities instinctively know that sometimes the parents’ (especially the mother’s) affection imprisons and suffocates them. Therefore, an interviewee in Okahara’s study urgently declares “post-family” orientation: “[we need to] distance ourselves from our own parents. Their overwhelming affection coils around us and leaves us nothing” (Okahara 80).

Shikano was such an individual, who chose to live in a community supported by a group of non-relatives, such as volunteers and paid caregivers (Watanabe 18-24). Watanabe detailed the last two years of Shikano’s everyday life until he died from muscular dystrophy in August 2002. Shikano could not live even a day without someone else’s help; his every move was accomplished with others’ assistance. To that end, he could never enjoy a moment of privacy. (Even when masturbating, Shikano was assisted by a helper who set and started a video, pulled his client’s pants down, and gave him a handful of Kleenex before leaving the room.) People entered and left his apartment every few hours, which sometimes fatigued Shikano (Watanabe 374-375). Shikano knew how difficult it is to share every inch of one’s life with a stranger.

Known as short-tempered, self-indulgent, weak, and tenacious about living, Shikano was not a “typical” disabled person. He was never thankful, apologetic, angelic or heroic (Watanabe 89-102). Some volunteers left Shikano because he never let them do things in their way, but many more were drawn to him for who he was. Shikano educated newcomers to the notion of “his way or the high way.” For example, Shikano awakened one of his volunteers in the middle of the night at hospital (Watanabe 32). The volunteer had been exhausted from his daytime work and was irritated by Shikano’s request to eat a



ripe banana. Though frustrated, the volunteer peeled the skin without a word, held the banana to Shikano's mouth, and waited patiently until he finished eating. As soon as Shikano finished, the volunteer crawled into his bed, half-asleep, but was brought back to reality by Shikano's voice, "Another one!" Shikano never compromised on what he wanted.

Many accounts of volunteers and caregivers begin by saying that Shikano was selfish because he persisted in his ways (Watanabe 305-320). Watanabe notes that when one's physical functioning is restricted and help needed by others, the dependent person is expected to be appreciative and humble (25). Such pressure is strong in Japan where the maxim "don't be a burden on others" is one of the golden rules. Asaka remembers from her own childhood that people with congenital disabilities were taught two things: first, "being a burden" is the most shameful state in which to find themselves and, second, when receiving benevolence from others, there is no room for arguing, just be thankful. For this reason, a "picky" helpee is accused of being selfish or inconsiderate of others. As we say in English, "beggars cannot be choosers"—anyone who is not independent, financially or physically, is pressured to swallow his or her needs, not to mention wants.

The ideology of independence fosters a strong sense of physical autonomy and self-sufficiency in individuals. For instance, during the childhood years, a child is trained and gradually expected to maximize his or her physical independence, thereby transforming him- or herself from an infant to a child. Later, during the school years, the young adult prepares to become a full-fledged societal member by obtaining paid employment status. However, this cultural assumption of "independence" has ostracized a group of people with disabilities, who fall short of being (physically and economically) independent. In today's capitalistic society, being physically dependent or unable to contribute directly to the labor market has stigmatizing moral connotations, such as the implication that such a person is "lazy" "needy" or "unmotivated."

## **VI: Disability Culture: A Common Bond Uniting Us**

When I started participating in conferences on disability and meeting other disabled individuals around the world, I was often amazed by our common daily experiences despite the cultural differences. Several years ago, when attending a conference in Washington, D.C., I stayed at a conference hotel in which my room had a

bathroom entrance too narrow for my manual wheelchair. I mentioned my situation to a fellow disabled participant who was a long-time disability activist in the U.S. He suggested to me that I ask the hotel maintenance staff to unbolt the bathroom door to spare some space. Indeed, with the door removed, the bathroom entrance became two inches wider! His advice was eye opening. I could not have come up with the idea by myself and, more importantly, the incident made me conscious of habitus, which is “constituted in practice and is always oriented toward practical functions” and “associated with a particular class of conditions of existence” (Bourdieu 52, 53). Using the notion of habitus, the characteristics of wheelchair users produce a unique habitus accompanied by a creative problem solving strategy (practice). Recognizing the common conditions of existence, or habitus, among PWDs presents a valuable opportunity to view the ontology of disability as well as a formation of disability culture that overcomes national sovereignties. Hereafter, I outline a theory of disability adjustment that seems to be common to Japan and the U.S.

Charlene DeLoach and Bobby Greer theorize the ways in which a person adjusts to a severe disability, such as a spinal cord injury, suggesting that there are three stages that a newly disabled person goes through: stigma isolation, stigma recognition, and stigma incorporation. Although DeLoach and Greer did not research the subject cross-culturally, the data derived from my Japanese participants with disabilities supports the identified process (Iwakuma 13-17).

Stigma isolation states that in the aftermath of a disabling incident, a newly disabled person encounters numerous frustrating incidents, including being deserted by old friends, but the person is unaware that the change originates from his having a disability. For example, many interviewees in my study recalled that after being flooded by visitors for the first few weeks, a majority of the friends stopped coming to the hospital after the first visitation. When discharged from the hospital, the participants found themselves being isolated from their pre-injury friends. Mr. K., with severe quadriplegia, lost contact with all of his baseball friends. He attributed this change to the fact that his old friends became extremely uneasy with him since he could no longer do anything by himself besides talk. Mr. K. felt his non-disabled friends saw him as the embodiment of “a fate worse than death.” The disabled participants sensed such uneasiness, or even fear, on the part of the non-disabled individuals, and their communication required much effort. Influenced by the works of Mary Douglas and Talcott Parsons, Robert Murphy uses the concept of “liminality” (131) to account for such ragged communication between the two parties:

The long-term physically impaired are neither sick or nor well, neither dead nor fully alive, neither out of society nor wholly in it. They are human beings but their bodies are warped or malfunctioning, leaving their humanity in doubt. They are not ill, for illness is transitional, to either death or recovery.... The sick person lives in a state of social suspension until he or she gets better. The disabled spend a lifetime in a similar suspended state... they exist in partial isolation from society as undefined, ambiguous people. This undefined quality, an existential departure from normality, contributes to the widespread aversion to the disabled.... (Murphy 131)

It is this ambivalent social standing of PWDs that makes the non-disabled feel rather uncomfortable and causes them to avoid PWDs.

DeLoach and Greer's second stage, stigma recognition, explains that the newly disabled individual comes to realize what his or her new identity as disabled brings to life. The person becomes conscious of social meanings of being disabled at this stage (Iwakuma 14). For example, one of the participants witnessed a child pointing a finger at him and the mother yanking the child, and another participant felt devastated to hear a parent saying to a child, "Be good or you'll be like that person." In this phase, the newly disabled person learns the discredited, stigmatized identity of the disabled in society. In the aforementioned episode of a woman who was advised to wear a pair of long pants, a disabled person learned the stigma attached to her prosthesis and the proper conduct for someone disabled: conceal one's identity as disabled to avoid making the non-disabled feel uncomfortable.

The last stage of disability adjustment is stigma incorporation, in which the newly disabled person assimilates his or her disability to the self. By this stage, the person knows not only both the disadvantages and advantages of disability, but also practical strategies to ameliorate negative consequences of a disability. Acquainted with others with disabilities at hospital or through disability sports seems to promote "feeling comfortable in one's own skin." I also observed a process in which some participants changed their perception of the wheelchair as they adjusted to a disability (Iwakuma 16). Mr. S., who has paraplegia, used to hate being in a wheelchair and insisted that he walk by dragging his legs. The next year, I saw him completely changed, and he told me that seeing wheelchair basketball players helped him accept his own chair. By reaching this stigma recognition stage, the person has developed creative ways of dealing with common scenarios such as receiving unwanted help, others' staring, or negotiating about inaccessible environments. My own experience at the conference hotel, removal of the bathroom door, is one such

problem-solving strategy. Additionally, it seems that some PWDs in this stage develop a sense of group solidarity—a “we” identity (Iwakuma 17). For example, Mrs. F., who plays wheelchair tennis and was once featured in a nationally televised car commercial, receives many questions about lives of PWDs in general. As someone representing a group of PWDs, she feels a sense of responsibility in fielding questions. On behalf of those silenced, she also raises her voice against non-disabled who park cars at spaces reserved for PWDs. Another participant, Mr. K., emphasized that communicating among the disabled is very crucial, since we have so much to learn from each other’s experiences. The disability community seems to function as a safety net and buffer zone for people with disabilities to adjust to dual membership in the world of PWDs and that of the non-disabled. The community also nurtures a positive, self-affirming identity.

## **VII: Concluding Remarks**

In my early graduate years at the University of Oklahoma, I became interested in the literature of cultural studies regarding disability. Although I am a native of Japan, my “disabledness” sets me apart from the Japanese mainstream culture, and the disability literature suggests where my estrangement originates. I do not deny the fact that paralysis sometimes sets limits on me. Nevertheless, without a doubt, my physical configuration has opened many avenues for me as a student, researcher, and private person. I became curious about this wonder. The literature has given me a sense of history concerning how disability is constructed and of how the social structure in which interaction with persons of disability is managed and maintained. To this end, the literature offers me a compass; this article aims to share that compass with others who also need a sense-making instrument to guide them in this seemingly chaotic world of disability.

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