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Why Disabled People Called for Independent Living: Japan's Experience

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1. Background to My Presentation and Critical Perspectives

First and foremost, my presentation focuses on why disabled people took action for independent living. As detailed below, independent living means that disabled people live separately from residential facilities and their parents. In this study, I address what caused disabled people to take action for independent living given that other Japanese studies lack such perspective. A crucial point for discussion is that even though disabled people and their parents sought the construction of additional residential facilities prior to the movement for independent living becoming active, it is unclear why disabled people stayed away from the facilities and demanded other options later. The answer to this question is predictable; disabled people found it uncomfortable to live in such facilities. So why then was action taken to call for the residential facilities? Was it impossible to predict that the disabled would face inconveniences and uncomfortable situations in such residential facilities? I aim to clarify the issues in this report.

2. What is Independent Living?

I think that independent living for disabled people has two aspects. First, it entails setting disabled people free from shackled environments (home and live-in residential facilities). Second, it enables disabled people to manage and take responsibility for their own lives.

Given this line of reasoning, action for independent living for disabled people can be defined as; first, setting them free from shackled environments; second, enabling them to manage and take responsibility for their own lives; third, seeking the necessary resources (accommodation, nursing care, income guarantees, and means of transportation) to achieve the first two goals; and fourth, creating local communities that are disabled people-friendly.

3. The Entire Landscape of Historical Backgrounds

The 1960s: Problems with residential facilities became clear. (On the whole, however, residential facilities were in a more advantageous position.)

1970: Disabled people protested about living at a residential facility in Tokyo and called for independent living.

Around 1972: Disabled people began to take action and called for the installation of elevators at a Kyoto subway station due for construction.

1973: The Tokyo metropolitan government launched a system to dispatch nursing care workers to people with serious and profound handicaps affecting the entire body, including those suffering from cerebral palsy.

1970: A disabled child was killed in Kanagawa and local residents appealed for reduced punishment for the criminal. Disabled people's organizations protested against this.

1976: A wheelchair-bound disabled person and his nursing care worker tried to ride a bus, but the driver refused to carry them. This became a contentious issue because disabled people in wheelchairs were not allowed to ride buses at the time.

1979: Internal debate among members of movement groups representing disabled people over schools for disabled children.

* During this time period, activities for disabled people were individual-based and they typically left their residential facility or home on their own to pursue recreation activities. The disabled also caused conflicts with the aim of changing society. However, the system for dispatching nursing care workers to the disabled (particularly those in urban areas), which was launched in 1973, became a significant part of the disabled people's movement.

1979: Edward V. Roberts visited Japan.

With the support of Duskin Co., Ltd., a group of Japanese disabled people made an inspection visit to the United States in 1980.

1981: The International Year of Disabled Persons (IYDP)

1983: Judith E. Heumann and Michael Winter visited Japan to hold training seminars on independent living.

1984: The Japan Center for Independent Living was established in Kyoto.

1986: The Human Care Association was established at Hachioji in Tokyo.

1988: The Public Nursing Care Association was established.

Subsequently, centers for independent living were widely established in many parts of the country. The 1980s and 1990s were characterized by the commitment of disabled people to act as organizers in the provision of services.

2003: Support systems facilitating independent living for disabled people were launched.

Many centers for independent living operated as nursing care offices.
2005: The Law to Encourage Self-Reliance Among the Handicapped was enacted.
Protest demonstrations over the burden of service fees were held.

*In the 1990s, independent living for disabled people was guaranteed and promoted by the establishment of centers for independent living and the development of public nursing care systems. In particular, a financial support system for independent living introduced in 2003 secured a variety of services and laid significant foundations for independent living for disabled people. Furthermore, in contrast to previous generations, many disabled people were now committed to organizing services. After the introduction of the financial support system in 2003, more and more disabled organizations conducted coordinating tasks for the dispatch of social caregivers. This worked well and enhanced the provision of stable public nursing care services and enabled not only highly motivated disabled people but also many other disabled people to realize independent living. Meanwhile, disabled people also became users of independent living services in which caregivers are coordinated by nursing care offices (Watanabe 2011). Disabled people were free to choose their favorite care workers. In such circumstances, disabled organizations became more like independent living service providers than activity groups for the disabled. This cannot be described as fully undesirable, but if this trend continues, the directors of independent living support centers are likely to become “ordinary” support providers of public nursing care services.

4. Why Did the Movement for Independent Living Begin?

As mentioned above, this study focuses on why disabled people moved to take action for independent living. I will closely examine the situation in the 1960s that was referred to earlier. Essentially, prior to the development of support systems, independent living for disabled people was considered dangerous. So why then did disabled people want to move away from their parents and residential facilities?

4-1 Home as a Problem

In 2011, the word *home* is generally considered to have positive implications. For example, home services are considered to be a significant support for both disabled and elderly people. However, the word had negative implications 50 years ago and implied that a person had nowhere to go. That is, staying at home meant that you were in need of your family's care and attention.

I will delve further into the details of this situation. First, what did family mean to disabled people? Family hindered a disabled person's freedom, in exchange for which they received the necessary assistance. The following are two statements made by disabled people on the subject:

> I stayed in a small room all day long. Actually, my family did not allow me to get out of the room. In summer, when I opened the window, children who happened to pass by my house threw dogs' excrement and stones at me. However, despite such harsh treatment, I wanted to play with those kids. My grandparents always said to me, "Emiko, you play with dolls. Dolls do not bully you." (Emiko Iwatate [1978], *I Want to Go to School*, Tsuge Shobo Publisher, 19)

> I stayed at home every day 20 years ago (1961). At that time, I spent much time with my mother. Eating and watching TV were my only diversions. (Text omitted.) Now, I cannot imagine my mother cleaning my bottom just as she did in those days. I well remember the fear of thinking about what I would be like after 10 or 15 years passed. I imagined a double suicide with my mother then. (Kazuaki Akiyama [1981], *Journey to Self-Reliance: Visiting a British cerebral palsy sufferer*, self-publishing, 2-3)

In the eyes of disabled people, family members supported their survival, but were also a hindrance to their freedom. Disabled people also felt uncomfortable with family support. Their uncomfortable feelings were amplified as their family members changed. According to reports compiled by organizations representing the disabled, disabled people were often taken care of by their brothers and sisters after their parents had died. In addition, when those brothers and sisters died, nephews and nieces adopted the carer's role. Disabled people felt more uncomfortable when their parents died and their brothers and sisters became caregivers because new family members became involved in their care. Disabled people placed a heavy burden on family members and this consequently made them feel more awkward and uncomfortable than when their parents were the primary carers. The key point is that family members can act as both a support and a hindrance to a disabled person.

Of course, it is both improper and oversimplified to regard family members as a hindrance to disabled people. From the family's standpoint, they are often on the receiving end of discriminatory treatment levied by the general public because of the reality of having a disabled person in their family, which induces the family to encourage the disabled person to stay at home. Socially, family members are supposed to raise disabled children without causing inconvenience to others. “Family love” is the keyword. In addition, mothers of Japan’s disabled children often feel a sense of guilt. Another important point is that prior to the development of public pension systems, children were considered to be significant assets to parents in their retirement; extrapolating, it is apparent that disabled children were regarded as defective assets.

In consideration of these factors, the situation surrounding disabled people and family members can be approached in the following three ways. First, from the standpoint of family members, they cannot avoid being on the receiving end of discriminatory treatment and this often induces family members to keep disabled family members out of the public eye. Second, from the standpoint of disabled people, such behavior effectively controls and restricts their freedom and makes them feel more uncomfortable. However, they have no alternative but to rely on their family for support in their daily life. Third, because parents typically predecease their children, other family members must assume the carer’s role and this leaves disabled people feeling awkward and uncomfortable. The combination of these factors can induce the disabled to live in residential facilities and away from family.

4-2 Transformed Evaluations of Residential facilities

As noted above, after the 1960s, disabled organizations called for the creation of more residential facilities. The following two points should be noted. First, disabled people who had actually experienced life in such residential facilities were in the minority among the organizations calling for change. Second, those who wanted to use residential facilities were divided into two different categories.

For example, one disabled person looked upon residential facilities as ideal places in which to live:

> Considering my life after the death of my parents, I strongly hope that I can live in close collaboration with cerebral palsy sufferers, however many years later it may be in the future. (Kimishima, 1960: 4)

On the other hand, another disabled person considered residential facilities to be the second best choice:

> As an individual person, I simply want to have my own family. I do not want to either live with my parents throughout my life or live with others at residential facilities. Neither choice makes it possible for me to have my own family. It just forces restrictions on me and gives me a hard time with how to deal with human relations. All these things mean that people with serious disabilities experience no happiness. However, we cannot commit suicide just because we cannot live as we like. Under these tough circumstances, we have to think about a way to improve our conditions and try to pursue happiness as hard as possible. Residential facilities are necessary in that sense. (Tomoi, 1961: 7)

These two opinions have one significant thing in common; both individuals think that living in a residential facility is better than staying at home. Information gaps about live-in facilities affect whether the disabled evaluate those facilities positively or negatively. The two disabled individuals above evaluate residential facilities in comparison to staying at home instead of regarding those facilities as ideal places in which to live.

The requests made for the construction of more residential facilities were based on these factors. In this context, it is notable that some disabled people requested more residential facilities and others, simultaneously, pointed out problems with their construction. This was quite natural in the sense that disabled people's requests for residential facilities were based on comparisons with staying at home. The following are excerpts from two books that present critical views of residential facilities before 1970:

> On the third day after I had moved to the facility, I did not have bowel movements in the morning due to an unfamiliar lifestyle there and I had one around 3 p.m. At that time, I needed someone's help for my bowel movements. I called the nurse, feeling uncomfortable. She did not come quickly. Looking at my desperate situation, Mr. A, who lived with me in the same room, went to call her on crutches. She appeared shortly and grumbled, "You should not call me for after-hours bowel movements next time." (Text omitted) She also said to me, "You rock the boat here. Get out." She knew that I had nowhere else to go and if I got out of there, I would be in trouble without social capability. An order to get out of the place was a declaration of death to me. I had no other choice but to live with her harsh treatment. (Hiroko Kimura [1967], *The Autobiography of My Life*, the Earth Society, 50-51)

> One day, I could no longer stand living in the room I used at that time. I asked a care worker to change my room I had believed that the care workers at the facility understood disabled people. However, unexpectedly, the care worker swore, "This facility is the only

> place that supports crippled people who live for nothing." This verbal abuse deprived me of every hope and glow of life. I felt helpless and escaped from the place with nothing but the clothes on my back. (Motoko Koshiba [1960], *Even With Slow Steps*, Inoue Shobo Publisher, 217-218)

A common factor detected from these relates to the restrictions placed on going out and on times for eating and bowel movements. Furthermore, in both cases the disabled individuals were forced to leave the residential facilities as a result of the harsh words and uncaring attitudes metered by the care workers. It was certainly true that disabled residents in the facilities had nowhere else to go at the time and this inevitably resulted in unequal relationships between staff and disabled residents. In the eyes of disabled people, the desperate conditions meant that they faced similar problems to those at home, even though they had moved to a facility to escape an uncomfortable home environment. These circumstances and experiences prompted disabled people to take action for independent living.

5. Conclusion and Suggestions

5-1 Conclusion

The focus of this study was to identify why disabled people took action in support of independent living. This study also considered why disabled people requested the establishment of more residential facilities before they began to take action. The following points answer these questions.

1. The requests for residential facilities by disabled people were based on dissatisfaction with awkward and uncomfortable home environments.

2. Disabled people residing at home lived with restricted freedom in exchange for which care and attention was provided by their family.

3. Disabled people residing at home could not avoid changes to their primary carer as family circumstances changed, resulting in more awkward and uncomfortable living conditions.

4. Few disabled people had actually experienced life in a residential facility and many

disabled people wanted to reside in residential facilities.

5. However, care workers within such facilities often displayed an arrogant and patronizing attitude, believing they were being generous and kind by providing support to helpless disabled people with nowhere else to go. This clearly was not an ideal situation for disabled residents.

6. When disabled people decided to leave residential facilities, they did not consider returning home since they had sought to escape from uncomfortable living conditions there. This induced disabled people to take action for independent living.

5-2 Suggestions

1. As in Japan, South Korea's rate of retired household expenditure as a proportion of public expenditures is high, while public expenditure on the unemployed is low. Therefore, it is conceivable that family plays a large role in providing care and attention for disabled people. On this basis, it is likely that disabled Koreans are prompted to reside away from their family members as in Japan.

2. Similar to Japan, South Korea underwent rapid modernization. The motivation for families to provide care and attention to disabled people has therefore reduced and this has increased the demand for residential facilities. In the meantime, as the Convention on the Rights of Persons with Disabilities suggests, the idea that disabled people have the right to choose where to live will also become more ingrained. It is likely, therefore, that some groups will emphasize the need to resolve the awkward and uncomfortable conditions faced by the disabled in their homes. Other groups will note problems with residential facilities. This leads to the logical conclusion that securing alternative living conditions is necessary.

3. It is clear that the requests made by disabled people for residential facilities and the demands for independent living are based on common logical threads.