

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

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# 1. Background of My Presentation and Critical Perspectives

- My presentation focuses on why disabled people took action for independent living.
- 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.

## 2.Methods of Study

- My study is mainly based on literature. I gathered many documents every where in Japan.
- I gave the most attention to autobiography and newsletters published by disabled people.
- My presentation focuses on subjective view of disabled people.
- I had supplemental interviews with disabled people who took part in independent movement.



## 2. What is Independent Living?

- It entails setting disabled people free from shackled environments (home and live-in residential facilities).
- It enables disabled people to manage and take responsibility for their own lives.
- It includes 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(1)

- The 1960s: Problems with residential facilities became clear. (On the whole, however, residential facilities were in a more advantageous position.)
- 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.
- 1970: Disabled people protested about living at a residential facility in Tokyo and called for independent living.
- 1976: A wheelchair-bound disabled person and his nursing care worker tried to ride a bus, but the driver refused to carry them.

## 3. The Entire Landscape of Historical Backgrounds(2)

- 1979: Edward V. Roberts visited Japan.
- 1983: Judith E. Heumann and Michael Winter visited Japan to hold training seminars on independent living.
- 1986: The Human Care Association was established at Hachioji in Tokyo.
- 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.

# 4. Why Did the Movement for Independent Living Begin?

## 4-1 Home as a Problem

- 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.
- Ex. (Kazuaki Akiyama [1981], *Journey to Self-Reliance: Visiting a British cerebral palsy sufferer*, self-publishing, 2-3)

## 4-2 Changed Evaluations of residential Facilities(1)

- 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.

① People looked upon residential facilities as ideal places in which to live

② Another disabled person considered residential facilities to be the second best choice

## 4-2 Changed Evaluations of Residential Facilities(2)

- Some disabled people left residential facilities because of restrictions and harsh treatments.
- (Hiroko Kimura [1967], *The Autobiography of My Life*, the Earth Society, 50-51)

## 5. Conclusion

- 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.

# 5. Conclusion

- 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.
- 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.

## 6. 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.

# Suggestions(2)



- Similar to Japan, South Korea underwent rapid modernization. The motivation for families to care disabled member 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.

# Suggestions(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.



Thank you!

