

The Independent Living Movement and Policy Issues regarding De-institutionalization in Japan

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1. History of the Independent Living Movement in Japan

In the 1970s:

- Cases of parents killing their disabled children (based on the internalization of eugenic ideology) ; issues raised by people with disabilities who see the problem
- Campaigns against the violation of human rights of residents in institutions
- Campaigns against the refusal of wheelchair users to get on public transportation or to enter stores
- Movement against segregated education system; and for education where children can learn and grow together

In the 1980s:

- Moves to create places for people with disabilities to live in the community; and to form a base for the disability movement (e.g. the creation of community workshops and the setting up of centers for independent living)
- Movement in urban areas for the establishment of "home-visit care support service for person with physical disabilities" (this was the prototype for the current "support (visiting care) for persons with severe disabilities" or "*JUUHO*" service, which could be described as a Japanese version of personal assistance)

*The DPI-Japan was formed in 1986 as a hub for movements led by disabled people.

In the 1990s:

- Nationwide campaign for access to public transportation; and campaigns for access (barrier-free community development) ordinances in local governments
- Improving the visiting care service system in many areas
- Movement of people with learning (intellectual) disabilities such as People First; and people with psycho-social disabilities (mental health issue) spread

*In 1990, the Japan Council on Independent Living Centers (JIL) was formed as a nationwide network of independent living centers for people with disabilities.

In the 2000s:

- A two-week fight against the capping of home help services in 2003.

- A new system of the "support payments" enabled many care support service suppliers start up.
- Intense campaigns for the abolition of the "Services and Supports for Persons with Disabilities Act", which introduced both a computerized disability rating system that is biased toward "the medical model" ; and user fees for welfare social services for persons with disabilities
- As a result, the law was revised to become the "Comprehensive Support Law for Persons with Disabilities"

*These movements over the last half century have achieved the following results:

- Care security, including the "support (visiting care) for persons with severe disabilities" service
- Enactment of the Barrier-Free Law (2000) and improvement of barrier-free accessibility
- Enactment (2013) and enforcement of the Act for Eliminating Discrimination against Persons with Disabilities
- Ratification (2014) of the Convention on the Rights of Persons with Disabilities (CRPD)

2. Challenges for policy change toward de-institutionalization

On the other hand, the current situation of de-institutionalization is hindered by the following deep-rooted problems:

- The school education system that is almost entirely based on segregated education
- Various policy schemes, including welfare/social services for the persons with disabilities are designed on the premise that care is provided by family members.
- The number of new admissions to institutions is not decreasing and the waiting list is increasing: As parents who have been caring for their children at home become older, they feel anxious about the future and tend to wish to place their child with disabilities in institutions.
- In other words, measures for transition to the community require two lines of work: de-institutionalization from institutions and hospitals into the community; and transition to independent living from parents or other guardians' home.
- Currently, it is left to the self-help efforts of the staff of institutions and community care facilities: measures to support the transition to the community are only ideological and do not have a policy framework.

*Due to the COVID-19 pandemic, the CRPD review of Japan has been postponed, but it is expected to take place in the summer of 2022. With the Concluding observations (recommendations) that the CRPD would issue for Japan as a tailwind, Japan's policy change and implementation needs to be directed toward de-institutionalization at all costs.