

Philosophy of Independent Living Movement and Independent Living Center

Shoji NAKANISHI
Chairperson, Human Care Association

Independent Living Movement in the World

In the United States, the 1960s was the era of vigorous civil rights movement by African Americans. As a part of minorities, persons with disabilities (PWDs) were also eager for the implementation of civil rights. Since then, the movements by PWDs have had strong influence from civil rights movement.

In 1972, Ed Roberts was about to graduate the University of California in Berkeley. He had disability from polio and used wheelchair equipped with respirator. When he was a university student, he could use on-campus services, such as, assistance, housing, wheelchair repair, or peer-counseling. However, these services would be cut off with graduation. Thus, he established Independent Living Center (ILC) in community with support from his family and friends. This was the beginning of Independent Living Movement.

But, in another countries in this period, the reality went to opposite from ideal direction. The government of Netherlands implemented policies of colonizing PWDs, and built large-scale residential institutions “Head Dorf”. In the United Kingdom, the government promoted the policy of collective living of PWDs, and built group-homes with care. The world trend of policies for the life of PWDs was still headed to residential institutions or group-homes except the cases of independent living movement in the USA and “focus house ” in Sweden.

The Center for Independent Living of Berkeley had four principles:

1. A person with disability should live in the “community” instead of “institutions.”
2. A person with disability is neither a patient who should receive medical treatment, nor a child who should be protected or a god who should be worshiped.
3. A person with disability is in a position to control aid.
4. A person with disability is a victim of “social prejudice” rather than

his/her “disability.”

Up to these days, PWDs have been imposed life-long goals to become like non-disabled persons under the name of rehabilitation. For example, in the idea of rehabilitation, they can have good evaluation if they change clothes without help from other persons even though it takes two hours. However, the philosophy of independent living did not consider that the use of assistance is shame or hurting subjectivity. Rather, it declared the significance of choice and decision based on one’s own will. Rehabilitation was the only medical treatment in the limited period and should not be the basis to control PWDs’ life.

Following the beginning in Berkeley, the IL movement was quickly spread around in the United States. In the same year of the Center for Independent Living of Berkeley, PWDs in Huston established their ILC. In 1974, Boston also had ILC. In 1978, the collective effort of PWDs in the United States won the revision of the Rehabilitation Act. Due to the revision, PWDs could have more aid from the federal government. In 1979, Gerben DeJong, up-and-coming sociologist in the United States, published *The Movement for Independent Living*, and theoretically proved effectiveness of ILC in the comparison with rehabilitation. Due to the spread of the IL movement and its theoretical support, the ILCs sprung up all over the United States like wildfire.

In Canada, Henry Enns has aimed “emancipation from rehabilitation” and made steady efforts to organize PWDs at grass-root level since 1980. He began the movement in Kitchener, Ontario, and criticized rehabilitation as enforcement of protection and control. It was this period that the world trend for PWDs began to shift towards “independence”.

In the last 30 years, ILCs gained extra-ordinary achievement. In the United States, through the vigorous movement, ILCs won the article 504 of the Rehabilitation Act and had the federal government recognized their significance. Then, ILCs proposed ADA, the first legislation to eliminate the discrimination of PWDs, and succeeded its enactment in 1990. Currently, many PWD leaders are participating into the core of federal administration and taking initiatives in federal affairs. Also, growing numbers of ILCs take in charge of Medicare assistant services of federal government.

In Canada, her first ILC was opened soon after the establishment of DPI in 1981. In 1989, ILCs succeeded in establishing Self-managed Care

and Direct Founding System in each state.

In the United Kingdom, the parliament passed Direct Payments Bill as Community Care Act. The national government consigned to ILCs the promotion of Direct Payments at local municipalities.

In Sweden, with the support of the personal assistance user's coop, ILCs have taken in charge of self-managed personal assistance services for 14 years. The services are assessed by PWDs by themselves.

During September 21 to 25, 1999, the world conference of independent living movements was held in Washington, DC. This was the first IL world conference in the history, and gathered more than 100 PWD leaders from 50 countries. Thailand also dispatched many participants. The global coalition of PWDs was established at last.

Independent Living Movement in Japan

The IL movement in Japan began from the activities of *Aoi-shiba* ("Blue Lawn") in Kanagawa prefecture in the 1970s. *Aoi-shiba* was formerly a service club of persons with cerebral palsy, and became a radical movement organization at the time of an affair. In May, 1970, a mother killed her two-year-old disabled child in Yokohama-city, Kanagawa prefecture. Soon after this affair, associations of parents of disabled children and neighborhood associations made a plea of commutation of punishment. But, Kanagawa chapter of *Aoi-shiba* took actions of opposing to the plea. Even though the court turned down the objection from *Aoi-shiba* in the end, this mother's criminality was widely understood. Such actions of *Aoi-shiba* strongly influenced movements by PWDs.

In November 1970, some residents of *Tokyo Fuchu Ryoiku Center* began hunger strike with protesting against poor treatments by the Center. In September 1972, they set up tents in front of the building of Tokyo metropolitan government, and began sit-in protest. Their sit-in protest continued about two years. As a result, the metropolitan government set the policy of reforming rooms of residential institutions into compartments. In 1974, the government also established and implemented the program to dispatch care workers for persons with severe cerebral palsy. Looking at this progress, the national government began to apply to persons with severe disabilities "a special criterion for adding welfare benefits for care" in 1975.

With the arrangement of these programs, the conditions of persons with severe disabilities for their living in community gradually improved in

some regions.

In 1976, Tokyo metropolitan government established a committee for discussing house with care. Tokyo chapter of *Aoi-shiba* and the network of cervical spine injury raised the issue of house with care. The committee was the attempt to seek for the realization of the houses in communities by modeling the complex housing with care assistants in the United Kingdom. Some committee members recommended the system of dispatching care assistants to each PWD's house for independent life in community. However, the committee chose the group-home style house with capacity of 20 residents. Some members insisted independent life in community and resigned the committee.

In 1977, the committee was re-organized as the council for the construction of houses with care. The first house was built in 1979 and began operation in 1980. About the operation of the house, however, there was conflict between *Aoi-shiba* and other members of the council. *Aoi-shiba* insisted to operate the house as the space for the disability movement. But, other members wanted the house only to be residential space. The conflict was not stopped, and dismissed the construction of another house. If the operation of the house were successful, there might not be IL center.

In 1972, the first national conference of wheelchair users was held in Sendai-city. The conference led to the installation of ramps on a street and promoted the movement for community building. Since then, the national conference has been held in every two years in major cities, such as, Kyoto, Nagoya, and Tokyo. The need to operate the conference also fostered the growth of young PWD leaders and grass-root PWD organizations.

Corresponding to the surge of the movements for community building, Tokyo metropolitan government established a board on community development in 1973. Some PWDs participated as board members. Around this period, the first public housing for wheelchair users was constructed in Kirigaya, Kita-ku, Tokyo. Activities for outing to community led to the improvement of transportation devices. In 1977, a welfare foundation by major Japanese newspaper donated 50 foreign made electric wheelchairs to PWDs. This donation stimulated the metropolitan government to set the committee for studying electric wheelchair.

In 1981, International Year of Disabled Persons, Ed Roberts visited Japan, and promoted Independent Living Movement. Following Ed Roberts, many activists of IL leaders came and traveled around in Japan for holding

lectures. They discussed philosophy of independent living with great zeal, and moved audience.

However, they did not speak about services of ILCs at all. Because of this, it took some more years for the establishment of IL center in Japan. In June 1986, Human Care Association, the first IL center in Japan, was opened in Hachioji, Tokyo.

Human Care Association

On the administrative board of Human Care Association (HCA), more than 51% of board members should be PWDs in principle. President and secretary-general should be PWDs, too. This principle is also applied to about 200 IL centers in Japan, which are established modeled after HCA. Being PWDs the board members and president means that those who have been the recipients of welfare services become the providers. This also means that, if they provide good services, the quality of their life will be improved because they are service users at the same time. If not, they have to bear the low quality of life. Hence, they have to make effort for better services. As a result, local municipal and other PWDs evaluate IL centers as very fine service providers.

The first user of our PA service was a woman with amyotrophic lateral sclerosis (ALS). When I met her at the first time, her disease often made her tumble. Soon, she became not to be able to stand up. Half a year later, she became even not be able to speak. Thus, HCA set up a team of 20 personal assistants, and began 24-hour support for her. With the support, she enjoyed life in community with reading Holy Bible and writing her autobiography.

Because of the progress of her disease, she even needed 2 hours to drink a glass of water. There was a high risk that she would be choked by food. HCA, however, strongly hoped to respect for her will and support her as long as she enjoys current life in community.

We went to see her doctor for consulting her condition. The doctor told us his wish that HCA continue her support. He said that her will to live in community sustained her life. She made efforts to open pages of Bible and to operate word-processor by hanging her arms with ropes from ceiling. Her efforts maintained her muscle.

However, if she dies when she is using her personal assistant, police

would have to investigate for her death. Hence, in case of her death, HCA consulted with a lawyer and decided to make written contract. In the contract, it was written that HCA would owe responsibility if she die from assistance.

We asked her whether she wants to continue to live in community. She answered, "Yes". She could understand her situation and make her own decision. Her will to live in community was her self-decision. It was she to have sovereignty to herself. Hence, they trusted her and decided to continue her support.

More than 51% of board members of HCA are PWDs. This meant that if she had to be hospitalized, so we were. This is the reason why fundamental principle of ILC that more than 51% of board members should be PWDs is significant. Persons without disabilities give priority to the protection of organization. But, we are not. We do not mind the dissolution of our organization. We believe that the society would support us even if the dissolution happens. If there were ILC that does not respect for PWD's will, it is better such ILC be dissolved.

HCA provides services of peer-counseling, independent living program (ILP), personal assistance (PA), housing information, and lift-van transportation. Courses of peer-counseling and ILP are held several times in a year. The purpose of peer-counseling is provision of psychological support for PWDs who have had to bear prejudice and discrimination.

ILP is support in which PWDs learn necessary skills and know-how for independent living. Many PWDs have difficulty in expressing their wants, hopes and dreams even to their parents and siblings because they are too much conscious about relations with surrounding persons. Thus, through ILP, they acquire skills to communicate with others persons. For example, using role-playing in ILP, they learn how to tell their will to get married.

PWDs who only stayed home before can go out and have experience to learn necessary skills, such as, asking a favor, for independent living in ILP. For example, a senior PWD took out to a woman to a department store as a part of her ILP. The woman could not go out before because she worried about her toilet. However, she could learn how to ask for assistance for toilet by looking at behavior of her senior PWD. Of course, she could not make it at a once. But, 6 months later, she phoned us that she could ask for

assistance for toilet by herself.

Through programs on shopping and cooking in ILP, PWDs learn how to give instruction to personal assistants. ILP for such purpose is conducted in actual living area, and use roads and shops they may use. This is because they can directly connect their experience into their life in community. Therefore, ILP cannot be conducted at institutions, such as, rehabilitation center, which are remote from living area. In fact, ILP that was organized by a rehabilitation center of Tokyo metropolitan government did not work at all.

As to PA service, HCA provided 125,800 hours in total amount in 2005. 364 persons with disabilities are using our PA service. HCA employs 28 staff (11 PWDs/ 17 non-PWDs) in the office and 460 active full- and part-time personal assistants.

Another service by HCA is provision of housing information. PWDs often cannot rent a room. Therefore, HCA cooperates with real-estate agencies for information of available housing. We also tie up with carpenters, and support to remodel rooms and houses.

Along with these services, HCA has activities of advocacy, provision of information, and negotiation with local municipal. We also provide service of free personal consultation, which is consigned by local municipal. We have about 100 consultations per month. We also have activities to check the accessibility of train stations by joining a committee for accessibility, and to demand subsidies for ILCs.

In 1988, Tokyo Metropolitan government set up a foundation. I negotiated with the government to support ILCs by explaining that ILCs would be established widely in the nation and also cover services for elderly persons. As a result, the foundation decided to subsidize 10 million yen to each ILC for ILP and personal assistance services. Since then, 25 ILCs have been established for 10 years in Tokyo.

In 1996, on the basis of activities of ILCs, the Health and Welfare Ministry of Japanese Government at that time started the project to support the living of disabled persons in community and institutionalized the support system through consultation. ILCs collaborated for the establishment of the system in which ILP and peer-counseling were acknowledged as fundamental programs for support. Due to this project, peer-counselors were widely recognized as significant staff working with subsidies from

national government. This was the indication of paradigm shift in community support from professional- to disabled person-led support.

In 2003, the national government launched monetary support system for disabled persons. This system finally realized the provision of public supports under the contract on the basis of needs and decision of disabled persons. This was the near completion of the support system, except for the issue of direct-payment, of which ILCs had demanded for 20 years.

In 2005, however, the Ministry of Health, Labor and Welfare (MHLW) attempted to convert monetary support system into so-called Independence Support Act for reason of financial shortage derived from the success of monetary support system. This Act introduced the systems of medical-model assessment and screening panel by professionals and had disabled persons to face restricted use of support services. Organizations of disabled persons with more than 12,000 members united and protested in order to stop passing the Act in the Diet. Despite of their protest, this Act was enacted and implemented on April 2006. Currently, to prevent further deterioration of support service, ILCs, as the body of social movement, seek for the construction of unified organization under the coalition between disabled and elderly persons.