

原 著

The grass-roots activism of people with cerebral palsy in Japan : Early protest confronting the inaccessible bus system

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Abstract : Japan has one of the highest proportions of people over 65 of any country in the world, and recently the Japanese government has made an effort to improve accessibility on public transportation for older citizens. This effort is rooted in demonstrations almost 30 years ago by people with cerebral palsy who objected to their exclusion from public transportation. This paper describes how Japanese cerebral palsied citizens who challenged inaccessible public bus systems and analyzes the significance of these challenges for the entire country. In time, the country became alert and sensitive to the challenges faced by the severely disabled and one group in particular-- "The Japanese Cerebral Palsied Association" "Green Grass" (JCP), a group devoted to promote independence and equality for those living with the most severe disabilities. Initially, a manual describing how to handle wheelchair users was made without consulting people. The manual had serious problems, one of which was that if wheelchair users could not transfer to the regular bus seats due to their limited mobility, bus drivers would refuse to grant them access. Because the JCP wanted the society to accept all people regardless of disability, they launched the protest. On the afternoon of April 12 1977, over 100 cerebral palsied wheelchair users from all around the nation gathered at Kawasaki station next to Yokohama city, and held up a total of 28 buses which resulted in chaos in the terminal that lasted throughout the evening. After this historical protest, little progress was made, and negotiations between protesters, bus companies and the government lasted 20 years until an acceptable agreement was reached. As a result of the negotiations however, the Yokohama bus system has become the most accessible in Japan today (43.3% of all buses equipped wheelchair ramp with lowered floor). Use of public transportation is one of the basic necessity and rights for any member of our society. Revisions made to the public transportation system, improving access to persons with disabilities was an example of an important first step towards inclusion and integration of our society.

Key words; Disability rights history, Public transportation, Accessibility, Disability advocacy, Empowerment.

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Introduction

Japan has one of the highest proportions of people over 65 of any country in the world, and recently the Japanese government has made an effort to improve accessibility on public transportation for older citizens and citizens with disability¹⁾. What seems to be lacking, however, is that there is a pioneering protest against inaccessibility of public bus almost 30 years ago. This paper describes how Japanese cerebral palsied citizens challenged inaccessible public bus systems and the long-term significance of these challenges.

2.0 Start of the cerebral palsied (CP) group:

Jun-ichi Terada²⁾, a former secretary general of Japanese Cerebral Palsied Association "Green Grass" (JCP) stated as follows. "By an initiative of three young adults with CP, "Green Grass Association" formally started its activities in November 3, 1957 in Tokyo. In post-War period, reconstruction of national economy was a supreme priority to the government and the industry. Statutory measures for the disabled in this country were only for those who were as vocationally rehabilitatable, and people with regarded severe disability from childhood such as CP were left to private maintenance by their families". From the above statement we can assume that a hierarchal system existed, not only within the general population but amongst people with disabilities. In nursing homes, special education and rehabilitation facilities, all

interventions relied upon the "non disabled model" which rests on the assumption that people with disabilities should strive to become as non-disabled as possible. The goal for disabled people was "normal" development, "normal" anatomy, "normal" neurology, and "normal" productivity, so on. The public had greatly bias of non disabled model, and individual with disability was no exception. This system fosters a sentiment suggesting that the more severely disabled segment of society had less worth than those with more subtle disabilities. In particular, people with Cerebral Palsy (CP), were consider to have very severe disabilities and were discriminated against most. This injustice led to the birth of, the Japanese Cerebral Palsied Association (JCP), a group driven to promote independence and equality for those living with the most severe disabilities.

2.1 The CP group growing up:

The JCP however faced numerous challenges as many of the obstacles faced by the most severely disabled existed as a function of persuasive physical and social environments of Japan at the time. The JCP was the first group of people with disabilities to protest directly to the government in Japanese history in 1962. According to Terada²⁾ "We started our struggle in fifties and sixties with finding out would-be members who were confined in their parental homes as ugly beings and were hidden from local communities; we organized meetings and recreational events to provide opportunities for self-training for real life. Since sixties, more and more members of the Green Grass left their parental homes or insti-

tutions, and started independent living in community on public assistance, with constant dispute with local government workers who intended to cut benefit and push them back to family maintenance. The number of married couples among the members exceeded fifty already in 1966.



Figure 1

Soon it became clear to us that many members of the CP group were not eligible for tiny disablement benefit in newly enacted (1959) National Pension System, because its anatomical criteria did not adequately cover involuntary muscular movement or jerk called athetosis and spastic, nor speech difficulty, both characteristic of CP handicap. Lack of accessible housing in community including small-scale residential homes is also a major problem to tackle with. So, in 1962, we went to the Health and Welfare Ministry and made a direct appeal to the national government, first time in history of civilian disabled community in Japan.”²⁾

2.2 First time disability went to public:

At that time, when people saw an individual with a disability in public, the typical thought

that crossed their mind was “which institution (nursing home) did he/she run away from?” It was so rare to see anybody with disabilities in public that when they did go out most people wondered “What are they doing in public? These people were all supposed to be hidden away in special institutions and not displayed in public.” Then there was an incident. A member of JCP with severe cerebral palsy was walking on his knees with handing out his poetry to people passing by on a street with other singers and performers. A policeman came running saying “who is responsible for this? This is public place, not a freak show.” It did not occur to the policeman that the poet with CP was not any stranger than the other street performers (from a documentary movie entitled “Good-by CP” directed by Kazuo Hara, in 1972. Shissou production, Tokyo.).

2.3 Importance of independence from parents

The JCP was started as a kind of brother/sister hood organization in its early days, and gradually became a leader of disability rights movement. The activities of the JCP also gave opportunities to their members to realize and evaluate their status of being a person with CP in the society and to reflect on how having CP affects them as a person. By accepting and developing a pride of having CP through protecting their rights, the simple brother/sister hood of the JCP members developed something deeper and unique for them to share. We propose to define it as “the CP hood”. The CP hood also helped the members and others with CP to live more independent-

ly. Many members of the JCP have got a partner, and began to live independently with help of welfare, which was improved because of protests at the welfare office by the JCP. Terada also detailed as the following²⁾.

“our goal has always been the independence from parents rather than” Rehabilitation” in vocational context. We identify our lack of experience in various areas of community life as a major aspect of our social handicap compared with that of people with disabilities acquired after maturation. We believe that, for adults with disability from childhood such as CP, cutting off from protective parents and ensuring opportunities for real life involving risk-taking as early as possible is essential to personality building and maturation as an independent and contributing member of the community.” In a book of “Independent Living Movement and Disability Culture” , Professor Seiichi Kitano from department of social welfare at the St. Andrew University pointed out that without contribution of the local independent living centers there is no place with excellent community care system all over Japan³⁾.

2.4 Don't ostracize your baby because of the disability :

The public had a lot of sympathy for the parents of children with disabilities, sometime too much. When a parent of child with disability murder the child, the public campaigned to reduce the penalty of the parent and often the parent was considered to have committed no crime and went unpunished. The public thought that people with disabilities should be institutionalized for their own good and that

lack of institutions caused the parent to kill the infant and therefore the parent should not be held guilty. The JCP protested fiercely against the campaigning that ignores disabled child's right to live⁴⁾. This issue was also very personal to the members of the JCP because most of the member's parents had attempted to murder them when they were young or just a child, or parents told them that they tried double suicide but couldn't when they are growing up⁴⁾. The story told from people with disabilities whose parents had attempted to kill them shocked the public greatly around 1972 when these stories became public^{4) 5)}.

2.5 Inaccessible society:

It was rare to find people with severe disabilities using wheelchairs in public settings. Some of them were isolated in their parent's home from out of the main stream of society even in their adulthood. Others were settled in nursing homes or rehabilitation institutions⁶⁾. Not only was the physical environment ill equipped to meet the needs of these individuals but stigma and social perceptions in combination with a lack of government support made it challenging for these individuals to achieve an independent life style. Therefore, it should come as no surprise that accessibility was almost nonexistent in public places such as train stations, and other public buildings.

In time however more Japanese became alert and sensitive to the challenges faced by the severely disabled and one group in particular. The JCP took the lead in confronting some challenges faced by individuals with disabilities^{4) 6)}. Many members of this activists

group relied on public transportation, specifically the bus system which posed numerous problems for the disabled and thus found it an appropriate starting point to drive change. Change related to the Japanese bus system did not occur immediately however. For example, early on in the movement many individuals with disabilities approached the problem of access to the bus system by asking for assistance from those immediately around them. Often times they would take the approach of simply asking to be physically lifted to get in and out of buses as wheelchair lifts were nonexistent⁶⁾.

2.6 Problem of the first manual:

Many bus drivers were hesitant to regularly pick up individuals with disabilities because of the time burden and inconvenience. Eventually, as the demand for access grew the bus company produced a manual describing how to handle wheelchair users. The manual was a good start however serious problems remained. One was that if the wheelchair user could not transfer to the regular bus seats drivers would refuse to grant them access. As many individuals with more severe disabilities lack the ability to transfer and or maintain balance on a standard bus seat, large numbers of individuals with more severe disabilities were ultimately alienated by this policy. Because the JCP wanted the society to accept even those with the most severe disabilities, the activists launched another protest⁶⁾.

3.0 The Protest :

On the afternoon of April 12 1977, to change the discrimination against people with disabili-

ties, around 120 people with CP gathered for a protest at the main bus station in Kawasaki city and boarded the buses there^{4) 6)}. Once these individuals were on the buses, the drivers announced to the other passengers “This bus cannot move because of unsecured wheelchairs. Please transfer to another bus.” After this announcement, drivers left the buses. Those with disabilities stayed on the buses to protest this discrimination. When the bus company made a temporary bus terminal so they could avoid the protesters and serve their regular customers, protesters went to the new buses to ride so the bus company could not ignore the protest. Protesters held up a total of 28 buses which resulted in chaos in the terminal which lasted throughout the evening. Kawasaki city government decided to order special force police to clear protester off the buses that night. Over a hundred of special force police surrounded the protesters’ buses illuminated by many projectors. They tried to get into buses and of course it was easy for them. And three or four special force policemen for each the JCP member dragged them away from the buses^{4) 6)}.

3.1 In addition :

Protesters were careful to have the non-disabled volunteers leave the busses and the station after helping the members of the JCP on to the buses. Back in those days when there were protests for disability advocacy, people including police and government all tend to think that; “people with CP were not intelligent enough to make any protest plans and execute them. Therefore somebody else like non disabled volunteers around them had to

be controlling the people with CP.” Protesters wanted to make it clear that they the people with CP were the ones planning and executing the protests against the bus company and no one was controlling them⁷⁾.



Figure 2



Figure 3

3.2 Tenacious effort :

In the next year of the protest, the government put stickers of international symbol for wheelchair access on all public bus, although wheelchair lifts were nonexistent. Furthermore, the stickers were following a shameful segregation of “Please fold your wheelchair inside of bus”. Of course, protesters run to the government for strict protests several times⁶⁾. Later, a representative of the protesters was invited as a member of government committee for public transportation accessibility. In 1997 the first accessible “Non-step” public

bus was put into service. It took twenty years to make the actual changes after the initial protest. Protesters continued making efforts to educate the government and bus companies until an acceptable agreement was reached. As a result, the metropolitan area bus system has become the most accessible in Japan today (43.3% of all buses are accessible at 2006; http://www.mlit.go.jp/jidosha/sesaku/koukyo/barri_free/bf_bus/pref.pdf accessed at September 30, 2007), but further improvements are needed for 100% access. The Japanese “public” transportation system is not yet opened to all, and is still underdeveloped.

3.3 Public transportation policy and disability rights:

A public transportation systems that accommodates people with and without disabilities is an advantage to our society than a private system that accommodates only disabled people because public transportation create more opportunity for non-disabled people in public to have interaction with people who have disabilities. Also, disclosure of disability in public is an ultimate JCP strategy for the society to be more open to all, including disabilities. It is important for people living with disabilities to interact with and participate fully with non-disabled people in main stream society on a regular basis in order to ultimately change people’s attitudes and perceptions of disability. Society shouldn’t ignore the presence and the rights and needs of people with disabilities⁸⁾. Use of public transportation is one of the very basic necessity and rights for any member of Japanese society. Revisions

made to the “public” transportation system and improving access to people with disabilities is an example of an important first step towards inclusion and ultimately acceptance of people with disabilities recognizing them as valuable members of the society.

4.0 Conclusions and implications

The significance of CP activism in Japanese disability rights history : People with CP are significant pioneers in the Japanese disability rights history. These pioneers had advocated disability rights before Independent Living Centers⁹⁾¹⁰⁾ began widely spreading out whole over the country³⁾⁴⁾⁵⁾. Terada (2000)²⁾ reported as following after his attending Disability Peoples International (DPI) the first world assembly at Singapore “When I attended First World Congress of DPI in Singapore in 1981 on behalf of our Cerebral Palsied Association ” Green Grass”, it was my astonishment to find that our self-help movement of people with cerebral palsy was really unique in international disabled community in many developed countries, groups for CP are controlled by parents, teachers, doctors or individuals with other disabilities. In some of other countries, the term “cerebral palsy” was unknown even to national disability leaders. Of course, there are national organizations of parents and of professionals also in Japan, but our movement has been totally independent from them.”

He is proud of the JCP and its activism which was never found in the world except Japan. The JPC have always stressed how the independence from control of parents or professionals is important for living with CP for

life long. The individuals with the severest disabilities are assumed as ultimate advocates of human rights in the JCP policy.

Living with disability is, in other words, to be aware and proud of having disability^{10) 11) 12)}.

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