

PA (Personal Assistance): Acquiring Public Expense and Seeking Self-Management

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Note:

This article is a document prepared for the “Conference on Multi-Disciplinary Research of Disability Policy in China” that was held on December 17th, 2017 in Wuhan, China. It is largely the same as the text I had prepared two years earlier for the “East Asia Disability Studies Forum 2015” that was held on November 30th, 2015 in Beijing. My electing to give reports with nearly identical content at two events in China was in part because the attendees at the two conferences were different, but this decision was also based on what I think needs to be talked about in today’s China.

Recently, and particularly in the last few years, social movements in China have been placed in circumstances that are quite severe. Assertions and activism that raise the issue of “rights” directly have become difficult. These circumstances themselves must of course be changed, but this is not an easy thing to do. Under such circumstances, where are civic movements to come from, and how is a society in which it is easier for people to live to be created? As in most other countries, the percentage of the population that is elderly is increasing in China. Indeed, this phenomenon has progressed faster in that country as a result of its longstanding one child policy. This aging society is, in other words, a society in which the percentage of people with a disability is increasing. Helping these people is a major issue, no matter what sort of society exists or what sort of government is in charge. The need to respond to this issue, the need for initiatives to respond to this issue, can thus be acknowledged. Through this need being acknowledged, these initiatives and the organizations that carry them out are seen as necessary, and it becomes possible to strengthen their influence. In Japan, the movement of people with disabilities has taken the form of the users of services themselves taking charge of the provision of these services, while at the same time demanding greater financial disbursement from the government. Caregiving services are only a part of the activities of this movement and its organizations, but they are an important part. If a stable financial foundation can be created by these services, this may allow more energy and resources to be allocated to other activities. If so, the realization of this approach in today’s China can be thought of as both possible

and wise. This is why I decided to talk about our experiences in Japan and the systems we have created when I visited that country.

I describe and examine these movements and policies in *Ars Vivendi: Sociology of Disabled People Who Have Left Home or Institutions*, the third edition of which we published in 2012. The second edition of this book has been translated into Korean, but it has not been translated into any other languages. In the future I hope it will become possible to learn about these circumstances in Japan and the results we have achieved in English and other languages.

■Summary

I will briefly introduce what the disability movement in Japan managed to achieve and create over the years. There are two main achievements. One is a public care system providing people with disabilities with personal assistance up to 24 hours per day. Another is that the large part of this service is provided by organizations run by people with disabilities themselves.

I believe that letting people in the world know about this background can lead both to acquirement of the foundation of the disability movement in each country and to the advancement of the disability movement in each country. Therefore, I am going to talk about it today.

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Personal assistance (PA = personal assistance / personal assistant(s)) has been conducted by family members in many cases and it is done so even now. And this is not just limited to Japan and East Asia. Although the norm that family members should care people with disabilities is stronger in Asia, the situation in the world is not so different.

And in cases family members had difficulties providing assistance for people with disabilities institutions were established to accept people with disabilities. In Japan a disability movement for establishment of the institutions for children with severe disabilities occurred in the early 1960s and it was implemented to some extent. Also in the late 1960s to the early 1970s institutions were established to accept adult persons with physical disabilities (the number of mental hospitals had increased before then and hospitalized much more persons than other institutions but I omit its details this time. I will add information about it when necessary) .

Such institutions basically received positive assessment since they reduced heavy burdens of the family members and the society incurs them instead. However, some disabled persons raised an objection to the movement in 1970.

My writing in 2010, which includes a little details background of this time, is translated into Chinese, English and Korean (Tateiwa 2010a). I appreciate your taking a look at the following URLs when you have some time ([\[English\]](#) / [\[Korean\]](#) / [\[Chinese\]](#) / [\[Japanese\]](#)).

Based on the above it is insisted that interests of family members and persons with disabilities are not the same at all and that persons with disabilities live without control of their family members. In 1970 a protest occurred against the movement of the petition to reduce the sentence of parents who killed their child with cerebral palsy. Moreover, a protest started against treatment of the institutions. It sought improvement of the treatment at first. However, it then led to criticisms against institutionalization itself and then to movements for life of persons with disabilities in local areas. In this way it can be said that a new disability movement started.

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The disability movement in Japan has been mainly led by people with severe disabilities, such as those with cerebral palsy, and these people needed almost constant PA in their daily lives. The problem they had to solve is how they can obtain the assistance they require to live independently in a community, in other words, assistance other than from their families or institutions. In the beginning of the movement, this assistance was shouldered by college students and other people who were sympathetic to the movement, and was (and only could be at the time) provided on a volunteer basis. But this assistance was by no means reliable. Also, as long as such duties are only performed by a limited number of supporters and volunteers, the rest of the public or the society at large, which is the real culprit that makes lives of those with disabilities difficult, is exempted from responsibility to take care of them.

Therefore, the movement claimed that the responsibility of guaranteeing the livelihood of people with disabilities including provision of proper PA shall be shouldered by the society in general. At the same time, it stated that people with disabilities should be the masters of their own lives, and their lives should not be managed or controlled by someone else. This was only natural, since the movement started as a critique of the system of management imposed on them by institutions. Thus, the movement started to look for the best system that would ensure that their livelihood is guaranteed by the society, but in such a way that they could still be in control of their own lives.

Since the change of the system since 1970s is complex, I omit it here. In my another writing in 2010 ([立岩 \[2010b\]](#), [\[English\]](#) / [\[Korean\]](#)) I explain about it briefly (and this presentation overlaps its writing extensively) .

What we need to understand is that in the beginning what the government guaranteed was very limited. In the mid 1970s it was just twice a week and two hours at one time. Since they could not make their living only with the guarantee, they asked for improvement of the system while relying on volunteers.

Concerning the system, there were different systems in different regions. Under the same system the actual amount of supply differed, depending on the local governments and it differs even now. Although it is not normally desirable, this is the reality in Japan.

Also direct negotiations with the state and municipal governments were made to ask for increase of PA time and it was archived. Thus, as a result of the long negotiations with the state and municipal governments, in certain parts of Tokyo by combining public systems people with disabilities became able to receive daily 24-hour assistance from 1993. And from that time onward assistant systems providing such long-time support gradually began to spread to other areas of Japan.

Although it is true that Tokyo was the first to receive the improved system, it was not made so only in large cities. Since the number of persons with severe disabilities who need long time assistance was not so many, their supporters and support organizations as well as they made direct negotiations with the state and municipal governments and magnified the time. And once a standard is applied to a person, it is also applied to someone who needs the same amount. The reason for this is that the state and municipal governments have no reason to reject it. Also in most cases what a state and municipal government archives can be also achieved in the neighbor state and municipal government, too. In this way, the system was improved little by little.

For example in Kyoto, where I live, long time was not guaranteed even after year 2000. However, in 2008 direct negotiation was made between supporters as well as the ALS person who needed 24-hour assistance and the Kyoto City's department in charge of assistance (and I also participated in the negotiation). As a result, they agreed that a fee for 24-hours PA should be paid. It then served as a precedent for other persons who need the same service.

And recently lawyers have been involved in this negotiation. In some cases lawyers call on the state and municipal governments to approve the rights of the persons who need PA. In cases it does not work, they contend at law in some cases. In this way there is an example in Wakayama prefecture, neighbor prefecture of Kyoto, that a trial enabled a person to receive 23-hour PA a day.

However, in Japan as a whole, the government does not pay fees of daily 24-hour PA to all persons who need PA for 24 hours a day. In some regions such system (24-hour PA) is already available.

Through the system some persons who probably die in other countries can live. It is not exaggeration.

In 2004 I wrote a book entitled, *ALS: Immovable Body and Breathing Machine* ([立岩\[2004\]](#),

[\[English\]](#) / [\[Korean\]](#)) and I thus came to know persons with ALS (Amyotrophic Lateral Sclerosis)

[\[Japanese\]](#) / [\[Korean\]](#)). As its symptoms progress, this disability requires 24-hour PA. If ALS

persons are on a ventilator, they can keep living. It is said that the percentage of such ALS persons is only 1 % in the West while it is about 30% in Japan and Korea. Probably this difference comes both

from family members' involvement in care and from differences of values. In Japan the system

which has been reorganized for about 40 years enables persons requiring PA to keep living without their family members' burdens. [cf.→[Masuda Boston Challenge](#)]

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What I have talked about so far is "amount". The remaining issues to consider is who is in charge of the work and what kinds of organizations are involved.

One way of thinking was that public servants should be in charge of the work and the state and municipal governments should manage it. The state and municipal governments did not increase the number of helpers of public servants; rather they tried decreasing it because they worried about its labor cost. Moreover, all users preferred not to have this system. Under the system helpers who were sent from the state and municipal governments often looked down on users. Even if they were unhappy with it, it was difficult for them to protest it or ask the government to exchange helpers.

Rather it is better for them to choose helpers by themselves. Also it is easier for them to choose helpers if there are multiple private organizations. As a result, it is good to achieve a good balance between funding by the government and management by private organizations.

There are two ways for this. One is that the government provides money for users directly and users provide money for PA and it is called "direct payment". In Japan such form is applied in additional

amount for nursing care which recipients of public assistance can receive (I examine this system in my another writing in 2010 ([立岩 \[2010c\]](#), [\[English\]](#) / [\[Korean\]](#) / [\[Chinese\]](#))

However, the majority is that the government provides money for business institutions who provide the services and the institutions provide money for PA as their salaries (In cases individuals manage institutions just for themselves, it comes close to direct payment).

Such form started in Japan in 1980s. In the area of nursing home (welfare for the aged with disabilities) users and their family members paid less fees (about half the amount of works paid by the hour) and middle-aged housewives worked for less money (there was a word of "paid volunteer") and local non-profit organizations brokered them with a little fees.[★01](#).

Under the system there were some problems--users could use the service only during the housewives' free times and only female PAs were available. When the Center for Independent Living (hereafter CIL) started its activities in 1986, they referred to this way of management.[★02](#). The big difference was that they insisted that the fees be guaranteed publicly and disabled persons themselves took the initiative of managing the organization using the money which came from the system they acquired through their own movement. By doing so it became possible for users to use for a long time and use without economic burdens of users and their family members. Also they achieved the system in which females secured female PAs and males secured male PAs and users and PAs kept a fifty-fifty relationship and the CIL coordinated them.

Although the business of the CIL started from a small scale, some CIL organizations earn money of more than a hundred million yen for this business (there is a big gap concerning its scale) and uses the revenue for the activities of the whole organization.[★03](#).

What such relationship between the government and private organizations means is that private activities are influenced by the government policy. However, if the government considers that such service is necessary, private organizations can give advice to the government while maintaining its management base as long as they are in charge of the business. Although the government is not active enriching the system (and private organizations thus have a lot of difficulties[★04](#), they can still exercise influence to some extent from the standpoint of users and suppliers. And in this way we can form and develop private organizations/movements. This is the aim of my presentation.

■Notes

★01 Concerning the welfare for the aged, a system using tax has existed since 1970s. However, the supply of at-home services was very limited. Appearance of "paid volunteer groups" since 1980s came out because the existing system did not meet the demand of users. However, this kind of form did not meet the necessity. The Public Long-Term Care Insurance system was adopted in 2000. This insurance system mainly targeted the elderly of 65 years old and above, but there were attempts to change it so it would also cover people with disabilities, including those under 65. However, people with disabilities strongly opposed. The reason for it was that if that system was used to obtain personal assistance by a person with a disability living independently, it would merely cover a small part of assistance provided by persons other than the family, and though there were several types of services, if the person was to use home-visit assistance only, even for those with severe disabilities the system did not offer more than two to three hours of assistance per day. For that reason people opposed to the plan to cover them by this insurance system. And at that time, though not because of their objections, the plan was dropped.

★02 To address this problem, independent living centers began their full-scale work as mediators between people with disabilities and their personal assistants. The term "Independent Living Center" (ILC, or CIL = Center for Independent Living) became known in Japan after seminars with leaders of the American Independent Living Movement were held in the beginning of 1980s, and some number of organizations began to use that name. Still "Human Care Association" (*) established in 1986 in Hachioji-shi, Tokyo, was the first full-scale organization, in which mediating between the personal assistants and the users of their services was one of the major components of the activities, on par with advocacy of rights and Independent Living Programs. It is often mentioned that independent living centers in the US provide information to registered users and personal assistants but do not engage in anything else. Japanese independent living centers, on the other hand, actively engage in such activities. The number of independent living centers has gradually increased in Japan, and a national organization called the Japan Council of Independent Living Centers (JIL) was established in 1991.

★03 The number of independent living centers increased and the scale of their activities expanded, partly due to financial support provided for their activities by some municipal governments. However, over the years passed, the government support has not shown any qualitative or quantitative progress. Rather, individuals used independent living centers to obtain any public services available at the time and centers received mediator's fees. Another reason, which contributed to expansion of independent living centers, was the reforms of the system made after

2000, which I shall describe later, which enabled ILCs to gain certain profits from personal assistant dispatch business. That reform made it possible for some organizations to provide services to people with severe disabilities with communicative impairments, services, which other organizations and private enterprises hesitated to handle. Independent living centers made profit by providing such services and used the funds thus gained for their work on advocating rights and other activities, by which it was difficult (or, in case of some areas, impossible) to obtain funds. In cases of some independent living centers, the organization's manager and its sole user is the same person. In fact, this mode of operation is very close to the system where users receive public benefits to hire and manage their personal assistants.

★04 "The public support system for (not elderly) people with disabilities was changed to "public support payment system" in April 2003. This system, while leaving users some freedom to still receive direct payments, fundamentally adopted the method where the fees were to be paid to the agency providing the service. This new system did not change much in the areas, where people with disabilities had already organized groups to provide services for them, and where contact-based relationships had already been established between the users and the personal assistants, with the costs paid by the public budget. Thus, the new system did not aim at a quantitative increase of the services, and the actual form of its implementation was left for municipal governments to handle. Still, the system showed that the services, which up to that time were available in limited areas only, can actually be made available for everyone. It showed to many people that the system does exist and is usable. And for that reason, in areas, where only a feeble system of support had existed before, the level of services provided increased, though not very much, as it became easier to organize and manage organizations providing services. It was expected that in the areas, where the system is employed, the number of users as well as the budget used will increase, and both did in fact increase. This was very much expected in the Ministry of Health, Labour and Welfare, so the Ministry tried to stipulate the limit for the service in January 2003, just before the new system was announced. However, people with disabilities strongly protested against it and the Ministry failed. Both the number of users and the amount of services supplied thus increased, and the expenditure exceeded the budget. It was a good thing, and the fact that the budget was exceeded simply means that the estimate was wrong. However, for some this development was a problem. The institution that supervised the system was the Ministry of Health, Labour and Welfare, and though the workers there did not particularly want to reduce the amount of services provided, they were under constant pressure from the government and the Ministry of Finance to enact their policies within the limited budgeted.

The Ministry of Health, Labour and Welfare announced that it is financially impossible to continue in the status quo, and a (new) proposal to integrate services for people with disabilities within the public "Long-term Care Insurance" system was presented. One argument given at the time was that if people with disabilities are to be covered by the Long-term Care Insurance system, there will be no reason to worry, since it is an independent financial resource. Another is that people should take advantage of the Long-term Care Insurance system because other systems shall remain, without being absorbed by or integrated into the new one. This issue was brought to public's attention in the fall of 2003, and people with disabilities had to deal with this "integration proposal" for some time after that. For the time being the proposal was shelved - partly due to the protests of people with disabilities, but not entirely. The main reasons were quite different, one of them being the concern in the financial circles, where worries about the costs of the insurance were strongly voiced.

The negotiations between the government and people with disabilities continued, and, in the end, the government overcame the opposition and the Services and Supports for Persons with Disabilities Act was established in April, 2006. This new system tried to curb the increases in both services and governmental expenses by making the users pay 10 per cent of any service received. Strong protests against the system started to appear, pointing out that it aggravates the conditions for people with disabilities. All around the country people went to courts claiming the Act to be unconstitutional. In 2009, there was a change of government and the Democratic Party of Japan, which became the ruling party, announced their plan to abrogate the law. The suits were dropped and many meetings between the government and the representatives of organizations of people with disabilities were held. At this point it is difficult to predict how the situation will develop in the future and it is too early to take an optimistic view." (Tateiwa [2010b])

I stated the above things in Tateiwa [2010b]. Then due to re-change of power, promises made in 2009 were not implemented in the end. After the excerpt it continues further as follows.

"As can be seen from the above, the situation for people with disabilities is difficult in Japan (though perhaps not more difficult than it is abroad). Still, we can say that what we see now is a "counter-reaction" to what the disability movement managed to achieve during the last four decades or so. I do not think that there is any data or scientific papers that would show the actual achievements of systems of personal assistance around the world, but even in the Scandinavian countries, which are said to have and actually do have a very advanced social service (and many Japanese activists, who were trying to promote social security and welfare services, were learning from the systems and practices of the Scandinavian countries) are reducing services for ordinary people with disabilities. Also, voluntary suspension of life-sustaining treatment based on the

patient's "own will" is also spreading. In that light I would like to stress that the significance of the achievement of the Japanese disability movement, which has always been based on the claim that even those with very severe disabilities have a right to live, cannot be underestimated.

How should we conceptualize the problem of limited resources, which always comes up whenever we try to deal with the main issue of right to live? I shall deal with this problem elsewhere. But, in short, I would say that there are resources and there always will be. And the fact that they seem limited is because since the 1980s those, whose duty was to promote social security and social welfare - systems that should be shouldered by everyone equally - envisaged them merely as systems based on the level of income or consumption similar to the system of insurance and promoted them in this direction."(Tateiwa [2010b])

For further details of the movements and policies until 1995 I wrote chap.8 "Challenges of CILs" in *Ars Vivendi, 2nd Edition* ([Asaka et al.\[1995\]](#)) whose [Korean version](#) is also available. Concerning the movements and policies until 1990 I wrote in chap.7 "Quickly / Slowly: Birth and Development of Independent Living Movement"(Tateiwa[1990]) . This chapter is available from the 1st edition to the 3rd edition. Concerning the transition from 1995 to 2012 I wrote in chap.9 "Mutual Help Versus Disabled People: About 15 Years Since the End of the Previous Century" of *Ars Vivendi, 3rd Edition* ([Asaka et al. \[2012\]](#)) (Tateiwa[2012b]) This is available in Japanese version only. I also discuss it in chap 8. "We Decide, the Society Supports: Theory on PA System" (Tateiwa[1995b]) (it is available both in the 2nd and 3rd edition) and chap.9 "The Basics Are Simple In Spite of Variousness and Complexity" (Tateiwa[2012a]) (it is available in the 3rd edition only).

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