

Comparative Study on Successful Advocacy Work to Develop the Participation of Disabled People

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Abstract

The aim of this study is to identify conditions of successful advocacy work that develops the participation of disabled people in the field of welfare policymaking. I will review and compare the advocacy work of disabled people's organizations in developed countries in reference to Esping-Andersen's welfare regime typology. The points for discussion are the organizations' history, fundraising strategies, ways of participating in the policymaking process, relationship to the government, and role and influence.

Universal conditions for participation by the disabled in every country are as follows; the role of disabled people's organizations to be a community for them to have an identity as a member of society is very important especially when we are dealing with a familistic welfare system. Definite strategies and international networks are required to respond to the domestic welfare system and gain power to negotiate with and protest against the government.

Keywords : Disabled People's Organization, Welfare Policy, Advocacy, Participation, Comparative Study

1. Introduction

In the process of formulating policies for the disabled, more emphasis is being placed on participation by the disabled themselves, both domestically and internationally. In developed countries, one of the most recent examples of this took place in Japan; in 2010 the government set up a "Committee for Disability Policy Reform", of which more than half of the members are persons directly concerned (persons with disabilities and/or family members of disabled persons), to discuss the reformation of the policy for the disabled, and developed dialogue and cooperation with them.

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participation of disabled people in the field of welfare policymaking. I will review and compare the advocacy work of organizations consisting of the disabled themselves in reference to Esping-Andersen's welfare regime typology. The points for discussion are the organizations' history, fundraising strategies, ways of participating in the policymaking process, relationship to the government, and role and influence.

2. Esping-Andersen's Welfare Regime Typology

First, I would like to briefly outline Esping-Andersen's welfare regime typology. In his theory, the characteristics of social security in developed countries are explained by means of the model of international comparison. He presented the "welfare regime", which has had a great impact all over the world, through meticulous historical and quantitative analysis. He identified three factors; state, market and family, as subjects that produce and provide welfare, and classified countries into three models according to the significance of the factors; social democracy regime, liberalism regime and conservatism regime (Esping-Andersen, 1990). I would like to clarify these regimes by taking up three countries as examples; Finland as a social democracy regime, America as a liberalism regime and Japan as a conservatism regime. However, the Japanese system is not quite categorized into one model because of its characteristics. In Japan, the benefits of social security for the elderly are relatively large. Familism is strong in terms of the division of labor by gender. These characteristics are applicable to the conservatism regime. Meanwhile, the size of the system is relatively small due to parental care support, and other supports being small compared those in European nations. This characteristic is specific to the liberalism regime. In addition, the Japanese social system is based mainly on full-time employment. For this reason, the government support system is weak for citizens who have become unemployed. Because of these characteristics, the Japanese system is said to be positioned between the conservatism regime and liberalism regime (Ministry of Health, Labour and Welfare, 2012). I classified Japan as corresponding to the conservatism regime model from the viewpoint of its welfare system and policies for disabled people. Although Japan has national mandatory insurance systems such as a health insurance system and a nursing-care insurance system, the main model in its social security system is male workers who work for a company full-time in the lifetime employment system, and there is a strong trend of familism in welfare for the elderly and disabled.

3. Finland: Social Democracy Regime

First of all, as an example of a social democracy regime, I will outline the history and features of disabled people's movements in Finland. Finland has a "Nordic-type" government social welfare system based on the principle of universal coverage and a strong tradition of popular social movements (Helander and Sundback, 1998). The welfare system for disabled people, however, had not been developed very much until the 1960's, although there were disabled people's organizations and organizations for families of the disabled. In the 1970's, Kalle Könkkölä established Kynnys Ry (the Threshold Association) and promoted the Independent Living Movement for disabled people, which greatly advanced social activism on the part of the disabled¹. He served as a member of Helsinki City Council and the Parliament in the 1980's, and acted as the chairperson of DPI (Disabled People International) in the 1990's. Kalle has been leading the disabled people's movement both inside and outside of Finland (Könkkölä and Saraste, 1996, 2014). While public welfare service was developed in the 1980's, the National Council on Disability was established by the Finnish government in 1986, and participated in welfare policymaking for disabled people under the control of the Ministry of Social Affairs and Health. Half of the Council members were representatives of disabled people's organizations and organizations for families of the disabled, and the chairperson was elected from such organizations, while the other half of the council members were representatives of the central government (Ministry of Social Affairs and Health Finland, 2006, 2012). The Council has contributed to the improvement of the welfare system for disabled people through participation in policymaking.

Even in Finland, where the government bears the responsibility for providing welfare service, private welfare service providers appeared in the 1990's, and the rate of welfare service provided by NPOs increased (Yabunaga, 2008). Disabled people's organizations established the Finnish Disability Forum in 1999 to strengthen the network of disabled people's organizations, which worked on the Finnish government to prevent the degradation of welfare service and fallback of welfare policies, and committed to EU's welfare policies for disabled people². The Forum was involved in discussions and negotiations for the improvement of the Finnish welfare system, with the aim of ratifying the Convention on the Rights of Persons with Disabilities. One of the leaders of the Forum said the following to me about changes in the relationship with the government:

The people in charge of government welfare policies changed their stance and started to listen to the proposals from the welfare organizations while they conducted discussions and negotiations³.

It seems that advocacy on the part of disabled people's organizations raised the awareness of the people in charge of welfare policies, and a cooperative relationship was established.

In Finland, funding for activities of NPOs acting in the field of welfare including disabled people's organizations is supported by proceeds of gambling, which are assigned by Rays Foundation under the law of Finland. These proceeds are continuously distributed to organizations that are working actively, and they can be freely used for a variety of purposes. Compared with organizations in other countries with a social democracy regime, they have less intervention from the government and do not need to worry about funding.

Finland ratified the Convention on the Rights of Persons with Disabilities and its Optional Protocol on 11 May 2016 (Ministry for Foreign Affairs of Finland, 2016). This is rather late, in comparison with other Nordic countries. After revision of domestic laws, such as the Social Welfare Act and the Act on Special Care for the Mentally Handicapped, this was ratified through negotiations with the Finnish government by the Finnish Disability Forum and other disabled people's organizations.

To sum up, as Finland has a strong tradition of popular social movements, it has a basis for supporting social activities and social organizations in ways that include the provision of financial support. Advocacy activities carried out by disabled people add to this basis, and have promoted their participation in policymaking.

4. United States: Liberalism Regime

Next, I would like to outline the history and characteristics of disabled people's activities in the U.S. as an example of the liberalism regime. The U.S. is a typical example of this regime, because Americans value equal opportunity and self-responsibility, and think that public welfare should be limited to a minimum. The tradition of self-support and self-independence is reflected in disabled

people's activities as well.

Founded by Ed Roberts and his group in Berkeley, California, the Center for Independent Living (CIL) emerged from the independent living movement of the 1960's as a powerful force in helping people with disabilities achieve their independence. CIL began as the Physically Disabled Students Program (PDSP). PDSP was formed by a group of disabled students at the University of California, Berkeley who joined forces to make the full academic and social life of the campus more accessible to themselves and others. They realized that deliberate action on their own behalf was the only way for them to enjoy all of the benefits of campus life. In 1972, these students, along with people in the community who believed in the ideals of the independent living movement, formally incorporated as the Center for Independent Living. Their philosophies and goals established that: 1. Comprehensive programs with a wide variety of services most effectively meet the needs of people with disabilities. 2. People with disabilities know best how to meet the needs of others with disabilities. 3. The strongest and most vibrant communities are those that include and embrace all people. CIL became a support network, giving people the knowledge and the tools to assert their civil rights. Advocacy was central to this work (Pelka, 1997).

American people with disabilities established their identities by resisting discrimination, and they introduced the idea that the disabled are not clients but service consumers. It has been pointed out that the civil-rights movement by black people, women and minority people in the 1960's and the consumer movement influenced the independent living movement.

Meanwhile, the style of organizations was innovative in the way that they consisted of various people with different types of disabilities. Since the early 20th century, advocacy activities had been conducted individually by organizations for disabled soldiers and specific disabilities, for the sake of individual profits. However, the trend of the times was for discrimination against disabled people to gradually become regarded as a social and political problem. In 1971, Judy Heumann established "Disabled in Action", a New York civil rights organization that fought for equality for people with disabilities. These various organizations cooperated in actions to enforce the Rehabilitation Act of 1973, particularly Section 504, which prohibits discrimination against disabled people with regard to participation in government-funded measures and activities. They asked the federal government to establish a Regulation for Section 504, make it government policy and put it into effect. They asked the federal government to establish the Regulation for Section 504 to be translated into

government policy and put into effect. They took various measures such as a demonstration march, a sit-in protest and class actions to negotiate with the government, and succeeded in the establishment of the regulation. Meanwhile, some organizations acted with government subsidies for support programs for disabled people and influenced policymaking related to disabled people (Scotch, 2001).

These activities promoted cooperation among organizations in working towards the establishment of the Americans with Disabilities Act (ADA), and influenced their relationships with the government and Congress. Disabled people's organizations successfully united with the civil rights community to promote disability policy as a civil rights issue. The disability community established extensive networks among its constituencies, Congress, and the White House. Numerous effective and talented leaders emerged from within the disability community to help guide the ADA through Congress.

The National Council on Disability (NCD) played an important role in the establishment of ADA. According to the Rehabilitation Act, it was first established as an advisory council within the Department of Education in 1978, NCD transformed into an independent federal agency in 1984 and was charged with advising the President, Congress, and other federal agencies regarding all federal disability programs and policies. In 1986, NCD recommended enactment of an Americans with Disabilities Act, and then drafted the first version of the bill introduced in the House and Senate in 1988⁴.

Without these developments, the ADA likely would have failed because in the process of establishing the ADA, there was strong opposition from businesses that were unwilling to bear the costs for barrier-free buildings, facilities and environments.

In addition, there are many legal advocacy organizations for the protection of and advocacy for disabled people's rights, which have developed from law offices for public benefit. Some of these have contracted with state governments to act as members of federally mandated programs, and they have been intervening in the infringement of disabled people's rights and participating in the formulation of policies related to people with disabilities. The money from government contracts helps with their funding. (Takahashi, 2008).

Although tax incentives have been given to NPOs in the U. S., fundraising is a major challenge for most advocacy organizations, regardless of whether or not they are disabled people's

organizations. When they get money from governments as commission fees or contract money, there is a worry that their activities might be constrained by government policies. It is necessary for disabled people's organizations to monitor government activities continuously and express their opinions to be involved in welfare policy-making as advocacy organizations, not simply as service providers. There is a feeling of tension in their relationship with the government. (Takahashi, 2009).

5. Japan: Conservatism Regime

The last topic is the history and features of the activities for disabled people in Japan as an example of the conservatism regime, as I have told the reasons why Japan is included in this regime. After World War II, many organizations were established by people with disabilities and their parents, but I will focus on the social movements initiated by disabled people themselves. These movements are characteristic of Japan and regarded as advanced activities in disability studies, although their scale is not very large.

In the 1960's, a minimum economic security system was established for disabled people; however, government policies were dependent on families and promoted institutionalization of disabled people in spite of the international trend towards normalization and de-institutionalism. The parent groups also requested the construction of facilities that would provide economic security for their children, even after losing their parents.

After that, around 1970, movements of a different kind began to emerge. Japanese sociologist Shinya Tateiwa commented on two incidents. One was the activism and assertions of "Aoi Shiba no Kai" in Kanagawa, an organization of people with cerebral palsy. It was a small but sharply critical of the sympathy for people with disabilities and their parents⁵ including the problematic nature of Japanese society in which the existence of people with disabilities itself was not accepted and affirmed. The other was the start of a movement criticizing the management of the facility for people with disabilities in Fuchu Ryoiku Center, a big facility located in Tokyo. The residents of the facilities were forced to lead a regimented life without privacy. Activism in opposition to this kind of lifestyle was carried out by some of the residents and their supporters in Fuchu Ryoiku Center. It focused on specific improvements to the standard of living inside the facility, and was also connected to the movement pushing for residents to leave the facility and live on their own. This led to the start of a movement that rejected the image of people with disabilities as being in the custody

of their families, presented them as individuals with their own interests/assertions distinct from those of their families, and sought to have them live independently, without the protection and care of their families. In the latter half of the 1970s, this came to be referred to as the "independent living" movement. (Tateiwa, 2010 a)

In the 1980's, in addition to this movement unique to Japan advocating independence from parents and resistance to controlled life in institutions, the philosophy of the independent living movement was introduced from America. In 1986, the Human Care Association, the first independent living center in Japan, which coordinates and provides services for disabled people living independently, was established by people with disabilities in Hachioji, Tokyo. After that, many independent living centers were constructed in big cities, and in 1991, the Japan Council on Independent Living Centers (JIL) was established. Also in 1986, DPI (Disabled Peoples' International)- Japan was officially founded. In 2002, DPI-Japan, hosted the 6th DPI World Assembly in Sapporo with 3,000 participants from 110 countries. These organizations have established a network in Japan and international networks with countries in Asia, Europe and America, and have gained power to negotiate with and protest against the government. At the time of the great earthquake of 2011 as well, many organizations such as DPI-Japan and JIL promptly responded to help establish a support system for people with disabilities⁶.

The solidarity of these organizations of people with disabilities influenced the negotiation of policies for the disabled. This movement led to the enactment of the Services and Supports for Persons with Disabilities Act (April 2006). This new system was designed to curb the increases in both services and governmental expenses by making the users pay 10 percent of the cost of any service received. Strong protests against the system started to appear; the Act was claimed to be unconstitutional, because it aggravated the conditions for people with disabilities.

In 2009, the Democratic Party of Japan replaced the Liberal Democratic Party as the ruling party of Japan. The Cabinet of the Democratic Party of Japan changed the system for the discussion of policies relevant to people with disabilities in 2009, and agreed to establish the Committee for Disability Policy Reform under the control of the Ministerial Board for Disability Policy Reform, to which all of the ministers belonged.

In order for people with disabilities to be able to actively contribute their opinions and participate in discussions, the Committee was composed in such a way that more than half (15 out of 26) of the

members (including observers) were people directly concerned (people with disabilities themselves and their families) (Cabinet Office, Government of Japan, 2012). The Committee held 38 meetings from 2010 through 2012, and presented the Ministerial Board with reports on how policies with regard to people with disabilities should be modified. There were many difficulties in the process of drawing up the reports, since the organizations had different perspectives and opinions. Also, their power of influence was limited in reflecting their proposals on the legal system, since they dealt with issues related to various aspects of employment, income security, education, medicine and discrimination. However, the legal system was developed based on their reports. Examples include the modification of the Basic Act for Disabled Persons, and the establishment of the Act for Supporting Persons with Disabilities and the Disability Discrimination Act (Cabinet Office, Government of Japan, 2014). The Convention on the Rights of Persons with Disabilities was passed in January and took effect in February 2014. This is one of the results of the activities of disabled people's organizations and other advocacy groups.

In Japan, organizations acting in public fields such as medicine, welfare, education and religion are recognized as non-profit organizations (NPOs), which are approved according to the NPO Law (1998). However, their legal status is diversified⁷. Disabled people's organizations such as Social Welfare Corporation (Shakai Fukushi Hojin), Public Benefit Corporation (Koeki Hojin) and Certified Specified Nonprofit Corporation (Nintei Tokutei Hieiri Katsudo Hojin) are given tax advantages. However, in many cases, organizations have to undergo strict screening and follow certain procedures to receive a tax advantage. The requirements for tax exemption with regard to income and donations are stricter in Japan than in the United States, and disabled people's organizations, especially those whose main activity is advocacy, have difficulty with fundraising.

6. Conclusion

I reviewed and compared the advocacy of disabled people's organizations in Nordic countries, United States and Japan. This discussion covers the organizations' history, fundraising strategies, ways of participating in the policymaking process, relationship to the government, as well as their role and influence.

My research results are as follows: Disabled people's organizations are actively participating in policymaking both in the Scandinavian countries, classified as having a social-democratic regime,

and in the United States, which has a liberal regime. However, there is a difference in the cooperative relationship with the government between these two regimes. In Scandinavian countries, welfare policymaking is done with stronger support from the government than in countries with other regimes. Although welfare for people with disabilities was not satisfactory initially, policymaking has been done smoothly, thanks to the activities and negotiations carried out with the government on the part of the network of disabled people's organizations. In the United States, on the other hand, there is often a tense relationship between organizations and the federal or state government when policymaking is carried out. The Rehabilitation Act, Article 504, which is the first law that bans neglect of reasonable accommodation as a form of discrimination against people with disabilities, as well as Americans with Disabilities Act were not enacted smoothly. The organizations have always checked and monitored the government and congress, fearing that if they didn't, welfare services and benefits might be cut. They try to develop and maintain a path for the participation of people with disabilities and the establishment of advocacy systems.

In Japan, people with disabilities had quite a lot of power to act, and they negotiated with local governments and organized a national campaign against the Services and Supports for Persons with Disabilities Act; they only achieved real participation in policymaking with the change of administration in 2009. However, the foundation for participation of people with disabilities and policy reform, which was constructed by the Committee for Disability Policy Reform, has been succeeded by the Council of Measures for Persons with Disabilities, which continued even after the Liberal Democratic Party returned to power in December 2012.

It is conventional in the domestic and national Japanese welfare policymaking process for councils consisting of professionals and stakeholders including disabled persons or/and their family to be established. In order for people with disabilities to express their opinions and substantially participate in policy-making, it is necessary to increase their numbers and empower them. Also, the idea that people with disabilities should be represented by family members is still common; the fact that people with disabilities and their families have different needs is not fully recognized. Under these difficult circumstances for advocacy activities, it may be important to establish networks regardless of the types of disabilities, and to take the opportunity presented by a change of government to have the government understand the international trends with regard to welfare for people with disabilities, such as the ratification of the Convention on the Rights of Persons with Disabilities and the promotion of participation by people with disabilities in policymaking with the

slogan “Nothing about Us without Us”.

Lastly, I summarize the universal conditions for participation by the disabled in the countries I studied. Universal conditions for participation by the disabled in developed countries are as follows. The role that disabled people’s organizations play as a community for the disabled is very important, as it enables them to have an identity as members of society, especially in the case of a familistic welfare system. Specific strategies and international networks are required to respond to the domestic welfare system and to gain the power to negotiate with and protest against the government.

There are issues to discuss, such as the pros and cons of the conservatism regime and the relationship with Esping-Andersen’s welfare regime typology. It is also necessary to make comparisons among countries that have the same regime. Furthermore, the theoretical validity of the regimes concept itself should be examined.

This time, I studied the conditions in developed countries, and as a future research topic, I would like to study the conditions in developing countries that have quite different welfare policies. This would enable me to examine the outcome of this study through comparison with the conditions in developing countries.

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Notes

- 1 See the website of Kynnys ry at <http://kynnys.fi/> (accessed 20 January 2017).
- 2 See the website of the Finnish Disability Forum at <http://www.vammaisfoorumi.fi/> (accessed 20 January 2017).
- 3 From my interview in March 7, 2012 to then chairperson of the Finnish Disability Forum Ms. Merja Heikkonen.
- 4 See the website of National Council on Disability at <http://www.ncd.gov/> (accessed 27 January 2017). It was under the Clinton Administration that most of the Council members became disabled persons for the first time

(Pelka,1997).

- 5 In the beginning of 1970's, Aoi shiba no kai engaged in criticism of efforts being made by local organizations and the association for parents of children with disabilities to secure a full pardon for a mother who had killed her two year old child who had suffered from cerebral palsy. These organizations' activities were reported in newspapers and on television, and there were calls for greater support and assistance for parents, criticism of the inadequateness of facilities, and growing sympathy for people with disabled children (Tateiwa, 2010 a).
- 6 See the website of Human Care Association at <http://www.humancare1986.jp/english.html>, Japan Council on Independent Living Centers at <http://www.j-il.jp/english> and Disabled Peoples' International- Japan, at <http://www.dpi-japan.org/english/e-japan.html> (accessed 30 January 2017).
- 7 For more information of the definition of nonprofit organizations and their conditions of tax advantage, refer to the Japan NPO Center Website at: <http://www.jnpoc.ne.jp/en/> (accessed 30 January 2017).

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障害者政策における当事者参加の比較研究

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要旨

障害者政策の進展とともに、政策形成の場への当事者参加が進み、その体制が整えられてきた。本論では、エスピノ・アンデルセンが先進諸国の社会保障の特徴をふまえて提示した福祉レジームの類型に基づいて、社会民主主義レジームに分類されるフィンランド、自由主義レジームに分類されるアメリカ合衆国、保守主義レジームに分類されるとする日本において、障害者政策の歴史、障害のある当事者組織の形成と運動の発展、政府との関係と参画のあり方を比較検討し、障害のある当事者組織の政策形成への参加を促進する背景と条件について考察した結果、障害のある当事者組織が果たす役割と障害種別を越えた国内外のネットワーク化という共通性を確認した。

キーワード： 障害のある当事者組織，障害者政策，アドボカシー，参加，比較研究