

Original Paper

QOL of People with Developmental Disability from the Perspective of Welfare Culture: Based on Deinstitutionalization

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Abstract

I compared internationally the role, the current situation and future direction of the “institution.” The role of the institution has played a big role in the area of QOL of adults and children with developmental disabilities. First, I made a comparison among the US, Nordic countries and Japan on the numbers of clients and professionals. I discuss the process, current situation and challenge to live in a community after deinstitutionalization. I suggest that we need to analyze the future of our social welfare system from the perspective of social welfare culture as soon as possible.

Introduction

When I was studying the QOL of children with developmental disabilities, and comparing differences in services and facilities among European countries and Japan, I came to realize the need to find a problem-solving method through essential discussion, not a superficial one, concerning the differences among the above countries. In other words, I believe we need to consider each country’s historical and cultural background and interpret these comprehensively before trying to deal with them.[1-3]

It is because we need to rethink the various characteristics of culture in the area of welfare that the term “Welfare Culture” is gradually being accepted in Japan.[4]

So, from the perspective of a person who works in a welfare facility, I shall discuss what kind of role we, as an “institution”, should take, and in which direction we should go. That is one of the challenges for QOL.

Especially, regarding “deinstitutionalization,” I explain tendencies in Europe and the US, compare them to our situation, and discuss which direction we should take.

Diversity of “Institution”

When the idea of deinstitutionalization was introduced to Japan, some people took the idea to mean “a movement to close all institutions.” So at that time, the idea of deinstitutionalization offended many workers at institutions and their families. It seemed too early to introduce the idea to Japan considering the level we were at in terms of community living. Also, many people did not really understand the principle of deinstitutionalization at that time.

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Hideo Itokawa, a leader of space engineering in Japan, has compared the differences in thoughts and behavior of Japanese and non-Japanese people. He describes it as a difference between “Why” culture and “How” culture. Influenced by Europe, even China and Korea, which are Asian countries, have a “Why” culture basically. Compared to them, Itokawa points out that Japanese people tend to think from only the perspective of “How.” [5]

In other words, we tend to think only how we can proceed with deinstitutionalization because European countries are doing it without asking if or why. Thus, Itokawa seems to give us a warning signal.

So, I think it is necessary to start asking *why* “deinstitutionalization?” That should be the starting point.

At first, we need to understand our history as to why we had to have an “institution” dealing with developmental disabilities including severe physical and mental disabilities. And, we need to share clearly our specific ideas of the direction that we should take. After that, we have to think whether each residential institution should still exist. Then, we have to decide the following: If it should exist, what kind of role should it have? Or, if it should not exist, why not, and how should it close?

From this perspective, I have studied Western institutions and facilities. I need to say that though all these programs or facilities are called “institutions,” their real roles are diverse. Thus, it is not rational to treat them all alike and discuss their roles without specifying their diversity and basic problems.

The History of Institutions in Europe and the US and their Current Situation

First, I focus on “institutions” in Europe and the US, precisely institutions for people with intellectual disabilities. In the US, public attention seems to have focused first on the issue of government-run facilities.

(1) Public Developmental Care Centers in the US

The picture book “Christmas in Purgatory,” [6] a number of slides by Wolfensburger, a leader of deinstitutionalization in North America, and a film about Willowbrook [7], which was the biggest government-run institution in the US, showed how institutions really cared for their clients and accused them of dehumanized treatment.

Recently, the film “Willowbrook after twenty-five years” was published. According to this film, Willowbrook had more inmates than the “Purgatory” institution with 4,727 people with intellectual disabilities packed into one facility. Three fourths of these people were below IQ 35 with severe or the most severe intellectual disabilities. One third were not able to control their epileptic seizures, and more than half had been placed in the institution for more than 20 years. In addition, the number of staff was continually reduced due to budget cuts. At the worst time, one worker had to care for 40 clients.

Four conditions were pointed out as defects: overcrowded conditions, unsanitary conditions, a lack of professional workers, and a lack of the medical and educational programs which were necessary for rehabilitation and development.

This was not only Willowbrook’s problem. Every government-run institution had a similar problem. That meant an intra-change was not enough to solve the problem. They found the best answer was to close the public institution.

In 1978, in New York State with a population of about 18,000,000, there were 20 public institutions where 25,000 people with developmental disabilities were placed. The average number of clients at an institution was reported as 1,250.

In sum, even in these government-run institutions, there were only 1.4 beds for every 1000 people in the community. There were other non-governmental facilities in New York; thus the ratio of beds to population must have been higher.

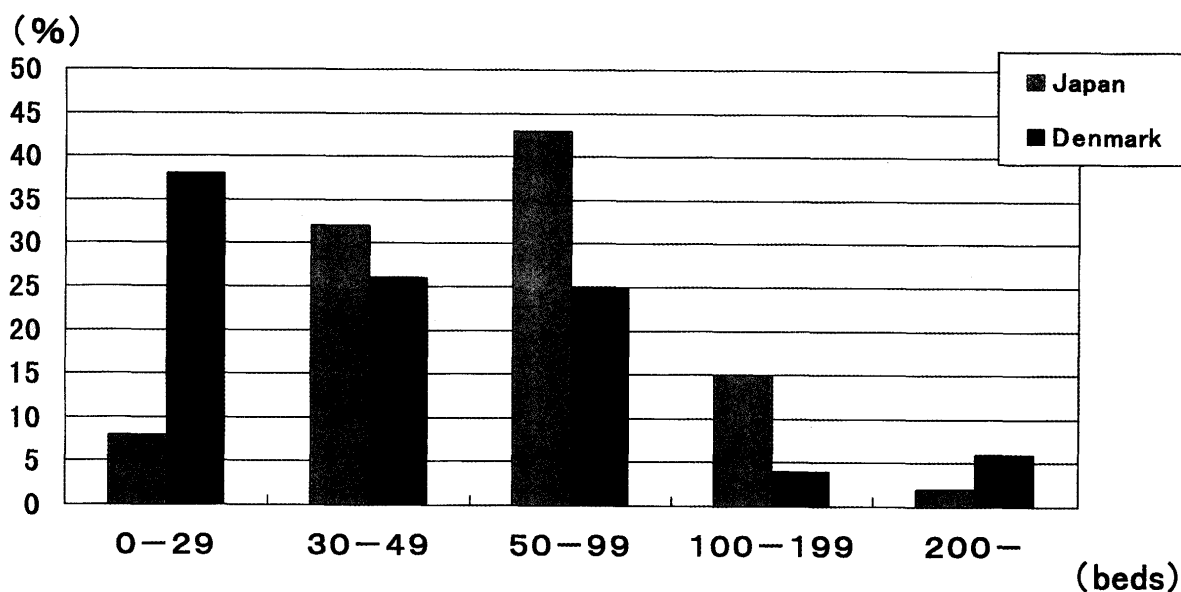


Fig. 1 Scale of Institutions for People with Developmental Disability in Denmark and Japan (1984)

(2) Institutions in Nordic countries

I now introduce the conditions in Nordic countries.

I once compared and discussed the size of institutions for intellectually disabled people in Denmark and those in Japan.[8] According to this comparison based on 1984 statistics, the most numerous type of institution in Denmark was a small size one with fewer than 30 clients, while in Japan a middle-sized institution with from 50 to 100 clients was the most common type.

However, in terms of big institutions with more than 200 clients, Japan had less than 2 percent versus Denmark with 6 percent, which was more than three times that in Japan. It is obvious that the Danes depended on big sized institutions because the central institutions had from 400 to 800 clients at that time in Denmark. Although the average number of clients in general was about 500 people, some institutions had more than 1,200 people. (Figure 1)

I realized that Denmark depended on large scale institutions, though not as large as some American ones, which had more than 1,000 clients at each institution. The Danes relied on large institutions more than Japan did in 1984. But around that time Denmark became the first country to propose the idea of "normalization" (small-scale institutions) and the idea came to be accepted in other countries, too. I felt something strange about this, so I started research on the history of "institutions" in Nordic countries and their development.

"Deinstitutionalization" in Nordic Countries

(1) Countries in Northern Europe

The Nordic or Scandinavian lands consist of small countries. Even in the biggest country Sweden, the population is only 8,800,000, about the same as the population of Osaka Prefecture. The populations of Denmark, Finland and Norway are about 4,000,000 to 5,000,000, about the same as that of Fukuoka Pref., Hyogo Pref., and Shizuoka Pref.. Also, Iceland has less than 300,000 people which means its population is less than half of the population of Tottori Pref., which has the smallest population in Japan.

In other words, in terms of population, an individual country in Nordic countries can be considered to be

the size of a prefecture in Japan. These five Nordic countries are all different in politics, economy, medical and welfare system and culture. Each country, whose size is like a prefecture in Japan, has its individual characteristics.

For example, Finland does not seem to be very “North European.” It seems to have more similarity to Russia in general. Another example is Denmark. Denmark has been deeply influenced by the culture, thoughts and politics of the European Continent. Thus, Denmark seems to be more European Continent oriented, unlike the other Nordic countries.

In this article, I shall compare and discuss some phases of an “institution,” such as the ratio of residential clients versus the public population, the basic role of an institution, the professionalism of the staff, and personal organization.

(2) The Golden Era of the Institution

Prof. Tøssebro, teaching at the school of sociology of Tront University, Norway, explains the condition of institutions for people with intellectual disabilities.[9,10]

According to Tøssebro, the 1950s were the golden era of the institution because the welfare system for people with intellectual disabilities was mainly based on residential institutions. Briefly looking at the situation in the Scandinavian countries as Tøssebro describes it, the author recognized two tendencies. Denmark and Finland relied on the model of a big size medical institution. On the other hand, Sweden and Norway offered their services through a system that included both large and small-size institutions.

In addition, services in both Denmark and Sweden were kept in good condition, but Norway and Finland did not reach the same level as these advanced countries. Tøssebro says there are four types of care system at institutions in Scandinavia. (Table 1)

Table 1 Types of “Nordic” Institutions for People with Intellectual Disability

	Advanced Country	Less-Advanced
Huge Institution	Denmark	Finland
Mixed Institution	Sweden	Norway

In the 1950s, in Denmark and Sweden, the advanced countries in the area of welfare system, conditions were as follows: In Denmark, whose population was 4,500,000, residential institutions for people with intellectual disabilities had 7,725 beds. That means 1.8 beds were available to every thousand people in the community.

In Sweden, the population was approximately 7,000,000. They had 9,185 beds, that is 1.3 beds for 1,000 people in the community. Later, they widened the capacity to take in more clients at an institution until, in 1975, they had 1.7 beds for 1000 people in the community.

By looking at Denmark, which had large institutions, and Sweden, which had mixed institutions on both a small and a large scale, and comparing them, we find that the average number of beds at an institution in Denmark in the 50’s was 483. While in Sweden, the average number of beds was only 54. If we look just at the average number, we might think that Sweden had mainly small size institutions. In fact, even in Sweden, large institutions, which had from 200 to 500 beds, existed.

From the 50s till the 70s, the theory of normalization began to be accepted widely. During that era, both Sweden and Denmark showed the following changes: Sweden increased their capacity until it was 1.6 times larger at each institution, and each institution was enlarged up to an average of 80 beds. They increased the scale but only temporarily.

On the other hand, Denmark began to decrease the number of beds. However, their average number of beds is still 233. Compared to Japan, the number is overwhelming. (Table 2)

Table 2 The Average Number of Clients at an Institution in Nordic Countries

	1950		1970
Sweden	54	→	80
Denmark	483	→	233

Even in the 70s, the situation at institutions in Denmark remained as above. Thus, it is easy to imagine how greatly they had been oriented toward large institutions in the 50's.

(3) "Deinstitutionalization" in Sweden

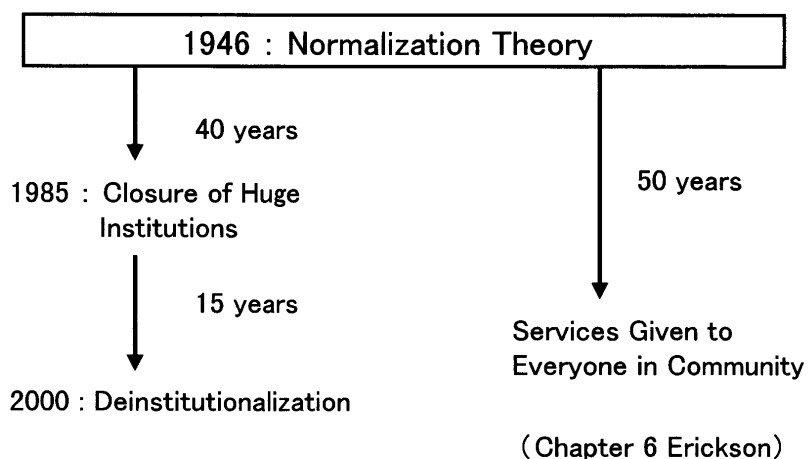
I will explain the change from "the Golden era of the institution" to "Deinstitutionalization." Sweden, the welfare state, reached its highest capacity to keep people in institutions in 1968. They had beds for 140,000. From that point on, they tried to decrease the capacity. In other words, they cut the number of beds and closed some institutions. In 1999, the capacity was reduced to 440. By 2000, it was supposed to be zero. It took 30 years to complete the change. (Table 3)

Table 3 Change in Number of Clients at Institutions in Sweden

Year	Number of Clients
1968	14,000
1985	8,000
1993	2,500
1997	960
1999	440

From another perspective, it took 40 years from 1946 when the theory of normalization was first proposed, to its implementation in 1985 through regulations which rejected the existence of institutions. Not only that, but it took an additional 10 years (over 50 years in all) to develop alternative services for people with intellectual disabilities in the community. (Table 4)

Table 4 Deinstitutionalization in Sweden



I'd like to emphasize that even Sweden, the welfare state, needed 40 or 50 years to complete the closing of institutions and the developing of services in the community, based on normalization.

(4) "Deinstitutionalization" in Norway

I will describe Norway, which was delayed in the area of welfare system.

Compared to other Nordic countries, Norway was behind in their services for people with intellectual disabilities in the 1950s.

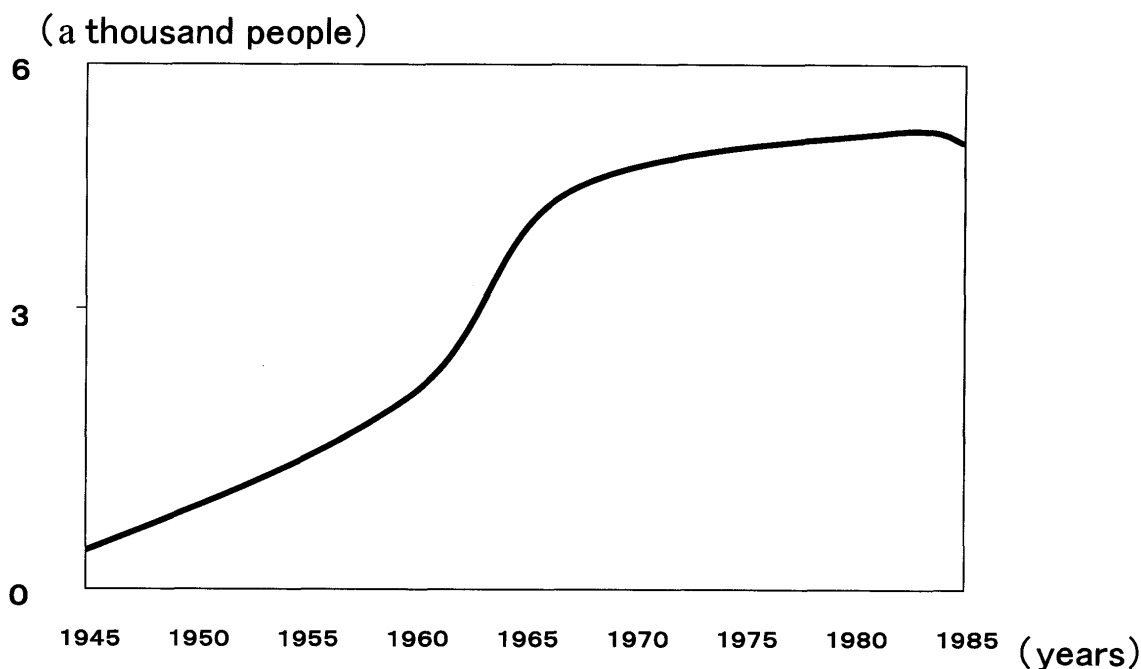


Fig. 2 Number of Users of Institutions for Developmental Disabilities in Norway from 1945 to 1985

In 1945, institutions in Norway and Finland were not fully equipped. Norway had only 600 beds in total for people with intellectual disabilities, thus only 3/10ths of a bed was offered to 1000 people in Norway at that time. Later, they tried to fill the lack of facilities and increased the average number of beds to 1.3 in the early 1970s.

After that, they built more residential institutions and the number of institutions became much higher up to 1981. Even though the concept of normalization became popular around 1965, Norway's institutions were expanded. (Figure 2)

Then, the concept of normalization was suddenly accepted. Sweden has completed zero institutions by 2000 and Norway had already completed it by 1995. Norway has been delayed in terms of equipment, but they are advanced in the area of Deinstitutionalization. Thus, their process can be a good model for Japan.

In the late 1960s, Norway had approximately 60 clients at an institution. In the late 70's, the average number was cut down to 50 clients and this number dropped to between 40 and 23 in the 80's. This was a smaller size institution than in Sweden.

Especially, from late the 70's to 80's, along with the development of equipment at existing institutions, they began to place only 10 to 15 clients at new facilities. These new facilities were listed under institutions, but they were similar to group homes in the US and Japan. These small facilities, which can be called group homes, played a role to help normalization proceed.

(5) "Institutions for People with Intellectual Disabilities" Were Originally Hospitals in Western Countries

Japanese people tend to assume institutions in Western countries are the same as those in Japan. However, as I described earlier, the scale itself is quite different. Also, the programs of care at these institutions are different. I shall point out differences concerning professionals and goals.

In the middle of the 1950s, a residential institution in Sweden was based on a medical model. The institution seemed to be based upon a hospital. "Deinstitutionalization and Community Living" (Nakazono and Suemitsu, 2000) says that users were treated as "patients."

At that time, even though a child with intellectual disability had a right to have an education, persons with a severe intellectual disability were likely to be treated as patients at a hospital. But as the concept of

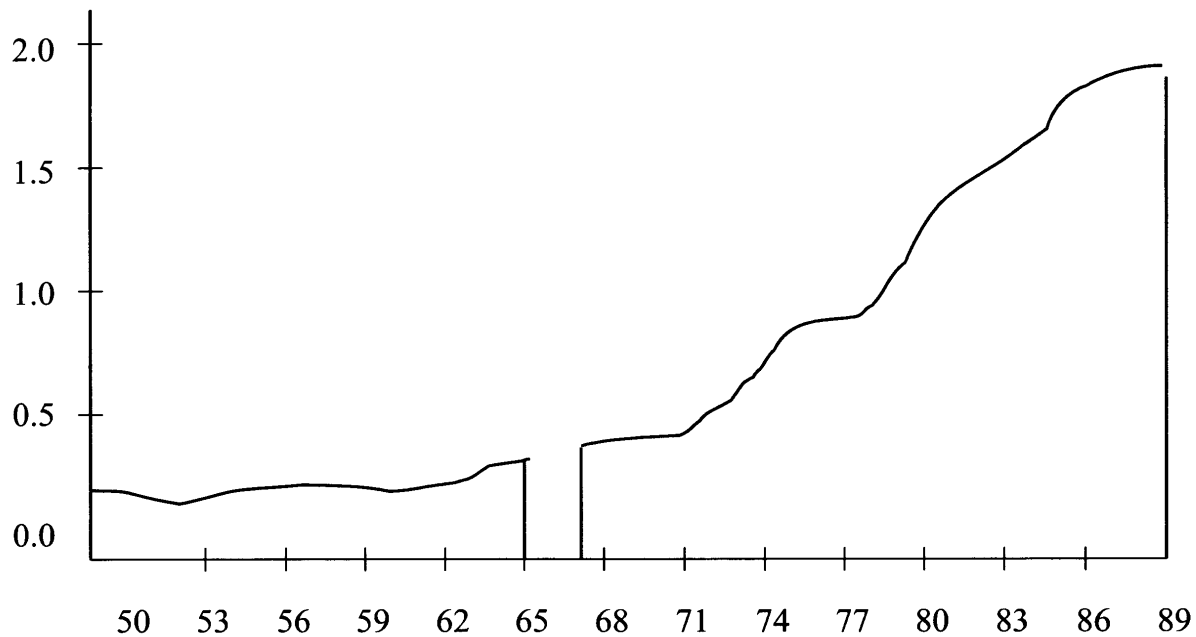


Fig. 3 Number of Workers at Institution: Ratio at Residential Institutions in Norway (1950-1989) (ratio of users to workers)

normalization penetrated into the minds of the community, citizens changed their view of an intellectually disabled person to seeing him or her as an ordinary citizen.

The situation in Norway was similar to the one in Sweden. An “institution” was formerly accredited and managed by the same regulations as a hospital.

There was a difference in the number of workers. In Norway, around 1950, the ratio was 0.4 workers to 1 user. In other words, one worker cared for 2.5 users. But, they improved this ratio and increased the number of staff till in 1989 1.8 workers cared for 1 user. (Figure 3)

In three decades between 1960 and 1989, Norway improved the ratio of workers to users from 0.40 to 1.81.

Looking at our situation in Japan, even though we try to add more workers, one worker still cares for 3 users. That is 0.3 or 0.4 workers to a user. We have to notice that our situation is like the situation in Norway 40 years ago.

(6) The Current Care System in Norway

I have explained the system in Norway, where deinstitutionalization has now been completed so far as I understand. Of course, the situation in Norway can not be the same all over. Here, I point out the situation in Trondheim county, whose population is 500,000, as an example.

Figure 4 shows three basic kinds of living, independent living, living with a family and living at a group home. People go to a day program or to work from these residences on weekdays and go to a leisure club on the weekend. If they face an emergency, they have 24-hour service from a rehabilitation center or a respite care program in the community. (Figure 4)

The above is the history and current situation of “deinstitutionalization” in Sweden and Norway, both of which have adopted the mixed care system with large and small institutions.

Looking back at the footsteps of both countries on their way to “deinstitutionalization,” I could say there are three steps. (Table 5) I think that the different attitudes they took at the second step, as to how to work on reducing the scale of an institution, made a gap of years between Sweden and Norway in the time it took to complete deinstitutionalization.

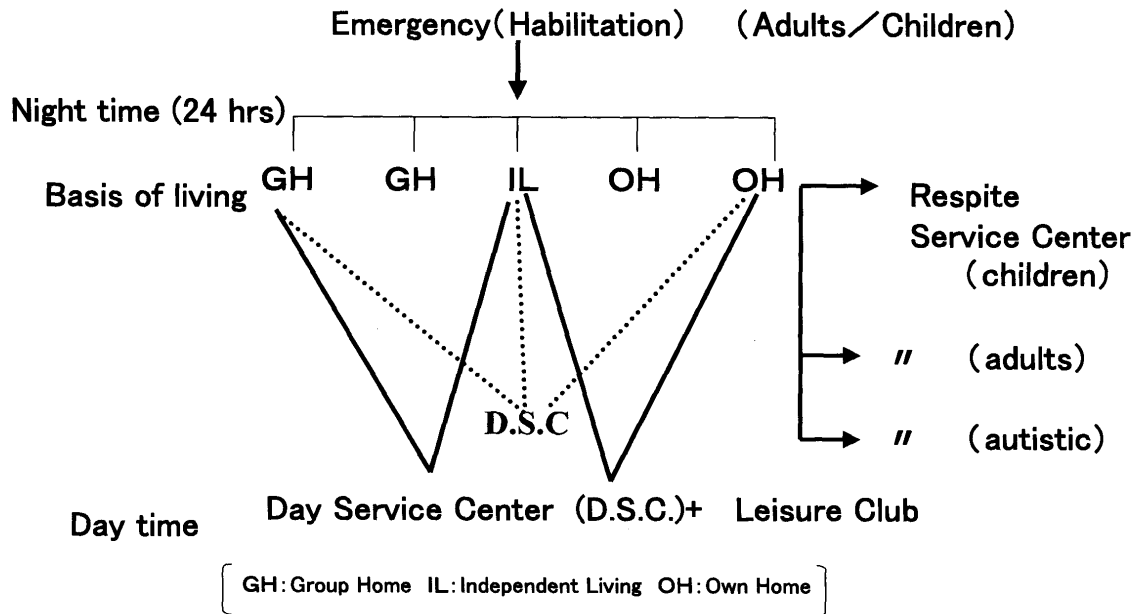


Fig. 4 Care System in Norway

Table 5 Steps to "Deinstitutionalization"

- 1st Step: Various Choices after the Institutions have been closed
- 2nd Step: Reducing Size of Institution
- 3rd Step: Stop Depending on Institution and Organize Community Support Services

(7) "Deinstitutionalization" in Denmark and Finland

How were the situations in Denmark and Finland, both of which had mainly large institutions? I shall introduce only the current situations.

First, Denmark seems to be just starting to undertake the process of deinstitutionalization seriously. They are reducing the scale of their institutions. They seem to need a lot of effort to make these large institutions smaller because they have worked mainly with large institutions.

For example, the central facility in the Fredericksburg region with a population of 540,000 used to have 1200 beds. First, they reduced the number to 879 and then they finally succeeded in making it 200. In sum, in order to form the central facility, they chose two groups of users, those users with medical needs and those with severe behavior disability. A person with little medical need and few behavior problems is supposed to be replaced in a group home. In addition, the placement of small children with intellectual disabilities to an institution is zero.

The condition in Denmark seems to be delayed. Just a few years ago, they finally stopped building new central institutions and started reducing the scale of institutions. They made the capacity of an institution half of that which it had at its highest time, but I would say deinstitutionalization will not be complete for a long time.

To summarize these four countries' situations, Norway has already zero institutions and Sweden was about to have none by 2000. On the other hand, Denmark left some institutions for some limited uses, but made them smaller. Finland finally stopped building new large institutions and started reducing the scale.

Table 6 Changes in Opinions of Parents (Family) - Before and After Deinstitutionalization

Before Placement	After Placement			Total
	Disagree	Neutral	Agree	
Disagree	2	4	9	15
Neutral	1	1	9	11
Agree	–	–	10	10
Total	3	5	28	36

As I explained earlier, the condition of “institutions” and the process of “deinstitutionalization” differ in Nordic countries. The history, current situation and the programs of the welfare system for people with intellectual disabilities in these four countries were different and still are.

(8) The Footsteps of “Deinstitutionalization” in the US

I’d like to go back to the situation in the US. From their experiences of “Christmas in Purgatory” and “Willowbrook,” the US government reduced the scale of institutions and closed as many institutions as possible. Simultaneously, they have tried to meet the needs of programs to support community living.

Seven states still have state institutions. These are New Hampshire, Rhode Island, Vermont, and four other states, Alaska, Hawaii, New Mexico and West Virginia joined with them recently. These states are not big states. New Hampshire has the smallest population among the 51 states of the US. Alaska State has a population of 580,000 and West Virginia has 1,820,000.

I understand that states with a huge population need a long time to proceed toward deinstitutionalization due to its complexity. However, New York State shows a remarkable improvement in the direction of deinstitutionalization. In a few years, they have a plan to close all state institutions. The process taken by a big state, not a small one, can be a good model for prefectures which have huge cities, such as Tokyo, Kanagawa, and Osaka, in Japan.

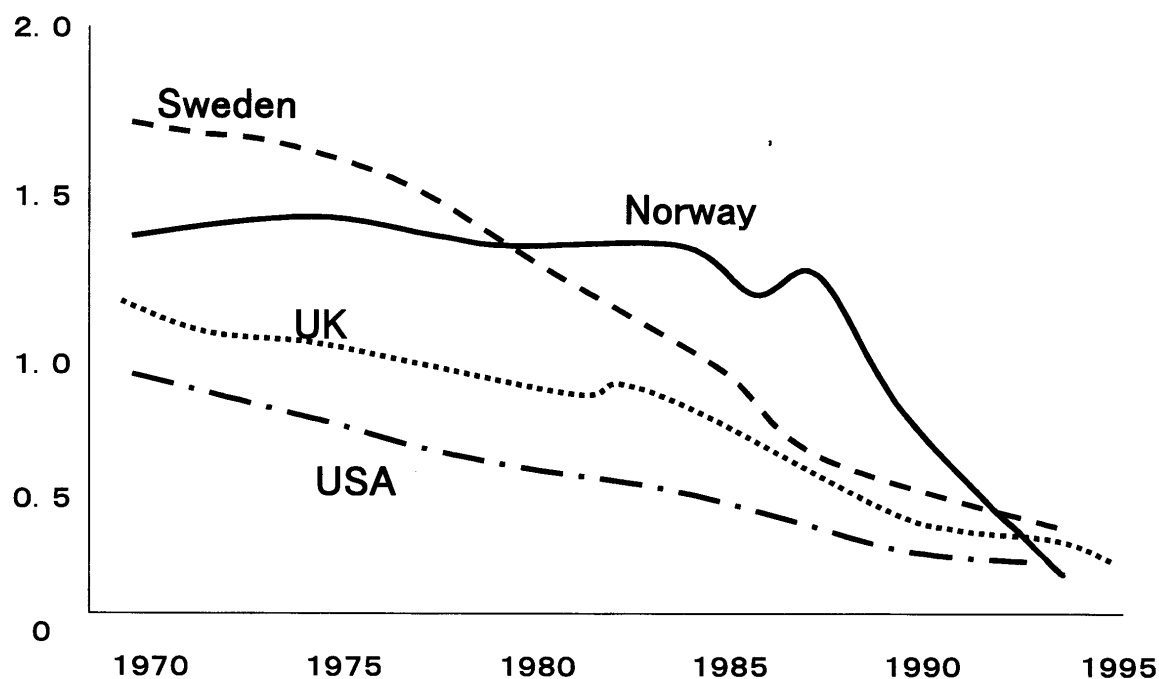


Fig. 5 Changes in Number of Users at DD Institution (out of 1,000 people in community)

Figure 5 shows the process of reducing the number of institutions and deinstitutionalization in North European countries and the US. After every country increased the ratio of beds to 1.0 for every 1000 people in the community, many of them further increased the number of beds to more than 1.3. Then, they began the process of deinstitutionalization. Japan has currently 1.0 bed to 1000 people and we are standing at a turning point.

(9) Comparison of Institutions for Intellectually Disabled People between Western Countries and Japan

To sum up again, Western countries have used the term “institutions,” but the reality was a psychiatric hospital. They were following the medical model.

Also, there were three types in terms of scale. Beginning from huge institutions like those in the US, which had 5,000 clients at one institution, Denmark and Finland had huge institutions, but not as big as those in the US, while Sweden and Norway depended on both small and huge institutions.

Among these three countries, Norway seems to be distinctive because they had already started building group homes in the 80's.

Also, every country had 1.3 to 1.8 beds to 1,000 population in the community. From that point, they took almost 30 to 40 years to go through the process of “deinstitutionalization.” Even Norway, where they had had a ratio of 1.3 beds to 1,000 people for 20 years, needed 10 to 20 years to complete it.

It is also hard to ignore the fact that the ratio of workers to clients in Norway shows a huge difference from us.

Regarding medical treatment at an institution for intellectually disabled people in Japan even now, only a part time medical doctor and a nurse are placed in an institution for adults with intellectual disabilities. A facility for small children is not even required to have medical professionals. In other words, these institutions are based on their living, not medical needs.

Thus, we have combined both needs, medical treatment and social welfare, at one institution for people with severely physical and mental disabilities. This system is very different from the one in Western countries and it makes our welfare system an exception.

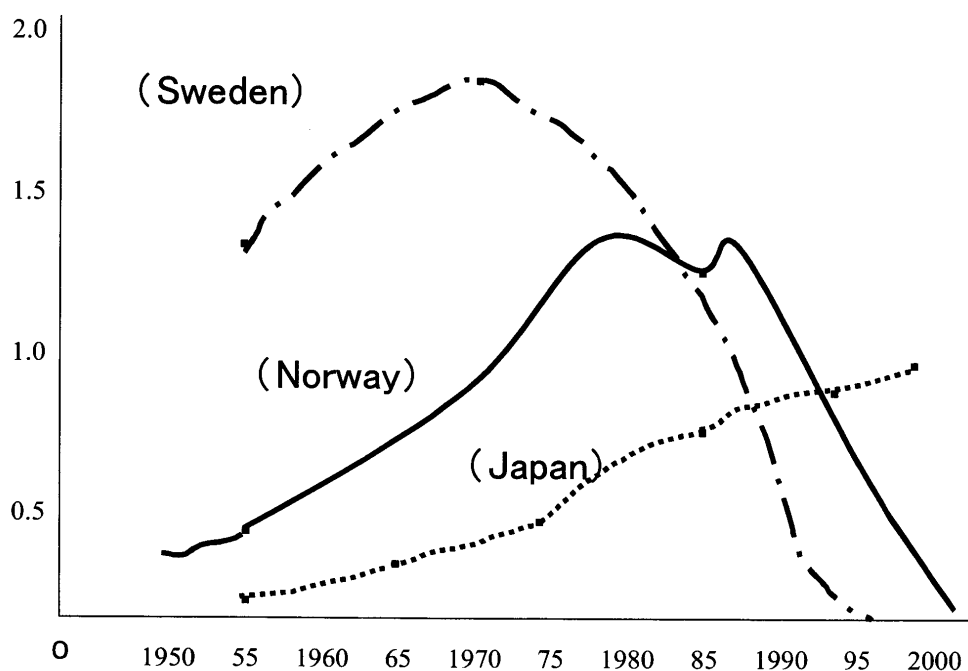


Fig. 6 Changes in Number of Beds at ID Institution in Sweden, Norway and Japan (out of 1,000 people)

Table 7 Changes in Number of Beds at Intellectual Disability Institution in Japan

year	1955	1965	1975	1985	1996	1997
population	90,007	99,209	111,940	121,049	125,034	126,170
#s of beds	5,033	19,901	50,297	85,742	110,809	120,011
Users/1,000 citizens	0.06	0.20	0.45	0.71	0.89	0.95

Numbers of Beds at Institutions for Intellectual Disability (except of Group Home)

Also, we have to notice that our institutions for intellectually disabled people are mainly middle scale, with 50 to 100 users at each facility. I think that this situation will play an important role for the process of deinstitutionalization in Japan.

The ratio of beds at an institution for intellectually disabled people used to be 0.06 in 1955 per 1,000 population, but the current ratio has become 1.0 to 1000 people after all. (Table 7) I put the ratios for Sweden, Norway and Japan in figure 6. Now we have finally attained a 1.0 bed ratio. But, in which direction should we go from now? The national government seems not to allow the building of new institutions. This decision seems appropriate. Time will tell us whether this move is too slow or too sudden, but I think users and their families should make these judgments. We need to discuss which direction our institutions for people with intellectual disabilities should take from various perspectives, decide the goals and rebuild them accordingly.

Discussion of Welfare Culture

I explained that there was a discrepancy between the roles that institutions have played in those Western countries which were called “welfare states” and the process of deinstitutionalization they took. Nordic countries share the common concepts, yet they have their own ways to put them into practice.

We Japanese have a very different historical and cultural background from the Western countries; thus it is no wonder if we take a different way to proceed with deinstitutionalization.

The Western countries and Japan have many differences in their social welfare systems, such as a community’s characteristics, traditional theories of welfare, the politics which regulate the theories, and the financial support for welfare. It is impossible to explain all the complexities in this paper, but I’d like to discuss a few issues.

Since the Nordic countries have strong local communes, they are said to have a “bottom up” social welfare system. A commune can be considered similar to a town or city in Japan, but it is rather a community basis arising from their strong commune bonds than an administrative division. However, in each country the commune has its own characteristics. For example, in Sweden, their strong centralization influences their regulation of the commune. On the other hand, in other countries authority is more decentralized; thus the authority’s power does not influence the commune as much as in Sweden.

Just focusing on population as it affects the commune, Sweden has a six times larger population than Norway.

Next, when we compare the share of the cost borne by citizens, Japan has 37 percent of social security and medical treatment, and there seems to be a similar percentage in the US. The ratio in England and Germany is about 50 percent and France has 65 percent. Swedish citizens bear the highest share of the cost and the ratio in Sweden is 70 percent. (Figure 7)

In my opinion, the gap between users and the citizens is a big problem.[12]

Compared to the Sweden’s ratio of 70 percent, our ratio is 37 percent which is half of that in Western

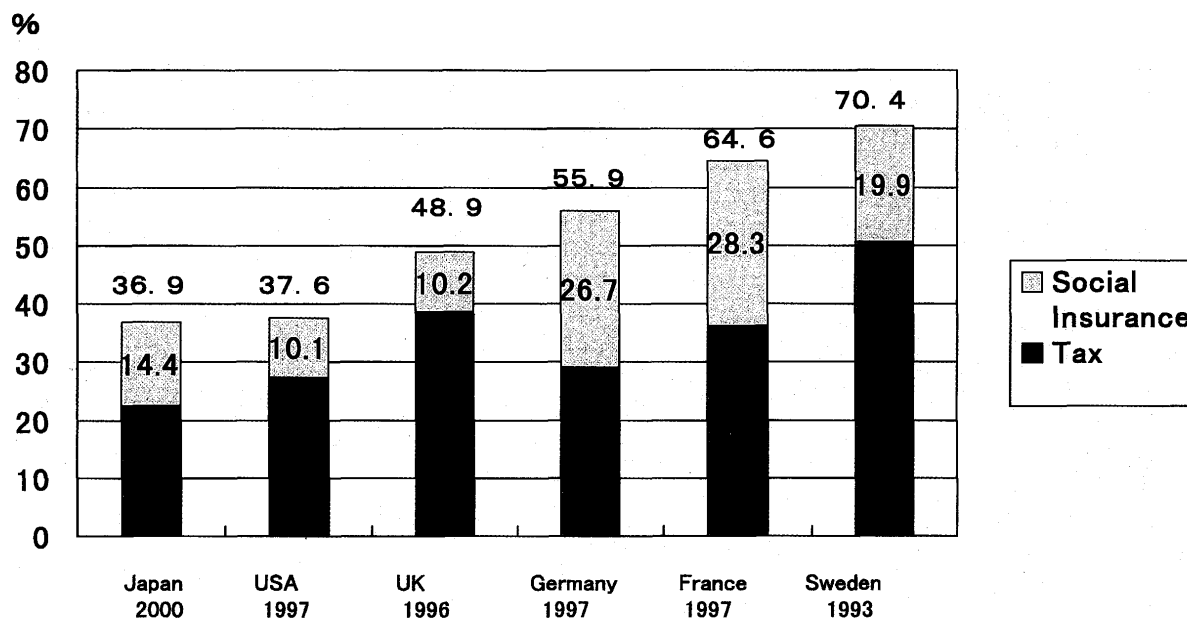


Fig. 7 International Comparison of Shares Borne by Social Insurance and Taxpayers (Incomes of Citizens)

countries. One of the causes of such a difference is our different living situation. Under Norway's social welfare system, the department of housing offers generous support to handicapped individuals and to a group homes for the users' independent living. These supports are much in advance of our system in Japan.

It is very important for us to think about what improves the QOL of people with disabilities and what makes their lives normative or normal. Also, we have to consider the difficulty of persuading more citizens to agree to support that QOL and those normative lives of people with disabilities. Therefore, we need to make all possible efforts to fill the gap between users' needs and citizens' consciousness.

It is said that the Western countries follow "High charge, high welfare" and we follow "Low charge, middle welfare." Our government is planning to follow "Middle charge, high welfare" for now. We must think how we can offer a good support with limited finance. Some people think that our welfare system has to have a certain cost efficiency. We need to avoid being too administrative, with too little efficiency, which have been issues in Sweden.

The Final Goal of "Deinstitutionalization?"

I would like to go back to my original question, "Is the closing of all institutions the final goal of deinstitutionalization?"

Prof. Tøssebro points out that other issues only became evident after Norway completed the closure of all institutions, which was the big goal of their deinstitutionalization process.[14] In Norway, half of the people discharged from institutions are living at the site of their former institution or in a group home around it. Thus, these people are not really integrated into their community. I realize that even in Norway communities are lacking in the support for people with disability and show a NIMBY (Not In My Back Yard) phenomenon.[15] Even though some people with disabilities succeed in moving into the community and their housing situation and physical needs are met, many people are feeling isolated due to a lack of friends. Also, it is difficult to keep the quality of staff members and professionals at a group home high. Prof. Tøssebro mentions the above three issues.

The closure of an institution does not mean that the process of deinstitutionalization is fully completed.

Real deinstitutionalization should mean more than that. We still have a long way to go for real deinstitutionalization.

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