

Confusing Circumstances Surrounding Deinstitutionalization and Inclusion in Japan: Sagamihara Attack and After

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Abstract

The aim of this study is to examine efforts towards deinstitutionalization of disabled people to live in the community in Japan. To that end, I will report the incident on 26 July, 2016 that 19 disabled people were killed at Tsukui Yamayuri En by a former employee, analyzing the discussion process with regard to coping with the facility and its residents in the future.

After the incident, the governor of the local government announced that a same type of residential facility would be totally rebuilt at the same location. However, there was a great deal of criticism that large residential facilities had become anachronisms and smaller-sized, community-based living arrangements had become the international standard. The underlying reasons of this confusion is a chronic lack of welfare services for the disabled person to live in the community and the situation such that family members of the disabled people have to bear burden of care, and crave for a conventional type of residential facility for his/her/their security.

Keyword: Tsukui Yamayuri En, disabled people, deinstitutionalization, transition to community, inclusion

1. Introduction

In Japan, 19 disabled people were killed and 26 others were injured on 26 July 2016 at a residential care facility for persons with intellectual disabilities in Sagamihara, which is located on the outskirts of Kanagawa prefecture, just south of Tokyo. This incident is referred to as the *Sagamihara shougaiisha sasshou jiken* in Japanese, and as the “Sagamihara attack” or “Sagamihara massacre” in English. Japan ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in January 2014 and enforced the Act for Eliminating Discrimination against Persons with Disabilities in April 2016. The incident took place despite increasing momentum towards inclusion with regard to disabled persons, and was a great shock to Japanese society. We

were confronted with the remaining reality of discrimination against persons with disabilities.

It was pointed out that behind this incident there was structural discrimination against disabled people, rooted in eugenic ideology of Japanese society (Fujii et al. 2016, Gekkan *Sou* Henshu-bu ed. 2018, Hori ed. 2017, Tateiwa & Sugita 2016). Nagase made the following criticism:

... names of those brutally killed are not public. The Kanagawa Prefectural Police decided not to release the names of victims, which was quite unusual. It said it made this decision based on the fact that the attack took place at a care facility for persons with intellectual disabilities and therefore the need for the protection of surviving families was extraordinarily high adding that the families had requested special consideration. This misguided decision constituted further violation of the dignity of those who brutally lost their lives (Nagase 2018:3).

The authors above also criticized the exclusion of disabled people from the local community. They claimed that residential facilities should be closed and community living must be promoted. In other words, deinstitutionalization has not been realized as expected.

This incident seems to be an unusual case because of the number of victims, but when we focus on the reason why many disabled people lived in the residential facility where the incident took place, there might be universal elements to consider with regard to the challenges of deinstitutionalization and inclusion of disabled people in the community.

In light of this, the aim of this study is to examine efforts towards deinstitutionalization of disabled people to live in the community in Japan and to consider the factors that prevent them from doing so. To that end, I will briefly report the incident and analyze the process of the discussion with regard to coping with the facility and its residents in the future. Data used for this study are; newspaper reports about the incident¹, statements made by disabled peoples' organizations (DPOs) regarding the incident and disability policies, records of discussions related to meetings of the committee for disability policies of Kanagawa Prefecture (Kanagawa-ken Shougaisha Shisaku Shingikai, hereinafter referred to as "the committee") and of the twelve meetings of the task force for the formulation of a basic concept for the renewal of Tsukui Yamayuri En (Tsukui Yamayuri En Saisei Kihon Kousou Sakutei ni kansuru Bukai, hereinafter referred to as "the task force"), which are made public on the website of Kanagawa Prefecture².

2. Brief History of Disability Policy in Japan

Before describing the incident and Tsukui Yamayuri En, I will briefly explain the history of disability policy in Japan in order to clarify the background of the incident.

In the 1960's, government disability 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 where their children could live out their lives even after losing their parents (Takahashi 2017: 36). In the 60's and 70's, the government built large residential facilities for children and adults with disabilities. Persons with disabilities lived there away from their families even if they were children. Care facilities were constructed away from urban areas because the lots to build on were large and the cost less expensive³. Since 1981, the International Year of Disabled Persons and following ten years for the disabled of the United Nations, criticism of large-scale facilities and the normalization principle became widespread (Takahashi 2015).

In the middle of the 1990's, "the Plans for Persons with Disabilities: 7-year Strategy for Normalization" drawn up by the government included support for daily life in the community and reconsideration of the desirability of large-scale facilities (Sone 2017:13). In the meantime, Japan had been engulfed by an economic recession since the beginning of the 1990's. This economic situation seriously affected Japanese welfare policy in the 2000's. Particularly, the Services and Supports for Persons with Disabilities Act enacted in April 2006 influenced drastically on disabled people to use welfare services⁴, because the new system was designed to curb the increases in both services and governmental expenses by making the users pay 10 percent of any service received (Tateiwa 2010). Strong protests against this system arose from DPOs. The solidarity of DPOs strengthened their power of negotiation with the government. Their participation in the process of disability policy making was developing more and more towards the goal of ratification of CRPD in the 2010's. They advocated for social inclusion more directly and actively, and requested enhancement of social resources for supporting independent living in the community, including personal assistance services (Takahashi 2017:38). Deinstitutionalization of disabled people and their transition into the community has been proceeding, however, its progress has slowed down in recent years, and residential facilities still have a small capacity (Sone 2017).

3. Outline of the incident and the facility

In the small hours of the morning of July 26, 2016, at Tsukui Yamayuri En (hereinafter referred to as “the facility”), a residential care facility for people with intellectual disabilities located in Sagami-hara City, Kanagawa Prefecture, a male former employee (26 years old at the time) forced his way into the building and stabbed 46 people with a knife. 19 residents were killed, and 27 people, including three employees, sustained injuries of varying degrees. In terms of number of victims, it was the worst Japanese murder case of the postwar period. As for the motive of the former employee who was arrested, he turned himself in at the police station, and in his statement said, “I wish disabled people would disappear,” negating their very existence⁵.

The facility was set up by the Kanagawa Prefecture government in 1964, during the period when the Japanese government promoted institutionalization. It is located in a mountainous area of Kanagawa Prefecture that is far from the prefectural capital Yokohama in terms of both time and distance, and that even now has very poor public transportation services. When the facility opened, there were 100 residents, and in 1968 that number increased to 200. In the first half of the 1990s, there were 160 residents, and in 2009 also, there were 160 residents, but 10 of them were only there on a short-term basis. Until 2005, the facility was directly managed by the prefecture, and in 2005, a social welfare corporation called Kanagawa Kyodokai took over the management. Since the group home opened, it has supported about 25 people in their transition to community life (Sone 2017:19-20), but because there were new residents, there were about 150 people with disabilities living in the facility at the time of the incident. Their ages ranged from 19 to 75 (with an average age of about 50), and the longest length of stay was 52 years (average 18 years), and about 80% of residents belonged to the most severe disability level⁶. After the incident, most of the remaining residents were moved to another facility by April 2017⁷.

4. The discussion process with regard to the facility after the incident⁸

After the incident, the governor of Kanagawa Prefecture announced that the facility would be totally rebuilt at the same location, as requested by the families of the residents and Kanagawa Kyodokai⁹. However, there was a great deal of criticism from DPOs and disability policy experts, who claimed that large residential facilities had become anachronisms and smaller-sized, community-based living arrangements had become the international standard¹⁰. The governor was

forced to change the policy, and he established a task force under the committee for disability policies of Kanagawa Prefecture to discuss the policy for dealing with the facility and its residents in the future¹¹.

All of the members of the task force were selected and appointed from the committee. The task force consisted of eight people: one person from the intellectual disabled people's organization, two persons from organizations for families of people with an intellectual disability, and five specialists in the field of welfare, including university faculty members. From February to August 2017 there were twelve meetings held, and a final report was compiled.

The discussion process is divided into three periods. I will describe and consider the characteristics of the discussion during each period, quoting important remarks in the context.

4.1. 1st -6th meetings : discussions in line with two basic policies

At the first session, after the on-site inspection of Tsukui Yamayuri En and hearing involving the managers of the facility, two basic policies were confirmed:

- Residents will be consulted about where and how they want to live from now on, and be provided with decision-making support.
- This consultation process will result in the decision to transfer the residents to living in the community; they would move to small-scale group homes.

Beginning with the second meeting, the subject of discussion was the method of providing decision-making support for the future lives of the residents, and at the third meeting, outside specialists with regard to decision-making support were invited, and the policies drawn up by the Ministry of Health, Labour and Welfare with regard to decision-making support were explained. At the fourth and fifth meetings, in preparation for the transition to community living, inspection tours and hearings were held at Kanagawa Prefecture group homes, and at the sixth meeting, possible locations and sizes of group homes were discussed. At this point, the proceedings can be said to have advanced sufficiently for the committee members to have reached an understanding with regard to the two basic policies.

4.2. 7th and 8th meetings : concerns and objections to the two basic policies¹²

However, concerns and objections with regard to the two basic policies arose at the hearing held with the families of the residents and employees of the facility in the seventh meeting, and at the hearing held with representatives from the community association of the area where Tsukui Yamayuri En is located in the eighth meeting.

4.2.1. Opinions of Family members

At the seventh meeting, five family members of the residents expressed their opinions, and four of those people advocated for the reconstruction of the facility of the same size at the original location. The people in favor of reconstruction made the following remarks, which can be categorized into three viewpoints as follows:

4.2.1.1. The safe place finally found after a long search

- Tsukui Yamayuri En is a place that our family found after a long, arduous search.
- The only way to have an environment where people can live securely as they did before the incident is to rebuild the facility (in the same place). If it isn't rebuilt quickly the parents won't be able to leave this world in peace.

4.2.1.2. Transition to community is not what the residents and families want

- I would like the renewal process to involve mainly the residents and the employees who support them.
- It isn't normal for a change of location to be considered for the facility's renewal. The residents moved into the facility according to the legitimate process. Other people have no business telling us what to do.
- The governor knew about the residents, the hardship of the employees, the worry of the families, and acted accordingly. Everybody has the residents uppermost in their mind. However, everybody felt pain when we heard heartless words such as "Listen to the voices of the residents, have you listened to them?"
- What is transition to community? And what is verification of the residents' will? Have all of the committee members met the residents? Do you think that you can really verify what they want? There are no children whose will can be confirmed right away. It would take five or ten years to

confirm their will. My son can talk, but it is difficult to know what he wants.

4.2.1.3. The advantages of a large facility

- The greatest thing about the facility is the excellent level of medical care....It was a very fun facility. It was fun for us to live in Tsukui Yamayuri En.
- I don't think a large-scale facility is bad at all. In a large-scale facility, residents can learn to be sociable, and prepare to move into a group home (thanks to the "educational power" of a group).
- If the facility were open to the community, it would be a "community", and also a "home". The deliberations held by the task force are separating members of this home, this family.

There was one family member who had a different opinion:

- I think the number of facilities should be reduced. Not everyone is satisfied with the life in a facility. Living in a facility reduces one's freedom.
- The people in a facility do not know what is going on outside of it and are unaware of the possibility of transitioning into the community. If the family members were informed about cases of transitioning into the community in various areas, their view on this matter would change.

4.2.2 Opinions of employees of the Tsukui Yamayuri En

Four employees attended the meeting, and after an explanation of the situation of residents who had been temporarily transferred to another facility, the following points were raised:

- Many employees are motivated by the fact that they will be able to return to the original place.
- There are many employees who, when they see and hear negative reports about the facility, feel as if the work they have done up until now is being negated.
- Large-scale facilities are being criticized these days, but I don't want downsizing to take place because of the incident. I think that family members are worried about the future, so they simply want the residents to return to their previous lives, and to be able to live in a calm, worry-free environment.

4.2.3 Opinions of the representatives of the community association

At the eighth meeting, two representative of the community association of the area where the facility is located expressed their wish to have the facility rebuilt as follows:

- Almost all of the employees working at the facility when it opened were local residents, and the local residents participated in all kinds of events and interacted with the people living in the facility, so everybody agrees that the facility should be rebuilt at its original location.
- I would like the community to be given an economic boost through the hiring of local residents and shopping at local stores.
- The facility's gymnasium and grounds can be used as a reassuring temporary evacuation center in the case of a disaster, and their use by local residents promotes exchanges with the facility residents.

4.2.4. Response of the task force members to the opinions expressed at the hearing

After hearing family members' opinions at seventh meeting, one of the task force members expressed his hesitation with regard to maintaining the basic policy:

It is obvious to me that transition to community living should be promoted as a policy, but Tsukui Yamayuri En is a bit of a special case. In the process of receiving support for decision-making with regard to transitioning into the community, to what extent are the residents aware that the transition would involve being separated from the familiar staff and fellow residents with whom they have been living for twenty or thirty years? I have no idea.

Another member said the following at the eighth meeting to show her respect for disabled people and to suggest the importance of decision-making support:

I was very shocked that the incident took place with, in the background, the defendant's idea that disabled persons don't have any will. Respect for the will is the starting point of welfare, and we will proceed with the discussion on the assumption that every disabled person has a will, in addition to making it clear in our final report. Through this discussion process we honor the

victim of the incident.

Following this statement, she expressed her understanding of negative family feelings with regard to decision-making support:

At the seventh meeting, one family member said that their (disabled) child did not have any will. But those words were probably spoken in the painful state of mind of a parent who wants to understand their child but can't. Decisions should not be left up to only the relatives; a system whereby the counseling staff and employees of the facility join forces with family members to think about issues would provide a lot of support for decision-making.

The task force members thought that the opinions of the family members, employees and the representatives of the community association that were expressed at the hearing should be respected. It was emphasized that transition to community living should not be imposed; there should be a repeated process of clear explanations and preparatory experiences.

4.3. 9th – 12th meetings: the work of summing up and compiling the final report

The work of summing up began at the ninth meeting. The discussion was expanded to include the necessity for systemic support in the areas of financial aid from the prefecture and the national government with regard to decision-making support and support for transitioning to community living, as well as the hiring of additional staff.

In the end, a report outlining the following main points was drawn up: the original location and small-scale facilities in Yokohama City were prepared, and existing prefectural facilities for the disabled were used to house all of the residents of Tsukui Yamayuri En. It was specified that the will of the residents should be respected when deciding on the place where they would live, that a “decision-making team” should be formed for each resident, made up of employees and specialists, and that it is important to transition to community living through the use of group homes (but this should not be imposed on anyone), and also, that it should not be assumed that the residents will return to their families. At this point there was no specification of a definite number of residents who would live in a rebuilt facility at the original location. As for the last point, the family members of the residents wishing to rebuild the facility on its original scale expressed dissatisfaction¹³.

The report was officially made public by the prefectural government in October 2017 as the “Basic Plan for the Renewal of Tsukui Yamayuri En”¹⁴.

5. Discussion and conclusion

The following points can be made based on a series of discussion processes of the task force described in the previous section.

5.1. Why did family members of disabled people object to providing them with decision-making support and transition to community living?

With regard to the strong unease and negative feelings on the part of family members concerning the introduction of decision-making support, the task force understood that the family members have a hard time communicating with the disabled person, and were probably worried because they lacked information about the decision-making support. Also, in the case of the disabled person returning to the family home, the family would probably be anxious about having to devote themselves to care again, and a policy of endeavoring to provide clear explanations and information to the families was added.

Among the families there are many different viewpoints; there are also people who agree with the ideas of respecting the wishes of the disabled person and the importance of community living in a group home, but there is still a strong tendency to hide the fact that there is a disabled person in the family, for fear of discrimination on the part of community members.

According to Esping-Andersen’s welfare regime typology, Japan has a conservatism regime, and the family plays a major role in caregiving for the disabled person (Takahashi 2017). It is difficult not only for the disabled person, but also for the family, which bears the heavy burden of care, to be included in the community. Living with a family member with disabilities is not an option they can choose but the inevitable burden or responsibility. Japanese government makes families play a major role in caregiving for the disabled person regardless of their will, that is, informal caregivers without guaranteeing the right. They are informal caregivers who don’t receive any benefits, allowances or services for themselves. There is no legislation that defines and protects the rights of informal caregivers in Japan.

5.2. Why does the local community association oppose a change of location for the facility and want a facility of the same size to be built at the same location?

The facility is also a place that hires local residents. In particular, during the time when the prefecture managed the facility directly, the facility staff were public servants, so it was a good place to work for local residents living in an area with very few employment opportunities¹⁵. Also, as a large-scale facility, many household items and equipment were required, so there was an economic advantage for the town's business people. Because of this situation, a certain number of local residents had a close relationship with the facility and its residents, and they also participated in various events. As a result, the facility might have been incorporated into the local economy and exchanges over the years.

5.3. Function of a large-scale facility

Japan has a policy of transitioning to providing support to the disabled for community living, but there is a chronic lack of welfare services, especially in the area of personal assistance. The system for supporting the disabled with their daily needs remains very weak; the situation is such that family members have to bear the burden of care. Because many parents are aging, siblings are unable to continue bearing the burden of care. They are busy with their work and raising their own children, and end up having to wait for space to become available at a conventional type of residential facility with live-in specialized care staff. On the other hand, if new large-scale residential facilities are built, they will have to be filled to capacity, and disabled people will be gathered to come and live there. Zenkoku Te wo Tsunagu Ikuseikai Rengoukai, a big advocacy organization for disabled persons' families criticized the prefecture's initial plan to rebuild the facility and pointed out that "as long as a facility for 140 people continues to exist with that large a capacity, residents will come from all over the prefecture, and it will function as a mechanism for reducing involvement with their own communities."¹⁶

Based on the above analysis, the relationship between actors¹⁷ such as family members, local community association, DPOs and disability policy experts criticized the initial plan of the prefecture, the task force and the local government in the discussion process regarding the facility after the incident can be illustrated as follows:

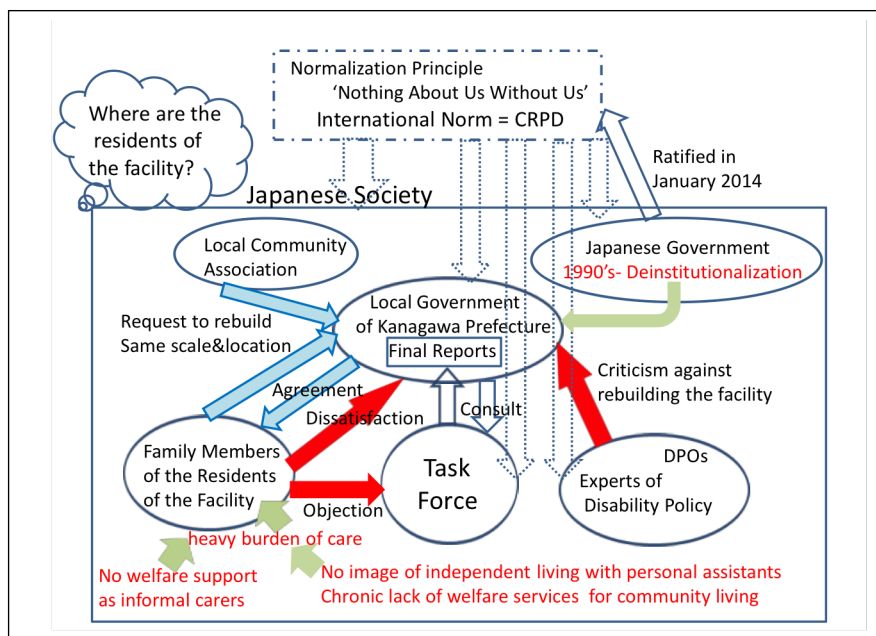


Figure 1. The relationship between actors in the discussion process

The premise for the objection on the part of DPOs and experts of disability policy to the initial plan of the prefecture to rebuild a facility of the same scale at the original location was based on the CRPD. The task force also seems to have discussed the issues with the principles of the CRPD in mind. The states that have ratified the convention have the responsibility of drawing up policies that advance normalization and inclusion. In particular, “Article 19: Living independently and being included in the community”¹⁸ imposes responsibility on the Japanese government to provide disabled people enough and various welfare services for living in the community independently not only in small-sized group homes but also by personal assistances. Local government should be responsible, too. A disabled person is an individual who has the right to decide where and how to live. The family members of the disabled should have the option of living with them, and must have rights with regard to their own needs as caregivers.

Acknowledgements

Earlier versions of this article were presented at the 29th Nordic Sociological Association Conference 2018 in

Aalborg, Denmark and the 8th Annual Conference of ALTER (European Society for Disability Research) 2017 in Cologne, Germany. This work was supported by a JSPS Grant-in-Aid for Scientific Research (KAKENHI) Grant Number JP26380675.

Notes

- 1 The information of the incident is based on the website of the Japan Times:
<https://www.japantimes.co.jp/tag/tsukui-yamayuri-en/> (last accessed 20 February 2020) (in English)
- 2 See the website of the committee for disability policies of Kanagawa Prefecture:
<https://www.pref.kanagawa.jp/docs/yv4/keikaku/shisakusinngikai.html> (last accessed 30 January 2020)
All records are only in Japanese. Translation into English was done by the author.
- 3 After the 1970's, expansion of residential areas and urbanization, along with the development around large care facilities sometimes resulted in conflict between the facilities and local residents. Recently such conflict has become more common when an attempt is made to build a smaller-scaled facility or group home for the disabled persons in a residential area. This issue should be examined in the context of discrimination against the disabled.
- 4 It means that the more severe one's disability and the more one needs services, then, the more expense one must bear. This system caused the situation that persons with severe disabilities sometimes reduced using services to avoid the burden of expenses.
- 5 The Japan Times, Jul 27, 2016, Care home massacre probed as mercy killing.
<https://www.japantimes.co.jp/news/2016/07/27/national/crime-legal/suspect-sagamihara-care-facility-mass-murder-says-no-remorse/#.XlIiqkpUuM8> (last accessed 20 February 2020)
- 6 Tsukui Yamayuri En no Gaiyou ni tsuite (Material No.1 presented at the 1st meeting of the task Force on 27 February 2017) <http://www.pref.kanagawa.jp/uploaded/attachment/868838.pdf> (last accessed 31 January 2020) (in Japanese)
- 7 Kanagawa Shimbun, 6 April 2017 <https://www.kanaloco.jp/article/entry-10933.html> (accessed 20 February 2020) (in Japanese)
- 8 Remarks and opinions from the meeting of the task force mentioned in this section were taken from discussion records posted on the website of the committee for disability policies of Kanagawa Prefecture. See Note 2.
- 9 Kanagawa Shimbun, 13 September 2016 <https://www.kanaloco.jp/article/entry-1366.html> (accessed 20 February 2020) (in Japanese), Tsukui Yamayuri En no Saisei ni muketa Ookina Houkousei nit tsuite (Press release material 23 September 2016) <https://www.pref.kanagawa.jp/documents/26354/844026.pdf> (accessed 20 February 2020) (in Japanese)
- 10 Kanagawa Shimbun, 11 January 2017 <https://www.kanaloco.jp/article/entry-6779.html> (accessed 20 February 2020) (in Japanese),
- 11 Tsukui Yamayuri En Saisei Kihonkeikaku Sakutei ni muketa Kongo no Susumekata ni tsuite (Press release material 27 January 2017) <https://www.pref.kanagawa.jp/cnt/f535096/p11106336.html> (accessed 20 February 2020) (in Japanese)
- 12 Summary of discussion at the 7th task force on 17 May 2017

- <http://www.pref.kanagawa.jp/cnt/p1145442.html#> (accessed 30 January 2020) (in Japanese)
- 13 Kanagawa Shimbun, 1 August 2017 <https://www.kanaloco.jp/article/entry-16724.html>, 15 October 2017 <https://www.kanaloco.jp/article/entry-20299.html> (accessed 20 February) (in Japanese).
- 14 Tsukui Yamayuri En Saisei Kihonkousou <https://www.pref.kanagawa.jp/uploaded/attachment/898517.pdf> (accessed 30 January 2020) (in Japanese)
- 15 It is said that the then mayor of Sagami Town conducted a campaign to invite the facility with the aim of creating employment for the residents (Sone 2017:19).
- 16 Kanagawa-ken-ritsu Tsukui Yamayuri En deno Jiken nitsuite (Seimeibun). Zenkoku Te wo Tsunagu Ikusei kai Rengou-kai. <http://zen-iku.jp/wp-content/uploads/2017/01/3b31ebfb417fbd291ffd6d05f8220032.pdf> (accessed 31 January 2020) (in Japanese)
- 17 A prefectural assembly is usually an important actor with regard to policy making, however the minutes of Kanagawa Prefectural Assembly showed no evidence of debate affecting policies regarding the facility after the incident, and the final report of the task force was approved with little modification. This is the reason why Kanagawa Prefectural Assembly is not shown as an actor in this article. (See the website of the minutes search system of Kanagawa Prefectural Assembly, <https://ssp.kaigiroku.net/tenant/prefkanagawa/pg/index.html> (accessed 18 March 2020)) (in Japanese)
- 18 Article 19: Living independently and being included in the community
- States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:
- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
 - (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
 - (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

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日本における脱施設化とインクルージョンの課題： 相模原障害者殺傷事件のその後をめぐって

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要旨

2016年7月に相模原市の障害者施設、津久井やまゆり園で元スタッフの男性が入所している障害のある人々を殺傷した事件は、日本社会の障害者差別とインクルージョンの困難を改めて示した。事件後、津久井やまゆり園を管轄する神奈川県が当初示した、同じ場所に同規模の施設を建設する方針は、入所型施設をなくし（脱施設化）、地域社会での生活を支援することを主眼とする国際的潮流に反すると社会的な批判を浴び、神奈川県は対応を改めて検討することとなった。その一連の過程と議論の記録を分析した結果、地域移行が遅れ地域生活支援サービスが不足しており、家族が依然としてケア責任を負わされる日本の障害者政策の課題を明らかにした。

キーワード： 津久井やまゆり園, 障害者, 脱施設化, 地域移行, インクルージョン（社会的包摂）