Finding a Political Voice: Improvement of Disability Policy and Disabled People in Japan from Comparative Perspective

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https://researchmap.jp/read0187723/?lang=english
PROLOGUE:
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- Three years after the Sagamihara Stabbings
  19 disabled people were killed and 26 others were injured on 26 July, 2016 at a residential care facility ‘Tsukui Yamayuri En’ for persons with intellectual disabilities in Japan.

- Recent Upper House election
  As a result of the Upper House election, 3 persons with disabilities were newly elected on 28 July, 2019. Especially, 2 are with severe disabilities.
Outline of this report

• The aim of this report is to examine efforts with regard to deinstitutionalization and discrimination against disabled people in Japan.

• To that end;

- outline history of disability policy and the disabled people’s movements and their advocacy activities for mainstreaming voices of persons with disabilities.

- to examine the murder incident at Tsukui Yamayuri En and analyze the discourse of the discussion of the task force with regard to coping with the facility and its residents in the future.
Framework of Comparative research

• Japan as a developed country, a democratic state in Asia
  - the earliest country in Asia to develop, however, later than western countries
  → ‘backwardness’ in various meanings
  - (Esping-Andersen’s Welfare Regime Typology)
    • Japan: Conservatism Regime
      a strong trend of familism in welfare system
    • Finland: Social Democracy Regime:
      ‘Nordic-type’ government social welfare system
      based on the principle of universal coverage and a strong tradition of popular social movements
History of Disability Policy, Social Movements and DPOs in Japan

In Japan, after the long history of DPOs’ social movements, the Committee for Disability Policy Reform was established after the 2009 change of government. The fundamental institutional base for DPOs to participate in policymaking was established, and the direction to take for the revision of domestic laws for the ratification of CRPD was determined.
History of Disability Policy in Japan

• 1960’s: a minimum economic security system
• 1960’s-1970s: Promotion of Institutionalization
• 1981: the International Year of Disabled Persons
• 1980’s: Criticism of large-scale facilities
• 1996-2002: Plans for Persons with Disabilities - 7-year Strategy for Normalization - large-scale facilities → support for living in the community
• 2000-: Basic Structural Reform of Social Welfare
• 2006: Services and Supports for PWD Act (2009 change of government)
• 2010-2012 Committee for Disability Policy Reform (2012 change of government)
• 2013 Act for Eliminating Discrimination against PWD
• Japan Ratified CRPD in January 2014
History of Social Movements and DPOs in Japan (1)

✧ 1960’s  a minimum system dependent on families & institutionalization

✧ 1970’s  anti-familism & de-institutionalization  activism

⇒  towards independent living in local community

• 1970 activism and assertions of a group of people with cerebral palsy
• 1970 activism in opposition to the management of a facility in Tokyo
• 1976 Zenshoren (a network of disabled people across disabilities)

✧ 1980～1990’s  Independent Living Movement & Networking

• 1980 Japan Council on Disability (JD)
• 1986 Human Care Association (IL Center in Hachioji, Tokyo)
• 1986 DPI-Japan officially founded
• 1991 Japan Council on Independent Living Centers (JIL)
History of Social Movements and DPOs in Japan (2)

✧ 2000s～ establishing network, developing a path for participation

- 2002 6th DPI World Assembly in Sapporo
- 2004 Japan Disability Forum
- 2006 Protest against Services and Supports for PWD Act
  (2009 change of government)
- 2010-2012 Committee for Disability Policy Reform
  ½= persons with disabilities themselves and/or their families
  2 reports on welfare policies for the disabled
  (2012 change of government)
- 2012- the Council of Measures for Persons with Disabilities
- 2013 Act for Eliminating Discrimination against PWD
  (enforced in April 2016)

✧ 2014.1 Japan ratified CRPD
History of Social Movements and DPOs Finland (1) (≈1960s; undeveloped welfare system for disabled people)

✧ 1970s ~ Independent Living Movement
   - The Threshold Association (Kynnys Ry)
     1973 ~ established by Kalle Könkkölä
     → 1983-87: a member of Parliament

✧ 1980s ~ developing welfare services and participation system
   - 1987: Act on Disability Services and Assistance (380/1987)
     Laki vammaisuuden perusteella järjestettävistä palveluista ja tukitoimista
   - The National Council on Disability (VANE)
     1986 ~ established by Finnish Government under Ministry of Social Affairs and Health
     ½ = representatives of DPOs & organizations for families → chairperson
     ½ = representatives of the central government

2016 ~ Advisory Board for the Rights of Persons with Disabilities
History of Social Movements and DPOs in Finland (2)

✧ 1990s～ private welfare service providers appeared
  • The Finnish Disability Forum
    1999～ established by the disabled people’s organizations
to promote network across all disabilities
to prevent fallback of welfare policies
  supported by the European Disability Forum
  active NGO not only in Finland but in EU
  “the people in charge of government welfare policies changed their stance and started to listen to the proposals from the disabled people’s organizations while they conducted discussions and negotiations.” (interview note)

✧ 2005～ network of DPOs for innovating PA system
  → Revision of Act on Disability Services and Assistance in 2008
✧ 2016.5  Finland Ratified CRPD
# Number of Persons with Disabilities in Japan (estimate)


<table>
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<tr>
<th></th>
<th>Total</th>
<th>Persons living at home</th>
<th>Persons accommodated in facilities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Children/adults with physical disabilities</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Younger than 18</td>
<td>76,000</td>
<td>73,000</td>
<td>3,000</td>
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<tr>
<td>18 or older</td>
<td>3,621,000</td>
<td>3,766,000</td>
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<tr>
<td>Unknown age</td>
<td>25,000</td>
<td>25,000</td>
<td>-</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>3,922,000</strong> (31)</td>
<td><strong>3,864,000</strong> (30)</td>
<td><strong>58,000</strong> (1)</td>
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<tr>
<td><strong>Children/adults with intellectual disabilities</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Younger than 18</td>
<td>159,000</td>
<td>152,000</td>
<td>7,000</td>
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<td>578,000</td>
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<tr>
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<td>4,000</td>
<td>4,000</td>
<td>-</td>
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<td><strong>Total</strong></td>
<td><strong>741,000</strong> (6)</td>
<td><strong>622,000</strong> (5)</td>
<td><strong>119,000</strong> (1)</td>
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</table>

<table>
<thead>
<tr>
<th><strong>Persons with mental disorders</strong></th>
<th>Total</th>
<th>Outpatient</th>
<th>Inpatient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Younger than 20</td>
<td>269,000</td>
<td>266,000</td>
<td>3,000</td>
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<tr>
<td>20 or older</td>
<td>3,645,000</td>
<td>3,336,000</td>
<td>309,000</td>
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<tr>
<td>Unknown age</td>
<td>10,000</td>
<td>10,000</td>
<td>1,000</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>3,924,000</strong> (31)</td>
<td><strong>3,611,000</strong> (28)</td>
<td><strong>313,000</strong> (2)</td>
</tr>
</tbody>
</table>

(Note)  
1. The figures in parentheses indicate the number of persons per population of 1,000 (base on 2010 Population Census).  
2. The number of persons with mental disorders is calculated by adding the number of epilepsy and Alzheimer patients to the number of patients of “Mental and behavioural disorders” of ICD-10 with intellectual disabilities excluded.  
   In addition, the number for each age group is rounded, thus the sum of breakdowns may not equal the total.  
3. The number of persons with physical disabilities who are accommodate in facilities do not include those accommodated in facilities for the elderly.  
4. The number of persons is rounded, thus the sum of breakdowns may not equal the total.
2016.7.26 SAGAMIHARA STABBINGS AND AFTER

Data:
- newspaper reports
- statements by the DPOs
- records of discussions of the committee for disabled policies of Kanagawa Prefecture and the 12 meetings of the task force (February – August in 2017)

http://www.pref.kanagawa.jp/cnt/f286/
Outline of the Incident

• July 26, 2016, at Tsukui Yamayuri En, a residential care facility for people with intellectual disabilities, 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.
• the worst Japanese murder case of the postwar period at that time
Outline of the facility

• set up by the Kanagawa Prefecture government in 1964.
• located in an area of Kanagawa Prefecture that is off the beaten track, and which even now has very poor public transportation services.
• directly managed by the prefecture →2005-: a social welfare corporation took over the management.
• About 150 people with disabilities living in the facility at the time of the incident.
  - ages ranged from 19 to 75 (with an average age of about 50)
  - the longest length of stay was 52 years (average 18 years)
  - about 80% of residents belonged to the most severe disability level.
• After the incident, most of the remaining residents were moved to another facility by April 2017.

(Photo by JIJI PRESS)
Location of the Facility

https://www.google.co.jp/maps/place/%E6%97%A5%E6%9C%AC%E3%80%81%E3%80%9252-0174+%E7%A5%9E%E5%A5%88%E5%B7%91%E7%9C%8C%E7%9B%B8%E6%A8%A1%E5%8E%9F%E5%B8%82%E7%B7%91%E5%8C%BA%E5%8D%83%E6%9C%A8%E8%89%AF%E7%9C%BC%94%E7%9C%BC%97%E7%9C%BC%96/@35.6136148,139.2108429,526m/data=!3m1!1e3!4m5!3m4!1s0x601919fa00d82da9:0xaaa1a53428d0210c!8m2!3d35.6136148!4d139.2130316?hl=ja
Defendant U

- During the investigation following his arrest, Uematsu, a former worker at the care home, said people with disabilities are not needed. A psychiatric test showed he has narcissistic personality disorder.
- In February 2017, public prosecutors indicted Uematsu on murder and other charges, judging that he was mentally competent enough to take criminal responsibility.
- The trial of a former employee, Uematsu accused of murder, will begin on January 8th 2020.
  - The Yokohama District Court is scheduled to hold the first hearing of a lay-judge trial of Uematsu, aged 29, on January 8th 2020. The court is considering giving a ruling by the end of March 2020.

The discussion process with regard to the facility 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.

⇔ a great deal of criticism from DPOs and disability policy experts: large residential facilities had become anachronisms and smaller-sized, community-based living arrangements had become the international standard.

• 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 new policies.(the task force for the formulation of basic concept for the renewal of Tsukui Yamayuri En)
Two basic policy orientation of the Task Force

Two basic policy orientation confirmed at 1st meeting

- Residents will be consulted about where and how they want to live from then on, and provided with decision-making support.

- This consultation process will result in the decision to transfer the residents to a different place and to a facility of small-scale group homes, and they will live in an urban area. (Transition to community living)
Concerns and objections from the families of the residents

- The facility is a place that our family found after a long, arduous search.
  “... If it isn’t rebuilt quickly the parents won’t be able to leave this world in peace.”

- Transition to community is not what the residents want; outside people should not intervene.
  “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. ...My son can talk, but it is difficult to know what he wants.”

- The advantages of a large facility
  “I don’t think a large-scale facility is bad at all. In a large-scale facility, residents can learn to be sociable, ...” “If the facility were open to the community, it would be a “community”, and also a “home”.”
After these objections, some members of the Task Force said;

- “It is obvious to me that transition to community living should be promoted as a policy, but the facility is a bit of a special case. Up until now, when moving with most of the employees and fellow residents, when moving to a group home for the first time, I have no idea of how much they are aware of being separated”.

- “…one family member said that their 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.”
Final Report of the Task Force

• The original location and small-scale facilities in Yokohama City will be prepared, and another existing prefectural facilities for the disabled will also be used to house all of the residents of the facility.

• 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.

• Transition to community living through the use of group homes is important (but this should not be imposed on anyone), and also, 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.
ANALYSIS AND CONCLUSION: DELIVERING MESSAGES AND IMAGES ABOUT ALTERNATIVE LIVING OUTSIDE FACILITIES

- The Social Position of Families As Informal Cares
- Dialogue between Family Groups and DPOs
- Documentary Film
Nomalization Principle
‘Nothing About Us Without Us’

International Norm = CRPD

Japanese Government

Ratified in January 2014

1990’s- Deinstitutionalization

Local Government

Request to rebuild
Same scale & location

Agreement

Criticism against rebuilding the facility

DPOs
Experts of Disability Policy

Final Reports

Consult

Task Force

Dissatisfaction

Objection

Family members of the residents of the facility

heavy burden of care

No Welfare support as informal carers

No image of independent living with personal assistants

Chronic lack of welfare services for community living

Where are the residents of the facility?
• Why do family members of the residents of the facility object to providing them with decision-making support and support for community living?

• Function of a large-scale facility
  - mechanism for reducing involvement with their own communities
  - mechanism of excluding disabled people from their own community
Families as informal cares

• Japan: no act to support and protect the rights of family members as informal cares
  ↓
  no benefit, allowance and service

• Finland: Informal care Act (937/2005)
  Laki omaishoidon tuesta

... For the past two decades in Finland, the development of services for people with intellectual disabilities has taken places at the intersection of a progressive disability policy and a neoliberal economic policy.

↓

Informalization / Familialization of care?

Function of a large-scale facility

“... 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.”

(from the statement made by one of the disabled people’s family organization which opposed to rebuild the facility of the same scale at the original location)

= mechanism of excluding disabled people from their own community
Dialogue Meeting: Family Groups and DPOs (on 27.1.2019)

Chaired by ‘津久井やまゆり園事件を考え続ける会’ (Tsukui Yamayuri En Jiken wo Kangae tsudukeru Kai)
A movie “MICHIKUSA” (=Grass by the roadside, Loitering on the road), released in 2018 is a documentary film of people with intellectual disabilities. It portrays their everyday life of independent living with personal assistants. (Director & Editor: Shishido, Daisuke) https://michikusa-movie.com/
EPILOGUE: THE LATEST POLITICAL VOICE:

Two severely-disabled candidates win seats in Japan Upper House vote in July 2019. (Data: Reuters World News and BBC World News)
Eiko Kimura

(BBC NEWS: August 1, 2019)

Yasuhiko Funago

(Reuters World News: July 22, 2019)
• Following their election, the Upper House carried out renovation work to provide barrier-free accessibility. While they are not the first politicians to use a wheelchair in the Japanese Parliament, they are the first who are severely disabled. Seats were removed so that a reclining wheelchair would be able to fit in and rules had to be changed to allow their carers to be present during sessions. ……

• Furthermore, the consideration of the issue that who should pay for their carers has begun, because the disabled people have not been expected to use care benefits based on Act on Comprehensive Support for the PWD for the purpose of doing paid work.

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• A series of events happening at the heart of politics may be a sign of changing disability policy and attitudes towards disabled people in Japan?