

Alternatives to guardianship  
Personal assistants  
Personal ombudsman in Skåne  
Family group conference

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# Service and support system for PWD in Japan

## History

From last 60's to early 70's people with severe physical disability went out of institutions at risk to their life and started independent living in the community with unpaid volunteer supporters.

Gradually they had gotten money from the government for supports and made the support system. But it was only for people with physical disability.

# Service and support system for PWD in Japan

These support systems had been enlarged to people with intellectual disability, but until 2005 people with psychosocial disability was excluded from these systems.

In Japan some people with severe disabilities-for instance, people with ALS using ventilators got 24 hours a day support from the system and it is rare but even people with severe intellectual disability can live independently in the community by this support system.

# One example of the good practice

- Until 1979 most of PWD has no rights to receive compulsory education and most of them left behind from the public education system.
- In 1979 the segregated school system introduced for PWD by the government and there was the strong movement against the segregated education system by PDOs, their family organizations and allies.

# One example of the good practice

- In the movement there was the unique activity to support children with severe intellectual disability in the community and not to send them to the segregated schools or the institutions.
- Then they are now adults and there are supporters who have been supporting them from their childhood and still are supporters of them and support their independent living in the community.

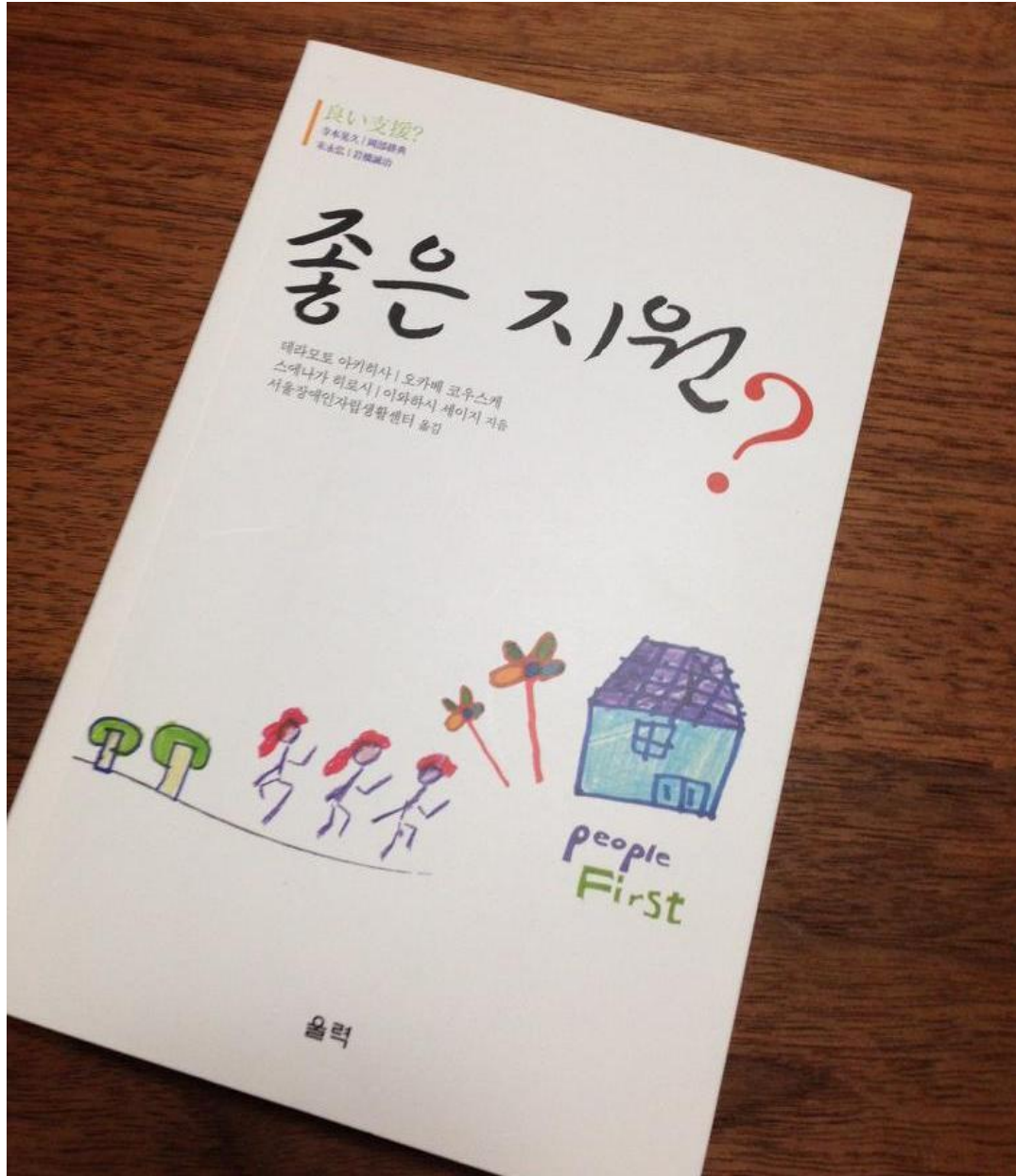
# One example of the good practice

- They do not use guardian system, but use the support system by the government. They make contracts with providers or apartment owners by themselves, though some of them do not write letters or speak ordinary languages.
- It is the results that all of them keep living in the community and people in the community know their existence and lifestyle and there are supporters as personal assistants and they are not denied their legal capacity and make their own decision supported.

# Supported decision making by personal assistants

- In Japan the guardians should respect the persons' rights and preference, but how can they get their preference and will, though they know nothing of their daily lifestyle and their life history?
- Personal assistants growing with persons with disability can more easily get their will and preference and not only family, but personal assistants are working as a group so they can discuss with their will and preference. And they stop not only institutionalization but also forced hospitalization.
- Just as Family Group Conference in The Eindhoven Model (see page ? )

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# Family Group Conference

- Most of people with psychosocial disability have the disability in adolescence or after grown-up so in most cases there are no opportunities to have supporters from childhood.
- But all of them have some friends, peers in work places, neighbours etc. or family members. And furthermore, if they could use personal assistants, in some cases, they can be a member of family group conference.

# The Eindhoven Model

- Family Group Conferencing as an alternative to forced psychiatry
- Aims to find desirable solutions
- The Netherlands did not yet ratify CRPD
- The Eindhoven Model is a user driven response to the Dutch law proposal on “mandatory mental health care”

# Family Group Conferencing

- How FGC works:

Stage 1:  
**Referral**

Stage 2:  
**Preparation**

Stage 3:  
**The conference:**  
-Information giving  
-Private family time  
-Agreeing with the plan

Stage 4:  
**Monitoring  
& reviewing  
the plan**

*Family group conference model (Source: Hayes & Houston 2007, p. 995).*

# Family Group Conferencing

Some benefits:

- Applicable with and without frame or condition
- Using expertise and resources already present
- Can combine formal and informal systems
- Practically useful plans
- Community based and inclusive
- Voluntary only
- **Identify desirable solutions and support** instead of proceeding to forced interventions

# Frames and conditions in Family Group Conferencing

- Generally on safety issues
- **Only when participants agree and are willing to commit to such a goal**
- no forced family group conferencing
- Search together for ways to live together in communities

# Personal Ombud in Skåne

- Neglect or Force?  
Some people refuse every support and there is no way to reach them, Do you neglect them?
- People ask always these questions for us about legal capacity.
- One answer is Personal Ombud in Skåne

# Principles of Personal Ombud in Skåne

- Independent from mental health system, social support system and all authorities.
- In Skåne POs are employed by users organization, but in some area they employed by the local governments. It is very problematic and most people are sceptical for POs and never become use POs

# Principles of Personal Ombud in Skåne

- The PO doesn't keep any records about his clients.
- No files, no forms to sign, no reports to authorities
- Without bureaucratic procedure



# Principles of Personal Ombud in Skåne

- “The PO doesn't keep any records about his clients. He may write down some notes about names, telephone numbers and addresses of friends and relatives of the client and other such practical things. And of course the PO often keeps copies of letters to authorities, which he has written on behalf of his client. But all these papers belong to the client. The client may see every paper whenever he wishes. And when the contact between the PO and the client is terminated, all papers are either given to the client or destroyed completely by the PO and the client jointly”

# Principles of Personal Ombud in Skåne

- “The client should have the right to be anonymous for the authorities. If he doesn’t want his PO to tell anybody that he has a PO this must be respected. PO-Skåne gets money from the community for the service, but there is a paragraph in the contract that says that the PO could deny to tell the name of their clients to the community.”

# What do people ask? Personal Ombud in Skåne?

- “The PO should be able to support the client in all kinds of matters. The priorities of the client are usually not the same as the priorities of the authorities or the relatives. According to 8 years of experience the clients first priorities are usually not housing or occupation, but existential matters (why should I live? Why has my life become a life of a mental patient? Have I any hope for a change?), sexuality and problems with relatives. A PO must be able to spend a lot of time talking with their client also about these kind of issues – and not just fix things.”

Thank you for your attention