Inclusion in Global Grass-roots Movements of Person with Psychosocial Disabilities

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Self-introduction

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◆ research theme:
global grass-roots movements of persons with psychosocial disabilities

◆ Why I study this theme?
I felt that conditions at the Japanese mental health hospital where I went as a trainee of therapist were awful, and became interested in the opinions of “patients” on those conditions.
Previous studies

Previous studies on grassroots movements of persons with psychosocial disabilities...

- mainly focus on movements in the USA and the UK, and
- have analyzed these movements as protests against mental health system.
Actual situations

♦ Persons with psychosocial disabilities have developed global grassroots solidarity, despite they are in various situations and have various opinions.

♦ This solidarity cannot be fully explained through an analysis of the relationship to mental health system.
Purpose

The purpose of this presentation is to describe how persons with psychosocial disabilities have tried to make their global movements inclusive.
Subjects

◆ Global network: World Network of Users and Survivors of Psychiatry (WNUSP)

◆ Continental network in Europe: European Network of Users and Survivors of Psychiatry (ENUSP)

◆ The member of WNUSP and ENUSP must be an organization or individual of user or survivor of psychiatry, which is anyone who defines themselves as a person who has experienced madness and/or mental health problems and/or has used or survived psychiatry/mental health services.
## Processes focused on

<table>
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<tr>
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<th>Global</th>
<th>European</th>
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<tbody>
<tr>
<td><strong>Established</strong></td>
<td>in 1991 with the name, “World Federation for Psychiatric Users.”</td>
<td>in 1991 with the name, “European Network of Users and Ex-Users in Mental Health.”</td>
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<tr>
<td><strong>Changed its name</strong></td>
<td>in 1997 to “World Network of Users and Survivors of Psychiatry”</td>
<td>in 1997 to “European Network of (Ex-) Users and Survivors of Psychiatry”</td>
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Methods

- I interviewed persons who led the processes.

  * Mary O’Hagan (from New Zealand), who was the first chair of the WNUSP; and

  * Maths Jesperson (from Sweden), who edited newsletters for both organizations.

- I evaluated documents of the both and other related organizations.
Movements of persons with psychosocial disabilities in the USA started with mental health professionals who were not satisfied with the practices in mental hospitals.

Then, survivors made organizations of only themselves in 1970s, influenced by the civil rights movements.

The federal government introduced the Community Support Program in 1977 and financially supported the movements. Then, the radical survivor stance was muted and moved to the background, while the reformist consumer position gained strength and recognition. Oppositions in the movements became clear in 1980s.
Pre-history in the UK

- Movements of persons with psychosocial disabilities in the UK also started with mental health professionals who were not satisfied with the practices in mental hospitals.

- Persons with psychosocial disabilities established their own independent organization in 1980s, influenced by the movements in other countries, especially in the USA and the Netherlands.
Establishment of the WNUSP

- The World Federation for Mental Health (WFMH) is a mixed organization of mental health professionals, persons with psychosocial disabilities, their relatives and others, and has been led by psychiatrists.

- Persons with psychosocial disabilities who participated in the WFMH thought that the WFMH failed to represent their opinions.

- They held separate meetings at the WFMH World Congress in 1991, and established the WNUSP at that time.
Some members complained about the name, World Federation for Psychiatric Users, because they did not identify themselves as users.

O’Hagan said about the name as follows;

* The problem with the word ‘federation’ was that it connected us to the WFMH.

* The users tend to represent the more moderate people and the survivors represent the more radical people.
Change the name into WNUSP

- The WNUSP continued the discussion about their name in correspondence and newsletters.

- The WNUSP adopted a position paper at the Fourth General Assembly in 1995 which noted that there were varying opinions among the movements on how to define an individual who had experienced the mental health system; they decided to use “user/survivor” for conciseness.

- The WNUSP members held the Fifth General Assembly in Lahti, Finland, in August 1997, and changed the name at that time.
Establishment of the ENUSP

◆ There were comparatively radical reforms of the mental health system in Italy from the 1970s. The reforms became world-famous, and established Italy as an important meeting place for those interested in the mental health movement.

◆ The movements in the Netherlands and the UK led to a 1991 meeting in Zandvoort, Netherlands, with the aim of establishing a continental network.

◆ There were difficult discussions about medical treatment at the meeting; nonetheless participants eventually agreed to establish the European network.
The Second General Assembly of the ENUSP was held in Elsinore, Denmark, in 1994.

Participants from Germany submitted a proposal to change the name to the “European Network of Users and Survivors of Psychiatry.” They had gathered 25 signatures.

The majority voted against this proposal; therefore it was not accepted.
Seminar on self-understanding

◆ There were intense discussions on the name at the Second General Assembly of the ENUSP. Consequently, a seminar was held on self-understanding in 1994.

◆ There were four topics discussed:
  * Self understanding:
    Are we different from average citizens? If so, why?
  * Self definition:
    How do we define ourselves without using traditional psychiatric or disability terms?
  * Self determination:
    How do we achieve self-determination in our own social surroundings?
  * Special rights or just equality?
    Should we demand special social rights?
Discussion at the seminar

◆ Many participants referred to their experiences of being defined by others against intention of themselves.

◆ They did not attempt to unify their identities, and some participants said that they did not want to be defined by others.

◆ It seemed more important to include various opinions of many members than to have one unified opinion.
Change the name into ENUSP

◆ The European network held the Third General Assembly in Reading, the UK in January, 1997. The name change went smoothly.

◆ Jesperson described the atmosphere of the discussion: “There was no call at all. It was immediate, oh, we changed the name, everybody agreed.”

◆ Then, point of discussion moved from the name to relationship with disability movements.
From the beginning, both organizations included members with opposing opinions.

After the establishment, it became more clear that unifying identification of members who have different opinions is difficult.

They intended to make sure that every member could feel to be part of the WNUSP or ENUSP, instead of split based on opinion.
Conclusion

◆ Both the WNUSP and ENUSP changed their names, in order to make it clear that members have different opinions.

◆ Therefore, it can be said that main basis of their solidarity is not similarity of insistence on how mental health system should be changed.

◆ Persons with psychosocial disabilities had intention to make their organization inclusive for people with different opinions.
Future issues

◆ The WNUSP and ENUSP do not try to include all people as their member. Their member must be only individuals or organizations of (ex-)users and survivors of psychiatry.

◆ What is the main basis of their solidarity in many differences?

◆ I think it may be experiences that what they think, demand, or experience have been denied by others, because they avoided to force one identification on all members.

◆ More survey is needed to reveal it.
Thank you so much for your kind attention.

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