Social inclusion of persons with psychiatric disabilities in Urakawa: social regards of the neighbors of Urakawa Bethel's House

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Introduction

It is well known that "the continued stigmatization of mental illness may well be the central issue facing the field" (Hinshaw and Cicchetti, 2000), and Japan is not an exception. Most persons with psychiatric disabilities don't disclose their diagnosis for fear of stigmatization, but this kind of coping may be more harmful than good for the QOL of them (Phelan, Bromet & Link 1998, Link et al., 1991). Policy makers, clinical staffs as well as the persons with psychiatric disabilities themselves aware of the importance of stigma mitigation and of advocacy campaigns against stigma that have been done in many countries. However, the effects of community-level interventions have been unclear (Pescosolido, 2003).

Some researches in Japan indicate that direct involvement in people with disability produce desirable understandings for disability (eg. Matsuoka, et. al. 2000), but the process or mechanism of such interaction is ambiguous.

Urakawa Bethel's House, the main target participants for our research, is a self-help group organized of several welfare facilities and a profit company in Urakawa, Hokkaido, Japan, and approximately 160 persons with psychiatric disabilities live in. The president or directors of the House are persons with psychiatric disabilities.

Social Skill Training (SST) is the highly employed skills there to find out solutions when members face difficulties in symptoms, social relationships, etc., almost everything. When a member identifies one of the difficulties in SST, other peer participants give advices to solve. Following the advice, he/she exercises role play with the others to apply it in the real world.

"Self-diagnosis" is another uniqueness of Urakawa Bethel's House. Members of Bethel's House diagnose themselves, like "schizophrenia, romance addiction type", "bipolar disorder with flattery" and so on, in addition to medical diagnosis. They explain their self-diagnosis in day-to-day situations and sometimes are invited to give lectures on their experiences to the public across Japan, so that Urakawa became well-known as

a town where persons with psychiatric disorders are able to live in a community, disclosing their disability status. The uniqueness of Bethel's House, which has been described in lectures and books published by the members, attracts more than 2,000 visitors per year across the country to come, though total population of Urakawa is only 16,000.

However, many reports on Bethel's House published have not been focusing on the relationship between members of psychiatric disability and residents without disability in Urakawa. Mukaiyachi (eg. 1997, 2000), one of the founders of Bethel's House and a social worker, has indicated on many conflicts between Bethel's House and the people in Urakawa. However, since a few papers and books written by observers have viewed Urakawa as "utopia", the readers could easily misconceive the town as "utopia".

Japanese mental healthcare community strongly hopes to learn from Urakawa to be generalized for other communities. However, it is still believed that "Urakawa must be special and the only place where people accept persons with psychiatric disability to live with".

Framework of "grand research project"

This study is a part of an intervening research project on disaster preparedness for all that could be developed by lessons from experiences of persons with severe disabilities. Japan is destined to live with natural disasters like earthquakes, tsunami and typhoons. Disaster preparedness is one of the most urgent issues for everybody today. Lessons from great earthquakes indicate that helping each other in neighborhood is essential to save lives in disasters. Besides, it might be the best intervention for social inclusion to develop disaster preparedness at community level through collaboration of all community members with and without disabilities.

Purpose of the intervening project is 1) to develop a successful prototype of community-based system for disaster preparedness include persons with stigmatized disabilities like psychiatric disabilities or autism, and 2) to evaluate performance of the system.

To achieve the goal, following strategies were employed. One is the development of accessible multimedia technology to promote understand on tsunami evacuation for the general public including people with psychiatric disabilities or individuals with autism. Enforcement of social networks for disaster preparedness is another essential component. Urakawa has been selected as the best test site for the project.

Purpose of this study

Under the "grand research project" scheme, it is essential to find the appropriate way for generating collaborative relationships with/without disabilities. As the first step, the purpose of this study is to explore the characteristics of Urakawa residents' attitudes towards persons with psychiatric disabilities who are able to disclose their needs and difficulties for living.

Research questions of this qualitative study are as follows; 1) Is it true that people in Urakawa is unique and something special? In other words, people in Urakawa have no deviant feeling against persons with psychiatric disabilities? 2) If people of Urakawa are not special, what characteristics in Urakawa make the persons with psychiatric disabilities to disclose their disabilities and needs?

Study Method

Qualitative study and ethnographic interviews have been conducted from August 2004 to May 2006. Primary informants, recruited by snowball sampling method, were residents of three residents-associations in the area where the group-homes run by Bethel's House also exist. Interviews included the notion of the interviewees as well as the rumors in neighbors because it is difficult for everyone to confess their deviant notion but it is easy to tell others' deviant notion as rumor. Eighteen independent interviews were tape-recorded with permission, and informal conversations at the meetings of the residents-associations and in other settings were recoded by field notes. Supplement interviews were conducted to members and staffs of Bethel's House for the episodes described by residents.

Bethel's House's approval as well as institutional ethical committee approval were obtained for this study. According to Bethel's House's principle, episodes are described with real names.

Characteristics of group-home residents in three areas

Depending on the characteristics of the location of group-homes, effective interactions are varied a lot. Our interviewed data covered three distinctive areas in Urakawa.

Area A is a residential area. One Bethel's House group-home was set up in 1984. Senior members, who founded the group-homes, have joined residents-association activities and keeps in touch with neighbors.

Area B is a commercial area. One Bethel's House group-home only for women with a souvenir shop on the ground floor was set up in 2003. It keeps good relationships

with neighbors as more than 2000 Bethel's House visitors per year have brought local economic effects to the area.

Area C is a residential area. It is close to a major hospital. Three Bethel's House group-homes were settled in last few years. Over 30 members (include the most critical patients) live in. No close relationship is established as members change so often. Very few can be identified by the neighbors.

Findings

Public attention and intangible complaints to Bethel's House

People of Urakawa mostly know the name of Bethel's House which relates to the persons with psychiatric disorders. However, the public attention to Bethel's House's daily activities is quite low.

In the past, persons who discharged the seventh ward for psychiatrics were called "7 ward guys". Today, psychiatry patients are all called "the Bethels."

(psychiatrist of Urakawa Red Cross hospital)

BH became very famous on TV, but not in Urakawa. Only few know what they do.

(shopkeeper)

Intangible complaints suggest that some residents of each area do have fearful and uncomfortable feelings against Bethel's House members.

I myself, don't mind anything, but someone worries who is going to secure against accidents. When it happens, who will take a responsibility?

(coordinator of residents association)

Tangible complaint toward Bethel's House

Many episodes of tangible complaints were told. There was no negative campaign against Bethel's House happened even in the case of fire. Following episodes show the uniqueness of the coping way employed by Bethel's House.

1) Episode on fire

In the past 20 years, Group-home A has caused fire three times because of their mistreatment of tobacco. A person lives in next-door, Mrs. P outraged on that. Mrs. P asked the apology and guarantee of prevention by "the persons in charge". From Bethel's House side, Dr. Kawamura, a psychiatrist and one of the founders of Behtel's House, told the situation like follows:

It is very natural that neighbors got angry on these fires. When they happened, we

discussed "Who are in charge? I'm a psychiatrist of red-cross hospital. Mr. Mukaiyachi? No, he is a PSW in the hospital, too." Our conclusion was that Mr. Sasaki (an official representative of Bethel's House with psychiatric disability) and Mr. Kiyoshi (a main member with psychiatric disability) should go and apologize as a person with responsibility because they two live there." They and I visited Mrs. P. She stormed them and said "You should leave." However, what they said was "We have no place to live other than here." I cannot remind it without the admiration on their maturity!

After the latest fire, members voluntarily made a rule not to smoke in the room (except outside).

On the other hand, Mrs. P accepted our interview in this study and narrated her feeling:

I still hope that they would leave. I always check their fire management from the windows. I know of the three, Mr. Sasaki, Mr. Kiyoshi and Mr. Okamoto. I have a chat with Sasaki on the corner, but I still don't believe he can manage well with troubles even if he is the representative of the House. I still have a chat with him though –omission- And Mr. Okamoto dumps empty milk boxes everywhere. We all are disturbed so much. In bad condition, he is very awful countenance. However, when he is in good mood, he's really a gentleman and wise person.

2) Episode on convention

Bethel souvenir shop (located in the ground flour of Group-home B) served light meal during the annual festival of Bethel's House and residents-association helped their service. After the festival, Bethel's House offered a party for thanks.

Mr. Q, an external supporter of Bethel's House and neighbor of group-home B, told the situation.

Mr. R. (chief Coordinator of residents-association) said "Participants from Bethel's House should be limited, because the Bethels usually come in group to our meetings". It looks that he and others are uncomfortable with the situation as overwhelmed.

Mr. Q advised Rika (a director of Bethel's House and live in group-home B) that "You should select one person from the Bethel's who joins the meeting. Do at Rome as the Romans do."

Rika: "I am not social enough and it is difficult to go along with neighbors."

Mr. Q: "Occasional greeting is important here. When you trip to somewhere, you better bring souvenir to Mr. R. We all usually have this kind of greetings."

Rika brought some souvenir after a while. That means that as a chief coordinator, Mr. R. was satisfied because he could save his face.

Understanding of "individuals"

Some who had good chance to interact with Bethel's House people independently, noticed that there is nothing to fear for them. They are understandable. Anybody has a possibility to get psychiatric disability too.

In bad condition, he is very awful countenance. When he is in good mood, he's really a gentleman and wise person.

(Mrs. P: neighbor of A)

The girl says "I'm schizophrenia", but she is much more polite than today's average youth.

(neighbor of B)

What are you going to do with a patient like me who has not been diagnosed, but surely sick? Everyone is a patient in some extent.

(shopkeeper around B)

Someone is getting suspicious of the Bethel's House when anything happens. I know them and insist that they definitely don't do such a thing.

(neighbor of C)

Discussion

Episodes told by neighbors revealed that intangible fears for members of BH actually exist. But there was no negative campaign against Bethel's House. At the same time, as neighbors got more familiar with Bethel's House members, he/she has tried to develop more understanding on Bethel's House members even if he/she initially had been reluctant to accept them. This shows that Urakawa was not "utopia", but a town with some deviance, just like other towns. At the same time, bad social-economic situation of Urakawa may affect the acceptance of persons with Bethel's House. Visitors for the House have increased up to more than 2000/year, that gives a significant economic effect to Urakawa. In addition to the economic impact, aging as well as under-populating condition makes the public strongly expect the increase of younger generations, and this expectation leads to acceptance of persons with psychiatric disability from outside Urakawa.

When some troubles occur, the coping style of the House was unique. The person who got into any troubles must face the negotiation or blaming directly, according to Bethel's House's principle, although neighbors expect Bethel's staffs

without disability to take guardian role for BH members and listen further complaints. Some “troubles” might be likely twisted into something negative, turning to ill feelings against psychiatric disabilities. Breaking down to a piece, however, Bethel’s House members can cope with independently, causing inevitable and direct interaction with neighbors. This principle helps neighbors face the members too, leading to empathetic understandings of each other although this kind of direct communication might be stressful for the persons with psychiatric disability. This is why Bethel’s peer support was essential to help confront the stressful situation.

Conclusion

This study in Urakawa revealed that; 1) People in Urakawa are ordinary people maintaining a certain distance from persons with psychiatric disability. It can not be said that they have totally accepted Bethel’s House members 2) However, there is no collective rejection against Bethel’s House. Positive economic effects on declining local economy and the increase of relatively younger generations both contributed by Bethel’s House have provided Urakawa with better ground to reduce stigma against psychiatric disability. 3) Eradicating stigma for social inclusion of persons with psychiatric disorders through generating empathetic understandings on the disability is being successfully promoted by direct communication between persons with psychiatric disability and neighbors in Urakawa. Those findings suggest that roles of professionals and staffs should not be guardian but intermediary of direct communication of persons with psychiatric disability, that must be required for social inclusion.

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