The Support for Siblings of People with Disabilities

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■The Focus and Purpose of My Research

The focus of my research is on the siblings of mentally disabled people. Most of them help mentally disabled people as a family member. But most of the earlier research focus on people with mental disabilities or their parents, but not siblings.

There are two purposes in my research. Firstly, I clarify a part of the problems that siblings have. Secondly, I clarify the meaning of self-help groups for siblings.

I give a definition of words in this report. Firstly, I define 'siblings' as brothers and sisters of mentally disabled people. Secondly, I define 'disabled people' as disabled people (not 'siblings'). Thirdly, I define 'mentally disabled people' as intellectual disabled people in Convention on the Rights of Persons with Disabilities.

■Evaluating this Report

The last purpose of my research: I consider the problems of siblings of mentally disabled people and the support they get from many angles and clarify the support which siblings truly need.

My research is based on the results showed by literatures, observations with participation and interviews.

This report is a part of the results of my research. My research is still on-going.

■The Reason I Focus on the Siblings of Mentally Disabled People

The mentally disabled people need to be helped especially because it is hard for them to live daily because of their mental disabilities. In Japan, the number of mentally disabled people is 547,000. Among them, the number of people who receive residential care is 419,000, and the number of people who receive institutional care is 128,000.

I focus on the siblings of 'mentally disabled people'. The two reasons are as follows:

(1)The siblings continue to have a relationship with mentally disabled people from their childhood to advanced age because of the characteristic of their disabilities.

A mental disability is either an inborn disability, or childbirth disability, or disability from childhood. It continues for a life. The percentage of mentally disabled people living with their siblings or their parents and siblings who receive residential care is 45.8% (The Ministry of Health, Labor and Welfare2007).So, about half of all siblings live with mentally disabled people who receive residential care.

On the other hand, some of the siblings having mentally disabled people living in an

institution help disabled siblings as a guardian. The siblings help more parts when their parents grow older or pass away.

(2)People with mental disabilities have hard time communicating by speech. When they have other disabilities, their siblings have more problems.

Other disabilities are developmental disabilities (ex. autism), behavioral disabilities (hurting themselves, attacking, hard feelings, disorder of sleeping/eating/discharging, not stop moving, being noisy) and more. It is harder for us to understand these disabilities including mental disabilities than physical disabilities.

It is inevitable that family members face the conflict between mentally disabled people deciding things themselves and their parents or siblings caring too much for their benefit.

■The Problems that the Siblings Have

The siblings' problems come from interaction among three problems.
①The Problems of Family Members (Disabled People / Parents)
②Incomplete Systems of Disabled People
③Discrimination and Prejudice in Society

The problems that the siblings have explained in earlier research have two points.

(1) The Psychological Problems in Family

The siblings feel lonely, angry, and bitter for family members. And parents demand the siblings of mentally disabled people to be perfect. In the background, it is hard for parents to pay attention to siblings because parents spend too much time and care for people with mental disabilities (Lobate1983, Donald & Vadasy1994).

(2) The Social Problems as Caretakers

Thinking that family members must care for other members in the family, the parents or society demand the siblings of mentally disabled people to be caretakers in place of the parents. In fact, some siblings spend too much time and care for people with mental disabilities though they are not mature enough to do so. And siblings play more parts when their parents grow older or pass away. But the siblings cannot get more information of the support for life of mentally disabled people than the parents, who had organizations to help them (Grossman1972, Donald & Vadasy1994).

In addition, three factors make problems of siblings complicated (Simeonsson & McHale1981).

① People with Disability :

The Kind of Disability, A Degree of Disability, Residential or Institutional Care, or Age

② Siblings :

The Order of their Birth, Sex[Gender], The Number of Siblings , The Ranges of Age, Personality, or The Number of Times Siblings Contact with Disabled People

③ Family :

The Size, The Economic Position, Religion, or Age   and so on.

■The Meaning of Self-Help Groups for Siblings

The problem of earlier research is that they only referred to the problem of siblings, but haven't focused on the support for him/her.

My research contributes to the solution of the problems of the earlier research. I think the solution is analyzing the meaning of self-help groups. Based on the result, I analyze the process of getting rid of problems, and consider the support for siblings.

I use references, observations with participation, and interviews in my research.

The flowing is part of the result of the survey carried out with the members of National Movement of the Siblings of Disabled People, which has the longest history in Japan as a self-help group involving the siblings (Database:p5-7).

(1) Mutual Understanding of Experiences and Feelings

Before siblings join in

・Siblings had the difference in the content of conversation between themselves and people with non-disabled siblings.

After siblings join in

・Siblings have encountered people experiencing the same difficulty in self-help groups.

・Therefore, it has been easy for them to talk about disabled sibling and feel comfortable in self-help groups.

(2) Getting Information for the Support for Disabled People

Before siblings join in

・Siblings did not know the systems of disabled people.

After siblings join in

・Most of the members in self-help groups have experienced the difficulty of disabled people.

・The members have advised siblings how to receive the support for disabled people.

(3) Considering again about Siblings' Life

<u>Before siblings join in</u>

・Some of the siblings thought they were better at coping with the support for their disabled sibling living on their own.

・They tried to become 'the parents' of their disabled siblings.

<u>After siblings join in</u>

・Some of the siblings consider their life again as 'the sibling of disabled people' in self-help groups.

(4) Empowerment

<u>Before siblings join in</u>

・Some sibling felt that they were leading a meaningless life after their disabled sibling passed away.

・Other sibling could not talk with their family members about her disabled sibling.

<u>After siblings join in</u>

・Some sibling found the meaning of talking about their experiences.

・Other sibling worked on their family members. And they gradually came to talk about my disabled sibling.

■The Conclusion

The number of earlier research about siblings is small. One of the reasons is that the problems of mentally disabled people and their parents are outstanding, but the problems of siblings are not outstanding.

The support systems of disabled people based on the problems of the mentally disabled or their parents. In the present situation, the self-help group for siblings is important.

In the self-help group for siblings, not only do siblings receive the good effect, but also mentally disabled people or their parents.

Database

■The Outline of My Research Methods: The Observations with Participation and Interviews

The Observations with Participation
・The Field :National Movement of the Siblings of Disabled People
・The Methods :Regular Meetings and Annual Meetings, Get-together.
  Attentions to sex[gender]and age groups of members, history and frequency of their activities

The Interviews
・The Subject :Members of National Movement of the Siblings of Disabled People
・The Number of Members :Sixteen (but over Fifty Observed)
・The Schedule :October 2010 (Twice, Area X and Area Y)

■An Example of The Siblings' Stories

Case1 (Female/Forties) :The Difference in the Content of Conversation between the Siblings and People with Non-Disabled Siblings

> "*Recently, I have been able to talk about my disabled sibling who hit me. But I have talked nothing about it. I have not been able to talk about my disabled sibling who cries on the veranda and hit my father and made him bleed, because I have thought people with non-disabled siblings are surprised to hear it.*
> * I can talk about it here, because I have not felt hesitant. I feel comfortable here.*"

Case2 (Female/Fifties) :The Prejudice about Good Siblings

> "*When I talk to people with non-disabled siblings about the troubles with my disabled sibling, they say that YOU ARE A GOOD SIBLING, and encourage me. Why?*
> *…I can show my true feeling here because the members experienced the same difficulty. It is easy for them to accept me as the sibling of disabled people.*"

Case3 (Male/Thirties) :Getting Information of the Systems for People with Disability

> "*My brother has a mental disability. He stopped working last year because of the problems of bullying in his workplace. I can talk about it here and feel comfortable. I have appreciated National Movement of the Siblings of Disabled People because the members advised me how to receive Disability Pensions, for example.*"

Case4 (Female/Forties) : The Consistency of the Purpose of Her Joining the Groups

> *"I wanted to get the information about the support for life of mentally disabled people. Surely I feel comfortable here. But it is not the reason I come here. My purpose has been to get information from the start.*
> *…After this, I want to know how to cope with the problems of disabled sibling or of my family when he gets old."*

Case5 (Male/Fifties) : The Change in the Objective of the Movement and His Thinking about His Life

> *"I cannot become 'the parents' of my disabled sibling. I consider my life again as the sibling of my disabled people in National Movement of the Siblings of Disabled People. Firstly, I thought I was better than my parents at coping with the support for my disabled sibling living on his own.…"*

Case6 (Male/Fifties) : The Difficulty of Disabled People Passing away

> *"I lost the purpose for joining National Movement of the Siblings of Disabled People in 1980s because my disabled sibling passed away. On the other hand, the regular meetings began in the 1980s. …My life was different from those of others, my disabled sibling passed away, but I could not live a life without disabled sibling. I was at a loss what to do."*

Case7 (Male/Sixties) : The Meaning of Action of the Movement

> *"When I was twenty years old, National Movement of the Siblings of Disabled People did not have the purpose of supporting siblings. Then, for example, I helped my disabled siblings to grow up, and contributed to the movement to reform the systems for my disabled siblings. These were the purposes of National Movement of the Siblings of Disabled People"*

Case8 (Male/Sixties) : The Inevitable Responsibility of People with Disability

> (He has three disabled siblings, one of whom has passed away.)　*"I could not shed tears when my father, my mother or my younger disabled brother passed away. Why did I not shed tears? Probably I'll shed tears after several years. Now I am still tense. …Now I care for my disabled siblings one-third of a week. Uh, I hope the time will come when I can cry."*

Case9 (Male/Sixties) : An Encounter with People Experiencing More Troubles

> (He encountered Mr. A, who experienced more troubles in National Movement of the Siblings of Disabled People)　*"I realized there were people like Mr. A who had more programs. I thought I must be more patient. His experience dispelled my hard feelings toward my family members. …I think I have enough motivation to establish again Movement in Area Y of the Siblings of Disabled People."*

Case10 (Female/Thirties) : The Change of Family Members

> *"It was hard for family members to talk about my disabled sibling because the topic is a taboo among them. But my family members gradually came to talk about my disabled sibling after I joined it. I told my mother that I became a member of National Movement of the Siblings of Disabled People. I got information about disabled people from National Movement of the Siblings of Disabled People, she became interested and became a member herself. My mother said that she now had a broader view.…"*

■The Members' Action Policy

In the conclusion based on the Cases 1 to 10, most of the stories demonstrated the change of siblings themselves. And the siblings talked about the relationship not only between themselves and disabled people but also between themselves and their parents.

Though it is not clearly pointed out in the cases, it is important that National Movement of the Siblings of Disabled People give its members the opportunities of thinking about the methods of care as 'siblings' , not as 'the representative of the parents' . The siblings have different ways of thinking about care for disabled people from their parents. The parents prepare themselves for people with disability. The parents want to care for people with disability over the period of their life. On the other hand, siblings are concerned how they should care for their disabled siblings in the life they are going to lead. They are sometimes forced to foster the relationship as a representative for the parents and they have conflicting relationship with their parents. The members discuss this problems with each other and think about their life.

■Self-Help Groups for the Siblings in Japan

One of the practical methods for helping the siblings is helping them with the help of self-help groups. In Japan, one of the self-help groups is National Movement of the Siblings of Disabled People. This is the earliest group. The main members are the

siblings of the mentally disabled with various kinds of disability.

The change in the objective of National Movement of the Siblings of Disabled People is as follows (Hajime,M ;Hiroki,Y 2003) :

(1) The 1st Stage (from 1963 to the first half of 1970s):

The time for the siblings to do away with discrimination and prejudice against disabled people;　The siblings are 'family members' of disabled people.

In the first half of 1960s, we began to realize the problems of disabled people in our society. National Movement of the Siblings of Disabled People was established when a variety of movements for disabled people were established. Takayasu Washida, who proposed to establish National Movement of the Siblings of Disabled People, maintained that family members received disadvantage in society when people had prejudice against disabled people. For example, it was hard for the siblings to marry, work, associate with their friends, and so on.

(2) The 2nd Stage (from the latter half of 1970s to the first half of 1990s):

The time that the siblings clarify the relationship between the siblings and disabled people;　The siblings are 'siblings' in family members with disabled people.

In 1980s, the systems of disabled people developed with The Year of International Disabled People (1981). Social welfare has changed from what was based on an institutional care to that based on a regional care. The systems were founded on condition that family members helped disabled people to live in the region. The members who were enrolled from the start grew up to be their forties or fifties. So, they began to be conscious of helping disabled people after the parents passed away. The members have gradually paid attention to the lives of their own.

(3) The 3rd Stage (from the latter half of 1990s to 2001):

The time that the siblings consider again the purpose of mutual friendship and support; The siblings are 'siblings themselves' in family members with disabled people

As part of Reform of Basic Structure of Social Welfare in 1990s, the way disabled people received the welfare service changed from the passive system to the system based on equal relationship supported by contact. However, it has been a major difficulty for the disabled to choose among services and make a contact.

The members were still worried about the relation between themselves and disabled people. So, it has been important for the members to consult on the relation between themselves and disabled people.

Therefore, the history of the support for 'siblings themselves' characterized in the 3rd stage is short.

The 1st Stage (from 1963 to the first half of 1970s):

The Problems of Discrimination and Prejudice

⇒ **'For Disabled People'** (The Problems of Disabled People＝The Problems of Siblings)

The 2nd Stage (from the latter half of 1970s to the first half of 1990s) :

The Problems of Helping Disabled People after the Parents Passed away

⇒ **'For Disabled People'** and **'For the Siblings'**

The 3rd Stage (from the latter half of 1990s to 2001) :

The Problems of Limiting Mature Systems for Disabled People

⇒ **'For the Siblings'**

The Figure :The change of the siblings' consciousness of the part in National Movement of the Siblings of Disabled People

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