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CHALLENGING STIGMA AND DISCRIMINATION:

The experience of mental health service users in Japan

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ABSTRACT

Mental health service users (hereafter referred to as users) are seen as 'inferior, undesirable, or threatening' on culturally normative grounds (Meyers, 1994, in Johnstone, 2001). Based on these stereotypes, users are subjected to systematic disadvantage in most areas of their lives. They are excluded socially at home, at work, in personal life, in social activities, in healthcare, and in the media (Thornicroft, 2006b).

The aims of this study were to identify how significant user groups were in supporting users to challenge stigma and discrimination and to explore ways to meet the challenge utilising their collective strength, in the Japanese context. It also aimed to gain a comprehensive understanding of users' experiences and the consequences of stigma and discrimination. To achieve these aims, a focus group interview and five individual interviews were conducted.

The Japanese government announced a policy to shift institutional care to community care (Ministry of Health and Labour, 2004). Moreover, the Japanese government has eventually signed the United Nation's Disability Convention, in September 2007. There is a long way for ratification; however, it is a significant step, which indicates their commitment towards equal rights of disabled people. Thus, this study, which explores ways to challenge stigma and discrimination, has contemporary relevance.

The outcome of this study indicated that stigma and discrimination which is created by society disables users, not an individual condition. Society excludes users, denies them their rights and robs them of their life opportunities unfairly by labelling them as 'inferior, undesirable, or threatening' (Meyers, 1994, in Johnstone, 2001), marginalising and oppressing them. User groups have the strength to challenge stigma and discrimination, however, the indispensable role of such groups in Japanese society is neither recognised properly nor utilised sufficiently in the current system. This paper concludes with recommendations to maximise the users' collective strength in the challenge.

Chapter One

Introduction

Stigma represents a kind of death – a social death.

Nonstigmatised people, through avoidance and social rejection, often treat stigmatised people as if they were invisible, nonexistent, or dead (Coleman, 1997: 226).

Stigma and Discrimination against Mental Health Service Users

Mental health service users (hereafter referred to as users) are seen as 'inferior, undesirable, or threatening' on culturally normative grounds (Meyers, 1994, in Johnstone, 2001). Based on these stereotypes, users are subjected to systematic disadvantage in most areas of their lives. They are excluded socially at home, at work, in personal life, in social activities, in healthcare, and in the media (Thornicroft, 2006b). Stigma emerges as one of the most widespread and tangible social barriers for users (Mezzina *et al.*, 2006) and extensive discrimination disables users.

Three key issues are identified in relation to stigma: lack of knowledge (ignorance); negative attitudes (prejudice); and rejecting behaviour (discrimination) (Thornicroft, 2006a). Discrimination usually means 'treating unfairly' (Marshall, 1998: 163). An individual or group face exclusion from opportunities to participate in some desired life, or exclusion from equal opportunities or benefit from limited resources (Davies, 2000). There are several forms of discrimination. Direct discrimination means treating some people less favourably than others, for example because of their impairments (Coote, 1991). Indirect discrimination means that some condition or requirement that seems to be equal has unequal implications or results for a certain social group (Alcock *et al.*, 2002). Similarly, passive discrimination is covert and unconscious attitudes (Barnes, 1991a). Institutional discrimination only affects some groups resulting in the majority of people merely adhering to existing organisational and institutional rules or social norms without thinking (Marshall, 1998). In most contexts, direct, indirect and

passive discrimination are entwined (Barnes, 1991a).

Different types of discrimination such as social exclusion, rejection, poverty and isolation can have a detrimental effect on people's lives – and can damage mental health (Sayce, 1998). It is not helpful to see ignorance, prejudice and discrimination simply as what is 'done to' users, because stigmatisation is applied not only by others but also by users to themselves (Noh, 2003 in Thornicroft, 2006a). Feelings of exclusion from social life have a great influence on how people perceive themselves in their social role (Mezzina *et al.*, 2006). Goffman (1968) made a distinction between 'discredited' and 'discreditable' within stigmatised people. Discredited means people who have visible stigmatising features, such as people with physical impairments. Discreditable refers to people with less visible features such as people with a condition called 'mental illness'. Discreditable people can conceal their user status to avoid discrimination. Scambler and Hopkins (1986) describe two kinds of stigma, namely enacted stigma and felt stigma. Enacted stigma is

discrimination against people due to their 'unacceptability or inferiority' such as with epilepsy (p.10). Felt stigma refers to the fear of enacted stigma including a feeling of shame which is associated with the condition. Users internalise the values of dominant groups of society and develop a negative self-image (Reeve, 2006), which is internalised oppression. It can make some disabled people feel devalued, useless and disempowered (Reeve, 2004) and it also prevents them from building confidence and having self-respect.

Situation in Japan

Kure and Kashida (1918), Japanese psychiatrist, stated:

Japanese people with a psychiatric illness are suffering a double misfortune, not only have they developed this illness but also they were born in this country (p.138).

Although approximately 90 years has past, their statement is still

veracious. Users are among 'the most stigmatised, discriminated against, marginalised, disadvantaged and vulnerable members of society' (Johnstone, 2001: 200) in Western countries. However, Kurumatani *et al.* (2004) report that the level of social rejection is comparatively stronger in Japan, although similarities of knowledge, beliefs and attitudes are identified between Japan and most Western countries (in Thornicroft, 2006a). Significant figures which indicate the degree of social rejection are the high proportion of psychiatric beds and lengthy hospitalisations. The ratio of psychiatric beds per 10,000 population is 27.9 in Japan (Seishin Hoken Fukushi Kenkyukai, 2004), whereas it is 5.01-10 per 10,000 population in Britain (WHO, 2001: 51). The average length of hospitalisation is 338 days in Japan (Ministry of Health and Labour, 2004b), whereas it is 18-19 days in Britain (DoH, 2004: 26). There are approximately 330,000 inpatients in Japan (Ministry of Health and Labour, 2003), of which about 30 % people have been 'living' there for more than 10 years. 'Social hospitalisation' was

created by a lack of support in the community (Seishin Hoken Fukushi Hakusho Hensyu linkai, 2006), which has been recognised by the Japanese government. It announced a policy to shift from hospital based medical care to community care and stated an intention to discharge 70,000 patients by increasing community supports in *'Reform Vision of the Mental Health, Medicine and Welfare,'* (Ministry of Health and Labour, 2004a). However, no radical change has been introduced in the system to promote it and support services in the community are still scarce (Seishin Hoken Fukushi Hakusho Hensyu linkai, 2006). Moreover, Ikui (2007) states that Japan is a country which rejects disabled people by law to the greatest degree in the world.

Some users who were formerly viewed as passive and dependant recipients of medical care and welfare are taking active roles not only in their own lives but also in society in Japan. They have organised support groups for providing peer support as well as achieving broader social objectives by

challenging the existing mental health system as a user movement, despite the lack of support and systems to back them up. They started to undertake research as the means of their political action. However, photographs of users on the website of a significant user organisation in Japan are blurred (Zenkoku seishinshogaisha nettowa-ku kyougikai, 2007). Some activists refuse to have their pictures and their names printed in newspapers and books (see Yahiro *et al.*, 2006). This indicates how fearful this society is even for users who are taking active roles in user movement in Japan.

Questions emerge such as ‘What is users’ experience of stigma and discrimination?’ ‘How are they coping?’ ‘Are there any ways to change it?’ However, the literature which investigates users’ direct experience is very limited, especially in Japan. Although voluminous literatures on stigma against users exist, few contributions have been made by users (Thornicroft *et al.*, 2007). Users have not been considered to be valuable participants or collaborators of research in the mental health

field (Rapp *et al.* 1993), notwithstanding they are the very persons concerned. It is important to understand their experiences and perceptions of stigma and discrimination and explore ways to challenge these, utilising users' strengths.

Aims and Objectives

The aims of this study are to identify how significant user groups are in supporting users to challenge stigma and discrimination and to explore ways to meet the challenge, utilising their collective strength in the Japanese context. Another aim is to gain a comprehensive understanding of users' experiences and the consequences of stigma and discrimination. Having considered the literature, I hypothesise that user groups do have a significant role to play in challenging stigma and discrimination in this society which excludes and isolates users. In order to examine these aims, three objectives were set:

1. to elicit users' experiences and perceptions of stigma and

- discrimination and the impact of these;
2. to identify users' strategies to handle and challenge stigma and discrimination and identity issue;
 3. to explore ways to challenge stigma and discrimination whilst utilising users' collective strength.

Choice of Language

It is important to clarify the meaning of language as each term indicates different standpoints. Several ways exist to describe people who have been given a diagnosis of 'mental illness' such as patient, mental health service user, consumer and psychiatric system survivor. Traditionally, in psychiatry, 'mental patients' is used, which emphasises their pathology (Pilgrim and Rogers, 1999). However, 'mental illness' is a contested concept (Murthy, 2001) as its diagnosis depends on observation or reported behaviours, which are defined socially, not by biologically-based tests (Chamberlin, 2006). Some users reject a medical model because they see it as intellectually unsustainable and deeply

damaging to 'labelled' people (Beresford and Wallcraft, 1997). Having considered the implication of each word, the phrase 'mental health service user' is chosen for the purpose of this dissertation. This simply indicates that they are using mental health services. This is because few Japanese people who use mental health services, including the participants of this study, describe themselves as 'survivors' 'consumers' or 'users (Yuuzaa in Japanese)'. These are newly imported Western words and concepts, which can be confusing. The word 'user group' within the context of this dissertation indicates both formal user organisations and informal user groups, which are run for users by users. Similarly, 'disabled people' is used rather than 'a person with a disability' to make it clear that it is society's failure to provide appropriate services to meet the needs of disabled people, not individual limitations that cause the problems (Oliver, 1990a, 1990b).

Structure

In the next chapter, significant issues regarding stigma, discrimination, identity and user groups are identified. Chapter Three examines the methodology underpinning this research including ethical considerations. The following three chapters present and analyse the findings regarding participants' experience of stigma and discrimination (Chapter Four), the way to handle stigma and discrimination and the effects of these on users (Chapter Five) and the way to maximise users' collective strength to challenge stigma and discrimination (Chapter Six). Finally, Chapter Seven concludes the discussion of the findings and makes some recommendations.

Chapter Two

Mental Health, Stigma and Discrimination: onsequences and responses

This chapter will begin by looking at the definition and structure of stigma. Then, 'enacted' and 'felt' stigma and internalised oppression will be explained. Following on from this, strategies to handle stigma and discrimination and identity issues in relation to user groups will be addressed. Subsequently, the reality of discrimination including the Japanese situation will be illustrated. Finally, the way to challenge stigma and discrimination will be explored.

Stigma: stereotype, prejudice and discrimination

It is worth stating the initial conceptual framework of stigma, as defined by Goffman (1968). The term stigma originally comes from Greece and refers to the bodily signs of disgrace usually eliciting negative attitudes. The signs indicate that the bearer is 'not quite a human' and is to be avoided and discriminated.

Bodily marking has decreased, however, a more cognitive appearance of stigmatization - social marking - has grown (Jones *et al.*, 1984, in Coleman, 1997) and such differences are used to exile the person (Coleman, 1997). However, Finkelstein (1980) argues that the identification of oppression in ancient Greek society has been greatly spoilt by Goffman, who has 'neutralised the role of "stigma" in the maintenance of an oppressive relationship between one strata of society and another' (p.20). Once stigma is neutralised as the mark of the 'unusual', stigma can be seen as the person's possession rather than a device for segregation.

Stigma, which is constructed by society, affects the individual's life experiences (Taylor, 2001). Spicker (1984) indicates three aspects regarding social relationships: lowering of social status, denial of social status and the denial of humanity. Social rejection/ isolation and lowered expectations are two of the most common ways in which non-stigmatised people convey a sense of fundamental inferiority in stigmatised

people. Goffman (1968) states that the main characteristic of stigmatised people's situation is a question of 'acceptance'. Hence, according to Goffman, disabled people seek 'acceptance' continuously from stigmatizing people who impose upon them a dependent role permanently, and thus have responsibility for their dependency (Finkelstein, 1980).

The view which sees disadvantaged people as victims tends to de-emphasise any analysis of cultural or social factors. In particular stigma theories merely take account of questions of power relations (Estroff *et al.*, 2004 and Morone, 1997, in Thornicroft, 2006a). However, stigmatization is the exertion of power over people (Gilmore and Somerville, 1994, in Taylor, 2001) and a strategy for social control, which marginalises or excludes a group from the community, and so reinforces societal values (Taylor, 2001). The user status, as a 'master status', which influences all other statuses (Scheff, 1966 in Segal *et al.*, 1993), creates a real obstacle to a user's ability to organise necessary and required resources (Segal *et al.*, 1993).

Link and Phelan (2001) conceptualised stigma and concluded that stigma is a prejudice, based on negative stereotypes, which results in discrimination. 'Stigma exists when elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation' (p.377). Stereotypes, such as dangerousness, incompetence and weak character, are knowledge structures which are learned by most members of society. Stereotype, prejudice, and discrimination can rob users' of life opportunities that are crucial to achieving their purpose in life (Corrigan and Kleinlein, 2005).

Stigma theories have not paid much attention to structural elements which indicate the little value given to stigmatised groups, such as comparatively low amounts of investment in mental health services (Corrigan *et al.*, 2004, in Thornicroft, 2006a). Furthermore, such theories have not done enough to help understand users' feelings and experiences, nor to know what is needed practically to promote social inclusion (Social Exclusion Unit, 2004, in Thornicroft, 2006a).

Enacted Stigma and Felt Stigma and Internalised Oppression

Scambler and Hopkins (1986) have made an important distinction between enacted stigma and felt stigma. As described in the introduction, enacted stigma denotes the actual experience of discrimination, whilst felt stigma relates to the fear of enacted stigma and a feeling of shame because of having the condition. Users may develop negative feelings about themselves, isolate themselves, lower their expectations and give up hope. Even if they have never been discriminated against in their lives, they anticipate discrimination and conceal their condition to avoid discrimination. They also develop a fear of revealing their secret i.e. their disability status. These fears, however, are founded in a practical judgment of the negative social consequences of stigmatization and reflect the long-term social and psychological harm to individuals (Coleman, 1997).

The most harmful effect of bearing a stigma is that stigmatised people may grow the same perceptual problems

that non-stigmatised people have (Coleman, 1997). The pejorative responses are the origin of individual stigma as users can internalise negative attitudes in society (Green, 1995, in Taylor, 2001). Social exclusion also indicates no expectation of them to achieve in society. Lowered expectations lead to diminished self-esteem. The negative identity that is derived becomes a general personality trait and hinders the user from developing other parts of self (Coleman, 1997). Users also experienced indirect stigma such as having heard stigmatised comments and having seen hurtful media portrayals, and feeling shunned or avoided (Wahl, 1999). In a culture filled with stigmatizing images, users may believe these ideas and experience lower self-esteem, self efficacy, and confidence in their future (Corrigan, 1998, in Corrigan and Kleinlein, 2005).

Internalised oppression is 'the feelings of self-doubt, worthlessness and inferiority which frequently accompany the onset of impairment' (Barnes *et al*, 1999: 177). Mason (1992) states;

Once oppression has been internalised, little force is needed to keep us submissive. We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives (p.1).

Disability is one form of social oppression which restricts disabled people's activities and leads to the socially caused undermining of their psycho-emotional well-being (Thomas, 1999, in Reeve 2006).

It is worth stating that stigma, prejudice and discrimination not only affects users but also their family members, because of their links with the user, which is named 'courtesy stigma' by Goffman (1963) (Corrigan and Miller, 2004). Scambler and Hopkins (1986) also report that felt stigma usually appeared to have originated from the family, who act as 'stigma

coaches' (p.12). The more they react negatively to a condition, the more likely the child thinks that it is something to be hidden (Schneider and Conrad, 1980, in Scambler and Hopkins, 1986).

Strategies to Handle Stigma and Discrimination, Identity and User Group

Users who are 'discreditable' (Goffman, 1963, see introduction) have several strategies to handle stigma. The first strategy is keeping a distance from others. They withdraw from social life to avoid enacted stigma (Åsbring and Närvänen, 2002). Users gradually give up hope, for example of employment. The use of mental health services could be categorised as keeping a distance from 'society', where users are less likely to face stigmatised attitudes and discrimination. The second strategy is concealment. Stigmatised people try to participate in social life by maintaining a façade, and giving a self-presentation according to others' expectations (Åsbring and Närvänen, 2002). Some people may divulge information about their condition to

only a few reliable people such as family, close friends, or other users (Wahl, 1999). The third strategy is challenge, by confronting discriminatory responses (Pinfold *et al.*, 2005). Some users have found it empowering and self-enhancing to confront stigma immediately and directly (Wahl, 1999).

Mason (1992) states that if a person has negative feelings about oneself, the person quite likely has negative feelings about the group one belongs to, and tries to integrate into a superior group. This is one of the phenomena of internalised oppression. Such users may have a certain aversion towards other users (Åsbring and Närvänen, 2002) and distance themselves from them. This places a conceptual and physical distance between oneself and tainted user identities, which involves collusion with stigma (Pinfold *et al.*, 2005). Some ex-users also place a distance from users. Some users, on the contrary, approach to co-users. They could feel solidarity and an acceptance of their situation with their fellow users (Åsbring and Närvänen, 2002).

However, to identify oneself as a user may not be easy due to the stigmatised status (Barnes and Shardlow, 1996). In addition to that, their experience of mental distress may be temporary or intermittent unlike physical impairment. Therefore, they have hope for their recovery. Users also feel that their label can affect people's views and their social relationships throughout their lives. These factors cause difficulties in identifying themselves as users (Barnes and Shardlow, 1996). Moreover, a stigmatised person, who moves from a non-stigmatised position to the present position, faces a difficulty in withstanding stigma (Coleman, 1997). Therefore, users draw not only on their own experiences, but also on the cultural categories arising from their understandings before they were disabled (Kelly, 1996). They deny their user status to avoid discrimination, which reinforces the stereotypes and discrimination as a result and also leads them to isolation. It can be too fearful to identify oneself as a user.

However, acceptance of an ex/user identity and work with

other ex/users enables users to find a valued sense of themselves as well as providing valued support for others (Barnes and Shardlow, 1997). 'Safe environments', which are provided by the groups, can sometimes support fragile identities and develop confidence and skills. Moreover, it was reported that disclosure of one's condition not only removed the stress of having the secret (Breitkopf, 2004, in Thornicroft, 2006a) but was also liberating and empowering (Corrigan and Lundin, 2001 in Thornicroft, 2006a), which can lessen isolation and loneliness (Thornicroft, 2006a). Many users stated how involvement with user groups built their confidence and enabled them to change damaging experiences into a positive outcome (Barnes and Shardlow, 1996). User groups not only support individual users but also try to change wider society collectively (Barnes and Bowl, 2001).

Discrimination

Discrimination is a most distressing and insidious problem for

users. Users may be derided, harassed and abused or may be just forgotten or ignored. Users tend to be scared of and avoided (O'Hagan, 2001). A body of literature provides evidence of the discrimination faced by users in spheres of life including employment, housing and health care (Sayce, 1998). Users also point to numerous occasions where mental health workers have behaved in a stigmatizing way, not just through their discouraging advice but also their disparaging remarks and rejecting behaviour (Wahl, 1999).

We are affected by prevalent and extensive kinds of institutional discrimination, which functions in the government as well as in general society, and is supported by history and culture. This embodies the drastic kinds of prejudice and intolerance normally linked with individual or direct discrimination, together with the more hidden and disregarding attitudes which lead to and nurture indirect and/ or passive discriminatory practices. Social policy including systems and the operation of the labour market is influenced by the government

and continues to disadvantage disabled people economically and socially, which is an example of institutional discrimination. It is apparent therefore that direct, indirect and passive discrimination are inter-twined in most contexts, and is not an easily distinguishable concept (Barnes, 1991a).

The poor quality of mental health services is perceived as the strongest form of structural discrimination. Patients experience a lack of community-based services. Deficits in quality of care are seen as the result of unfair resource distribution within the health care system, due to the disproportionate allocation of mental health services in health care expenditure (Schulze and Angermeyer, 2003). This also applies in the Japanese context, where only 5.7% of medical care expenditure is spent on psychiatric care (Seishin Hoken Fukushi Kenkyukai, 2004). This causes diverse problems such as a lack of community support services, lower staffing ratios and cheap medical expenses for psychiatric care, which lead to superfluous psychiatric beds, lengthy hospitalization and social

hospitalization (Inomata, 2006b).

The high ratio of psychiatric beds i.e. 28 beds per 10,000 population and the lengthy hospitalization i.e. 338 days on average (Seishin Hoken Fukushi Hakusho Hensyu linkai, 2006, see introduction) are significant examples of institutional discrimination. Although the government stated their policy to shift institutional care to community care in *Reform Vision of the Mental Health, Medicine and Welfare* (Ministry of Health and Labour, 2004a), the changes in these figures are subtle over the last decade. The government has announced their intension to discharge 70,000 patients, who are regarded as 'social hospitalisation' by 2014 (Ministry of Health and Labour, 2004a). However, no concrete measures have been proposed to promote this (Inomata, 2006a).

Another significant example is disqualifying clauses written legislation. These are examples of 'legitimate' discrimination, which prevents disabled people from getting vocational qualifications and licenses even if the person is able

to undertake these. The Japanese government eventually reviewed 63 qualifications and licenses in 1999. Clauses which discriminate against disabled people have been abolished in relation to only six qualifications. The rest have been changed to 'relative condition', which gives consideration to the state of the impairment, from 'absolute condition', which denies eligibility automatically. However, clauses still exist in more than 300 laws in total (Citizens' Committee to Eliminate Disqualifying Clauses on Disability, 2007). The clauses directly indicate how Japanese laws and systems have been discriminating against disabled people based on the notion that disabled people are 'inferior and dangerous' (Usui, 2002). Thus, Japanese society excludes users and imposes second class citizenship by denying people their rights and potential.

Challenging this Disabling Society

The 'stigma problem' lies at the root of the difficulties users face as they attempt to obtain the same legal and social status as

people without psychiatric labels. This is an issue of rights protection and advocacy to ensure equal rights, as a matter of basic social justice (Chamberlin, 2006). Therefore, words such as 'discrimination' and 'exclusion' are more feasible than 'stigma' to help us conceptualise and work out, although the key issue is to establish thinking and practice in an examination of unfair behaviours (Sayce, 1998). 'Discrimination' also locates the onus on the individuals and groups that are practicing it (Chamberlin, 1997, in Sayce, 1998).

As previously stated, it is evident that disabling barriers are to blame rather than personal limitations. Discrimination exists not merely in prejudiced individual attitudes, but in the institutionalised practices of society (Oliver and Barnes, 1991). The only way to eliminate institutional discrimination is with the introduction of anti-discriminative legislation, which emphasises social rights rather than individual needs and focuses upon the disabling society (Barnes, 1991b). Also it is only possible to eradicate institutional discrimination and prejudice through the

activities of a vigorous and independent disabled people's movement (Barnes, 2006). If we succeed in creating a society in which users are treated with greater value, the sense of shame is more likely to be removed (Sayce, 1998). Disabled people have set up their own organizations which have provided both an ideology and a practical work for their political emancipation. Evidently, more and more disabled people are willing to identify with the disability movement and adopt a more radical approach to removing institutional discrimination (Barnes, 1991a).

Conclusion

Stigma is a prejudice based on stereotypes and results in discrimination. Stigma and discrimination against users are prevalent and have detrimental effects upon users. Society not only restricts their activities but also undermines their psycho-emotional well-being (Thomas, 1999, in Reeve, 2006). Felt stigma may cause self-exclusion and withdrawal. Internalization makes users feel spoiled and less valued (Green

et al., 2003). Both discrimination and internalised oppression make it difficult for users to identify themselves as users, although this seems to be key for their liberation. User groups appear to have a significant role to play in challenging this disabling society. The next chapter examines the methodology underpinning this research including ethical issues.

Chapter Three

DATA GENERATION

This chapter examines the significant issues in this research. It begins by looking at the aims and objectives and the standpoint. Then, the research strategy and design will be discussed. Subsequently, the procedure of the research will be illustrated. Finally, the ethical issues will be examined.

Aims and Objectives and Standpoint

The aims of this study are to identify how significant user groups are in supporting users to challenge stigma and discrimination and to explore ways to meet the challenge, utilising their collective strength in the Japanese context. Another aim is to gain a comprehensive understanding of users' experiences and the consequences of stigma and discrimination. Having considered the literature, I hypothesise that user groups do have a significant role to play in challenging stigma and discrimination in this society. In order to examine these aims, three objectives

were set:

1. to elicit users' experiences and perceptions of stigma and discrimination and the impact of these;
2. to identify users' strategies to handle and challenge stigma and discrimination and identity issue;
3. to explore ways to challenge stigma and discrimination whilst utilising users' collective strength.

As the researcher's ontology and epistemology have a significant influence on the research and its results (Blaikie, 1993), it is important to clarify standpoint. I believe that 'People's knowledge, views, understandings, interpretations, experiences and interactions are meaningful properties of the social reality' (Mason, 2002: 63), and this is my ontological position.

Having worked as a social worker in the mental health field for 20 years, I have realised not only the detrimental effects of stigma and discrimination upon users but also the users'

strengths to challenge these. I aimed to understand the nature of social reality of stigma and discrimination through users' first-hand direct experiences and their perspectives based on the social model of disability, which places the problem and its cause within society and not within the individual, for example with functional limitations (Oliver, 1990b). This is my epistemological standpoint.

Research Strategies and Design

Having considered research methods, both qualitative methods such as interview and observation and quantitative methods, I have chosen a combination of a focus group interview (hereafter referred to as FGI) and in-depth interviews for three main reasons. First, as I have already stated, I believe that people's views, understandings, experiences, and interactions are significant attributes of their social reality (Mason, 2002). Qualitative interviews are particularly suitable to grasp the depth, nuance and complexity of users' direct experiences and

perspectives, rather than quantitative methods which would give a broad picture of surface patterns (Mason, 2002). Second, a preliminary FGI would provide an opportunity to identify key issues for both researcher and participants, which would enable the researcher to explore the relevant issues in the individual interviews (Morgan, 1997). Finally, the strength of each interview would enable me to collect data which I aimed to obtain, that is users' lived experience and perceptions. In other words, other methods such as observation or documentary research would not generate the knowledge which I aimed to gather. The purpose and the strength of each interview will be described below.

The purpose of FGI is to formulate a conceptual framework and to devise items for examining stigma and discrimination. I have chosen FGI because of its three strengths. First, it would enable the researcher to gather rich data from discussion on the topics of the researcher's interest (Morgan, 1997). Second, it generates multiple lines of communication and

creates a safe environment for users to share their experiences and thoughts with people who have similar experiences. The familiar atmosphere helps to facilitate communication on difficult issues such as stigma (Steward and Shamdasani, 1994, in Schulze and Angermeyer, 2003). Third, the group dynamics would stimulate and encourage participants to think and express themselves (Morgan, 1997, Schulze and Angermeyer, 2003). The group itself, however, may affect the nature of the data because FGI have a tendency towards both conformity and 'polarization', which may become a weakness (Morgan, 1997).

The purpose of the individual interviews is to understand the users' experience, opinions and feelings in detail, which may be difficult for the users to talk about in a group (Morgan, 1997). I decided to conduct individual face-to-face interviews rather than telephone interviews or self-complete questionnaires such as e-mail interviews because of three reasons. First, I think knowledge and evidence are related to context, situation and interaction and interviews provide the social situation in which

people construct or reconstruct their experiences or perceptions (Mason, 2002). Second, I wanted to clarify any confusions arising from both the questions and their answers and investigate feelings verbally as well as non-verbally. Third, I think that the interview situation would encourage people to talk about experiences which would be both personal and sensitive. I decided to conduct a semi-structured interview because it would provide interviewees more freedom and control in the interview compared to a structured interview (Mason, 2002), which would reflect my ontology and epistemology position.

I have decided to interview 5 users as it is a realistic size for this study. Two criteria for participants are set as users who

- 1) have experienced hospitalization due to mental distress and
- 2) have been actively involved with user group(s). The experience of hospitalization is included as I judged that it had a significant meaning, namely being labeled as a 'psychiatric patient'. I have chosen users who meet the criteria from the users whom I have known through my work. Thus, purposeful

sampling has been employed to access information-rich participants from whom the researcher can obtain a great deal of knowledge on the issues (Patton, 1987). It could be seen as a strength because I could approach eligible users directly, but also as a weakness because the selection process brought some limitations. There was a married couple within the interviewees and their answers may influence each other. However, I decided to include this couple because a marriage relationship does not mean that they have identical opinions and experiences. As the number of participants is small, the results cannot be generalised, however, these interviews would illustrate their own experiences of stigma and discrimination and their challenges. Three male and two female users attended both interviews. They were in their 30s and 40s. The length of use of medical services is between 7 and 30.5 years. Three of the four participants who are receiving disability pension are also getting either a salary or wages. One participant is on income support (Appendix 1).

I developed a set of FGI guidelines which include an opening question and further questions (Appendix 2). The individual interview schedule was designed based on the results of the FGI and research which was done by Wahl (1999). I developed an interview schedule with numerous questions (appendix 3) due to my anxiety arising from lack of experience. However, I have chosen core questions for all interviews as well as the questions for each interview based on the FGI. Ambiguous jargon such as 'recovery' was eliminated in the questionnaire to avoid confusion, which occurred in the initial letter which I sent to participants.

It is valuable to understand the complexities of the interaction. As knowledge, views and understanding are constructed through dialogue and interactions in the interview (Mason, 2002), the characteristic of both interviewee and interviewer such as gender and age may affect the outcome, for example interviewees might answer more willingly – and differently – depending on these characteristics (Moser and

Kalton, 1971). My characteristics, such as non-disabled female lecturer, may have affected the answers. The response effect should also be taken into consideration. Some factors such as the participants' eagerness to please the interviewer may influence data (Borg, 1981, in Bell, 1993). The fact that I have had relatively good relationships with the participants may have affected their responses.

Procedure

After I outlined the draft of the research, I asked two users their opinions of the interview procedures and ethical considerations. I received valuable advice, which I will explain later, especially from a user who had an unpleasant experience involving research in the past. As he turned down the request of participation, I contacted a sixth user.

I contacted users by telephone and/or e-mail and explained my research in terms of the purpose, procedure and schedule, and I explained their right to withdraw and other

ethical considerations such as confidentiality. I also checked if there are any concerns arising from this research. Then, I sent a letter with the details, which I had explained verbally to ensure their understanding. Once their agreement of participation had been ascertained, the interview date, time and place were arranged at their convenience. The interview schedules had been sent prior to both interviews to give an opportunity for participants to see the questions.

In order to ensure their agreement for participation, participants were given a sheet with details of the interviews including the intention of recording, and other issues such as confidentiality and the right to withdraw before each interview. Participants were asked to sign this sheet.

In the FGI, self-introduction of each participant was used at the beginning to develop rapport and a sense of group (Steward and Shamdasani, 1990). I used some of the questions in the interview guideline to cover the issues. In the individual interviews, I asked some questions which are relevant to the

interviewee as well as some core questions based on the interview schedule. I always asked interviewees to add anything they wanted to say at the end of each interview.

The FGI was conducted in July 2007 and individual interviews were conducted in August 2007. The locations of the interviews were in the university (FGI and 3 interviews), the interviewee's flat (1 interview) and the community support centre (1 interview). The FGI took approximately 2 hours and the individual interviews lasted about 1.5 - 2.5 hours. Each interview was recorded and transcribed. The data was analysed manually to identify key issues and themes. Tables were used to compare and contrast the data and identify any enlightening outcomes. Then structures of data analysis chapters, the citations, preliminary conclusions and their pen pictures were sent to interviewees to check. The findings which relate to interviewees' perceptions and experience were presented in an English translation of their own words. Although every effort was made to select the most appropriate words, I may have been unable to

convey some of the nuances in English, which is my second language. This paper will be disseminated to participants and other parties who are concerned.

Ethics of Research

Researchers are responsible to ensure that the research does not affect participants' physical, social and psychological well being adversely. They should make every effort to protect their rights, interests, sensitivities and privacy. Research participation should be based on the freely given informed consent of participants as far as possible in sociological research (BSA, 2002). In order to ensure informed consent, I explained the research details and the users' rights on several occasions by telephone, e-mail, letter and at the interviews and gained written consents. I reassured users several times of the right of withdrawal, especially the user who was uncertain about participation in a FGI.

Participants should be informed of how their anonymity and confidentiality will be preserved (BSA, 2002). I used names which the participants chose to be presented in this dissertation to preserve anonymity. I also asked participants to check the citations and gained their consent.

A risk always exists that the interviewee finds even quite innocent questions disturbing (Blaikie, 2000). Painful issues can be raised in interviews, which can potentially cause harm or distress in the absence of appropriate support (Truman, et al., 2000). One prospective participant who I mentioned earlier, had found it unpleasant to be asked about painful experiences in an interview in the past. Based on his advice, I made some amendments to my initial plan, for example I provided the interview schedule prior to the interviews to give users some control over how much they would reveal of themselves. I also gave participants a choice to have an advocate in the individual interview, however, no one wished to have one.

Traditionally human rights issues are less often identified

in research ethics. Participants are treated as objects, represented in ways that distort their experience, or excluded from the research process. The participants, however, must not be imposed upon by the researcher's own understandings (Truman, *et al.*, 2000). Therefore, I asked participants to check the way in which I used their citations to avoid such distortion and gained their consent. As some interviewees found the usage of the word 'user' unclear and imposing, I decided to explain the usage of the word 'user' that is as a neutral way of describing the usage of the mental health service. I also did not use the word 'survivor' because I wanted to avoid the danger of imposing an identity which some of them did not identify with.

Conclusion

In this chapter, the aims and objectives and my standpoint which is the basis of this research, have been discussed. Then the research strategies and research design were illustrated. Following on from this, the procedure was explained. Finally, the

ethical issues were considered. The following three chapters will look at these issues closely based on research with users in Japan.

Chapter Four

Experience of Stigma and Discrimination

This chapter will begin to look at users' experience of stigma and discrimination in their family and social life and will describe their experiences with mental health professionals will be described. After that, their experience of the mental health system will be addressed. Finally, the effect of legislation on interviewees' lives will be considered.

Family and Social Life

Experiences of stigma and discrimination within the family and in social life such as with friends and employer were very individual. A strategy of concealment had been used by some participants, and this will be closely examined in the next chapter.

Two participants reported their experiences of discrimination by family and relatives. Neko feels that he was treated an encumbrance because he has hardly been invited to

any weddings despite many weddings occurring in his family. His family may have tried to avoid 'courtesy stigma' by the new extended family.

Users' experiences in social life are not always negative. Tomoko states "It is not true that everyone is startled when he/she hears about mental illness" as Tomoko found her family, friends and neighbours caring and accepting. She found that her disclosure prompted her friend and a neighbour to talk about their family's mental health issues. Neko also found solace in his university friends as they just enjoyed their time together, despite Neko having seven hospital admissions during his time at university, whereas he was rejected by his high school friends.

Three users who were job hunting faced difficulties in concealing their condition because there were some periods when they were neither in employment nor education for example, due to hospitalisation. Neko, however, lied in his CV because:

Mentioning being a user alone puts them off employment. They would not employ us. We know. We know that, don't we? If we write about hospitalisation in a psychiatric hospital on our CV, we would be immediately turned down. It is Japanese society.

He was convinced that he would face enacted-stigma although he has no experience of being discriminated against. He has successfully avoided the situation which he envisages to be discrimination. Aozora's experience, however, indicates that this is not always the case. She was giving up hope of employment with concealment after having been turned down several times. She decided "to bet to being open" about a nearly 15 years gap in her CV after some advice from a job counsellor. Then, she not only won the bet but also got empathy. She was told "You must have stretched yourself too much, haven't you?" by the employer whose daughter was a user.

However, Koji's experience was different. He was actively involved in setting up a sheltered workshop for people with physical impairments. The head of the workshop, who is a wheelchair user, decided to register Koji as a volunteer to pay travel expenses and submitted his CV with a photocopy of his official 'disability (means 'impairment')' certificate to the city council. However, he was asked by someone in the council, "Who takes responsibility if anything happens?" The registration was turned down. Koji states:

Although the head of the workshop told me that I could work as a volunteer, people in the council who have *never* met me said 'No'. I have realised the meaning of the certificate once again.

This clearly indicates prejudice based on distinctive negative stereotypes attached to users such as "dangerous" "incompetent" (Corrigan and Kleinlein, 2005), "undesirable and

threatening” (Meyers, 1994: 43, in Johnstone, 2001: 204), which leads to discrimination. Thus, prejudice hinders users from obtaining a role, even as a volunteer, in this society. Three participants also faced discriminatory remarks in the community. When Koji and Tomoko were involved with not in my back yard (hereafter referred to as nibmy) campaigns, they faced antagonism by people in the community. They were asked:

What would you do if something happens to children?

Who takes the responsibility if an incident happens?

Tomoko thinks that people in the community are usually indifferent to users, however, once it comes too close to their lives, their message is ‘dangerous people should be locked up.’ These nimby campaigns based on prejudice make it difficult or sometimes impossible to create support services in the community, which is unfair treatment for users.

Both Neko and Koji strongly believe that negative

stereotypes of users such as ‘dangerous’ ‘potential criminals’ are strengthened by news reports and papers.

When an incident happens, the media reports “Why has such a dangerous person been discharged to the community?” I am furious with such reports. They use a label that ‘These people are dangerous’. I feel very angry with the way these are reported. They just appeal to people’s emotion without paying any attention to the background. People just believe this is users’ actual ordinary state (Neko).

Koji also warns of the danger of reporting a verdict which often mentions ‘illness’ despite no ascertained causality. Readers and viewers would immediately make a link with incident and the ‘illness’.

Professionals

Participants found professionals' attitudes "patronising" (three participants reported this), "undermining" "disrespectful" "violent" "supportive" and "caring." Participants acknowledged that there were some supportive and caring staff members but the overall judgement is negative. Neko states that discrimination by medical staff was his worst experience. Participants stated numerous examples of unpleasant comments and attitudes of professionals such as being ignored and being told off for being lazy, despite the tiredness being caused by the side effects of medication. Koji often come across patronising and disrespectful remarks.

Staff members do not understand how much we are hurt by being treated like children. A staff member who visited us (community activity support centre) from a day hospital talked about their users as 'Our children can not become like you...'

They describe users as if they were their children or possessions in fact not quite an adult. Koji asked staff members not to treat users like that but they often did not understand what was wrong. Tomoko gave an example of patronising attitudes of a professional. When Tomoko talked about the difficulty in creating a welcoming atmosphere in a community support centre by talking to new comers in a meeting of a family group, a young public health nurse told her:

Don't push yourself! It may deteriorate your condition.

You are just a user of the centre. You do not need to do it.

Tomoko had been involved in setting up the centre and fought with the nimby campaign as a representative of users. However, she was treated as if she was unable to take responsibility for what she does and to take control of her condition and assume a passive patient role. Both Koji and Tomoko state how difficult to make professionals realise how they were hurting users even

when they explained this to them. Tomoko states:

I think that it requires a steady effort to change things when the person is not aware of the situation, that they are hurting users.

On other occasion, Tomoko found a psychiatrist arrogant, dismissive and rude as he showed “no intention to listen to patients”. She had been opposing *Shinshin Soushitsu Touno Jyotaido Jyuudaina Tagaikouei wo Okonatta Monono Iryou Oyobi Kansatsu Tou Ni Kansuru Houritsu* (Medical Observation Act) (Japan, 2003), which detains forensic patients in a special unit. The psychiatrist who runs the unit told her “Please say whatever you want. We just run the unit our way”. Tomoko states:

I think that the biggest barrier is such a lack of understanding and sociability. We say ‘system’ but the system is created by human beings.

The values and the way of thinking of the professional affect how the system is run. Koji, was shocked and appalled during his distance learning course to become a qualified psychiatric social worker, because the lecturer explained the procedure of users' rights protection under the *Seishin Hoken Oyobi Seishin Shogaisha Fukushi ni Kansuru Houritsu* (Mental Health and Welfare Act) (Japan, 1995) as if these were just cumbersome. He also could not find any proper explanation of why these procedures were crucial in the text book. Koji states:

They do not see patients as someone with a mind. They do not think that this kind of treatment would hurt and leave scars in patient's mind.

Koji warns that for social workers to see the procedure as just 'cumbersome' is a serious problem because these procedures were introduced following several incidents, in which patients

had lost their lives.

As Wahl (1999) found in his research, the participants wished not to be judged by their labels, but for a greater understanding, showing empathy and respect for them as an adult, and for their opinions to be listened to, which are supposed to be fundamental professional attitudes.

Mental Health Service and System

For each of the five interviewees, use of the mental health services was a distressing and painful experience in terms of compulsory admission, lack of informed consent, lengthy hospitalisation and the hospital environment. Three users stressed that forced treatment and detention were human rights' violations.

As coercive treatment is clearly stated in *Seishin Hoken Fukushi Hou* (the Mental Health Act), even if they say we

have our rights, for people whose rights are not respected, it is unjust (Tomoko).

Lack of explanation and informed consent was a shared experience amongst all interviewees. For example, when Sato was sleeping in bed, six men entered his room and took him to hospital, where he was detained compulsory.

I would have agreed with hospitalisation if either my family or the psychiatrist prevailed upon me properly and sincerely. I was actually in distress, distress in my head and I had a peculiar feeling. (Edit) As they did not do so, grudge and hatred remained for a long time.

The experience has left him with a profound scar. Medical care must be given in the least restrictive environment, with use of the least coercion and restrictions for the shortest time (O'Hagan, 2001). Participants strongly believe that proper explanation

should be given. Aozora states that she was never given any explanation for two months' use of the seclusion room, four years' hospitalisation and medication. She wanted to have a proper explanation even if she was a little bit confused or agitated.

Sato and Aozora were detained in psychiatric hospitals for nearly four years in their twenties in the first admission. Sato, who was discharged just three and a half years ago states:

The time which I spent in the hospital was a waste of time. It is absolutely wasteful. I really regret it at some point. (Edit.) The three and a half years. People of my generation have got a job, got married and had children during that time. I wished that I did not have it.

Thus prolonged hospitalisation, especially of young people, deprives them of their life opportunities. Furthermore, incarceration robs them of the volition to lead their lives. Aozora,

who was hospitalised for four years until she was twenty four years old, recollects:

As they have deprived me of so much time, I should be angrier with them. However, I myself thought that I may stay here (for good), under the influence of a high dosage of medication and the habit of being there.

At the age of twenty four, she accepted life as inpatient. This indicates that prolonged institutional care not only reduces a person to despair but also takes away their desire to live their own unique lives. However, her parents, who were shocked by her filthy condition, fought with the head of the hospital and eventually rescued her, after three rejections of their discharge requests. Then they later found that her status was voluntary. It seems as if a proper explanation about her status and/or her rights had been given to neither her nor her parents. Aozora adds:

As I was there for 4 years, I have become like Urashima Taro. I could return to neither university nor society.

(Note: Urashima Taro is equivalent to Rip Van Winkle)

Therefore, she went to a day hospital for 8 years. Thus segregation also cuts their important existing social networks and imposes a life as a 'psychiatric patient'.

Interviewees also revealed their life in psychiatric hospitals.

poorly ventilated and closed environment, where

harassments are easily taking place

50 patients took a bath within 30 minutes twice a week

forced labour in the garden for a few hours and being

given a couple of cigarettes

Neko states that he saw "the real ugly side of human beings".

People hit other people for just one cigarette. Things are scarce. People rule people. People force other people. (Edit.) I think that psychiatric hospital is a picture of hell. It deprives human beings of their dignity.

The environment may have improved over the last few decades, however, such institutions have similar characteristics. Institutional life removes people's external sense of self, identity and individuality and brings a demoralising and dehumanising effect on the person. Professionals control and enforce social contact, define rules and regulate everyday life. The atmosphere can be oppressive (Rogers and Pilgrim, 2003). These environments impose a passive patient role, which further undermines users and deprives them of their self-esteem. Tomoko states that the segregating policy is like a crime and "I still feel that we are treated as sacrifices".

Law

It was after a few hospitalisations that Koji became interested in becoming a clinical technologist. He had got some information about the qualifying course in which he found the disqualifying clause against users. He was cast into the depth of despair when he was only 18 years old. He realised the social implication of hospitalisation, in other words, the meaning of the label. His dream had been denied, which led him to 18 years of reclusive life at home.

The existence (of the disqualifying clause) itself deprives the purpose of life from young people (Edit.) The disqualifying clause makes them think that 'it is something I must not talk about in public and must hide'. I think that it is a problem if it is exercised in practice; however, the existence itself is serious discrimination.

Society use labels and rejects users regardless of their ability to

undertake a job, which indicates there is no expectation from them by society. Society bluntly crushed Koji's dreams and hope for a life. Many clauses have become a relative condition from an absolute condition recently, however, Koji warns that users are made to believe that they cannot get the license/qualification and so give up, which means that their life opportunities have been stolen and their lives are damaged. He testified calmly and tentatively:

I think that the system may breach human rights.

Neko also pointed out an aspect of the Japanese welfare system based on the household income rather than an individuals income, which puts users with no or low income in subordinate position.

In the United States, people become independent when they become twenty but (in Japan) even a user who is

forty or fifty years old, (the share of the expense of mental health services) depends on the household income. I think that this is a problem. A forty year old person is treated as a dependent.

The amount of disability pension is too low to live independently, which makes users dependent on their family often their parents in Japan.

Conclusion

Each user's experience of stigma and discrimination within their family and in their social lives was individual. However, the interviewees revealed that institutional discrimination is embedded in mental health systems and law in Japan. Users' testimonies have given some examples of how they were placed as subordinate citizen and how they were treated. Their life opportunities and aspirations were robbed by stigma and discrimination which were created by society. The next chapter

looks at how interviewees cope and challenge stigma and discrimination.

Chapter Five

Coping and Challenging Stigma and Discrimination

This chapter will begin to address individual strategies to handle stigma and discrimination. Subsequently the psycho-emotional effect of stigma and discrimination on users will be described and identity issues will be examined. Finally, interviewees' experiences of coming out will be looked at.

Individual Strategies to Handle Stigma and Discrimination

As stated in chapter two, there are mainly three strategies to handle stigma and discrimination; keeping a distance from others, concealment (Åsbring and Närvänen, 2002) and challenge (Pinfold *et al.*, 2005). The interviewees' individual strategies have changed over time and their strategies differ.

Some users withdraw from various areas of social life to avoid enacted stigma based on felt-stigma. Koji resigned from social life in despair when he found out about disqualifying clauses. The 18 years of reclusive life during which he kept a

distance from society that labeled and rejected him, could be understood. Aozora stopped contacting high school friends because:

I am anxious how they would react. (Edit.) If I tell those, who are working actively, how I am now, they may say “you are lazy”.

Aozora said that her ‘illness’ cannot possibly be understood by them and she worried that they would judge her based on negative stereotypes and ‘myths’ of users such as ‘lazy and not trying’ (Thornicroft, 2006a). Aozora also stated that she faced “rough waves of society” for the first time when she started job hunting after approximately 15 years’ of using mental health services such as a day hospital. Her applications were turned down on many occasions. These experiences may discourage users from trying to return to ‘society’, which reinforces their second class citizenship.

Concealment was/is used by several users. Aozora has not revealed her condition to her in-laws because she believes that her younger sister may be blamed as “the member”. She stated “it would be a disadvantage for my younger sister if she was seen as a sibling of a person with the illness”. Thus, she anticipates a negative reaction based on prejudice not only towards her but also to her younger sister due to the link with her, namely courtesy stigma.

A study by Wahl (1999) indicates that users who conceal their status were burdened with a persistent fear of disclosure on top of their mental distress. Neko undertook more than 10 jobs without declaring his condition. Then he was forced to work for long hours until late, which made him exhausted and unwell. Each employment did not even last for 6 months because of his deteriorating condition. Thus, stigma and discrimination can exacerbate existing conditions (Link et al., 1997, in Sayce and Curran, 2007).

No participants reported that they used challenge as their

strategy; however, Tomoko expressed her wish to be able to confront professionals' patronizing and arrogant attitudes on the spot.

It is worth reporting an individual strategy for handling antagonism in the community. Koji has faced several nimby campaigns including a campaign against the support centre where he works. People in the community make discriminatory comments such as "institutions for (people who are) physically disabled and intellectual difficulties are all right but not for mental (illness)" and "the land price will go down". Koji explained and challenged their prejudices in meetings. He, however, avoids getting involved with it squarely now. He states:

I think we should not feel uneasy about such comments. Each comment is based on prejudice and discrimination; however, we would be exhausted if we argued with them and focused on such comments. I feel as if we would be stuck in a quagmire, the morass of prejudice and

discrimination.

This comment endorses the importance of focusing on discrimination, which enables us to conceptualise and plan work rather than stigma which is difficult to change (Sayce, 1998).

Stigma and Discrimination and Internalised Oppression

Attention should be given to the effect of fear and the perception of discrimination. It is also evident that stigma, whether en-acted or felt, is internalised and affects self-image negatively. Especially, internalised oppression may spoil a user's identity due to the close association of mind and personality (Green *et al.*, 2003). The psychological effects of prejudice, discrimination and exclusion need to be acknowledged to understand internalised oppression (Thomas, 1999, in Reeve 2006).

Aozora fears telling her friends about her situation because,

I think that they would shun me. Maybe, they wouldn't.

(laugh) It may be an overstatement. Maybe it is because I have internalised prejudice that I am anxious they may think of me as a person with such an illness, if I tell them.

She also states that it is not a matter of whether she meets her friends or not, with whom she has not met for nearly 20 years.

However, it *is* a matter for her.

I feel that I am stigmatising myself and I must be treated as having a disability (means 'impairment') that must be cured. It is stigma. I think that I have become the existence which must be cured. I think that I need to be cured. I still feel as if I am announcing that I have become a harmful person publicly.

Aozora seems to have internalised a negative view of society that users are harmful and need to be cured, which she is

ashamed of. Although she is aware that the view is based on prejudice, she finds it very difficult to free herself from the view. It maybe because she remembers her gut feeling towards a news report of an incident which was committed by a user, when she was a junior high school student. She states that “I thought it (occurrence of the incident) happened because such a dangerous person was left in the community”.

Aozora seems to be anticipating people’s reaction according to prevalent stereotypes based on her experience. The stereotypes especially shape a powerful element of anticipated reactions in the relation of identity to present self (Kelly, 1996), which makes it difficult for her to identify as a user. Shame indicates an important self-judgement of Aozora who is convinced that she has broken some covert regulation to be a full member of society (Morone, 1997, in Thornicroft, 2006a). Thus users who label themselves as having a mental ‘illness’ may internalise people’s negative responses and as a result, their expectations of stigma increase (Link et al., 1989, in

Dickerson et al., 2002), which makes it difficult for Aozora to come out. Koji states:

There is an expression called 'internalised discrimination' which indicates people cannot come out. However, they cannot come out because of the discrimination in the society. I think that it is wrong if you call it as internalised discrimination and make users daunted.

As Sayce (1998) also states, the actual discrimination in society, which is the background of users' attitudes and beliefs, must be considered rather than understanding stigma as the users' problem. Their sense of shame would disappear, if they were more valued in society.

Identity Issues

Interviewees did not identify themselves as users when they 'used' mental health service either voluntary or involuntary. It

has taken from 3.5 to 22 years for them to identify themselves as users. They had some idea of the social implication of the label 'psychiatric patient' before they had actually been labelled. Koji felt that "If you develop the illness, your life is ended". Tomoko also recollects "I think that the fact I have tried to commit suicide indicates my value that if I have acquired the disability, it is the end." Thus, the implication of the label was bleak. Neko states that attempted suicide became the moment for him to accept a user identity. "It was my resignation that I must live if I cannot die". This indicates how difficult it is to identify oneself as a user, which means 'a social death'. When Koji found out his diagnosis was schizophrenia, he read an old medical book which explained that with schizophrenia hallucinations and delusions appear and that personality is disintegrated. This dreadful image was the only image he had until he read a book which was written by a person with autism. It made him realise that there were disabled people who were living with pride as human beings, which made him identify

himself as a user and a survivor. This suggests that it becomes less fearful to identify oneself as a user if many users are living their own unique lives with pride in this society.

Three participants expressed their frustration with ex-users who concealed their ex-user status. Although Aozora shares the difficulty of coming out, she states:

They are not open about it. They (would say that they) are not related (to mental illness). This is a world which they have no relation with. It is the past. As they have not come out, the fact is not known that users who used to take medicine can recover fully. (Edit) They have a prejudice and they just want to be away from such a world.

Users strongly believe that the concealment of ex-users strengthens the prejudice that users cannot recover. Ex-users have succeeded in re-integrating into the superior non-disabled

group. They may want to be away from the 'taint' status or may be fearful that their ex-user status might be revealed, which can affect social relationship throughout their lives (Barnes and Shardlow, 1996). Identifying oneself as an ex-user can be difficult, however, concealment would reinforce the prejudice.

Coming Out

Concealment of user status not only causes a constant fear of revelation but also reinforces prejudice. If people have not known a user, they might imagine a monster based on negative stereotypes. Therefore, coming out and encountering users is important to promote an understanding which may change people's views and behaviour.

All users apart from Aozora have made their names and pictures public through news papers and/or television programmes to convey their life experiences and express their opinions as a representative of users. Participants found it a natural experience, however, Neko had some hesitation:

I thought it would get my family into trouble actually. As I was living by myself, (I came out). (People would say things like) “the son of that person is mentally disabled”. “Their family line has mental illnesses”. (Edit) Although I have overcome this, it was quite a gamble when it was printed. It was like betting.

Neko was concerned about the courtesy stigma. He, however, took a chance because:

I thought it would be cowardly if I did not give my name. I thought someone must become ‘an advertisement tower’. Someone must speak for users. It should be a user, not a family member.

He was thrust ahead by his belief that users must speak out, which he strongly believes to be his duty as a survivor of the

mental health system. However, three interviewees did not think 'coming out' was anything special. Koji just wished that people would understand users. Tomoko stated "I never thought that we should worry about such things (becoming public) basically". She had been encouraged by other users who had come out. Tomoko added:

I would not have existed if I hit a different part of my body.
(Edit) Why must patients suffer to such a degree in Japan? I think it is deep-rooted. In that sense, I would rather take action than to be scared by something.

Tomoko has attempted suicide by throwing herself into the path of a train, which led to her first and sole hospitalisation. She states "We must either give up or fight (with stigma and discrimination)" and she is strongly committed to fight.

Neko and Koji have been reprimanded by their families for having come out. Neko was told "How could you do such a

dreadful thing?” from his mother and his siblings. Koji was also told by his mother “Do not go to the extent of speaking to news papers.” He, however, thinks it was because of her sincere concern that having a user in the family might affect her grandchild’s marriage and employment. Thus, they were treated as encumbrance of their family although it is not their fault to have become users. Koji and two other participants stated that coming out would not have been possible if they had been living with their parents and depending on them financially. It seems as if financial independence is one of the keys to be able to come out.

Except for the two family comments, users reported good effects and reactions about their articles and television programmes. Coming out turned out to be a good chance for Neko as it opened up an opportunity to be invited as a speaker in training, conferences and workshops, although “most users are frustrated because they are neither given any responsibility nor work”.

When Aozora was interviewed by a national news paper about the organisation for recovery which she represents, she felt she needed to ask the opinion of her parents, whom she lives with, about coming out. They advised her to conceal her user status, which she agreed to. She stated “it seems it is disgraceful for my family if it (her user status) is made public”. Her parents may have tried to protect their daughter from stigma or tried to avoid courtesy stigma, however, they seem to be playing a role as ‘stigma coaches’ (Scambler and Hopkins, 1986), although she is now an adult. But Aozora also had some hesitation to become public:

If I revealed my face, friends would recognise me wouldn't they? I do not want them to find out (how I am) indirectly and think “Oh, *that* person has become like *that*.”

It seems as if she is still entangled with inferior feelings and

shame. It was her decision not to come out, however she felt “a touch of regret” when she read the article because if she had stated her status, she could have made readers aware that a user was taking an active role. The difficulty indicates how deeply internalised oppression is embedded. In other words, how oppressive this society is.

Conclusion

Some participants concealed their user status because of the fear of being discriminated against (felt-stigma). It has been identified that stigma and discrimination have a profound psycho-emotional impact on users. Interviewees’ experiences indicated that users internalise the values of dominant groups of society and develop negative feelings about themselves (Reeve, 2006) such as self-doubt and inferiority (Barnes *et al.*, 1999), which re-injures themselves (Mason, 1992). Concealment not only creates a fear of revelation for users and ex-users but also strengthens prejudice. However, users’ strong will and

commitment to change their current situation has lead users to come out despite the risk of discrimination and courtesy stigma. The next chapter looks at users' challenge to stigma and discrimination through user groups.

Chapter Six

The Way to Maximise the Strength of Users

This chapter will begin to address what user groups have brought to users' lives. After that, the roles of user groups to challenge stigma and discrimination will be examined. Subsequently, obstacles facing user groups in their challenges will be described. Finally, ways to utilise users' collective strength in the challenges will be explored.

Meaning of User Groups

Interviewees reported a significant impact on their lives as a result of their encounter with user groups. User groups have given interviewees:

“the meaning of my life” “the courage to live” “chance”

(Neko)

“my role in this society” (Neko/Tomoko)

“potential” “confidence” “broaden life” “pride” (Aozora)

“contacts with wider society” “skills” “personal growth”

(Tomoko)

“a place to belong to and a place where I can actively work” (Koji)

These comments clearly indicate not only how users value the groups but also what society has deprived them of by excluding and marginalising them. Neko states:

I think the fact that I am needed by other people gives a meaning to my life. I am needed as I am doing user activities. I can have a role in this society, which gives me courage to live.

Aozora recollects that she was dispirited because she left university and resigned from everything after 4 years' hospitalisation. “I *cannot* work and I *cannot* do anything”, was the way she saw herself when she was in “a cage in the day

hospital". This view, however, has been changed by her encounter with a user group. She felt "I *can* do it". Then, Aozora started to take charge of her life. For example, she realised the detrimental effects of high dosages of medicine through user groups, therefore, she discussed this with her doctor, then the dosage, 30 tablets a day, was dramatically reduced, which "expanded her sphere of activity beyond her imagination". She became frustrated and regretted having left university, although she thought that it was the best decision at that time. So she started to take a distance learning course to study law, which qualifies her as a teacher. She works part time in a community support centre and she is also a head of an organisation for recovery now. Aozora's experience indicates how social isolation could hinder users from developing their self and identity and limit their opportunities for growth (Barnes and Shardlow, 1996).

Tomoko values user groups as a way of social participation. A sheltered workshop was not "the place to spend

a long period” for her. Neko, who also went to a sheltered workshop for 10 years, stated that a user group is “more creative” and “much more fun” than making small things at a sheltered workshop. Tomoko thinks the merit of user groups is that “users can continue to do” because:

if it is a job, you must pass the interview. Then when you are accepted, you should (be careful) not to be sacked. However, user groups do not require any qualifications. Anyone can do it.

Her comment suggests how difficult it is for users to obtain and sustain a role in this society. User groups, however, may become a spring board because development of new skills can increase confidence and self-esteem and can also broaden opportunities beyond the movement (Barnes and Shardlow, 1996). Tomoko states:

As these (user groups) develop, it broadens my view of things, I can grow . (edit.) I can meet people in various positions, foster sociability, build up connections and cooperate together not only with users but also supporters.

It seems as if accepting identity as a user and working with other users enabled interviewees not only to provide valued support for others but also to find a valued sense of self, to discover their strength and build confidence and self-esteem, as Barnes and Shardlow (1996) found in their research. Moreover, user groups provided them with contact with the wider society and an important role in society.

Challenging Stigma and Discrimination as User Groups

Corbett (1994) states:

On our own, all of us are vulnerable and relatively

powerless. Together, in group solidarity, we are a forceful presence, not to be ignored (p.353).

(edit) through self-respect and collective power, we challenge social prejudice, hostility and discrimination (p.356).

Collective power is indispensable for challenging discrimination.

Koji states:

With other users, I can live with stigma and discrimination hoping that we can change it little by little and believing the potential.

The interviewees, who have been challenging stigma and discrimination through user groups, identified three areas to work on as user groups; individual support, education and political action.

1) Individual Support

As identified in chapters two and five, users may develop negative feelings about themselves (Coleman, 1997). However, involvement with the group seemed to have freed participants from, or reduced, such negative feelings. All participants are involved with self-help groups and/or peer-counselling, either running these or arranging training course. Koji states:

We should stop families and users from being manipulated by prejudice and distressing themselves first.

Otherwise we would be exploited.

Direct work with users regarding stigma and self-worth issues is a significant goal to empower users. A user is defined by status, therefore, it is important for user groups to modify the meaning of the status for members, it is especially important to change the negative stereotypes which attack user identity and produce

felt-stigma (Segal *et al.*, 1993)

2) Education

Participants identified education, not only for the general public but also for professionals and students as an important area where they can make use of user experiences. All participants have been involved with education as a speaker and/or arranging workshops and lectures regarding mental health issues.

Three interviewees believe that it is important to make the general public aware of and understand mental health issues to combat stigma and discrimination. As many individuals just live their lives without recognising themselves as oppressors (Young, 1990), education may contribute to consciousness raising. Two participants stress the importance of educating professionals and students. Neko states:

The text book is based on the medical model. The actual

scars of our mind are not described there. I want to speak out about it. I want to express what users are feeling and thinking.

Tomoko found giving a talk rewarding.

This is my role in society. Especially when I talk to people, I receive some responses, their thoughts and questionnaire, which become my most (important) motivating power and encouragement.

A body of research suggests that direct contact with users can alter stigmatising views and discriminatory actions (Thorncroft, 2006b). Opportunities must be provided for users to talk to the community directly, perhaps also to hear their story. Without this truthful conversation, we cannot expect deep-rooted prejudices to disappear (Rose, 1996).

3) Political Action

Koji and Neko strongly believe that users must speak out and challenge mental health system and law.

Hospitals should heal the wounded mind, however, Japanese psychiatry and mental health services are not functioning like that. As they can not improve their practice by themselves, users must speak out. If we do not speak out, it remains hidden. It will not change if it does not come out to the surface (Koji).

Many users have committed suicide. Psychiatric medical care is absolutely inhumane, which we must change. (Edit.) Survivors have a responsibility (of the commitment) towards people in agony and the dead (Neko).

Neko is also convinced that user research plays an important

role in political activity, which he is committed to. Presenting data from users' points of view would have a significant meaning. Koji, who gave up his dream due to a disqualifying clause, states:

Individual are powerless against the legal system. We are just left to be knocked down in front of prejudice, discrimination, disqualifying clauses and medical laws. If we are devastated, we are just left devastated. If you are alone, you cannot change it. Existence of peers is important and I could survive, although I was devastated.

Introduction of anti-discrimination legislation, which could provide a benchmark for discrimination, would be the most promising strategy to tackle discrimination (Sayce, 1998). However, it should be backed up with practical programmes to expand opportunities; grassroots initiatives to promote access to general social opportunities; and public education and media

work to change people's views. Involving users in planning seems to promote the work more quickly, because people would meet with users with whom they have previously been scared of or even detested (Sayce, 1998). User groups seem to have a unique role in challenging internalised oppression, ignorance and prejudice and institutional discrimination.

Challenges of User Groups

The challenges of user groups, as stated by interviewees, are categorised into three areas; financial resources, recruitment of skilled users and cooperation within user groups.

The lack of funding was the first problem which was addressed by all participants who run independent groups. The main sources of income for their groups are membership fees except for a group which got some subsidies. Aozora states that "money is power" because the amount of money decides the degree of their activities. If the group has no subsidies, activities will be limited to the local area, which makes it difficult to build

user national networks as well as to attend training, conferences and assemblies. Koji states:

Prejudice and discrimination will not change if professionals set slogans without involving users. So, a system (is necessary) to allocate an appropriate budget from the government, or some kind of foundations, to user groups which need funding.

As O'Hagan (2001) states, the user movement must be supported by the state to build support networks and user run services.

Second, difficulties in recruiting skilled users were addressed. Neko stated that lack of users with administrative skills, which is a weak point for user groups, limits his work because he became unwell two years ago due to overwork.

Aozora was also frustrated:

There are several competent users but I cannot involve them as they cannot be open (about their user status). They would rather get a competitive job (than be involved with user groups). (Edit) They want to live their life *not* as a user.

Thus, the more competent the user is, the stronger he/she wishes to be integrated into society, which creates difficulties to expand user activities.

Third, difficulty in uniting user groups has been stated by all interviewees, who have been deeply involved with the user movement locally and nationally. They strongly believe that collective action is needed to challenge stigma and discrimination at a national level. However, it has been difficult to unite these groups due to differences in values, philosophies and principles. Neko states:

I think that fragmented organisations must reach a

consensus at some point and act together. It would become a kind of spear to eliminate discrimination and prejudice. It would become a power to penetrate and make a hole like a spear.

Neko also suggested that research can become a core activity to unite user groups. He thinks that user groups do not disagree with the importance of user research despite the differences. In order to utilise users' strength fully, changes are required, which will be explored in the next section.

The Way to Maximise Users' Collective Strength

Three issues have been identified by interviewees to enhance their contribution. First, a system, which involves users must be set up in policy-making and service planning. Tomoko strongly believes that users' participation in the decision making process of policy is inevitable to change medical systems and law. As O'Hagan (2001) states, user involvement with the planning and

evaluation of services at all levels is necessary. Users demand participation not only because they want to express their own views and their needs but also they want these to be included in the mainstream debates and developments such as political and social issues (Beresford and Campbell, 1994).

Second, the need for a network was identified. Koji believes that users must involve professionals and citizens to change society as prejudice and discrimination are deep-rooted formidable opponents. Estroff (2004) also stresses the collaboration with users, citizens and professionals as one of the keys in stigma and discrimination reduction.

Finally, adequate funding was identified as essential. Koji states:

I think the Japanese mental health system should be reformed fundamentally. If you flow money into just a medical system and do not give money to people who are determined to change the current situation, this society

would last for ever.

User groups are recognised as a source of specialised knowledge because they are successful in providing services and they develop power as experts (French and Raven, 1960, in Segal *et. al*, 1993). In order to enable user groups to develop and achieve their aims, It is necessary to provide financial and human support such as subsidies and rooms for them locally, nationally and internationally at a considerable distance (Thornicroft, 2006a). It is also important that their expertise is recognised and valued properly in society. Neko states:

If I couldn't get income support, I would have been unable to run the user groups. As I was able to get it, I was free during the day. It enabled me to run them.

Until he went on benefit, his life was in a vicious circle of "got a job with concealment" then "became unwell". Neko added:

as long as society judges people by their job and income, users are seen as a troublesome existence in society, someone who uses up the tax.

Neko is a representative of a national user organisation for user-led research and negotiates with the government; however, he would not have been able to take the role if he was not on benefit. This clearly indicates that users are put in a subordinate and dependent position whilst they are ostracised for it (Sayce, 2000). Neko has visited user groups in the United States.

Users (in US) are making their living from user groups and paying tax. It would be wonderful if such a system was introduced in Japan, although it is just a dream. We cannot make our living like this in Japan. We are on income support.

Their expertise must be recognised justly. It will free them from being second class citizen and experiencing internalised oppression. Neko also thinks that a proper salary to make a living would attract more users, including skillful users who can support the group. Some kind of mechanism is needed to offer disabled people individual and collective redress. This can not be accomplished without sufficient funding of a national network of organisations of disabled people (Barnes, 1991a).

Conclusion

This chapter has addressed the significant impact of users group on participants' lives and ways to challenge stigma and discrimination as user groups. Problems of a lack of skillful users, cooperation and funding are identified as obstacles for user groups. Systems of user involvement, building networks and secure funding have been recognised as the way to utilise the expertise and strength of users in their challenge. User groups seem to have their own role in challenging internalised

oppression, ignorance and prejudice and institutional
discrimination, which anyone *cannot* do.

Chapter Seven

Conclusion

This final chapter summarises the significant issues and themes outlined in the previous three chapters and addresses some implications for future development.

Summary

The aims of this study were to identify how significant user groups were in supporting users to challenge stigma and discrimination and to explore ways to meet the challenge utilising their collective strength, in the Japanese context. It also aimed to gain a comprehensive understanding of users' experiences and the consequences of stigma and discrimination. Having considered the literature, I hypothesised that user groups have a significant role to play in challenging stigma and discrimination in society, but the role is neither recognised properly nor utilised sufficiently in the current system in Japan.

To achieve these aims, a focus group interview and five individual interviews were conducted. As this is a small scale study, the findings cannot be generalised to the wider population, but the findings have provided some insights into issues such as stigma, discrimination and users' collective strength.

Based on the literature review and the findings of this research, I have come to the conclusion that stigma and discrimination which is created by society disables users, not an individual condition. Society excludes users, denies them their rights and robs them of their life opportunities unfairly by labelling them as dangerous, deviant and inferior, marginalising and oppressing them. User groups have the strength to challenge stigma and discrimination, however, the indispensable role of such groups in Japanese society is neither recognised properly nor utilised sufficiently in the current system.

Why is the Involvement with User Groups Important?

One of the purposes of this study was to identify how significant user groups were for users in challenging stigma and discrimination. The issues which have been identified in this research will be outlined.

As stated in chapter two, stigma is a prejudice based on negative stereotypes, which results in discrimination (Link and Phelan, 2001). Stigma is internalised and affects a user's self-image negatively (Green et al., 2003). Users' groups have a role to play in challenging these issues.

1) Challenging internalised oppression: individual support

Participants' experiences indicated that the encounter with user groups had a profound effect on their lives and how they feel about themselves. Through user groups, respondents found strength and a valued sense of self and built confidence and self-esteem by having 'a role in this society', 'a meaning in life' and 'contacts with the wider society'. Safe environments within user groups provided support and enabled users to change

damaging experiences into positive outcomes (Barnes and Shardlow, 1996).

2) Challenging ignorance, prejudice and stereotypes: education

Participants identified education, not only for the general population but also for professionals and students, as an area where they have an important role to play. Research also indicates that direct contact with users is effective in tackling prejudice (Thornicroft, 2006b). Involving users in planning would be a quick way to change people's views, because they would meet users for whom they had previously feared (Sayce, 1998). However, such effective ways would not work without the support of users who have come out, in other words, if users are too scared to reveal their status, such strategies cannot operate.

3) Challenging discrimination: political action and research

Eradication of institutional discrimination and prejudice is only possible through the activities of a vigorous and independent disabled people's movement (Barnes, 2006). Only users can

bring expertise based on experience into the decision making processes of policy, systems and services, which should exist for the best interest of users. Research data from the users' point of view, which is important information for informing future direction, cannot be obtained without involvement from users.

Thus, users have a significant role to play in challenging the three strands of discrimination; internalised oppression; ignorance, prejudice, stereotypes; discrimination.

Collective power is so valuable as it can sustain a vision of what could be done, when current structures continues to be oppressive, because if a person is alone, he or she tends to accept the *status quo* as the only possible reality (Corbett, 1994), as Koji states, 'With other users, I can live with stigma and discrimination hoping that we can change it little by little and believing the potential'. Many testimonies have been made by participants who were encouraged to stand up and challenge stigma and discrimination through user groups.

Challenging Stigma and Discrimination Utilising Users' Strength

The other main purpose of this research was to explore ways to meet challenges utilising users' collective strength. Collaboration between users, relatives, providers, commissioners and the government is important to challenge discrimination at a wider level of policy development and advocacy (Sayce, 1998). In order to challenge stigma and discrimination utilising users' expertise, each party needs to play its part. The implications for government, local authorities, professionals and users will be illustrated.

1) Government and Local Authorities

It has been revealed that users are facing institutional discrimination in the mental health system and from legislation manifested in lengthy hospitalisation and disqualifying clauses. Fundamental changes in the mental health system, abolition of disqualifying clauses and introduction of anti-discriminative legislation are urgently required. Two issues have been

identified in this research as important roles of the government and local authorities in utilising users' strength. First, a system which involves users in policy making, planning and delivering services must be established with full recognition of users' expertise. Second, secure funding, which enable users to make a living from user groups is necessary without 'strings attached' to enable user groups to continue and expand their activities. Their expertise must be recognised justly. Fair recognition of their expertise may solve the problem of recruitment of skilled users, which was identified as an obstacle of user groups in challenging stigma and discrimination.

2) Mental Health Workers

Interviewees revealed problematic attitudes such as patronising and arrogant attitudes of mental health workers. Attitudes which convey empathy, respect and understanding are fundamental. Mental health workers must be aware of the strength of users and user groups as experts based on their experience, as well

as the disabling effects of discrimination in society. They have enormous potential to support users to challenge discrimination and improve their social and economic lives (Sayce, 1998). Workers are in a good position to introduce users to user groups by distributing information and providing human support for user groups (Thornicroft, 2006a).

3) User Groups

As identified in this study, user groups have an important role to play in supporting users. User groups must continue to respond to individual's experiences of distress and their use of services, whilst developing effective strategies to achieve change (Barnes and Shardlow, 1996). In order to utilise their strength, three main obstacles were identified by participants: financial resources; recruitment of skilled users; and cooperation within user groups. Of the three, cooperation within user groups is the only issue which user groups can work on. Respondents identified an urgent need for collective action at a national level, which could

become a power to penetrate social barriers like a spear, to challenge stigma and discrimination, especially institutional discrimination.

Further Research

As this is a small piece of research in a limited area, further research with a larger number of users in wider areas would be beneficial to further test the results of this research. More focused research to explore ways to utilise users' collective strength would be beneficial. For example, it would be beneficial to conduct research on user groups in other countries, where users' expertise has been recognised and utilised as this would provide useful information based on their experience. It would also be important to conduct research with users who are not involved with user groups to investigate not only their situation regarding stigma and discrimination but also what hinders them from being involved with user groups.

Where do We Go from Here?

This small research added to evidence that users who were born in Japan were still 'suffering double misfortunes' (Kure and Kashida, 1918: 138), however, this research indicates that users were not devastated by 'misfortunes' as passive dependant recipients of mental health services but actively challenged the disabling society as a result of utilising their collective strength.

As previously stated, the Japanese government announced a policy to shift institutional care to community care (Ministry of Health and Labour, 2004a), which requires vigorous challenges against stigma and discrimination. Moreover, the Japanese government has eventually signed the United Nation's Disability Convention, in September 2007. There is a long way for ratification; however, it is a significant step, which indicates their commitment towards equal rights of disabled people. Unjust legislation such as disqualifying clauses and discriminatory mental health systems must be eliminated. Radical change is needed, otherwise the government's statement about community care and their commitment to equal

rights for disabled people will be no more than rhetoric and they will continue to exclude, marginalise and oppress users in this society. The results indicate users' strong determination and commitment to challenge society for their equal rights. Users have set up user groups which provide both ideology and a practical work for their emancipation (Barnes, 1991a). Users have been playing their indispensable roles and have enormous potential to contribute in challenging stigma and discrimination in pursuit of equal rights of disabled people in their society. The time has come to challenge discrimination utilising users' valuable expertise in earnest.

(15581 words)

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PARTICIPANTS

Aozora: Female 30s

Part time worker at a community activity support centre/ Student

Representative of a National Organisation for Recovery

Use of medical services: 20 yrs including a hospitalisation (4 yrs) and day hospital (8 yrs)

Income: Salary and Disability Pension

Koji: Male 40s

Head (acting) of community activity support centre

Qualified General Social Worker/ Psychiatric Social Worker/ Care Worker

Representative of a local user group

Councillor of Prefectural network of people with a mental disability

Use of medical services: 14 yrs including 5 hospitalisations (total: 3 yrs)

Stayed at home (18 yrs)

Income: Salary and Disability Pension

Neko: Male 40s

Representative of a national user organisation for user research

President of Prefectural Mental Health Alliance

Use of medical services: 30.5 yrs including 12 hospitalisations (total: 3 yrs)

Income: Income Support

Sato: Male 30s

Part time job and voluntary job

Representative of a user group in a community activity support centre

A member of the implementation committee of a peer support course

Use of medical services: 7 yrs including 2 hospitalisations (total: 3.5 yrs)

Income: Disability Pension and Wages

Tomoko: Female 40s

Managing/ Council member of National Organisation of users

Management member of a local user group

Use of medical services: 15 yrs including a hospitalisation (2 months)

Income: Salary and Disability Pension

Appendix 2

Experiences of Stigma and Discrimination and User Groups

Focus group guidelines for exploring the stigma and discrimination of users and user groups

1. People's attitudes, What are stigma and discrimination, Experience
(Participant's understanding of experience of stigma and discrimination)
 - 1) How did people around you react when they found out you were a mental health service user?
(if necessary, probe: work, family, friends, education, everyday life)
(if necessary, probe: withdrawal. interest, gossip, support?)
 - 2) What does stigma mean for you?
 - 3) What does discrimination mean for you?
 - 4) Have you ever experienced stigma and discrimination because you are a user?
(if necessary., probe: When? Where? How? Can you describe?)

2. The effects of stigma and discrimination on their lives, feelings and the strategies to handle them
 1. How does stigma and discrimination affect your life and feelings?
(if necessary, probe: self-doubt, worthlessness and inferiority, giving up employment)
 2. How do you handle stigma and discrimination?
(if necessary, probe: did you tell other people that you were a mental health service user? Whom? When? Why? Why not?)

3. The effects of encounter with other users and involvement with user groups in relation to stigma and discrimination
 - 1) Has the encounter with other users and the involvement with user groups changed your perception of stigma and discrimination, your way of life, your feelings about stigma and discrimination and the way of handling stigma and discrimination?
(if necessary, probe: hope, empowerment, coming out, challenge, fight)

Appendix 3

Experiences of Stigma and Discrimination and User Groups

Individual interview guidelines for exploring the stigma and discrimination of users and user groups

The aim of this interview is to investigate mental health service users' (hereafter referred to as user) experience of stigma and discrimination, the effects of these on users' lives, feelings and the strategies to handle them and the meaning and roles of user activities.

You do not need to answer any questions which you do not wish. You can stop the interview at any point. Your identity remains anonymous by using a pseudonym and proper nouns such as the names of groups will be changed to A. B. C. in the report.

This interview will be recorded and partially transcribed to support my memory. You will have the opportunity to check the citation and how it is used in the report. Please make changes to your comments if it requires any correction. I will not cite your comments without your consent.

The following are the planned questions. However, this is just a guideline and will not be followed strictly.

1 . Experience of Stigma and Discrimination

- 1) How did people around you react when they found out you were a mental health service user?
- 2) Would you explain more about the situation which was significant? (By whom, When, How)
- 3) Have you been in a situation where you have heard others say unfavorable or offensive things about users or seen or read such things or in the mass media (television, films, books)?
- 4) Have you been turned down for a job or excluded from volunteer or social activities when it was known that you are a user? (within/ outside mental health field)
- 5) Have you had difficulties or been denied a place to live, educational opportunities, a passport, driver's license or other kind of permits when you revealed that you are a user?
- 6) Have you had the fact that you are a user used against you in legal proceedings?

- 7) What were the attitudes of mental health workers? (If any to add)
- 8) How prejudicial and discriminatory is the mental health system? (If any to add)
- 9) How prejudicial and discriminatory the law? (If any to add)
- 10) Are there any other experiences of stigma and discrimination as a user?

2 . The effects of stigma and discrimination and the strategies to handle them

1) Image of users

- (1) What kind of image did you have towards users before you became a user?
- (2) What made you identify yourself as a user?
- (3) How does becoming /being a user make you feel?
- (4) Is there anything you gained from the experience to be a user? Please explain.

2) Effects of stigma and discrimination

- (1) How does being a user affect your life?
- (2) Have you ever given up anything because of your condition as user? For example qualifications, work, volunteer work)
- (3) Do you experience fear and anxiety that you may be treated unfairly because your condition are a user?

3) Strategies to handle stigma and discrimination

- (1) Have you avoided indicating that you are a user on written applications or in interviews for jobs for fear that information will be used against you? Please explain.
- (2) In what situations, would you say you avoid revealing that you are a user?

4) Coming Out

Have you come out? (Has your name and picture been presented in newspapers or TV?)

{Yes} (1) Why did you come out?

(2) What made you come out? (What prompt the decision?)

(3) How did coming out affect you and with whom?

(for example. your life, psychologically, family relationship)

(4) What made it possible for you to come out?

(such as independence from family, existence of other users)

(5) Is there anything which you feel good/ bad about having come out?

{No} (1) What stops you to coming out? (e.g. the effect to yourself, family)

(2) What would happen if you come out? How would it affect you and others?

(3) Have you thought about coming out? How do you feel about it?

{Both} (1) Has anyone been against/ advised you not to come out/ hide your condition?

(2) What did you do about it? {Followed the advice, disagreed etc.}

3. Meanings of involvement with user groups in relation to stigma and discrimination

- 1) How did you get to know a user group?
- 2) What made you become involved with user groups actively (motivation/ the source of energy)
- 3) Has the involvement with user groups and encounter with other users affected you?
 - The way you perceive users, How you see users
 - Your life and feelings
 - The way of handling stigma and discrimination
- 4) What does involvement with user groups mean to you?
- 5) What do you want to do /what do you think that user groups must do?
- 6) What are the challenges/ difficulties in running user groups?
- 7) What is needed do you think to utilise the strength of users and user groups?
- 8) What is needed do you think to eliminate discrimination against users?
- 9) Are there any other things which you would like to say about stigma, discrimination and user groups? Do you think that we have covered all the important issues?

4. I would like to ask some personal details and the details of the user group which you have been involved with. You could answer these either before the interview or in the interview.

User groups indicate the groups which are run by users for users.

1) When did you become a user?

(1) Showa · Heisei (years ago)

2) Please tell me the total number and length of hospitalisations. When was the last hospitalisation?

total number of hospitalisations : total length of hospitalisations :
last hospitalisation : (Years ago)

3) (1)When did you encounter other users and start to talk about various things? (2) How?

(1) (2)

4) (1)When did you get to know the user groups for the first time? (2)How?

(1) year (years old) (2)

5) Please give information about the user groups which you have been involved with.

Name of User Group	(1)	(2)
Main Activities		
Your Role	a. Representative/ Head b. Managing/Board Member c. Other:	a. Representative/ Head b. Managing/Board Member c. Other:
Period of involvement	Year(s)	Year(s)
Main Source of Income	a . Membership fees b . Subsidies c . Donation c . Other :	a . Membership fees b . Subsidies c . Donation c . Other :

6) Age (Please select one answer)

(1) 30-39 (2) 40-49 (3) 50-59 (4) 60+

7) Please tell me the main source of your income (You can select more than one answer)

(1) disability pension (2) income support (3) salary/wages

(4) support from parents (5) other :

8) What is the pseudonym by which you wish to be called in the dissertation?