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AN ADJUSTMENT PROCESS AND COMMUNICATION DILEMMA
OF PEOPLE WITH DISABILITIES IN JAPAN

A Dissertation

SUBMITTED TO THE GRADUATE FACULTY

in partial fulfillment of the requirements for the

degree of

Doctor of Philosophy

By

MIHO IWAKUMA
Norman, Oklahoma
2002

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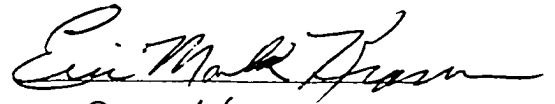
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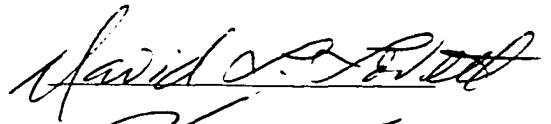
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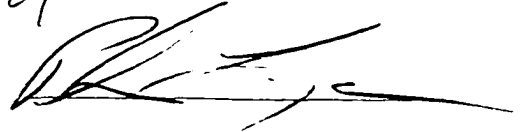
A Dissertation APPROVED FOR THE
DEPARTMENT OF COMMUNICATION

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ABSTRACT

Throughout their lives, people make various kinds of adjustments. Most people are capable of making adjustments in order to survive challenging experiences. This fact is especially true for newly disabled individuals whose lives have been turned upside down. An adjustment to a severe disability is accompanied by significant psychological (lowered self-esteem), physical (restricted mobility), and social (changed social identity, “disabled”) changes, and such sudden changes also require short-term (physical) and long-term (psychological and social) adjustments. In other words, the investigation of adjustment to a disability gives social scientists a unique opportunity to study various facets of human adjustment strategies and processes. This research focuses on how people with disabilities in Japan have changed their worlds after acquiring a disability. The researcher used ethnography and an interview method to follow the participants’ disability transformations for three years. Several themes emerged, such as information pooling places for the disabled, interacting with others with disability and adjustment to the disability, negotiation with the non-disabled, an early going-out as a prologue to the disability adjustment, changed perceptions toward the wheelchair, and changed communication with others, just name few. Moreover, based on these themes, this researcher generated three binary oppositions. They are integration-separation, defying disability-accepting disability, and independence-dependence. In the end, it was concluded that communication was the main vehicle for the disability adjustment. The researcher summed up that communication with others facilitated the participants’ disability transformations, and in return, they adjusted their communication as they adjusted to their disability.

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CHAPTER I

INTRODUCTION

Throughout their lives, people make various kinds of adjustments. Most people are capable of making adjustments in order to survive challenging experiences. This fact is especially true for newly disabled individuals whose lives have been turned upside down. Among different kinds of adjustments, the sudden onset of a disability, such as a spinal cord injury, can be one of the most traumatic and stressful experiences. Acquiring a severe physical disability brings drastic life changes, and these changes have a significant impact on both a newly disabled person and people surrounding the person. An adjustment to a severe disability is accompanied by significant psychological (lowered self-esteem), physical (restricted mobility), and social (changed social identity, “disabled”) changes, and such sudden changes also require short-term (physical) and long-term (psychological and social) adjustments. In other words, the investigation of adjustment to a disability gives social scientists a unique opportunity to study various facets of human adjustment strategies and processes.

Current Research Status

Although disability research in the field of communication has a relatively short history compared to other communication sub-disciplines, disability research poses several important communication issues. The perspective of people with disabilities (PWDs) can add a unique contribution to the communication studies because disability issues affect self-image, communication with others, and/or immediate experiences in the world (*umwelt*) which are all major concerns in communication studies. Communication phenomena between the non-disabled and PWDs can be investigated

from an inter-group perspective, as well as from an interpersonal perspective (Hewstone & Giles, 1986). A salient physical marker, disability, creates a “you verses Me” or “I don’t belong to your group” communication climate¹. Both the non-disabled and PWDs are under the influence of cognitive biases (e.g., expectations, stereotypes, or attitudes), and these biases determine the course and nature of communication which tend to be distorted, miscommunicated, or stigmatized (Coleman & DePaulo, 1991; Goffman, 1963). Hence, the outcomes of this inter-group communication between PWDs and the non-disabled are more likely to be different than communication between the non-disabled both verbally and non-verbally (e.g., Deegan, 1977; Hart & Williams, 1995; Hewstone & Giles, 1986; Worley, 1996; Worthington, 1974). Cross-culturally speaking, living environments of PWDs are undoubtedly diverse around the world because disability is treated differently and defined differently by different cultures (Davis, 1997; Edwards, 1997a, 1977b; Iwakuma & Nussbaum, 2000).

Objectives of the Study

This research focuses on how people with disabilities in Japan have changed their worlds after acquiring a disability. More specifically, this investigator’s primary foci are 1) communication behaviors of individuals with disabilities, 2) the transitional path from being a non-disabled to being a person with a disability, and 3) the cultural dimension of disability adjustment. The transformation from being a non-disabled to being a PWD entails a unique phenomenon. Newly disabled individuals are

¹ Interestingly, this you-verses-I tendency, which indicates a contrasted group identity, appears unconsciously in writing (Feinberg, 1971). When asked to describe interactions with persons with disabilities, Feinberg’s 25 research participants used non-inclusive nouns, such as “you and Me,” far more often than an inclusive noun, “we.”

forced to reorganize their familiar and taken-for-granted environment to a new environment in order to suit their new desires, physical status, relationships with others, and so on. In addition to physical transformations, newly disabled persons experience inner changes which perceive the life-world (*lebenswelt*) quite differently partially because their spatial and temporal senses are altered. The transition, however, may result in people becoming isolated. Murphy (1990) describes these individuals as “aliens, even exiles, in their own land” (p. 111). This investigator researched how some Japanese with disabilities communicate with others and society.

CHAPTER II

LITERATURE REVIEW

People with Disabilities as Hidden Minorities in the World

Worldwide, the population of PWDs is growing rapidly along with the world population because of medical advances, aging in society, and/or the on-going wars in world regions. In the U.S. alone, between 36 million to 43 million people are currently estimated to have disabilities (LaPlante, 1992; Davis, 1997a). This population figure is larger than those of other groups in the U.S. such as African-Americans or Hispanics (Allen & Turner, 1990). Despite this fact, voices of individuals with disabilities have rarely been heard, and their existence has largely remained invisible as a collective group to others. For example, oftentimes, students with disabilities are not considered “minority” students (Linton, Mello, & O’Neill, 1995), and books regarding disability or persons with disabilities are not included with other “diversity” books, and these disability books are often found under the heading of “self-help” in a bookstore (Davis,

1997b). Likewise, issues pertaining to PWDs are rarely discussed within an academic context of multiculturalism, minority studies, or diversity curriculum (Linton, 1998). Even in face-to-face interactions, many PWDs have experienced being ignored or avoided. Additionally, the non-disabled often talk to a third-person who happens to be with PWDs as if they are invisible to the world, for example, in a restaurant, (Murphy, 1990; Hockenberry, 1995). Due to this “invisibility,” PWDs are called the “hidden minority” (Kleinfield, 1979).

Who are “the disabled”? : impairment, disability, and handicap

It is not uncommon to hear a person referred to as “disabled,” “handicapped,” or “she has a visual impairment.” Such terms, “disability,” “handicap,” and “impairment” are often used interchangeably. Nevertheless, the distinctions between these terms are crucial; therefore, let us turn to these differences.

The World Health Organization (WHO) defines these concepts as follows: an “impairment” refers to a physical and/or psychological disorder or damage. For instance, if a person has damaged one of his or her eyes, this is an impairment. To go one step further, a “disability” denotes a functional incapability caused by an impairment. A disability for the person with the damaged eye is an incapability to see because of the visual impairment. Finally, the definition of “handicap,” according to WHO, denotes a *social* disadvantage caused by a disability. Therefore, if the person with a visual impairment cannot go to school, use public transportation, or obtain a job due to an environmental barrier, these social disadvantages become “handicaps” for the

person².

The United States government also recognizes the multi-dimensional definition of “disability.” According to the Americans with Disabilities Act of 1990, disability consists of a physiological dysfunction or impairment of a person, diagnosis and documentation of the impairment, and consequences of having the impairment. It is estimated that currently 14% to 20% of all people in the U.S. are considered PWDs (Disability Statistics Abstract, 1991; LaPlante, 1992), if people with functional limitations are included. Therefore, a person who has difficulty in going up a flight of stairs, is considered a PWD in the U.S. (Disability Statistics Abstract, 1991) while in many other countries, s/he is not considered to be “disabled.”

In fact, the population of PWDs in Japan is estimated to be only 4 % of the total Japanese population (Sori-fu, 1998) while the same figure is 30% in Sweden (Hayer, 2001; Ono, 1992). It is noteworthy that the disabled populations in these countries vary greatly from 4% to 30%, in spite of some similarities among these nations. None of these countries are currently involved with wars. All these countries are developed, with relatively stable economies, and are experiencing a fast-growing aging population which has become a major national concern. It is most likely,

² Therefore, according to WHO, an impairment results when an individual has a disability, and a person with a disability always has an impairment. Conversely, the fact that a person has a disability does not necessarily mean that s/he is also a “handicapped,” which refers to having social disadvantages. This fact is because the person’s “handicappedness” is a socio-cultural artifact and, thus, it can be lessened by, for instance, using a wheelchair, living in a barrier-free apartment, or living in a less stigmatizing society toward a person with disability. In brief, one’s “handicap” is not independent from one’s culture (context-dependent), while the first two, “impairment” and “disability,” are (context-independent).

thus, that actual possibilities of acquiring impairment in these three nations is quite similar. Therefore, this gap in the numbers from 4% to 30% clearly indicates that disability is not a discrete entity, rather it is a socio-cultural concept with fluidity and multi-layers.

Disability in Context: People with Disabilities (PWDs) in Japan

Japanese people with disabilities today

According to the Japanese government, the numbers of Japanese people with physical, intellectual, or psychiatric disabilities are 3,170,000, 413,000, and 2,170,000, respectively (Somu-sho, 1998). Among those with physical disabilities, 1,657,000 (56.5%) of the people have disabilities with limbs, 621,000 (21.2%) have internal disabilities (e.g., heart diseases), 305,000 (10.4%) have visual impairments, and 350,000 (11.9%) have hearing impairments. According to the law, *Shogaisha* refers to a person “whose daily life or life in society is substantially limited over the long term due to a physical disability, mental retardation, or mental disability” (*Shogaisha kihonho* Art. 1). The Japanese population with disabilities represents 4.8% of the total population of the nation. This total is significantly lower than other developed countries (Hayer, 2001). This proportion of the disabled population in Japan comes from the fact that those people having “temporary” disabilities, chemical/alcohol dependency, or AIDS are not considered “disabled” under the current law (Hayer, 2001). In addition, Hayer (2001) points out that the Japanese disabled population is based on the number of people who obtain a disability handbook: an identification card to “legally” certify a person as “disabled” in Japan. Without this small book, one is not entitled to receive any welfare benefits; however, because of the stigma associated with carrying this handbook, many

people with disabilities refuse to have one³. So, the aforementioned disabled population, 4.8%, refers to the percentage of people with the handbooks.

As of 1996, there are 285 institutions in Japan and about 18,000 individuals with physical disabilities are living in these institutions (Sori-fu, 1998). While those institutions are similar to “nursing homes” in the U.S., there are other kinds of institutions mainly for “rehabilitation.” A person with a disability stays from a year to five years, usually at boarding houses, to (re)learn various life techniques from changing clothes and bathing, to driving a car with a handcontrol. (Several participants for the present research stayed in this kind of rehabilitation institutions and eventually returned to their hometowns.) In 1997, for students with physical disabilities (not including the students with visual or hearing impairments), there are 800 special schools in the nation and 75,280 students studied at these schools. The number of students at special schools tends to decrease, however, partially because of an “integration” policy and access improvements for schools in general. Among junior-high graduates, 89% of the students furthered their education to high school⁴. (In Japan, the mandatory education level is obtaining a junior-high school diploma.) After high school graduation, about 1% of the students go to colleges, 3% of them enter vocational schools, 27% of them get jobs, and 54% of them stay at medical/welfare institutions (Sori-fu, 1998).

Because of the economic recession of the country, an employment situations surrounding PWDs has been quite pessimistic. Japan employs a quota system in order to promote hiring PWDs. Currently, the quota for private companies is to have 1.8% and

³ The primary focus of the following discussion is PWDs who are recognized by Japanese law.

public companies to have 2.1% of employees with disabilities. Nevertheless, due to a lack of understanding and/or access, almost half of all private corporations (49.8%) did not reach the quota (Shimizu, 1998; Sori-fu, 1998). More disturbingly, larger companies tend to employ fewer PWDs than smaller companies: while 54% of small companies (with less than 100 employees) kept the quota, and only 33% of large companies (with more than 1,000) did so (Shimizu, 1998). Larger corporations can afford to pay a penalty for not hiring enough PWDs, and they would rather pay the penalty than have employees with disabilities.

At the same time, situations surrounding PWDs in Japan greatly have changed. This situation is partially due to an “aging” trend in society. In the past, “social welfare” was needed only for “special” people (for example, the elderly), but the Japanese people started to realize that the number of those “special people” is growing so fast that they can no longer ignore them. Indeed, the Japanese “aging” tide is the fastest in the world, and people in the country are starting to see that an aging-friendly environment should be normative for the sake of everyone. Today, the government acknowledges that information and environmental barriers for the elderly and PWDs have prevented these individuals from full participation in society; therefore, these obstacles should be removed immediately (Sori-fu, 1998). Japanese culture always has been a conformitistic, assimilationistic society. Nevertheless, due to an ever-increasing minority, a “majority” society is faced with major accommodations for the minority, maybe for the first time.

Disability Issues and Theories

Communication with People with Disabilities

As stated previously, the United Nations estimates that currently about 10% of the world population is the group of people with disabilities (Bryen & Shapiro, 1996). In the United States alone, the number of PWDs exceeds that of racial minorities such as African-Americans (Davis, 1997a). Yet, the group of people with disabilities has remained as a “hidden, misunderstood minority” (Shapiro, 1993, p. 11) to this day.

There are distinctive characteristics in communication with/of PWDs. One of the characteristics is patronizing behaviors when communicating with PWDs (Fox, 1994; Hewstone & Giles, 1986). It is not uncommon to see a non-disabled person talks or interacts with a PWD as if s/he is weak or a child. This kind of communication is derived from the non-disabled’s perception toward a PWD as the person being “sick” (Parsons, 1951) and incompetent (Wright, 1960). The latter view is particularly called “spread” which is generalizing from a physical trait (e.g., inability to see) to unrelated other characteristics (e.g., being emotional, incompetent, or unhappy). Communication and attitudes toward PWDs are greatly influenced by such factors as severity/visibility of one’s disability, affected body parts, and contagiousness (Livneh, 1991). In addition, even after controlling these factors mentioned, there is a difference in “acceptance” of different kinds of disabilities. An “acceptable” rank of PWDs indicates that cerebral palsy, skin disorders, and body deformation are least accepted by others (Siller et al,

1967). Generally, PWDs tend to appear in the media as dependent, abnormal, sick, “superheros” or “sadcrips,” if covered at all⁵.

While there are some distinctive communication traits, communication characteristics of/with persons having disabilities share common themes with other minority groups (Goffman, 1969; Murphy, 1990). Coleman & DePaulo (1991) suggest that interactions between the non-disabled and people with disabilities tend to be miscommunicated due to a heightened intergroup climate. More particularly, both groups of people are subjects of stereotypes and prejudice (e.g., Coleman & DePaulo, 1991; Emry & Wiseman, 1987). Their communications tend to be awkward and tense (e.g., Kleck et al, 1980), and both groups of people are treated as “others” and, thus, differently (e.g., Braithwaite et al, 1984). Once they started using a wheelchair, Hockenberry (1995) and Murphy (1990) who are both white felt that their fellow whites tailored communication according to the social scripts with “the disabled” and turned their back on them and that their disability overrode other social traits (e.g., race or religion). These individuals with disabilities became “fellow Outsiders,” as Murphy (1990, p. 127) puts it. Just like race or skin color, one’s disability becomes a main attribution factor which guides others’ communication with PWDs (e.g., Hastorf et al, 1979; Thompson, 1991). Having these common traits, it is not so surprising that 45% of persons with disabilities felt, even before ADA was passed in 1990, that they were a minority group like racial minorities such as blacks and Hispanics (Lewis Harris and Associates, 1986).

⁵ Regarding the media and PWDs, see The disabled, the media, and the information age edited by Nelson (1994).

Goffman's Work

In his classic work, Stigma, Goffman (1963) parallels for the first time being a PWD with that of being a racial minority person, such as African-American. His stigma research has a tremendous impact on studies about PWDs. Goffman (1963) explained that the stigma derived from the physical markers (for example, a skin color or physical disability) “spoils” communication with others. Goffman (1961) also introduces a “moral career” which represents “similar learning experiences regarding their plight, and similar changes in conception of self,” and is “both cause and effect of commitment to a similar sequence of personal adjustments” (Goffman, 1963, p. 32). He raises an example of persons with mental disorders who go through a sequence of changes as they enter mental institutions, regardless of their diverse pre-mental-patient history. This stripping of self is also seen among institutionalized PWDs. In addition, according to Goffman (1963), stigmatized individuals use such tactics as “passing” or “covering” to lessen the stigma in communication. The first term describes concealing one’s stigma, posing as one of the majority, and is for the “discreditable” (e.g., mental patients or ex-criminals) whose stigma is not so overt to others. On the other hand, the latter term, “covering,” is intended to hide one’s stigma symbol (e.g., a white cane for a person with a visual impairment) to reduce tension in interactions and is mainly utilized by the “discredited” who have an obvious stigma.

Positive Experience of Disability

Traditionally, a great amount of research has indicated that having disabilities negatively influences people’s intrapersonal and interpersonal communication. It is concluded in many studies that the non-disabled feel uncertainty, anxiety, and

discomfort when being with a PWD (e.g., Kleck, 1968), and therefore, increase physical distance (Worthington, 1974), tend to avoid interactions with the person (Thompson, 1982), and are less likely to choose the person as a friend or neighbor (Farina, Sherman, & Allen, 1968). Surely, acquiring disabilities can be traumatic. Nevertheless, the perception of disability which is experienced as negative, frightening, and a “worse-than-dead” feeling is overwhelmingly embedded deep into the psyche of non-disabled individuals, including the researchers. This fact might have contributed to, inasmuch as reflected the reality of, the prejudice and frightened feelings held by the non-disabled for PWDs. As a result, sometimes while the non-disabled appreciate their able-bodiedness, they innocently say to others, “I don’t know how these folks with disabilities can make a day with their handicaps” or, more candidly, “I rather be dead than be disabled.”⁶

However, previous researchers seem to assume uncritically the notion that having a disability is negative and dreadful, and never attempt to examine the other side of disability experiences; that is, the positive consequences of having disabilities. None of these studies above, including a study by Emry and Wiseman (1987), who are communication scholars, mentions this area. Although positive aspects of disability is mentioned in some personal narratives of individuals with disabilities in academia (Oliver, 1996), systematic research devoted to this subject is severely scarce. The study

⁶ This general frightening sentiment of having a disability is directly related to a “hot” ethical issue of euthanasia of PWDs and abortion of pre-born babies with disabilities. Recently, a Princeton professor Peter Singer who advocates for euthanasia of infants with severe disabilities debated Adrian Asch on this issue. Their debate was observed closely by the disability community as well as by more than 200 interested students at Princeton.

by Herman & Miall (1990) and the study done by this researcher (Iwakuma, 1999) are two among the few studies regarding positive aspects of having disabilities.

Stage Theories

There is an abundance of literature with regard to the adjustment of newly disabled individuals. A great number of studies have developed adaptation phases or models to explain the phenomena. Among those disability theories, stage theories are prominent. Although a theory originated by Kubler-Ross (1960) is not directly concerned with disability experiences, the theory, which includes stages of denial, anger, bargaining, depression, and acceptance, has been used as a framework for some disability theories. For example, Hohmann (1975) theorizes a sequence of disability adjustments from denial to hostility and reaction against dependence. Most stage theories in psychology for people with spinal cord injury (SCI) include the phase of depression in an early course of the adjustment (Hammell, 1995), and these theories imply that without the stage of depression, one may never be able to adapt to his or her disability fully. Hammell contends, however, that these theories are insensitive to heterogeneous environments surrounding people with SCI, such as one's age of having a disability.

On the other hand, with a sociological background, DeLoach and Greer (1981) propose the progressive phases: stigma isolation, stigma recognition, and stigma incorporation. This model of stigma incorporation illustrates one's adjustment in tandem with the transformation of the self. DeLoach and Greer (1981) explain that stigma isolation is a defense mechanism employed by a newly disabled individual attempting to reduce unconscious stress associated with a disability by isolating himself

or herself from the reality. A next stage, stigma recognition occurs when the person with disability realizes his or her stigma of disability by interacting with others. In this stigma recognition stage, s/he starts to explore his or her “new” surroundings from the viewpoint of a person with a disability. After going through these stages, the final phase of stigma incorporation comes when the person with a disability incorporates the stigma into his or her self-identity, and s/he communicates with others from a minority perspective. DeLoach and Greer (1981) theorized this adjustment process under the influence of works by Goffman and Wright.

A communication scholar, Braithwaite (1989, 1990) uses DeLoach & Greer’s stage theory of stigma incorporation, and applied it into her research. Braithwaite (1989) has written an article, “Isn’t it great that people like you get out?” based on an extensive interview with “Helen” who had an accident a decade ago, became paraplegic, and has used a wheelchair since then. The essay narrates Helen’s personal story in terms of her adjustment and cultural shift from that of a non-disabled to a PWD. Braithwaite (1989) mentions the five “key life functions” which are affected most by having a disability (Crewe & Athelstan, 1985). These functions are as follows: self-care, mobility, employment, communication, and socialization. Similar to Murphy’s assertion (1990), Crewe and Athelstan (1985) note that among five major changes in life functions, communication and socialization are less obvious, but are the most challenging. In another study, Braithwaite (1990) demonstrates how people with disabilities adjust to a disability via communication using the Stigma Incorporation Theory. Braithwaite’s main focus in this research, however, deals with one’s *communication* adjustment, that is, how people with disabilities develop their

communication strategies through interacting with the non-disabled, and how these PWDs form their identities as people with disabilities.

While stage theories are neat and straightforward, they also contain some shortcomings. This investigator is concerned with these theories of the adjustment due to the fact that there is little reliable evidence to support these stage theories (Buckelew et al., 1991; Oliver et al., 1988; Silver & Wortman, 1980). According to the study done by Buckeler and others (1991), for instance, there was no significant correlation between age and time since injury and health benefits or psychological stress. Additionally, these stage theories are, in nature, one-directional: from the first stage to the last “desirable” stage. However, according to Silver & Wortman (1980), the majority of people with disabilities experience distress or psychological disorganization long after “achieving” the stage of adjustment. In other words, regression is very possible for the disability experience. Finally, and most problematically, many physicians and/or health professionals impose these stage theories when assessing their patients’ recovery. Just so, if a patient does not experience (or express) “depression” at the early stage of disability adjustment, then the person is labeled as “mal-adjusted” (Ernst, 1987).

Recovery Process

Deegan (1991) criticizes traditional rehabilitation programs as unrealistic and misfitted for the recovery process of newly disabled individuals. She refers to the concept of “recovery” to a “process, a way of life, an attitude, and a way of approaching the day’s challenges,” and the recovery process is not perfectly linear (p. 50). Deegan (1991) further stresses an active role of these PWDs themselves in a process of recovery,

the process that is accentuated with discovery of inability by, paradoxically, accepting their inability.

Coping Strategies

Another line of adjustment research looks at the relationship between coping strategies of individuals with disabilities and their adjustment degree. Hamburg and his colleagues (1974) stress the need of studying coping strategies in order to assist people in distress. A transformation is needed mainly in order to bolster one's positive self-image in a crisis situation. Similarly, Adams and Lindemann (1974) discuss how the maintenance and support of self-image are crucial to one's adaptation to disability. On the contrary, Hanson et al (1993) find no significant correlation between coping strategies and the adjustment degree of persons with SCI.

Personality Theories

The notion of "locus of control" plays a central role in personality theories. Some studies identify a positive relationship between one's adjustment degree and the degree of internal locus of control that refers to one's belief that s/he has a high degree of personal control over events (Rotter, 1966). According to personality theories, the higher the locus of control one has, the better adjustment to the disability s/he can make. Personality theorists caution, nevertheless, that the internal locus of control is not the same as the actual reality of control, instead, locus of control represents one's *belief or perception* of control over his or her life. Based on the personality theories, therefore, it is possible that a quadriplegic person with a high locus of control may adjust better than a paraplegic person with a low sense of control does. Correspondingly, a study done by

Oliver et al. (1988) demonstrates that there is no significant correlation found between the participants' life satisfaction and their injured lesion levels.

Personality theories are heuristic in asserting that one's belief about life control, rather than actual physical state, may facilitate disability adjustment. At the same time, nevertheless, these theories seem to say that only a PWD is held accountable for his or her adjustment process. In other words, personality theories underestimate external factors influencing his or her adjustment degree, such as family support, people's prejudice or stereotypes toward PWDs and/or insufficient services by the institutions. Personality theories, thus, tend to view disability as a personal issue, rather than a social issue.

Social Model of Disability

The sociological disability model is a result of criticism from previous disability theories or models that put the burden or responsibility of adjustment only on PWDs. The majority of previous disability theories or models assume that the disability experiences were nothing but a personal tragedy (Oliver et al., 1988). A typical medical framework is Parson's work (1951). In his "illness model," an individual with a disability is a passive actor to be assigned a role of being sick, and as a result, s/he starts behaving as such. The "sick" model focuses on modifying the PWDs, and similar to personality theories, the medical model of disability fails to mention the problems hampering PWDs' adjustment.

The sociological model, on the contrary to the medical model, originated under the assumption that problems associated with the disabilities are not mainly from people who have disabilities, but from stereotypes held by others, inaccessible architectural

barriers, and other external factors, such as vocational and educational resources (Oliver, 1996). Social theorists, some of whom have disabilities themselves, are radically against the medical model with its mission of “curing” and “fixing” PWDs in order to make them “normal.” Social modelists also pay attention to the impact of the SCI incident on other family members’ psychology. For example, Cleaveland (1980) investigates family members’ adjustment to their kin’s traumatic disabilities. According to the study, many facets of the family (e.g., task organization, affection structure, communication structure, power structure, and/or family unity) also went through drastic changes after a sudden on-set SCI occurrence of their family members. Conversely, Rintala et al (1996) assert that the degree of disability adjustment is greatly influenced by the quality of family relationships of PWDs. Oliver (1996), who is a major social modelist, summarizes how “the process of social adjustment arises both from the interactions between the individual and his physical and social environment and, more importantly, from the meanings that these interactions have both on the individual and his family” (p. 235).

Karen Yoshida’s Pendular Reconstruction of Self and Identity

While DeLoach and Greer’s model represents an uni-directional, linear, and progressive model, Yoshida’s pendulum model proposes a non-linear transformation of identity (Yoshida, 1993). This model views the reconstruction of self and identity after SCI as a pendular-like movement. The transformation process swings back and forth between five predominant identity views: the former self, the supernormal identity, the disabled identity as total self, the disabled identity as an aspect of the total self, and the middle self. Furthermore, these identity views are influenced, but not determined, by

five experiences: loss, sustainment, integration, continuity, and development of the self. Yoshida's model (1993) is heuristic for its acceptance of "the idea of dual directionality" (p. 221) and, unlike other theories, her model separates the self transformation (outcomes) and experiences (process). The pendular model seems to be able to solve the dilemma of "I'm no different from what I was before, but I am different." Yoshida cautions that the linkage between experiences and the self reconstruction is not causal.

"Adaptation" and "Adjustment"

For the current research, a term, "adjustment," is used over others, such as "adaptation" or "assimilation." There are three reasons for this choice. One of the major adaptation theories is the one by Gudykunst and Kim (1992, 1997). Gudykunst and Kim (1992, 1997, Kim, 1995) call the theory "cross-cultural adaptation." The theory explains how a person (for example, an immigrant or sojourner) changes *cross-culturally* by leaving his or her own culture and by entering a new environment, and it has been used extensively for research of the geographical relocation of people (Gudykunst & Kim 1997). Although Murphy (1990) likens a newly disabled to a person who is surrounded by unfamiliar situations, it is not conclusive to the researcher if a transformation from being an able-bodied to a person with a disability is a *cross-cultural* experience. This is the first reason that the researcher avoids using the word, "adaptation," which has a close association to cross-cultural adaptation in communication studies.

Second, the conceptualization of “the host culture⁷”, into which the newcomer steps, poses some problems for the case of PWDs. In the adaptation theory, the host society is a new, unfamiliar, and dominant environment (Gudykunst & Kim, 1997; Kim, 1995). According to Kim (1995), the newcomer (or “the stranger,” as Gudykunst and Kim call) goes through the experiences of “beginning their adaptation processes as ‘cultural outsiders’ to and of moving in the direction of cultural ‘insiders’ over time (p. 175). Additionally, the host society is a dominant one partially due to the population difference between the numbers of the natives and of the newcomer’s folks in the host culture (Gudykunst and Kim, 1997). Given the power of the host culture, Gudykunst and Kim (1997) further explain that “[t]o the extent the dominant power of the host culture controls the daily survival and functioning of strangers, it presents a coercive pressure on them to adapt” (p. 338). While their theory presupposes the host community’s dominance and unfamiliarity to the newcomer, a case of a newly disabled person seems to portray more complicated scenarios than the stranger in the cross-cultural adaptation theory. The stranger and the newly disabled person both start with a majority status prior to the transformation process: the stranger is in the original, “home” environment, and the newly disabled person used to be the able-bodied with a majority status in society. When the stranger enters a new society, s/he becomes a minority in the host culture. The same status change occurs to the newly disabled person after acquiring a disability. However, unlike the stranger’s case, what is “the host society,” is quite

⁷ Besides “the host culture,” Gudykunst and Kim (1997) also use such synonymous terms as “host society” and “the host environment;” therefore, they are used interchangeably in this section.

ambiguous for the person with a disability. According to Kim (1995), there are some characteristics of “the host environment” mentioned in the boundary conditions of the theory.

- (a) the strangers must have had a primary socialization in one culture (or subculture) and have moved into a different unfamiliar culture (or subculture);
- (b) the strangers are at least minimally dependent on the host environment for meeting their personal and social needs; and (c) the strangers are engaged in continuous, firsthand communication experiences with that environment (p. 175).

Based on the descriptions above, “the host environment” is the one that is unfamiliar to the person, that s/he relies on to some degree, and with that the person has continuous and firsthand communications. So, is it the able-bodied’s or PWDs’ society to “host” a newly disabled person? According to the adaptation theory by Gudykunst & Kim (1997) and Kim (1995), “the host society” can be either community, or both. It can be the able-bodied’s society because it outnumbers PWDs and is dominant. Also, it is the able-bodied environment which the newly disabled person had a “primary socialization” prior to having a disability. (In fact, his or her most immediate, primary environment, the body, becomes a foreign object to the person at the beginning of disability experiences.) At the same time, the PWDs society too can be “the host environment” for the person because of its “unfamiliarity and newness.” As Murphy (1990) puts it, a group of PWDs is “radically distinct from the general population and exotically different in their accommodation to social life (p. 172). In addition, the newly disabled person often relies on other PWDs for advice or obtaining disability information which is not available in the able-bodied society. From these evidences, both societies can be “the

host environments” for the newly disabled persons to communicate. (There are rare situations where PWDs are completely isolated from the larger society and live in institutions, for example, leprosy patients in the past. However, most PWDs today have contacts with both the able-bodied and PWDs societies.) Furthermore, for the case of PWDs, two transformations often occur simultaneously: socialization with the PWDs environment and *resocialization* to the able-bodied environment. Thus, the adaptation theory by Gudykunst & Kim seems to be inadequate for the case of PWDs due to the ambiguousness in the concept of “the host society” for PWDs and their dual transformations.

Finally, the meaning of “adaptation” used in the adaptation theory is problematic for PWDs, especially when looking at their reentering the able-bodied society. For Gudykunst and Kim (1997), adaptation is a “one-sided change” and is “toward *assimilation*” at the expense of the strangers (p. 338; emphasis in original), and adaptation requires both behavioral and cognitive synchronicity with the natives of the host environment. They further argue that host communication competence “is equivalent to a full membership in the host communication system: this mastery, after all, is one of the key features that distinguish strangers from the host nations” (Gudykunst & Kim, 1997, p. 342). In short, the adaptation theory assumes conformity of the dominated to the dominant. From their perspective, an “adaptation” for most PWDs to the able-bodied environment becomes virtually impossible. No matter what they do or think, they are not the able-bodied. How can a person in a wheelchair wish to adapt or assimilate to the larger society, when that environment assumes “walking?” Wheelchair

users never adapt to the able-bodied society: they cannot climb stairs or use inaccessible bathrooms. Murata (1996) argues,

There are stairs everywhere in the buildings. Conventionally, people think that I should modify my body so that I can climb up stairs to enter the buildings. They operated on my bent legs, put corsets on them, gave me crutches and expected me to climb stairs step by step. But no matter what I do, I can't go up stairs, even one. They expected the impossible of me. Now, I want you to think carefully here... Instead of modifying my body, it is the environment that needs to adapt to my body... For fifty years of my life, I have constantly struggled with the bathroom issue. You don't have to endure this bathroom urge because there are so many restrooms you can use in town; it has nothing to do with your walking. I have to put up with the bathroom issue all the time because there are only a few bathrooms the wheelchair users can use; it too has nothing to do with my mobility impairment (1996, p. 26, p. 173; my translation).

One of the participants for the study was rejected for an admission by a public high school because of his disability. Since he cannot assimilate to the "walking" environment, the adaptation for him must be accepting the rejection and giving up his hope for education. Instead of fixing his disability, nevertheless, he chose changing the environment by "rocking the boat." He called the board of education and threatened them with suing the school. He demanded that the environment change to suit his need.

Kramer (2001) points out the adaptation theory only looks at changes by social agents; therefore, the theory falls short in explaining why social changes occur. Kramer (2001) calls the theory "the Master/Slave dialectic" because "the happiest sojourner is

the one who surrenders most completely and most quickly” (p. 19, p. 20). On the other hand, Kramer (2001) introduces the theory of cultural fusion with a premise that “the synthetic process of fusion is dynamic and characterized by synergy” (p. 29). More specifically, he describes the process:

When a person encounters new information as when a sojourner enters a new cultural environment, there is a process of reading or interpreting that occurs. And volumes have been written on the complexities of interpretations. The text is never finished and the “reading” process of making sense [of] it also never finishes. Both the text and the reader, the host culture and the sojourner are altered by the contact, and furthermore, due to the reversibility and simultaneity of the process, the sojourner and host are both text and reader at once (Kramer, 2001, p. 29).

One’s disability alters not only a PWD himself or herself, but also the host environment, in both physical and psychological dimensions. For the case of having paralyses, houses need to be remodeled for newly disabled people, and also people surrounding them often reorganize themselves and seek alternatives in transportation, human reproduction, and roles in relationships. Kramer (2001) calls a boundary between the outside world and a social agent a “skin.” This “skin” is similar to a divider in a room; while the room space is split by the divider (or “skin”), the divider is always touching both spaces. As the divider moves to right, the left space expands, and vice versa: both spaces are affected by the divider, the skin. The cultural fusion theory presupposes both the environmental alternations, and transformations from the sojourners’ side (it is an “adjustment” in the

fusion theory). This is the last reason that the researcher uses “adjustment” in the present study, rather than “adaptation,” and that she uses the cultural fusion theory.

“Embodiment” and “Modern object”: Phenomenology and body

From an unknown history in the past, finding a cure for physical malconditions such as illness, pain, injury, or disability has been an obsession of humans. Various medical metaphysics in history viewed the human body as profoundly different (Zaner, 1992). However, since Cartesian dualism was introduced in the 17th century, the body has been treated as a composition of corps and the “dead body” (Leder, 1992, p. 21). The soul has departed from its body. This is also the beginnings of object/subject dualities.

After three centuries have passed, there is a medical paradigm based on the Cartesian dualism which is still predominant today. The body is artificially divided into manageable pieces in order to compensate for ignorance and inability to study a phenomenon as a whole. The body became, what Foucault (1979) refers to, “Man-the-Machine” - - a lifeless and dividable machine (p. 136). In this paradigm, unobservable human phenomena such as pain, suffering, or anxiety, which are inseparable from the body, are a secondary concern (Leder, 1992). Likewise, this medical/scientific fascination has resulted in disability as a prime focus and a person who possesses it as a secondary interest. Traditionally, research pertaining to disability has been done primarily in the para-medicine field, including rehabilitation or special education, with a mission of “cure.” Disability has been studied as a medical entity or category to be “fixed,” which is called the medical model of disability, and, above all, persons with disability are perceived as having “something wrong.” Under the medical model of

disability (or “medicalization” of disability, as Manning and Oliver (1985) puts it), a person with disability is viewed predominantly as a patient, rather than a fellow-human. Consequently, these individuals with disabilities are expected and encouraged by others not to become satisfied with their being until they become “normal,” and their physical conditions are devalued - - “damaged goods,” as Phillips (1984) asserts in her study.

One’s experiences are devalued today because they are “subjective.” This lower status of “subjectivity” to “objectivity” is one of the direct consequences of the Cartesian dualism.

The body for him [Rene Descartes] was a machine, an obvious cultural prejudice drawn from his fascination with the mechanics of his day, a prejudice that would expand into the industrial world... As human culture strives to become more and more objective, a process of dimensional accrual/dissociation occurs.. the fruition of modernity as extreme perspectivism that involves the irony of ego-hypertrophy.. manifested as extreme individualism proclaiming objective status for itself... In the modern world, both the body and communication are means to ulterior ends (Kramer, in press).

Modernity starts with the hatred with the subjectivity for its ambiguity and unpredictableness. However, in order to gain knowledge of others, people have to take others’ perspectives into account: their being-in-the-world. The being is situated in the body due to the fact that the body is the most immediate, intimate environment. For example, people in wheelchairs view the world from the angle of waist-high, which is significantly different of standing persons’ views (Hockenberry, 1995; Mairs, 1996; Straus, 1973). Likewise, people with visual impairments live in the auditory world, and

deaf people belong to the visual-oriented world. Thus, bodily differences create and/or limit our perceptions toward the world, which Husserl explored in “kinaesthesia.” For Husserl, the body and mind are not separated, but one to constitute “incarnate consciousness” (or “incarnation” for Gabriel Marcel and Merleau-Ponty).

Within the field of phenomenology, the issue of the body is taken quite seriously because the body situates in a matrix of specific time and space, and it plays a role as a medium for experiencing and perceiving. The study on body with a phenomenological approach is known as “somatics,” which was originated in the late 19th century in Europe and the U.S. (Behnke, 1997a). The field of somatics finds its root in diverse areas, including Husserl’s research on “kinaesthesia” in 1907 and in Isadora Duncan’s modern dance movement. From the beginning, in the field of somatics, bodies are not only perceived as “socially shaped” but also “our own history in particular has been geared in many ways toward molding ‘docile bodies’” (Behnke, 1997a, p. 666). The somatic notion of “critique of corporeal experience” contrasts with the “objectified” body which detaches with our own bodily experiences and with the “ideal” body which is synonymous to the “normal” body today (Paci, 1963; cited in Behnke, 1997b). Another useful notion to investigate in regard to the body is “prominence by absence” which is an extension of the “free phantasy variation” method. This “prominence by absence” technique seems to be especially beneficial when studying people with disabilities since this method makes it explicit that “disruption in motor functioning reveal that familiar actions usually flow off as an integrated whole in a ‘kinetic melody’” (Behnke, 1997a, p. 69). In other words, “prominence by absence” calls for awareness by considering a case when the “habitualized” body is in disturbance.

Another phenomenological paradigm in relation to terms of the body is “embodiment.” Merleau-Ponty, whose background is a phenomenological perspective, is one of the prominent scholars in the embodiment paradigm. For Merleau-Ponty (1996), the body represents a “grouping of lived-through meanings which moves towards its equilibrium” (p. 153) which cannot be fragmentized into the soul and the body. Embodiment means, for Merleau-Ponty, interconnectedness, and the “extension of the bodily synthesis” with a rise of consciousness is a process of embodiment (Merleau-Ponty, 1996, p. 152). Familiarizing with assisting objects, such as wheelchairs and canes and extending them as a part of the body are also the embodiment process. Adjustment to one’s disability requires embodiment, or rearranging his or her *lebenswelt* (life-world) according to a new circumstance of disability. A disability experience provides a person with a disability a different angle to view the world, including the self. Interestingly, some interviews with newly disabled people revealed that they discovered “this world (or society) of the disabled” after returning home. The theory of embodiment can explain this transformation of the outside world perceived by PWDs: the world changes as one changes. People’s individual, yet collective experiences cannot be explained without their “subjective” accounts situated in their bodies.

Research Questions

This research aims to detail what it means to be “disabled” in today’s Japan, and how the participants took the journey of disability adjustment. The study also attempts to uncover the wealth of information of what is happening in mundane interactions of people with disabilities, what method(s) these people use to present themselves, and how

they adjust to the disability. Based on the aforementioned literature, research questions below emerge.

- 1) How does acquiring a disability change one's communication/relationships with others (e.g., friends, family members, or strangers)?
- 2) Do people with disabilities have communication styles or norms that are different from the non-disabled's?
- 3) How does acquiring a disability alter a perception of the self?
- 4) What are the experiences of people after acquiring disabilities?

CHAPTER III

RESEARCH METHODOLOGY

Participants

The researcher recruited people with physical disabilities to study⁸. Moreover, most of them had “visible” disabilities of the limbs, which were “unhidable” to others. Many of these people used their wheelchairs all the time, while others used the wheelchairs only sometimes. Still others used canes or crutches. Many of the participants had paralysis and others had amputations. Despite these differences among the participants, all participants for the present study were PWDs who were once non-disabled and have become people with disabilities after their adolescence. So, they all knew “what it is like to be non-disabled and a person with a disability.” All participants

⁸ Therefore, none of them had a sensory disability (e.g., visual or hearing impairment), nor cognitive disability.

were informed of the purpose of the study in advance by the researcher, and they were free to stop their participation at anytime they wished.

Data collection

The data for the present research consists of several sources. The first kind of data is gathered by a participant observation and observation. These two terms are intended here to distinguish a participant observation method from an observation method. The researcher has thought in the past that while she gains information interacting with the participants, she also missed other rich information because of these same interactions. The researcher has frequently failed to take notes in the middle of noteworthy communication transactions. This omission was since she became a “friend” or “fellow-person,” not a researcher, to her participants, and taking notes during a conversation would make her look distanced. Or, the researcher had to render her attention to immediate conversation in which she was engaged while something worth observing was taking place outside that conversation circle. It is against social rules to leave those people without a legitimate excuse to do so. Based upon those valuable lessons from the past, thus, the researcher deliberately differentiates, at least conceptually, among these two data gathering methods. In sum, the researcher gathers the data in three ways: while interacting with the participants, observing people without interactions, and interviewing. This choice of research methodologies was selected based upon the nature of the study that is highly contextualized and explanatory.

In order to conduct ethnography, this researcher routinely visited several observation spots over the years, such as a local rehabilitation hospital, a recreation center for PWDs, and a gym where individuals with disabilities play table-tennis.

Besides these routine places, she visited a seminar hosted by the Japanese disability institute in Tokyo, a karaoke gathering, and spontaneous meetings with the participants. In addition to observing the people, the researcher communicated, interacted, and played tennis or table tennis with the participants. The researcher took field notes based on her observations, and tape-recorded conversations. The main ethnographic data was collected during the summer of 2000. Since the researcher visited them three times, her appearance was not intrusive to their activities. She also sought the ethnographic data outside of the rehabilitation hospital and recreation center to see how they lived and communicated once they left these disabled-oriented contexts.

During the observations, she looked for behavioral patterns of people. She started witnessing repeated communication themes among the participants as observations continued. Some of those patterns were expected from the literature or her experiences in the past, but others were not. Some incidents were insignificant at first, but later, they were intertwined with other occurrences. Besides the field notes, the researcher took the reminiscent notes, in which the researcher recalled her free thoughts while being in the field. The notes were useful to deepen ideas and find themes among seemingly separate phenomena.

The second source for the study was the interview data. She interviewed thirty individuals with disabilities, and some of them were interviewed more than once over the years. The researcher interviewed the participants with a set of questions. The researcher asked the same set of questions with small variations to every person, such as asking questions regarding sports to wheelchair basketball/tennis players. These questions were generated and refined from the preliminary conversations with and

observations of a small number of PWDs in 1998. In the summer of 1999, she returned to Japan to conduct the main interviews with thirty people with disabilities. This two-step interview schedule was taken for several reasons. First, this researcher lived in the U.S. and therefore, had an opportunity to collect the data only during summer breaks. Because arranging and interviewing thirty people took substantial time, this part had to be done separately from the ethnography. Second and most importantly, the researcher intended to ask the participants follow-up questions for verification and clarification of their comments. The researcher followed phenomenological analysis steps developed by Colaizzi (1978) that include returning to the participants with transcriptions which gives the participants an opportunity to reflect what they really meant in the main interviews. Therefore, in order to ask follow-up questions, the main interviews had to be done much earlier because transcription of the tapes took a painstakingly long time.

In sum, the investigator used the data generated by interviews, recorded conversations, participant observation, and observation. Although the investigator arbitrarily separated these data sets, these were not independent, but intertwined and influenced each other. It was not so uncommon that observing the participants resulted in generating interview questions, or conversely, interviewing people steered the researchers to “what” or “where” to observe in a midst of free-flowing communication phenomenon.

Finally, this researcher’s legitimacy of conducting the present research is briefly mentioned hereafter. As a person with a disability herself, she familiarized herself with communication patterns with/of people with disabilities in Japan. For example, she understood disability “jargon” which people with paralysis used and communication

scripts shared by these individuals. Also, she was capable of picking up non-verbal “cues” alluding to their physical/emotional states. Moreover, because of her “visibility” as a PWDs, she could immerse herself into observation places easily (e.g., rehabilitation hospital). At the same time, she was aware of a possible downside of being a member of the disabled community; that is, she was so familiar with communication of/with PWDs that she might not be able to notice other communication characteristics which were evident for “outsiders.” In addition, it was true that her atypicalities, such as being a doctoral candidate or U.S. educated, might have influenced communication with the participants. In fact, in the past, she has experienced that communication climate changed as soon as she introduced herself as a Ph.D. student in the U.S. studying communication at the beginning of conversations. This was due to the fact that in Japan, a population of people with doctoral degrees was much smaller than in the U.S., not to mention with disabilities. Therefore, people in Japan seemed to be uncertain about what to expect and how to interact with a Ph.D. student in a wheelchair. From these experiences, she delayed disclosure of her credentials until establishing “normal” communication with people.

Settings for the Research

Finally, brief descriptions of observation settings need to be mentioned. There were two primary observation “spots” where this investigator engaged in data gathering. These places were a local rehabilitation hospital in Japan and a recreational center primarily for people with disabilities.

The Japanese rehabilitation hospital was built more than a decade ago as the first and only rehabilitation-specialized hospital in C-prefecture. The hospital building was

placed on the top of the hill, and a community surrounded the hospital. There were special schools for students with disabilities, from an elementary school to high school, and a boarding school for those students whose homes were too far to commute, which were both connected to the hospital. Besides these facilities, there is an apartment complex for nurses which was within walking distance from the hospital. Also, across the street, there is a children's hospital.

Compared to other places outside the hospital, the hospital stayed amazingly the same inside, and the environment was almost self-contained as a community. Inside the hospital, there were a little grocery store, a beauty/barber shop, a restaurant, occupational therapy rooms, and a gym. The researcher still saw familiar faces there of doctors, nurses, cooks, waitresses, therapists, nurse assistants, beauticians, and even janitors since she left the hospital as a patient more than a decade ago. Furthermore, there were small "clubs" inside the hospital where the same people met each other over a long period of time. One of them was a tennis "club" at which some ex-patients, and sometimes current patients, gathered at the gym to play tennis once a week. Also, since there was a special school connected to the hospital, other kinds of people (students, teachers, parents, and housemothers/fathers from a boardinghouse) frequently visited the hospital for dining, shopping, haircutting, or meeting people. To summarize, this sphere created a quite unique environment: the place was open for everyone as a hospital while keeping a "family-like" atmosphere. The hospital is built on the top of the hill. This hill's slope is so steep that it is oftentimes used as a "hard-core" exercise course for patients in wheelchairs. Additionally, this environment is quite self-sustaining, many patients at the hospital cannot or do not have to leave the place. However, the danger is

that these people may be cut off from the rest of Japanese society as they stay at the hospital.

Let me briefly state about access to the rehabilitation hospital (other places were “open” for public). First, the researcher contacted a local rehabilitation center to obtain permission to observe. Often, people with disabilities visited local rehabilitation centers, even after being discharged, to continue their rehabilitation exercises or to see “hospital buddies.” Whenever the researcher went to the rehabilitation hospital where she used to stay, she always encountered familiar faces and witnessed other PWDs who were “hanging out” without specific purposes at the hospital. She even heard a hospital joke that people would worry if a hospital friend has become sick when the person did not show up at the hospital. These people seemed to come to the hospital not only to see the doctors, but also to make friends or exchange information with others - - to communicate. A therapist at the hospital whom the researcher has known for more than ten years told her that many of her ex-patients swing by once in a while to the hospital. The therapist remembers that one of these persons, who now had returned to society after rehabilitation and works at a company, showed up at the gym “out of blue” and shot basketball for a while without a word. Just before leaving, he said to her that he was having some problems at the company, but he felt “much better” after shooting basketball at the gym in the hospital. This local rehabilitation hospital was, thus, not just a medical facility, but a multi-purpose place and a “buffer zone” for many people with disabilities, which will be discussed more fully in the next chapter. For these reasons, this place was a suitable environment to observe PWDs or recruit participants for the study. This investigator especially spent her time at a gym, waiting rooms, an

occupational therapy room, and a physical therapy room in the hospital where groups of PWDs engage in some activities. At the stage of recruiting participants, the researcher observed in these settings, “hung out” with people there in order to make her existence as least intrusive as possible.

While this researcher has known the rehabilitation hospital for more than a decade as a former-patient, the recreation center was a fairly new environment for her. The facility was built in a suburb of C-city, and the place had an indoor gym, office, accessible bathrooms, and Braille for persons with visual impairments. This facility was quite similar to what a senior recreation center looks like in the U.S. Various groups of people or clubs, from an English conversation club to wheelchair basketball team, reserved the place for use in advance. Although persons with disabilities were given the first priority to reserve the time blocks for free, the non-disabled also could use the place for a small fee. Therefore, the place was one of few places the researcher knew where both the non-disabled and individuals with disabilities were seen together on daily basis.

Despite the difference in the investigator’s familiarity with the hospital and the recreation center, there were also profound similarities. First, PWDs became majorities in these places. For example, people with disabilities at the hospital received less stares from others (except from the non-disabled newcomers who had never seen so many “disabled people” at once), because they were no “different” from the rest of the people there. In addition, both the rehabilitation hospital and recreation center were fully accessible places, and they were designed to be disability-oriented, which is rare in the outside world.

Second, due to this characteristic, the settings of these facilities created a unique communication atmosphere. This investigator noticed that the conversations taking place, especially at the hospital, were quite different from other types of conversations. After the initial greetings, people immediately started disclosing sensitive issues in “chitchat” conversations, such as bladder (or bowel) control or the levels of the injured persons’ lesions, which could be considered inappropriate to discuss elsewhere.

Data Analyses

This investigator used multiple approaches for the data analysis. While a phenomenological method was used mainly for the interview data, an ethnographic method was used mainly for the participant observation and the observation data. She intended to provide rich contextualized information of studied communication phenomena by combining these approaches. Hereafter brief backgrounds of these approaches are mentioned.

Ethnography

In the past, although often people did (or could) not articulate the answers during the interviews (they sometimes said “I don’t know” or “I have no specific opinion”), this researcher observed that these participants sometimes offered the information during casual conversations, which was related to the interview questions. Needless to say, an interview atmosphere can be different from that of casual conversation. Thus, having both interview data and ethnographic data enriches the information for the study and checks the reliability/validity. According to Van Maanen (1988), an ethnographic paradigm overarches many other studies such as ethnomethodology, semiotics, symbolic interactionism, or conversation analysis. They all share a premise of the “derivation of

generalization through inductive and inferential logic,” which is a rule perspective (Van Maanen, 1988, p. 130). In addition, ethnography is a unifying point of anthropology and sociology (Van Maanen, 1988). Ethnographers aim for describing a particular culture, learning from people, showing “alternative realities” of the “Other,” and unfold systems of meanings (Spradley, 1973, p. 13). Ethnographic work is often done as a prerequisite phase for theory/model building because its work can provide rich contexts of a target culture, and in return, these descriptions help to comprehend the language of social life (Hymes, 1974). It should be recalled, however, that ethnography is sensitive to a number of factors, such as personalities (and social/cultural memberships) of ethnographers, their power/political tendency, a different kind (or degree) in rapport with informants and/or access to the settings (Barreman, 1962; Golde, 1970; Warren and Rasmussen, 1977; cited in Van Maanen, 1988). Furthermore, as Van Maanen (1988) contends, the ethnographers serve as interpreters (or translators) of a studied culture to the readers: thus, interpretation is always manifested in ethnography. Equally important, the language plays a crucial role for the ethnographers (Hymes, 1974; Spradley, 1973; Van Maanen, 1988; Wieder & Pratt, 1990a; Wieder & Pratt, 1990b). Or more accurately to say, an ethnographic study presumes language exchanges among people because “the properties of conversation is a process of social interaction” (Moerman, 1988, p. 12).

Phenomenology

The present study utilized the phenomenological method to analyze mainly the interview data. The inquiry of phenomenology was first introduced by Husserl, who was

trained as a mathematician, in his book, *Logical Investigation*⁹. Although Husserl established this science of essence at the beginning of the twentieth century, basic phenomenological ideas have a long history traced back to the classic philosophers Socrates, Plato, and Aristotle (Stewart & Mickunas, 1990). Merleau-Ponty (1996) summarizes phenomenology as:

Phenomenology is the study of essences; and according to it, all problems amount to finding definitions of essences:... But phenomenology is also a philosophy which puts essences back into existence, and does not expect to arrive at an understanding of man and the world from any starting point other than that of their “facticity.”... It is the search for a philosophy which shall be a ‘rigorous science,’ but it also offers an account of space, time and the world as we ‘live’ them. It tries to give a direct description of our experience as it is, without taking account of its psychological origin and the causal explanations... (Merleau-Ponty, 1996, p. vii).

Husserl called phenomenology the “science of science” since it alone investigates that which “all other sciences simply take for granted (or ignore), the very essence of their own objects” (Husserl, 1931, p. 23). Phenomenological method is widely employed not only in various social science areas, but also in such para-medical fields as nursing (Carpenter, 1995). A phenomenologist is “interested neither in affirming nor in denying anything, but in exploring, or... in *making explicit* what has hitherto been *implicit*”

⁹ According to Stewart and Mickunas (1990), however, Hegel started to use the term, phenomenology, to refer to “all reality *is* mind” (p. 16; emphasis in original), which is quite different from Husserl’s definition.

(Zaner, 1970, p. 50; emphases in original). Phenomenology can reveal rules governing social phenomena.

The present research followed a four-step phenomenological process. First, a phenomenological method starts with “bracketing” which is a suspension of one’s metaphysics, prejudices, and taken-for-granted beliefs (they are called “natural attitudes” in phenomenology). The first step is critical for seeing “the things themselves” (or “essences”). The next step is a description of phenomena. The third step is called “phenomenological reduction” which renders “the very object of reflection precisely in order to become conscious of it” (Madison, 1981, p. 147). Merleau-Ponty (1996) argues that this reduction renders “[t]ranscendental subjectivity” (p.361). This reductioning step reminds the researcher of boiling water in order to extract salt crystallization. When all water including natural attitudes evaporates, “the very object,” crystallization, remains. Essences are things that refer not only to empirical objects, but anything perceived by a person - - of anything which he or she is conscious. Therefore, it is worth stressing that “the things” can be, for example, memories, lies, numbers, sensations, logic, and so forth. Husserl puts the issue of consciousness at the center of doing science. For Husserl, a phenomenon and consciousness are synonymous; therefore, studying a phenomenon is nothing but studying consciousness itself. Finally, describing essential dualities of meanings which overarch the participants’ disability experiences are rendered in the last chapter.

Advantages of the present research

The researcher was not interested so much how the non-disabled viewed and communicated with PWDs. Instead, what the researcher was interested in was

documenting how the participants with disabilities communicated with others (in the ethnography chapter), and revealing how PWDs themselves perceived the world, society, or their environments after acquiring disabilities (in the interview chapter). However, asking these questions demanded that the researcher face a tough challenge. Needless to say, either talking about one's disability or becoming a person with a disability was highly personal; therefore, no one dared to disclose this kind of information to a stranger on a genuine level. An ethnographic method is, thus, the most appropriate for the present research because this methodology emphasizes establishing rapport with the participants. In addition, ethnographic technique enables the researcher to observe the reality in which PWDs belong most intimately.

Conducting both ethnographic study and interviews indeed is time-consuming. Moreover, the researcher has been in contact with a group of newly disabled individuals since 1998. Despite these complexities, however, the researcher has experienced several times that this painstaking process paid off. One example is when she was visiting a wheelchair basketball team, the "Eagles." The "Eagles" is one of the most prestigious wheelchair basketball teams in Japan, and four players from the team were chosen for 2000 Paralympics. During the summer of 2000, people from local and national newspapers frequently came to the gym for the Paralympics stories. Due to this publicity, the team members have oftentimes been asked to fill out disability-related questionnaires by researchers or college students because, besides their visibility to the public, collecting samples of people with disabilities is fairly difficult.

One day, this researcher came to the local recreational place to watch their practice. It was still too early and there were only a few players. Then, a male who

worked at the center brought a stack of questionnaires to Mr. K, who was one of the chosen Paralympics players, and asked the team to answer these questions regarding accessibility issues in C-prefecture. Mr. K accepted the offer and started filling out the first questionnaire. Then, the researcher saw that Mr. K was writing the second and the third ones for “his teammates” with “little deviations” on each. Even the researcher filled out two questionnaires for them¹⁰. These players were used to and tired of being subjects for research, even though they admitted that they played a role of spokespersons, willingly or unwillingly, for other “silent” individuals with disabilities. Nevertheless, they would consider pencil-and-paper research as “just one of those disability studies;” therefore, it was not appropriate for them. The researcher was assured that her research methods, ethnography and interviews, both of which required face-to-face communication, were suitable with these individuals.

In addition, the longitudinal plan of the present research has given some advantages to the researcher. To observe and interview the participants, the researcher visited them once in a year, usually in summer. During the course of research, she has witnessed that sometimes the participants, especially some newly disabled individuals, changed over the years. Some individuals needed more time to trust the researcher than other participants did, and some participants were more open to her than the previous year. Also, since she only met the participants once a year, adjustment paths of several newly disabled participants became evident, which might be too subtle for others who

¹⁰ As a researcher, answering these questionnaires posed an ethical dilemma. However, at the same time, she was flattered by the offer because Mr. K asked her to be a part of his ingroup. Therefore, she prioritized her position as an accomplice, rather than a researcher, in this context.

are close to the participants to distinguish. These gradual changes along the timeline can be tracked only by revisiting the participants. Whenever she revisited the participants, she always asked “is there anything that has changed since my last visit?” In response, although they all said, “nothing particularly,” the researcher sometimes could notice one or two differences in them. In the next chapters, this researcher will mention adjustment paths of two newly disabled participants, Haru and Masa, which became apparent through ethnography and interview.

CHAPTER IV

Ethnography

The patients at the rehabilitation hospital were provided different kinds of therapies, such as physical therapy (PT), occupational therapy (OT), or Multiple System Therapy (MST), based on their doctors’ recommendations and their preferences. Since I¹¹ knew the MST therapist, Rie, I mainly observed the MST activities at the gym. In the gym, a group of PWDs was playing sports, exercising, or enjoying conversations with other PWDs. Some were inpatients while others were outpatients who came to the hospital to have the therapy. Unlike other therapies at the hospital, the patients often have group activities during MST. The MST therapist, Rie, assigned patients to groups based on mobility, age and/or personality. For example, the patients at the Monday group were mainly PWDs with paraplegia while quadriplegic patients gathered on Fridays. In this way, the new patients could meet others with similar concerns. In

¹¹ It is more common to use “I” than “the researcher” in ethnography. Therefore, “I” will be used in this chapter.

addition, since family members of the patients usually came to the hospital and waited during the MST sessions, they exchanged valuable information ranging from welfare benefits to tips for bowel control. These kinds of information were hard to obtain outside the hospital. Some groups developed an esprit de corps from MST, and they spent time together outside of the hospital. The scenes at MST were quite similar to the ones seen in ethnic communities, such as, China Town or Little Tokyo, where minorities gather to exchange and pool information that only circulates within the community. Rie knew that MST was not only for mere physical training, but also a “gateway” for disability adjustment and returning to an “outside society;” therefore, she accepted some patients with the most severe disabilities, so severe that they could not do any training.

An adjustment path: A Haru’s case

Among the participants with disabilities at the rehabilitation hospital, Haru has changed most since 1998. I interviewed him twice in Japan, and have contacted him on the Internet from time to time since the first meeting. When I met him in 1998 at the rehabilitation hospital, Haru had had his disability less than a year. A traffic accident in the previous year paralyzed both his hands and legs. He was a college student then in his early twenties who used to enjoy mountain hiking. Because of the accident, he took a leave of absence from his university and moved back to his hometown for intensive rehabilitation training.

In 1998, he was a thin and pale-looking person who was struggling to manage his “new” body. I heard that he was still physically and emotionally unstable; thus, Rie was apprehensive about interviewing him. According to Rie, Haru sometimes took his anger out on parents or the nurses, and refused to see his friends or go outside the house, even

to the porch. The only place he would not mind coming in 1998 was to the rehabilitation hospital. Haru was not, however, an exceptional case among people with disabilities in Japan. After acquiring a disability, people suddenly realize that now they are in a familiar, but different, environment. Oftentimes persons can no longer go to favorite places because of the transport constraints and/or physical inaccessibility of the buildings. Friendships from the pre-accident time tend to change, and PWDs often become apprehensive of staring strangers. As a result of these changes, newly disabled persons often find themselves being “stuck” at home. These social and interpersonal changes will be discussed further in the next chapter.

A rehabilitation hospital is usually the most accessible place in a community. There, the newly disabled persons start meeting people in similar physical conditions, and this situation helps the person to adjust to his or her new conditions. When Haru was exercising in the gym, his parents were also there with other family members and watched him. Rie, the therapist, commented that Haru’s parents were “too protective.” In fact, his parents were “information-hungry” for Haru. When I asked for permission to interview him through Rie, I heard later from Rie that, in return, the parents asked many questions about me. This was because the members of his group were much older than he was, and both Haru and I had quadriplegia. (This information-seeking strategy by the participants will be discussed later in this chapter.) Rie also told me that Haru sometimes fainted due to hypertension in the middle of exercises, which is not uncommon for the newly disabled with spinal cord injuries. Although Rie was concerned about him being interviewed by me at the beginning, Haru accepted my request. When I interviewed Haru in 1998, he seemed to be calm, but was not yet fully

cognizant of the full implications of his impairment.

I revisited him in 1999. He was in a rehabilitation/vocational school in a different prefecture attempting as much independence as possible. While staying in a boarding place, PWDs gradually learn tasks ranging from the least difficult to the most challenging. According to Haru, these tasks were anything from “transferring from the wheelchair to the bed, using the toilet, and bathing.” He met many others with disabilities, started smoking, and lost quite a lot of his weight. Although he still did not “get used to being stared at,” he slowly started to see the world again from a different angle - - a much lower, sitting angle. Haru gradually has explored his “new environment,” including his physical capacity, by countless times of trial and error. In 1999, he mentioned a difference from the previous year in that “(in 1998) I had no idea why I collapsed forward out of the blue. But I soon found out I lost stomach muscle to support my posture.” He told me that he “still can’t get a full grasp [of his bodily capacity].” One day at the rehabilitation/vocational school, he went outside by himself¹². Then, he fell from the wheelchair. Since he had no strength to pull himself up to the chair and there was no one around, he had to lay down on the ground for “an hour.” Then, “a man was coming up the hill and I asked for help, but he passed by while looking at me.” He felt “miserable.” Haru’s story, nevertheless, was not an isolated case. I heard similar episodes from other participants, such as falling from the chairs or

¹² From personal experience, the researcher became interested in the participants’ early going-out episodes. These experiences were usually the very first encounter to the outside world that was altered since acquiring the disability. Their stories of the adjustment process to disability will be discussed in the interview chapter.

stumbling¹³. Maneuvering the wheelchairs (or any other assisting device) requires adjusting one's proximity from the standing one to the one of sitting. Just as infants learn walking by stumbling, people who start using a wheelchair learn its proximity by falling (eg., a right angle on a slope). Deegan (1991, p. 50) asserts that the recovery process is "marked by an ever-deepening acceptance of our limitations...in accepting what we cannot do or be, we begin to discover who we can be and what we can do." The participants who commented in this way have adjusted to their disability by giving up what they used to be and were able to do. By letting the pre-injury time go, they started to see a new life with hope. Despite his "embarrassing" incident, Haru kept going out and has adjusted to his new condition. He has passed a test to drive a car with a hand-control. Most of all, Haru, who used to be so fearful of leaving home and of being seen by others, decided to return to his university¹⁴.

"Nanban?": Information-seeking strategy of people with disabilities and adjustment to disability

¹³ Another participant, Mr. Ishi once slipped and fell. He made such a scene and felt embarrassed. However, the most shocking incident the researcher heard was Masa's story. He was a wheelchair basketball player and had paraplegia. A year after he left the hospital, he and his friend visited a wheelchair basketball game for the first time, and then, he fell down from the chair. On the top of the situation, he was having diarrhea. His friend found a big stain on Masa's pants, and told others "not to come." Masa had to borrow his friend's pants and spent the rest of the day for watching the games. Although his story may sound horrifying, the researcher could not help but giggling during the interview because of Masa's animated story-telling. For people with paralysees, toilet control becomes a crucial issue in order to return to society. This theme will be revisited in the next chapter.

¹⁴ Both Haru and his parents wished him to obtain a college degree, so Haru and his mother moved to the K-city and rented a house. However, they had to come back home only after four months largely because they lacked assistance. The mother grew exhausted from non-stop care for her son. Currently (as of 2001), Haru is enrolled in a long-distance university in C-prefecture and he studies at home.

When meeting a new person for the first time, people tend to engage in a series of rituals in order to familiarize him/herself with a stranger. One of those rituals is asking personal questions (Berger, 1979)¹⁵. However, asking questions requires sophistication not to be “too nosy or gossipy.” In addition, in each community or culture, people have assumptions regarding acceptable questions. Due to these conflicting desires of wanting personal information and being polite, people use subtle strategies to elicit target information. For instance, instead of asking directly “how much money do you make?,” people may ask, “in what area of town do you live?” or “what do you do for a living?”. Or, some may ask, “what does your husband/wife do?” to obtain information if the person is married or single. Conversely, an answer to such a simple question, “from which university did you graduate?,” can encode a wealth of personal information while avoiding the interpersonal friction of being too direct. In brief, people are in a constant dilemma between desires for gathering personal information and being socially moderate, and what is acceptable to ask is determined by a culture or community. In this regard, the case of PWDs is not exceptional.

While I was observing PWDs, I have witnessed a number of times how people with disabilities “get to know” each other. One of the common expressions exchanged in an early stage of interaction was “*Nanban?*” This utterance literally means “what’s the number?” in English; however, in this context, it was understood among the participants, especially those with paralyses, to mean, “which spinal cord did you

¹⁵ Research on initial interactions and information gathering is a well-investigated domain in communication studies. For further discussion, see Burger and Calabrese (1975) and works by Gudykunst, whose theory, Anxiety/Uncertainty Management Theory (AUM), is based on uncertainty reduction theory.

injure?” Despite this seemingly simple question, an answer to this query can contain highly personalized information, such as from toilet habits to an (in)ability to have a child.

For example, at the table-tennis club for PWDs, a small group of players gathered and talked about one of the club members after the practice. One of them said, “what’s his number?,” and other participant replied that it was one of the cervical vertebra. Then, another person noted humorously, “oh, so he can make his wife pregnant.” Similarly, whenever I introduced myself to a new person with a disability, I was frequently asked “*nanban*?” The answer to this question gave a rough idea about my physical condition and my life in general.

Also, when PWDs were talking about someone, A, unknown to their peers, they usually mentioned “the number” of A, in addition to his or her name, sex, or hometown. An example of this information-gathering occurred when I was at the recreation center to observe the players of the “Eagles.” Two males with disabilities came to see wheelchair basketball practice¹⁶. They were classmates of Masa, the youngest player on the team and a candidate for the Paralympic 2000. Masa was one of the newly disabled participants for the study, and I interviewed him several times over the years. In 1999, Masa went to a vocational school for PWDs, which I once visited, and he brought his interested classmates to the practice. While Masa’s friend was shooting a ball, Mr. S, who was an experienced player, looked at him shooting and asked Masa, “*nanban*?”.

¹⁶ Because of the publicity of the “Eagles,” it was not uncommon to have observers, both the non-disabled and PWDs, to see their practice.

without even asking his name. Often, the “*nanban*” question initiated such other questions, “can you sweat in summer?”¹⁷ or “how do you control bowel movement?” Or conversely, a person with a disability anticipates these personal questions when the “*nanban*” question is mentioned. Mr. S summarized that after obtaining the “*nanban*” answers, he can foresee if a person “can go up stairs” or “takes more than 10 minutes to finish bathroom.”

Interestingly, some participants reported that as time passed after acquiring the disabilities, they could “guess-timate” fairly well about newcomer’s “number.” This was especially true for PWDs who enjoyed sports and paid close attention to the body. Hiroko, who has been one of the best wheelchair tennis players in Japan commented that

The funny thing is that appraisal ability grows [as time goes by]. [Now I can assess that] “hmm.. this one must be a ‘*chuto*’ (an “acquired disability”) and that person must’ve had a motorcycle accident. Yes, I can see if one’s legs still move, or if she has a complete paralysis. When a newcomer comes to the tennis court,

¹⁷ The nerves in the spinal cord govern any mobility and bodily functions of a person, including sweating. Generally, the higher the lesion of a person’s injuries, the more mobility and bodily impairment s/he has, except the reproductive function for males. (It is known that a paraplegic male has fewer chances of having a child than a quadriplegic male.) When a person injures a higher lesion, such as cervical vertebra, the person loses a function of adjusting one’s bodily temperature, which requires great attention in daily life. Especially in summer, a quadriplegic person can easily have a heat-stroke, even inside a building, because the person has lost the sweating function and the body temperature is never released. I have experienced this heat exhaustion once when I went to see the wheelchair tennis practice. I felt dizzy and my head was pounding, so I had to lay down on a couch for three hours. It was a frightening experience. This functional difference between the paraplegic people and quadriplegic became apparent when watching practices of the “Eagles,” in which most players were the paraplegics, and the “Pirates,” in which all players were the quadriplegics.

we talk about the person, like “she seems to have a complete paralysis ‘cause the legs don’t seem to move at all.”

In comparison, many participants with disabilities rather complained that the non-disabled “think all the disabled using wheelchairs are the same,” which, however, these participants used to think in their pre-disability days. Several participants used to think that “all disabled are the same among themselves.” It is only after becoming a PWD that one starts to notice significances among a group of PWDs. This phenomenon was in accordance with the findings of inter-group research that out-groups are seen as more homogeneous and indifferent than in-groups are (Brewer & Miller, 1984). In other words, in-group members have finer categories about themselves than about out-groups. To summarize, after becoming a PWD, s/he starts gathering information by, for example, meeting other PWDs and/or reading books; and this information increase seems to accelerate in creating finer categories and, most importantly, adjustment to the disability. The “*nanbun*” question initiates this information-seeking process of PWDs.

The “information pooling places for the disabled”

Many participants commented to me that when he or she acquired a disability, a PWD and his or her family sunk into a bottomless uncertainty because of a lack of information about living with a disability, or the only information they had was “too depressing.” Most of them had been informed by the doctors soon after the disabling incident that their bodies had been damaged and that they required the use of the wheelchairs (or other devices, such as prostheses) for the rest of their lives. Therefore, they have known from an early phase what their mobility impairments were, for example, “can’t walk anymore.” Nevertheless, what they had not recognized yet was

what these mobility impairments would “mean” to them. The aforementioned Hiroko remembered those days when

At first, when I was told I would be using a wheelchair [for the rest of my life], I couldn't picture a life using the chair, I mean, you didn't understand what not being able to walk means, did you?... I had been depressed a lot because I used to think I couldn't do a thing by myself. I was clueless about not being able to walk and a life I would have without walking.

Most of the participants had spent some time, usually several weeks, at other hospitals for acute care before coming to the rehabilitation hospital. At the rehabilitation hospital, patients were usually hospitalized for about three months for intensive rehabilitation training, as well as for a smooth transition to disability. During this period of time, they gradually opened their eyes to see the lives of people having disabilities and to live as one of them. At the same time, the staff at the hospital coordinates many things that aim for their adjustment to a “new” life with a disability. For example, unlike other hospitals, the patients at the rehabilitation hospital were strongly recommended, almost forcefully, to go home every weekend. Unlike illnesses or diseases, resting in a bed was usually not the best remedy for adjusting to one's disability, and the inpatients needed to be ready for returning to society. By coming home frequently, a newly disabled individual starts, willingly or unwillingly, to reorganize family and architectural structures at home according to his or her new

condition.¹⁸ At the rehabilitation hospital, the web of information and personal connections were woven. Mr. Su referred the hospital as “a information pooling place for the disabled.”

A major function at the rehabilitation hospital, thus, is not “curing” a disability; rather, it is providing guidance to lead a life with a disability. In order to have a good grasp of the needs of the patients, the staff at the rehabilitation hospital often researches their patients’ personal background, including family structure and communication style among the family members; and based on the information obtained, each rehabilitation menu was customized for a person’s needs, preference, family situation, and/or life-style in general. For example, if a housewife happened to have a disability, she would have an extensive OT therapy in which she learns a different way to cook with a disability, and an OT therapist would usually advise the family to reform the kitchen for her, e.g., lowering the sink. When a newly disabled person was a student, as in the case of Mitsu, rehabilitation focused on returning to school, and s/he sometimes went to school from the rehabilitation hospital. Mitsu, who was one of the participants and became a PWD from a snowboarding accident, went to school in the morning and came back to the hospital in the afternoon for rehabilitation training. Since Mitsu’s disability was paraplegic, his rehabilitation menu aimed at

¹⁸ At the special school boarding house for the students with disabilities that was connected to the hospital, pupils were also sent home every weekend. I stayed at the boarding house during my senior year in high school, and I was once told by one of my teachers that the students had to go home frequently or their families would start, unconsciously, to organize activities, eg., family trips, without taking their child with a disability into account. This episode signifies that a disability adjustment cannot be completed without the involvement of the family members.

maximizing his mobility while using a wheelchair, rather than walking again. At the rehabilitation hospital, he learned how to overcome steps, the “wheeling” technique, and to recover from falling by reaching a hand to the ground. On the other hand, Mr. Ko, whose disability was severe quadriplegia, had OT training in which he learned how to use the computer without using his hands, and an MST therapy where he enjoyed interactions with his friends. For Mr. Ko, it was evident that “rehabilitation training” was geared toward enriching his life and a smooth adjustment to a disability, rather than regaining his physical strength. Overall, rehabilitation required a re-coordination of one’s life in total, which signifies that the magnitude of acquiring a disability goes far beyond mere medical attention.

When Mr. Ko came to the hospital in the morning with his wife, he met his “hospital friends” and chatted in a hall or at the gym while eating or drinking. They discussed various topics from the next outing to the latest assistive devices. Mr. Ko was information-rich. Mr. Ko used to be an engineer and he was interested in the latest disability-related technology. Each year, he and his friends, including Haru, went to the welfare technology convention. He has sent many E-mail messages to me. He wrote these messages with the help of technology without using his hands, and once he reported to me that he started teaching how to use the computer to a young woman who recently acquired a disability. Also, he had purchased a compact bathroom lift that was easily operated by water pressure. The lift was an advanced one compared to the “old” ones which used to require massive construction on the ceiling and cost a fortune. After using the lift for himself, Mr. Ko recommended that Haru, whose house needed some remodeling for his disability, buy the same one.

Since those assistive products for PWDs, such as the wheelchairs, were rarely advertised on television or in magazines, word of mouth among the users was quite powerful. For example, I noticed that sometimes when I visited the observation places, the wheelchairs that people were using were completely different ones from the previous year. This kind of shift was often triggered by the “grapevine” advertising among the PWDs, which was quite different in the past. When I bought my first wheelchair more than a decade ago, I did not have any choice but to buy a wheelchair that was ordered by the doctor. Nowadays, there is a competition among several wheelchair companies for getting customers. Also, many people, especially young individuals with disabilities, consider the wheelchair a part of their fashion items. So, in order to prompt “buzzing” in the disabled community, sometimes wheelchair manufactures asked the “celebs” with disabilities, for example, the Paralympics athletes, to use their products for free.

Characteristics of “the information pooling place for the disabled”

The observed places - - the rehabilitation hospital, the recreation center for PWDs, or the table-tennis club - - are a few places where there is an “information pooling place for the disabled,” as Mr. Su put it. According to Mr. Ko, “the able-bodied even behave differently in the hospital.” Indeed, non-disabled individuals were the minorities at the hospital because they were the ones who had to adjust to the environment. While observing, the non-disabled walked slowly and carefully to avoid disturbing the patients practicing walking with a PT therapist.

On the other hand, people with disabilities at the hospital seemed to behave freely and, sometimes even recklessly. In the restaurant inside the hospital, children who could not stop raising an odd voice did not receive others’ staring. People at the

restaurant were eating and talking as if nothing strange was happening. This situation was quite different in other restaurants where families with children with disabilities easily became the center of attention. Another group of PWDs, “Kamikaze riders,” who were young wheelchair users, raced and competed in their wheelchair techniques with each other. Sometimes I was near the entrance to observe people coming. It was easy to notice persons who came to the rehabilitation hospital for the first time to visit the inpatients. They always had some souvenirs for the patients, and also looked a little overwhelmed by being surrounded by all kinds of “the disabled.” The place was a different, disabled’s society. I saw a visiting family who could not help looking around to see the various kinds of PWDs. Then, a young boy who was wearing braces ran by them in the hall. He was dragging his feet, but he sure was fast. The family looked astonished and turned around to look at the body who just breezed by them. An old lady gasped, “oh my, he can run THAT fast.” Non-disabled visitors seemed to be shocked by stepping into “the world of the disabled,” as some participants referred to it, because their perceptions of a PWD as fragile and weak were shattered.

Also, some participants mentioned that “the time flows differently at the hospital” than in the outside society. Mr. Tsu, who was a wheelchair basketball player, uttered that the time inside the hospital proceeded slowly according to the pace of PWDs. For example, the elevators inside the hospital opened for a longer period of time than others elsewhere because many rehabilitating patients need time to use them. Many non-disabled, however, became impatient with these “slow” hospital elevators, and often they immediately pushed a “close” button. Haru also remembered that time stayed still until “a birthday card sent to the hospital reminded me that a year had passed.” In the

light of disability adjustment, the comments of the participants implied that, conversely, once a newly disabled person is discharged from the hospital, s/he must adjust to the pace of the outside society, or “people there would leave us behind,” as Mr. Tsu said.

E. T. Hall (1966) contends that time is experienced differently in different situations. For example, when having a severe pain, a minute seems to be an eternity. On the other hand, when having a great time, “time flies.” Accordingly, Charmaz (1997) demonstrates that having chronic illness can drastically alter one’s self and flow of time. She contends that for people with disabilities,

...their meanings are imbedded in experiences of time...both meanings of illness and self take root in subjectively experienced duration of time... living with serious illness and disability can catapult people into a separate reality - with its own rules, rhythm, and tempo. Time changes – drastically (p. 4).

Time is no longer an ironclad objective entity, but can either “drag on” or “fly” based on the condition of the self. This notion of different times will be revisited.

Interacting with others with disabilities and adjustment to the disability

Newly disabled persons (and the family) had so many questions to ask, ranging from bureaucratic procedures to dietary issues. However, they often were information-isolated among the able-bodied friends and families with no knowledge of the disability life. Meeting others with disabilities served to lessen their anxiety and uncertainty, and gathering information seemed to be crucial for newly disabled individuals for their adjustment.

The environment at MST was arranged to proceed the patients’ adjustment process by mingling them together. I observed many transitions of the participants at

MST, which often occurred in tandem with the information increase about disability and PWDs. As mentioned previously, the members of the groups were decided based on the patients' disability levels, ages, and personalities; so that among the groups, a newly disabled individual could see how others, whose disabilities were similar to his or hers, live a "normal" life while having a disability. In addition, the hospital staff often introduces a newly disabled person to a more "experienced" person with a disability, which is rare in other kind of hospitals.¹⁹ Mr. Ko, whose disability was the most severe one among the participants, looked forward to coming to the rehabilitation center. He acquired his disability more than seven years ago during a car accident which left him paralyzed below his neck and killed his daughter. He now uses use a motorized wheelchair and was amazingly active.

Rie, the MST therapist, knew that his disability could not be lessened by the exercising, but she included Mr. Ko into the Friday group. Although he could not exercise, Mr. Ko²⁰ was informative and good at listening so that, others, especially the newly disabled, benefited from his presence. Mr. Taku, who was a friend of Mr. Ko, told me that "they [the newly disabled] can ask me any kind of question, even about the toileting. I would not be offended or embarrassed [by the questions]." Similarly, Mr. Ko contended that "I think they [the newly disabled] should ask questions to the 'senior' disabled. Looking back in the past, I have integrated many things I heard from others

¹⁹ While I stayed in Japan in 1999, I was also introduced to a male with a disability who was then a university student. He later started working at an organization that supported PWDs to live independently, which I visited in 2000.

²⁰ He also cared deeply about younger people with disabilities, such as Haru, and he invited him over to his home, or took him out to a nearby park. Mr. Ko even asked me to contact Haru from time to time from the U.S.

[who were more experienced in living with the disabled] into my life.” Therefore, he further commented that, “communicating with other disabled is very important. And we should talk about ourselves when asked.” Their comments indicate that these participants were conscious of their common experiences and wisdom as PWDs, and that they felt an obligation to pass down this information to help the “younger” generations.

Conversely, sometimes, “experienced” PWDs were provided a good “shake-up” to prompt a further challenge by communicating with “rookies.” One day at the lounge after MST, a group of PWDs was gathering. Mr. Owa whose disability was quadriplegia²¹ said to Yoshi that “thanks to you, I decided to have a driver’s license.” Yoshi started coming to MST in 1999 and he was the youngest of the group then. Prior to meeting Yoshi, Mr. Owa had never imagined having a driver’s license and his family drove him to the hospital. Mr. Owa used to think that his disability was “too severe to get one [the license]” till he met Yoshi, who was much younger and had a more severe disability than him. Among the Monday group members, Yoshi had the most severe disability. Yoshi has lost the muscles to use his fingers. Since his fingers were all stretched out and never bent, when I had lunch with him and his mother, Yoshi was using a fork and spoon to eat. Despite his disability, however, Yoshi mastered the “wheeling” technique, which one of his group members with paraplegia even could not master, and received a driver’s license to drive a car with a hand-control. Mr. Owa

²¹ Despite the fact that his disability was quadriplegia, it was incomplete. For this reason, although Mr. Owa had a difficulty in using his fingers, he could walk using crutches even while pulling weights.

continued to say at the gathering that “Watching Yoshi driving a car made me think I should push the envelope further” and “although I had no complaint to being transferred [by someone], it’s much better to drive around by myself.” Yoshi was listening quietly to him with smiling. Self-pitying was irrelevant when meeting others with disabilities.

Meeting others with disabilities also facilitated a learning process of norms, behaviors, life-styles, and/or know-hows of PWDs. One day, at the table-tennis club, a group of players were chatting about vacations. A man using a wheelchair mentioned a hot-spring spot where he once visited. Then, a woman using a wheelchair asked him how he used the hot-spring bathroom while using the chair. He told the group that he used the chair until he got to the entrance, and “went down [to the floor] and crawled from there.” She asked again, “Wasn’t anybody staring at you?” The man replied, “There was, but they didn’t bother me much.” She gasped, “I would never do such a thing [crawling]!” The man said again, “We, the disabled, can’t stop our lives each time they [the non-disabled] get to you.” One day, Haru and Goto were talking at the gym. Haru had had his disability less than two years in 1999, while Goto was more “experienced” in a disability life. They both were in their twenties, and they have stayed in the same rehabilitation/vocational school. Haru seemed to have learned some common behaviors of the quadriplegic there. He saw others eating with one of the knees up on the chair so as “not to lose consciousness while eating” due to the anemia tendency among individuals with quadriplegia. Haru also picked up a less desirable habit, smoking, from these PWDs. Goto learned techniques of how to put a chair into a car by watching others. He told me that “watching those with more severe disabilities was especially helpful.” During the conversation, I asked them if they have gotten used

to being looked at by others. Haru said, “it’s still bothersome” because “some even come back to glance at me around from head to toe.” Goto, on the other hand, said, “we can’t stop living life.” He even continued to say that “when a nosy women asked, ‘what happened to you,’ I said, ‘a suicide’ to shut her up.” Through the communications with others, an individual with a disability learns how to deal with situations in a life as a PWD.

Negotiating with the non-disabled

The aforementioned sections have depicted ethnography of PWDs through my eyes. In the observation places, I was predominantly an observer who witnessed how the participants with disabilities interacted with their environments. These sections mentioned above are, in a sense, “their” stories. On the other hand, this section outlines a more immediate tale in which I, with a disability, became an actor and a stimuli in the environment. I positioned myself as an “object of inquiry” (Crawford, 1996, p. 167) and, in return, I observed how my sites reacted to the stimuli - - my visible disability. This section is, thus, so-called a biographical ethnography, a branch in ethnography, - - a tale of “mine.”

This story started when I decided to participate in a seminar in T-city, Tokyo. The seminar was about independent living for PWDs, and it was sponsored by the T Center for Independent Living²². To be honest, I was not very enthusiastic about the trip in the beginning. I felt that the trip was, rather, an “assignment” for this research. Up to

²² I learned about the seminar and the center from my acquaintance who had stayed in T-city to research the Japanese Independent Living movement. She strongly recommended that the researcher visit the center to meet the disability activists, who were known as the “radicals,” and have contributed to the Japanese disability movement.

this point, I had only witnessed the participants communicating with other PWDs or with familiar non-disabled; for example: nurses or therapists. I could not have access, largely because of time constraints, to see the participants in their unfamiliar sites where they communicated with strangers. I only saw the participants in their most comfortable places, where things were arranged for them. I felt an obligation to see the majority of the society, in which PWDs become the minority. However, this study was not an experimental study (and I did not have power to put the participants into different conditions with various treatments). For these reasons, I decided to be a “guinea pig” and experience being in an unfamiliar environment, and to communicate with strangers as a traveling person with a disability.

After deciding to go, I first thought about how to get there. Although it was possible to drive to T-city, the West side of Tokyo, I chose to use public transportation: the train. I was interested in how strangers would communicate with me and how the Japanese transportation system had changed, if any, since I had traveled to Tokyo in high school more than a decade ago. During the two-day trip, I kept the tape-recorder running as often as possible. To start the trip, I went to a nearby station that was only five minutes away from my home. When I arrived at the station, I already felt at a loss because of the complicated train line displays and the ticketing machines that I have not used in years. It was a foreign area for me. The inside of the station had not changed much since I had used it the last time in 1997. It was a less busy time, but people at the station seemed to be in a hurry, and the flow of the people was constant and undisturbed. I carefully read the line display, and managed to use the ticketing machine, which was too high for my chair. No one was bothered by my awkwardness, nor offered help.

Then, I found a station employee to inform that I would use the train to go to Tokyo. The station had stairs with no elevator, and the last time I had used the station, several station employees carried me to the platform. This time, I was guided to a folded lift on the side of the stairs. Although the employee was experienced in operating the machine, it took at least fifteen minutes to go up the stairs. People were looking at the employee and me on a strange lift which made an alarming noise. Obviously, the lift was not for “commuting” since it requires staff attention each time it is used. On the platform, I was guided to the very end in order to get into the first (or last) carriage of the train. Station staff informed other stations of my coming to T-city, and I was told that “they’d be waiting” for me. Indeed, each time when I changed trains, they relayed me to a next person to attend me down the line. It was amazing teamwork - - a cultural hallmark of Japanese. I have met similar treatment when using the airports in Japan. The staff followed me everywhere. In Japan, I was secured and worry-free in “good hands,” but had no spontaneity, which was the opposite from my experiences in the U.S. In the U.S., I never had a “guide” making sure I chose a right train or telling where an elevator was. I was expected to be on my own in the U.S. These experiences have made me conscious of my changing role as “the disabled” in Japan and the U.S. My role changes due to the fact that people’s assumptions and expectations toward a person with a disability vary in different cultures, and whenever I return to Japan (or the U.S.), a cultural adjustment is required for smooth interactions with people.

On the way to T-city, I noticed several things. At the Tokyo station, which was the largest and busiest station in Japan, I told the station employee that he would not have to guide me if he gave me directions to a platform. I intentionally asked this

question because I was curious to see how much its accessibility had improved for wheelchair users since my last visit in high school. (I vividly remembered when teachers, my classmates with parents, and I used the Tokyo station to have a school trip to Kyoto. The group made a line and proceeded down a long and complicated “backstage” route, which was otherwise used for loading, because the station did not have enough access.) However, my idea was softly rejected by the station employee. Nothing has changed since the school trip, and the path was still too long and complicated to remember without a guide.

While using the trains, I also observed strangers. In the hall inside the station, people were walking so fast that they never stared at me. When I got on the trains, I caught some attention, but most people steered away or went back to sleep a moment later. Although people disregarded me out of courtesy on the surface, they were conscious of my presence because each time the train stopped at the stations, some, especially those were close to me, paid the slightest attention if I would need some help to get off the train. When the train finally came to an arrival station, I looked for a station employee to lead me off the train. There was a large divide between the platform and the train floor, in addition to a dangerous gap between the train and the station home, both of which were fairly common at the stations in Japan. No employee showed up. Next to me was a young, male student. While I became frantic, I saw that the student was also uneasy with the situation. He was sitting stiffly and staring at me. He was ready and willing to help me, but did not know whether or not he should.

According to Thompson & Cusella (1988), the non-disabled often feels anxious and uneasy with PWDs, particularly in helping situations, such as this case. Thompson

& Cusella (1988) further contends that the non-disabled are “between a rock and a hard place” due to the conflicting social norms of “be kind to the disabled” (or “help the handicapped”) and “treat them like everyone else.” This ambivalent feeling that the student held was well understood. In Japan today, since the increased media exposure of the athletes with disabilities in the Paralympics or a national bestseller by a congenital amputee, a new perception, “it’s not polite to pity the disabled,” has been added to social etiquette regarding interactions with PWDs (Kato, 1999). At the same time, it might have added a layer of complication in the helping situations today compared to the past when PWDs were considered as solely “needy and dependent.” Helping PWDs nowadays requires a careful calculation to determine if it is “appropriate” and “not offensive.”

The people whom I met in the office were hard-core activists and had a long history of disability advocacy. Most of these employees had disabilities. The headperson had the most severe disability and was using a powered wheelchair. Besides me, a woman from N-prefecture arrived at the office for the seminar, and she, the headperson, and I had tea together in the office. The woman came to Tokyo because she wanted to start CIL in her area. She talked about people in her region, which was a rather remote area. She said that in her region, PWDs rarely had a chance to go out, and they knew no other way of life but staying at home all the time. She drove to home by home to take PWDs out, but they were hesitant. “There is no place for us to meet each other. People are living so far apart from each other,” she said. Also, she mentioned a girl with a disability who could not leave or enter the house without someone to help her because of the inaccessible entrance. The woman has been negotiating with the local

bureaucracy to provide a public apartment for the girl. There were some accessible public apartments, but they were occupied by the non-disabled. “I just can’t believe this!” I replied. According to the woman, this happened because people, both PWDs and non-disabled, were chosen by lottery for all rooms, regardless of accessibility. So the non-disabled could be given an accessible room, or vice versa²³. The woman was told by the officials that they “couldn’t keep the accessible rooms only for the disabled because it’s discrimination [against the non-disabled].” I was stunned and speechless while listening. Negotiating with the officials is never an easy task because they rarely see the world from a viewpoint of a person who cannot leave his or her own house without help. The woman continued to say that one of her acquaintances with a disability, who had never mentioned independent living before, once told her that he “wanted to run away from home.” He has lived at home for thirty years, never appeared dissatisfied with his life, but finally opened his mouth when he and others with disabilities started meeting each other. “It took several years to open ourselves up and to talk about what we were really thinking,” the woman said. Talking about CIL might be a “Pandora’s box” for them - - releasing all the agonies and pains which they ignored for a long time. The CIL office in T-city seemed to have many visitors like this woman who, after discovering all that was in “Pandora’s box,” had only hope left.

It was my first time to visit T-city. Prior to the visit, I had heard that the city,

²³ I personally knew the opposite case; that was, a couple who were provided an inaccessible public apartment by lottery. The apartment had a 5 –inch step in the toilet room. (In Japan, a bathroom and a toilet room are usually separated.) The wife, a high school classmate of mine, said that her husband who was a wheelchair user never used the toilet at home. Instead, he always went out to use outside bathrooms, which astonished me.

including the surrounding area, was one of the most advanced and accessible areas for PWDs in Japan, and that many PWDs “migrate” to this region because of the services and environment there. Many individuals with severe disabilities left institutions in their hometowns to live independently in T-city, which was impossible in other cities in Japan. According to the chairperson of the office, “some of them were disowned by their family who were too concerned, maybe too protective, when they came to Tokyo.” Indeed, T-city was considered a model city for independent living and heaven for individuals with disabilities. Their success, however, did not happen overnight. A young employee with a disability commented that the relationship between the governmental bureaucracy or city officials and the activists with disabilities used to be hostile, and these activists with disabilities were much more aggressive. One of them was Mr. Taka who was called a “samurai warrior” because of his aggressiveness. Negotiating with the city officials or government bureaucrats were the “battlefields” where he snapped at people, kicked the table with his unparalyzed leg, and had sit-ins for the rights for PWDs. Mr. Taka, who passed away recently at the age of fifty, used to say, “I don’t want these disabled children to experience what I have. I want to change the society for the time these kids become grown-ups.” When Mr. Taka was a child, situations surrounding PWDs were much worse than they are now. Futsukaichi (2000) reveals a cruel childhood when Mr. Taka “never went to any school, even once, and he had spent years hidden inside the house until the age of twenty-five. He had eaten alone in a different room from the rest of the family. His family allowed him to go out once in a year, only at the night so that the neighbors never saw him” (p. 11). T-city’s “heavenly” environment for PWDs was built upon dedications and sacrifices of such

activists with disabilities as Mr. Taka.

The seminar invited PWDs who lived independently in the community, and to my surprise, city officials. I heard that nowadays the relationship with the government or officials has changed drastically. It was because, according to a CIL employee, the Japanese society has become the super “aging” society in the world, and the field of social welfare was no longer only for “special” people because of the fast-increasing population of the elderly. Also, since the Japanese family structure changed, including women in the work force, filial care of the elderly has become a major social issue. Because of these societal changes, CIL’s grass-roots network with local communities and the know-how’s for PWDs have become valuable assets in this aging society, the wisdom has been accumulated over last three decades. This new circumstance was due to the fact that PWDs and the elderly have much in common in terms of their needs and care requirements. A CIL employee noted that “nowadays, they [the bureaucrats and officials] rely on us and ask for our advice.”

The invited PWDs talked about welfare taxis that were provided by the city, relationships with attendants, and welfare services in general. To tell the truth, the disabilities that the invited PWDs had were so severe that I first could not believe that they were not living in institutions. Many of them came to the seminar with their attendants, including the CIL chairperson. These attendants’ behaviors impressed me. They never behaved as “custodians” to PWDs, which happens frequently in a PWD-and-attendant relationship. Among them, the chairperson’s attendant was a middle-age male, and his care was so subtle and thorough that his existence was shadow-like. The communication between the chairperson and the attendant was high-context, and words

were rarely exchanged between them, especially in a feeding situation. If one has experienced feeding someone, especially adults, s/he would understand that feeding is a state of the art situation. (I have experienced it during my student-teacher internship period when I had a chance to feed students with disabilities.) I observed that the man feeding the chairperson, who was also talking with a city official, did so in such a graceful and unintrusive manner that they looked as if they were “dancing,” as Hall (1983) would put it. I learned later that the man was not a “volunteer,” but a professional attendant who made a living by attending PWDs. The seminar was successful and informational. However, what happened after the seminar seemed to be significant to me.

After the seminar, the whole group of people, including the city official, went to a nearby mall with many restaurants. First, I was surprised because the city official also joined the gathering. It was an unofficial gathering, and they were not obligated to have a drink with them. A scene in which the CIL chairperson and the officials sat next to each other and had a drink together signified a “partnership” between them, rather than a mere “service providers and welfare recipients” relationship. It seemed that nowadays disabled advocates and the city officials have a common interest; that is, looking for the best alternative in order to survive this “super aging” society. Next, I felt odd due to the fact that the worst place was chosen to hold the gathering. The Italian restaurant used for the gathering was fashionable, but the least accessible restaurant in the mall. The restaurant had a seven-inch step at the entrance that led to a small private space, where we gathered. The space was at the very back of the restaurant so that each time someone had to go to the outside bathroom (there was no bathroom inside), at least two restaurant

employees, sometimes four for those with heavy powered-wheelchairs, were required to help at these steps. Especially, assisting the CIL chairperson required the greatest attention since he was using a powered-wheelchair and could not maintain body posture by himself. In addition, the hall of the restaurant was so narrow that even I, with a small chair, could not get through without asking other customers to stand to make way for me. As a result, the group received much attention in the restaurant whenever someone was helped. The group must have been such a “hassle” for the restaurant, and might have even been viewed as “unwelcome” customers. When I peeked into other restaurants on the same floor in a middle of the meeting, I was stunned because none of them had any steps, except the one we were using. It was evident that they deliberately chose the place because the restaurant was *not* accessible.

Then, I understood the meaning of this seemingly harmless gathering. The meeting was another protest of theirs and an important part of the seminar that was about living in this society and negotiation with the non-disabled. Their demonstration was delivered eloquently about the lives of PWDs, which were surrounded by many barriers, without picketing or raising a voice. In Japan, PWDs are repeatedly told “not to be a burden on others.” When PWDs are bound by this spell, however, they often become afraid of leaving their houses because the outside world, except for a few places, is not arranged for them. Nevertheless, in order to live “independently,” PWDs need to be “a burden on others” and to ask for help whenever the person enters an inaccessible store or uses a station without an elevator. CIL people became “dependent” on purpose in order to promote “independent living.” They must have known that “independence” for PWDs is based upon endless “dependence” on others.

Discussion

In this chapter, I have depicted the participants and the places where I observed using an ethnographic method. In the first section of the chapter, I mainly illustrated “information pooling places for the disabled” where PWDs gather, exchange information, learn norms of PWDs, and facilitate a smooth transition to living with disabilities. In other words, these places functioned as a “buffer zone” between the outside society and their homes. These sites were where PWDs became the majority, and the environments, including the time flow, were arranged according to them. In the latter part of this chapter, I became an actor to observe her surrounding environments using the biographical ethnography method. My trip to T-city and the day of the independent living seminar were detailed. In addition to my changed role in the field, the studied sites were quite different from the ones in the earlier part. These sites were characterized as fast paced, unfamiliar, and constantly negotiating with the non-disabled - - the “outside” world for the PWDs. In the next chapter, phenomenological “essences” on various disability topics are extracted from the interviews.

CHAPTER V

Interview Study

In the previous chapter, the researcher described the participants and the observation settings through ethnographic descriptions. A main difference between the ethnography and the interview is that in the latter, the researcher had more control and structure. After obtaining the permission of the participants, the investigator set an appointment to interview them. The researcher had a list of interview questions to ask

based on the preliminary interviews and observations in 1998. The main interviews took place in 1999, and were augmented by follow-up interviews in 2000. (In the follow-ups, the researcher asked questions that had surfaced while transcribing). The main interviews were semi-structured, and therefore, the participants were asked the same questions with small variations. Interviews ranged from thirty minutes to more than two hours, and all of them were audiotaped and transcribed by the researcher. Most of the interviews were one-to-one. The researcher sometimes decided to have small group interviews (no more than three people). This decision was made because some of them were newly-disabled individuals and she felt strongly that listening to other participants' stories would be beneficial to those newly disabled. Similarly, Deegan (1991) asserts that "[v]ery often a disabled person who is only a few 'steps' ahead of another person can be more effective than one whose achievements seem overly impressive and distanced" (p. 53). In addition, a small number of the participants had interviews more than once over the years. The adjustments of newly disabled individuals particularly became apparent. Since she could only visit Japan once in a year, she sometimes observed significant changes, which were probably overlooked by family members or close friends. For others, repeated interviews seemed to help "break the ice."

Repeated interviews

Mae, a young man with quadriplegia was distant and disinterested during the main interview in 1999. He often uttered "that's all" or "there is nothing to say" which gave the researcher the impression that he was not speaking on a genuine level, and he wanted to terminate the interview as soon as possible. In 1999, he seemed to emphasize that having a disability was not such a "big-deal" and that his life in general has not

changed much since the accident. Similar claims were echoed by other participants, especially the young ones²⁴. Toward the end of the interview in 1999, nevertheless, Mae murmured that

I hate it when I can't help nagging about the situation to my buddies. I don't even like this situation now a bit (being interviewed) [because] I hear myself grumbling again. I don't like myself like that. I want to display only the bright side of me to others.

Indeed, talking about disability experiences could be painful, personal, and reveal “the darkest side” of these individuals’ lives. It was not an easy task for the researcher to ask about the unpleasant past of someone. In the next year, 2000, Mae agreed to a second interview. Since the first interview, he had gone back to high school, bought a car, and visited the U.S. There he installed a “joy stick” hand-control for his vehicle. (There are only two cars so far with this instrument in Japan). He looked happier, and, most of all, more open than he was in the previous year. In fact, he apologized at the beginning of the interview that he was not so cooperative the time before.

The interview in 2000 with Mae went much smoother than the previous one. While comparing both interview transcripts, his changes became evident. In 1999, he

²⁴ It was, thus, more challenging for the researcher to interview these young participants due to the fact that they were often reluctant to talk about the lowest point in the disability experience, which the researcher understood completely. Some of the participants were hesitant to call themselves “the disabled,” especially the young who were eager to “blend in” with their able-bodied cohorts. These people seemed to want to avoid being labeled “depressing,” “whining,” or “sticky,” images which were unpopular with other teenagers. Also, the young participants seemed to avoid falling into the existing stereotypes of PWDs by telling their disability stories to the researcher. Nor did they want to reemphasize those “depressing” and “pitiful” images of PWDs.

answered that “there was no one who left after the accident,” and he was reluctant to talk further. In 2000, nevertheless, he said, “to tell the truth, I had many friends who grew distant from me because of the disability.” Another difference in the interviews was that during the first interview in 1999, he described, “the awkward moment [with the friends after the accident] didn’t last very long, and everything went back to normal,” but in 2000, he stated, “I could see the terror in their eyes. They looked uneasy because they must have been thinking what not to talk about.” The interviews with Mae taught the researcher the importance of establishing rapport with the participants, which sometimes takes time. Over time, she has built trusting relationships with some of the participants, and managed to maintain these relationships. Even after her returning to the U.S., some participants and the researcher continued corresponding on the Internet.

Adjustment path: A Masa’s case

Masa was a friendly and funny man who was in his early twenties. He injured his lumbar vertebrae in 1997, and could walk with canes, but unnaturally. The researcher met him for the first time at the wheelchair basketball team, the “Eagles,” in 1999. He had just started learning how to play. Energetic, eager to learn, and the youngest of the team, Masa was liked by his teammates. In 1999, the researcher saw Masa walking most of the time. Nevertheless, he could not raise his knees as high as the non-disabled do, so he dragged his legs and walked slowly; his walking seemed unstable and unsafe. So the researcher asked Masa in 1999 why he never used a wheelchair which was safe and energy saving. He then said to her, “I don’t want to use a wheelchair. I don’t feel comfortable being in it. It makes me look disabled. I can

walk.” He was determined to walk in 1999 at any cost.

In the next year, 2000, the researcher revisited the “Eagles.” At the gym, the researcher saw Masa, whose play was so improved over the year that he became one of candidates for the Paralympics in Sydney, Australia. He also graduated from a vocational school, and worked at a credit card company. Between the years, Masa went to several wheelchair basketball camps, and became a basketball fan (he said, “I only think of the basketball now”) despite the fact that he never had liked the sport before the accident. Most importantly, the researcher saw Masa using a wheelchair in 2000. Other changes became apparent during the interview. During the interview in 2000, the researcher mentioned the use of wheelchair, and Masa admitted that he has become more accepting and comfortable in a wheelchair (“it’s safe and easy”). He confessed that “because of my disability, I still have an inferiority complex toward the able-bodied.” Nevertheless, compared to the past, “I don’t feel sorry for myself as much as I used to do.” Masa further commented about changes by saying,

I used to hate going out. But joining to the Eagles and seeing other disabled players changed me. I started to think using a wheelchair was not that bad. I had never used the chair before coming here. I was determined to walk no matter what. [Now, using the chair is] easier and more comfortable [than walking.] Nowadays, I show-off my chair to others, instead. I use an escalator, and go down several stairs [with the chair]. I want to tell others that we can do anything with the chair.

His statement above included such adjustment themes as “sports and disability adjustment,” “changed perceptions toward wheelchairs,” and “communicating as a

PWD.” These themes were repeated in other interviews, and therefore, each will be revisited in later sections.

Toward the end of the interview, Masa uttered, “when I stand up, I can’t help feeling ‘oh gee, it’s quite high. I became a Gullivar.’” Mitsu discovered the same thing as soon as he started using the wheelchair. He said, when sitting, “the ceiling is so far above.” Mitsu, whose standing height is more than six feet, realized that he was talking “up” to others because he was in a chair, and felt, “other people looked bigger than before.” Since Mitsu became used to a sitting eye level, he felt “frightened” by his height when he stood up. Mr. Ta articulated further that “eye-level changed my psyche quite a lot.” He explained this relationship between his height and inner self in the following manner: “the angle of sight has changed my personality. I became softer. I used to be very short-tempered and aggressive. I used to ‘look down’ on people, but now I ‘look up’ to them.” Others also mentioned this mellowed, less aggressive, personality, such as Yoshi who used to snap at the smallest reasons and get involved in fights.

Desmond Morris (1969), who is a zoologist and anthropologist, asserts that in the world of animals (including humans), higher and larger postures are decoded as aggression or higher social status. (Therefore, the largest primate usually becomes a boss. For humans, such artifacts as shoulder pads, thrones, or platforms are the remains of this urge.) Conversely, the lower or smaller posture signifies submission. More specifically, lowering the eye-level contributes to one’s psychological status, which the aforementioned participants stated. Morris (1969) affirms that one’s psychological state

is greatly influenced by his or her posture. Indeed, being “looked down” upon implies both a metaphorical psychology and the actual physical situation.

Phenomenologically speaking, these individuals’ experience was due to a transformed “*umwelt*” since having a disability. “*Umwelt*” means “environment” in English, and in phenomenology, it connotes an immediate world with a sense of familiarity. The participants’ actual heights, of course, did not change, but they started to see the world from a different angle. As a result, they became conscious that a different posture influences the perception of the world, including of people. Straus (1973) investigates the body from a phenomenological view. He explains that one’s posture greatly influences his or her “*umwelt*,” including the psychological state.

A biologically oriented psychology must not forget that upright posture is an indispensable condition of man’s self-preservation. Upright, we are, and we experience ourselves in this specific relation to the world... Environment is not a stage with the same scenery set as one and the same for all actors who make their entrance... Upright posture pre-establishes a definite attitude toward the world; it is a specific mode of being-in-the-world (Straus, 1973, pp. 234-235).

The statement above implies that “sitting” individuals with disabilities, such as the participants of the current study, have a different “attitude toward the world” than the “standing” non-disabled. Merleau-Ponty (1996) similarly notes that, one’s disability adjustment cannot occur without rearranging his or her “body synthesis,” or, in other words, “embodiment.” The dynamics involved in the relations of disability adjustment, *umwelt*, and embodiment will be re-mentioned in the next phenomenological chapter.

An early going-out: A prologue to a disability adjustment

The aforementioned Haru fell off the wheelchair when he went outside by himself for the first time. He bitterly remembered the incident when interviewed. Most PWDs have unforgettable, often painful, early going-outs. These occasions serve as initiation rituals for the newly disabled signifying the involvement of “the community in the transformation of an individual from one position in society to another” (Murphy, 1990, p. 131). As a newly disabled individual leaves a hospital or institution, immediately he or she is reminded that the “old” and familiar environment has changed, physically and socially, along with the self. This phase is usually a beginning of “stigma recognition,” as DeLoach & Greer term (1981, p. 219). Stigma recognition entails recognition of one’s own disability as a fact, and explores the consequences of having a disability. There is a massive gap, nevertheless, between knowledge of being unable to walk and actually experiencing its implications. As a woman relates, “I had no idea what it meant to be ‘wheelchair-bound’”. The descriptions below illustrate “what it means to have a disability.”

Mr. Haya hated to go out. He even hesitated to go into his own backyard. Mr. Haya remembered the first outing, when he went to a once-favorite place, and realized that the aisles were too narrow for his chair. For Yoshi, the reality hit when he went to a summer festival that he used to enjoy. Its atmosphere changed quite a lot after the accident. He soon realized that it was “too dangerous to be in a crowd.” He could not proceed without bumping into others because walking people and people in wheelchairs do not share the same sense of spatiality and tempo. As a result, he gave up trying to keep pace with walking people, and decided to stay aside. He asked others to go to buy

things for him. The same things happened to him in China Town, another over-crowded place in Japan. Yoshi no longer had a desire to go to any crowded places that brought more stress and frustration than enjoyment.

Besides physical barriers that exist outside a hospital or institution, many participants were reminded of their transformed position in society, and an altered sense of self, both of which were rather psychological barriers. A concept of “moral career” seems to be useful in explaining this disability adjustment. Goffman (1961) defines it as any social strand of person’s course through life. The perspective of natural history is taken: unique outcomes are neglected in favor of such changes over time as are basic and common to the members of a social category, although occurring independently to each of them (Goffman, 1961, p. 127).

The moral careers of individuals in a given social group go through a “standard sequence of changes,” and one can uncover the patterns of development by listening to people’s “moral experiences and overt personal stands” (Goffman, 1961, p. 168). For a group of PWDs, Birenbaum (1979) asserts, the moral career is negotiated, shaped, and learned in communication with the non-disabled.

Tu, who was a wheelchair basketball player, remembered his experience in early post-injury time. He went to a restaurant, and soon he noticed that “everyone was watching each time I moved. Whenever I looked back, our eyes always met.” In addition to other’s change, some participants felt ambivalence toward themselves. Take

was “ashamed of being in a wheelchair,” and was hesitant to go out²⁵. Keiko also remembered the first outing with her young son when she “couldn’t help worrying about others’ eyes.” She was only one of many who became hypersensitive about being under observation. Another female participant, Hiroko, went to a shopping mall with her sister as the first outing, and she, too, “couldn’t look up throughout the trip.” Hiroko, who now is a top wheelchair-tennis player and travels internationally, described this going-out experience as the first realization of the change in social position “from one who stares to being the subject of stares.” This disability adjustment is usually accompanied by a psychological pain due to the experience of going from being in a majority to being in a minority (Braithwaite, 1990). The researcher’s stigma recognition occurred when she was using a long slope in front of her apartment, which compensated for four steps. There were several children, who seemed be around the age of six or seven, alongside of the slope. They were playing at first, but soon they all stopped playing to stare at the researcher while she passed by them. Then, a boy yelled at the others, “don’t look at that pitiful girl!” At that moment, the researcher understood the implication of having a disability. Her social position had changed. The child saw her as “pitiful,” and this fact was more startling than the staring. He, by the age of six or seven, already learned a social

²⁵ This sense of shame was so pervasive and strong that some even “cocooned” at home after being discharged from the hospital. This reticence can last from several weeks to even several years. Those participants had become prisoners of their psychological barriers. Interestingly, though, there were several participants who were never hesitant or ashamed of being seen by others.

script for a PWD - - to feel sorry for the person. For newly disabled individuals, returning to society starts with realization of a new self as “the disabled” and learning a new way of communicating with others.

Changed perceptions toward the wheelchair

Yoshi had ambivalent feelings toward his wheelchair. He was devastated when he got “his” first wheelchair. He had felt that “my life would be defined as ‘disabled’ by having ‘my’ chair.” Unlike a “temporary” wheelchair, which is seen at hospitals or shopping malls for unspecified users, a “permanent” chair is manufactured individually to suit one’s body size, lifestyle, preference, and/or disability. Having a personal chair means it is engineered to replace one’s legs, and begins a process of including an object (wheelchair) into flesh and self: a process of embodiment.

When Yoshi was interviewed in 2000, he admitted, however, that his perception toward the wheelchair changed as time went. Although he still felt that “I can’t be in such a thing (the wheelchair) forever,” nowadays, he “came to a full realization” that he “can’t function in daily life without it.” Yoshi’s change in attitude toward the wheelchair was not an isolated case, as seen in the aforementioned Masa’s case. Tu was a wheelchair basketball player and hardly felt anxious about being observed by others. Still, even Tu “emotionally rejected the chair to a great degree.” He injured his spinal cord at the age of eighteen, and was officially told he would have a permanent disability, paralysis, when he was nineteen. He continued to say, “I used to hate wheelchairs in general” since they reminded him of “bad images of ‘the disabled’ I used to have.” Mr. J wrote about this ambivalent feeling toward the wheelchair in his book as follows.

[in my early disability years,] although I hated going out in a wheelchair, I didn’t

mind using canes. This made a huge difference in consciousness. Using canes, I could remind myself that I was still *walking*, on the other hand, being in the chair made me conscious that I have become “disabled,” which I couldn’t stand (Jinbo, 2000, p. 34; my translation).

In summary, the wheelchair was not a mere object, rather, it was stigmatized and “the symbol of disability” (Murphy, 1990, p. 61). This fact was the very reason why many participants were resentful about using the wheelchair despite its practical merit. These participants became fearful of incorporating the stigma symbol into the self. With regard to the incorporation of a wheelchair, the researcher noticed many participants (and their family members) saying, “when I (or s/he) became a wheelchair” or “before/after becoming a wheelchair” to mean “when the person became ‘disabled’” or “before/after becoming the disabled.” Some even used the term “the wheelchairs” in preference to “disabled.” These remarks also seemed to signify that the wheelchair occupied a large part of who they were.

Changed communication with others

A. “My wife doesn’t even touch me any more:” disability and intimate relationships

One day, a male participant gasped to a group of PWDs after the exercise, “my wife doesn’t even touch me anymore.” Inevitably, acquiring a disability has shaken some participants’ lives, including the most intimate relationships. Although their stories were not the majority for the present research, it is not uncommon that a couple drifts apart when one of them acquires a disability. A partner’s disability not only changes their roles in a relationship, but also demands a couple to reevaluate every aspect of their lives. After the accident, the aforementioned person’s roles in the family

drastically changed: his wife went to work and he decided to stay at home. This family even changed its residency. When the researcher talked to the wife in 1998 soon after his accident, the wife confessed, “I know this sounds ridiculous, but I can’t go out with him in a wheelchair. I don’t mind going out with him outside of my area. My town is rural and people there are pretty nosy.” She was longing to move from her “nosy” small community and to start a new life in a different area²⁶. The wife of Mr. Ko, who has a severe disability, elaborated on this role change, “[after the accident,] everything came onto my shoulders, his care, financial management, and taking care of our child,” she had to become everything, a husband, wife, mother, and father. Just as Mr. Kawa and Mrs. Ko successfully managed this transition, many couples survived their marriage together and even strengthened their ties. For example, Mr. K, a Paralympics player, was engaged when he was injured by a car accident. He was driving on the way to a wedding rehearsal. In the depth of despair, his then fiancée hurried to marry him in order to “support him in such a difficult time.” The couple has had children by in-vitro fertilization.

Some, however, have gone separate ways since the point of the partner’s disablement. In 1998, when Yoshi was staying at the rehabilitation hospital, his girlfriend frequently visited him at the hospital. They seemed to be inseparable. In the next year, the researcher heard that they had broken up. Kyoko²⁷ was in her mid-

²⁶ This difference between the rural and urban setting for lives of individuals with disabilities became quite apparent during the interviews and observations. Also, this aspect was eye opening for the researcher who was brought up in an urban area in Japan.

²⁷ She was an interesting character as a Japanese woman with a disability. Unlike some others who lost their interests in fashion after having the disability, Kyoko always wore the latest fashion and make-up, and drove a “flashy” car loaded with many accessories.

twenties. When she was paralyzed, her then-husband told her that he would look after her the next five years, but he asked her for a divorce after that because he “would be too young to stop having fun” because of her disability. Outraged by the proposal, she refused to stay in her marriage, divorced him, and took the child. Another woman, Tae, who had her right leg amputated under the knee, also broke up with her boyfriend. She was a truck driver at the time of the injury. When the researcher went to a vocational school, she was the “loudest” in the class. During the 2000 interview, Tae talked about a trip to a hot springs in Japan with her then-boyfriend soon after being discharged from the hospital. She repeatedly emphasized during the interviews in both 1999 and 2000 that she was never ashamed of herself for having a disability. According to her, they were still good friends. However, Tae suspected the reason of their break-up was that her ex-boyfriend could not bear her “new” physical state - - “it must’ve been too painful for him to see me no longer the same.” Despite her traumatic amputation, Tae’s disability was “mild” compared to other participants. She started enjoying scuba diving, and driving a motorcycle and bike again, and the only difference from before was that she needed help in carrying an oxygen tank for diving. Still, her relationship with her

The physical therapist referred to her as “stubborn” because she refused to do anything that did not interest her, including rehabilitation activities. In a sense, she was no different from other young Japanese today, except for the fact that she had a disability. When the researcher met her for the second time in 1999, she went to a chiropractic clinic five times a week to “fix it (her disability),” and was having an affair with a married person. Charming enough, she had no problem finding a boyfriend. In the summer of 2000, the researcher met her again. Kyoko told the researcher that she would like to stay in a foreign country for awhile. She said, “I want to spend the rest of my life for myself,” knowing well that she would be accused of being “selfish” as a mother of a child, and that her way of lifestyle would not fit in with the general perception of PWDs in Japan.

ex-boyfriend was severely damaged. Mr. Su also experienced a break-up with his ex-girlfriend, but he explained that the incident was on account of his “skepticism.”

Looking back, he had felt that he was not the same person whom the ex-girlfriend used to know. The worst of all, he had accused her of seeing him as a burden despite the fact that she never said so. This researcher suspects that adjusting pre-disability relationships is harder than starting new relationships. For the former case, both a newly disabled person and the surrounding people tend to hold onto an “old” perception of the person who used to be, and both parties cannot help but comparing the current situation and what could have been without his or her disability.

B. Quantitative and qualitative changes in communication

Acquiring a disability changed not only the participants’ social status, but also communication, quantitatively and qualitatively, with others. Mr. Taku used to be a typical Japanese artisan who hardly spoke to his wife in his pre-injury time. He was an ambitious carpenter who had left his rural hometown to become successful. He left early and came home very late everyday, which was quite typical among the working Japanese, especially of his generation. His wife supported him as a housewife - - until his accident. Since the accident, Mr. Taku’s communication with his wife has changed. Now he stays at home, and she works outside the home. During the interview, he told the researcher that he had more time to communicate with his wife. Similarly, many participants reported to the researcher that they spent more time talking to the family than they did before their injury. Mr. Kawa, who used to be a farmer, became a househusband and closer to his daughter than before the accident.

Especially for those with the most severe disabilities, communication became vital for survival because of their physical dependency on the family. When the researcher was observing Mr. Ko, who had the most severe disability among the participants, and his wife, they were inseparable and were constantly communicating. Although he moved himself by a motorized chair, with both hands and legs paralyzed, he needed someone's help for doing anything else. He even had to tell his wife where to itch a spot on his scalp. As a former-engineer, Mr. Ko liked to try new technologies. Whenever he bought a new thing, his wife needed to set-up or install it for him. He felt "very frustrated" at having to give her detailed instructions that had once been a simple thing to do for him. During the interview with the Kos, Mr. Ko and his wife mentioned a difficulty that arises sometimes in their "intimate" relationship. According to the wife, a difficult time came whenever they fought. Unlike other couples, she could not "leave him alone while cooling down." These people were literally together in good times and bad times. Just like Mr. Ko and his wife, for PWDs with severe disabilities, everything is accomplished as a result of communication, ranging from sipping coffee to using the latest software. These individuals' lives are highly dependent on communication. Therefore, the researcher believes research pertaining to communication and PWDs (especially with severe disabilities) is worth studying.

In addition to the quantity of communication, many people interviewed mentioned a qualitative change in communication. Yoshi, who was in his early twenties, said,

[After the accident,] I was reminded I was their child. [Before the accident,]

there was no communication in the family, and we didn't know about each other.

[In the hospital,] we were put in a situation where we had to communicate. We started talking naturally. I didn't lose everything. I gained some other things out of my disability.

Generally speaking, their disability brought the family closer and tighter.

However, tight-knit relations within the family sometimes work negatively in relation to communication with the non-family members. The family, especially the parents, sometimes becomes over-protective of their family members with disabilities. During the interview, Mr. Ta mentioned an interesting communication behavior of PWDs who started coming to the wheelchair basketball practice²⁸. He was puzzled to see that those who came to the practice for the first time never talked directly to others. According to Mr. Ta, these individuals always asked their family for something, and it was the family who asked others to help the person. There was no exception in this behavior. So every time a new person came to the team, Mr. Ta taught him or her that "YOU must ask others with your own words. You need to start from there."

According to Mr. Ta, while those first-timers had to relearn communication with others outside the family, a similar dynamic was also noticeable; that is, often the non-disabled talked to the person accompanying a PWD, but did not talk to the person with a disability directly. For example, whenever the researcher was traveling with her friend, often people asked the friend if the researcher could walk or what she would eat. In

²⁸ His team was a "quad" wheelchair basketball team, and, unlike the "Eagles" players, many players in the "Pirates" needed constant care and assistance, from transferring to the chairs to opening a lid. Thus, one of the main differences between the two wheelchair basketball teams was that during the "Pirates" practices, there were always family members at the recreation center for assistance. Most of them were either mothers or wives of the players. They usually waited in a lobby during practice.

other words, the non-disabled and PWDs sometimes communicate through a “middle-person,” whom Goffman (1963) would call “the wise” (p. 28). “The wise” are the ones who are expected to know both the worlds of the non-disabled and PWDs, and, willingly or unwillingly, speak for both groups of people. Examples of the wise are often family members or close friends of PWDs. Mr. Ta analyzed this filtered, indirect communication between the non-disabled and PWDs:

We are different kinds of beings [to the non-disabled]... There is a psychological barrier between the disabled and able-bodied, of course. We are different creatures. And prejudices toward the disabled exist. It is the same thing when we Japanese usually choose another Japanese, rather than a foreigner, to talk to. It [communication with the disabled] is the same. It works on an unconscious level.

Interestingly, Mr. Ta pointed out that communicating with a foreigner and with a PWD share common themes, such as unfamiliarity and prejudices.

Mae, who was in his early twenties, became keenly aware of a relational change which resulted directly from his disability. He felt that communication played an important role in maintaining (or terminating) friendships after the accident. He contended that the very first meeting with the friends determined the nature of an after-injury relationship.

The idea of being unable to walk haunted my friends when meeting me, and it might have contributed to those relationships that died. Also, on my side, I had a shame of not walking. I immediately noticed the relational changes after the

injury... I think it's our responsibility to explain what's going on to the best of our knowledge...

Mae articulated "a lack of information" on the friends' side as a major factor which scared the friends away. He concluded, "without communication, nothing is delivered."

Changing perceptions toward a group of PWDs

In a pre-disability era, most participants with disabilities had no association with a group of PWDs. These participants used to have the same perspectives as the non-disabled toward a group of PWDs, and they confessed that many of those images were negative. For example, both Yo and Ishi had an image about PWDs that was "kurai" ("dark or depressing") before coming to a vocational school. However, both of them quickly learned at the school, "they are no different from the able-bodied." Interestingly, Ishi had this assumption, despite the fact that he had no friend or acquaintance with a disability during his pre-disability life, and he confessed that he had "no idea where it originally came from." Likewise, Hiroko recalled that during her pre-injury days, "my image of the disabled was 'depressing.' When I think of it now, I feel really bad.. for those disabled. I now realize I was prejudiced against the disabled." Hiroko continued to say that what horrified her most was the idea of "becoming a member of that pitiful group." (This notion of "becoming" deserves more attention, and is discussed later in this chapter.) Her fear was the same as what parents whose children were born with disabilities felt (Yohda, 1987). Even though these parents themselves did not have disabilities, they came to the realization that their social identity could be "polluted" due to the children's disabilities. As a mother talked about her mother during the interview,

She [the grandmother] sounded shocked. She was still shaky. 'Born disabled'

upset her most. [The grandmother said,] “people would point at us now.” We used to be in a position of pitying them, in the position of staring. She [the grandmother] was devastated because now she became the one to be stared at (Yohda, 1987, p. 472; my translation).

These people, both the participants and the mother, felt that they were marginalized from the majority in society. They became “one of those people.” These comments signify that social stigma is associated with disability, and these remarks were made from the standpoint of the non-disabled. (The “pollution” theme of having disability is revisited in the discussion section.)

However, the interviewed participants frequently stated that as time passed, their images and views about PWDs have changed. Tu agreed that his perception of “the disabled” changed “quite a lot” after the injury. He went on to say that he used to think, “I only had able-bodied friends. [During that time,] I used to think all wheelchairs were the same. I knew nothing about the disabled, and I couldn’t care less about them.” The captain of the “Pirates” likewise admitted that his images about the wheelchair and “the disabled” changed as he learned more about a group of PWDs. He said, “at first, I didn’t even know there was a difference between quadriplegia and paraplegia. This may sound prejudiced, but I used to think all wheelchair people were CP (cerebral palsy) people. After I was injured, I started to see differences among the disabled.” The aforementioned Hiroko similarly mentioned that as time passed, she could not only see diversity within a group of wheelchair-tennis players, but could also specify their disability information, for example, causes of their impairments (accidents, illnesses, or congenital disabilities), injured areas, or lengths of having disabilities, which are

unnoticeable to most of the non-disabled.

These comments above, which were shared by many other participants, can be summarized as this: the participants who used to see a group of PWDs as homogeneous, started to see individual differences among PWDs after the participants became “the disabled.” and much of their perceptions toward PWDs also improved. This shift may be explained by a phenomenon of “outgroup homogeneity” (or, conversely, “ingroup heterogeneity”) (ex., Brewer & Miller, 1996) - - seeing outgroup members as “they are all alike.” Outgroup homogeneity largely comes from the little amounts of information people have for the outgroups. Surely, in their pre-disability time, the participants had little information about a group of PWDs, but their disability information increased much more after their disablement. In addition to the amount of information, Brewer and Miller (1996) add a dimension of “motivation” to outgroup homogeneity.

If outgroups are seen as homogeneous, there is little motivation to attend to individual individuating information about an outgroup member, or to acquire new information which might serve to correct stereotyped views of that person (Brewer & Miller, 1996, p. 53).

Tune’s remark, “I knew nothing about the disabled, and I couldn’t care less about them.” seemed to represent the dynamics explained above. In listening to the participants’ comments, learning new PWD information facilitated changing perceptions and/or creating finer and more categories of PWDs. The latter is referred to as “subcategorization” of a group (Brewer & Miller, 1996). (This process is poorly understood and is worth researching quantitatively in a future study. The researcher speculates, however, that the information increase and other concepts are positively

correlated.)

A learned role: Communicating with others as a PWD

In addition to the changed perception toward PWDs, interestingly, some participants reported that they now interacted with the non-disabled as “we, as the disabled.” Tu worked at a pharmaceutical company in Japan. When the researcher asked him about his workplace, he stated that “my coworkers may change depending on me.” He was the only employee with a disability, and he was conscious of his role as a representative of a group of PWDs (“disabled billboard,” he described). Tu felt strongly that he needed to manage both playing basketball and work and to be better than what he actually was at work in order to “promote a positive image of the disabled.” Hiroko, a tennis player, told the researcher that she often became hesitant to refuse unnecessary help from others because

If I say ‘no’ to them, it may not be good for other disabled who actually would need help more than I do. It must’ve taken courage to offer to help me. If I refuse their help, they may stop offering to other disabled people, which I don’t want to be responsible for. So, I am careful about saying ‘no, thanks’ to the able-bodied.

She further commented that she once scolded a woman who “had the nerve” to park a car at a handicapped spot²⁹ for “many other disabled who can’t express themselves.” In

²⁹ The issue of “the handicapped parking spots” has become a large concern recently among the disabled community, and it was mentioned by many participants during the interviews. In Japan, there are many “handicapped spots” at public places or malls, presumably, reserved for PWDs. However, without a forceful law and proof in a car of having a disability, often these places are occupied by the non-disabled.

other words, these participants communicated with others on behalf of other PWDs at home or institutions, which alludes to a collective social identity as a group of PWDs.

While some participants seemed to have added a social identity as “the disabled” to the self, others, especially the “rookies,” were still in a process of learning societal expectations as “the disabled.” These expectations are embedded in interactional scripts, and participants with disabilities have learned those expectations *in situ* - - through communication. A story of a newly disabled woman below represents a prologue of this learning process.

The aforementioned Tae was an animated person in her late twenties. The researcher met her at a vocational school and interviewed her in 1999. When re-interviewed in 2000, Tae worked at a government office. Tae’s right leg was amputated below her knee, and she wore a prosthesis. However, besides a slight dragging of her feet, she was indistinguishable from the non-disabled and was amazingly active. Tae “walked around in short pants in town while others looked shocked” and she “took off the prosthesis at a hot-spring while the kids were pointing and the parents were scolding them not to watch” her. She did not care about the people who stared because she “didn’t do anything wrong.” During the interview in 1999, nevertheless, she revealed an interesting episode:

When I was getting a prosthesis, an old woman and I happened to have a conversation. I told her that I wore short pants during the summer because I didn’t do any thing wrong. The woman replied to me that ‘you can walk like the ablebodied and nobody would know you’re wearing prosthesis. It’s more considerate if you hide it.’ I never thought about it that way before. Her saying

banged my head and made me think of ‘the courtesy’ of not showing my disability... Shouldn’t I expose it to others? It’s not that I became anxious about being stared at, but it’s courteous to *others* to hide my disability.

This courtesy of hiding one’s disability sounds illogical given the fact that one’s physical disability, ex., amputation, is neither contagious nor a physical threat for society. Nevertheless, what the old woman was concerned about was an emotional arousal by the disability; a “psychological” contamination to ruin interpersonal communication (ex., Braithwaite, Emry, & Wiseman, 1984; Coleman & DePaulo, 1991; Emry & Wiseman, 1987). Therefore, the old woman recommended Tae “passing.” The phenomenon of “passing” is observed among other social minorities, for example, African Americans whose skin complexion is light, in order to “blend in” to the majority and avoid stigmatization (Goffman, 1969). Most of the interviewed/observed participants had “obvious” disabilities, and they had no luxury of “passing.” Tae was one of few who had a choice of the disability disclosure, which, ironically, provided her an intrapersonal conflict. This friction occurs, according to Deschamps (1982), based on the social identity of minority in terms of “objects” (as opposed to “subjects” for majority). He argues that

The former [the dominant] do not think of themselves as being determined by their group membership or their social affiliation. They see themselves above all as individualized human beings who are singular, ‘subjects’, voluntary actors, free and autonomous. Their group is first and foremost a collection of persons. This is not the case for the dominated who are defined as undifferentiated elements in a collection of impersonal particles, and are thought of as ‘objects’

rather than 'subjects' (Deschamps, 1982, p. 90).

Based on his theory, Tae's social identity as the non-disabled used to be the individualized one, or a "subject," and she did what pleased her - - wearing short pants in summer because "I didn't do anything wrong." However, as a person with a disability, Tae became an "object," a particle of "the disabled," and she was expected to behave accordingly. Using an example of mental patients, Goffman (1961) also argues that the self of the social minority does not belong to them, but it "dwells rather in the pattern of social control" (p. 168). Tae was stunned by this collective, not individual, social expectation for her as a person with a disability. Her disability journey, a moral career, only has begun in this social milieu.

Sports and disability adjustment

For the present research, approximately half of the participants were people involved in sport on a regular basis, such as basketball, tennis, archery, or table tennis. Their skills and devotions varied from semi-professional to having fun. While conducting interviews, the researcher frequently heard them saying, "I began to change when I started sports." Goffman (1961) recommends taking notes of people's turning points to trace their moral careers. For many interviewed participants, starting sports was a turning point for their disability adjustments. Therefore, this section discusses sports and the disability adjustment.

A. "There are so many of us who never even leave the house:" Three barriers to overcome

Prior to discussing sports and the disability adjustment per se, the researcher noticed that the participants cleared several hurdles to merely come to the places (ex., at

the hospital gym or recreation center). First, they all passed physical/physiological barriers, including securing means of transportation, living in accessible houses, and maintaining “healthy” conditions. The last, body care, was the foremost important issue. Among the common health issues, many participants (especially with paralyses) were greatly concerned with avoiding a bed sore and managing urine/bowel control.

The bed sore issue was quite critical for PWDs with paralyses. It is quite easy to get a bed sore (it takes only several hours for some PWDs), while it usually requires several days, even months, to heal it. With a bed sore on the bottom, a PWD only can do only few things while resting on the stomach, which is the best remedy. As a result of having a bed sore, doing sports, or even going out, becomes the secondary, trivial issue for the person. Needless to say, anyone’s mood and motivation (regardless of having a disability) is greatly influenced by one’s physical status; however, a person with a disability tends to have to take more factors into consideration.

Another major body concern for PWDs is control of bowel/urine movements. Many participants admitted that they were reluctant about even leaving home prior to establishing “toilet control.” Most PWDs with SCI usually had a few embarrassing episodes, which was an open secret among them (Mr. Ko said, “we all have the same problem”). For example, Mr. Ta “took four years” until he “established the toilet rhythm.” He used to be most fearful about having “accidents,” rather than being stared at, and he went through “many trials and errors.” Over the years, he learned several tactics, such as looking for “public places, like a police station or ward office” because “they usually have one (an accessible bathroom).” Many participants told the researcher they set a “number two day” and they decided activities based on that schedule. The

aforementioned Masa was one of those people. He learned from his past mistakes and he “never left the bathroom at least for two hours ‘till it’s all done.” Since there are few accessible bathrooms in town, many others reported that they often saved fluid intakes and ate less outside their home. In addition, the participants were amazingly candid and open in talking about their toilet habits. The researcher once visited the wheelchair-tennis practice. Before coming, she was warned that there was no wheelchair accessible bathroom at the court. To use a restroom, a person would have to drive back to the wheelchair table-tennis place in the same town. When she arrived at the court, the researcher noticed that there was a “Japanese-style” bathroom which required crouching and was useless for PWDs. An amazing moment came when she needed to use the restroom. She told a group of players with disabilities that she would go back to the table-tennis place to use the bathroom. Then, a man in the group asked her in front of everyone if she would need a “plastic bag.” According to him, most of the players there had plastic bags for self-catheterizing inside the cars, instead of driving to the table-tennis club. After a moment of shock, the researcher felt flattered by the offer because he asked her as a member of the in-group. If she were non-disabled and, therefore, could use the bathroom at the court, there was certainly no need for a “plastic bag.”

Unlike the bed sore care, controlling the bowel/urine movements has strong social connotations related to “personhood.” In today’s society, any person, except a child, is devalued as a human if s/he cannot control bowel/urine movements (Scheer, 1983). The excretion issue is closely intertwined with adulthood, including the notions of self-control and being independent. Therefore, people become quite fearful of losing independence when facing incontinence. Livneh (1991) points out,

Childhood stages of development (oral, anal, phallic, genital) were wrought with anxiety-laden premises regarding the etiology of certain illnesses; therefore, the association with ongoing disabilities and disabled persons, as past transgressors, is ready made (p. 183).

This fear aroused by seeing a person with a disability results in harboring avoidance and resentment against PWDs (and the elderly). For a person with a disability, the aforementioned physical maintenance was the minimum basis for returning to society and to having a social life again.

Besides physiological conditions, the physical barriers often hampered an individual with a disability from engaging in social activities. As mentioned in the previous chapter, living in inaccessible housing made it quite difficult for a PWD to leave his/her own house. Therefore, a newly disabled person was first advised to remodel his or her home at the rehabilitation hospital. At the same time, the doctors at the rehabilitation center would suggest strongly that the person (or a close family member) obtain a driver's license because public transportation in Japan is far from being accessible. However, having a driver's license requires financial assets³⁰ and family's acceptance about driving (again). The latter factor especially becomes crucial given that many of these participants acquired their disabilities by car accidents. Without a license, however, the person is most likely to be a "prisoner" at home.

³⁰ Unlike in the U.S., it is quite hard to obtain a license in Japan. Usually, a person (with or without a disability) spends a lot of money and takes at least three months to pass exams. For PWDs, there are some driving schools with dormitories where they can drive cars with hand-controls.

Securing transportation, via the driver's license is the first step to regaining independence.

The second issue is related to an information barrier before participating in activities. For example, the researcher was stunned when she learned that there were several table-tennis places available for PWDs in her own community. She happened to know about the clubs only after having associations with other disabled players for the present research. It was discussed in the ethnography chapter that the information for PWDs, from the latest assistive technology to small get-together parties, tends to circulate in a small circle of people at "information pooling places," and if persons are "out of the loop," the disability information is unreachable for them. For newly disabled individuals, this is a vicious cycle. These people are often afraid of leaving their houses because they have little knowledge or information for PWDs (and where to get it), and not leaving the house makes it more difficult to be in the information circle.

Finally, the third issue refers to a motivational/psychological barrier. Even if these indicated barriers were removed, many PWDs feel great anxiety and stress in reconnecting to outside society. This situation is especially true for those who stayed at "total institutions," (for example, hospitals) for a long time (Goffman, 1961). Mr. S, who was a veteran wheelchair basketball player at the "Eagles," asserted, "When a person becomes disabled and he is put in a hospital for a while, he adapts to the situation, no matter how horrible or unusual for the outsiders. The person soon wouldn't care even if someone is pooping in front of him." Humans are highly adaptable. The researcher finds this statement quite insightful; it alludes not only to a lack of privacy at institutions, which is quite common, but also to a desensitization to what it is to be

“abnormal” in a wider society. This is a consequence of a “civil death,” in which a person so adapts to the hospital environment that s/he no longer can function in the world outside³¹ (Goffman, 1961, p.16). In the a process of a “civil death,” the person’s contact with the outer society becomes less and less and fear for engaging in the society grows larger. More specifically, the core of this fear is a perceived communication difference/gap with others. An interviewed person comments that after having “stayed at home for a decade after the injury,” the person lost the “social skills.” and communication readjustment with people and this loss presented “the biggest challenge” to coming back to the community (Watanabe, 1993, p.37). In addition to communication differences, some participants for the current research reported that they could tell if someone lived in an institution from other subtle cues, such as clothing or facial expressions.

Considering these barriers for PWDs, coming to the rehabilitation hospital or recreation center, unfortunately, is an “accomplishment” for PWDs. All participants for the present study overcame the barriers, and they were, in many ways, more fortunate than others. A male participant stressed that “there are *so* many of us who never even leave the house.” (This fact indicates that there was a much larger “unreachable” population of PWDs, who were unable to come because they did not have those resources.) Nakagawa (1993) makes a startling claim that “among 70,000 disabled people in Kyoto, only 70 of them routinely enjoy sports” (p. 13; my translation). This

³¹ Goffman (1961) writes in “Asylums” that “civil death” starts with “disculturation,” stripping of one’s identity, at one’s admission to the institution, which is followed by a series of initiation ceremony to the institution.

fact suggests that the situation has not changed much for PWDs since the 70's when a surveyed PWD wrote that the person went outside three times in a month, for going to a hospital (Ukita, 1997). Given this environment for PWDs in Japan, let us now turn to sports and disability adjustment.

B. "Wheelchair basketball was like an oasis found in the desert:" How sports change PWDs

Mr. J went to the Paralympics several times, and now plays in an American wheelchair basketball team in Alabama. He quit his stable job in Japan as a public employee and came to the U.S. to play wheelchair basketball more seriously. He even published his biography recently (Jinbo, 2000). It is hard to imagine now that he used to shut himself up for years. Mr. J "cocooned" himself at home for two years after leaving a rehabilitation hospital where the environment was arranged for PWDs. He was thrown into an able-bodied society and felt completely alone (Jinbo, 2000). He was a tall person and used to "look down" on the world (literally and metaphorically), but after the accident, his sitting-angle created a completely different world view for him (Jinbo, 2000). In this wider society, he was surrounded by numerous barriers, and he felt rejected by the world. Mr. J hit the wall of reality, and gradually slipped into solidarity. In his book, he notes that during these years, he left home in the daytime only twice.

A silver lining came when he saw wheelchair basketball for the first time. Immediately, he joined a club in Tokyo and this changed his life. Mr. J (2000) describes his changes as,

... after the day [of watching the play], I soon became crazy about wheelchair basketball... My best-friend also noticed that I became much happier... For me,

wheelchair basketball was like an oasis found in the desert (Jinbo, 2000, p. 46; my translation).

Among the members of the “Eagles” and “Pirates,” Mr. Jinbo’s case was not exceptional. Many others expressed that starting sports gave them a chance to climb up from the bottom. Mr. Dai also turned a corner when he started playing for the “Pirates.” Until then, he had stayed at home for three years. When he first came to see the practice, he did not have a driver’s license, and his older sister drove him to the gym. His life also has changed since then. As the researcher listened to their stories, she became interested in adjustment to disability and sports for PWDs. More specifically, she sensed that engaging in sports for PWDs has a wider meaning than a mere physical activity. Many interviewees commented that starting sports led them to “*shakai-fukki*” (“returning to society”). So, the question is: How have sports changed their lives and influenced their disability adjustments?

Another participant and Paralympian, Hiroko has “changed quite a lot” since she started wheelchair-tennis a decade ago. Prior to that time, she was depressed by sudden social and physical changes as a result of her disability. She was deeply hurt whenever “kids were staring and the parents steered them away.” One day, her friend at school brought her to the tennis courts to watch practices. She was stunned to see wheelchair players moving so fast and powerfully that she could not believe they were also PWDs as she was. Witnessing what PWDs can do amazed her. During the first years, nevertheless, Hiroko was not so serious about playing wheelchair tennis and dragged herself to each practice because tennis coaches persistently called her to come. While she could not say “no” to coaches for those two years, she gradually changed. Hiroko

decided to get a driver's license because she did not like the situation where "everyone else drove a car to go to the tennis courts and game places, except me and I was still relying on my parents." Her teammates also changed Hiroko's perceptions toward PWDs which she said that they were "depressing and pitiful." Vexed by losing in many games, she became more involved and serious with wheelchair tennis. She met her husband through tennis, married, and moved to C-prefecture. Above all, she became "tougher," and declared that "others can stare me as they want."

Mr. Haya was in his 60s and played archery and table tennis. He and the researcher stayed at the rehabilitation hospital during the same period of time. The researcher remembered that Mr. Haya's wife and family were always supportive, and she never saw Mr. Haya depressed or angry. After many years of knowing him, the researcher had an impression that he never had a difficult time adjusting to his disability. However, despite her assumption, Mr. Haya told the researcher that he too avoided leaving his house, even go to the backyard. Many of his friends came to see him, but "I [Mr. Haya] didn't want anyone to see me in a wheelchair." He started to heal when he learned how to play archery several years after the accident. Since then, he began reconnecting to society by going to games. In addition, meeting with other players with disabilities had a great impact on his disability adjustment.

I met a lot of people around the country while playing archery. Some people's disabilities were more severe than mine. I compare theirs' with mine, and I am often encouraged to play more by them. And, I could make many good friends [with disabilities through archery.] We see each other once or twice in a year.

Each time, we tell each other how we're doing... Also, we support each other by exchanging information.

Most of all, Mr. Haya "became emotionally strong" and "didn't care about staring people anymore." When the researcher asked Mr. Su about sports for PWDs, he told her:

I think sports and the disabled's "*shakai-fukki*" ("returning to society") and regaining "*jiritsu*" ("independence") are related. By all means, people can be positive by doing sports. If your teammate has a job and plays sports, you'd want the same things... Seeing someone coming to practice from work makes you feel you're left behind...

Another "Eagles" player, Tu also noted that "I decided to get a job because I wanted to play basketball. I began to think I want to work using skills I learned while playing basketball." In fact, most of the players in the "Eagles" and "Pirates" had full-time jobs, and some unemployed players started working while the researcher was conducting the present research. Mr. Su further told the researcher that:

I started to change two and half or three years after starting to play basketball. four years since the accident. I was chosen for the All-Japan team, and others started to see me in the media. I was no one before the accident. Seeing myself in a wheelchair on TV or newspaper made me be conscious that I'm disabled. If you're confident about yourself, others' staring doesn't bother you much.

Take thought that engaging in sports influenced interpersonal relationships. Soon after he entered a vocational school where he met other players, he learned that he would need to overcome his shyness because he "can't live without communication with

others.” As a person with quadriplegia, he needed other’s constant help. Unable to use his fingers, he asked a child to put money in a vending machine. Each time, he needed at least two people to transfer him to his basketball chair. Someone had to take his basketball wheelchair out of a car. He was “physically” dependent in many ways. As argued previously, PWDs are expected to maximize their physical and psychological independence as much as possible. Especially in the context of sports, in which this cultural theme of self-reliance and autonomy is celebrated most, PWDs are put in a dilemma when needing others’ assistance (Promis, Erevells, Matthews, 2000). Additionally, despite existing laws mandating the rights of enjoying sports for all Japanese citizens, a deep-rooted Confucian ethic, “no work, no play,” often makes PWDs feel guilty for participating in sports while not being employed. Nevertheless, in order to enjoy a sport, Take and others no longer became anxious about relying on others. Participating in a sport taught Take that sometimes PWDs needed help from others to enjoy what they loved, and it was OK.

The aforementioned Mr. Su also pointed out intrapersonal change resulted from sports participation. He said:

“Not being able to walk” and a disability inevitably influence our social life because it is not about “not walking,” but is about “can’t walk.”... When being confronted by stairs, we can do two things; either curse our fate of “can’t walk.” or unconsciously turn around and look for a slope, “not walking.” Through sports, the “can’t walk” thinking tends to weaken, though I wouldn’t say it goes away completely.

Mr. Su's comments above summarize sports and disability adjustment. According to him, sports activity facilitates the decreasing the "can't walk" mentality in a PWD because meeting other PWD athletes can show the person other possibilities of the "not walking" way of life.

Positive consequences of having a disability

It is true that many participants had friends who drifted away after acquiring disabilities. Some terminated friendships because they no longer could do such activities as fishing or baseball together with the old friends. Others were passively avoided by the friends "who did not know what to say" to them. When Mitsu, who was a high school student when injured, returned to school, he became "famous" because "I was the only student [in a chair]" and "even teachers I don't know ask me if I'm doing fine." Mitsu used to think his friends at school would become hesitant to talk to him after having the disability. Despite his "fame," his school friends did not change at all and that surprised him most. He told the researcher the most positive consequence out of having the disability was "people I met afterwards." He explained as follows,

Before I was injured, my relationship with my friends was rather superficial. I assumed it wouldn't last after graduation. Now I discovered many friends at school whom I can see for the rest of my life. They treated me no differently than before the accident and I am grateful for that.

During the interviews, the researcher asked all the participants if there was someone who drifted away after having disabilities. To her surprise, she heard mixed responses. Some participants, including Tu and Mitsu, insisted that none of their friends left them because of the disability. Others agreed that the disability experience "filtered" pre-

injury-relationships. Some people left, but those who stayed have become life-long friends for the participants. Keiko, whose marriage was ended soon after her illness, also raised an interpersonal relationship as a positive disability outcome. She discovered the “world of the disabled” which she would not have known unless she acquired her disability. Although her divorce was painful, she felt that “my ‘vocabulary’ as a person has increased” and that she “has grown” because of her disability experiences. Mr. J agreed with Keiko in the light of adding to one’s “vocabulary.” He now “understands both sides.”

Having experienced being both able-bodied and disabled, I can say that what I could see as able-bodied and what I realized and felt as disabled are quite different. My perspective [as a person with an acquired disability] is different from those who were born with disability or the able-bodied with the deepest sympathy. I truly sense this difference. There are so many things I didn’t have a slightest idea of when I was able-bodied.

Mr. J believed this “knowing both lives is the best thing” for PWDs with acquired disability because “if born with a disability, you wouldn’t know the able-bodied’s feeling. Without a disability, people don’t know where the disabled are coming from. Having lived both lives is someone’s valuable asset.” Phenomenologically speaking, acquiring one’s disability gave a different viewpoint, or a “vital horizon,” that is an “atmosphere of mute, concealed, but co-functioning validities” (Husserl, 1970, p. 149). This “horizon” never completes; it is in a constant change, just as the same scenery is perceived differently as one proceeds. Hiroko also mentioned self-determination as a personal growth resulting from disability. She told the researcher

I became tougher, emotionally. [When I was able-bodied,] there were many ways to avoid things you don't want. I used to give up easily before. My disability gave me a chance to face myself truthfully, including living in the disabled body... I don't deny difficulties because of the disability. But I also could have experienced many good things because of the disability. So, nowadays, I don't feel uncomfortable with my life in a chair. I have gained more than I lost.

Murphy (1990) similarly experienced this "situation without loophole." He states that he used to run errands, or do chores such as painting the house, to avoid facing his work. However, he accomplished more in his work due to narrowed focuses from his mobility restrictions; he could do nothing, except writing and reading.

While some "never come up with good things about having a disability," many others could point out at least one or two. Tu said, "there are so many good things which have happened because of having a disability. I can't think of too many bad things." For him, the best outcome was "I could find a goal in my life and a job I like." The researcher further asked him whether he could not have found these without experiencing a life with his disability. He replied as follows,

I had the accident when I lost my goal in my life. Before the accident, I did nothing but *kendo* ("Japanese fencing") at junior and high school. I was so into *kendo* that I hardly studied at school... when I stopped practicing [in his senior high school year], I found myself so empty - - being nobody. Then, I started getting involved with a series of troubles 'till the accident.

He was convinced that the accident was “a wake-up call” to find meaning in life and “who I am.”

A life is a continuous flow in which daily routines have been accumulated over time, and many of us do not have a chance to stop to reflect on our lives. This everyday, mundane life, however, was discontinued when the participants acquired their disabilities. Soon, they were “removed” from their familiar environments, and admitted to hospitals as the patients. As Parson (1951) notes, while people stay in the hospital, they are temporarily suspended from their social roles and obligations, and the only persona they have is “the sick people.” Removing layers of one’s ordinary roles, expectations, and interactional scripts boils down to a bare “self.” Many participants reported that in the early period of having a disability, they had plenty of time to think, and all they could think as they were lying in their beds. Although it was true that having a disability was not their choice, the participants were given an abundance of time and an opportunity to reexamine their lives and ask “who am I?” Many things, including interpersonal relations and the self, were reevaluated after the disablement, and many participants raised this point as a positive disability consequence.

Discussion

This researcher gained a wealth of information by listening to the participants’ stories about their lives with and without disabilities. This chapter outlined their transformations from being the non-disabled to PWDs by extracting the “essences” in their experiences. Conducting both main interviews and follow-up interviews was especially beneficial for the researcher. The later interviews clarified their accounts, compared the data between the years, and “broke ice” with participants. Indeed, the

researcher could observe some participants' drastic changes as she returned to home. Some of Masa's experiences as a PWD, his moral career, were shared with other participants. For example, some participants noticed their mood change as they started using a wheelchair and seeing the world from waist-high.

As illustrated in the previous ethnography chapter, a rehabilitation hospital was one of very few "disability-centered" places in society. People there were usually more understanding than people elsewhere, and physical environments were coordinated for the needs of PWDs. However, a hospital environment was not found in the outside world. As such, a "real" disability adjustment, the challenge, started when a newly PWD was discharged from this comfortable environment. As the participants indicated, a reentry to society often made PWDs aware that they were no longer the same persons as before the pre-disability time: their social role transformed into "the disabled." Many participants were reluctant about using a wheelchair because of its stigma. This situation also changed as time passed and the participants started to accept the chairs as a part of themselves.

Acquiring a disability was not a mere physical change, rather, it had a significant impact on interpersonal relationships. (This is a reason that disability research with a communication perspective is crucial.) The participants' communication with their families was often changed after incurring their disability. Some relationships died while others were strengthened. Going beyond communication within the family, some participants reported "mediated" communication between PWDs and the non-disabled. The "wise" sometimes play a role in bridging this kind of communication. Another interesting theme pertaining to the disability adjustment was "outgroup homogeneity"

and “ingroup heterogeneity.” Many participants used to have negative, depressing images toward a group of PWDs despite of the fact that they had no close friends or acquaintances with disabilities. As the non-disabled, their perceptions of PWDs were homogeneous - - “the disabled used to look all the same.” The participants had no information or motivation to diversify their views of PWDs. However, after acquiring their disability, they increased disability information, changed their PWDs perceptions, and had more interpersonal categories of PWDs. This process is well documented in intergroup research, i.e., people have more ingroup information and see themselves as a heterogeneous group than they have information for outgroups and view the outgroup members as a homogenous group. The researcher once saw a television program about the “peace” camp for Palestinian and Jewish youngsters where they spent several weeks together in the U.S. This camp was intended to develop “interpersonal” ties among the children and to break down an “intergroup” climate. Starting from a “Jews verses Palestinians” atmosphere, which was impersonal and “faceless,” those children gradually began to see each other as people with names and personalities who happened to be Jewish/Palestinian. This is a process of “personalization” of a group of people which occurs with an information increase. The participants for the present research also experienced this path as they interacted more with other PWDs.

From the interviews, the significant notion of “becoming the disabled” emerged. These individuals experienced the transformation of social status (from people who stare to people who are stared at), and became the minority in their own culture. Although being a PWD and being a racial/ethnic minority share several communication issues, such as stereotypes or emotional arousal in interpersonal encounters, (Coleman &

DePaulo, 1991), this notion of “becoming” raises a fundamental difference between these groups of people. In other words, when one was born Japanese, for example, s/he will remain as such for the rest of his/her life. Moreover, a Japanese child is generally born from Japanese parent(s) and is raised in a Japanese family. In contrast, many PWDs acquire a disability after their birth and had lives as the non-disabled, which was the case of the participants for the present study. Most of PWDs were born from the non-disabled parents, and children with disabilities have few opportunities to see adults with disabilities as their role models to internalize. Yokota (1989) quotes Yokozuka’s comment as, “CP people’s curse is that they don’t have a child with CP” (p.63). Yokota (1989) elaborates this curse as follows:

When a CP person has a normal child, the person reflects his or her desperation for normalcy on the child. As a result, the CP person sometimes suffers from self-hatred [of not being normal] (p.63; my translation, parentheses added).

The aforementioned points indicate that a group of PWDs tends to have a less vertical, biological continuity than racial/ethnic groups of people do, and because of this tendency, PWDs seem to have a difficulty in positive self-affirmation compared to other groups of people.

While there is a universal characteristic among PWDs, a strong cultural influence pertaining to the disability and PWDs also exists. In Japan, many people still believe that having a disability is a punishment resulting from a different life. Yohda (1987) contends that a family (especially the mother) of a disabled child is often isolated and accused for the child’s disability. According to Yohda (1987), a typical reaction from the relatives is searching for a “criminal,” who is responsible, through a blood

relationship. Some relatives suspect a bad karma of an ancestor (eg, who killed a snake by mistake) while others blame the other family side's defected gene (for the case of a congenital disability).

In addition, social stigma associated with a disability is highly "contagious" in Japan (Iwakuma & Nussbaum, 2000; Namihira, 1977). A concept of "*kegare*" includes anything considered social disorders, abnormalities, and outside of Gods' blessings (Matsudaira, 1946; Namihira, 1977). "*Kegare*" includes such things as the sick, death, natural disasters, unclean things or people, the blood, and "the disabled" who physically deviate from normalcy (Matsudaira, 1946; Niimura, 1989). Niimura (1989) analyzes that after the Heian period, discrimination against "the disabled" was strengthened based on the "*kegare*" and karma beliefs. The latter, the notion of karma, has become popular from Buddhism which includes reincarnation. Even Buddhist priests cannot be free from "*kegare*" of having a disability. It has been customary in Japan that once a priest becomes "disabled," he is deprived of his priesthood and has to leave the temple. Additionally, this "pollution" is perceived to spread through the kinship (Namihira, 1977). As a result, although the Japanese today may seem to be modernized, it is not uncommon that a family member (without a disability) of a PWD is refused a marriage by the fiancée's family from the fear of contacting "*kegare*." In sum, people with disabilities in Japan have been viewed, especially in the past, as follows: they are "polluted/polluting" people sometimes for their wrongdoings in a previous life, and most of all, they need to be isolated from the society for not disseminating their "*kegare*." This researcher suspects that this belief system pertaining to PWDs has contributed to the separationism in Japan and that discrimination against PWDs is harsher than in the

U.S. For example, unlike in the U.S., rehabilitation hospitals for PWDs in Japan are usually built in remote, isolate areas (Onaka, 1997). As described in ethnography, the rehabilitation hospital for the present study was one of those “isolated” hospitals, and people staying there were disconnected from the rest of the society. Mae also commented that, especially in a country-side, the families of PWDs keep PWDs inside, just like the case of Mr. Taka. For these stigmata of “the disabled,” it was well understood why Japanese, including the participants for the study, were quite fearful of having a disability.

Tae’s “passing” episode uncovered that the conformity pressure of being able-bodied, or being “normal,” was quite strong. Many people with amputations wear “cosmetic” prostheses despite fact that they function better without them (Frank, 1988). Not only those with physical disabilities, but also many people with sensory disabilities, such as “the deaf” or “the blind,” try to “pass” as able-bodied (Goffman, 1963; Phillips, 1984). The issue of “passing” also is related to the body aesthetic and normalcy. What is “normal” is good and praised, and should be pursued, on the other hand, what is “abnormal” is bad, shamed, and needs to be hidden, if not removed. When the researcher was attending her special high school, the students with disabilities there had a popularity vote at a school festival. This innocent voting reflected upon rather “realistic” views of those students concerning “who is the cutest and most likeable.” Interestingly, those “popular” girls had less severe disabilities and therefore, looked more “normal” than other girls did. Interestingly, people without sight are also not free from “visual” aesthetics defined by the sighted people (Kuramoto, 1998). Kuramoto (1998) mentions an episode regarding his friend who cannot see. This person once

introduced his girlfriend to his sighted friend. The sighted friend later commented to him that the girlfriend was not so pretty. This remark made the girlfriend less desirable to her boyfriend despite the fact that he never saw the girlfriend's face. These stories illustrate that socio-cultural standards of what is "normal" or "beautiful" defined by the non-disabled are shared by PWDs, and that PWDs are under a great pressure to pursue those qualities.

The next section of this chapter is devoted to how sports participation influences disability adjustment. First, the researcher detailed three barriers that PWDs needed to overcome in order to be integrated into society. Then, the researcher illustrated how sports participation has changed many participants' lives. Through sports, these PWDs seemed to have cleared three obstacles (physiological/physical, informational, motivational obstacles). For example, securing transportation and getting useful information to go out are two important aspects to start. In fact, once a newly disabled person is included in a sports group as a peer, the person gains access to disability information that helps to break down these barriers. Psychologically, seeing others with disabilities who were active and living a "normal" life made the newcomers motivated to be challenged further, to feel good about themselves, and above all, to become comfortable about being one of "the disabled."

While overwhelming research pertaining to the negative consequences of acquiring a disability exists, several positive outcomes also mentioned by some of the participants are raised in concluding this chapter. Some participants mentioned improved interpersonal relationships with the friends. Others pointed out a personal growth by knowing both the non-disabled's and PWDs' accounts, which is

phenomenologically called, “expanding horizon.” As Mr. J commented, most PWDs live in both societies. Individuals with acquired disabilities in their later life added a new bulk of “vocabulary” by communicating with the disability community, which has different values, agendas, and worldviews that stand in sharp contrast with the non-disabled’s. Some participants for the present study have thought that having multiple “languages” is a positive thing, something that came from painful disability experiences.

CHAPTER VI

ESSENCES OF DISABILITY EXPERIENCES

In this chapter, “essences” of disability experiences are extracted by the free-phantasy variation method, which Zaner (1981) calls “the most significant and important phenomenological method, the most powerful and most fruitful” (p.244). The method of free-phantasy variation is one of the ways to reach essences in phenomenology. Zaner (1981) describes the method as follows:

The method of free-phantasy variation is itself the “way,” the method, for detecting and grasping contextures. Out of the *context* or *field* of actual and possible examples (“parts”) there emerges a *contexture* (“whole”): the invariant, the common, the *eidos*. *In brief: what are called “essences” turn out to be contextures appearing (reflectively) from a wider context, a field. The “essences” of whatever it may be is thus a “whole”: that is, a system (significance) which is the totality of the functional significances (intrinsic references) exhibited by each of the actual and possible constituents (“examples”)* (p.248; emphases in original).

Furthermore, Zaner (1981) claims that the “wholeness” paradoxically emerges by a prominent absence. This prominence by absence method is especially helpful in analyzing experiences of those having chronic illness or a disability in which the body is in disturbance. The body is not just the sum of parts, but it is a “grouping of lived-through meanings which moves toward its equilibrium” (Merleau-Ponty, 1996, p.153). The lived-body is “forgotten” under normal circumstances; however, once s/he experiences a pain or sickness, the body calls for attention. The equilibrium is disturbed, and the person suddenly “remembers” the bodily existence (Baron, 1992; Tooms, 1992). For example, a person becomes conscious of the fact that s/he has a head only when having a headache. Similarly, acquiring an impairment renders a more keen bodily consciousness in order to restore a new equilibrium (Zaner, 1981). For a newly disabled person, each bodily act, such as wearing a sock or raising a knee, becomes a conscious, unhabitualized task to accomplish: the body becomes the center of attention. Additionally, since the body is the medium for all perceptions, one’s disability alters his or her being-in-the-world, including temporality, spatiality, relationships with others, and the self (Tooms, 1992).

Several dialectic themes pertaining to the participants’ disability paths will be mentioned in this chapter. Braithwaite and Harter (2000) argue that PWDs “constantly find the need to strike a balance between living in the able-bodied and disabled worlds and manage ongoing oppositions ever present in their relationships, oppositions that can be heightened by the presence of disability of one of the partners” (p.21). Yoshida (1993) theorizes that the self of PWDs keeps swinging between the polarized identities between the self as the non-disabled and the self as PWDs. Both identities reside in

individuals with a disability, according to Yoshida, and the identity formation is not unidirectional. In a similar vein, Westhaver (2000) finds several binary themes (including, I felt different/I felt disabled—I am different/I'm not different, ability—disability, and masculinity—femininity) in her participants' accounts. In summary, the disability adjustment is a never-ending process in which seemingly contradicting themes coexist. Now, let us turn to these temporal and spatial senses that are disturbed by disability.

Embodiment of Disability

Any person knows from past experiences that when working hard or having a good time, time does not exist, or a tick of clock becomes like eternity when having a tense time or excruciating pain. Time “bends” in relation to one's state of being. Also, when being bed-laden for awhile, one's spatial sense “shrinks” (Toombs, 1992). These incidents indicate that both time and space have a subjective dimension, as well as an objective, measurable dimension (Merleau-Ponty, 1996; Husserl, 1962). Above all, the body is the medium centered in the world that perceives time and space, and the body creates different subjective experiences pertaining to time and space (Toombs, 1992). In relation to disability experiences, Toombs (1992) asserts that temporal and spatial senses of PWDs are not the same as the non-disableds' for different bodily experiences.

A. Temporality

In the ethnography chapter, Tu commented that hospital time is slower than the outside time and that once a newly disabled person is discharged, the person needs to catch up to the pace of others outside the hospital. While the researcher was observing or listening to the participants, she sometimes felt that they were living in a different

time zone from the non-disableds'. Although the researcher did not ask questions about their temporal sense (she did not know how to ask), she retrospectively remembers several incidents.

Goto was a young man with quadriplegia. Once he told the researcher that it took twenty minutes to get his chair out of his car. His comment shocked the researcher because for her, it takes less than thirty-seconds. Goto further explained meticulous techniques in this task. Indeed, taking the chair in and out was the “task” to be accomplished for Goto while the same act was part of a “process” in the flow of locomotion for the researcher. The researcher cannot remember how she completes the task anymore, just as the non-disabled cannot explain extensively how they drink a cup of coffee or how they get up from the couch. Hull (1990) who has a progressive blindness notes, “You [people with disabilities] are no longer fighting against the clock but against the task. You no longer think of the time it takes. You only think of what you have to do. It cannot be done any faster” (p. 80). For those people like Goto, Haru, or Mr. Ko with the most severe disabilities, nothing is taken for granted. They have to be conscious and alert with each move. Since PWDs with severe disabilities allow much more time for each task to be finished, it appears that they have more spare time than others with less severe disabilities. Actually, they do not. Mr. Taku whose impairment was also quadriplegia told the researcher that what he usually accomplished in the morning was “literally” getting up and being ready for the rest of the day. He was busy all morning with this task, and this may sound strange for other people who do not share his temporal sense. It is not surprising, thus, that the non-disabled who are “trying to cram every minute with necessary tasks and to squeeze the last drop of time” (Hull,

1992, p, 78) get frustrated with a PWD who impatiently allocates ten minutes to put a shirt on or fifteen minutes to brush his or her teeth. Above all, a newly disabled individual feels baffled with his/herself for this “stretched” temporal sense because the person can no longer “squeeze” his or her time, and for being surrounded by newly emerged numerous tasks which used to be assumed in pre-disability time. This temporal change unavoidably influences the nature of interactions of the PWDs with others. As mentioned, Yoshi gave up going to over-crowded places, where he used to love the atmosphere. After his accident, however, Yoshi realized that he could no longer immerse himself into a flow of people. He could not keep pace with the non-disabled anymore. Just like Yoshi, other participants also commented that they withdrew from associations with old friends from the pre-injury time for fear of disturbing activities. Their concern was about being “in sync” (or “syncing”) with others (Hall, 1983, p. 232). According to Hall (1983), a group/culture of people unconsciously define the unique rhythm among them. If a person cannot be in sync, s/he not only disturbs the tempo of the group, but also feels left out.

In addition to the notion of being “in sync” with, a lack of spontaneity is also recognized regard to the disability experience. To illustrate, the researcher obtained a driver’s license at the age of 19 (as a college sophomore). Prior to having the license, her mother drove her to and from school, or anywhere the researcher wanted to go. Everyday, her mother drove the car for fifteen minutes to the college in the morning, and the researcher called her from school when the classes were over. Although the mother always encouraged the researcher to hang out with her friends after school, she did not have her own transportation, and her mobility was restricted. She could not plan her

schedule by herself without coordination with her mother's schedule. The researcher's time was not only hers, but it was interlocked with someone else's. If a person was scheduled to participate in numerous meetings or group activities despite his or her will, the person would feel frustrated or powerless. The source of distress in these examples comes from a lost sense of control of his or her own time. Being able to rule someone's time is ruling the person (Ikeda & Kramer, 2000). Conversely, giving up one's scheduling time signifies his or her submission to others (Goffman, 1961).

In the light of disability adjustment, newly disabled individuals need to change their temporal coordination. For example, Yoshi who had quadriplegia seldom stayed at home in his pre-injury life. Now, he said, "I still want to go out everyday." During the interview, however, he admitted that he spent "more time at home than before" because "on a bathing day," he "must go straight to the bed [from the bathroom] and spend the rest of the hours on the bed." He needed other's help, so, his schedule, from taking a bath to coming to the rehabilitation center, was coordinated with his family's. This coordination with others is what Schutz & Luckmann (1989) calls "reciprocally immediate work" which is "performed in the common surrounding world with synchronization of the actor's inner time" (p.83). As mentioned, Yoshi described how his personality after acquiring the disability softened down. His adjustment to new time controlling tasks might also have contributed to his personality change. Generally speaking, the more severe disability one has, the more time sharing with others was noted. Additionally, sharing one's time renders a lack of spontaneity. Mr. Ko, who had the most severe disability among the participants, needed to plan everything ahead because his time was tightly intertwined with his wife's and helper's. Nothing could be

done “on the spur of the moment.” People with more severe disabilities seemed to have a longer list of things to be attended to than PWDs with less severe disabilities. Agich (1995) notes that a disability or chronic illness experience disturbs the temporal experience between the decision to act, the action, and the result, which in normal circumstances, this temporal stream flows without stagnation. Some people may be able to make their own choice, but unable to act upon this choice without others’ help. In this case too, their habitual temporality between the choice of action and the action itself is hampered. Newly disabled people, especially those with severe disabilities, need to adjust to coordinating their time with others and losing spontaneity as a part of the disability adjustment.

B. Spatiality

Both in the U.S. and Japanese cultures, “standing” renders moral connotations, such as “standing up to” or “standing on one’s own two feet”; therefore, a standing ability signifies one’s autonomy, independence, and willfulness. As noted in the previous chapters, some participants were uncomfortable with the idea of sitting in wheelchairs despite their practical merit. Straus (1973) argues, “[U]pright posture is not confined to the technical problems of locomotion. It contains a psychological element... Upright posture characterizes the human species. Nevertheless, each individuals has to struggle in order to make it really his own. Man has to become what he is” (p.232-236). Christopher Reeve, the former “Superman,” has been a quadriplegic with a respirator since his horse riding accident and is determined to walk again. Several years ago, he appeared on the Superbowl commercial. In the commercial, Reeve’s name was called out at a ceremony; he gradually rose up out of his seat, and walked down the aisle,

which was, of course, all digitized to create his ultimate dream. Nevertheless, it is interesting that “walking” was a primary focus. In the ad, the act of walking (rather than using his hands or even breathing without a respirator) culminated Reeve’s cure, defiance, and hope.

While walking and standing encodes such symbolic meanings as independence and determination, being unable to stand or walk often means, in contrast, passiveness and dependency (Straus, 1973). In addition, the sitting posture has a larger impact on PWDs psychologically than a mere physical sense (Scheer, 1983). Masa, who insisted on walking in 1999, believed he would look better when standing. Tooms (1992) noticed that when using her wheelchair, a stranger often talked to her husband and referred to her as a third person (“Would she like to sit at this table?”). Many other participants in the study also experienced this reaction. Another participant, Mr. Atu hoped to use prostheses so that he would be able to keep his standing height. His legs were amputated below the thighs because of a farming accident. When the researcher met him in 1998, his wife was expecting their first child. Mr. Atu felt especially sad for the unborn baby because the child would never see him standing on his own feet. Some participants were resistant to the chair and “sitting” because of the negative symbolism.

Additionally, participants experienced a disability adjustment from standing to sitting which manifested in a radical shift of “mobile body-zones” (Zaner, 1981, p.61). These zones rule “the distinctive forms of seeing, hearing, reaching, grasping, and holding, as well as the primary forms of spatiality, gesturing, and social deportments” (Zaner, 1981, p.62). For instance, when the researcher goes to a cocktail party, she often sinks into solitude despite the fact that she is surrounded by a group of people.

Everyone else at the party talks to each other while standing, and all the conversation takes place above her head. She feels as if she is at the bottom of the stormy ocean - - no matter how rough and noisy on the surface, it is serene beneath. When two people standing and the researcher happened to be talking at a party, those standing seemed to have difficulty keeping eye contact between each other and the sitting researcher because with the researcher, they had to shift their gazes vertically which was unnatural and awkward. Soon, the researcher gave up participating in the conversation. The researcher's experience was not an isolated case, but other wheelchair users also experienced the same situation (Murphy, 1990; Mairs, 1996). In this case, it was "spatially" inaccessible for her to join the conversations. PWDs who use wheelchairs have a different lived spatiality from standing individuals (Scheer, 1983), even if they share the same space. Straus (1973) notes, "Upright posture pre-establishes a definite attitude toward the world" (p.235). Correspondingly, wheelchair users and standing people have a different "attitude toward the world," and therefore, their being-in-the-world is also different. This statement alludes to the idea that by acquiring a disability, a newly disabled person faces an adjustment to a new attitude toward the world and being-in-the-world.

C. A wheelchair and embodiment of disability

For many participants, the wheelchair was a symbol of dependence as well as independence. Some people with disabilities became repulsed about using the wheelchair at first. Because of their pre-disability perception of "the disabled" that was quite negative and pessimistic, these PWDs refused to associate with anything that had to do with "the disabled." These individuals saw the chair as a symbol of being "the

disabled,” and most of all, their new dependency. These participants avoided this “symbol of disability” (the wheelchair), it was not a mere object at all, but it carried a larger meaning, mostly negative, for these people (Murphy, 1990, p.61).

Since a chair is individually measured and manufactured as a replacement for the participants’ legs, it is not, therefore, anybody’s chair, but his or her own. Using “my own chair” created an internal dilemma within the participants who were avoiding the “dependency” symbol (the chair), and longing for physical “independence.” Yoshi’s remark, he “can’t be in such a thing (the wheelchair) forever,” but he “can’t function in daily life without it” symbolizes that these conflicting themes coexisted. People like Yoshi had an ironic inner conflict because the chair was meant to help them to get around, rather than to cause them additional pain. However, as time passed, newly disabled individuals started embodying the chair, the symbol of disability, into their flesh. Soon they embodied a new “mobile body-zone” of sitting, including reach and width; these PWDs “extended their bodily synthesis,” as Merleau-Ponty (1996) would put it. Embodiment amounts to an extension of their somatics, a new body-consciousness.

As the chair became a part of his or her self, the inner conflict with it seemed to be resolved. The researcher repeatedly saw that wheelchair athletes were spending quite some time adjusting their sports chairs before each practice (Iwakuma, 2002). Their chairs became half-flesh and half-object. Their adjustment was an embodiment process, and these athletes were engineering their legs. As a result, these skilled athletes could tell right away if a single nut of the chair was too loose or tight. Not only these disabled

athletes, but non-athletic participants nowadays feel the ground through the chair; they too “extend” their bodies as a result of the disability adjustment.

Integration—separation

The researcher met a woman with a disability at a table-tennis club. She once told the researcher that “before coming to the club, I had lived only in the able-bodied society. I got married, had kids, and knew few other disabled. I guess I was satisfied with the way it was and never questioned my life. But when I started coming to the club, I realized that I felt at ease more because I was with others who had similar experiences with mine. I feel comfortable.” Her comment above illustrates the dialectic tension of integration-separation which many PWDs are attempting balancing.

There have been worldwide “integration” and “normalization” movements for breaking the barrier lying between PWDs and the non-disabled. Additionally, in recent years, the term, “barrier-free” has become a buzzword in Japan in order to integrate PWDs into the larger society. Everyone agrees that integration is the way to go (Oliver, 1996). However, as mentioned in the previous chapter, there were several disabled-oriented places where the participants with disabilities gathered, and disability information was pooled. In many ways, these places were special and separated from the world outside; nevertheless, many participants said those places played a vital role in their disability adjustment because they were able to talk to others with disabilities and exchange information. Most of all, they seemed to be very relaxed and comfortable in these places. For example, the rehabilitation hospital was a “saloon” for Mr. Ko and many other participants. Mr. Ko once commented that “the hospital is very comforting, to tell the truth. The place is my second life itself after the accident. We can exchange

information here. We can talk a lot because we understand each other. Communicating with the disabled here is quite different from talking to the able-bodied.” Under the integration theme, however, “separationistic” places were considered out-dated, or even discriminatory spaces. Not only the non-disabled, but also PWDs themselves have internalized this rhetoric that separation is nothing but negative. A woman with a disability confesses:

I love the so-called disabled places, like a sports center for the disabled. I feel at ease when playing sports there. But I used to have a great fear in accepting what I truly feel... I used to deny myself being comfortable and relaxed in these disabled places with other disabled. I used to label myself as a weak person to feel that way (Tsutsumi, 1998, p.94; my translation).

She was bound by the “integration” spell, and denied her inner feelings that she preferred the disabled places. Tsutsumi (1998) was educated in integrated schools with non-disabled students, but she had constant pressure to “try harder” to keep up with her non-disabled peers. The first time when she was released from this pressure was being at a camp for children with disabilities (Tsutsumi, 1998). Interestingly, even Judy Heumann, who was an assistant secretary for the Office of Special Education and Rehabilitative Services in the U.S. Department of Education, felt the same way when she joined summer camps for kids with disabilities (Shapiro, 1994). Just like Tsutsumi, Heumann always felt different from her non-disabled peers but found peace in her mind by bonding with other youngsters with disabilities at these camps.

While observing and listening to the participants, the researcher noticed this tension between integration and separation. When the researcher asked about the need

for “integration” or “normalization,” not surprisingly, no one disapproved of these ideas. All participants hoped that more places would be “barrier free” because PWDs today, by large, choose places based on where they “can” go, rather than where they “want” to go. Nevertheless, while they embraced the notion of “integration,” the participants could not let “separationism” go. As Mr. Ko admitted, many participants with disabilities felt that they needed those separationistic spaces for themselves. These “information pooling places,” including the rehabilitation hospital, were essentially separationistic; however, many participants seemed to feel comfortable precisely because the places were “special and isolated” from the rest of the world. Many ex-patients kept going back to the rehabilitation hospital mainly for socializing with their hospital friends, despite the fact that they had local hospitals in their communities. Although these local hospitals were also equipped with rehabilitation facilities, these people would be minorities in these hospitals. Accordingly, when the researcher asked the participants whether disabled-oriented places would or should be discontinued when society becomes fully integrated, mixed feelings were expressed. Keiko noted that “they [the information-pooling places] won’t have to be closed. Some people would feel at ease in those places.” Take, the captain of the “Pirates,” who commented about the recreation center for the disabled, “to be honest with you, I hope the place will remain [the way it is now]... although this might be a selfish idea, we need places where the disabled can meet each other. No matter what, we are not the same as the able-bodied.” Similarly, Mr. I who was a Paralympics player contended, “[even if society is completely integrated,] these places should exist and be available for the disabled. I believe we need those exclusively-for-the-disabled places. If the able-bodied come to those places, it is very possible the

disabled are pushed out.” These individuals were conscious of what Murphy (1990) articulated:

But no matter how well they become assimilated into society, their struggle sets them apart from the able-bodied fellows, they have a different history and follows a separate agenda; they remain part of the Other. Their otherness, however, is positive and creative, for their self-assertion is a profound celebration of life (p.161).

In the light of a difference between a disabled-centered place and an accessible/integrated place, Mr. Ko told the researcher about his experience at the Tokyo Disney Land (TDL), which was known as one of the most integrated places in Japan³². He said, “One of them [non-disabled there] was about to bump into us, and the person tried to step over me [in trying to avoid hitting me]. It was quite different [from the rehabilitation center.] The place (TDL) was scary.” Although TDL was completely accessible and a fairly disabled-friendly place, PWDs who visited TDL still had to keep with up the pace of the able-bodied and behave accordingly to their rules. On the contrary, as described in the ethnography chapter, anyone who visited the rehabilitation hospital had to adjust to its environment: PWDs were the majority there. Therefore, many participants wished not to lose their “territories” as a consequence of integration. This integration–separation was also a dilemma for the rehabilitation hospital staff. While the rehabilitation hospital staff encouraged their patients to interact with others

³² Many PWDs go to TDL because of its well-known accessibility and well-trained staff for PWDs. In addition, the place is often chosen by special school teachers for their school trips. When she went to TDL more than a decade ago, she noticed so many people in wheelchairs, whom were never seen elsewhere.

with disabilities in the hospital, the staff knew that the patients might feel too comfortable at the hospital to leave and return to their communities to make new friends there. People with disabilities must keep a balance between the integration-separation tension. As of December 2001, the researcher learned from one of the participants that Rie's MST was cancelled for out-patients, which included Mr. Ko, Haru, and Yoshi. They were forced into the larger society to be integrated.

Defying disability—accepting disability and rhetoric of “try harder”

As described in the ethnography, the rehabilitation hospital had two, seemingly contradicting purposes for their patients. One of the missions was restoring the lost physical capacity as much as possible. Phillips (1984) argues that the ethos of “try harder” is deeply embedded into the rhetoric surrounding people with disabilities. Celebration of the “try harder” theme is well in accordance with such other notions as “if one tries hard enough, one will succeed” or “when there is a will, there is a way.” In the disability context, the “try harder” ethos is geared toward the ultimate goal of curing disability and restoring normalcy (Phillips, 1984). Although Phillips (1984) was referring to PWDs in the U.S., this “try harder” theme was also popular in Japan, especially in a rehabilitation situation. In a PT room, the patients were walking slowly or trying to turn over on a mattress, and they encouraged by a therapist's “try harder!” Recalling the very beginning of PT training, the majority of the participants noted that they had believed that they would have a full recovery after an intensive rehabilitation or operation. In 1999, Yoshi was the hardest worker in the Monday group despite his having the most severe disability in the group. He urged himself to work furiously

under the slogan of “try harder.” He told the researcher in 1999 about having instantaneous orthostatic hypotension while staying in a wheelchair,

During the first year after the accident, I lost my conscious all the time [in the chair]. I could tell I was going to faint. But I held on staying in the chair and insisted not laying down on the bed. I wanted to improve my physical condition.

I tried so hard and each time [I fainted], the nurses got angry at me.

Yoshi pushed himself to lessen his disability. He was motivated by a hope that “things will get better in the future” and by a determination that he would leave the chair very soon.

On the other hand, the rehabilitation center had a different goal; that was, providing alternative ways of life while having a disability. Learning how to put the chair into a car or to type using computer keyboard with a pointing-stick are examples of this second type of rehabilitation. While the first rehabilitation purpose attempts to defy one’s disability as much as possible, the latter sought a “soft-landing” by accepting his or her disability. Both missions are, though contradictory, called “rehabilitation” (Sunahara, 1980). A disability is a “disease of medical progress” (Sunahara, 1980, p. 16). which means a disability signifying what medical progress fails to fix. However, because people have a great faith in today’s medical technology, newly disabled people (and their families) tend to look for the first kind of rehabilitation, and they sometimes are disappointed or even offended when offered the second type of rehabilitation. Generally speaking, as time goes by, a rehabilitation focus shifts from the first type, eliminating a disability, to the second, living with a disability.

Nevertheless, this shift in rehabilitation focus demands a change in PWDs' minds. Mr. J notes in his biography that he was frustrated with his rehabilitation menu which focused on upper-body strength, rather than walking per se (Jinbo, 2000). In addition, ordering a new chair was met with strong resentment. These individuals became resentful because the making of his or her chair forced them to start accepting the disability, as well as the stigma associated with it. (This complex relation with the chair will be discussed in a later section.) When the researcher returned to the rehabilitation center in 2000, she immediately noticed Yoshi's change. While others were pulling a weight tied to the chair, throughout the therapy session, Yoshi was talking to his new friends, who later joined the group, in a smoking area. His change was rather shocking for the researcher who knew how enthusiastic he was before. Yoshi seemed to have lost his "try harder" urge to walk again. Barnard (1995) notes that people with disabilities are living in a paradoxical reality in which they are "impelled at once to defy limitations in order to realize greater life possibilities, and to accept limitation in order to avoid enervating struggles with immutable constraints" (p.39). At some point, a newly disabled person needs to accept his or her limitation in order to embrace what is ahead of the person while having a disability. This shift is also what Mr. S referred as to moving from the "can't walk" mentality into a psychological state of "not walking."

Independence—dependence and rhetoric of "do not be a burden on others"

Another dialectical issue seen in the disability experience was that of independence-dependence. The notion of "independence" emerged as quite problematic for the participants after acquiring a disability. A newly disabled person loses his or her

independence for awhile immediately after having an impairment; however, as the prominent absent theory suggests, s/he became quite conscious of the meaning of independence (and dependence) precisely because of this situation. The researcher observed that the participants were constantly balancing between this independence-dependence spectrum by compromising and/or negotiating. Hereafter, several aspects of independence-dependence duality are discussed.

In Japan, in addition to this “trying harder” ethos, another powerful cultural code was operating in the disability rhetoric; that is, “do not be a burden on others” (or “do not burden others”). This notion of “do not a burden on others” is a mantra of the Japanese, and it is applied in everyday life. For instance, many soon-to-be parents mention the only, ultimate wish for their child is to become a person who “doesn’t be a burden on others” (“*tanin ni meiwaku wo kakenai*”). Although they may seem similar, this “don’t be a burden” theme differs from the “trying harder” ethos. The former springs from a Japanese group-oriented, collective tendency which harshly criticizes disturbing group harmony and not following cultural scripts. More precisely, a “burden” (“*meiwaku*”) is referred to as being different from others, or doing something that violates cultural norms and expectations. Conversely, the latter, the “try harder” ethos is manifested in an individualistic culture which pushes a person to be self-reliant (Phillips, 1984).

The Japanese family, especially parents, sometimes become overprotective of a PWD, and some people’s worst fear is that their kin with a disability will become a societal burden (Osano, 1998; Yohda, 1987). In an extreme case though, the researcher heard that many PWDs living independently in Tokyo had to run away from their

concerned parents who wanted their children to live safely at home or in institutions. A woman from N-prefecture mentioned her community member with a disability who could not leave home for thirty years despite his wish to live independently. In Japan, taking care of individuals with disabilities has been predominantly considered a family issue. Society, including social workers and paramedical staff, expect the parents to be guardians regardless of the disabled childrens' age. Needless to say, the majority of PWDs' parents feel a great responsibility of looking after their children with disabilities (Iwakuma & Nassbaum, 2000; Okahara, 1997). Takeuchi (1996) introduce an episode which illustrates this strong determination to protect their children with disabilities. Takeuchi has organized numerous matching meetings for single PWDs for more than thirty years in Japan. Mr. O joined one of these meetings with his mother in 1981. He was a college graduate, and has edited texts and translated a book. However, he had CP with a speech impairment and quadriplegia, and he relied on others (most likely his mother) for almost all activities of daily living (ADL). Both Mr. O and the mother were fully aware of the fact that his marital "prerequisites" were not so perfect. Out of desperation, the mother pleaded with other participants explaining that her husband and she were willing to give sufficient properties, including real estates and assets, to their son and his wife who would take care of him after the couple died. The researcher also remembers that a mother of one of the participants said that they prepared a piece of land for their son and his future wife to live together, and she was asked to visit their house.

Parents' strong concern for their children, particularly for the disabled ones, may be universal. However, parents of PWDs often feel so strongly about their children's

safety that they often cannot let the children go, and these parents put children into a prison of parental affection. The parents often do not say “try harder” to their children with disabilities. Mae, who lived in the country side, commented that the separationistic mentality was quite strong, especially in the country area. People in a remote area, according to Mae, seldom let their kin with a disability and the elderly go outside out of their custodial mentality for these people. Mae analyzed that the separationism and safety concern are manifested in making a prison of affection.

When this prison is firmly bolstered by the notion of “don’t be a burden” and there is no way out, sometimes a tragedy occurs like the killing of a disabled child (Okahara, 1997). An interviewed woman with a disability describes this twisted relationship,

My mother really loved me. But when the relatives and acquaintances visited our home on the New Year’s Day or the Bon festival³³, my father and grandparents hid me in a different room. My mother helped them. She said she had to do it because she loved me. Because she loved me so much, she wished I died before she had to die (Okahara, 1997, p.80; my translation).

Yohda (1987) asserts that the “don’t be a burden” rhetoric pressures the parents of PWDs to be isolated even from their relatives. The studied parents talked about “cutting kinship relationships” for fear of putting a social “burden” on the relatives of having disabled kin (Yohda, 1987). Their logic may be incomprehensible for U.S. people.

³³ The Bon festival is a festival honoring the dead ancestors in Japan. Many Japanese believe in the folklore of Bon that the dead return to their home in the mid-August. Japanese people usually have a summer break around the Bon season and return to their hometown to “welcome” the dead.

Compared to the “try harder” theme, this “burden” notion is concerned mostly with one’s social position in a web of interpersonal relationships, of which Japanese are anxious most. The social position of a PWD in Japan is being a dependent of their family (Iwakuma & Nussbaum, 2000; Okahara, 1997; Yohda, 1987) and escaping from this role is considered to cause a “burden” on others. Osanai (1998) with a cerebral palsy lives outside her home, got married, and had a child. Since her life has been a series of Japanese cultural violations about being “disabled woman,” she has numerous episodes of this social code of “don’t be a burden.” When she was pregnant with her child, she overheard others saying, “What kind of parents are they who let a disabled daughter get pregnant?” (Osanai, 1988, p.50; my translation). The taxi driver who was asked to get money from Osanai’s pocket retorted to her, “You, you shouldn’t go out without your parents” and “How could they let you be alone?” (Osanai, 1998, p.112; my translation). Not surprisingly, her parents were harshly scolded by city officials for not looking after their daughter when Osanai (1998) decided to leave her family to live independently. Often PWDs’ “try harder” defiance was met with the opposition of the “don’t be a burden” pressure of others, sometimes even from the parents.

The researcher observed that the participants for the present study were trying to balance acts of independence—dependence and “try harder”—“don’t be a burden.” The aforementioned Mae expressed these dilemmas as, “I feel I am a bird in a cage. I can see the free world between the bars. I can sustain my life; my safety is promised as long as I stay inside the cage. But I have nothing further.” Surely, some paid a cost of being on their own (ex., falling from a wheelchair or having heat-exhaustion). Nevertheless, many PWDs in T-city escaped from their safe cages for the pursuit of independence.

CHAPTER VII

CONCLUSION

In this chapter, the responses for four research questions are summarized. These research questions are 1) How does acquiring a disability change one's communication/relationships with others (e.g., friends or family members)?; 2) Do people with disabilities have communication styles or norms that are different from the non-disabled's?; 3) How does acquiring a disability alter a perception of the self?; and 4) What are the experiences of people after acquiring disabilities?

In response to research question one, throughout this research, it is evident that communication patterns of the participants changed after acquiring disabilities. Some relationships of PWDs were severely damaged while others were strengthened in the aftermath of their adjustments. Many PWDs mentioned that they spent more time with their families which accompanied a role change in the family. Generally speaking, the more severe disability a PWD has, the more frequent communication the person needs with others. In terms of quality of communication, participants reported that their disabilities brought the family closer. For people with most severe disabilities (for example, Mr. Ko), nothing could be done without communication because of their physical dependency. Communication became vital for these people's survival. Interactions with non-family members also changed as a result of having a disability. Some participants acknowledged an indirect communication between PWDs and the non-disabled; that is, communication is mediated through a third person: "wise." Others pointed out that some friends terminated the friendship and left PWDs for not having

enough information regarding the PWDs' conditions.

In addition to communication changes with family members and friends, acquiring a disability tremendously influences a newly PWD's relationship with other PWDs. Almost all participants had no friends or close relatives with disabilities. However, these PWDs had already formed negative perceptions of people with disabilities in their pre-injury time, and when they acquired disabilities, they were haunted by the idea of "becoming one of them." (It seems that stigma associated with disability in Japan is more severe than in the U.S. because of the notions of "*kegare*" and the disability karma. Also, some mentioned that discrimination and prejudice against PWDs in rural areas are worse than in urban areas.) As a theory of "outgroup homogeneity" explains, nevertheless, newly PWDs started meeting other PWDs, and with added information, these participants changed their perceptions of other PWDs. Most importantly, as they increased information regarding PWDs, these participants felt more comfortable about living as "the disabled". A rehabilitation hospital or a recreation center played an important role in meeting other PWDs and the participants' disability adjustments, which relates to research question two, "Do people with disabilities have communication styles or norms that are different from the non-disabled's?"

The researcher observed participants' communication in various locations. Mainly through ethnographic research, she noticed communication patterns and/or norms of PWDs that are unique to this group of people. PWDs used disability jargon, including information solicitation using the "nanban?" remark. Some private matters, bathroom issues or body care, were openly talked about among the participants. Many

participants contended that they were not the same as the non-disabled, and they interacted differently among themselves than between the non-disabled. Several PWDs were convinced that it was quite important to meet other PWDs and to share what they had experienced with others. Those individuals who have had disabilities for a number of years were willing to help “newcomers” (newly disabled persons), by passing on their disability information and wisdom, and they sometimes communicated with the able-bodied on behalf of other “silent” PWDs.

The researcher observed this socialization process of “newcomers” at the so-called “information-pooling places for the disabled,” such as the rehabilitation hospital or recreation center. These places are disabled-centered spaces, and unlike other places, the non-disabled must follow agendas according to PWDs, including temporality and spatiality that are different from the outside world. Many participants felt at ease with in these places because of their majority status which is rarely experienced elsewhere. In addition, despite the popularity of the “barrier-free” and “integration” notions, these PWDs hoped to keep these places’ exclusiveness to themselves. Several participants noted that they “turned a corner” when they began to participate in sports. A disabled sports context is another information-pooling place for PWDs. In sum, at information-pooling places, newly disabled individuals not only internalize new communication norms and rituals, but also individualize among the group of PWDs and feel comfortable about being one of them.

In the autobiographical section, the researcher noticed the CIL activists’ silent, but eloquent protests in the able-bodied-oriented society. Their advocacy, rendered from a collective group identity self-labeled as “the disabled,” has been shaped through their

history of struggles and negotiations with the non-disabled. These CIL people promote independent living by sometimes paradoxically being dependent on others. This act makes a strong claim against the ethos of “don’t be a burden on others” and a declaration that in order to change society, one sometimes has to “rock the boat.” The researcher also learned that PWDs’ lives in remote areas are quite different from those PWDs’ in city areas. The CIL people’s new relationship with city officials is mediated by a common fast-growing concern - - the aging society of Japan.

In terms of research question three (How does acquiring a disability alter a perception of the self?), newly disabled persons add a new social self, “the disabled,” through communication. As interacted with others, these participants learn their social roles, expectations, and communication scripts as PWDs. Some people, like Tae and the researcher, were perplexed and stunned by other’s perceptions of them. This social identity change shifts from being a majority member to being a minority member.

As newly disabled persons adjust to their disabilities, they also acquire new spatial and temporal senses. For wheelchair users, their eye-level becomes lower than standing people’s; they incorporate their wheelchairs into the flesh, and their “mobile body-zones” go through a radical change. These individuals’ sense of time also alters because the disability impacts the temporal sense. A flow of mundane activities, for example, washing a face or opening a jar, are accentuated with suddenly emerged new tasks that require careful calculations. This changed temporal sense unavoidably affects newly disabled’s interaction with others surrounding them. Especially for those with severe disabilities, their time is shared with other people which signifies a loss of spontaneity. As mentioned previously, each activity is accomplished as a result of

communication, and patience is often required for both parties. Additionally, some participants instinctively became aware of psychological differences since beginning to use their wheelchairs.

There are several themes that emerged in response to research question four: What are the experiences of people after acquiring disabilities? First, newly disabled people need to overcome three obstacles in order to have a normal life again. These are the physical/physiological barrier, the information barrier, and the motivational/psychological barrier. The physical/physiological barrier relates to body care and is the most basic condition to be maintained as an interactional etiquette. As stated before, newly disabled people, and their families, sink into bottomless anxiety and uncertainty because of a lack of disability information, which is not openly circulated in the non-disabled community. New PWDs need to be a part of the information circle in order to reconnect to the world. If PWDs are left out for a long time, they often lose social skills with people outside, and they will be further isolated.

The researcher followed adjustment processes of two newly disabled participants, Masa and Haru, over the years. Several issues are recognized through their experiences. These issues are managing new physical conditions, being emotionally unstable, meeting other PWDs at information-pooling places, relearning ADL (activities of daily living), facing embarrassing early going-outs, changing their perception toward the wheelchair and toward other PWDs, and embodying disability. It is important to emphasize that the adjustment processes that Haru and Masa experienced are mentioned by other participants during the interviews. This fact indicates that a moral carrier, a collective experience, of “the disabled” exists. Furthermore, several participants pointed

out positive consequences of having a disability despite a common perception that being disabled is worse than being dead.

In conclusion, through conducting this study, the researcher had the opportunity to meet numerous PWDs and record their disability journeys. In spite of the diversity among the participants, acquiring their disabilities, to some degree, has shaped their course of relationships with others, their world views, and their social positions. This fact also alludes to a point that their impairments' impact went far beyond physical aspects, and their adjustments were also necessary in terms of psychological, interpersonal, and social dimensions. From this analysis, this researcher suggests that more research from a communication perspective pertaining to PWDs should be conducted, in addition to research in para-medical fields. Communication is the main vehicle for the disability adjustment. In light of future study, it would be interesting to research if what the researcher discovered with these participants is shared with PWDs in other world regions. In closing, this research finds that communication with others facilitated the participants' disability transformations, and in return, they adjusted their communication as they adjusted to their disability.

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