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TOWARD A CO-VIVIAL COMMUNITY: HOPES FOUND IN THE FRIENDSHIP AMONG PEOPLE WITH INTELLECTUAL DISABILITY LABELS

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Abstract

This is a qualitative study of friendships among people with intellectual disability labels in two countries – the United States and Japan. As a field to study friendships among adults with intellectual disability label, I gained access to two sheltered workshops (“The Farm” in the U.S. and “The Kapu Kapu” in Japan) and conducted participant observation, through which I wished to identify broader, multiple, and more humane ways to define competence and human value that could validate people labeled intellectually disabled whose humanity and citizenship are often doubted by dominant standards in industrialized societies. In addition to resisting social standards and presenting broader meanings of participation and competence, the informants of this study seemed to try to resist giving significant authority to the concepts of competence and utility in relation to human worth and to build community that does not question who should or should not be the valid members of the community. The observed communities helped me to imagine a different, more just world, and were characterized as “co-vivial” (a term coined by a Japanese philosopher to mean “live with different others convivially”). The informants of this study cultivated co-vivial communities by staying connected, seeing others as irreplaceable individuals, being responsive to others, being open to interdependent way of life, and affirming every existence unconditionally.
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INTELLECTUAL DISABILITY LABELS

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DISSERTATION

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Introduction

It has been quite a while – a lot more than I had originally planned – since I first started my field work at the Farm (a pseudonym¹), an organization located in the state of NY, in September 2005. The Farm provided day habilitation programs for young adults who had been given a label that made them eligible for services funded by the New York State Office for People with Developmental Disabilities (at the time of my research, it was called the New York State Office of Mental Retardation and Developmental Disabilities [NYS-OMRDD]; therefore, it is referred to as such throughout this dissertation). Completing the year-long fieldwork at the Farm in August 2006, I then flew to my home country, Japan. I wanted to study and collect data in Japan as well as in the U.S. for two reasons: First, I personally wanted to learn more about the life situations of disabled adults in Japan because my pre-U.S. experience focused on teaching and interacting with young children with disability labels. Second, I expected that collecting data from countries with different histories, cultures, and societal organizations would allow me to examine the contextually influenced construction of various concepts such as ability/disability and human value as well as to identify themes that transcend cultural differences. Additionally, I expected that doing fieldwork in Japan would encourage me

¹ All names but the name of the research site in Japan (Kapu Kapu) used in this dissertation are pseudonym.
to read Japanese literature in addition to the English-written literature that I have been fortunate to be able to learn from during my study in the U.S. and thus to incorporate insights gained from Japanese thinkers as well into my discussion.

So I began my fieldwork in Japan in September 2006. The research site, Kapu Kapu (using an autonym with permission), was a sheltered workshop, though it is more accurately referred to as a café open to and grounded in the local community where it is located. Completing my engagement with Kapu Kapu for a research purpose in August 2009, I decided to stay and remain to this day involved with Kapu Kapu as a part-time worker. Though I do not collect data any more in a formal sense, I am sure that my understandings, interpretations, and writings are influenced by my ongoing interactions with the people and the community of Kapu Kapu.

My research focus has been shaped and reshaped through the time spent in the field. The unchanged fundamental drive throughout the course of research, however, was to identify perspectives or relationships that could validate the existential value of all living things, including myself who will likely become disabled, aged, frail, demented, and dependent at some points in life. As a part of this larger inquiry, in this study I particularly concentrated on the construction of human value of people with intellectual
disability labels².

On pursuing this core interest, I followed the trend of the “optimistic approach” (Bogdan & Biklen, 2003, pp. 216-218), which frames issues “in ways that people can visualize the future” (Bogdan & Biklen, 2003, p. 217) instead of posing a “skeptical question” (Bogdan & Biklen, 2003, p. 217); Thus I sought close, humanizing relationships, in which the humanity and human value of a labeled person is positively constructed, and asked “How does it occur?” instead of “Can it occur?”

I also found one of the theoretical frameworks for my research in Bogdan and Taylor’s call for “a sociology of acceptance” (Bogdan & Taylor, 1987) as well as in Hanasaki’s call to establish “ethics of co-viviality” (1993, p. 158). Bogdan and Taylor argued that negative reactions and exclusions were not inevitable outcomes in the life of people regarded as social deviants. Rather, they argued that an accepting and caring relationship can indeed exist between “people who are different and typical people”

² Historically and culturally, various terms have been invented and accepted as a label to indicate that a person's intellectual faculty is disabled. Past terminology includes “imbeciles,” “feebleminded,” “idiots,” “mentally retarded,” and “morons.” While those past labels have been found to be degrading and prejudicial, new terminology has been invented and accepted as more neutral and objective, such as “intellectual disability,” “developmental disability,” and “learning difficulty” (preferred in the U.K.). Mostly following the terminology and definitions imported from the U.S., Japanese terminology adopts the labels of “intellectual disability” and “developmental disability.” In this dissertation, I collectively call those labels as “intellectual disability labels” while I also use other past and current terms depending on the contexts.

³ A Japanese writer and philosopher who met, had dialogue with, and worked alongside many oppressed people since the 1960s, particularly indigenous people in Japan as well as in a wider Asian region.
(Bogdan & Taylor, 1987, p. 35) and that such a relationship deserves sociological study rather than to be dismissed as a form of deviance. Bogdan and Taylor (1987) defined an accepting relationship as follows:

An accepting relationship is one between a person with a deviant attribute and another person, which is of long duration and characterized by closeness and affection and in which the deviant attribute does not have a stigmatizing, or morally discrediting, character. Accepting relationships are not based on a denial of difference, but rather on the absence of impugning the different person’s moral character because of the variation. (p. 35)

Quite similarly, Hanasaki (1993) defined a term “co-viviality,” which he coined to represent a Japanese word Kyosei⁴, as to live with others who are different by embracing “relationships in which differences do not generate discrimination” (Hanasaki, 2007, p. 187). Working alongside with various groups of oppressed minorities for many years, Hanasaki (1993) reached a conclusion that what we needed beyond finding against oppression for a single cause was to derive a manner of life, or ethics of co-viviality, from the lived experiences of those various movements.

Aligning also with other pioneer studies in which accepting relationships between

⁴ Kyosei literally means “live together” and tends to be used rhetorically as a fine slogan for a discrimination-free, inclusive society.
the labeled and the non-labeled were highlighted (e.g., Biklen, 1992; Bogdan & Taylor, 1989; Edgerton, 1967/1993; Goode, 1994; Kliwer, 1998; Linneman, 2001; Taylor & Bogdan, 1989). I had originally planned to study a humanizing relationship between a person with an intellectual disability label and a person without a disability label. However, my plan got gradually modified due to several factors, the first of which was when my potential informant, Lois, proposed that I do my research *at the Farm* where she worked instead of studying her and her relationship with another person with an intellectual disability label. I was introduced to Lois by one of my classmates in a research class that I took in Spring 2005. My classmate recommended a friend of hers, Lois, as a potential informant for my research as Lois worked for “mentally challenged adults” and had “really grown attached to her client” who was “a young mildly retarded woman who still lives at home, and is in her thirties” (personal communication, May 24, 2005). Visiting Lois at the Farm for the first time after the summer in 2005, I explained to her that my research focused on studying close relationships between a person with an intellectual disability label and a person without a disability label where a labeled person is accepted, appreciated, and valued regardless of societal assessment of disability. Although she welcomed me and was excited about the study, Lois sounded as if she was rather uncomfortable being a primary focus of the study and proposed that I should
instead keep my options open and explore other potential informants at the Farm who enjoy positive relationships. Lois’s proposal sounded appealing to me because the staff of the Farm seemed to care a lot about and to enjoy working with the labeled program participants of the Farm and therefore I expected to be able to observe many examples of close relationships and intimate moments that I was interested in observing.

In addition, there was yet another, focus-shifting motivation for considering Lois’s proposal. During the summer before I first visited the Farm, I had started to question my almost automatic decision to focus on the relationships between a person with a label and a person without. Of course, given the history of discrimination that segregated labeled individuals and deprived them of opportunities to live ordinary lives, including opportunities to meet and develop relationships with non-labeled others, the pioneer research that studied accepting relationships between the labeled and the non-labeled were, and still are, a paramount need in order to help the world envision unimagined inclusive ways of living. However, I felt it inadequate to justify my research interest only on this point. I felt I needed to delve into my motivations. As I questioned myself about what might be making me hesitate to study relationships that involved only labeled individuals, I was reminded of one scene from the days when I worked in Japan as an early childhood special education professional and visited regular preschools as an
itinerant advisor on including and teaching children with disability labels. In the class I was observing, there were three labeled children: two with Down syndrome and one with a mild paralysis. When the classroom teacher announced that it was a time for free play, everyone but the three labeled children went outside. As I looked at the three children remaining in the classroom and playing happily together by themselves, I remember I saw their relationships mostly as problematic, as “evidence of failure to integrate into the non-disabled community” (Chappell, 1994, p. 424), as locked in “the confines of mental handicap sub-groups” (Atkinson, 1983, p. 20, cited in Chappell, 1994, p. 424), or as “protection from feelings of inferiority, rather than as a positive choice” (Chappell, 1994, p. 424).

Such prejudiced perspectives still lurk deep down in myself, ready to jump in anytime and formulate my quick impressions toward various things. For example, when my classmate in the research class who recommended Lois as a potential research informant casually mentioned that Lois also had some kind of learning disability and therefore she, my classmate, was often discouraged by her parents in childhood to hang around with Lois, I instantly felt hesitation to pursue her recommendation. As soon as I was made aware that a person who I assumed to be a representative of non-disabled population had in fact one of her legs in the disabled circle herself, all of a sudden, Lois’s
relationships with the labeled woman or her motivation behind maintaining close relationship with the person seemed questionable or a bit different in kind than the relationships involving a non-labeled person, just like I doubted the validity of friendships among the three labeled children in the class I observed.

As much as it was disappointing, disgusting, and disturbing to admit such prejudice within myself, I knew that I could not ignore it. I must squarely face the possibility that my hesitation in considering close relationships between labeled individuals as a focus of my research might reflect to some degree a personal, or even social prejudice as Chappell (1994) warned. Chappell (1994) critically examined the impact of the normalization principle, particularly Wolfensberger’s version of social role valorization theory, which argued that socially devalued people should not follow a vicious circle of deviance, that devalued people should try instead to engage themselves in socially valued roles, and that “grouping together disabled people reinforces their deviancy and stigmatized identities” (Chappell, 1994, p. 423). Chappell warned that such arguments that implicitly or explicitly suggest it is better to be associated with non-disabled people are “very damaging” (p. 425). She further explained:

It implies that the problem for disabled people is other people who are disabled, particularly those who have severe impairments. The solution is to become
distanced from other disabled people and aligned with non-disabled people.

Discouraging disabled people from associating together as friends undermines the basis for political action. The relative lack of interest in and the low value placed on relationships between disabled people damages their perception of themselves and each other. (pp. 425-426)

As such, Lois’s proposal to study at the Farm instead of focusing only on Lois’s relationship with one of the labeled persons she worked for was appealing to me as it would allow me to keep my options widely open and to observe relationships between and among labeled individuals as well as labeled/non-labeled relationships.

Once I began my fieldwork at the Farm, I soon decided to shift the priority of my research and to focus on the relationships between and among the labeled individuals as I noticed the glimpses of what might be only or advantageously understood by those who shared the societal location as a person labeled intellectually disabled. Williams, a disability rights activist and a poet with cerebral palsy, has once called such insider sensitivity as “the subtleties of the moments” (Williams, 1989, p. 13) that the non-disabled people often don’t pick up on. Furthermore, it was rather evident right

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5 In his poem, *Dick and Jane*, Williams (1989) described two disabled lovers, who were laid by an institutional staff on a same mat but in a way that they faced in opposite directions of one another to avoid “any funny stuff” and who nevertheless gave caress to each other by “spasmodic strokes of her arm” and by “running his whiskers through her
from the outset of the fieldwork that the institutional division of staff versus program participants (i.e., labeled individuals) had significant, and often time restraining impacts on the life at the Farm. For example, the labeled program participants were often careful about what to talk about and what not to say when the staff was around. At the beginning of my fieldwork at the Farm, there was also a conversation about “Who is Maho?” among several labeled individuals. When they reached a conclusion that I was a volunteer and not a staff, one of the program participants further assured them as, “No, she’s not a staff! She doesn’t keep an eye on us. She’s good.”

By the time I finished the fieldwork at the Farm, my research focus was once again reshaped: I became wanting to study the community as a whole much more than dyadic relationships. Eventually, as such, the research questions that guided data analysis were formulated as follows:

1. How do labeled friends see each other?

2. How do they work and communicate with each other? How do they negotiate and maintain their friendship community?

3. How do they validate others and themselves?
4. How do they resist societal standards that work to invalidate others in the community or themselves?

5. And what can the non-disabled others learn from their friendship community in terms of achieving a more just, inclusive society?

By foregrounding and seeking the relationships between and among people who are categorized as “intellectually disabled,” I do not mean to endorse categorical separation of those so labeled or to submit to pessimistic and easy resignation that building genuinely equal relationships that cross social division of intellectual disability is impossible (though I do think that it should not be envisioned as easily achievable). Rather, I value the “situated knowledges” (Haraway, 1988) and “shared perspectives” (Young, 1997, p. 385) of people who are socially positioned as intellectually disabled. I believe that the situated knowledges of marginalized people are an invaluable source of challenging the dominant oppressive structures and of conceptualizing alternatives precisely because of their lived experiences of being marginalized and invalidated by current standards. In other words, I believe that the perspectives of devalued “outcasts” contain crucial knowledge, ideas, and visions for the realization of a different, more just, inclusive world. As Young (1997) has stated: “acquiring the social knowledge needed to formulate the best solutions to conflict and collective problems requires learning from the
social perspectives of people positioned differently in structures of power, resource allocation, or normative hegemony” (p. 401). Thus, in this dissertation, I focus on the humanizing relationships between and among people who share and bear the first-hand experiences of living with the intellectual disability labels, their perspectives that validate others and themselves, and their strategies toward building and sustaining community that does not reject idiosyncratic others.
CHAPTER 1

Literature Review on the Social Construction of Mental Retardation

What is “Intellectual Disability”? The least disturbing (thus most popular) way to answer this question from the perspective of the majority is by safely referring to the definitions developed and authorized by various professional organizations and framed as scientific and objective facts. However, this certainly is not the only way or even the most authentic way to answer the question. As Pollner and McDonald-Wikler (1985/2001) stated, the world is a “continuously developed and sustained construction” (p. 393) and “[t]he maintenance of a collective construct requires work – information must be selected, edited, and interpreted; anomalies must be explained; heretics from within and critics from without must be discounted, dissuaded, managed, or avoided” (p. 393). As such, we, as members of the privileged dominant group without intellectual disability labels, have worked to develop and to sustain the concept of intellectual disability, which as Kliewer (1998) maintains, is “a cultural illusion” (p. 18).

Sociological Analysis of Deviance

Though it never formed a mainstream trend of the time, cultural workings defining “normal/abnormal” and creating “deviance” have long been the subject of anthropological and sociological analyses. For example, Ruth Benedict (1934), an
American anthropologist, wrote an article titled, *Anthropology and the Abnormal*, in which she questioned the “customary modern normal-abnormal categories” (p. 60) that had been formulated through the standardizing process of modern civilization according to Western beliefs and habits. Based on her analysis of various studies on diverse cultures, such as a study of American Indian tribes where “homosexuals” were regarded as “leaders in women’s occupations, good healers in certain diseases, or among certain tribes, as the genial organizers of social affairs” (Benedict, 1934, p. 65) and a study of an island of northwest Melanesia whose culture was built on traits “which we regard as beyond the border of paranoia” (p. 65), Benedict argued that “normality is culturally defined” (p. 72). Moreover, Benedict not only recognized the relativity of normality and morality in terms of understanding cultural differences (i.e., not judging other cultures by the standards of our own) but she also discussed individuals who “betrayed [the person’s] own culture” (p. 74) and therefore were regarded in their particular community as “the deviants” (p. 74). Similar to the tenets of the later-emerging social model of disability that resists understanding disability as individual deficits (e.g., Oliver, 1990), Benedict contended as follows:

The relativity of normality…suggests that the apparent weakness of the aberrant is most often and in great measure illusory. It springs not from the fact that he is
lacking in necessary vigor, but that he is an individual upon whom that culture has put more than the usual strain. (Benedict, 1934, p. 75)

Sociological attempts to understand deviance continued after Benedict and, by the 1960s, enough analyses had accumulated to develop sociological theories of deviance, most notably labeling theory. Labeling theorists contended that “deviance is not a property inherent in certain forms of behavior” (Erikson, 1962, p. 308, cited in Burbach, 1981, p. 365); rather “it is the responses of the conventional and conforming members of the society who identify and interpret behavior as deviant which sociologically transform persons into deviants” (Kitsuse, 1962, p. 253). Moreover, “social groups create deviance by making the rules whose infraction constitutes deviance, and by applying these rules to particular people and labeling them as outsiders” (Becker, 1963, p. 9, cited in Burbach, 1981, p. 365). Carried to its logical conclusion then, even neurological differences among human beings could not ‘naturally’ equate with ideas of normal and abnormal. The binary notion of identity requires social construction.

**Early Efforts of Critically Analyzing Mental Retardation**

Gaining insights and impetus from the attempts to deconstruct the concept of deviance as well as from the emerging trends to critically analyze “social problems” in ways that challenge naturalizing explanations and instead highlight social factors working
to legitimate the inequalities, a critical analysis on the category of “mental retardation” has also emerged and slowly developed. The works of Lewis Anthony Dexter, a political scientist who wrote a book titled “The Tyranny of Schooling: An Inquiry Into the Problem of ‘Stupidity’” in 1964, is one example of such early efforts. Using an analogy of an imaginative society in which graceful movements are so valued that clumsiness is discriminated as a social defect, much like our modern societies value the concept of intelligence and “abhor stupidity” (Dexter, 1962, p. 222), Dexter illuminated “the sociological nature of the problem of retardation” (p. 226). He suggested that efforts be made to rethink the problems of mental deficiency, paralleling the efforts that clarified that “the 1929 type of depression is a consequence of systems and institutions, rather than a necessary product of the nature of man in industrial society” (p. 222). Dexter further asserted that “the common-sense assumptions about mental deficiency” (p. 227), or what Josiah Royce had described as “regulative principles of research” (1921, cited in Dexter, 1962, p. 222) need more criticism.

Similarly, Wolfensberger (1969) explained that deviancy was socially constructed and therefore could be prevented by not attaching negative value to certain types of differentness, using an example of “medieval Catholicism and the more contemporary Hutterites [that] did not place excessive value on intellectual achievement,
and therefore were less likely to view the retardate as a deviant” (p. 67). In his essay, The Origin and Nature of our Institutional Models, Wolfensberger (1969) further presented an analysis of societal “role perceptions of the retardate” (p. 68), such as a view to regard a labeled person as sick, as a subhuman organism, as a menace, as an object of pity, as a burden of charity, as a holy innocent, and as a developing individual, and discussed how these role perceptions had shaped societal management of those so labeled, including the architecture of institutional buildings and operations.

In much the same vein, Dorothea and Benjamin Braginsky (1971) were early critics of the dominant conception of mental retardation. In their earlier work published in 1969 on inmates of mental hospitals, the researchers closely examined the patient’s pre-hospital lives, finding that they were “rootless and rejected rather than defective” (Braginsky & Braginsky, 1971, p. 36) and that “the incarceration is primarily a function of society’s wish to keep its house in order rather than the result of any defects of the mind” (p. 35). This earlier study led the researchers to anticipate that “similar social sanitation problems exist with respect to children” (Braginsky & Braginsky, 1971, p. vi), thus to find “rootless and rejected, rather than defective, children in institutions for the retarded” (p. 36). In short, the researchers suspected that:

the diagnosis of cultural-familial (or educable, origin unknown, and so on)
mental retardation was to the child what the diagnosis of mental illness
(functional psychosis) was to the adult: a myth which conveniently and
effectively serves society, enabling it to misconstrue completely the nature of its
needed reforms. (Braginsky & Braginsky, 1971, p. vi)

In addition, drawing on Sarbin (1967) who critically analyzed a historical process of
“metaphor-to-myth transformation” (p. 448) in regard to the label of “mental illness,”
Braginsky and Braginsky (1971) argued that “[t]he term mental retardation is simply a
metaphor” (p. 15) and that “retardation exists, from our perspective, only to the extent
that certain people persist in calling certain other people retarded” (p. 30). Mercer (1971)
shares this “social system perspective,” defining mental retardation as “an achieved social
status” (p. 191). To illustrate this point, she examined the clinical referral, measuring, and
labeling process, which she believed to be a key mechanism that produced
overrepresentation of persons from lower socioeconomic statuses and/or ethnic minorities
in the mental retardation category (For contemporary discussions on this issue of
overrepresentation, see Losen & Orfield, 2002; Parrish, 2002; Connor & Ferri, 2005;
Ferri & Connor, 2005; and Harry & Klingner, 2006). Mercer (1971) analyzed data from
one school district in California and found that, while at the time of study approximately
81% of students in the district were “Anglo,” the proportion of “Anglo” students among
those who received an IQ of 79 or below (and thus were considered eligible for placement in a special education class) was only 47.4%. The “Anglo” students represented only 37.9% of those who were recommended by psychologists for special education placement and only 32.1% of those who were actually placed in the status of mentally retarded. In contrast, students from ethnic minority groups, such as Mexican-American and Black students, as well as those with low socioeconomic status (SES) significantly increased their visibility throughout the referral, measuring, and labeling process (e.g., Black students, who comprised approximately 8% of the student population, represented 19.8% of those found eligible for special education placement, 21.2% of those whom psychologists recommended for placement, and 22.6% of those who got placed in the status of mentally retarded). Along with a different set of analysis, which revealed “persons from nonmodal sociocultural backgrounds are systematically handicapped” (Mercer, 1971, p. 202) in the process of being measured by socio-culturally standardized intelligence tests, Mercer concluded that people “from low socioeconomic level and ethnic minority groups were more vulnerable to the labeling process” (p. 198), highlighting the socio-culturally constructed nature of mental retardation category.

Meanwhile, what normalcy is inevitably defines and in fact creates a category of what it is not. For example, Salvia (1978) astutely pointed out that age appropriateness of
behavior was not judged by absolute standards, but rather “[o]ne’s behavior is ‘delayed,’ only and obviously, in comparison with the behavior of others” (p. 27). In other words, there must be always a group of people considered as “delayed” or “abnormal” as a comparison point in order to establish, sustain, and operationalize the categories of normal. This is a definitional proposition, Salvia (1978) contended; “just as 50 percent of the population is always below the median, there is always a bottom 5 percent of the population” (p. 28). Salvia also maintained that the prevalence of mental retardation is subject to social manipulation as “it can be increased or decreased simply by redefining normality” (Salvia, 1978, p. 30).

Burton Blatt, who was a national leader of the deinstitutionalization movement in the U.S., discussed the arbitrary nature of defining and counting persons with mental retardation (Blatt, 1987). Noting the definitional changes (from a general agreement in the field prior to 1959 that about 3% of the general population were mentally retarded with the cut-off point being 1.5 standard deviations from the mean on a normal curve; to the 1959 redefinition of the American Association on Mental Deficiency, or AAMD, by which the cut-off point moved to 1 or more standard deviations, resulting in the prevalence of mental retardation increasing to 16%; to the 1973 further redefinition by AAMD to shift the cut-off point to 2 or more standard deviations, dramatically
decreasing the volume of the mental retardation pool down to about 2%), Blatt expressed the irony that the committee ‘cured’ thousands of people overnight with a stroke of the pen (Blatt, 1977/1994, p. 71, cited in Linneman, 2001, p. 188). Based on such analysis, Blatt (1987) presented a view that mental retardation is essentially “an administrative category” (p. 79). He continued: “People are mentally retarded because, at this particular time, society has deemed it necessary to identify them as such and treat them (or not treat them) because they are so identified. Mental retardation is nothing more and nothing less” (Blatt, 1987, p. 79).

**Category of Exclusion**

As Ferguson (1987) pointed out, most of the early reformers and critical theorists explicitly or implicitly limited their analysis to milder categories of intellectual disability referred in such terms as “the cultural-familial, educable, unknown-origin retardates” (Braginsky & Braginsky, 1971, p. 11) or “morons” (Gelb, 1987, p. 254), creating a new “category of exclusion” (Ferguson, 1987, p. 52). Researchers took for granted the reality and validity of mental retardation as a concept for individuals deemed to belong in this excluded category by describing them in naturalizing language, such as suffering “from a known physiological defect” and “abnormal in the orthodox sense” (Zigler, 1967, p. 292). Other descriptions that justified the application of mental
retardation concept included: “organically impaired” (Braginsky & Braginsky, 1971, p. 179); “profoundly and severely brain-damaged or genetically impaired” (Braginsky & Braginsky, 1971, p. 12); being “literally able to do nothing more than vegetate” (Edgerton, 1967/1993, p. 2); “so delayed in their development – so incompetent – that any person, professional or lay, would recognize and classify them as abnormal” (Salvia, 1978, p. 42); having “real, severe, cognitive limitations” (Ferguson, 1987, p. 54), or, looking quite close to “the absence of agency” (Ferguson, 1987, p. 54).

While most researchers simply ignored the members of the excluded category and remained silent about how their analysis of the concept of mental retardation excluded “the most extreme cases” (Salvia, 1978, p. 43), Braginsky and Braginsky (1971) starkly made explicit the scope of their attempts to challenge the traditional concept of mental retardation. While noting that “[o]ne’s pity for the profoundly retarded is tempered somehow by the obvious nature of their defects, and one is relieved that institutions exist which assume this human burden” (Braginsky & Braginsky, 1971, p. 11)), the researchers expressed their confusion and sympathy for the “thousands and thousands of mildly retarded children living in the same institutions, children who in many ways so much resemble children on the outside” (p. 11). Braginsky and Braginsky (1971) then announced: “It is this group of mentally retarded children, the
cultural-familial, educable, unknown-origin retardates…, rather than the profoundly and severely brain-damaged or genetically impaired persons, with whom this book is concerned” (pp. 11-12).

Ferguson (1987) pointed out that the “category of exclusion” (p. 52) had always been maintained in disability analysis and social reform movements regarding disability policy. Ferguson painfully admits that a socio-cultural understanding of disability unintentionally justifies the continued exclusion of those categorized in a severe range of intellectual disability, as the theoretical weakness of the social construction perspective emerges, so he argues, at those examples “where culture seems beside the point; where physiology has gone so far awry that it threatens to overwhelm the social context” (1987, p. 54). Borrowing the phrase of the historian E. P. Thompson, Ferguson called this challenge a “poverty of theory” (Ferguson, 1987, p. 52).

**Understanding Intellectual Disability as a Social Construct**

Despite the challenge, there remains much theoretical potential in re-conceptualizing intellectual disability, not as an intrinsic biomedical problem that “we cannot sociologize” (Chappell, 1998, cited in Goodley, 2001, p. 211), but rather as a social phenomenon regardless of assumed severity (Biklen, 2005; Blatt, 1987; Bogdan, 1974; Bogdan & Taylor, 1982/1994; Carey, 2003; Chappell, Goodley, & Lawthom, 2001;
Goode, 1994; Goodley, 2001; Kliweer, 1998; Linneman, 2001; Taylor, 1996). For example, Bogdan (1974) proposed that the theory of symbolic interaction, which suggests that meaning is not intrinsic to objects, experiences, and phenomena but rather conferred upon them through the process of interaction, interpretation, and defining, offers “a fresh, comprehensive and challenging, if not revolutionary, approach to the field of mental retardation” (p. 260) as it clarifies that “mental retardation is not a characteristic of the individual but a characteristic of the definers” (p. 258). Adopting this theory, Bogdan and Taylor (1982/1994) put forth a non-exclusive analysis of the concept of mental retardation as follows:

[W]e believe that the crucial issue in regard to the concept of mental retardation is not that some people (the poor, minority group members) are falsely labeled, or that the ‘mildly retarded’ are unfairly grouped with the severely or profoundly retarded. Rather, we dispute the efficacy and validity of the concept ‘retarded’ for any person, including those with the most profound organic neurological impairments. (p. 5)

Symbolic interaction theory points to there being multiple truths. That is, those labeled as intellectual disabled may present “a different view of the concept than those who have judged them” (Bogdan, 1980, p. 77). Competing views of intellectual disability,
however, are rarely sought or treated seriously by professionals in the field (Bogdan, 1980). In order to better understand the making and working of the intellectual disability concept as a social construct, the perspectives of those who so labeled must be sought out.

**Perspectives of Those Who are Labeled Intellectually Disabled**

A small collection of literature that either has been written by individuals classified as mentally retarded themselves, or has documented the orally delivered accounts of those who live with the label is beginning to develop. For example, *Inside Out: The Social Meaning of Mental Retardation* (Bogdan & Taylor, 1982) documents the autobiographical accounts of two “mentally retarded” persons; *Raise my eyes to say yes: A memoir* (Sienkiewicz-Mercer, 1989) was written by a person labeled “imbecile,” with a help of her friend and many other professional staff; *Know Me As I Am: An anthology of prose, poetry and art by people with learning difficulties* (edited by Atkinson & Williams, 1990) collected various stories of labeled individuals in the U.K.; and seven authors with a label of autism contributed their own stories in *Autism and the Myth of the Person Alone* (edited by Biklen, 2005). Below, I review the perspectives of labeled individuals concerning the social practice of labeling someone as “intellectually disabled” and present them in the following five themes: (a) abusive effects of labeling, (b) the issue of
power differences, (c) invaded personal dignity, (d) resisting/avoiding the intellectual
disability labels, and (e) toward a moral commitment not to label anyone.

**Abusive effects of labeling.** What is it like to be labeled as “intellectually
disabled”? Murphy, an ex-resident of a state institution and one of two narrators in the
life history research conducted by Bogdan and Taylor (1982/1994), states, “The problem
is getting labeled as being something. After that you’re not really a person” (p. 33). Seen
as a non-human, it follows that a labeled person is justifiably subjected to inhumane
treatment. One of the contributors to an anthology (Atkinson & Williams, 1990) of life
stories of people labeled as having learning difficulties (a U.K. terminology to refer to an
intellectual disability), described such inhumane treatment as being “treated like dirt” (p.
152). Sienkiewicz-Mercer, who had cerebral palsy, could not speak, and was labeled
“imbecile” upon commitment to an institution, also echoed this. In her own book,
Sienkiewicz-Mercer recounted using word boards, how she had been handled “like a sack
of flour” (Sienkiewicz-Mercer & Kaplan, 1989/1996, p. 40) in the institution. Essentially,
the label attached to Sienkiewicz-Mercer had determined how the nurses and attendants
were to treat her, and no matter how hard she tried to use her sounds and facial
expressions to communicate and to correct staff’s evaluation of her, the staff simply
“ignored any and all evidence [she] could present to the contrary” (Sienkiewicz-Mercer
& Kaplan, 1989/1996, p. 39). Despite her desperate efforts, “any sound or expression I made to attract attention, or to vent my frustration, was perceived as a nuisance and nothing more” and “nobody on the staff took the time to talk to me or get to know me” (p. 47). Given the professional diagnosis of “imbecile,” it was simply beyond the belief and imagination of the institutional staff that Sienkiewicz-Mercer had thoughts and feelings and a desire to communicate.

Thus, the accounts of the labeled reveal that the authoritative power of a label works to abuse the rights and humanity of the labeled individual as their rich communicative intents are interpreted as meaningless, or as confirmatory evidence of assumptions connoted by the label. Sienkiewicz-Mercer had not yet understood this when she decided to “go on strike” and refused to eat in order to be kicked out of the institution and return home. When she saw that the attendants simply opened her mouth and forced the food down her throat, she realized that such “problem behaviors” were “what they expected from me” and merely “reinforced the image that Dr. Soong’s evaluation had established” (Sienkiewicz-Mercer & Kaplan, 1989/1996, p. 42). Murphy, the informant in the life history research of Bogdan and Taylor (1982/1994), must have figured this out too from his experiences. He advised others that you “can’t give in to that mental retardation image. You strive to be extra careful. You struggle to be not what the image of
the retarded is. You can’t look the way they say you are if they call you retarded”


**The issue of power differences.** Murphy also spoke of the issue of power, or lack of it, in relation to being labeled and institutionalized as something like a permanent spell he could never break: “One thing that’s hard is that once you’re in it, you can’t convince them how smart you are. And you’re so weak you can’t convince them how smart you are. And you’re so weak you can’t really fight back” (Bogdan & Taylor, 1982/1994, pp. 29-30). Rubin, a self-advocate with a label of autism who types to communicate, agrees with Murphy and expresses the desperately heavy weight of the label imposed on her as follows: “Being looked upon as feebleminded is something I have been forced to endure my entire life. What an extremely difficult hole to have to climb out of, to fight for your own intelligence and capabilities” (Rubin, 2005, p. 107).

Sienkiewicz-Mercer, too, soon became aware of the power that institutional staff had over her. She wrote, “As long as these people considered my brain useless and my facial expressions and sounds meaningless, I was doomed to remain ‘voiceless’”


Such power differences between “the judged” and “the judges” (Bogdan & Taylor, 1976) did not disappear in a less-controlling environment that explicitly aimed to
build a reciprocal community between people with and without a disability label. Felt (2000) who wrote about her life in L’Arche reflected on her relationships with non-labeled house assistants and critiqued the power differences that existed between her and them, particularly in relation to the structure of decision making, which often excluded labeled house residents. Felt expressed: “What I like is to make decisions and figure out house rules either on my own or together with people, but not with them doing it for me. (p. 222)

Felt (2000) also highlighted the complexities involving developing friendships with the non-labeled assistants by reflecting on the moments when they acted on the power differences and behaved toward her in a way that deviated from her general expectations of behaviors based on friendship. Felt expressed her confusion caused by an ambiguity over the boundary and the power line that seemed to be conveniently removed and then restored at the will of the non-labeled assistants as follows:

One thing that’s hard is having assistants who act like friends sometimes and staff other times…. It’s confusing. In my mind, I’m thinking they are my friends, then all of a sudden they go and do something where I’m not sure. (Felt, 2000, p. 223)

Felt continues, “All in all, I do know that there are some assistants who are my friends.
They may say or do things I don’t like sometimes, but I do know they’re my friends” (Felt, 2000, p. 223). Felt does not deny the possibility of building genuine friendships beyond the label, nor does she mean that it is a matter of agreeing with her all the time.

The embodiment of power differences can be subtle and nuanced yet often has real consequences that “the judged” could not afford to ignore. Once the society sorts its members into two kinds and a wide array of social operations rely on the label, the created boundary could not be erased simply by trying to make friendly faces or to act radical. Murphy, the informant in the life history research (Bogdan & Taylor, 1982/1994), also attested to the die-hard, staining consequences of labeling on relationships as follows:

You get the feeling that they love you but that they are looking down at you. You always have that sense of a barrier between you and the ones that love you. By their own admission of protecting you, you have an umbrella over you that tells you that you and they have an understanding that there is something wrong – that there is a barrier. (Bogdan & Taylor, 1982/1994, p. 86)

We may gain a hint at achieving the difficult ideal of developing equal relationships beyond the boundary of intellectual disability labels from the following comment made by a young man with Down syndrome named Mitchell Levitz on his friendship with
Jason Kingsley who shares the experience of living with Down syndrome: “to me the very important thing about our friendship that makes it special is how we help each other out. The way we listen to each other [emphasis added]” (Kingsley & Levitz, 1994, p. 33).

**Invaded personal dignity.** Kennedy (1994), an ex-resident of a state institution for the “mentally retarded,” published an article, *The Disability Blanket*, in which he analyzed based on his own experiences what happens when a person gets labeled and thrown under “the disability blanket” (p. 75). Kennedy particularly highlighted three consequences of being designated as a disability service recipient, the first of which was that “your privacy is invaded” (p. 75). Kennedy described how there were monthly team meetings while he resided in an Intermediate Care Facility for the Mentally Retarded (ICF/MR) where staff and professionals discussed his progress or failure on goals that had been set with only limited or no inputs from him. When asked why he was not properly working on the goals, Kennedy responded that “the goals were degrading, for example, having to tell them every time I went to the bathroom and what I did there” (Kennedy, 1994, p. 75). Kennedy continued:

> Don’t get me wrong, I set personal goals for myself, and I think this is a good thing to do. But the goals I have are in my head and my heart, not on paper where everyone can see them. (p. 75)
An invasion of privacy was also evident in Murphy’s life story: Murphy was furious and disgusted when he saw that a social worker “zips in and zips out” of the house next to his, calling the house residents “boys,” and brings community people and professionals to the house and gives them a tour without even a hint of awareness that she was invading the residents’ privacy and dignity. Capturing the nature of the social worker’s disrespectful attitude, which swept away the individual humanity of the labeled residents, Murphy depicted her demeanor and rebuked it as “It’s bad enough when they own you, that they own your ass and mind. They own body and soul” (Bogdan & Taylor, 1982/1994, p. 78).

The sense of being *owned* by someone else rather than being trusted and respected as an owner of one’s own life damages trusting relationships with others. Felt, who wrote about her life in the L’arche community, expressed her anger as follows:

I didn’t feel some of them trusted me. The family talked for you; it wasn’t you talking for yourself. They made lots of decisions for me without asking. The biggest one was sending me to the institution. Also, in the institution I was in, I only trusted a very few people. It’s hard to trust people who act like they don’t trust you. (Felt, 2000, p. 223)

At the same time, being labeled and institutionalized damages the sense of
self-confidence as well. Murphy said, “The whole idea of having been in a state school makes you nervous about why you were ever put there in the first place” (Bogdan, 1980, p. 78). Once a person is burdened by the label of intellectual disability, the struggle for the labeled person is “to realize that she or he is a human being” (Bogdan & Taylor, 1982/1994, p. 57). Indeed, as Murphy asserted, labeling and institutionalization would “take the human character – you’ve heard of raping a girl – they rape the character” (Bogdan & Taylor, 1982/1994, p. 89).

Resisting/avoiding the intellectual disability labels. Mukhopadhyay, a person with a label of autism living in India who types to communicate and who contributed a chapter in Biklen’s (2005) edited book, rebuffed the label of mental retardation as “the most disgraceful label” (Mukhopadhyay & Biklen, 2005, p. 136). Similarly, Burt, the other of the two informants in the life history research done by Bogdan and Taylor, disclosed that “the worst word that I hate to be called is retarded. That’s because I am not retarded” (Bogdan & Taylor, 1982/1994, p. 200). Thus, not surprisingly, resentment against the label (“I am not retarded”) and against the condemnation of abnormality (“I am normal”) is prevalent and repeatedly heard in the accounts of labeled individuals (e.g., Atkinson & Williams, 1990; Attfield, 2005; Heshusius, 1981; Kingsley & Levitz, 1994; Worth, 1988).
Edgerton (1967/1993) interpreted such negation of the mental retardation label observed in his study of ex-state school residents as an attempt to pass as normal and to deny the reality. He stated as follows:

And so, again and again, the process of denial continues by employing this excuse. By attributing their relative incompetence to the depriving experience of institutionalization, and by insisting that the institutionalization itself was unjustified, the ex-patients have available an excuse that can and does sustain self-esteem in the face of constant challenge. (p. 153)

To this, Bogdan (1980) argued that Edgerton’s interpretation stemmed from a clinical perspective, which assumed that the real reason why the ex-patients had been institutionalized was “because they were ‘mentally retarded’” (Bogdan, 1980, p. 75) and which treated the ex-residents’ explanations on their unjust institutionalization as “lies, as fabrications” (Bogdan, 1980, p. 76). Treating the concept of mental retardation as “an administrative category, a metaphor rather than a tangible phenomenon” (Bogdan, 1980, p. 75) and treating the labeled informants who participated in interview research conducted by Bogdan and his colleague, Taylor, as “experts on what it is like to be labeled retarded” (Bogdan, 1980, p. 75), the researchers presented a different interpretation of the declaration, “I am not retarded” as follows:
Ed and Pat are saying something more profound, more sophisticated, than can be
revealed by treating their viewpoint merely as a defense mechanism. What they
are denying is not just they are retarded, their claim is not just for them, or not
just based on misdiagnosis – rather it is grounded in an analysis that the system
used to classify people as retarded or normal is misleading. (Bogdan, 1980, p.
77)

**Toward a moral commitment not to label anyone.** Ed Murphy sharply
criticized the practice of judging and assigning people a label by observing
verbal/nonverbal outward behaviors and performance on intelligence tests because “you
can never really tell what is inside the person” (Bogdan & Taylor, 1982/1994, p. 91).

Recalling one of his institutional friends, P. J. Tommy, who “was locked into what the
other people thought he was” (Bogdan & Taylor, 1982/1994, p. 91), Murphy described
him as follows:

> I’ve watched that guy and I can see in his eyes that he was aware. He knows
what’s going on. He can only crawl and he doesn’t talk, but you don’t know
what’s inside. When I was with him and I touched him, I know that he knows.

(Bogdan & Taylor, 1982/1994, p. 91)

Murphy’s humble, insider truth “generated in a different place in the service delivery
system” (Bogdan 1980, p. 77) echoes with Donnelan’s “criterion of the least dangerous assumption” (Donnelan, 1984, p. 142), which asserts that educational decisions should be based on assumptions that will make the least dangerous effects on students in case the assumption was incorrect, as well as with a principle of Presuming Competence, which was coined and theorized later by Biklen (Biklen & Cardinal, 1997; Biklen, 2005).

Murphy argued:

We have to assume that the mind is working no matter what it looks like on the outside. We can’t just judge by appearance. The people can’t see what it is like inside…. If you take away the label they are human beings. (Bogdan & Taylor, 1982/1994, p. 56)

As Worth, a Canadian self-advocate, once declared, “It is demoralizing to see someone as a label instead of [as] somebody. I am somebody. My name is Patrick Worth. I am not retarded. I don’t think anyone is. I think labels are unnecessary” (Worth, 1988, p. 48, cited in Biklen & Duchan, 1994, p. 174), and as Murphy advocated to presume competence for everyone, the insightful knowledge of those who know firsthand what it is like to be labeled intellectually disabled seems to be condensed as a moral commitment not to label anyone. We find one of the clearest declarations against labeling in the account of Ruth Sienkiewicz-Mercer. She wrote:
When you’ve spent as much time as I have with people who have been totally rejected by society, when you have been written off by nearly everyone around you, it becomes very difficult to draw the line at which life is no longer worthwhile. *I choose not to draw that line at all* [emphasis added].

(Sienkiewicz-Mercer & Kaplan, 1989, p. 92)

**Impairment as a Social Construct**

Targeting the deconstruction of disability as a form of social oppression, the social model of disability does not deal with “the personal restriction of impairment” (Oliver, 1996, p. 38). While defining disability as a social phenomenon, it distinguishes and defines impairment as “lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body” (Oliver, 1996, p. 22). Though the model treats impairment as if it is simply an objective, de-politicized fact of biology, the term impairment “is not a neutral” (Davis, 2002, p. 23) one, deeply rooted in “medicalised discourses” (Goodley, 2001, p. 208) of normal/abnormal. Such a naturalizing way of talking about impairment hinders our ability to understand the phenomenon of certain disabilities, such as what we call intellectual disability, as a social construct and makes it seem as if it is inevitable that a personal tragedy perspective must be accepted for those cases. Simone Aspis, a self advocate of London People First, testified to this as follows:
People with ‘learning difficulties’ face discrimination in the disability movement.

People without ‘learning difficulties’ use the medical model when dealing with us. *We are always asked to talk about advocacy and our impairments as though our barriers aren’t disabling in the same way as disabled people without ‘learning difficulties’*. (cited in Goodley, 2001, p. 210, emphasis is Goodley’s)

In critiquing the limitations of the British social model of disability, Shakespeare and Watson (2001) exemplify the view of intellectual disability that Aspis resented in the above quote as follows:

> It is impossible to remove all the obstacles to people with impairment, because some of them are inextricable aspects of impairment, not generated by the environment. If someone has an impairment which causes constant pain, how can the social environment be implicated? If someone has a significant intellectual limitation, how can society be altered to make this irrelevant to employment opportunities, for example? (pp. 18-19)

Goodley (2001) agrees Koegel (1986) that “[h]owever much we pay lip service to the influence of socio-cultural factors, we do primarily see mental retardation as a biomedical phenomenon and do, as a result, tend to attribute incompetent behavior exclusively to physiological causes” (cited in Goodley, 2001, p. 211). Goodley (2001) further highlights
“a worrying omission” (p. 209) of intellectual disability in the emerging arguments to “re-socialise impairment” (p. 208) by abandoning it as “the category of naturalized, irrational ‘other’” (p. 211) that is “devoid of meaning and history, presocial, inert and physical” (p. 211). If we believe that intellectual disability marks “the biological we cannot sociologise” (Goodley, 2001, p. 211), Goodley (2001) questions, “this raises real concerns about the starting points of disability theory (and its impact upon politics and policy)” (p. 211).

To say that impairment is socially constructed is not to deny the experiential realities of living with physiological differences. For example, Robert Bogdan (1974), who argued for an application of symbolic interaction theory to the concept of mental retardation, clarified that symbolic interaction perspective “does not deny the fact that there are some demonstrable differences in the physiology of some individuals placed in the category of mental retardation” (pp. 258-259). When symbolic interaction theory argues that intellectually disability is a creation of society, it suggests examining “the meaning these differences come to have in specific settings” (Bogdan, 1974, p. 259) as well as the defining process.

As such, the cultural nature and significance of bodily differences depend on “how we view and interpret them” (Bogdan & Taylor, 1982/1996, p. 7). In his excellent
analysis of cultural meanings of Down syndrome, Kliewer (1998) called physiological differences that have been demarcated as impairments and associated with “the idea of defect” (p. 10) as “differences that matter” (p. 3). For example, in relation to the bodily differences often experienced by children with Down syndrome, Kliewer (1998) particularly highlighted what he called “the dilemma of movement” (p. 64) and “the dilemma of speech” (p. 68). Kliewer argued that both controlled motion and ability to speak “are important performance modalities when one wants to be taken seriously as a student and as a useful human being” (p. 67). When conforming to these standards of movement and of speech are difficult, Kliewer continued, “children are often interpreted as incompetent, and generally this incompetence is inferred to be due to a low level of intellect” (p. 67). Individuals with a label of autism often express similar dilemmas where their performative differences culturally matter and get interpreted as evidence of intellectual deficits. Tito Mukhopadhyay, for example, wrote, “You know that your intelligence or stupidity would be measured by that performance of yours. You tend to get very clumsy…. The person says, ‘Come on, I am waiting,’ which means ‘You are a stupid person’” (Mukhopadhyay & Biklen, 2005, p. 122).

Under the naturalizing perspective of impairment, pathologizing interpretations abound: For example, there was a pediatrician who examined a child deemed to have
impairments, observed physical symptoms of sexual abuse (e.g., vaginal injuries, anal scars, and a sexually-transmitted disease), and yet concluded that those symptoms “could be due to an obscure syndrome” (Goodley, 2001, p. 213). Kliewer (1998) similarly described a scene where an assistant teacher of an inclusive classroom instinctively interpreted the behavior of Lee Larson, a second-grader with Down syndrome, as ineptly trying to eat glue, although the unrecognized whole story would have revealed that Lee in fact was diligently working on the assignment and trying to manage his movement difficulties. As Goodley (2001) cautioned, “We are allowed to view behaviour, at convenient and conventional times, as an indicator of embodied impairment, precisely because the residue of thinking associated with impairment-as-natural remains” (p. 214). Uncritically accepting the concept of impairment as natural and neutral reinforces a personal tragedy perspective, exemplified in such comments as: “There is something profoundly unfortunate about severe cognitive limitations” (Ferguson, 1987, p. 54).

In the midst of such a dominant view, labeled individuals have felt it dangerous to talk about their realities of living with impairments, or bodily differences, especially the difficult and distressing aspects of their lives. For example, Jenny Morris (2001), a disabled feminist in Britain, wrote:

Indeed, I worry myself that if we do start talking about the negative aspects of
living with impairment and illness, non-disabled people will turn around and say, “there you are then, we always knew that your lives weren’t worth living.” (p. 10)

Similarly, Liz Crow (1996) succinctly expressed this pressure as, “Impairment is safer not mentioned at all” (p. 209). Resisting silence and defying the medicalized interpretation of the accounts of people labeled autistic, who have been known to “complain about an unruly body that will not always comply with intention” (Biklen, 2005, p. 66), Biklen (2005) cautioned himself and others not to “enter this discussion through the framework of pathology” (p. 66). Similarly, Shinohara (1980), a Japanese psychologist who has long been a keen critic against educational policy of segregating labeled children, tried to listen to the words of a wheelchair-using woman with a self-critical attitude. Commemorating her 26th birthday, Emiko Iwadate, a woman living with cerebral palsy, wrote a poem part of which reads (in English translation) as follows:

I will soon be twenty six.

But I have never walked.

At least once, I dream, before I die.

Of walking on my own feet.

I would have had a wonderfully romantic life.
If I had not had such a body.

I am tired of living in a wheelchair.


Faced with her aching desire to be able to walk, Shinohara (1980) strictly refrained from interpreting her words through the dominant and oppressive perspective of “It is better to be able to walk than not.” Shinohara then read in her words a story of social oppression than of a personal tragedy: “We must rather recognize in her words that her yearning to walk becomes more and more inflamed not only by the reality of having the non-walking body but also by being subjected to the oppressive treatments of institutionalization because of it” (p. 172).

Liz Crow (1996), a disabled artist and activist in the UK, affirmed that impairments (or I would reframe as bodily differences as the term “impairment” connotes “damage”) carry “no intrinsic meaning” (Crow, 1996, p. 211) and thus are not categorically and inevitably undesirable, highlighting the importance of autobiographical narratives of those living with differences and of paying attention to the specific nature of individuals’ experiences. Biklen and Kliewer (2006) also argued that “such accounts suggest how these differences can be negotiated in social and cultural contexts and how
others can make performance easier” (p. 183). That is, the meanings of impairments, or bodily differences, as well as of “suffering” get constructed and shaped in relational contexts. For example, Frugone (2005), a person labeled autistic in Italy who became able to communicate via typing, insightfully and effusively wrote how the meanings of his life with autism changed in communicative relationships with friends as follows:

Communication freed me from the pain of compressing the human dimension into empty silences. Examples of what life should be came to me from real relations with my classmates…. Less today I would modify myself. I am no longer so maniacal with the obstacles of my disabilities. I show an objective, modified property of answer to the depressive states known. By this I mean that I can fight depression when I confront myself with my peers. (Frugone, 2005, p. 196)

Frugone’s testimony resonates with Naoki Higashida, a Japanese young man with a label of autism who also types to communicate. In his book, Higashida (2007) responded to questions posed from the perspectives of non-autistic readers, one of which was “Do you want to be cured of autism and become normal?” In response to this question, Higashida shared an analysis based on his own experiences: That is, what was needed to be liberated from the agony of living with the differences socially considered...
as “deviant” is not to be cured of autism, but to be in relationships where he could feel accepted for who he is. Resonating with Frugone’s account, Higashida (2007) concluded: “To me, it’s not that important any more whether I am ‘normal’ or ‘autistic’ as long as I can be who I am” (p. 63).

The accounts of Frugone and Higashida testify that even the experience of killing pain – emotionally or physically – can be turned from unmanageable to manageable if its meaning is negotiated in an accepting relational context, thus rejecting the naturalizing view to define pain as a personal and immutable misfortune. Heshusius, a long time disability studies scholar who survived a near-fatal car accident and since then has been living with severe and chronic pain for more than a decade, also described how being in a relational space where she could feel that she did not have to hide her pain and that “I am not a stain” (Heshusius, 2009, p. 115) allowed her “to let me hear my own deepest thoughts, fears, and longings, which in turn adjusts my perception of the parameters of my present life” (Heshusius, 2009, p. 115). It was a time spent with one of her “paid friends” (Heshusius, 2009, p. 113), a psychotherapist named Dr. Grady who embodied a kind of empathy that Heshusius explained as requiring “a deliberate ethical stance that desires to imagine the other’s pain, to listen, to be present” (Heshusius, 2009, p. 128). Heshusius (2009) described with wonder how it was “miraculously freeing to be
with a professional who really wants to understand – my devastating experience is worth of being understood” (p. 114).

Kingsley, a man labeled as Down syndrome, also has spoken of “suffering” in relation to living as a person with a disability, stating “How I want [disability] to get away” (Kingsley & Levitz, 1994, p. 39). He explained further:

When kids are busy and teachers are marking grades, I’m alone with no other people to help. I’d like to have more friends – to share and get together with and have fun and even to help me study more. I want this disability have to go away.

I want to be just like everybody else. (Kingsley & Levitz, 1994, p. 40)

Similar to the poem written by Iwadate (who dreamed of being able to walk on her feet), Kingsley’s accounts reveal his critical analysis of his “suffering,” ultimately understanding it not as an inevitable consequence of his biological makeup but more as the consequence of a societal institution called school where standardizing principles of competition, efficiency, and productivity dominate and the “differences that matter” (Kliewer, 1998) get penalized as burdensome deficiencies. Moreover, Kingsley further proposed a solution: “The only way to make the disability go away is to have people treat me differently” (Kingsley & Levitz, 1994, p. 39). In other words, in order to “cure” his disability, nondisabled others must change, perhaps by developing a deep realization that
“we are all impaired” (Shakespeare & Watson, 2001, p. 24) and that the bodily differences called impairments are part of the “inherent nature of humanity” (Shakespeare & Watson, 2001, p. 24). With this realization, a challenge posed by Morris (2001) of creating space “for recognizing the negative aspects of impairment without undermining the values of our lives” (p. 10) would be overcome.

**Contextual Understanding of Competence**

Another critical element in understanding the concept of intellectual disability as a social construct is contextual and relational understanding of such concepts as competence, incompetence, humanness, and mindedness. For example, Goode (1992) reported a clinical portrayal of a 50-year-old man with Down syndrome named Bobby who was placed in a small-scale institution: It described him as “a mental age of approximately 2.8 years,” “severely mentally retarded with severe brain damage,” “difficult to communicate with,” and best to maintain “in a protected environment as he can never function independently” (Goode, 1992, p. 200). Meanwhile, Bobby’s friends at the institution presented a different view of him, reporting that, as far as they were concerned, Bobby “had no communication problems and ‘talked fine’” (Goode, 1992, p. 205). Similarly, Bianca, who had been born with rubella syndrome and was deaf and blind, could clinically be described as “a very low functioning, multihandicapped,
alingual, and nonambulatory child with poor cognitive, social, and medical prospects” (Goode, 1994, p. 53). Bianca could even look to the average person on the street as “a pitiable, hopeless, monstrous child to be feared or resented” (Goode, 1994, p. 53). However, her family saw Bianca very differently: They regarded their daughter as knowledgeable and competent. Bianca’s parents proudly explained to Goode, a researcher, how Bianca was knowledgeable of family routines and how she would monitor whether they were appropriately carried out – for example, during the bedtime routine, Bianca would monitor whether the right numbers of blankets were put on, whether the bed rail was up, and whether her leg braces were stood in the corner of her room. The parents also advised Goode that Bianca “could teach routines ‘if you let her’” (Goode, 1994, p. 68).

Bogdan and Taylor (1982/1994) told a somewhat similar story that highlighted a contextual/relational nature of competence/incompetence: Six residents of a large state institution, who had been defined by institutional staff and professionals as the “worst cases,” the “most violent,” the “most aggressive,” and the “hardest to manage” (p. 223), were transferred to an experimental living arrangement, which was a house with support staff that “emphasized their humanness” and where the residents “were called by their real names, not by their diagnosis” (Bogdan & Taylor, 1982/1994, p. 224). After 3 months in the new respectful environment, the researchers witnessed that the residents
“had changed dramatically” (Bogdan & Taylor, 1982/1994, p. 224) and were well involved in activities and day-to-day operation of the house and responding to the positive expectations of them. Bogdan and Taylor (1982/1994) contended that those individuals were different not because they had been trained or cured but because “they had been placed in an environment that expected change, that didn’t define their problems as ‘retardation’ or any innate condition, but rather defined them as people who could live and grow” (p. 224).

Melvin, too, dramatically changed after he was adopted by Mary Lou Accetta, his foster mother, and moved out of an institution in which he had been placed at the age of 5 for 2 1/2 years (Biklen, 1992). Mary Lou was not the first foster family to take Melvin: Five different foster homes had been tried before Mary Lou and each of them sent Melvin back to the institution, complaining of his problem behaviors such as climbing on the roof in the early morning or putting his hand over a flamed stove (which was one of the ways he was believed to have been abused by his birth parents). Therefore, it was probably out of kindness when an administrator of Melvin’s institution coincidentally saw the mother and the son at a church service 4 months after they had started living together and warned Mary Lou, “He’s not going to make it….and I just want you to know it’s all right to send him back” (Biklen, 1992, p. 22). Though Melvin
had been labeled “severely retarded, severely behavior-disordered, hyperactive, and epileptic” (Biklen, 1992, p. 24), Mary Lou saw in Melvin competence and promise as she said, “I always had the sense that there was a bright little kid under there” (Biklen, 1992, p. 24). As such, Mary Lou was “bewildered as much as furious that other people couldn’t or wouldn’t see what she saw in Melvin (Biklen, 1992, p. 22).

What she saw was Melvin’s tremendous growth, including but not limited to learning 200 signs in 3 months, and his need for assurance: “guarantees that he wouldn’t be returned to the institution, evidence that there was enough food in the house, proof that he was loved” (Biklen, 1992, p. 23). By attempting to ask such questions as “What is his world like? How has life treated him? What do people expect of him and how do they show it? How does she herself behave toward Melvin?” (Biklen, 1992, p. 27), Mary Lou gradually became able to understand the stories or reasons behind what seemed like absurd behaviors, such as hoarding food under his mattress and pillow, sleeping under his bed, running away from school, and becoming furious at the sight of a can of pudding, which were all related to his experiences of having to survive in an institutional environment. One day at school, when everyone in Melvin’s class but him was working on a test, Melvin became upset and started to run around the room, throwing things. Melvin finally calmed down when his teacher secured a pre-reading level test and
included him in the activity. Melvin quietly worked on the test, all the time saying to himself, “same as the kids, same as the kids” (Biklen, 1992, p. 27).

As Biklen (1992) noted, “It’s not as if Melvin suddenly became a different person. He is the same person, but his life circumstances have changed” (p. 24). All of the stories – Bobby’s, Bianca’s, that of the six ex-residents of an institution, and Melvin’s – attest to the fact that contexts matter to an interpretation and a realization of anyone’s competence, or incompetence for that matter, as opposed to in/competence being an individual attribute (Biklen, 1992, 2005; Bogdan & Taylor, 1982/1994; Booth & Booth, 1998; Goode, 1992, 1994; Hayman, 1998; Kliwer, 1998; Linneman, 2001; Steeves, 2006).

**Toward a Sociology of Acceptance**

Researchers who take the stance to regard in/competence not as biological but as contextual have sought to identify contexts in which a realization of others’ competence is promoted, the label of mental retardation is made to be meaningless, and the labeled person’s humanness is validated. For example, Bogdan and Taylor argued that “we need a sociology of acceptance” (Bogdan & Taylor, 1987, p. 35) in order to understand how accepting relationships can be built, in which someone’s demonstrable differences do not get stigmatized (Bogdan & Taylor, 1987; Taylor & Bogdan, 1989) and rather the beliefs
in the humanness of the labeled individuals are sustained (Bogdan & Taylor, 1989).

Bogdan and Taylor identified four dimensions in the accepting relationships that could positively construct labeled individuals’ humanness, or could effectively conduct what Linneman (2001) called “people-making business” (p. 3), as follows: “(1) attributing thinking to the other, (2) seeing individuality in the other, (3) viewing the other as reciprocating, and (4) defining social place for the other” (Bogdan & Taylor, 1989, p. 138).

Kliwer (1998) adopted Bogdan and Taylor’s (1989) above framework to identify the critical elements in “establishing a recognition of citizenship for students with Down syndrome in schools” (p. 79) and presented a number of important ideas, such as “broadening the definition of valued intellect” (p. 80), “believing in a child’s mind” (p. 83), replacing the categorizing attitude with a respectful emphasis on the child’s individuality and personality that is “hidden under the cloak of incompetence” (p. 85), rejecting the image of community burden attached to Down syndrome and instead living by the principle of “human reciprocity” (p. 4), and regarding the “community as a point of origin” (p. 89) as opposed to making inclusion conditional upon the child’s successful demonstration of socially defined criteria such as certain IQ scores. To Kliwer, a democratic community is where “our humanness (or our construed lack thereof)
emerges” (Kliewer, 1998, p. 5) and is “a web of dynamic, constantly shifting relationships that encompass the individual with Down syndrome and all other human beings” (p. 95). He urged: “To eliminate a single person through any form of banishment, no matter how benevolent the logic, reduces the web and makes the community a less democratic and less rich place” (pp. 95-96). Kliewer’s vision of democratic community resonates with the image of co-vivial community, defined by a Japanese philosopher as to live with others who are different by embracing “relationships in which differences do not generate discrimination” (Hanasaki, 2007, p. 187). The term was coined to represent a Japanese word Kyosei by Hanasaki, an important figure in Japanese anti-discrimination and emancipatory movements.

Steeves (2006), a mother of Matthew who “was born with multiple disabilities” (p. 105), called such community that Kliewer and Hanasaki advocate for as dialogue “enacted through imaginative play and improvisation, shaping relational spaces from which to compose lives” (p. 106). Matthew sought to engage others at his school in such dialogue through “playful and improvisatory ways to participate, communicate, and contribute to the world” (p. 107) by bringing his toy cat, Tony. Recognizing this, Steeves defended Matthew for bringing Tony to school when Matthew’s teachers raised the “issue of the stuffed cat” as an age-inappropriate behavior for an 11-year-old: “Tony was funny
and could do things that would make other people laugh, and then Matthew could join in, too. Matthew wanted more than anything to belong, to have a place. Tony helped him to do that” (Steeves, 2006, p. 109). Winning the survival of Tony, Matthew, too, survived the school. Steeves (2006) urges schools to become such environment that promotes “relational spaces to facilitate the storytelling and dialogue” (p. 107) and the “structures of participation… that enable expression of [the labeled children’s] embodied personal practical knowledge” (p. 113).

Linneman (2001), who maintained a focus on “the question of mindedness” (p. 4) in relation to the social and scientific pronouncement of mental retardation, articulated that “mindedness to a large extent depends on others granting that accession” (p. 228). That is, we, as a part of others’ “interpretive community” (p. 241), are confronted with, in Gubrium’s words who studied the construction of mindedness of Alzheimer’s patients, the “common responsibility” (p. 230) to “recover, discover, preserve, interpret, and, in effect, realize the mind” (p. 65) of others, particularly those for whom speech is inaccessible. Similarly, Goode also spoke of “consciousness-granting interpretation” (Goode, 1994, p. 104) based on his own experiences of working and communicating with Christina, a 9-year-old girl with deaf-blindness, as well as on observing how the families of deaf-blind children communicated with their non-speaking child utilizing bodily
knowledge and expressivity. Goode concluded that his work validated the idea “that competence – indeed the whole identity of a deaf-blind child – had to do with the social context in which the child was experienced as well as the role and background of the person describing or assessing the child” (Goode, 1992, p. 198). Borrowing anthropological concepts, Goode distinguished clinical approaches to understanding others and a first-person point of view by the terms “etic” and “emic” perspectives. While the etic perspective, which is objective, analytic, and clinical, is oriented toward finding faults in comparison to a set of normative standards, the emic perspective, which attempts to see the world through the subjective, insider point of view, permits the observers “to gain a better sense of the rationality, purpose, and efficiency” (Goode, 1992, p. 198) of others’ behaviors that might look irrational, purposeless, and inefficient to outside observers.

Just as Linneman could discover “little people who had a name, a mother and a father, sisters, brothers, uncles and aunts, a face, a voice, a dream, and a story” (Linneman, 2001, p. 230) out of labeled children about whom he wrote by taking their mindedness for granted, Biklen advocated that we begin with an attitude of presuming competence upon meeting others with a label that defines the person as incompetent, look for it through the emic perspective and if a person’s competence is not yet revealed in an
expected way, we should “turn inward and ask, ‘What other approach can I try?’” (Biklen, 2005, p. 73). Blatt, whose educability hypothesis that presumes “all people are educable” (Blatt, 1987, p. 7) strongly influenced Biklen’s idea of presumption of competence, also put forth that the work of those involved with teaching children with a label of intellectual disability is “not to judge who can or cannot change, but rather to fulfill the hope that all people can change; each person can learn” (Blatt, 1977, p. 6). All of these pioneers highlight the shared responsibilities to nurture humanizing and validating contexts.

**Friendships as a Humanizing Context**

As Richardson and Ritchie (1990) noted about friendship in relation to the people labeled intellectually disabled as “the engagement that friendship brings confirms and strengthens people’s sense of feeling valued and valuable” (p. 93, cited in Chappell, 1994, p. 421), friendship is one of the critical elements to nurture humanizing and validating context. Given the growing trend of normalization and community integration in the field of intellectual disability, most scholarly efforts on the issue of friendship have been directed toward relationships between people with the intellectual disability labels and people without a disability identification, many of which reported limited social networks and the sense of loneliness experienced by people labeled intellectually disabled (Bigby,
2008; Chappell, 1994; Knox & Hickson, 2001; Matheson, Olsen & Weisner, 2007; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). Furthermore, adopting a deficit oriented perspective dominant in the field of intellectual disability, researchers tend to regard difficulties with developing and maintaining friendships experienced by those with the intellectual disability labels as primarily caused by their insufficient and immature social skills, and thus to argue for the importance of a social skill development program. For example, even in a study that claimed to “consider the concepts and experiences of friendship from the points of view of the teens [with a label of developmental disabilities] themselves” (Matheson et al., 2007, p. 319), the researchers’ clinical view framed the findings as follows:

In fact, such friendships [based on companionship, similarity, and stability/proximity] are considered in the developmental literature to be less “mature” than friendships characterized by reciprocity, loyalty, support, disclosure, and conflict management (Siperstein, Leffert, & Wenz-Gross, 1997). Doing things together and liking one another are normatively developmentally early expectations of friendship; our teens continued to use these features to define friendship. (Matheson et al., 2007, p. 327)

Some other researchers however highlighted environmental, institutional, and
political barriers for labeled individuals to develop and sustain friendships, such as a lack of transportation, lack of privacy, lack of resources, and lack of autonomy (Chappell, 1994; Knox & Hickson, 2001; McVilly et al., 2006). For example, based on her ethnographic investigation into the lives and experiences of people labeled intellectually disabled who lived in three private residential homes in England, Chappell (1994) revealed various factors in the informants’ living environments that inhibited their social relationships, one of which was the organization of staffing. Chappell reported that one of the three observed homes had only one live-in staff and because she had to prepare her husband’s meal she tended to arrange residents’ baths early in the evening so her duty to help the residents take baths did not conflict with her meal-making activity for her own family. For the residents, this practice meant that they were in their nightwear from about 7 o’clock, which restricted the possibility of them going out later in the evening to socialize with others.

Chappell (1994) also presented an analysis that, under a goal of normalization and community integration, friendships between labeled individuals “may even be seen as evidence of a failure to integrate into the non-disabled community and be described in such phrases as locked in ‘the confines of mental handicap sub-groups’ (Atkinson, 1983, p. 20)” (p. 424). Clarifying her own position as “I am not suggesting that disabled people
should not befriend non-disabled people” (p. 424) and as “I am not advocating a return to
the batch-living of the long-stay institution” (p. 426), Chappell (1994) argued that
“relationships with non-disabled people should not be assumed to be more valuable than
those between disabled people” (p. 425). Furthermore, she firmly distinguished herself
from the advocates of segregated education that congregate labeled children in a
disability-only setting who often rationalize the practice based on a discourse that says
“educational integration may damage the self-esteem of children with learning difficulties,
because they compare themselves unfavourably to their non-disabled peers” (Chappell,
1994, p. 424) or because of the potential bullies by classmates without disability label in
a regular class. Chappell (1994) sensed a devaluing perspective in such arguments that
regard friendships between labeled individuals more “as the protection of feelings of
inferiority, rather than as a positive choice” (p. 424). In other words, Chappell reaffirmed
an untarnished value of friendships between people labeled intellectually disabled.

Given the mainstream trend however, close examination and analysis of
friendships between labeled individuals are not widely available. Although, casual
descriptions of such relationships can sometimes be found, embedded within the accounts
of labeled individuals or of researchers focusing on other legitimate topics. For example,
Goode (1992) noted on some comments made by institutional friends about Bobby, a man
with Down syndrome who was clinically described as possessing an intellectual level of 2.8 years old and for whom “speech or language therapy is not recommended as prognosis for improvement is poor” (p. 200). As the fieldwork proceeded, Goode learned the value of friends’ perspective, according to which Bobby had “no communication problems” and “talked fine” (Goode, 1992, p. 205).

Murphy’s accounts in the life history research conducted by Bogdan and Taylor (1982/1994) also included a description of his nonverbal friend, P. J. Tommy, at an institution as “I’ve watched that guy and I can see in his eyes that he was aware…. When I was with him and I touched him, I know that he knows (p. 91).” Similar testimony is provided by Ohgoe (2008), a Japanese nonverbal woman with cerebral palsy who had been thought of as a non-thinking person until she learned to communicate via writing and pointing to letters. Ohgoe described nonverbal understanding established between her and her nonverbal friends at a special school as follows:

Lying on the floor with my classmates of the “class for the multi-disabled students” at a special school, I had a sense that we could understand each other via sharing of the eye contacts. It was an experience that could not be explained by developmental stage theory where understanding occurs linguistically and intellectually. When our eyes met, something clicked and I knew that the friend
was thinking, feeling, and communicating. (p. 99)

There is also a case study that specifically inquired into the possibility of friendship between “two severely retarded institutionalized males whose I.Q.s place them within the ‘imbecile’ range” (MacAndrew & Edgerton, 1966). Describing the communication between Lennie and Ricky, the “retarded friends,” the researchers noted:

They talk, observe, interpret and speculate with a contagious gusto, their words punctuated by bursts of laughter, sweeping gestures and a near total lack of self-consciousness. Their conversation is memorable: it is virtually without interruption; it is lively; it is accompanied by dramatic facial expressiveness; and to the outsider, it is almost completely incomprehensible. (p. 615)

Those accounts of friendships suggest the knowledge, morality, creativity, sensitivity, as well as humanizing and alternative perspectives that may be enhanced especially within a marginalized friendship community of people labeled as intellectually disabled.
CHAPTER 2

Literature Review on the Methodological Issues Regarding Understanding the Perspectives of People for Whom Language is Not Accessible or Significantly Limited

Dehumanization and abuse begin at a casual point where we start to talk about others over their heads (Linneman, 2001) – at a point where we assume a partiality or a complete lack of someone’s “mindedness” (Linneman, 2001). Especially when faced with people for whom language in a conventional sense appears not very accessible or significantly limited, it tends to feel natural, or even justified, to minimize our efforts to understand their perspectives, and as a result to speak for them. Such equating of linguistic abilities and the presence of (or the lack of) a conscious mind has long created a discriminatory hierarchy between human and non-human as well as within the human community (Biklen, 2005; Goode, 1994; Linneman, 2001; Rubin et al., 2001).

As such, it is imperative to seek ways to better understand the ignored, abandoned, and discounted perspectives that are less accessible through language (Lloyd, Gatherer, & Kalsy, 2006). Among these are the perspectives of people labeled intellectually disabled, which are the focus of this research. It is imperative to understand these perspectives because “it allows for an expanded dialogue with prevailing ideas, and as a matter of
equality” (Biklen, 2005, p. 5). Indeed, we need those voices to imagine a different world and to work toward achieving a more just, inclusive, and democratic community. I join Kliewer (1998) in arguing that “[t]he oppressive silencing of even one voice through any form of segregation eliminates that set of experiences from our collective conversation and diminishes the culture of the community” (p. 5).

**Understanding through Language**

Inaccessibility of language does not completely preclude the possibility of gaining perspectives through language. In fact, most efforts made so far to understand the perspectives of people with an intellectual disability label have relied on language as a primary mode to access their perspectives, utilizing such methods as interviews, focus groups, narrative analysis, and a life history approach (Lloyd et al., 2006). Reviewing the body of those pioneering works, I have drawn the following five methodological lessons: (a) ground the conversations in the informants’ everyday lives; (b) be cautious about disrupting the informants’ flow of talking; (c) be a flexible, creative and respectful communicator; (d) strive to understand the informants’ logic; and (e) as a researcher, challenge my own perspectives.

**Ground the conversations in the informants’ everyday lives.** Attempting to analyze the narratives of stroke survivors in a way that is meaningful to and is anchored
in the everyday practices of the narrators, Faircloth and his colleagues (2004) advocate energizing the “ordinary” (p. 402). They argue that “familiar, mundane personal experience is a featured building block for the self-through-time” and that “[o]rdinary resources are something that are always there and provide the most readily available source for biographical construction” (Faircloth, Rittman, Boylstein, Young, & Puymbroeck, 2004, p. 402). They further contend that paying attention to the ordinary, or “biographical particulars” (p. 403), rather than focusing on whether a story conforms to a traditional framework of narrative construction, which presumes a pattern of linear developmental progression, would enable us to recognize “the active and agentic subject” (p. 410) in those narrated stories.

Energizing and utilizing the interviewees’ ordinary resources have also been recommended to extract richer responses from individuals deemed to have intellectual disabilities. For example, Stalker (1998) adopted a strategy in which the researcher invited her labeled informants to take her on a “guided tour” of the hospital grounds on which they resided as a way to get to know the informants and to facilitate interactions. During the tour, the researcher, with the residents’ permission, took photographs of various locations and people they met, which were later used to further enhance conversations during the interviews. Discussing the issue of eliciting user perspectives in
the field of geriatric care, Stalker and her colleagues (Stalker, Gilliard, & Downs, 1999) introduce other studies that used a similar approach, such as “neighborhood walks,” to gain the perspectives of elderly people with limited speech and highlight the potential of such “energetic methods to facilitate conversation” (p. 125).

Similarly, conducting interviews in the respondents’ own living environments or in their “local context” (Goode, 1992, p. 205) has also been reported as effective by some researchers (Atkinson & Williams, 1990; Biklen & Moseley, 1988; Cambridge & Forrester-Jones, 2003). A personal living space contains rich sources of concrete material such as photo albums and objects that reveal various aspects of the interviewees’ lived experiences and that could elicit comments about people, events, situations, and future plans. These stimuli could also trigger “deeper layers of memory” (Atkinson 2004, p. 696) and therefore encourage the interviewees to reflect on their own past, which may not otherwise emerge during the limited time frame of an interview or may be difficult to explain without supplemental materials to help a researcher understand their stories.

Grounding the conversations in the informants’ everyday lives also leads to recognition of the importance of taking time to get to know the person and of combining interviews with observations of her or his daily practices and surroundings (Angrosino, 1997; Biklen & Moseley, 1988; Bogdan & Taylor, 1982/1994; Booth & Booth, 1996;
Lloyd et al., 2006; Mactavish, Mahon, & Lutfiyya, 2000; Owens, 2007). Bogdan and Taylor (1982/1994), for example, conducted weekly in-depth, unstructured interviews over a 2-year period to assemble an autobiography of Ed Murphy, who had been labeled mentally retarded. Meanwhile, Biklen and Moseley (1988) suggest that some of the interview questions be based upon what has been observed in the informant’s “natural environment” (p. 160). Furthermore, based on their review of qualitative interview research with people with expressive language difficulties, Lloyd et al. (2006) highlight that brief conversational interviews which took place during the observations often enabled the researcher to obtain richer responses and insights. Observations can also offer the researcher opportunities to take notes of conversations among various individuals who are part of the informant’s life, and thus opportunities to learn about the vocabularies, cultures, and relationships in which the informant’s world is grounded.

Finally, spending time together and becoming more knowledgeable about the person’s background as well as communicative styles are also important in that this “allows both the researcher and the informant to become familiar with each other’s speech as well as any nonverbal cues that aid communication” (Low, 2006, p. 162). Thus time can enhance the communicative competencies of both parties who are involved in the construction of an interview.
Be cautious about disrupting the informants’ flow of talking. A feminist researcher, Kathryn Anderson, warns of the danger that our listening could become severely restricted by a research agenda, such as to produce materials that suit particular purposes and outcome goals (Anderson & Jack, 1991). She painfully speaks of “lost opportunities” (p. 13) for her female informants to “discuss the complex web of feelings and contradictions behind their familiar stories” (p. 13) due to her interrupting their spontaneously flowing reflections. My own experiences of working at a group home for women with intellectual disability labels in Japan and of listening to those women telling their stories while we ate, while we watched TV together, when I visited their individual rooms, or while we cleaned the house together taught me the tremendous value of naturally occurring “free-talk.” By holding myself back in order to remain nonjudgmental and to listen attentively to their free-flow talk, I often could learn the narrator’s perspectives and gain rich insights into her lived realities.

Upon interviewing people with intellectual disability labels, some researchers have also let the labeled narrators decide what to talk about themselves, keeping the interview agenda open or only loosely structured (Angrosino, 1997; Bogdan & Taylor, 1982/1994); however, even in structured interviews guided by predetermined questions, there are ways to recognize, respect, and try not to disrupt the interviewee’s flow of
conversation as much as possible. Particularly in interviewing people who experience difficulties with expressing themselves via speech, it is critical not to jump in too quickly and interrupt the “pause for thought” (Richardson, 2002, p. 51), which would cause the person “to lose her train of thought” (Low, 2006, p. 162).

Understanding miscommunication as an interactive phenomenon, in which both the researcher and the informant with speech difficulty play a role, Low (2006) was able to gain valuable insights from the experiences of interviewing individuals living with Parkinson’s disease. For example, Low (2006) finds that inserting the word “Right” when she could not instantly understand what was said by her informants allows her to acknowledge the statement in a way that does not break the person’s train of thought or to avoid making the respondent feel awkward by interjecting words that convey a message that the person’s utterance is not clear enough. Low (2006) finds that it allows “the natural flow of conversation to continue” (p. 157).

Low (2006) also recognizes the potential value of repeating questions when the first attempt does not elicit a response on a targeted topic from her interviewees experiencing Parkinson’s disease. Though some researchers caution that this practice potentially makes an interview more like an interrogation, Low (2006) concludes that “repeating or rephrasing questions need not resemble an inquisition” (p. 158), if the
researcher remains flexible and respectful of the responses that are contributed by the informant. Refraining from persisting only with her original question and flexibly going along with the dynamic and unexpected flow of conversation led by the interviewees’ off-the-topic-yet-valuable responses, Low (2006) was able not only to elicit her informants’ views on the initial question after several attempts at coming back and repeating the originally intended question, but also to enable the respondents “to express opinions and beliefs concerning issues of importance” (p. 159) to themselves.

When it comes to interviewing people deemed to have intellectual disabilities, researchers tend to hesitate to follow the general principle that we should pose open-ended questions in interviews (e.g., Sigelman, Budd, Winer, Schoenrock, & Martin, 1982). While there may be times when open-ended questions do not instantly allow us to access the informants’ perspectives, we must not uncritically attribute such difficulties to the presumed intellectual disabilities, providing us an easy excuse to abandon our efforts to seek their views and to restrict “the wonderful prospect of answering” (Mukhopadhyay & Biklen, 2005, p. 134) to a more simplified, closed question. Rather, the difficulty with answering open-ended questions should be re-examined in the historical context of how the voices of those labeled intellectually disabled have been discounted, silenced, or even punished (Bogdan & Taylor, 1982/1994; Richardson, 2002; Rapley & Antaki, 1996). On
this point, Tito Mukhopadhyay, a man with a label of autism who had once been labeled also as mentally retarded before he acquired a means to communicate by typing (Mukhopadhyay & Biklen, 2005), critiques and encourages as follows:

> When the prospect of an answer is so narrow and the tendency to escape is more, how could the person grow and organise his reasons? So although it is difficult to face an open question, it should be introduced. (p. 134)

**Be a flexible, creative and respectful communicator.** When interviews are conceptualized as presentational, social, interactive, and co-constructed (Block, 2000) – that is, seen as “reflections of how research participants relate to the interview context as actors” (Block, 2000, p. 758-759) and “how the interviewee constructs the interviewer, their relationship, and the purpose of the interview” (Block, 2000, p. 758) much more than as mere “reflections of research participants’ memories of events” (Block, 2000, p. 758) – interviewees’ responses are “not to be taken in isolation” (Rapley & Antaki, 1996, p. 211). Rather, what an interviewer says and does are also treated as equally active constituents of the interview, co-producing the resultant accounts and performances of the interviewees (Owens, 2007).

In particular, some researchers have offered suggestions on how an interviewer can best utilize her or his own words to enhance the conversations. For example, upon
interviewing people who experienced speech difficulties due to Parkinson’s disease, Low (2006) finds that repeating informants’ words or phrases is especially useful in giving them a chance to confirm or correct the researcher’s understanding of what they have said. Also, Biklen and Moseley (1988) highlight the value of modifying questions when needed. For example, when framing a question in a way that demanded an interviewee to make a comparison only in one’s mind and then to instantly present the result of the analysis orally (i.e., “How are supervisors different than counselors?”) proved to be an insufficient approach to gain the interviewee’s perspective, Moseley flexibly modified his approach and instead asked, “What does the supervisor do?” (p. 158), which successfully elicited the interviewee’s perceptions of a supervisor.

Being flexible, creative, and even inventive is an important quality for a good communicator in general; but it is even more so when communication takes place among people whose communication styles or modes differ from each other, such as people who speak different languages or for whom language in a traditional sense cannot be taken for granted as a shared mode of communication. For example, with regard to the inclusion of informants defined as having learning difficulties in narrative research, Booth and Booth (1996) recommend the practice of “creative guesswork” (p. 64), in which an interviewer guesses at what an interviewee tries to communicate and presents her or his guess in a
form of successive yes-no or brief questions so the interviewee can either reject or confirm the presented storyline.

Although it may sound too creative or unorthodox especially in a research context, parents who successfully live inclusive lives with their child with a disability label often employ such a communication strategy. For example, Biklen (1992) characterizes a communication practice he observed in one such family as “a bit like playing Twenty Questions” (p. 31) as the parents tried to guess what their child meant by a particular word. Biklen (1992) also learns from this family, the Lehrs, another creative communication strategy that they used with their son, Ben, who had extreme difficulties with expressing himself via speech to the point of resorting to self-abusive behaviors such as smashing his head to express his frustrations. Biklen (1992) observed that the parents sometimes offered an incomplete sentence, such as “You are feeling happy because…” and hoped that Ben could communicate what was on his mind by filling in the blank.

Offering potential words at the interviewee’s disposal, or to “loan them the words” (Booth & Booth, 1996, p. 65) has also been recommended in the context of interview research with people for whom language has limited utility. Low (2006) for example reports that she at times find it necessary to offer her informants with
Parkinson’s disease the candidate words that they might be looking for. Low (2006) acknowledges the potential usefulness of such a strategy to help her informants “find the words they were thinking of but could not express at a given moment” (p. 161). Certainly it must be recognized that this practice could end up “putting words into the interviewee’s mouth” (Booth & Booth, 1996; Low, 2006), especially if there is not an opportunity and the kind of atmosphere that enables the informants to reject the interviewer’s choice of words when needed. However, as a Japanese person who daily experienced language difficulties myself while living in English speaking countries, I can certainly see a significant benefit that “such interviewer intervention can ease the experience for the interviewee by reducing the effort he or she must make to consciously form each word” (Wenger 2002, cited in Low, 2006, p. 160).

Researchers have also suggested utilizing “imaginative strategies of communication” (Goodley, 1996, p. 342) or “pluralistic methods” (Owens, 2007, p. 306) that could complement the limited usability of language. Such creative tools include visual stimuli such as pictures, drawings, diagrams, videos, a semi-structured questionnaire, and a visual chart of an informant’s life history (Goodley, 1996; Owens, 2007; Stalker, 1998). Audio- or video-recording of the interviews can also give researchers opportunities to become more competent at understanding the informants’
speech as well as opportunities to review and reflect on the interview process (Biklen & Moseley, 1988; Goode, 1992). In an ethnographic case study with a 50-year-old man with Down syndrome named Bobby, Goode (1992) finds that “[o]nly on reviewing videotapes of our interactions with Bobby were his competence and abilities fully revealed to us” (p. 201). Critical review of recorded interactions enabled Goode to recognize the rationales, logicality, superior knowledge, and efficient strategies behind Bobby’s behaviors, and to better understand Bobby’s “unintelligible” utterances. Prior to this discovery of Bobby’s competence, his utterances had been thought to be “nonsensical,” thus the researchers “largely ignored them” (p. 204).

Among “pluralistic methods” to be employed upon interviewing people deemed to have learning difficulties, Owens (2007) include an approach to use “the knowledge of people who know the interviewee well” (p. 306). There are both advantages and disadvantages (Biklen & Moseley, 1988; Low, 2006; Stalker et al., 1999) to the approach of incorporating proxy data by inviting the research participant’s significant others or someone who is thought to know the person well to join the interview or by conducting separate interviews with those third party persons. The most important issue seems to me to be the motivation behind our desire to seek input from people who are not the informants themselves. In regards to interviewing individuals living with Parkinson’s
disease, Low (2006) finds the presence of third party and her or his nuanced prompts well informed by the intimate knowledge of the interviewee are “the valuable assistance” (p. 165); asking those who are close to an interviewee to join the interview can certainly be helpful. Especially their knowledge of factual background information about the interviewee, such as the names of people and places and specific dates or events, can help an interviewer better understand the accounts of the interviewee (Biklen & Moseley, 1988; Stalker et al., 1999), reducing the high pressure put on the interviewee to explain everything to an ignorant interviewer. However, if the desire to seek others’ input is rooted in a belief, as cautioned by Stalker and her colleagues (1999), that “people’s opinions should be faithful to some ‘objective truth’” (p. 124), then the proxy data will end up being used simply to judge the “validity” of the stories told by the “unreliable” interviewees.

A marked divergence is often found between the views expressed by people who receive some kinds of social services, including those labeled intellectually disabled, and the views of people who provide services as well as those of service users’ families (Biklen & Moseley, 1988; Stalker et al., 1999). If we want to include the excluded voices as a matter of equality and if we are to learn from those perspectives to build a different and better future, as set out at the beginning of this chapter, then we must treat such
divergent views, not as if one is valid and one is invalid, but rather as data that allow us to learn something about how “each felt about a particular issue and something of the dynamics of their relationship” (Biklen & Moseley, 1988, p. 159). That is, we must always be aware that there are “a multiplicity of interconnected narratives that make up ‘the story’” (Low, 2006, p. 166) and must take a critical stance that understands the interviewee’s accounts as emerged and situated in the web of complex relationships and multiple subjectivities.

**Strive to understand the informants’ logic.** Qualitative research does not assume that there is one objective truth in any phenomena (Lloyd et al., 2006). Rather it seeks “multiple truths” (Biklen, 2005, p. 3): It believes that “multiple ways of interpreting experiences are available to each of us through interacting with others, and that it is the meaning of our experiences that constitutes reality” (Bogdan & Biklen, 2003, p. 23). In order to access the informants’ perspectives and to understand their logic, we must work within their realities (Lloyd et al., 2006)

One of the women I worked for in a group home for individuals considered to have intellectual disabilities in Japan, for example, often told me stories in which she would witness someone being severely reprimanded by another at a store, in a train, on a street, for buying toys, and so forth. As I listened to her stories again and again, it became
quite irrelevant to think of whether it actually happened or not. Rather, it poignantly revealed “some aspect of [the narrator’s] reality and perspective” (Lloyd et al., 2006, p. 1396). In real life situations, she was often the one who got reprimanded or blamed for her behaviors, or at times out of frustration became angry to the point of shouting and screaming, a behavior that further branded her as a “difficult-person-to-deal-with.” But in her stories, she was never rebuked or got angry. She often clarified to me that she was a mere observer and pronounced “I wouldn’t yell at someone like that.” To me, her stories were the “stories of survival” (Atkinson, 2004, p. 695) in which “the story-teller becomes the ‘hero’ who, at least in the telling, challenges authority and fights back against oppression” (Atkinson, 2004, p. 695). It could have been one of her “coping strategies that make life possible” (Angrosino, 1997, p. 4). Only by listening and working within her reality, could I learn something about her experiences and perspectives on the everyday oppressions as well as about her resistance against authoritative and disrespectful treatment she received from others.

Though having a benign intention of seeking ways to elicit excluded perspectives of those with an intellectual disability label, convinced by the socially constructed definition of intellectual disability and believing in the objective truth, researchers often get caught in asking “Are they intellectually and/or morally capable of telling the truth?”
“Can we trust their stories?” Such doubting of the accounts of labeled individuals was further authorized by a series of influential studies conducted by Sigelman and her colleagues in 1980s; they concluded that “the validity of answers given by mentally retarded individuals can never be assumed” (Sigelman et al., 1982, p. 518). Sigelman especially focused on the issue of acquiescence, “the tendency to respond affirmatively regardless of a question’s content” (Sigelman et al., 1982, p. 511). Sigelman’s research and contentions were widely accepted, even generalized to holistically negate the validity of responses by labeled persons regardless of the question formats, and sometimes used as a rationale for not including those people in research (Owens, 2007; Rapley & Antaki, 1996).

Understanding a story as negotiated through the complex web of histories, positionalities, and power-laden relationships, we can move forward and engage with “the role of critical inquiry” (Biklen, 2005, p. 7), which is to make visible “the contextual complexity of the discursive community” (Gallagher, 1999, p. 76, cited in Biklen 2005, p. 7). One such invisible factor that contributes to the contextual complexity is the indelible power differences between the “judged” and the “judges” (Bogdan & Taylor, 1976). Most labeled individuals have had to endure a history of being tested by professionals and having to prove their competence (Rubin, 2005). Ed Murphy who was labeled mentally
retarded and accordingly placed in a state institution elegantly testified about such power
differentials: “One thing that’s hard is that once you’re in it, you can’t convince them
how smart you are. And you’re so weak you can’t convince them how smart you are. And
you’re so weak you can’t really fight back” (Bogdan & Taylor, 1982/1994, pp. 29-30).
Given the history and the power inequality, any interview can be perceived as threatening
by labeled interviewees (Stalker et al., 1999) including the possibility of having a serious
impact on their lives such as placement or replacement in an institution (Rapley & Antaki,
1996) or deprivation of rights and/or privileges (Bogdan & Taylor, 1982/1994). The fear
could affect interviewees’ performance and may pressure them into responding to
interview questions in such a way as “to foster impressions consistent with professionals’
definitions of appropriate behavior” (Bogdan & Taylor, 1982/1994, pp. 19-20).

Squaringly challenging Sigelman’s notion of acquiescence, Rapely and Antaki
(1996) also argued that such power differences gave interviewers inadvertent authority
not to accept interviewees’ responses and shepherd them into forming answers that were
more acceptable to the interviewers; to frame questions in a way that complexity
expressed in the interviewees’ responses was made to sound more like contradiction; or to
easily blame any miscommunication on the labeled interviewees and use it as evidence to
confirm their presumed incapacity. Rapely and Antaki (1996) contended that such power
imbalance produced “pseudo-acquiescence” (p. 215).

Taking a broader stance of understanding labeled individuals’ accounts within historical and cultural contexts, some researchers have recognized strategies employed by the labeled informants and the wisdom contained in what could be seen as submissive, incompetent, or invalid responses. An example would be to avoid speaking in the face of a risk that the respondents’ performance would be perceived in a stigmatizing way more than it would promote meaningful conversation (Broderick & Kasa-Hendrickson, 2006; Yearley & Brewer, 1989), or to give a “don’t know” answer in order to avoid a sensitive issue (Richardson, 2002). Lucy Blackman, who lives with a label of autism and who eloquently communicates by typing yet has difficulties communicating by speech, described a conversational strategy she would employ in situations where the meanings of others’ speech get lost to her as soon as the speaker turns to her: Blackman explained that she devised a strategy of making “the answer that experience had taught me made the exchange worthwhile as a social activity” (Blackman, 2005, p. 161). Thus in those situations, she managed to “smile and look pleasant, and say ‘Yes,’ or echo” (Blackman, 2005, p. 161), which in appearance would fit Sigelman’s profile of an acquiescent, retarded interviewee.

As a researcher, challenge my own perspectives. Trying to see things from the
perspectives of informants necessitates that researchers consciously question, not
informants’ words, but their own perspectives, assumptions, and prejudices (Goodley, 1996). For example, Douglas Biklen (1995), who studied the first-person accounts of
people who have been labeled with autism, reflected on his conscious and continued
efforts as follows:

The qualitative researcher’s role as inquirer about the other person’s perspective
and the other person’s understandings proved to be a workable protective strategy
against imposing my own or, worse yet, the autism field’s dominant
interpretations on events or actions; I will not claim to have avoided this entirely,
but it was a constant goal. (pp. 12-13)

Similarly, Bogdan and Taylor (1982/1994), who interviewed and compiled
autobiographies of two individuals labeled mentally retarded, also reflected on the
process and reported what they needed to do as follows: “We tried to be reflective and to
let our own feelings and reactions to what he told us alert us to the prejudices and
preconceived notions we carried around as transmitters of our culture” (p. 22).

Bogdan (1980) and Gerber (1990) both agreed that this was what was lacking in
Robert Edgerton’s *The Cloak of Competence: Stigma in the lives of the mentally retarded*
published in 1967. They argued that the lack of self-critical stance upon interpreting and
analyzing the labeled individuals’ accounts made Edgerton unsuccessful in his attempts to “see these people through their own eyes” (Edgerton, 1967/1993, p. 6). Recognizing the importance of Edgerton’s pioneering work, which pushed the field of mental retardation to seek and to incorporate the voices of labeled individuals, Bogdan and Gerber, with due respect, sharply critiqued Edgerton’s failure to adopt “enough skepticism about the validity of the label ‘mentally retarded’” (Gerber, 1990, p. 15) and rather treat the informants’ stories “from a clinical perspective” (Bogdan, 1990, p. 75). As a result, they contended, Edgerton dismissively interpreted his informants’ criticisms toward institutions they had been placed as denial of their mental retardation, as “fictions that explain away their deficiencies” (Gerber, 1990, p. 16), and as “an excuse, a symptom of their inability to deal with their ‘mental retardation’” (Bogdan, 1980, p. 75).

As Edgerton used the “study of mental retardation” and the “study of incompetence” (1967/1993, p. 6) as interchangeable, to him incompetence was a real and stable characteristic of the “mentally retards.” Working in this paradigm, Edgerton’s interest was directed at the issue of how his informants “manage their relative incompetence” (Edgerton, 1967/1993, p. 7) and “spoiled identity” (Goffman, 1963), to which he concluded that they had accomplished this mostly by passing for normal, pretending to be competent, and striving “to cover themselves with a protective cloak of

Working from a different paradigm, which does “not assume that mental retardation exists” and treats “mental retardation as an administrative category, a metaphor rather than a tangible phenomenon” (Bogdan, 1980, p. 75), however, “a different interpretation” (Bogdan, 1980, p. 74) was indeed possible. Based on the narrative interviews with two individuals who had been labeled mentally retarded and thus placed in designated institutions, Bogdan (1980) presented an interpretation of the informants’ statement, “I am not retarded” not as a denial of the reality but as a valid analysis, as a critique of social inadequacies, and as sophisticated knowledge about human competences.

What they are denying is not just that they are retarded, their claim is not just for them, or not just based on misdiagnosis – rather it is grounded in an analysis that the system used to classify people as retarded or normal is misleading. Based on the data in their own lives, it is wrong, programmatically, to classify people as retarded because it does not produce the kinds of services they need most….

Having lived among them and having been called one of them, they have come to look for and see the intelligence in themselves and in their friends, not the retardation. (p. 77)
When we hear the stories of socially discredited people with a serious intent to learn about their points of views, we must first learn about ourselves (Bogdan & Taylor, 1982/1994) and challenge our own “(often generalized) understandings of the tellers” (Goodley, 1996, p. 335).

**Understanding Through Nonverbal Interactions**

Based on two participant observation studies that sought to understand (or to understand the understanding of) the perspectives of children born with Rubella Syndrome and who demonstrated no discernible speech, David Goode (1994) concluded that “[u]nderstanding the world and others begins without the resources of language” (p. 99). Goode’s work suggests that in order to understand the perspectives of labeled individuals, to learn their logics, and to unmask the masked competence, we must first abandon “the remedial stance” (Goode, 1994, p. 23), which treats differences as deviances and focuses on correcting and teaching rather than on listening and learning about others’ worldviews. We must “burst the ‘bubble’” (Goode, 1992, p. 134) of the socially privileged “etic perspectives,” which represent “objective, analytic, or clinical approaches” (Goode, 1992, p. 198) in order to understand others and instead attempt to adopt subjective “emic perspectives” that require intimate relationships between those who observe and are observed. Aiming to uncover “the rationality, purpose, and
efficiency of native behaviors” (Goode, 1992, p. 198), emic perspectives are better designed to recognize “the value and creativity” (Goode, 1992, p. 198) of what may be considered as deviant behaviors according to the etic frame of reference.

Similar but perhaps more fundamental principles to understanding nonverbal others have been submitted by a handful of scholars using various phrases, such as “presuming competence” (Biklen, 2005, p. 258), “attributing thinking to the other” (Bogdan & Taylor, 1989, 139), seeing others “as people with whom [we] can have dialogue” (Biklen, 1992, p. 48), and “taking other’s mind for granted” (Linneman, 2001, p. 231). When we embrace these principles and employ emic perspectives, we begin to recognize that the abundant “communicative resources” (Goode, 1994, p. 115) other than language based on a “mutual membership” and on “being in and sharing a world together” (Goode, 1994, p. 102) are available to us.

One critical element of such communicative resources is intimate knowledge about the person whom one aims to understand. Goode (1994), for instance, observed that a mother could easily understand the meaning of nonverbal sounds and fidgeting that her daughter, Bianca, had demonstrated at an evening meal, and effectively responded to her request for milk. The communication was achieved by the mother and the daughter utilizing the shared knowledge about their daily routine. Participating in the family
routine himself, Goode (1994) also experienced this way of understanding Bianca, who was born with rubella syndrome, had no formal language, and had been labeled as “profoundly retarded.” For example, when Goode failed to apply the knowledge that he had gained by observing the mother helping Bianca drink her milk, Bianca grabbed his hand and a saucer, and moved them into the correct position to catch the spilled milk under her chin. Because he knew what he was supposed to do and yet failed to do, Goode could understand the instructional value of Bianca’s behavior. As Goode (1994) noted, “[b]y the use of the shared resource of ‘what goes when’ (and ‘what goes where’), a very limited set of expressions were allowed to take on an incredible variety of meanings” (p. 71).

Intimate knowledge about the person as a communicative resource should also extend to the past. Knowing where the person is coming from is a key to understanding much verbal and nonverbal communication. For example, Biklen (1992) described how one mother, Mary Lou, could understand her son’s screaming, kicking, stealing, and trying to run away as signs of wanting to be included, of wanting a regular life, and of needing assurances. The key to her understanding was to see her son’s current behaviors in the broader context of his past life and experiences; Melvin, her son, had been placed in an institution until he was adopted at the age of 7. Melvin would hoard food under his
mattress and pillow, and become hysterical if they ran out of certain items such as milk. Melvin would also become furious when he saw a little can of pudding. And Melvin would quietly cry when he saw the pictures that depicted institutional lives. Despite the fact that Melvin had only few signs and words, including “big house” which meant the institution in which he had been placed, Mary Lou could understand the meanings of these behaviors when she learned about his past experiences in the institution and how he had been treated there. As Biklen (1992) concludes, “To understand Melvin you have to understand his history, how he thinks about it, and how he relates what is happening in his life now to that history” (p. 28).

Another important element of communicative resources is our body itself (Sanders & Arluke, 1993). For example, Goode (1994) described “a conversation with our bodies” (p. 111) with Christina, a girl who had no formal speech. Within their bodily conversations, Goode and Christina used their bodies to communicate with each other by gesturing, by directly moving each other’s body parts to guide a desired action, and also by sensing intentions and feelings in each other’s body movements. For example, Goode (1994) described:

I would greet Christina by placing her hand on my face. She would then gesture for me to pick up. I would pick her up, and Chris would lock her legs around my
waist and vigorously bounce up and down, indicating to me that she wanted me forcefully to throw or lift her up and down with my arms. I would do that often until my arms tired, which Chris could sense. (p. 111)

In the above exchange, not only had Goode sensed Christina’s wanting to be thrown in the air or to be lifted up and down in her bouncing actions, Christina too could sense Goode’s fatigue in his arm movements. Sensing other’s intentions and feelings through bodily touch and a direct engagement with the other’s moving body is something that defies quantitative documentation and scientific rationalization; and yet it is very much a part of the reality of our daily lives – of how we learn, how we teach, how we dance together, and how we understand each other. For example, regarding his experience of teaching a girl, Emily, how to use computer software through a hand-over-hand approach, Linneman (2001) answered a question as to how he knew when Emily was behaving in a minded manner as follows: “All I had to go by was feeling: I could sense her movements” (p. 233).

Although Goode (1994) may have romanticized a bit when he called this kind of understanding “esoteric communication” (p. 118), I agree with Goode that it “can be substantiated, in any practical sense of the term, only through experience, and then becomes a kind of knowledge revealed only to those who are practitioners” (Goode, 1994,
This serves as a reminder of the limited ability of language to describe our
everyday communication and understanding, which is a complex phenomenon that is
nuanced, subjective, negotiated, and experienced. The caregivers and concerned others of
people experiencing Alzheimer’s disease have also expressed the dilemma of not being
able to put into words the shared communication with and the experientially gained
understanding of the nonverbal others (Gubrium, 1986). If, as Goode (1994) argued, and I
argue many of us must know experientially, communication is more than language and
understanding is more than communication, it would certainly point to the possibility of
understanding the perspectives of others for whom language serves only limited utility.

At the same time, this also poses a tremendous challenge for researchers who greatly rely
on language to describe, to analyze, and to represent our understandings. Challenging the
traditional approaches of academic writing, for example, Gubrium (1986) observed
caregiver support groups of Alzheimer’s disease patients and found that “the folk poetry
not only reveals how the ultimate structure of mind is envisioned by those concerned, it is
also a way of voicing, by means of words, what words cannot convey” (pp. 46-47).

One thing remains a great challenge to researchers regardless of whether the
informants’ perspectives are sought primarily via language or through bodily
understandings. That is, the challenge of interpreting others. As researchers are inevitably
“telling our stories of their stories” (Ferguson, Ferguson, & Taylor, 1992, p. 299), there lies in our hands both responsibilities and possibilities to bring about change when we, as researchers, tell stories about others (Alcoff, 1995; Kvale 1995). We are always a part of the story and part of the story-making, regardless of whether we mostly present raw materials of what the informants themselves have said or we use our own language to present our understandings gained through bodily conversations and/or verbal and nonverbal interactions. As Burton Blatt wrote in an article titled How to destroy lives by telling stories, one way “we can reduce human abuse is to be very careful about the stories we tell about people” (1981, cited in Linneman, 2001, p. 4). Blatt’s clarification of the social justice responsibility that researchers hold calls for the kind of validity in research that Rowan conceptualized. According to Richardson, Rowan (1981) identified four principles to arrive at a valid understanding, the second of which was that “the phenomenon should be made maximally reasonable in human terms” and thus researchers should look for “dignified explanations” (Richardson, 2002, p. 55). Thus, critical to the integrity of research, we must place researchers’ reflexivity (Alcoff, 1995; Biklen, 2005; Bogdan & Taylor, 1982/1994; Goode, 1994; Owens, 2007) and the commitment to the people we attempt to represent (Goodley, 1996; Reid, Ryan, & Enderby, 2001) at the heart of all activities throughout the research process.
Listening as a Critical Means of Understanding Others

We must first learn to stop talking and to listen in order to hear less-privileged others’ telling of their own stories (Alcoff, 1995). Mere listening, however, may not be enough. Simone Weil, a 20th century French philosopher, said, “Those who have received one of those blows that leave a being wriggling on the ground like a worm half crushed, those people don't have words [emphasis added] to express what is happening to them” (Weil, 1951). Drawing on Weil, Washida (1999) wrote, “Telling the story of affliction barely starts, not upon being asked to tell, but upon being listened to passively, as if the words trickle down as the faintest muttering” (p. 163).

Similarly, based on her own experiences of interviewing women, Kathryn Anderson reflected on what she had learned about “learning to listen” as follows: “We need to hear what women implied, suggested, and started to say but didn’t. We need to interpret their pauses and, when it happens, their unwillingness or inability to respond” (Anderson & Jack, 1991, p. 17). As Kliewer (1998) suggested, “to enter the dialogue of citizenship does not require spoken, or indeed outspoken, language. Rather, communication is built on one’s ability to listen deeply to others” (p. 73). Such deep, passive listening would communicate back to the storyteller that “You are worth listening to” (Kliewer, 1998, p. 100). Furthermore, sharing Washida’s notion of “passivity and
acceptance” (1999, p. 235), Goode (1994) highlighted the importance of “obedient passivity” (pp. 117-118) in order to listen to the bodily interactions and learn about the other through bodily conversations.

In addition to such a critical, deep, and passive listening that prays and waits for the liberation of others’ nonverbal and verbal “voices,” listening as a critical means for understanding others requires an engagement in a dialogue where “we listen to the Other and simultaneously risk confusion and uncertainty both about ourselves and about the other person we seek to understand” (Schwandt, 1999, p. 458). Douglas Biklen (2005) expressed this as a researcher’s obligation when he said, “I am obliged to welcome complexity, even contradictions, as they arise” (p. 3).

That is, we must be willing to be challenged and to change. When we expose ourselves to such a communicative process, and when we each go on listening and speaking the interpretations back to the speaker, “we come to hear differently or better, and this is expressed in a new, amended understanding – a better account” (Schwandt, 1999, p. 456). At this moment, “truth is developed in a communicative process, both researcher and subjects learning and changing through the dialogue” (Kvale, 1995, p. 32). In other words, there is no such thing as “empowerment of the researched” or “emancipatory research” unless researchers themselves go through a transformative
process (Lengel, 1998). When we acknowledge the agency of those marginalized others and acknowledge that they, who have the histories of negotiating and resisting the norms, are “best positioned to create a transformative space” (Lengel, 1998, p. 246), the expanded dialogue and resulting new understanding will liberate all of us to envision a different, better future together.
CHAPTER 3

Methods

The Research Sites and the Informants

The Farm. Forcibly segregating people and being therefore necessarily oppressive, disability-specific institutions such as special schools, day habilitation programs, sheltered workshops, group homes, and other residential institutions nevertheless offer opportunities for the labeled individuals to develop solidarity and friendships. For example, Larry Bissonnette, an artist with a label of autism, wrote of his experiences living in an institution as follows: “My pent-up time in tested for learning patterns of best behavior institution wasn’t entirely greys; it offered personal periods of great relationships with friends with disabilities” (Bissonnette, 2005, p. 174).

The Farm – a pseudonym – was also such a disability-specific institution. The Farm offered various services such as day habilitation, supported employment, and respite for young adults with the intellectual disability labels. Located in the state of New York, the Farm was founded in the 1980s by a couple who believed that farming and rural life would offer a therapeutic venue for people with developmental disabilities to grow and to become independent. The Farm prided itself on the family-like services it provided based on the principle that “the person comes first, not the disability.” The Farm also
prided itself on the training and skill development opportunities it offered for labeled individuals through various activities such as caring for the barn animals, working in the gardens and greenhouse, engaging in wood-work or crafts, and going out into community (e.g., shopping, movie, library, gym, etc.).

The labeled individuals, who were the primary informants for this study, were called “participants” at the Farm. It did not matter to me whether an informant had a specific kind of disability label, such as Down syndrome or autism, or had a more general label such as intellectual disability or developmental disability. It also did not matter whether one had been determined to have a mild, moderate, or severe disability. Thus, I did not seek to obtain such details as the kinds and severity of disability they were deemed to have or the intelligence scores that had been recorded on them. For the purposes of this study, informants only needed to have the experiences of living a life with a label that had brought them to the Farm as the eligible service recipients.

Since this study was exploratory of an unexplored topic, a close examination of how various cultural differences (e.g., gender, social class, race or ethnicity, etc.) might affect a formation of humanizing friendships among labeled individuals was not conducted. Thus, such factors were also not considered as essential criteria of the informants in this study. Although age was also not a particularly important factor in this
study, the Farm primarily served high school graduates; therefore most of the primary informants were in their late teens or their 20s. Many of them had known each other for a long time as colleagues at the Farm or at other disability-related organizations. Some also had been to the same school, or had known each other during childhood. In terms of communication styles, most had a reasonably good command of verbal language, although a few communicated more through signs, facial expressions, tones of voice, gestures, and actions.

While I maintained a primary focus on seeking the perspectives of those with disability labels, I did not completely abandon the perspectives of those without disability labels, nor the possibilities and values of accepting relationships that emerged between the labeled program participants and the non-labeled program staff. I however was careful not to treat the voices of staff as if they were inherently more credible than that of disabled informants, or to treat the words of those with disability label as if they were in need of validation by someone who is not categorized as disabled. The number of research informants totaled 23 (14 labeled program participants and 9 non-labeled program staff). Half of the labeled informants were females and half males. Female staff outnumbered male staff 7 to 2.

Kapu Kapu. I became acquainted with and interested in Kapu Kapu, the
research site in Japan, through reading a book titled “There is Seiko” (1998) written by Saishu Satoru, who was one of the key founders of Kapu Kapu. He is a professor of environmental philosophy whose professional career at Tokyo University, one of the most prestigious universities in Japan, began (and in some sense ended) with his participation in radical student activists’ rallies against university authorities and political forces – a signifying event of the era in Japanese history that aligned with similar national/international movements of the late 1960s. The youngest daughter of Professor Saishu, whose name is Seiko, has Down syndrome, is a non-verbal communicator, rarely walks even with an assistant’s help, is blind, and mostly lies on the floor day and night, listening to her favorite music. In the book There is Seiko, Saishu describes what he calls “Free and Hot Space (FHS).” It is a space where everyone can freely and hotly be who they are and in which “[b]eing there – one’s existence itself – is deemed for everyone (including a person like Seiko) as a valuable contribution and as a form of meaningful work” (Saishu, 1998, p. 251). The founding of Kapu Kapu was mentioned in the book as an embodied example of efforts to create FHS within the society.

As such, although Kapu Kapu, to use an autonym with permission, is a sheltered workshop under the governmental disability policy framework of Japan, since its founding it has always aimed to be a place where traditional and discriminative values
around dis/ability are challenged so alternative possibilities can emerge. Mr. Suzaki, who has been the director since Kapu Kapu’s inception in 1997, told me at an interview that one of his core principles was “To not kill the color of each person.” He explained that he believes that simply by restraining ourselves from judging and problematizing others’ ways of being based on our own narrow conceptions of how things ought to be, we can emancipate oppressed potentials and as a result change the world, little by little, toward a different, diverse, and more just one.

Starting as a sheltered workshop in 1997, Kapu Kapu opened a log-house-like café in 1998 in a small shopping mall that serves 1970s apartment complexes and residential neighborhoods that increasingly contain a high proportion of elderly people, most notably those who live alone. It is located in Yokohama city (adjacent to the Tokyo metropolitan area), although the district in which Kapu Kapu lies is far from the popular and stylish center of Yokohama that reflects its long history as a leading international trading port in Japan. Thirty minutes drive from the central area of Yokohama, the district in which Kapu Kapu is located, developed as a suburb. The district is also unique in that it contains a large number of disability related institutions, such as sheltered workshops (including many cafés), residential institutions, and group homes compared to other districts in Yokohama city, reflecting the active efforts to build disability related services
within the district.

As in the case with the Farm, many of the labeled workers at Kapu Kapu were in their 20s, and had come to Kapu Kapu directly after graduation from their high schools, which were uniformly disability-only special high schools. None went to an inclusive, regular high school, although several had some inclusive schooling experiences in their elementary years. Several were in their 30s, 40s, and 50s, and had started to work at Kapu Kapu after spending some time at home or working at other places. The oldest worker among the labeled individuals, a woman who was in her late 50s at the time of my research, had almost no experience of going to school except one year of being placed in an institution which purportedly had offered some educational programs. There were 14 labeled workers at Kapu Kapu when I began my research, then 5 new workers joined in the third year of my fieldwork, for a total of 19 labeled informants (12 female and 7 male) who agreed to participate in my study. Additionally, 5 non-labeled staff (3 female and 2 male) agreed to be research informants.

Data Collection

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6 In 1979 the Japanese government enacted a law that made it compulsory for students considered to have physical, intellectual, or other disabilities to attend special schools. Under the international pressure to make its education system appear more inclusive, the Japanese government somewhat loosened the rule and launched a system in 2002, under which students with disability labels are allowed to enter a regular school upon approved that there is a "special situation" that makes it appropriate for the student to learn in a regular school. Even though the Japanese government signed in 2007 the Convention on the Rights of Persons with Disabilities that requires the signees to ensure an inclusive education system at all levels, it still defends its segregative law and policy. The education experiences of the informants at Kapu Kapu clearly reflect the national education policy of Japan.
My primary data collection method was participant observation (Bogdan & Biklen, 2003). As an integral aspect of this approach, I visited the research sites and both observed and participated in the informants’ world. Participant observation over extended time periods has been recognized as one of the ideal strategies for research involving individuals with intellectual disabilities (Mactavish, Mahon, & Lutfiyya, 2000) as it effectively communicates the presumption of credibility for the informants, entails an appreciation of the informants’ world view, and builds trust and rapport between the informants and the researcher. In order to not carelessly impose “explanations that originate in the dominant narrative of the discourse community” (Biklen, 2005, p. 13), as I continually observed, described, and interpreted, I tried to abide by the notion that “nothing is trivial, that everything has the potential of being a clue that might unlock a more comprehensive understanding of what is being studied” (Bogdan & Biklen, 2003, p. 5). I also adopted an “emic” perspective, through which Goode (1994) was able to appreciate an instructional value of Bianca’s behaviors that could have been dismissed as meaningless, patterned movements of some non-verbal, severely disabled person, or Bobby’s superior knowledge and prominent skills to survive institutional lives that Goode (1992) could not see until he repeatedly reviewed video-recorded interview of Bobby with a clear intention to depart from pathological views and instead to adopt a
perspective to see a labeled informant as a competent person. In sum, the utmost
challenge of my fieldwork was to be there “not as a person who knows everything, but as
a person who has come to learn” (Bogdan & Biklen, 2003, p. 73).

The Farm. I began visiting the Farm on September 14, 2005 and continued
even through August 9, 2006, except for a month from December 2005 to January 2006 when I
was home in Japan. During the 10 months, I visited three times per month on average,
resulting in a total of 30 visits to the Farm. During each visit, I generally stayed at the
Farm for about 4-5 hours, from morning to early afternoon.

Typical days at the Farm began with a morning meeting during which the
informants were told what team they had been assigned to, each with a designated
activity and a designated staff person as team leader. After the meeting, each team set out
for the assigned morning work and activities, and then everyone came back together
again for lunch at noon. After the 1-hour lunch break, people once again were broken into
teams to do the afternoon work until close to 3:00 pm, which was the end of the day at
the Farm for the informants. I was allowed to choose and follow whichever team I wished
on a particular day and therefore to observe different relationships in different activity
settings, such as doing the barn work, working in the garden, doing chores, playing
games, cooking, engaging with artwork, going shopping, and going to the library.
After I left the Farm at the end of the day, it was customary for me to stop by a coffee shop to reflect on the day and to expand the notes that I jotted down on site so I could have a record of what I did, what I observed, what I heard, what I felt, and what I wondered, while the sense of “being there” was still fresh. For some of the visits (12 out of the 30 visits), these hand-written field notes became the primary data, while for the other 18 visits, I was able to type up the field notes more fully later. For the latter half of my visits, I brought a digital camera and took photos at the Farm with informants’ permission. In addition, for the last third of my visits, I obtained a digital voice recorder and, with permission, carried it with me, enabling me to gather the sounds of life at the Farm. These visual and auditory records of the observed days as well as the hand-written field notes that reflected my fresh memories and reflections greatly helped me to construct the typed field notes when I could do so later.

The participant observation offered me a lot of opportunities to engage in free-talk conversations with informants, during lunch time, breaks, waiting time in between activities, as we worked on tasks, and so forth, and to conduct brief, informal interviews with them. Remembering my research interest, some would also occasionally seek me out to explain and discuss a friendship with a particular member of the Farm. Additionally, I also conducted more formal individual interviews at a later stage of my fieldwork when I
became more familiar with the life at the Farm with four labeled informants who participated in the respite program that the Farm offered during weekends. Utilizing three Friday late afternoons (after all other program participants left the Farm at 3:00pm) from the end of June through mid of July in 2006, I conducted interviews in one of the bedrooms in the Farm’s respite house. The interviews lasted from 20 to 50 minutes per person, during which I asked the interviewees to describe two to four colleagues at the Farm by completing several sentences I presented. The sentences that I asked the interviewees to complete were as follows:

- The funniest memory that I have about her/him is…
- The nicest thing that she/he has ever done is…
- The smartest thing that I saw her/him doing is…
- What I value about her/him is…
- She/He is a kind of person who brings…
- Time when I think I should learn form her/him is…
- What I wish everybody would see in her/him is…

The sentences were presented to the interviewees both orally and as a written text on a sheet on which the name and photo of a person to be described were also displayed. All four interviewees were female and could communicate verbally well. A total of 10
labeled informants, 6 females and 4 males, were described by the interviewees. The interviewees selected at least one person themselves whom to describe. Interested in how the interviewees would talk about “less popular” persons or those with whom they had not been often observed to closely interact during my observations, I chose at least one person to be described for each interviewee. All individual interviews were voice recorded with permission and later transcribed. The total number of pages of single-spaced typed data, including both field notes and the interview transcripts, was 225.

At the beginning of the fieldwork, I sent a letter to each family of the Farm participants as well as to the staff introducing myself and explaining the purpose of my research and the anticipated research activities. In order to explain the research to the labeled informants, I made a pictorial version of an informed consent form, although it in fact seemed for many of them that the text was as helpful as or even more helpful than the pictorial icons that were meant to represent the key elements of the presented contents. Many of the labeled informants were very willing and seemed even excited to have me study their friendships. They would find me and report that they had signed the consent letter and dropped it off in the office so I should make sure to pick it up. Following the advice of the program director at the Farm, I obtained the consent to participate in my
research from the families of five of the labeled informants, while all the other informants
signed the consent themselves. In regard to the names to be used in this paper, since I did
not take sufficient steps to ensure the preferences of each informant and/or their families,
I use pseudonyms for all research participants as well as for the name of the farm.

**Kapu Kapu.** The data collection at Kapu Kapu was divided into two periods: The first period consisted of 4 months, from September 2006 through December 2006. During this first period, I visited Kapu Kapu as a volunteer 3 to 4 times a week and conducted participant observation (Bogdan & Biklen, 2003) for approximately 6 hours per day (e.g., from 10:00am to 4:00pm). The second period started in April 2007 and continued until August 2009. Relocating myself from the U.S. and moving back to my home country in early 2007, I began working part-time at Kapu Kapu, once or twice a week from 10am to 6pm.

A day at Kapu Kapu started at around 10:00am. Although the official, paid, working hours for the labeled workers were from 10:00am to 4:00pm, many came early, some as early as 9:30am, and began work on the morning routine of preparing to open the café. As a workshop, Kapu Kapu had three main sources of income (which was paid back to the labeled workers according to the total hours of work per month): the café sales, the cookie sales, and the income gained from selling donated used materials. As such, people
engaged in a variety of tasks: taking orders; making and serving coffee; entertaining and thanking the shoppers and customers; baking and packaging the cookies; washing dishes and cleaning the kitchen; collecting, cleaning, and pricing the donated goods; organizing the store items; drawing menus and creating decorative signs; and so forth. Labeled workers could choose what they wanted to do, although they often agreed to help when a certain task needed more effort. Therefore, everyday was not the same, and often the morning was chaotic until people settled into their work. An outline of a day’s schedule included a morning meeting at 10:00am, lunch at noon, tea break at around 3:00pm, cleaning at 3:30pm, and an end-of-the-day meeting at 4:00pm. The café closed at 6:00pm.

Similar to the fieldwork I did at the Farm, I equipped myself with a digital voice recorder, a camera, and a memo pad and pen with informants’ permissions during the first period of my fieldwork. The sound, visual, and descriptive data augmented my memories and helped me construct field notes after each observation. In addition to the brief, free-talk informal “interviews” with informants that the participant observation afforded me during the regular hours of working, I also conducted three individual interviews in December 2006: two with the labeled informants and one with the director, Mr. Suzaki who was in his 30s. I selected the two labeled interviewees based on the fact that we
could rely on speech to sufficiently establish communication as well as on the fact that
the interviewees enjoyed relatively high level of mobility and thus we could arrange to
meet outside on weekends. Each of the two interviews with the labeled informants lasted
about 1 hour and was conducted at a coffee shop. As a rough outline of an interview, I
prepared guiding questions, which were visually and orally presented to the interviewees
as well. The guiding questions were as follows:

- Tell me about your life that led you to work at Kapu Kapu.
- Describe a typical day at Kapu Kapu.
- What do you like about working at Kapu Kapu?
- What are the difficulties in relation to working at Kapu Kapu?
- Describe a good day at Kapu Kapu.
- Describe your colleague at Kapu Kapu with five adjectives and explain why.

Similar to the interviews conducted at the Farm, the interviewees selected at
least one colleague to describe and I picked at least one person to be described. As a
visual aid, I brought a sketch pad and a pen and occasionally jotted down key words from
interviewees’ responses and drew simple pictures or diagrams to capture their stories. As
for the interview with the director, Mr. Suzaki, it lasted about 2 hours and was conducted
in a kitchen of Kapu Kapu after the café was closed. The guiding questions for this
interview sought to uncover the histories of the following three: (1) Kapu Kapu (e.g., its inception, its philosophy, the process of diversifying working activities, the potentials and difficulties of building café in a community), (2) Kapu Kapu workers (e.g., how they came to be a member of Kapu Kapu, how they have or have not changed since then), and (3) the director himself (e.g., how he came to be the director of Kapu Kapu, how he has or has not changed particularly in relation to the concepts of dis/ability). All three interviews were voice recorded with permission and later transcribed.

I typed field notes in Japanese, my mother tongue, and combining the field notes and interview transcripts, the singled-spaced, typed data totaled 268 pages. During the second fieldwork period, I did not carry a voice recorder but primarily used a camera to capture various moments of daily life at Kapu Kapu. Although typed field notes and full descriptions of daily observations were not produced during this second period, I instead wrote occasional notes at home in which I reflected on the past day or two, especially in relation to the emerging themes (from the Farm data as well as from the Kapu Kapu data of the first period), and jotted down the developing analysis and newly emerging questions as well as descriptions of certain scenes that had caught my attention as possibly relevant to the research questions.

Before I started my fieldwork, the director, Mr. Suzaki invited me to join a
monthly coffee gathering for the family members of the labeled Kapu Kapu workers. It gave me an opportune time to introduce myself and to explain my research to several mothers face to face in an informal atmosphere. I also sent a letter to each family of the labeled workers as well as to the nonlabeled staff, in which I introduced myself, summarized the purpose and expected components of the study, and expressed my intention to invite all of the Kapu Kapu workers, labeled and nonlabeled, to participate in the study. Explaining the research to the labeled individuals themselves, I again utilized a pictorial version of the Japanese-translated, informed consent form. After I completed a round of explaining to each labeled worker, I sent the pictorial information sheet home and asked their families to review it with their daughter or son. I decided to let each family decide who would sign the consent, either the research participants themselves or their family members. Most, 15 out of 19 families, chose to sign the form on behalf of the labeled persons. The only autonyms that appear with permission in this paper are the name of the research site (i.e., Kapu Kapu) and of one labeled worker, whose name had already been published in the book *There is Seiko* (Saishu, 1998) written by her father. All other names from Kapu Kapu that appear in this paper are pseudonyms.

**Data Analysis**

Following data analysis procedures guided by the grounded theory (Bogdan &
Biklen, 2003; Glaser & Strauss, 1967), I read through the field notes, both typed and hand-written, as well as interview transcripts several times and looked for any clues related to the research questions. As for the Farm data, research questions that guided my data analysis were as follows:

1. How do they work and communicate with each other?
2. How do they negotiate and maintain their friendship community?
3. How do they validate others and themselves?
4. How do they resist societal standards that work to invalidate others in the community or themselves?
5. And what can the non-disabled others learn from their friendship community in terms of achieving a more just, inclusive society?

As I read and marked the segments that seemed to be related to any of the research questions, I tentatively assigned words or phrases to represent key elements of the marked segments. As I kept reading and re-reading the data, I refined those key words with intent to form coding categories. Six coding categories were generated for the Farm data as follows: (a) including (excluding) and validating (discounting) others; (b) care about each other and sensitivity; (c) mutuality, interdependence, and community; (d) resistance, claiming, and advocating; (e) doubted, trusted, trying to prove; and (f)
staff-participants divide.

As I will describe it later, the focus of my research had to be changed at the end of the fieldwork at the Farm as the primary question became not so much one of multiple meanings of human value as one of community where human value can be presumed for anybody. As such, in regards to the Kapu Kapu data, I reviewed and analyzed the data with a focus on the relationships, interactions, negotiations, communications, and creativity that seemed to be associated with the development and maintenance, or hindrance of an inclusive community where human value is presumed and affirmed rather than questioned. Following thirteen coding categories were generated and used to categorize Kapu Kapu data: (a) responsible communication; (b) validating others; (c) expanded meanings of work; (d) blurred boundary/significance of in/competence; (e) value of incompetence and opportunities for collaborative work; (f) value of inefficiency and detour; (g) promoting self-changes as well as societal changes; (h) negotiations, forgiveness, and arts of living with different others; (i) humor; (j) resistance; (k) sensitiveness and concerns for others; (l) doubts; and (m) power relationships.

Once satisfactory coding categories were established, I re-read the data and categorized each of the marked segments according to the coding system. Finally, I examined the relationships among the categories, modified them if needed, and tried to
gain a (albeit admittedly limited) holistic sense of how the categories related to each other and how they could be organized so as to capture what I believed to be important elements of the community that I observed and experienced at the Farm and Kapu Kapu.
CHAPTER 4

Findings: Community at the Farm

I dare not claim to have understood or to have the ability to represent the fullest complexities that constitute the community at the Farm. I also do not mean to romanticize that the community at the Farm is all “good,” as in a utopian dream where everyone is kind to each other all the time. Although much more relative, temporary, and non-universal compared to societal exclusions of labeled people, there were moments of exclusion at the Farm. Nonetheless, there were indeed important lessons to be learned from the ways the informants went about being, interacting, and working as members of a community. I discuss them under the following two headings: (1) Valuing interdependence, incompetence, and relational spaces; and (2) Fighting against institutionalization.

Valuing Interdependence, Incompetence, and Relational Spaces

Within the framework of utilitarian individualism, products and achievements are envisioned as being derived “solely from one’s individual utility, intrinsic ability, and personal performance” (Kliwer, 1998, p. 3). Thus, we are pressured to detach ourselves from others and to present an appearance of being independent in order to be regarded as a valid and sole author of production and contribution – or in order not to be disregarded
as dependent and a “burden to the community” (Kliwer, 1998, p. 3). We indeed have a fear of appearing to need someone’s help. I myself, even now, still tend to say, “I am okay” and gently reject helping hands when offered, deeply enslaved by the principle of independence.

Therefore I was taken aback when Ben proposed an idea that “We can both carry it together.” The proposal was made in regard to what to do with a bucketful of water to be carried to the barn for the animals. During the course of working on various tasks at the Farm, Ben, who is a short, young man with glasses and a friendly smile, often said, “I’ll help you!” but also often said, “Do you want to do it?” Interestingly, he seemed to feel no sense of contradiction between these two statements. Now I can see that they certainly do not have to contradict if we redefine the meaning of “help” broadly and understand them from the principle of interdependence. However, up until the day when I had a chance to work closely with Ben in the animal barn, I did not really think about such logic and tended to regard Ben more as a “dependent person” who liked to ask for help rather than trying to do a task by himself. I was also inclined to interpret his preferred style of working, which was to contribute more by talking and making conversation than by engaging in the physical aspect of work, as “being lazy.” Therefore, it was a possibly mean-spirited question when I asked Ben, “Do you want to carry it [the
bucket]? Or do you want me to carry it?” In response, he presented the above-mentioned alternative solution that my enslaved mind failed to envision.

On the same day, Ben further showed me the power of interdependence when I was struggling to clean the chicken coop with a shovel, a task that I was unaccustomed to do. Seeing how I was struggling to scrape off materials stuck on the floor with my tool, which was a plastic shovel, Ben entered the chicken coop, handed me a different shovel made of metal with a pointy-head, saying, “I brought you the best shovel,” and took mine instead. As I had begun to appreciate Ben’s way of work earlier on the day, I did not care much about whether Ben would participate in physical work of cleaning with the exchanged shovel in his hand or if he simply stood there to be a part of that time. Ben did start to join us in a literal sense of cleaning, but once again, he made it into a collaborative, interdependent venture: Since what needed to be removed from the ground was concentrated in one area, Ben and I were working in close proximity. Working in the same area and struggling to negotiate with the small space, Ben proposed that I make little scoops with my smaller and sharper shovel and put them on his bigger shovel, which then he would throw in the barrel. I instantly fell in love with the idea, and Ben and I started to work together.

Thanks to Ben’s work ethic as well as leadership that embraced the principle of interdependence and activated the disconnected human connections, what could have
been mere hard, isolated work was transformed, and there emerged a relational space that embodied a radical, communicational, and hopeful possibility of how to co-construct a world together with other members of the community.

In a place where the principle of interdependence prevails, an act of getting help becomes a norm rather than a marker of incompetence. As such, help can be rather casually sought, offered, and appreciated at the Farm among the primary informants. For example, one day I spent time in a room where only labeled informants were working and chatting unattended by staff, which did not happen very often at the Farm (I might have been considered as “sub-staff” by the team-leading staff person who left the room temporarily). Within the relaxed atmosphere of staff-free space, someone shared her difficulties with spelling, to which Hailey resonated, saying, “I’m not a good speller” and openly sought help on writing from Becky who was considered by the women in the room to be good with spelling.

Publicly admitting one’s difficulties with spelling is not very easy in a society where literacy is a socially expected skill and where reading/writing skills tend to be regarded as equal to one’s intellectual capacity or even as a validation of one’s humanity (Biklen & Kliewer, 2006), much like not being able to speak has long been equated with not being able to think (Biklen, 2005). Moreover, at a place like the Farm that proudly
and diligently fulfills the State requirements to work on improving the insufficient skills of labeled program participants by incorporating certain numbers of skill development goals into various aspects of lives at the Farm, the pressure to prove one’s competence or to maintain a competent outlook was visible with real consequences. If one could prove mastery of targeted skills, a door may open to engage in other activities that potentially could better match with one’s own preferences and dreams, or even to grasp a paid job opportunity. Hailey, who casually admitted that she was not good at spelling and asked for her friend’s help with writing in the staff-free room, was one of the people I had observed to exhibit the tensions around proving her competence with socially expected skills. One day I followed Lois’s team as they drove to a store in the community to do some shopping. As a troop of six persons, we were wandering around in the store, having finished with the official part of the trip, which involved the shopping skill activities of reading and finding appropriate items written on the shopping list. At one point while wandering in the store, Lois asked the troop, “Who can tell me the time?” Hailey was quick, anxious, and happy to answer. “That would be quarter to 11!” Hailey exclaimed. As casual as it sounded, I first did not pick up any teaching or testing intentions in how Lois posed the question, but apparently I was wrong. When Hailey boldly challenged Lois, asking “Why don’t you look at your watch?”, Lois revealed that it was after all a
testing question: “I wanted you to tell me the time.” Grasping the nature of the interaction, Hailey toned down and claimed that “I got the time skill.” She then added in an even lower tone of voice, “quote and quote,” as if to express her insecurity, diffidence, and also a hint of resistance about being tested for and having to prove her competence all the time. Remembering the tightness in Hailey’s responses to the “skill-talk” from that day, the ease with which she talked about her “insufficient spelling skills” was surprising to me. She even looked liberated when she laughed and exclaimed, “We are too weird!” Lois, who once again was the staff leader of the team, came back to the room, heard Hailey’s statement, and consoled her with, “No you are not.” Hailey’s claim, however, was positively affirmed and substantiated by Becky, who had previously helped Hailey with spelling. In the same kind of proud voice that Hailey had exhibited, Becky rejected Lois’ intervention, adding: “I hate to say this but I’m afraid we are!”

McKnight (1987), who warned that “institutionalized systems grow at the expense of communities” (p. 57), elucidated that “[t]he community environment is constructed around the recognition of fallibility” (p. 56). Putting aside the fact that I am intrigued by a word like “fallibility,” which seems to imply that making errors can be regarded as capability, I would yet expand McKnight’s statement to argue that the community environment is constructed around the recognition of incompetence. That is, in
community, fallibility, or I would say incompetence, is recognized not as a reason to be “labeled, exiled, treated, counseled, advised, and protected” (McKnight, 1987, p. 57) but rather simply as a part of being human. In other words, the meaning of “incompetence” is re-constructed and it ceases to be a significant measure that jeopardizes one’s membership in the human community. Furthermore, as McKnight noted, and as Ben and Hailey embodied, with a vision of community, fallibility and incompetence are in fact valued, as they are capable of invoking “a network of relationships involving work, recreation, friendship, support, and the political power of being a citizen” (McKnight, 1987, p. 57). This contrasts with the institutionalized systems that objectify those with particular fallibility or incompetence as “the clients and consumers of institutionalized products” (McKnight, 1987, p. 57). Hailey and Becky’s self-claiming “We are too weird” seemed to effectively unbound them from such objectifying institutional systems by proudly recognizing the differences they embody.

As if to agree with McKnight’s argument, Jade, another young man at the Farm, strategically used “dependency” as a way to create opportunities for interaction and to mobilize relational spaces. On one day, during the lunch time, Jade kindly shared his chips that he had brought as a part of his lunch with me, which I gratefully accepted. We shared a bag of chips together and enjoyed the nice food. When I stood up, finishing
lunch, Jade casually asked me to throw away his paper plate as well as the paper plate
that we shared as we ate his chips together. It felt natural for me to take the shared plate
and throw it away because I was eating from it too. And then because I would be standing
up and throwing something away anyway, I didn’t really mind throwing away his plates
altogether. Besides, I was closer to the trash box. So Jade’s request did make sense
between him and I, although Sara, a staff, saw it as Jade’s problematic behavior and
rebuked him as, “What is wrong with you, Jade?!”

It was not that Jade was particularly “lazy” (though the staff often interpreted him
that way), as he would be equally willing to do something for others as expect others to
do something for him. Rather, it seemed to me that he had a superior knowledge about
the fact that fallibility, incompetence, or dependency, which are often regarded as
something that lowers human value, actually had invaluable power to invoke
communication and to engage others. It was not that Jade could not do it himself when he
asked me to get some napkins for him on another day – they were right behind him; just
like I enjoyed sharing Jade’s chips not because I was hungry but because it allowed me to
be engaged in a pleasant interaction with someone during lunchtime when otherwise I
might have nothing to talk about or no one to interact with. For Jade, who has Down
syndrome and has limited command of speech, asking someone for help must have
served him as “an alternative to being left out of ‘normal’ conversations” (Biklen, 2005, p. 50), just like a naming-the-American-states narrative did for Sean Barron who has autism and has difficulty participating in oral-based conversations. Sean Barron explained, in his autobiographical account, There’s a boy in here (Barron & Barron, 1992) that he co-authored with his mother, how he strategically used his knowledge of American states’ names in order to join conversations that otherwise left him excluded; at every opportunity, he would ask his parents’ friends whether they had ever visited particular states. Though admitting that the listing-the-states narrative was “fragmented and disjointed” and that it “led nowhere” (cited in Biklen, 2005, p. 49), Barron also explained that it was nevertheless valuable as it enabled him to feel a sense of normality and control.

Similarly, asking others for a small favor could place Jade at risk of being seeing as lazy, but nonetheless, he must have valued the strategy as it also enabled him to engage in pleasant interactions with others, in which someone would receive Jade’s smiley thank-you and a blown kiss.

Communication was valued at the Farm not as a mere means of exchanging information or achieving a goal but more as a way to establish a relational and inclusive space, or to access what McKnight (1987) referred to as “the forum within which citizenship can be expressed” (p. 57). Alden, for example, would grab any opportunity to
find an audience to listen to his story and instantly build a stage around himself to put on a show, of which I was a big fan. He would often approach me and start with such a line as “You won’t believe what happened, Maho.” And I could not resist asking “What? What happened?” wanting to hear his story. Alden’s story often consisted of several lines that described key events, and each sentence was often repeated more than once (and in fact, the entire story was also repeated more than once). It also seemed that Alden tended to omit transitional details from one key event to a next one, which might have made his story “incomplete,” “immature,” or “incoherent.” Or, it might have been me who was not able to understand all of what he said and picked up only major lines. Either way, it was not very important in terms of understanding and enjoying Alden’s story.

The first line of Alden’s story of one day, for example, was, “We went to an animal hospital.” And he mumbled something about “my dog.” The next line I could understand was “I got off the (examination) table.” A bit confused with the story development, I asked him, “What, you (rather than his dog) were on the table??” Alden did not answer my question but proceeded to a critical part of his story: “I brought up my dog.” Alden placed a prolonged emphasis on the word “dog” as he dramatically acted out the movement of picking up his dog from the floor and holding him up in his arms. Then the concluding or climax scene came next. Alden continued, “And I ran,”
with a significant emphasis placed on the word “ran.” Unable to understand the
emphasized word, I tentatively repeated it, “raaan,” which caused Alden to put his face
closer to mine to correct my enunciation as, “ran.” Ah! Ran! Seeing that I finally
understood the most important part of his story, Alden repeated the last line one more
time with acting movements, beginning from a posture of “holding” his dog in his arms,
looking intently to his right, slightly swinging his arms and his body toward his left,
storing an energy that was soon to be released in the action of “run.” He coordinated the
oral aspect of his performance so that the word “ran” synchronized with his last action
of mimicking the beginning of a running motion. Completing his story, he quickly
looked to me and smiled satisfactorily (and ready to do it a few more times!).

It was relationship that mattered to Alden, and he always tried to build relational
spaces that “facilitate the storytelling and dialogue” (Steeves, 2006, p. 107) and where he
could “author his own life” (Steeves, 2006, p. 107). In fact, building relational spaces
seemed to be of utmost importance to him. At a place like the Farm where people were
expected to move at an institutional pace according to the predetermined schedule,
Alden’s story-telling was often seen, treated, and managed as a deviant behavior that
caused disturbances to the scheduled order of the institution. Thus I was frequently
instructed by staff, “Don’t listen to him” or “Just ignore him” as I stopped and was drawn
into Alden’s story-telling and his relational spaces. One day, for example, Lois, a staff
who saw Alden telling me his story of the day, told Alden that he needed to stop
“bothering Maho.” Lois said to Alden, “Alden, Maho is very busy. You can’t keep talking
to people like that.” She also told me that I needed to stop listening to him and to move
forward, then left us to enter the bathroom. A few minutes later, Lois came out of the
bathroom. As soon as she saw us still continuing what she had told us to stop, Lois
interrupted us, and this time, she told me in a more straightforward, forceful way, “Maho,
you’ve gotta tell him good-bye sooner or later.” Out of respect for Lois, I tried to show
that I did listen to her at least to some extent by hesitantly and slowly moving my body
away from Alden. Recognizing that I was still wanting to hear his story, however, Alden
continued on telling his story with a somewhat urgently raised pitch and he even
mentioned one element that I could not quite understand, which was about a “nurse.” As
soon as he said something about a “nurse,” I stopped my moving-away motion and turned
back to him and asked, “So, there was a nurse?” At this time, I could sense that Lois gave
up on us, which released me from a restraining order that I felt like I was given.

At the Farm, as people passed and left him behind, Alden would often call out,
“Don’t go!” “This is important!” He seemed to have understood that in order for us to
build a just, inclusive community, “[e]ach of us need connections to others so that we
have a setting and audience to express unique aspects of our personality” (McMillan, 1996, p. 315) and thus we must fight for it.

**Fighting against Institutionalization**

The Farm was an institution, in the sense that, as a New York State Office of Mental Retardation and Developmental Disabilities (NYS-OMRDD) funded program, it was organized as “a structure of control” that delivered a “service” rather than “care” (McKnight, 1987, p. 57). Complying with the rules dictated by the State, the Farm did their best (and prided themselves in regard to this effort) to incorporate a certain number of skill development goals into each aspect of life at the Farm. Sometimes the labeled informants’ wishes were turned down because what they wanted to do might or might not address one of goals that had been identified for them. Lisa, who was vocal about her frustration with the program and the staff, once cried out, “Goals suck!” and angrily put her face down on the table when her desire to work on her book-making project was at risk of being rejected on the grounds that it might not be related to the goals defined in her service plan. Lisa’s anger sharply resonates with how Michael Kennedy, a long-time self-advocate and a former resident of an institution, critiqued the disability service system based on his own experiences. In an article, *The Disability Blanket*, Kennedy (1994) revealed his critical analysis from a service-recipient perspective that the
disability service system often invaded privacy, ignored personal goals, and degraded the meanings of life. Kennedy (1994) critiques as follows:

Third, under the disability blanket everything you do must be part of a “program” rather than just living your life. It’s like everything that you want to try to do for yourself has to be labeled, or logged, or decided by professionals…. When I first started working at Syracuse University, Medicaid said my job had to be written up as a program, with goals and objectives, verbal prompts, and all. I had to report what I did during my workdays, and these reports were brought to my team meeting so they could make sure my goals and objectives were being met. It made my job feel like it was just a program, and it made me feel like they thought I wasn’t responsible. Finally, I just refused to do it. I didn’t care what the consequences were. (p. 75)

Staff at the Farm often reminded, rewarded, or reprimanded the labeled informants using the language of “such-and-such skills” that they were supposed to be working on during a certain activity, such as time skills, money skills, computer skills, number skills, safety skills, shopping skills, directional skills, being-flexible-skills, and the like. Furthermore, based on this skill-oriented, developmental perspective, staff often perceived interdependency as laziness or incompetence, and imaginative, playful or
non-verbal communication as inappropriate and immature.

There was a time and place, however, where staff could liberate themselves from the developmental perspective and from the rule-enforcing role of the institution, and could enjoy the interdependent, inclusive, and responsive relational space with the labeled informants. Although, as Steeves observed with teachers and therapists, such liberation occurred primarily in “small one-to-one ‘secret’ places” where the staff felt “safe enough to improvise and play” (Steeves, 2006, p. 110), such as in a car or in the community where they were free from other staff’s scrutiny regarding their fidelity and ability to maintain order and to enforce the institutional rules on the labeled informants. For example, in the car on our way to a large craft shop 30 minutes away, Mary, one of the team leaders, was more relaxed and less rigid in terms of executing her role as staff.

Jade, who has Down syndrome and whose speech is limited, employed an array of impressively creative strategies to engage others and to build relational spaces, one of which involved making fun of someone’s “smelly feet.” Typically, however, this strategy did not work well with staff at the Farm and often resulted in a reprimand to him about how it was not a nice thing to say to other people. Mary, who sat across from Jade in the car, initially took the regular staff position and replied as such, but soon she decided to let it go and, instead, to have fun with it: Mary began making fun of Jade for “liking my
smelly feet” and even challenged that his feet were possibly smellier than hers.

Mary knew, however, that she could do this only because she was outside of the Farm and no one was judging her ability to successfully control the labeled participants. On our way back, therefore, Mary needed to return to her formal role as a staff member accompanying participants who obeyed her order and demonstrated good behaviors. This sudden transformation was first directed toward Jade when he and I were playing “Hang Man.” The challenge word I came up with was “Smelly Feet,” which Jade marvelously figured out with a good laugh. At this point, Mary decided to put on her “staff voice” and reminded Jade that he needed to calm down as we were getting closer to the Farm. Mary went on to say that when we were out in the community, people, including herself she admitted, tended to get excited, relax, and act sillier. But we could not be acting silly and distracting people when we got back to the Farm as people would be properly and quietly eating lunch in the dining room. Mary added that this applied to everyone, not just Jade, after which she effectively executed a warning and reprimanded Lisa to stop tickling Tailor and to “Hands off” from him. At a lunch table, Lisa angrily expressed her frustration saying, “Girls get caught for murders, and boys don’t!” thus pointing out an injustice in blaming only one person for a collaborative act.

As such, the Farm, as a site for operating disability programs that were designed
to provide services rather than care, was an institutionalized system that McKnight (1987) warned as growing “at the expense of communities” (p. 57). The labeled informants (as well as the non-labeled staff), therefore, needed to fight against such institutionalization in order to protect their community. One of the ways they did so was through claiming and validating themselves. Suzanne, for example, who was well known for and sometimes seen as annoying for her routine questions such as “What did you do last night?” or “What are you going to eat tonight?” , occasionally made sudden, assertive announcements such as, “We are working!” or “I am busy!” When I first heard her make this statement, we were wandering around in a store after having completed the official shopping activity. Thus, this wandering seemed to be a rather aimless activity, at least from my perspective. However, Suzanne, as if to challenge my view that did not find much meaning and value in what she was doing, looked into the face of another team member and validated their activities with the assertion, “We are working!”

Suzanne also sometimes claimed which group she wanted to be a part of, even though she had a perfect knowledge of the Farm’s rule that the labeled participants had to stay in an assigned team during the day and work on assigned tasks. One day, for example, Suzanne boldly asked to be allowed to change her assigned team and instead work with Lauren. She was a staff person who seemed to employ Goode’s (1992) “emic
perspectives” (i.e., trying to assume a perspective of others by putting oneself in their shoes) more than “etic perspective” (i.e., seeing non-standard behaviors as deviants and abnormal) and was therefore liked by many of my labeled informants – especially by the ones who less relied on speech for communication and thus had to employ a variety of non-traditional strategies to communicate with others, such as Suzanne, Jade, and Alden.

Suzanne inquired of her assigned team leader, “Can I work with Lauren?” Even when rejected, she did not simply give up but rather followed up with a very reasonable question: “Why not?” On a different day, Suzanne’s team was making cookies in the kitchen, and Lauren’s team had an art teacher to work on drawing in the adjacent dining room. After having finished the cookie baking, serving the cookies to people in the dining area, and receiving compliments from the guests, Suzanne then decided that she should attempt to join Lauren’s team and paint. Seeing an open easel on one of the dining tables, Suzanne approached Karen, the art teacher, and claimed, “I paint. Can I paint?” To me, it was a bold statement in the sense that it broke the boundary artificially set by staff regarding which group to stay with and what activities to do, while being completely knowledgeable about the dynamics of those institutional systems (Suzanne often recited the Farm rules, such as “I am not supposed to repeat questions”). Karen, being an outsider and therefore less bound by the institutional rules like myself, was simply
pleased that Suzanne showed a voluntary interest in art and welcomed her.

Despite its out-of-context appearance, Alden’s story also often contained an element of claiming and validating. For example, at the same store where Suzanne made the validating statement of “We are working,” Alden too, all of a sudden, looked into my face with a very serious expression and said, “Do I look like a monkey? I am not an animal. I am a person.” Hit by such a fundamental declaration, I replied with the same seriousness that Alden had displayed, “Yes, you are a person. You are not a monkey.”

Not only claiming and validating their own existence, people at the Farm also often validated others. For example, Alford, who was a tall man with black hair and big black eyes, validated Jade’s silliness with, “You are being funny.” Jade, as I introduced him earlier, had a limited command of speech and thus often strategically used creative and playful means of communication, such as asking someone for help; playing games; making funny faces; expressing himself in a lively manner through a combination of signs, words, non-words, howling, dramatic tones of voice, and mimicking sounds; and making physical contact such as touching, shaking hands, and giving hugs to people. It was quite an impressive repertoire of communication that Jade employed but most of these strategies, except signs, words, and “appropriate” hand shaking, were often disregarded, reprimanded, and prohibited as inappropriate behaviors by staff, which was
very sad to see.

So I became anxious when Jade started to “act silly” with Alford, touching his hair and head. I was anxious first because I was worried that Jade might be in trouble again if the staff saw him doing it, but also because an ingrained “special education” habit in myself began to doubt whether Jade could control himself so that things did not get too wild. Hating to act like staff or a teacher, I did my best to sound light and like a peer when I finally expressed my concerns, “Let him alone, Jade!” In response, Alford gently rejected my intervention by presenting a sharply different interpretation of Jade’s behavior as “You are being funny.” In other words, Alford resisted the devaluing meanings imposed on Jade’s behavior using “the foreign language of studies and reports…that ignores their own capacities and insights” (McKnight, 1987, p. 58) and validated Jade’s way of being and contributing as a member of the community.

“Being funny,” which could easily be regarded as an irrelevant or inappropriate quality at a site of work or training, was frequently acknowledged and expressed as a valued human quality at the Farm by the labeled informants. For example, Ben, who taught me the power of interdependence and whose preferred working style was by making conversations more than by actively participating in the physical aspect of completing the task, was positively recognized during an interview by his fellow worker,
Lucy, as “A good worker” and “Funny.” Being funny and having fun blurred “[t]he line between work and play” (McKnight, 1987, p. 58) and helped to transform the institutionalized space into a community. As McKnight (1987) stated, “[y]ou will know that you are in community if you often hear laughter and singing” (p. 58). In such relational space, a boring and simple task like folding and taping a pile of newsletters could become enjoyable, vibrant, multifold, and inclusive: Thanks to Ben, who created a significant amount of conversation in a conference room while he took the newsletters I or someone else had folded, made them into a neat pile, and placed them in front of others who taped the newsletters, even staff were relaxed and enjoyed the conversation. Alden, who would be likely to be excluded or marginalized as a non-contributing burden if the meaning of work was defined narrowly, was also able to be a valuable part of the folding-the-newsletters task by contributing some of his jokes and bringing laughter to the community. The best of Alden’s jokes on that day was, “What does a dog say to a new sand paper?” “(In a really dog-like voice) Rough!” Alden’s joke even encouraged Lindsey, who was shy and soft-spoken, to offer her specialty joke, which was later repeated (or stolen!) by Alden. Alden seemed to be especially happy: He was jumpy with a smiley face and giggles, and he needed to run a little, almost driving himself out of the room.

Another example of validating others could be observed around Dean, who was
mostly quiet but often succinctly responded “Yeah” in his low, attractive voice to people’s questions. Dean wore thick glasses, had Down syndrome, and loved cars and girls. Lisa, who considered herself as talkative and who recognized that this sometimes got her in trouble with staff or with her colleagues at the Farm and at another work program she attended, expressed in an interview how she admired a person like Dean. She said, “I can learn a lot from him. The way he acts. I can learn the quietness from him.” For Lisa, Dean’s less talking was a commendable character rather than a speech defect caused by his disability. Similarly, Lisa saw it as an expression of his preference and decision making when Dean quietly slid pens and a paper to the next person without adding anything to the “Farm Book” – a project that Ben proudly initiated, creating a “Who Is Who” book about the Farm. Lisa interpreted and explained that “He doesn’t like that kind of thing.” In a situation where Dean’s actions could have been interpreted simply as passiveness or incompetence, Lisa recognized and validated Dean’s agency.

The labeled informants at the Farm fought against institutionalization also by resisting and challenging institutional rules, values, and relationships. For example, Lisa, who did not hesitate to express her frustration with the staff’s prioritizing program goals over her wishes to work on her book-making project, also did not hesitate to challenge the power differences that existed between staff and the labeled informants. This occurred
when Malik returned from outside after he threw out some garbage before lunch. Mary, a young staff member, asked Malik if he had washed his hands, and when Malik said no while looking troubled for being questioned over such a matter, Mary told him to go back and wash his hands before eating his lunch. This was when Lisa’s sharp comment was thrown into the air: “Look who’s the boss!” Understandably, this comment was not easy for Mary to take in. She said, with a hint of defensiveness in her voice, “I am not a boss! I’m just giving him a… helpful suggestion!” Lisa did not back up but further asserted how she saw it. “No, you are the boss.”

Being as vocal as Lisa, one might think that it must be easy for persons like her to express objections toward staff or that she is just a problem-causing rebel by the nature of her disability, which I believe was not the case. For a less institutionalized outsider like me, the authoritative power that the staff held over the program participants was significant and felt overwhelming. Staff often spoke in sentences that designated them as agents and decision makers and placed the program participants in passive positions, such as “We allow them to take the phone,” “We allow them to drive the vehicle,” or “We let them sit wherever they like with whomever they like so they can have time to socialize on their own [during lunch]”. From the start of my fieldwork, I was painfully made to realize the significant power differences between the staff and program participants as
well as the different positions occupied by labeled informants and myself. For example, when a team leader, Lois, temporarily left the craft room and there were insufficient materials for the assigned task (sanding wood plates), I felt free to roam around the room and search the shelves for more materials, while three labeled informants including Lisa just remained in their seats. Such “restrained-ness” was particularly evident in Lisa. After a while of sanding small pieces of wood plates, Sandra (one of the labeled participants on the team) started to draw on paper with markers – a choice Lois offered her with necessary materials before she had left the room. Seeing Sandra doing it motivated Lisa to draw as well. Lisa claimed that she didn’t like markers and she could only draw with pencils. So she wondered if there were any pencils available in the room. I wondered that too. And I saw Lisa unmoving, frozen in her seat, despite the fact that it had appeared that pencils might have been on the long table along the wall that was only two steps from where she was sitting. My quick first instinct was to see it as “laziness.” But then when I got up off my seat, walked around the semi-circle table, and freely wandered around the room and examined what was on the long table when our supervisor was absent, I could not help realizing the privilege contained in the “freeness” that I had taken for granted. I wrote in my field notes as follows:

I don’t know if [Lisa] saw my act as evidence of the ultimate different positions
we each occupy at the Farm or saw it as a brave act or what. It was a concrete moment when I experienced our differences: I did not see the barrier that was holding Lisa back and restraining her. I did not have to deal with it. It was like she was on a different side of an invisible cage. (field notes #1, Sep 14, 2005, p. 13)

When I finally found a pencil and paper for Lisa to draw with, she tentatively took them, saying “I hope Lois doesn’t mind me drawing (instead of sanding as she was initially instructed to do).” When Lois came back to the room, without much thought, I joyfully shared Lisa’s beautiful drawing with Lois. Lisa seemed startled by my reckless act and quickly said, “Oh NO!” But then she was comforted by Lois’s bright smile and enthusiasm for her artwork. Happy for her, I also felt bad that I had acted carelessly without getting Lisa’s consent. I just did not think about it. I did not understand how it might startle Lisa. I did not understand how the societal and institutional divide had been working on the labeled individuals, violently regulating and oppressing their bodies and actions.

As such, Lisa was as conscious, afraid, and affected by the staff-participants divide as any other program participants at the Farm. There was in fact once a conversation on “Who is Maho?” among the labeled informants. It happened in the afternoon when program participants were gathered to watch a movie and the only staff in charge of the room temporarily left the room, seeing that I was there. As soon as the staff left, Lisa whispered excitedly, “No staff!” Then Tailor, a large young man, pointed out that there was still Maho in the room, to which Malik who sat in a wheelchair parked right next to me immediately jumped in and responded, “Oh Maho is not staff. She’s a volunteer,” and asked me for a confirmation. When I agreed that I was not staff, Lisa, as if to advocate for me, concluded that “No, she’s not a staff! She doesn’t keep an eye on us. She’s good.”
Understanding the authoritative power that staff had over program participants, it must not have been easy for Lisa (or anyone) to challenge the imposed boundary and to express her resistance against the institutional system. Lisa, therefore, was indeed proud of herself: She once stated, “I know I am bad. And I am proud of it!”

Jade, who was disadvantaged in terms of orally resisting and talking back, also seemed proud to express his resistance by action whenever possible. For example, when Lisa saw Jade inviting me to exchange our chips and cautioned him that it was against the rules, Jade, with a challenging look on his face, did not stop and continued to invite me. Joining his resistance and appreciating his way of creating community, I too did not stop and accepted his offer.

Although it does not lessen the reality that the nature and degree of the consequences caused by the power differences significantly differ for staff and for labeled program participants, the institutional systems also put strains on staff as well. At one time or another, many staff were observed to demonstrate conscious or unconscious acts that could be interpreted as frustration or resistance against institutionalization. Lauren, introduced earlier as a staff member who was well liked by many program participants, was the type of staff member who seemed to question the validity of institutional systems much more than the behaviors of the program participants. For example, when her team was playing Uno and Suzanne asked for help getting a card from the stack, Lauren did
not adopt a dominant, institutionalized interpretation that defined Suzanne’s frequent requests for help as inappropriate dependence requiring encouragement and redirection to get her back on task. When Malik, a male program participant, said to Suzanne, “No, you do it,” mimicking what staff usually said to Suzanne, Lauren stopped Malik, interrupting the institutional pattern, and instead validated it as a legitimate call for help with, “She can’t reach them.” Lauren then pushed the card stack toward Suzanne. Malik said “Oh,” to the alternative interpretation of Suzanne’s behavior that Lauren had presented, and took one card and gave it to Suzanne.

In contrast to Lauren, Lois was the type of staff person who strongly believed in the validity and effectiveness of understanding the labeled program participants’ behaviors from the developmental point of view. She faithfully devoted herself to training the labeled program participants to follow the Farm rules, improve their insufficient skills, and develop independence. As Lois herself once described the Farm--“It is kind of a family business”--her husband as well as her daughter also worked for different parts of the Farm such as the respite program. Lois was a long time staff member at the Farm, and devoted herself enough to go beyond her formal job requirements, sometimes inviting or accepting a program participant who, for instance, needed a place to stay, into her own house. Her bright personality as well as compassion
for the labeled program participants were probably part of the reason why Lois was also well-liked and trusted by many program participants, even though she was rather strict about rules and skill development training. As this type of person, Lois sometimes seemed frustrated by, or even jealous of, an outsider like myself who was not constrained by an institutional staff role and was not very concerned with or worried about rules. For instance, when I resumed my visits to the Farm after a 1-month absence, I decided to break the rule of “No hug for Jade,” which appeared to have been created to teach socially appropriate personal space to Jade who loved people and who relied on both verbal (albeit limited) and non-verbal communication tools, including physical contacts. Having greeted everyone in the morning with a hug, I felt it was appropriate to do the same with Jade to celebrate our reunion.

As I moved to get closer to Jade and hugged him, I saw a glimpse of Lois’ smile, as she was standing next to me. This smile was immediately contradicted, though, by her command of, “Jade, no more hugs! You know the rule. Only hand shaking!” (field notes #9, April 12, 2006, p. 83)

At the time, I was too confused by the contradiction – the smile and the reprimand – and failed to recognize until later that Lois did allow this one-time hug accompanied by a generous smile. She did break the rule, in other words. She let it go for a second and allowed Jade to do what was forbidden. She, in fact, even looked as if she was happy for
us and enjoyed seeing the human-to-human moment in which we were able to connect
and exchange appreciation of one another. In a sense, Lois at this moment acted as herself,
resisting being defined by the institutional system. However, after only a brief instant of
freeing herself from the institutional role, Lois again returned to being a faithful staff
member. She even declared, jokingly, as if to make the community-to-institution
transition as light as possible, that “Yes, I’ll be a law enforcer!”

Alden, whose stories were often regarded as a disturbance to the scheduled pace
of the institution and who was always instructed to pick up his pace so he could move
along with others, one day protested to a staff, Sara, “Why do you pull my hand? You
don’t have to pull my hand.” Trying to get him to move and to sit at the dining table for
lunch, Sara justified her act with, “Because you are resisting!” to which Alden explained
his perspective, “I’m not resisting,” implying that he would in fact sit if she would only
let him move at his own pace.

Alden tended to be seen as stubborn and resistant, and thus as a “big task” to be
assigned to work with. Staff often wished “Good luck” to someone who had gotten Alden
on her or his team for a day. However, Alden in fact negotiated as much as he resisted and
claimed. For example, one day, I was with the same team as Alden and we were out
shopping. When it was time to leave the store and go back to the van, Alden stalled,
seemingly stuck, and could not move. After we had remained in the same spot for about 10-15 minutes, during which I occasionally begged Alden to move, Tasha, a team leader, came to let us know that everybody was now in the van and ready to go. It was time to increase the seriousness of my begging. I pleaded, “Let’s go Alden! I need to go! I am freeeeeeezing!” Alden quickly looked into my eyes with what seemed like a compassionate gaze. But this did not result in any movement by him. Thinking he might need physical prompts to initiate a body movement, I touched the side of his hip and gave him pressure so his hip would turn toward the store exit. Alden’s hip turned a bit but his feet did not. His feet looked as though they were glued to the floor. Alden then proposed a different workable plan, “Can I go this way too?” looking the opposite direction of the way I was pushing him. So I said, “Sure.” Alden was finally able to move and we all left the store.

As such, Alden moved on and allowed others to move on, but only after he was also listened to and after his needs were given a fair consideration and negotiation. He was resistant against simply being imposed on by others’ demands. In a sense, through his way of being, Alden “interrupt[s] a smooth landscape” (Steeves, 2006, p. 113) and reminds, demands, and helps us to resist institutional structures within which some control others, and to change them into community structures where people come
together to communicate, to negotiate, and to build creative solutions and consensus.

**Conclusion**

I initiated this study in order to seek alternative ways to conceptualize human value that would not put people into a hierarchical order based on the narrowly defined utility value. However, as I spent more time at the Farm, I gradually realized that the question of human value might be rather irrelevant or unimportant in the community that was being woven and fought for by the labeled informants of the Farm. For example, in my effort to discover what counted as contributions from the perspectives of labeled informants, I asked during an interview with Becky about Alford (whom Becky identified as one of her friends at the Farm) and, in particular, what she thought was the nicest thing that he had ever done. After a few seconds of thinking, Becky then formed her answer as, “Just being himself!” It seems that my question was rather foreign to Becky’s conception of what people bring to the community: Becky’s response seemed to clarify that it was not what people did or did not do that made them valuable. Rather, it was the unique existence of each person that was most important, meaningful, and valuable beyond question. The radical insight contained in Becky’s statement coincides with what Judith Snow (n.d.) wrote: “Our presence is the fundamental gift that we bring to the human community. Presence is the foundation of all other opportunities and interactions, of
everything that is meaningful” (“Gifts,” para. 11) It is a radical argument that presumes, not questions or argues for, anyone’s value, just like Biklen’s notion of “presumption of competence” (Biklen, 2005) and Mutsuharu Shinohara’s notion of “presumption of humanness” (Shinohara, 1986).

Thus, the research focus had to be changed. The question became not so much one of re-conceptualizing human value as one of community where human value can be presumed for anybody. As illustrated in the previous section, what mattered most in the friendship community of the labeled informants at the Farm was relationship. Based on the principle of interdependence and on valuing of “incompetence,” people at the Farm fought against disconnection and institutionalization, and instead sought to establish relational spaces, in which people could claim, validate, resist, negotiate, and respond to each other.

In other words, it can be said that Levinas’s idea of ethics prevailed in the friendship community of labeled informants at the Farm, which began with “answering the call of responsibility from the face of the Other” (Arnett, 2003, p. 39). Levinas, a Lithuania-born French philosopher, reframed the self “from a willful agent to a responsive creation, moving from a traditional focus on autonomy and independent agency to interhuman responsive action responsible for the Other” (Arnett, 2003, p. 39).
Responsible communication exhibited by Sandra and Jade embodied such ethics. Sandra and Jade, who both have Down syndrome and a limited command of speech, often communicated with each other via a combination of speech, gestures, facial expressions – most notably making funny faces and returning dramatic reactions to each other – and babbling, nonunderstandable (to my ears) tones of voice. They also enjoyed conversations in which they imitated and made fun of a staff person’s bossiness, such as giving them orders and telling them what to do or what not to do. One day, as usual, Sandra and Jade were conversing in a creative, imaginative, and playful way in the dining hall. Their excited talk, however, drew the staff’s attention, causing them to be reprimanded for engaging in inappropriate behavior and even to be separated. Sandra was ordered to leave Jade and move to a different table. Sandra, with a rather blank expression on her face, got up and started to leave Jade. As she walked away, Jade howled at her, “Auuuu! Auuuuu!” Though still moving further away from him, Sandra howled back at him. She looked as though she just could not ignore and had to respond to Jade’s howling as she stopped her movement, a bit awkwardly turned her head and chest toward Jade, and howled back to him across the hallway. At that instant, Sandra might have acted on her understanding that she had an obligation beyond her will, an obligation to be responsive to the Other, as Levinas would say. She might have understood that

When there is a responsive and responsible relationship, a mindful and hopeful response could emerge and alter the world. On one day, for example, Jade asked Mary, his team leader, using signs, whether he could listen to his own CD in a car during the going-out-to-the-community-task. Mary, who had skillfully understood his signs, could have dismissed this request immediately exercising staff’s power over the participants. But she did not. Posing a moment with a thoughtful look, Mary said, “Wait a minute,” and turned around to go back to the dining room to ask Tasha (a little more experienced staff) for her opinion. Meanwhile, Jade proceeded to his locker in the hallway, opened his backpack, and was about to grab his CD player out of his bag when Mary came back with the “no” news. Mary told Jade that, because not everyone had a CD player, it was better if he did not bring his own CD player either. Jade did not seem to mind the rejection. He only said, “Oh,” and put his CD player back into his backpack. Going out of the door, Jade even threw “Thank you, Mary!” to her back. Mary looked a little surprised (or pleasantly troubled) that she received a thank-you from Jade after she had rejected his request, returned him a thank-you, and added “That was kind of you to ask.”

Mary’s troubled look demonstrated that Jade’s reaction betrayed her expectation. In her logic, it probably did not make much sense that he thanked her even though he did
not achieve what he wanted. But for Jade, it must have been relationship and what he could gain through the process of communicating that mattered more than merely obtaining a tangible outcome. And Jade certainly gained a lot: He was heard, validated, taken seriously, and received a response. In a way, human connections that contribute toward building community were restored and strengthened. Through such connections and a responsive relationship, Jade’s logic could in turn touch on and bring about a change in Mary’s logic as well. When Mary thanked Jade saying, “It was kind of you to ask,” she neither used the institutional language of “good job” nor sounded as though she was merely giving him positive reinforcement for “desirable” behavior. Rather, Mary’s response sounded genuine and personal as if to express that she was touched by and appreciated Jade’s kindness - his kindness, generosity, and maturity to forgive her for turning down his small wish with no good reason, and even to gracefully thank her for taking his communication seriously enough to listen and consider the possibility.

Thus, it is in this relational space, in which such a mindful response emerged, that we can find hope that “[a] unique way of seeing the world is shared and the world is altered” (Steeves, 2006, p. 113); that is, the hope that we can indeed change the world.
CHAPTER 5

Findings: Community at Kapu Kapu

"Kurambon laughed ‘Kapu kapu.’"

A verse from “Yamanashi (A Wild Pear)” by Kenji Miyazawa, 1923.

In an attempt to understand, capture, and represent the construction of an inclusive community that I experienced at Kapu Kapu, I identified and chose to delineate it by the following four themes: (1) Affirm, respond, and maintain relationships with others, (2) The art of living with different others, (3) Cultivate alternative meanings, and (4) Open to vulnerability.

Affirm, Respond, and Maintain Relationships with Others

When Kapu Kapu first opened the café in the local shopping mall in 1998, other storeowners were not very welcoming; they were concerned and defensive. Mr. Suzaki, the director, recalled how Shiori, a woman with Down syndrome and one of Kapu Kapu’s original members from its early days, would drop by each store every morning on her way to Kapu Kapu and personally greet the shop owners one by one. Mr. Suzaki attributed the good relationships with the neighbors that Kapu Kapu now enjoys to such acts that gradually melted prejudicial defensiveness and cultivated a foundation on which to develop more personalized and less categorized relationships.
As such, approaching, greeting, and expressing interest in others, was an important way for Kapu Kapu workers to build an inclusive community. In a sense, it both demanded and invited others to be responsive and get involved. Seiko, for example, who was blind and mostly lied on the floor when she was at Kapu Kapu, actively sought out others. She often changed her body position so that she was closer to somebody, sometimes even burying her face in someone’s lap. Such actions never failed to evoke responses, and the called-on person often responded to her by tapping her back or talking to her.

Similarly, Yuji, who mostly communicated not via speech but through his actions, often built relational space around himself by physically approaching and directing actions toward others. For example, one day when I was sitting at the edge of a flat, raised working space at the end of the café area, Yuji walked toward me smiling, so I invited him to sit with me. Yuji accepted my invitation and sat on a step. Then after a while, all of a sudden, Yuji threw his right hand up in the air, landed his friendly hand on my thigh, and leaned his body slightly on mine, making me feel included and thus affirmed. Responding to Yuji’s initiation, I too bodily communicated my affirmation of him by jointly maintaining our bonded and interdependent posture.

Interests and concerns for others were frequently expressed, even for someone
who was not there on a particular day. An important part of the morning meeting at Kapu Kapu was to announce the names of people who were absent for the day, to report the whereabouts of those who had been absent for a while, and to celebrate the return of those who had not been at Kapu Kapu on a previous day or days. This kind of information was important for Kapu Kapu workers; there was often someone who told me as soon as I arrived about another worker who was absent or another who had returned. Similar conversations were also often repeated throughout the day as if they could not ignore and just move on like nobody was missing; absence had to be mentioned and recognized. It seemed that in this way Kapu Kapu workers reaffirmed the membership of individuals who were absent and thereby strengthened their community by expressing recognition of and concern for the missing members. For example, Mrs. Saishu, the mother of Seiko, directed a genuinely happy and appreciative smile at Fujii, a kind young man who was also often described as noisy or wild, every time he astutely observed that only Mrs. Saishu came, wondered about her daughter, and asked, “Where is Seiko?”

Thinking about and missing others not only affirmed the community membership for those who were missed, but also could promote “the habit of inclusion” in the community, as opposed to “the habit of exclusion” (Paley, 1993,) and thereby
secure places for everyone including the person who expressed the concern for others.

For example, one day Mariko, a soft-spoken woman with short hair, glasses, and a bright smile, was getting ready to leave for an assigned half-day shift at a small café that Kapu Kapu operated in a nearby community care center. Miwa, a short and thin woman, half-jokingly and half-seriously told Mariko, “I’ll miss you, Mariko” then pleaded dramatically, “Please do not go!” clinging and almost collapsing on Mariko. It was only a half-day shift, so Mariko would return to Kapu Kapu after a few hours. But it nevertheless was a chance for Miwa to express and send a message that she wanted Mariko to exist. Mariko, too, happily smiled, looking pleased to receive Miwa’s humorously dramatic affirmation of her existence, welcomed her bodily contact, and responded Miwa by mutually affirming statement, “I’ll miss you too!”

As such, affirming others by approaching, greeting, and expressing concerns and interests was one thing: Responding to those expressions and interactions was a complementary element. The labeled workers at Kapu Kapu seemed to understand the importance of responsiveness so much that they sometimes even seemed as if they were obliged to respond; this reminded me of interactions that I observed between Sandra and Jade at the Farm. For example, Shiori, the person who every morning diligently greeted each of the store owners of the local shopping mall in Kapu Kapu’s early history, looked
as if she had to get up and chase after Hime when she suddenly dashed off of a bench at a
bus stop. It was at the end of the day and both Shiori and Hime were waiting for their bus
to come. Shiori and I were engaged in a lively conversation and Hime was rather quiet.
Then suddenly (or so it seemed to me), Hime dashed off the bench. Shiori immediately
ran after Hime as she called her name, caught her, gently put her arm around Hime’s
shoulder, and came back to the bench together. It was not new; it had happened before, I
was told. I myself saw this rather “patterned scene” several times. Perhaps it was me who
made Hime feel left out as I must have disturbed the typical balance of Shiori’s
distribution of her attention among her friends and others who shared the same bus. It
could have been dismissed as a mere attention-seeking behavior that one must extinguish.
Shiori, however, did not see it that way. Shiori never doubted its validity as a
communicative behavior that required a response; She faithfully got up and ran after
Hime every time she dashed away. As Shiori and Hime walked together back to the bus
stop, Shiori would further assure Hime by telling her, “You are sweet,” then sometimes
even added a light kiss on Hime’s cheek, at which Hime screamed with a delighted smile.

Patterned behaviors or utterances are often regarded as socially inappropriate
and as such discouraged and prohibited, as was the case at the Farm: Suzanne’s “routine
questions” and Alden’s “story-telling” were often silenced based on institutional rules. At
Kapu Kapu, institutional power did not define patterned behaviors and utterances as inappropriate, and therefore people at Kapu Kapu could safely employ them as part of a creative communication system. For example, Shiori, who had superb conversational skills despite a limited vocabulary that could be understood by others, often involved others in conversations by posing her favorite questions such as “Do you like…?” and “Where did you buy…?” Both questions often worked excellently in terms of evoking responses on original as well as on derivative topics and expanding the circle of conversation. One day, for example, during a monthly sewing club with an invited instructor, Shiori created lively conversation by posing a series of “Do you like…?” questions, to which various people participated and responded with personal opinions or further questions. At one point, I thought she asked, “Do you like celery?” so I took up the question and offered my experiences of eating celery with a dip of peanut butter in the U.S. (which is not customary in Japan). After quite a period of excited talking, someone with a better ear informed me that Shiori had in fact asked “Do you like jello?”

Miwa, who was often shy at initial encounters but in fact, betraying a quiet image that her thin and pale outlook presented, could be quite talkative, albeit disadvantaged in speech, also frequently utilized patterns of witty questions and statements in order to create conversation and to engage others. One of her best
conversational tools was to claim that a particular person resembled somebody else or something. It could launch lively conversations and in fact was sometimes adopted by other members of Kapu Kapu as well. For example, during the monthly sewing club described above, Hime was the first one to employ this tool. She claimed, in her distinctive way of talking with some stuttering and musicality, “Yukiko, you look like a bear!” This occurred after Yukiko had been asking me whether there were bears in Canada. Yukiko was the only wheelchair user at Kapu Kapu and presented a “hairy” image as she had dark short hair, dark thick eyebrows, and round black eyes with thick eyelashes that outlined her eyes. So Hime’s statement was right on target and led to a lot of laughter, followed by more claims of this kind. Shiori claimed Miwa looked like Suneo, who is a well-known character in a popular Japanese animation called *Doraemon*; Suneo did somewhat resemble Miwa in the sense that both Suneo and Miwa had a thin chin and narrow eyes. Then Miwa claimed that Hime looked like Giant, another character in *Doraemon*, and once again Hime did somewhat look like Giant. Because the claims were made subjectively and there were no right or wrong answers, it depended more on the listeners’ imagination to find the resemblance between the claimed pairs as well as to appreciate the amusing quality of each statement.

As such, to a large extent, it was the responsive relationships that determined the
quality of communication, rather than, for example, whether the conversations were grammatically sophisticated or not. One day, for instance, six of us were working in the kitchen making cookie dough and shaping it into small balls, and while doing so, we enjoyed quality conversation that might be considered as immature and meaningless based on societal standards. The six people present in the kitchen included Shiori (who used to greet the mall store owners every morning), Hime (who dashed away at the bus stop), Mariko (who was happy to be asked to stay at Kapu Kapu by Miwa), Yuji (who had placed a friendly hand on my thigh), Mrs. Watanabe, a long-time staff in her 60s, and myself.

Shiori: My home, my home (*One of her favorite phrases; a title of Japanese animation)
Mariko: Re-re-re no sweeping man. Ge-ge-ge no Kitaro. (*Both are titles of popular Japanese animation.)
Maho: Re-re-re no Kitaro. Ge-ge-ge no sweeping man. (*I switched the latter parts of the two animation titles)
Shiori: Mariko Grandma. (*An improvised rhyming phrase)
Mariko: Then Shiori is a Grandpa!
Shiori: Hime is a doggy!
Mariko: Then Shiori is....
Shiori: A piggy!
Mariko: I am a cat!
Maho: Then Mariko is a cat and Shiori is a piggy.
Mrs. Watanuki: I want to be something too!
Mariko: You are... a rabbit!
Mrs. Watanabe: Wow. I have to jump then! Shiori, what do you think I am?
Shiori: I don’t know. Maybe a koala panda?
Mrs. Watanabe: Then what about Mr. Suzaki?
Shiori: A big fox.
Mariko: I think Mr. Suzaki is…. a koala panda!
Maho: That would be too cute for him!
Mariko: Then he is a panda…. This is fun!
Maho: Yuji is….Hmm. What do you think he is?
Mariko: He is Monk Ikkyu! (*Name of a main character in Japanese animation)
Shiori: Maho is a house painter! (*I was wearing overalls.)
Hime: Ke…Kenji is him. (*Kenji is a very popular part-time staff in his early 20s. Hime pointed to a handsome man in her comic book and claimed that Kenji looked like him.)
Shiori: I want to go to the sea. I will go.
Maho: I love the sea too.
Shiori: I will go by train, tomorrow….. With my priest.
Maho: Shiori, you are thinking of going on a date with the priest of your dreams, aren’t you? You are blushing!
Shiori: You can’t come!
Maho: Oh, you are in love.
Shiori: I used to be! (Everybody laughs)

As Mariko said, it was a lot of fun. Conversations were initiated, responded to, expanded, and carried on. Everyone was encouraged and energized by the responsive relationships and the mundane task of making cookies was transformed into quality time and space in which a community emerged. Everybody laughed when Shiori said, “I used to be!” not because it was out of context but because this well-known phrase of Shiori’s had been said and heard so many times in this community at Kapu Kapu that it now had a certain persuasiveness that made people laugh – or the Kapu Kapu workers had developed a shared sensibility to “get” the humor and to laugh beyond reason at Shiori’s
punch line.

Kapu Kapu was indeed not a utopia. There were conflicts, quarrels, and intense moments. For example, Ms. Noda, who in her late 50s was the oldest among the labeled workers, often complained about some of the younger Kapu Kapu workers. She was short, round, and fit in the traditional image of a Japanese mother. Busily moving her hands to knit or sew, Ms. Noda continuously muttered about something or loudly gave others sought or unsought advice. Upon my interviewing of her, for example, Ms. Noda complained a lot about Fujii, the young man who was kind but also tended to be regarded as noisy or wild partially due to his loud voice – as loud as Ms. Noda’s. Ms. Noda kept on complaining that Fujii was too loud, impolite to the elders, and did not listen to what she told him to do. Finally, I felt an urge to ask her, “Do you hate him?” Her face immediately changed and looked uneasy. Ms. Noda uncomfortably denied that she hated him. “It’s just he’s a bit disrespectful to the elders,” she added as if to make an excuse or to correct my misunderstanding. Surprised by Ms. Noda’s uneasy reaction, I further asked her, “So you do not hate him?” Then Ms. Noda replied, “No, I do not hate him. I would never hate anybody.” “Why not?” I inquired. Ms. Noda answered, with an increasingly assertive tone of voice, “Because we are all the same – we are all humans. No?” Ms. Noda seemed to declare her commitment not to deny anybody in an absolute sense and
not to dishonor the existential value that should be equally accorded to all members of the human community, no matter how well she got along with them or not.

Similarly, Mr. Suzaki (the director) explained to me how Shiori, the long-time worker of Kapu Kapu with Down syndrome, once admonished him not to exclude someone. It was a story from early days and Kapu Kapu workers had a day off to enjoy a bus trip to Tokyo. One of the members started to have a problem with another member and he began shouting violently at her in the bus. Mr. Suzaki stopped the bus, got off with the male member, and tried to calm him down, but he continued to be violent, yelling and pushing Mr. Suzaki. People on the bus including labeled workers of Kapu Kapu as well as some family members, staff, and volunteers watched the two, mostly sympathetic toward Mr. Suzaki. The problem was solved when another staff member arrived on the scene with his own car and drove the male member separately to the destination. When Mr. Suzaki got back on the bus, people were relieved that the problem had been solved and now the trip could resume without the male member. Shiori, however, sitting alone in the furthest back row, looked at Mr. Suzaki and succinctly stated, “No fighting, Mr. Suzaki.” Amid an atmosphere in the bus that overwhelmingly supported and justified the exclusion of the male member, Shiori’s admonishment was, to Mr. Suzaki, a call to not abandon hope and commitment to stick with and live with others despite discomfort or
The Art of Living with Others

Ms. Noda, the oldest of the labeled workers at Kapu Kapu, was originally from Miyazaki prefecture, which is located in the southern region of Japan. It is often said that people born in this area tend to be wild and talk roughly; Ms. Noda was not an exception. She had epilepsy and could not go to school in her childhood, except one year of being placed in an institution that supposedly provided some educational programs. All through her childhood and adulthood, Ms. Noda mostly stayed home and helped at a small Chinese diner that her mother ran. At Kapu Kapu, Ms. Noda often recalled, sometimes fondly and sometimes angrily, how her deceased mother, who was a widow, was tough on her. As if to follow the model of her own mother, Ms. Noda tended to be or sound tough toward others, which was not always easy or pleasant to deal with. Sometimes it resulted in conflicts or created tensions, but not always. Many Kapu Kapu workers seemed to have developed a way to get through potentially harsh interactions with Ms. Noda, and they often did so without denying her existence.

For example, Miwa utilized her superb sense of humor. Miwa was talkative (albeit disadvantaged in speech), largely because she simply loved people and loved talking, but also because talking was her way of participation and contribution, given that
many physical tasks were hard for her to execute. However, according to the perspective that Ms. Noda had learned from her mother as well as from the society, talking without engaging in some kind of tangible jobs was regarded as lazy, and therefore something for which to be reprimanded. Ms. Noda often confronted Miwa and preached, “Stop talking and move your hands!” or “Stop wandering and get to work!” One day, for example, Miwa and I were talking as I rearranged the used items that were sold outside of the café to make them more appealing to the customers, Ms. Noda came outside to call us in for the morning meeting. When Ms. Noda saw Miwa wandering and talking, she approached Miwa and let out her irritation at the sight of Miwa’s laziness (from her perspective) by howling at her and pretending to bite her. The humorous quality of Ms. Noda’s action might have helped Miwa to not take it seriously and to respond with humor as well. Howled at by Ms. Noda, Miwa overdramatically screamed and staggered. Ms. Noda, seemingly satisfied as if she expected exactly this, loudly laughed and went back inside. Miwa then turned to me and exclaimed, “Ms. Noda is like a weird mother!” We laughed together. It seemed that Miwa’s artful way to manage potentially stressful interactions was by turning them into a joke that people could openly laugh about or make fun of rather than a serious problem that led to exclusion of the unpleasant person.

Sense of humor was an invaluable art for living with others and its usage was
critical in maintaining and enriching the inclusive community at Kapu Kapu. One day, for example, I was given the task of walking around the old residential complexes in Kapu Kapu’s neighborhood with three labeled workers to distribute flyers in mailboxes. The people who shared the task with me that day were Shiori, Yuji, and Mr. Higashino. Mr. Higashino, who had Down syndrome and was in his 50s, was one of the two older labeled workers at Kapu Kapu. He was a rather new member though; he had been institutionalized, had worked at a different sheltered workshop, and then had stayed home for a long time with his parents after he left the last workshop prior to joining Kapu Kapu in the same year I started my fieldwork. Mr. Higashino came to Kapu Kapu only three times a week as he had to go to the hospital every other day to receive dialysis treatments. Shiori, as a veteran worker and as someone who loved doing things for others, wanted to take care of Mr. Higashino as we walked around various complexes and inserted flyers into mailboxes. Shiori would try to hold Mr. Higashino’s hands and guide him through the procedure step by step by showing which way to go, which compartment to go in, which mailbox to insert a flyer and which flyer to insert. At first Mr. Higashino accepted Shiori’s help without much resistance but I could see it was gradually becoming annoying to him. At one point, Mr. Higashino suddenly increased his walking speed, as he comically raised his shoulders and put his hands on his hips, so he could avoid Shiori’s
physical management of his body. Thanks to his comical form of resistance, however, we all laughed including Shiori who nevertheless tried to catch up with him and continued to offer him her help.

We finished distributing all the flyers so it was time to go back. As soon as we started walking, Shiori quickly positioned herself to the left side of Mr. Higashino and tried to hold his hand. Mr. Higashino, on the other hand, randomly moved his left hand and tried to avoid being held. Shiori did not give up though; she was determined to catch and hold his hand. Then Mr. Higashino adopted a creative way to alter the situation, grabbing my left hand and resting his head on my shoulder as he continued to randomly move his left hand to escape from Shiori’s grasp. Once again, Mr. Higashino’s humorous and non-blaming way of protesting brought us laughter. I was impressed. I never thought of such a way of expressing one’s protest. Yet, I also wondered if there was an excluding potential to this approach. That is, as long as Mr. Higashino attempted to escape from and reject Shiori’s hands, it could result in excluding her. Just when I started to think about this, Mr. Higashino took further action to dramatically change the dynamics of the situation: He stopped moving his left hand away from Shiori’s intervention and instead raised it high and put it around Shiori’s shoulder, holding her closer to himself! Impressed by Mr. Higashino’s bold and embracing act, I followed his lead and held Yuji’s left arm,
inviting him to join the line that the four of us now created together. As a leader and the
initiator of this movement, Mr. Higashino leaned forward, picked up our walking speed,
and moved us forward, making lilting strides. Feeling the lilting rhythm myself, I
improvised a chant, “Zundoko zundoko.” At first, Shiori tried to escape from Mr.
Higashino’s embracing shoulder to regain control. But soon, the enjoyment of making
lilting strides all together seemed to win the day. Shiori laughed, called out “Team,
team!”, and joined my chanting, which gradually became the tune of “Jingle Bells.”
Shiori sang, Yuji laughed, and Mr. Higashino, who mostly communicated by gesture and
actions, added a Santa-like “Ho!” at the climax of the song.

It is inevitable to encounter unpleasant interactions or unwanted interventions
sometimes when we live with others. Therefore, it is critical for all of us to develop skills
to deal with those moments in non-exclusive ways. The approach practiced by people like
Miwa and Mr. Higashino seemed mundane at first, but gradually helped me to imagine
hopeful alternatives to an approach that pointed fingers, condemned, tried to correct, or
excluded others as wrongdoers.

When conflicts do arise, relationships must be restored. And the art of living
with others practiced by Kapu Kapu workers could be observed in this regard as well. For
example, one day a conflict arose between Shiori and Mariko on the driving way back to
Kapu Kapu after distributing flyers in a residential complex. In the van, Shiori and Mariko sat together in the middle-row seat. At one point, Mariko cried out, “No, Shiori!”

Apparently, Shiori, who liked to keep things with her, had grabbed some of the remaining flyers from Mariko’s paper bag and put them in her own bag. Mariko, who also liked to keep things with her, tried to get the flyers back, but Shiori adamantly resisted Mariko’s attempt and hid the flyers between her body and the door, adding a justifying explanation as, “It’s okay. It’s okay. I can carry these for you.” It was not assuring for Mariko, however. A soft-spoken person, Mariko raised her voice and objected, “That sucks, Shiori!”

It was only flyers, but Shiori’s sudden action, without consent, was quite unpleasant for Mariko. I myself had experienced a similar situation with Shiori so I sympathized with Mariko. Not knowing what to say, I remained quiet in the back row seat with two other Kapu Kapu workers. A young staff that was driving the van recognized the conflict and tried to mediate the situation by telling Shiori that we would have more flyers tomorrow. Mariko looked straight ahead quietly and Shiori worriedly watched the side of Mariko’s discontented face. Miwa, who sat in the front passenger seat, turned back and, half-jokingly, said something in reference to Shiori’s misbehavior. Shiori nervously responded, “Stop, stop! Be quiet, be quiet.” Interestingly, however, this
broke the silence and gave Shiori a chance to act: She put her arm around Mariko’s shoulder and moved her closer while looking at her with a concerned gaze. What was puzzling to me, at this instant, was the fact that Mariko did not reject Shiori’s consolation – an act that could be regarded as leaving the matter vague and unresolved. To my surprise, however, as if she heard and accepted Shiori’s action as a statement of regret and perhaps even apology, Mariko quietly rested her head on Shiori’s shoulder. Shiori then gently rubbed Mariko’s cheek with her fingers. The conflict had passed.

This resolution did not make sense to me inasmuch as it did not follow my own familiar scenario of reaching reconciliation, in which the wrong-doer admitted the infraction and apologized for the misconduct, followed by the aggrieved person openly accepting an apology and forgiving the person. Rather, just as Miwa did not blame Ms. Noda as an utterly undesirable person but instead made it a joke to laugh about, and just as Mr. Higashino did not attack Shiori’s unsought help as a problem and instead managed to create a space where everyone could share and live, to Mariko as well, so it seemed, Shiori’s behavior was not an act that called for punishment or correction, but rather was a part of who Shiori was and something to be negotiated in order to maintain an inclusive community.

Cultivate Alternative Meanings
Despite their disability labels that grossly stigmatized them as intellectually incompetent, Kapu Kapu workers were undoubtedly competent in various ways. Particularly, their localized knowledge reflecting their history and experiences at Kapu Kapu was, not surprisingly, far superior to mine. For example, Fujii, the one who tended to be seen as wild and noisy, posed an astute question as to how Yukiko would return to Kapu Kapu from the café that Kapu Kapu operated in a nearby community care center. Typically, those assigned a half-day-shift at the café, including Yukiko, who was the only wheelchair user at Kapu Kapu, were driven to and from the café by a staff member. It was rare, therefore, that Yukiko drove her own electric wheelchair directly to the café because she was late for work in the morning and decided that she had no time to stop by Kapu Kapu to change to her manual wheelchair. In this situation, Fujii expressed concern that Yukiko could not ride on the van if she had her non-foldable electric wheelchair – a question that did not come to my lay mind.

Similarly, Shiori, the veteran Kapu Kapu worker with Down syndrome, demonstrated superior memory skill one day. It was when the families of labeled workers were attending a monthly coffee gathering. There were about 10 family members jammed in the café and taking their orders was chaotic. Shiori stood by the large wooden table in the center of the room with an order sheet and a pen in her hand. As the customers rather
randomly called out what they each wanted, Shiori held the order sheet close to her face and carefully marked them down. Just in case she mistook notes, I stood near Shiori, tried to count the orders, and jotted them down on my own order sheet. Soon after all of the orders were taken, drinks were ready to be served. First up were a few cups of hot coffee. When Shiori brought the coffee to the table, I once again accompanied her in case she needed my help. But when we reached the table, I suddenly realized that I did not remember who ordered hot coffee. My mind went blank and it did not even occur to me to ask the customers who should get the hot coffee. While I was frozen, however, Shiori proceeded to serve the coffee saying, “Mrs. Hot Coffee, there you go.” It turned out that Shiori did not count the orders but instead remembered who wanted what.

Not only was the meaning of competence challenged, diversified, and grounded on the everyday realities and experiences; the meaning of incompetence also was deconstructed and reconstructed at Kapu Kapu. Miwa, for instance, who was thin and physically unstable and thus often required others’ assistance, humorously and radically redefined a situation where she needed to be held and supported to walk up and down the stairs: She exclaimed, “It’s like we are dating!” thus providing a positive angle to this. Miwa also often contested a dominant conception of competence/incompetence, by which labeled individuals were doomed to be identified as inherent possessors of
incompetence and thus as the ones who were solely responsible for failure. For example, when someone could not understand what Miwa said, she often dramatically expressed her disbelief by saying something like “Oh boy” and raising her shoulders, effectively resisting the idea that incompetence was located within her. Or, when she needed someone’s help to perform a task, she would comically act bossy and give others permission to help her by saying things like, “Yes, you may!”

Furthermore, what could be referred to as “the value of incompetence” was also suggested; that is, it was not necessarily a negative matter to be unable to do or to comprehend something. Kapu Kapu workers often demonstrated that a phenomenon called “incompetence” could in fact engage others, motivate collaboration, and enrich relational space. One day, for example, trying to reorganize a cluttered fabric box outside, I requested Miwa, one of labeled Kapu Kapu workers who was busy with entertaining a customer enjoying her morning coffee (e.g., Making her laugh by posing such question as “Do I look like a puppy?”), to get me a rubber band:

Seeing that Miwa was busy, I interrupted and asked her to get me a rubber band. Miwa, however, did not move as if she did not hear me. Thinking that she might need some cheering, I clapped my hands and chanted, “Rubber band! Rubber band!” Being a jovial person, Miwa soon joined me in chanting and cheerfully called out, “Rubber band! Rubber band!” also clapping her hands. Miwa’s comical stooging-like performance made me want to act as a straight person, and I said to her, “Hey, bring me a rubber band! Don’t just chant!” Watching and enjoying our
comedy performance, the guest laughed and a young staff, who recognized our comical interaction, found a rubber band from somewhere and gave it to Miwa so she could hand it to me. Laughter brought; and even a mission completed. Perfect, I thought. (field notes #28, p. 4, November 15, 2006)

It was unclear and not important whether Miwa did not understand the word “rubber band,” or could not comprehend my verbal instruction, or pretended that she could not understand me. The point was that, while Miwa could not or did not simply execute what I asked her to do, we were able to transform a simple following-an-order type of interaction into a performative act that entertained others, mobilized local resources, and critically blurred and challenged the monolithic boundary of in/competence.

Under the mission of Kapu Kapu to diversify the meaning of valuable work, the labeled workers sought and tactically crafted various ways to participate and contribute. For example, when people were busy bringing out used items from storage to sell or from inside the store to display outside in the morning, Miwa, for whom such physically demanding work was not a best match, often invented a way to participate and took on the role of cheering others. One day, for example, tactfully capturing the style of cheering at the Volleyball World Championship when fans cheered the Japanese teams on TV, Miwa drifted among those who busily moved around to do the physical work and cheered
them on with, “Go, Japan! Go Japan!”

Fujii too, who had paralysis on the left side of his body and needed physical assistance, often found a way to participate and demanded that others include him in a process that could exclude him. For example, one day Fujii was sitting at a table outside tending the shop for the flea market customers; this was his specialized job every Tuesday when various items were displayed in front of the café. A female customer was wondering whether she should buy a kimono coat that she found. Rearranging the shop items, I told her it was one of my recommended items. Inspecting the coat further, the customer decided to buy it so I moved on to find an appropriate bag to put it in. It was then that Fujii called me and asked, “Can I help?” Once asked, and belatedly realizing that there was indeed something Fujii could do, I modified my initial plan, handed him the coat, and he put it in the paper bag while I held it open. As I apologized for nearly excluding him and thanked him for his help, the customer asked us, “Should I pay him?” to which I answered yes. The customer handed him the change, which he handed to me and I went back inside the store to put the money in the cashbox. Then I came back outside with the change, which again was handed from me to Fujii, then from Fujii to the customer. Finally, the purchased item in the bag took the same route and reached the customer’s hands. As if enjoying the detour, which could be devalued as inefficient, and
appreciating the service Fujii offered, the customer thanked us in a tender and relaxed voice.

There were some key words that Kapu Kapu workers often said to each other, one of which was “Yoroshikune,” which is difficult to translate into English. It is basically a word that recognizes interdependence. It was often exchanged by people who shared mutual expectations and responsibilities to make a good time together. The word was exchanged most often between two labeled workers who were assigned to share the same half-day shift of work at the café operated in the nearby community center. I too was offered this call for interdependence when I shared the same bus after work with a few labeled workers. For a while, it did not make much sense to me as I could not understand the need to make such a significant call for collaboration upon simply leaving Kapu Kapu for a half day or riding on the same bus. It felt overly dramatic and I hesitantly repeated the word and gave the person a superficial reply. Gradually, however, as I became immersed in the culture and the interdependent way of life at Kapu Kapu, this expression entered into my vocabulary as well. Kapu Kapu workers seemed to share the understanding that work, as well as life itself, was a collaborative venture.

Resisting definitions or declarations based on the dominant perspectives and cultivating alternative meanings seemed to be motivated and empowered at least partially
by the labeled workers’ experiences of being discriminated against. Ms. Noda, who had been institutionalized and deprived of educational opportunities in her childhood, for example, refused to discard Fujii – she said she did not hate him even though she admitted that he was often annoying to her. Similarly, Ms. Noda also resisted the opportunity to abandon Miwa and insult her human potential. When several workers were being asked by a young staff member to write down a “Happy New Year” message on paper as a logo to be used for a holiday card, Miwa was exempted from this work as she could not write, or was thought to be unable to write. Nevertheless, Miwa wanted to try it along with everybody else. She exclaimed, “Maho, I want to write it too!” Ms. Noda nearly instinctively shouted, “You can’t write!” but before she completed her pronouncement, she halted, swallowed her words, and quickly added a humble question, withholding her judgment to negate Miwa’s potential, saying “…or can you?” When I proposed to Miwa that she and I try to write together, Ms. Noda, who herself had difficulties with reading and writing and yearned for learning opportunities, nodded approvingly and cheered Miwa, “Do your best!” to which Miwa responded “Got it!”

Open to Vulnerability

Being at Kapu Kapu, I often felt vulnerable as my own prejudices and discriminatory patterns of thoughts and behaviors were painfully exposed. There were
also times when things did not make much sense to me and I therefore felt uneasy and disturbed. In other words, being at Kapu Kapu challenged my existing framework and confronted me with an imperative for change.

I particularly remember how I used to get nervous every time I encountered a situation where I felt I was presented with “evidence of intellectual disability.” Especially when I witnessed someone seemingly unable to write, read, or comprehend a simple verbal instruction, though I might display no visible evidence of discomfort, I winced inside. No matter how naturally I felt otherwise with the labeled workers, when my monolithic and prejudicial expectations regarding competence were triggered, I had a passing fear that I was starting to see labeled individuals as Others. For example, Shiori, whom I had regarded as having a good general knowledge of dates, days, and the weather forecast, once said, “It is Friday today” when it in fact was Wednesday. It turned out that it was actually an error on my part as Shiori had in fact said, correctly announcing important information for workers, “It is payday today.” At the instant, however, when I thought I had just witnessed her incompetence that I carelessly associated with her Down syndrome and presumed intellectual disability, I winced and felt an urge to doubt, after all, the validity of Shiori’s performance that I had once trusted, without or beyond prejudice.

Engaging with Kapu Kapu workers who continuously sought and demonstrated
diverse ways of being competent as well as the value of “incompetence” surely affected my existing framework and the world started to look differently to me. In a way, the matter of in/competence gradually ceased to be a focus of my attention as it became more detached from the societal function to rank or divide human beings. Rather, phenomena that could be described with the terms “competence” and “incompetence” began to resolve as part of a mundane and complex local landscape, and began to bear a new, more fluid meaning that reflected histories, contexts, relationships, and emotions that formed a particular moment of individual lives. For instance, when Shiori looked at parts of drawings done by various Kapu Kapu workers to decorate the cookie packages, and named the artist of each drawing, Kapu Kapu workers, including the non-labeled staff, generally trusted her statements, and more importantly, highly admired her experiential knowledge of Kapu Kapu. Even at times when her argument sounded questionable, there was a general attitude not to easily doubt Shiori’s expertise, and people often considered the possibility that they could be wrong and she might be right. Furthermore, when part or all of her information turned out to be incorrect, it still did not taint the fact that Shiori’s local knowledge was celebrated and appreciated, or that she had her own logics on which her statement was based.

I was certainly not the only one restrained by socially constructed concepts and
values. Kapu Kapu workers, labeled or not, were also bound by them to various degrees, which meant that they too were vulnerable in the sense that they had to negotiate with a need to change in order to cultivate the inclusive community. For example, some or many still adopted a narrow definition of “work” as engaging in tangible tasks and producing outcomes or achieving set goals. Many labeled workers had been reprimanded, remedied, disciplined, and oppressed by such narrow standards of being a worthwhile citizen; and yet some also felt proud in working hard, “overcoming” their “deficits,” and acquiring “better” working skills compared to other labeled individuals. For those who managed to conform to societal standards and were therefore bound by them even more deeply, nontraditional ways of working that various Kapu Kapu workers crafted could seem useless, meaningless, or even annoying. Kaoru, a short young woman who was considered as one of the most skilled and efficient workers especially in regard to the cookie-making, for example, tended to devalue Fujii, who talked loudly, and contributed mostly by goofing around, saying silly things, and laughing.

Having palsy on the left side of his body and needing much physical assistance, Fujii valued and made best use of oral participation despite difficulties in speaking and being understood. It was therefore a perfect match for Fujii to sit outside at a table and do the job of attracting and entertaining the flea market customers each Tuesday. He was
loud, funny, and bold. Fujii diligently called out refrains such as “May I help you?”,
which gradually began to sound like “Big hit!” as if he were at a baseball stadium, and
“Do you want curried rice?”, something that is not served at Kapu Kapu. He was key to
the successful business of the weekly Kapu Kapu flea market. Many shoppers and
passers-by were drawn into Fujii’s performance, unknowingly chuckling or leaving with
a comment such as “You are funny!” He also contributed to vitalizing the rather quiet and
inactive shopping mall, of which Kapu Kapu was a part. Other mall shop owners missed
Fujii when he was not present at the weekly Kapu Kapu flea market.

Fujii’s performance and his way of working were, nevertheless, nontraditional
and could be seen as simply goofing-around. Therefore, in order that Fujii’s
improvisational working style could stimulate the reconstruction of the meaning of work,
it had to be verbalized and explicitly recognized and appreciated as valuable work. Kaoru
seemed rigid, however, often making comments that implied she saw Fujii’s performance
mostly as noise making that could not be considered as valuable work. But, this did not
mean that she was entirely closed to the possibility for change and incapable of renewing
her existing framework. At a morning meeting one day in December, for example, Mr.
Suzuki announced that some people would be working at a one-day lottery station for the
Christmas sale at the local shopping mall and helping to make the event lively and festive.
Given his expertise at entertaining the flea market every Tuesday, it was no surprise that Mr. Suzaki particularly enlisted Fujii as part of the merry-making team, although Fujii played the clown and acted as if he was surprised by the request. It was then that Kaoru embraced Fujii using the language that she or other Kapu Kapu workers often used to embrace those who were to depart for their assigned half-day shift at the nearby café. She encouraged him with, “Go for it, Fujii!” Fujii smiled as if he was pleased that his performative way of work had been validated and his call for change in existing frameworks had been answered.

**Conclusion**

Very similar to the Farm, responsive relationships and relational space, in which the constituting members of the community mutually responded and validated each other, were the essential mechanisms in developing and maintaining a validating community at Kapu Kapu. Based on such an affirmative foundation as well as on a commitment not to exclude others, people interacted and negotiated every day, crafting the art of living with others. Additionally, as in the community observed at the Farm, the elements of resistance against imposition of the dominant value system were also prominent at Kapu Kapu: Questioning of taken-for-granted concepts was promoted, including the radical deconstruction and reconstruction of the meaning of in/competence, which was also
suggested by the Farm data.

Compared to the Farm, however, where there seemed a lot of need to direct resistance toward fighting against institutionalization, at Kapu Kapu, which clearly aimed to promote alternative space where traditional and discriminative values around dis/ability are challenged, resistant energy could be fueled more directly into the cultivation of alternative meanings and possibilities. The validating community at Kapu Kapu was maintained and enriched on a daily basis by creative, improvisational, and thoughtful communication, which was also supported by Kapu Kapu workers’ sharpened sensitivity and ability to listen to each other. Moreover, the resistant energy of the Kapu Kapu community exposed their own inner discrimination, encouraging the community itself to become vulnerable, fluid, and squarely open to an emancipatory call for change.
CHAPTER 6

Discussion: A Manner of Life Toward Co-Viviality

In search of practices that work to emancipate all living things from various kinds of discrimination, violence, and oppression, Hanasaki Kohei, a Japanese writer and philosopher, met, had dialogue with, and worked alongside many oppressed people since the 1960s, particularly indigenous people in Japan as well as in a wider Asian region.

Looking back at the history of anti-discrimination and emancipatory movements in Japan, Hanasaki recognizes that those efforts have managed to push minorities’ issues on a political agenda and have helped to grow prayers amongst citizens for an alternative culture that celebrates diversity and interdependent way of life. Hanasaki also recognizes what is needed beyond fighting against oppression for a single cause:

In the days ahead, we will need to try to derive a manner of life [emphasis added] that is necessary to actualize co-viviality, or living together with validating each others’ differences, in the concrete day-to-day living practices from those experiences of various movements. (Hanasaki, 1993, p. 158)

He speaks of this as an ethics or philosophy of co-viviality.

In this chapter, I use Hanasaki’s challenge as a framework and try to derive a manner of life from the observed examples of validating community, or co-vivial
community, to use Hanasaki’s term. He coined this term to represent a Japanese word *Kyosei*, which he defined as to live with others who are different by embracing “relationships in which differences do not generate discrimination” (Hanasaki, 2007, p. 187). The co-vivial community that Hanasaki imagines resonates with the accepting relationships that Taylor and Bogdan focused as a key to develop the “sociology of acceptance” (Bogdan & Taylor, 1987, p. 35). The researchers clarified that “[a]ccepting relationships are not based on a denial of the disability or difference, but rather on the absence of impugning the disabled person’s moral character because of the disability” (Taylor & Bogdan, 1989, p. 27).

**Stay Connected**

In the bus where the exclusion of one “trouble-making” person was largely welcomed as a necessary and justified measure to be taken in order to handle a problem and to restore peace, Shiori, a veteran Kapu Kapu worker with Down syndrome, succinctly expressed her protest as, “No fighting, Mr. Suzaki!” Similarly, Ms. Noda, one of older workers at Kapu Kapu, urgently negated my suspicion that she might hate Fujii, about whom Ms. Noda had frequently complained. Stated as a life principle that she had adopted not just with Fujii but with everybody, Ms. Noda, in spite of her continuous complaints about others, declared that “I would never hate anybody” because, in her
words, “we are all humans.”

Living among and with others necessitates that each of us develop “competence and habits – such as thoughtful consideration for human relationships, empathy and imagination, and physical/linguistic abilities for conflict-solving” (Hanasaki, 1993, p. 158) so we can deal with difficult situations and disagreements in a way that does not deny a place for others: In other words, we must develop the competence and habits for co-viviality. However, as Hanasaki warns, “we have been losing abilities to care for and to sustain pluralistic and nonhierarchical relationships with others, to untangle conflicts, to compromise and to reach a mutually agreeable solution, and to strengthen associations” (1993, p. 158).

Fujita Shozo (1985/1997), a Japanese thinker and political scientist, agrees with Hanasaki and raised concern about a worrisome trend observed in postwar Japan, which he termed Anraku-syugi (the doctrine of a pain-free, trouble-free, discomfort-free society). By this, Fujita refers to a strong, enslaving desire to eliminate every potential cause for discomfort so that there is not even a need to avoid difficult situations and that one does not need to struggle with mastering the competence and habits for co-viviality. Fujita (1985/1997) passionately critiqued such a mind-set:

[T]he mind-set that wishes the total elimination (i.e., eradication) of the source
of discomfort itself will not grapple with the pain, distress, or discomfort that should vary in outlook and degree depending on each individual circumstance. Rather, it wants nonexistence of opportunity to encounter discomfort…. Within such a mind-set, there is no space for negotiations with unpleasant matters, and what is more, there dominates a lust for the eradication of every things and phenomenon that might possibly make one uncomfortable. I must say it is appallingly egocentric barbarity. (pp. 30-31)

Fujita predicts that pursuit of the discomfort-free life will result in a “fatal loss” (Fujita, 1985/1997, p. 41). As life processes are bulldozed and all the bumps and detours are straightened out, a life gets so flattened that it is deprived of fulfilling experiences – the sources of enjoyment, patience, ingenuity, perseverance, and intrinsic satisfaction. In turn, Fujita foresees, the meaning of enjoyment becomes pathologically altered and people will begin to seek a competitive satisfaction of defeating and demeaning others. Fujita theorizes that such a mind-set is deeply and structurally embedded within an overarching social organization of mass-production and mass-consumption that demands efficiency, competitiveness, and obedience. Especially during the time when alternative social structure has not yet been envisioned, Fujita urges, joining Hanasaki’s call to develop competence and habits for co-viviality, that each individual vigilantly overcome the fear
of facing discomfort and be open to differences at every opportunity arises in their
everyday lives. Fujita finds his only hope in such daily practices and personal decisions
of individual citizens: He believes this is the only way to restore the rhythm of life as
well as the sense of fulfillment and to resist the structural deterioration of human
connections.

Indeed, the community I observed and experienced at the Farm and Kapu Kapu
embodied the hope that Fujita strived for: The informants did not stop communicating,
did not abandon a relationship, and did not wish for (or actively resisted) the eradication
of any existence. Rather, they daily crafted the art of living with different (and potentially
unpleasant) others, and ingeniously (and often humorously too) devised way to deal with
relational tensions and unwanted interventions from others. For example, Miwa at Kapu
Kapu turned a situation where she was at a risk of being reprimanded into a shared joke
(“Ms. Noda is like a weird mother!”) and wittily protected both herself and the “attacker”
(Ms. Noda). Meanwhile, Mr. Higashino embraced Shiori, instead of attempting to escape
from her annoying intervention and to exclude her, and led a lilting troop that sang a
jingle-bell song as we all headed back together to Kapu Kapu.

In other words, the informants were committed to stay connected and were not
afraid to be “enmeshed in the relationships with others” (Washida, 2001, p. 219).
Washida Kiyokazu, a professor and president at Osaka University who coined a term “Clinical Philosophy” to describe his fieldwork project that aimed to apply philosophical insights to actual everyday lives, visited and interviewed people who were working at various sites of caring for others, such as a woman who was both a Buddhist nun and a nurse; an architect who deconstructed and constructed a fluid concept of family with his clients; an owner of a small gay bar in Shinjuku, Tokyo; and an 82-year-old flower arrangement artist who described the heart of arranging flowers as involving oneself with the life of a flower in a way that opens the artist himself to be disturbed by the flower’s turbulent response to his interaction. At the end of his journey to meet these people, Washida identified a commonality among his interviewees, which was that they were not afraid of being enmeshed in the relationships with others. Providing further explanation, Washida wrote:

Those were the people who either voluntarily or involuntarily stepped into a relationship and became enmeshed in the relationships with others: They trembled, wobbled, or even collapsed at times in the relationships, and yet stayed connected. Struggling to find a way, sometimes on the verge of giving up or sometimes blaming oneself, they did not leave the relationships. (Washida, 2001, p. 219)
Just as Fujita found his only hope in individual everyday decisions to stay involved and 
connected with others rather than enslaved by the fearful mind-set to seek an egocentric 
discomfort-free life, Washida saw a hopeful vision in the stories of those who are deeply 
involved with others and called the sceneries depicted by the interviewees’ stories as 
“hospitable landscape” (Washida, 2001, p. 174). The competence and habits for 
co-viviality that Hanasaki urged us to develop must be nurtured in such a hospitable 
landscape.

For the relationships to remain intact and withstand conflict, the community 
requires a practice of relational restoration. For example, Shiori and Mariko, the Kapu 
Kapu workers, had mended a temporal rift and restored their relationship in a way that 
left me rather perplexed: Shiori took away Mariko’s flyers, Mariko got upset, but in the 
end, they somehow unsteeled the contentious atmosphere and restored a relationship 
when Shiori (the “wrong-doer”) put her arm around Mariko’s shoulder and Mariko rested 
her head on Shiori’s shoulder. It was perplexing, and even disturbing to me because it did 
not follow a familiar scenario of reconciliation and justice, in which a “wrong-doer” had 
to admit and apologize for her sin and a “victim” had to accept the apology and forgive 
the sinner, sometimes given that the offender will face a certain penalty.

As this scene lingered in my mind and as I mentally replayed it repeatedly, I was
reminded that I had been perplexed and disturbed in a quite similar way before. It was
when I finished watching a documentary film, *In Rwanda we say... The family that does
not speak dies* (Aghion, 2004), on the aftermath of the Rwandan genocide that occurred
in 1994. The film focused on the release of and return to the community of one genocide
perpetrator – one of 16,000 prisoners who was released after having been detained for
nearly a decade awaiting trial by national courts or the international tribunal. Confessed
to have participated in the genocide, those offenders were released in 2003 to be judged
by a government-promoted new system of citizen-based justice called *Gacaca* (meaning,
“judgment on the grass”), which originally was an indigenous way to moderate disputes
and achieve reconciliation at an open community meeting literally “on the grass”
convened by the elders of the community. In its traditional form, *Gacaca* can be
considered as a model of restorative justice whose goals are “to repair the harm, heal the
victims and community, and restore offenders to a healthy relationship with the
community” (Tiemessen, 2004, p. 60), thus differentiated from a modern retributive
approach to justice in which legal professionals determine charges and appropriate
punitive measures. In the film, the camera shot a scene from *Gacaca* trying the freed
offender in a small hillside village: The survivors told stories of how their beloved family
members were killed by the man and challenged him to tell the truth. Despite the
government-led campaign for forgiveness and reconciliation, the film production team noted that “reactions to this imposed co-existence reel from numb acceptance to repressed rage” (Gacaca Productions, n.d., p. 3). According to the director of the film, Anne Aghion, it took nearly a year for the survivors and the offender to begin to have a real dialogue about what had happened and how to live together. Close to the end of the film, there was a scene where neighbors, including the offender, gathered at a local bar and shared a drink. The director reveals that the gathering was in fact suggested by one of the younger surviving community members who challenged the director to call a meeting with everyone whom she had interviewed so they could have a talk with their killer. The production team noted about this meeting: “Over the course of four hours, in this emotionally charged place, they began to negotiate how they would talk about the past and the future” (Gacaca Productions, n.d., p. 4). One such scene included an old woman, who after speaking about her anger and fear of living with a killer, recalled how she used to change the diaper of the accused killer when he was a baby. In other words, she began to speak of the killer as a child of the community – one of them.

I remember, watching the film, it felt disturbingly anticlimactic as I expected something much more dramatic. It did not make much sense to me, just like the scene of reconciliation between Shiori and Mariko did not make sense to me initially. Essentially,
I wondered how they could forgive others, or at least begin to speak with or about others in a forgiving manner, that easily (compared to the scale and degree of pain inflicted).

My logic, indoctrinated in a retribution-based justice approach that would expect an apology and payment of a certain price before a wrong-doer can be forgiven, had been both betrayed and challenged by the demeanor of the Rwandan woman who began to speak of the genocide perpetrator as someone whom she had known well; and in a similar way, my logic was once again severely challenged by the demeanor of Mariko who had accepted the consoling hands of Shiori without further accusing her or seeking to penalize her, and rested her head on Shiori’s shoulder.

Their perspective-altering demeanor resonates with a conclusion reached by Ogata Masato, a Japanese fisherman who was made ill by industrial pollution that contaminated the Minamawa Bay and the Shiranui Sea (located in a southern region of Japan) with deadly toxic chemicals in the 1950s and became one of the leaders of the Minamata Disease Patients’ Movement in the 1970s. In 1985, Mr. Ogata decided to leave the movement and to withdraw his application for official recognition as a Minamata Disease patient (a necessary condition to receive compensatory payment as part of the reconciliation process). Accused by other members of the movement as a betrayer who abandoned an important battle, Mr. Ogata squarely posed himself a difficult question of
what, if not money, could bring reconciliation. Frantically struggling for 3 months, Mr. Ogata finally reached the conclusion that “To take responsibility for one’s own conduct is to share the other’s pain that it has caused” (Ogata, 1996, p. 166). Mr. Ogata also questioned a binary polarization of “perpetrators” and “victims,” coming to see his own role in constructing and benefiting from the modern, industrialized, and anthropocentric way of living. Leaving the “victims’” movement, Mr. Ogata accepted the responsibility that he himself bears and called out to others – both “perpetrators” and “victims” – to reunite and restore their humanity.

Returning to the scene of reconciliation between the two Kapu Kapu workers, when Shiori, who took away flyers from Mariko’s paper bag, put her arm around Mariko’s shoulder and gently rubbed her cheek, Shiori might have been trying to feel and share the pain of Mariko that she had inflicted. And when Mariko accepted Shiori’s consolation and rested her head on Shiori’s shoulder – or when the Rwandan woman started to speak of the killer as a child of the community – their demeanor seemed to overlap with Mr. Ogata’s prayer for the restoration of humanity both for himself and for the offending others.

In a philosophical analysis offered by Hanasaki, the embodied demeanor of Mariko, the Rwandan woman, and Mr. Ogata can also be regarded as a humane act of
caring and hospitality toward others. As a fundamental spirit needed to realize co-viviality, Hanasaki (1981/2009) once defined *yasashisa*, a Japanese word that means “kindness” in a rather literal English translation, as follows:

The first emotion emerged after the true realization that both the wall distinguished oneself from the others and the scale that hierarchically ordered people by assumed competence or incompetence are illusion, and that we are all simply a collective of atoms only differing in shape and size – That emotion is probably the one that we can name *yasashisa*. (p. 10)

Or, Washida might regard their demeanor as embodied examples of hospitality – especially the kind that expects nothing in return, which Washida (1999) described as “reaching out to others who stand at a point where sympathy seems impossible” and “facing someone who may lose his or her humanity and who is at risk of becoming a ‘non-human,’ and nevertheless trying to touch the person” (p. 258).

The informants of this study often tried to touch others, nevertheless. For example, Jade, a labeled worker with Down syndrome at the Farm, did not stop inviting me to share his chips or inviting others, including staff, to interact with him by asking them to do something for him, even though he knew that there was a high risk of being reprimanded by staff as being lazy or as breaking the institutional rules. Alden, too, never
gave up inviting others to listen to his stories, sometimes even calling out, “Don’t go!

This is important!,” even though the institutional rules forbade him to do so. In another
example of such a hospitable landscape, Shinobu, a labeled worker at Kapu Kapu, did not
give up on one mother who intentionally ignored Shinobu’s greeting due to some
relational tensions between Shinobu and the mother’s daughter who was also a worker at
Kapu Kapu. On another day, Shinobu again welcomed the mother by approaching and
greeting her. The commitment to stay connected with others no matter what and the
hospitality of the informants served to revitalize the co-viviality of the observed
communities.

**See Others as Irreplaceable Individuals**

In a study of relationships between people with and without disabilities, Bogdan
and Taylor (1989) identified “seeing individuality in the other” (p. 141) as one of four
dimensions through which the humanness of nonspeaking others was validated. Similarly,
members of the observed communities, labeled or not, mostly regarded each other as
individuals with distinctive personalities, tastes, styles, background, and history. For
every example, when Dean, who has Down syndrome and who rarely talks, quietly pushed pens
and a paper over to the next person without adding anything to the Farm “Who’s Who”
book, Lisa saw it not as a sign of incompetence or passiveness but rather as an expression
of Dean’s individuality and explained to me that “He doesn’t like that kind of thing.”

Shiori, at Kapu Kapu, also was attuned to and respected the individual artistic styles of other Kapu Kapu workers: She was proud to give visitors a lecture on which drawing was done by which artist.

Shiori also valued individualized person-to-person relationships. In the early history of Kapu Kapu, she would greet the store owners in the mall in which Kapu Kapu was located one by one every morning on her way to Kapu Kapu. Shiori was known by name to people in the community, for example those who shared the same bus or bus stop with her, thanks to her daily practice of introducing herself and greeting them.

Furthermore, even taking orders could not be reduced to counting numbers for Shiori: She paid attention to and remembered who ordered what, instead of merely counting how many cups of hot coffee had been ordered. Hanae, a Kapu Kapu worker with a label of autism, too, personalized the orders as much as possible by remembering the individual preferences of familiar guests, such as no spoon for one guest or two sugars for another.

In rural Uganda, “to be a person is to have a place in a nexus of kinship relations” (Whyte, 1998, p. 154). Similarly, in Inuit communities, “the naming of a child confers upon it the status of a social person” (Nuttall, 1998, p. 188). Douglas Biklen (1992), in his efforts to derive lessons for school inclusion, studied families who came to
appreciate their children with disabilities as “ordinary people” (p. 8) with names, interests, habits, and abilities and who succeeded in achieving regular lives in which the child with disability was a full participant well known by her or his own name. Japanese culture too, the significance of naming and calling someone not by a label or a social category but by her or his own name in relation to the construction of humanness has been recognized.

For instance, Washida (1999) argued that calling others by their names was essentially “to accept the other as an individual” (p. 238), to resist against objectifying others as classifiable elements, and to respectfully recognize the irreplaceability of the person’s existence (pp. 238-239). Tsurumi Shunsuke (1999), one of Japan’s most distinguished philosophers, also expressed how the individuality and irreplaceability of each person is fundamentally affirmed by the practice of giving and calling people by their names as follows:

At home, everyone is famous, or has a good name. We were all born as babies, were given names, and well-known at home. Very famous, indeed. No one is anonymous or nameless. The fact that one is well-known by her or his own name gives the person a tremendous satisfaction. I think it is wrong for us to desire more fame than this. To cherish the assuring feeling that “I have a name” as one’s own asset is what I think is important. (p. 26)
As if to know that calling out to others by their names validates the irrereplaceability of each existence and prevents their being marginalized to anonymous invisibility, Ms. Noda once called out to Seiko, “Why don’t you come over here and draw with us?” The existence or humanness of Seiko, a non-speaking and non-walking person whose lenses had been removed from both of her eyes in her childhood, was established and reaffirmed in such everyday interactions at Kapu Kapu. At the same time, Seiko too initiated interaction and called out to others (and thus validated their existence) via her action: She would often change her body position, while lying on the floor, so she could present herself in proximity to others and did so in a way that could evoke responses such as pushing her head against the other’s leg, crawling up and burying her face in another person’s lap, or dramatically standing up amid others’ gasping and warnings not to fall.

**Be Responsive to Others**

Responsiveness in relationships was prominent in the observed communities. Indeed, it sometimes even seemed as if some of the informants **had to** respond to others beyond reason: Shiori at Kapu Kapu faithfully got up and ran after Hime every time she dashed away from the bench at the bus stop. While it could have been dismissed and discouraged as an immature attention-seeking behavior, Shiori nevertheless treated it as a valid, communicative behavior and responded each time with sincerity by chasing after
Hime and gently affirming her both verbally and physically. Similarly, at the Farm, even after reluctantly leaving Jade following an order given by a staff person to stop the “silly” interaction and to sit separately, Sandra could not ignore Jade’s farewell howling at her. As she moved away, she awkwardly turned her body and head toward Jade and howled back at him across the hallway, as if she could not betray and abandon her responsibility to respond to his call. In a sense, Sandra and Jade valued “dialogue enacted through imaginative play and improvisation, shaping relational spaces from which to compose lives” (Steeves, 2006, p. 106).

The informants worked hard to build relational spaces that “facilitate the storytelling and dialogue” (Steeves, 2006, p. 107) in order to enrich their community and to fight against institutionalization. Alden, for example, often urged others not to ignore him, to resist the institutionalized pace, and to stop to listen to his story by calling out, “Don’t go!” “This is important!” McKnight (1987) agrees with Alden that it is indeed important to build and to ensure access to such relational spaces, or “the forum within which citizenship can be expressed” (p. 57).

Linneman (2001) called such relational and validating space as “interpretive community” (p. 241), within which members share “common responsibility” (p. 230) to “recover, discover, preserve, interpret, and, in effect, realize” (p. 65) the mindedness, or
the humanness, of someone. MacKay (2003), a person with aphasia, also talked about “collective responsibility for making sense” (p. 824) based on his research in which he interviewed people with aphasia and on his own experiences. In the communities I observed, a responsibility was surely shared among the members of the interpretive community to make sense, to carry on conversations, and to make them convivial. As McKnight (1987) asserted, in a community “[t]he line between work and play is blurred and the human nature of every-day life becomes part of the way of work” and “[y]ou will know that you are in community if you often hear laughter and singing” (p. 58). On that day in a conference room at the Farm, convivial conversations were abundant and people shared much laughter, especially Alden who contributed to the community by offering his specialty joke (e.g., “What does a dog say to a new sand paper?” “Rough!”) while we engaged in the monotonous task of folding and taping a pile of newsletters. Similarly, on another day in a kitchen at Kapu Kapu, as six of us made cookies, we together constructed and enjoyed conversations, which could have sounded rather meaningless to outsiders, by responding to each other’s chanting of favorite phrases and animation titles. When everyone in the kitchen laughed at Shiori’s punch line of “I used to!” (A response that could be regarded as out of context from an outsider’s perspective), we might have together established “a new structure of language” (MacKay, 2003, p. 824) that goes
against conventional rules of conversation and yet is empowering and brings “collective strength” (MacKay, 2003, p. 824) to the community.

**Be Open to an Interdependent Way of Life with Others**

As Washida (2001) suggested that “‘weakness’ evokes concerns and care” (p. 181), what could be termed the value of “incompetence” or the value of “dependence” in involving others and building relational spaces was suggested both by the Farm data and by the Kapu Kapu data. For example, at the Farm, my incompetence to skillfully handle a shovel to do the barn work encouraged Ben to get involved and motivated his creative problem solving: Ben first brought me a different shovel from the one that I was using – the one that Ben considered as “the best shovel” – and then he conceived of a different, collaborative approach and suggested that we worked together (i.e., I used a smaller shovel to scoop a small amount onto Ben’s bigger shovel, and when his shovel was full, he dumped it all off). Jade, another worker at the Farm, also understood that asking someone for help, such as to get something or to throw something away for him, did not have to be devalued as a sign of incompetence or dependency but rather could be used as a valuable tool to create opportunities for interaction and conversation. Risking himself to be labeled and reprimanded as dependent or lazy, Jade nevertheless often utilized the tool probably because the institutionally approved means of communication via speech or
sign language were not sufficient for his abundant desire and willingness to communicate with others.

At Kapu Kapu, too, Miwa demonstrated how “incompetence” could engage others, motivate collaboration, and enrich relational space when she could not or did not follow my verbal request to get a rubber band: Miwa stood still, not initiating a move to search for the requested item, and instead joined me in clapping and chanting cheerfully, “Rubber band! Rubber band!” Our comedy-like performance entertained the guest who was enjoying her morning coffee and, furthermore, mobilized a local resource resulting in my need for a rubber band being successfully met by another member of the community who observed our interaction.

In his book titled Yowasa-no-chikara (The value of “weakness”), Washida (2001) wrote of Endo Shigeru, a Japanese man with cerebral palsy who arranges for himself around the clock (24 hours per day, 7 days a week) personal assistance to live in his own apartment in the community. Washida cites a line from Mr. Endo’s diary in which he revealed how he had struggled, in his twenties, to decide to participate in a demonstration for the students’ activism movement while distressed by a thought of possibly causing trouble to his friends. Several months after the demonstration, Mr. Endo put a concluding thought in his diary as follows: “Causing trouble to others – It is
Continuing his analysis, Washida (2001) further introduced a documentary film about Mr. Endo titled *Entoko* (Ise 1999). *Entoko* was how his apartment was called by his friends and helpers. *Entoko* also meant “a place where people meet.” Washida (2001) described how various people, both professional care workers and lay part-timers including high school students, college students, seasonal workers, a musician living by the river in a tent, and foreigners such as a Chinese student, gathered at *Entoko* and took turns filling the shifts to take care of Mr. Endo. Washida particularly notes how helping Mr. Endo’s stiff body paradoxically loosened the helpers as if they were liberated from a silencing pressure while they helped Mr. Endo by his bed, and how it empowered them to voice personal concerns. Based on his analysis, Washida (2001) reached the following conclusion: “At Entoko, there is an open landscape in which exposing oneself to others to the point of vulnerability paradoxically helps those in a helping position to open themselves and unbind their minds from enslaving armor” (p. 178). The film informs the viewers that Mr. Endo’s vulnerable dependence had drawn over a thousand people to *Entoko* during his first decade of living in the community, inviting them into the interdependently fulfilling relationships.

As Mr. Endo had once hesitated to ask for help so he could participate in a
demonstration, asking for help and possibly inconveniencing others cannot be easy in a society that places a monolithic value on the illusory concept of independence, which simplistically means, “You take care of your own needs,” and that devalues and penalizes “dependency that is an essential quality of being a human” (Saishu, 1996, p. 97). Burke, who lives with a label of autism and who types to communicate, also confessed that “I rarely, if ever, ask for that accommodation [that he feels reasonable and fair for his learning at school], as it screams of disabled” (Biklen & Burke, 2006, p. 4). Washida (2001) therefore not only calls for reconsideration of the meanings of various concepts used to hierarchically determine the existential value of lives, including weakness/strength, in-dependence, and in/competence, but also advocates for the importance of relationship in which “causing trouble” is not something that requires an apology. Illustrating such a relationship, Washida (2001) draws on a favorite phrase or living motto of one comedian, Tako Hachiro, who had once been a professional boxer and Japanese champion and had died in 1985 from a heart attack when swimming in the sea while he was drunk: Tako Hachiro often said to others, “I caused you troubles, and I thank you for that.” Washida (2001) interpreted this as follows:

I must have made you miserable; even inflicted pain and suffering. But I will not say “Sorry,” for you never abandoned a trouble-maker like myself. I will not
turn my back, act like a stranger and aloofly apologize to you, who keep including and embracing me. If possible, I would rather die in your embracing arms, telling you “Thank you.” (p. 181)

“Yoroshikune” – Kapu Kapu workers often exchanged this phrase, a Japanese word that recognizes the interdependent and collaborative nature of a joint venture, such as when they were assigned as a team to work at the café in the nearby community center, or to make cookies together in the kitchen, or even when they shared the same bus to go home. When the Kapu Kapu workers exchanged this phrase, they might have been mutually assuring each other that they were on a same boat and that they shared responsibility to jointly build a validating community where “causing trouble” is not something to apologize for but rather reflects the strength of the community and thus warrants appreciation.

**Affirm Every Existence Unconditionally**

In addition to challenging the socially assigned values of incompetence and dependence, the informants often performed in a way to blur the boundary of in/competence, such as Miwa’s performative and unconventional response to my verbal request for a rubber band; or her overdramatic expression of disbelief (i.e., raising her shoulders, making a hand gesture as if she were an American, and saying “Oh boy”)

when someone could not understand her speech; or her radical redefinition of a situation where she required assistance to walk up and down the stairs as, “It’s like we are dating!”

Meanwhile, a call has been submitted by several researchers to reconsider the hegemonic and economical campaign to promote independence and to shift our focus more toward “supporting individuals’ exercising agency” (Broderick & Kasa-Hendrickson, 2006, p.185, emphasis in original). As a mother of a son, Matthew, who was “born with multiple disabilities that challenge him, particularly in the expressive domain” (Steeves, 2006, p. 105), Steeves has also come to recognize how “Matthew was continually trying to author his own life” (p. 107) and hopes for the re-imagination of education as “mindful and facilitative of the continual identity formation and agency of children with disabilities and their families” (p. 113).

The informants of this study exercised their own agency or “leadership” (McKnight, 1987, p. 56) (in addition to responding to others’ agency and leadership) in various ways. At the Farm, for example, Alden literally authored his own stories and created a stage around himself that proceeded according to his own pace. Suzanne also sometimes challenged an institutional rule to not change an assigned team in the middle of the day and asserted her desire to work with another team. Even after her request was turned down by staff, being reminded that it was against the rules, Suzanne tactically
approached an art teacher, who was less bound by the institutional rules as someone who only came to the Farm a few days a week and who happened to work with the team to which Suzanne wanted to convert, and announced, “I paint. Can I paint?” Pleased with Suzanne’s voluntary interest in art, Karen, the art teacher welcomed her.

Just like Ben’s leadership while he and I worked together in an animal barn altered my views, the leadership of Mr. Higashino, one of two older workers at Kapu Kapu with Down syndrome, helped arrogant myself to become a little more humble: After a few humorous attempts to avoid Shiori’s “annoying” control of his body (such as to comically walk fast while raising his shoulders and putting his hands on his hips or to dramatically rest his head on my left shoulder while randomly moving his left hand so Shiori could not hold it), Mr. Higashino eventually invited Shiori to walk with him by putting his embracing left arm around Shiori’s shoulders. Mr. Higashino also invited me in by putting his right arm around my shoulders, which motivated me to invite Yuji into the line that the four of us created together. Mr. Higashino led the troop by leaning forward, picking up our walking speed, and adding a lilting rhythm to it, from which the chanting of “Zundoko, zundoko” emerged and gradually evolved into the convivial singing of “Jingle Bells.”

Being a non-walking, non-speaking, blind person, Seiko’s agency and leadership
was also prominent at Kapu Kapu. It was always Seiko herself who decided whether or not to follow others’ requests to stand up, to walk, or to drink. If Seiko decided not to respond to requests, there was nothing others could do except wait until she felt like doing it. On one day, Seiko was lying face-down on the floor, and I tried to get her to stand up so I could carry her on my back to the kitchen where everyone gathered for an end-of-a-day meeting. Seiko decided that it was not a good time, or perhaps the way I talked to her was not very appealing. So I waited, occasionally tapping on her back and begging her to stand up. Another staff came, seeing that Seiko was still on the floor, and said, “Oh you are taking your time to get ready, Seiko?” As casual as it sounded, it was, to me, nevertheless one of the “stories of hope” (Linneman, 2001, p. 240) as her words essentially recognized Seiko’s intention and agency in what could seem like mere inactiveness or incompetence. In other words, there emerged an “interpretive community” (Linneman, 2001, p. 241) that employed what Goode (1992) called an “emic perspective,” which presumes and tries to uncover “the rationality, purpose, and efficiency of native behaviors” (Goode, 1992, p. 198) no matter how incomprehensible or meaningless that behavior may appear: Such an interpretive community works based on what Linneman (2001) calls “[t]he assumption of mindedness” (p. 240) and on what Biklen (2005) referred to as “the presumption of competence” (p. 1, emphasis in original).
Shinohara Mutsuharu is a Japanese psychologist and a long time critic of mainstream ideology in the Japanese special education system that advocates for and justifies specialized education for students with disabilities in separate, specialized settings in order to meet their “special needs” and to protect their “human rights for development.” Shinohara sharply rejects a theory of hierarchical human development, in which humanity is deemed as something to be learned and earned, and therefore those who are considered “uneducable” can be written off as “non-human.” Rejecting this ideology as oppressive, Shinohara (1980) articulated a “presumption of humanness” (p. 182), according to which humanness is presumed, not trained or earned.

Refusing to set any prerequisites for being a human, Shinohara questions the emancipatory power of radical discourses that aim to deconstruct the modern, monolithic concept of “competence” as follows:

To counteract those mainstream ideas about competence, we could argue that, even though intellectual tests may not capture it, competence can be observed in close relationships and say to a skeptic that “You are not close enough to this person.” But then I pause and think why would we need to bother to keep emphasizing “competence,” as in the efforts to re-conceptualize competence as something to be co-constructed in relationships, and to perpetuate the discourse
that negates “incompetence.” To say it more boldly, why do we need to be

“competent”? (Takeuchi & Shinohara, 2008, p. 281)

Shinohara certainly does not accept a modern and individualistic conceptualization of in/competence nor advocate leaving it unchallenged. But at the same time, he calls for reexamination of our focus, with a liberation from the societal obsession with competence as well as the fear of incompetence, and urges a shift in the arguments for humanity more toward the chaotic reality of living together itself (Takeuchi & Shinohara, 2008, p. 284).

As I struggle with the difficult question of whether we could really advocate for competence for each and every human being without devaluing the essential human quality of incompetence, I think about the significance of one scene I observed at the Farm: It was in a staff-free craft room where several women chatted as they worked on assigned tasks. At one point, one of them shared her difficulties with spelling, and in response another woman, Hailey, vigorously resonated with, “I am not a good speller” and sought help with writing from Becky who was considered to be good with spelling among the women in the room. Considering that whether or not one could write often gets linked to the question of humanity (Biklen & Kliewer, 2006), the fact that there was a space in this community where casual admission of inadequacy in one’s writing skills
and a frank request for others’ assistance were possible without risking devaluation should offer us important insights and encourage us to conceive of a different world.

Another scene lingers in my mind: It was at Kapu Kapu on a day when many of the workers were engaged in writing a message for a New Year’s card. Miwa, who was thought to be not a person of letters and therefore exempted from this task, nevertheless demanded that she be given a chance to try. Hearing Miwa’s request, Ms. Noda, who herself experienced difficulties with writing and yearned for learning opportunities that she had been deprived of in her childhood, instinctively shouted, “You can’t write!” but before finalizing her pronouncement, she halted, swallowed her words, and quickly added a humbling question, “…or can you?”

The matter of competence and incompetence was indeed a part of everyday lives at the observed communities: adopting traditional concepts in feeling good about oneself or determining relationships with others; challenging conventional images and embodying diverse meanings and the co-constructed nature of the concepts; blurring the boundary as well as cultural significance given to the concepts; fighting with authoritative and oppressive declarations of incompetence; resisting dishonor of others’ human potentials, and so forth. By dissolving the matter of competence and incompetence as part of the everyday realities of community lives that are fluid, complex,
contradictory, interdependent, and convivial, the informants in this study may have been working to shift in the arguments for humanity more toward the chaotic reality of living together itself as Shinohara called for.

In his book, *Idiots: Stories about Mindedness and Mental Retardation*, Linneman (2001) cites a story from a book, *The Mask of Dementia: Images of “Demented Residents” in a Nursing Ward*, written by Hava Golander and Aviad E. Raz (1986). It is a story about an old man named Shimon who had been admitted to a hospital by his wife. In the hospital, Shimon wandered aimlessly, entered other patients’ rooms and sat on their beds for long periods of time in wet pajamas, talked loudly and incoherently, walked about with no pants on, and periodically disappeared, only to be found cold, wet, and even more disoriented by the police or other authorities. The hospital staff speculated about potential reasons for Shimon’s behaviors, but were soon convinced that he was simply a confused, deteriorated patient with senile dementia.

Meanwhile, Linneman points out, other residents saw Shimon quite differently from how the hospital staff saw him and spoke in respectful terms about Shimon. Linneman (2001) shares a strikingly different image of Shimon constructed by his fellow residents:

He was an early settler, a *Halutz*, a respected breaker of the soil, a giant of the earth in Israel. His *distaste* for confined spaces was predictable and reasonable....
The never-finished tasks of a farmer—milking and selling of cattle, breaking and harrowing of the land—accounted for his behavior (at least to the other residents), who exalted and humanized Shimon, despite his wet pajamas. (p. 66, emphasis in original)

MacKay (2003) too cites a story from a book *Recovery with Aphasia* (1972) written by Scott Moss, an academic who had aphasia. In the story below, recounted by Moss’s wife, he had just been taken to the hospital and phoned his wife:

[The nurse] apparently gave Scott the phone and he uttered a sound but that’s all it was. I could not make head or tail out of what he was trying to say to me….

[His wife asked] ‘Do you have any children?’ He’d indicated that he did. Then I say, ‘how many children do you have?’ Sometime he’d indicate four and sometimes five (we actually have three). And I never knew exactly but I still think that he didn’t lose his sense of humor, because we’ve played that way with each other. I think he was displaying a sense of humor, which is incredible! I knew perfectly well he knew how many children he had. He was just playing with me. (Moss, 1972, p. 23, cited in MacKay, 2003, p. 824)

The above stories serve as a reminder that humanness of others is validated and reaffirmed by those who know, share, or are humble enough to stretch their imagination.
to others’ living histories – the experiences, the time, the relationships – and who can recognize others’ stories as “knowledgeable” (Steeves, 2006, p. 107). When one witnesses, realizes, or imagines the knowledgeability of someone, one is awed by the preciousness and irreplaceability of the person’s existence, or what I would like to tentatively call the “idiosyncratic authority” of each presence: Shiori’s respectful attention to individuality that made a mundane activity like taking orders a matter of listening to individual voices and that made her want to recognize and name each creator of the small drawings; a discreet act of Dean, a mostly non-speaking (or “quiet” from the perspective of Lisa who respected his quietness) man with thick glasses with a low, attractive voice, to move one of the chairs at his table to make space for his wheelchair-using colleague looking for a space to have his lunch, only to return the chair to its original position, unnoticed by anyone, when the colleague found a space at a different table; and Mariko’s thoughtfulness to place a cup of tea at a particular spot on a table, the reason for which was soon revealed to me when Yukiko came into the kitchen, parked her wheelchair at the table near the entrance, and easily reached her tea cup on the table without special notice.

Overwhelmed by the “idiosyncratic authority” or the knowledgeability and history embodied through each existence, there emerges a feeling that “I want you to
exist,” strongly resonating with the following remark written by Christopher Kliewer (1998). Kliewer notes: “Community membership [of alienated people with Down syndrome] would be seen as essential to the evolving completeness of society as a whole” (p. 7) and that “[t]he oppressive silencing of even one voice through any form of segregation eliminates that set of experiences from our collective conversation and diminishes the culture of the community” (p. 5). Similarly, Judith Snow, a Canadian disability rights activist, insightfully stated: “Our presence is the fundamental gift that we bring to the human community. Presence is the foundation of all other opportunities and interactions, of everything that is meaningful” (Snow, n.d.). Washida (1999) also joins them when he asserts, “‘Being present’ is not zero. It is wrong to think that you have to do something in order to make it a plus value” (p. 206).

Because every existence is invaluable and irreplaceable, the informants often thought about others who were not present at a particular moment. For example, at the Farm Jade expended significant energy, with finger spelling, speech, hand gestures, and facial expressions, expressing concern for Jamieson, who had been absent for a while. It took him a few minutes to get his message across but nonetheless his concern for Jamieson persevered. At Kapu Kapu, morning greetings often contained news about someone who was absent for the day, which was to be announced again officially at the
morning meeting. At the morning meetings, the whereabouts of those who had been absent for a while were reported and the return of someone who had been absent on a previous day or days was also celebrated. Within such a culture, Fujii astutely recognized when only a mother came, wondered about her daughter, and asked the mother, “Where is Seiko?” Or Ms. Noda immediately linked a request to use a vacuum cleaner to clean the floor space in the morning with the existence of Seiko and talked to herself, “That’s right, today is a day Seiko comes. I should have known better.”

When there are “reciprocal relationships in which people give each other their presence as gifts” (Washida, 2001, p. 202) through an act of caring about and for others, responding to others, and exposing themselves to be vulnerable and allow others to care for them, each existence is “affirmed, unconditionally” (Washida, 1999, p. 252). Co-vivial living with others by unconditionally affirming each existence, by negotiating with each other’s differences, disagreements, discomforts, and deficiencies, and by realizing each other’s humanity within the chaotic reality of living together is a vision that Fujita (1985/1997) urged us to strive for in order to be freed from the Anraku-syugi (the doctrine of a pain-free, trouble-free, discomfort-free society). The observed communities of the Farm and Kapu Kapu helped me to see beyond “a limited vision of human potential and what the world may become” (Blatt, 1977, p. 5) and to imagine a
different world.

Conclusion

In the Chapter 2 of this dissertation, I reviewed literature and drew methodological lessons on researching with and understanding the perspectives of people for whom language is not accessible or significantly limited. In my own fieldwork, I tried to apply various lessons that those pioneer studies offered. Now, at the end of the journey, what I found the most difficult throughout the course of doing a research project was to look for “dignified explanations” (Richardson, 2002, p. 55) by abandoning “the remedial stance” (Goode, 1994, p. 23) and instead adopting an “emic perspective” that aims to uncover “the rationality, purpose, and efficiency of naïve behaviors” (Goode, 1992, p. 198), even though this was something that the training I received before entering the field had most emphasized and therefore about which I knew very well its importance. For example, when Becky, one of the informants at the Farm, looked troubled by my question, asking her to identify “the nicest thing” that one of her colleagues whom she named as her friend had ever done, and replied as “Just being himself!” I was instinctively disappointed by what sounded as a rather immature, childish, and out-of-context response. I was disappointed that I could not obtain something more deep, something more important, and something more thoughtful. I was so disappointed that I nearly dismissed
her response. Similarly, when Mariko rested her head on Shiori’s shoulder in Kapu
Kapu’s van after a quarrel over who should hold a paper bag of flyers, I initially
interpreted it as Mariko’s incompetence to keep her anger or her tendency to be easily
evaded due to her deemed intellectual disability.

Honestly, I feel like it was only the matter of luck that I managed to not dismiss
those responses of the labeled informants as meaningless; I was so close to the situation
that I might have been unable to gain perspective, so I cannot say clearly what stopped
me, except to say that I did not ignore the inside feeling of being confused.

Retrospectively, by not discarding the feeling of confusion that arose in myself and by
withholding my initial judgments, I could begin to engage myself in a dialogue where
“we listen to the Other and simultaneously risk confusion and uncertainty both about
ourselves and about the other person we seek to understand” (Schwandt, 1999, p. 458).
Douglas Biklen (2005) expressed this as a researcher’s obligation when he said, “I am
obliged to welcome complexity, even contradictions, as they arise” (p. 3).

So Becky’s response emancipated my initial mind-set that one has to be (or be
regarded as) competent, contributing, and valuable in order for the person to entitle a
valid membership within a community (or a society); thus the focus of my observations
shifted, allowing me to recognize how the informants not only resisted current standards.
I began to consider much broader meanings of participation and competence. I stopped questioning who should or should not be the valid members of the community and resisted giving significant authority to the concepts of competence and utility in relation to human worth, for that is what I observed the community members doing. In her soft-spoken voice, Becky successfully defied the line of reasoning that says one is valuable because one does something to prove her or his utility. Becky’s emancipative response reflects the kind of community that the informants of this study strived to cultivate – a community where each person is considered valuable without explanation; thus no one has to prove him or herself deserving of membership. Certainly some people got along better with particular people than others; dominant or institutional standards were sometimes used to admire or disapprove of others, or to determine individual relationships to some degree. However, those standards of competence and utility were never given a status that would question anyone’s existential value or undermine membership in the human community. In a sense, the observed communities were comparable to the school examples of community that Kliewer (1998) studied where citizenship of students with differences called Down syndrome had been realized and where community was “reconceptualized as a web of relationships that shifts and extends to encompass the experiences of all its members” (Kliewer, 1998, p. 132) instead of being
imagined as a “privileged location” (Kliewer, 1998, p. 132) that one has to meet certain standards to gain valid membership.

The community cultivated by the informants was characterized as “co-vivial,” a term coined by Hanasaki to represent a Japanese word *Kyosei* defined as living with different others by embracing “relationships in which differences do not generate discrimination” (Hanasaki, 2007, p. 187). The concept of co-viviality resonates with the idea of “accepting relationships” that Bogdan and Taylor (1987) highlighted in regards to the relationships in which a person “with a deviant attribute” (p. 35) is accepted without having his or her difference denied or stigmatized. Responding to Hanasaki’s challenge to derive a manner of life toward co-viviality so we can choose to adopt co-vivial ways of conduct in the concrete day-to-day living practices, hopefully this dissertation serves as a starting point to deepen our understanding of the concept of co-viviality.

A prominent feature of the observed co-vivial communities was that everyone was recognized as “knowledgeable,” or, to say it differently, everyone developed mutual sensitivity and respect toward each other’s knowledge. When five of us in the cookie-making team on one day at Kapu Kapu laughed at Shiori’s punch line, “I used to be!,” we laughed not because it was out of context but rather we had heard this well-known phrase of Shiori many times enough to develop a shared sensibility to get
Shiori’s humor that skillfully punctuated the lively conversations we had created together.

This way of communicating and of creating community was similar to how Steeves (2006) came to interpret her son Matthew, through stories derived from living with him, as “knowledgeable” (p. 107); or as Linneman (2001) wrote of “common responsibility” (p. 229) shared in an interpretive community “to recover, discover, preserve, interpret, and in effect, realize” (p. 65) the mind of others, including that of an Alzheimer’s patient.

In other words, there was a realization of “human reciprocity” (Kliewer, 1998, p. 5) as the co-vivial community was cultivated and maintained in relationships “in which the experiences that form our individuality are recognized as communally valuable” and “we are nourished by the experiences of others” (Kliewer, 1998, p. 5).

The informants of this study also daily crafted and demonstrated the artful arts of living with different (and potentially unpleasant) others and of maintaining the co-vivial community. For example, when a humorous attempt made by Mr. Higashino at Kapu to avoid Shiori’s helping hands that tried to manage his body did not work marvelously and when I just started to worry that his humorous yet avoiding attempt could end up excluding Shiori, Mr. Higashino dramatically changed his approach: He held Shiori’s shoulder with his embracing arm and invited her to walk with him. Mr. Higashino inviting two more members (including myself) to join the troop and adding a
lilting rhythm by his own walking movements, Shiori, who initially tried to regain control, could not help joining and enjoying the jingle bells song that we sang together. Miwa, too, did not accuse Ms. Noda who tended to be hard on other younger Kapu Kapu workers, following the model of her deceased mother. When Ms. Noda became irritated at the sight of Miwa “not doing any work but talking” and howled at her, Miwa mobilized her sense of humor and turned the situation into something that could be openly laughed about (i.e., After Ms. Noda left, Miwa turned to me and exclaimed, “Ms. Noda is like a weird mother!”). I was also deeply confused and challenged by how Mariko and Shiori mended a temporal rift when Mariko, who got upset toward Shiori grabbing Mariko’s work materials without her consent, quietly accepted the consoling hands of Shiori without seeking an apology from or a penalty on Shiori. Similarly, Mary – one of young staff at the Farm – seemed troubled and challenged by how Jade graciously thanked Mary who had just turned down his small wish (i.e., playing one of his music CDs in a van upon going out) based on an institutional rule for her considering a possibility and checking with a senior staff. Furthermore, just like Jade and Alden at the Farm were persistent in creating relational spaces and opportunities for interactions – Jade inviting others to share lunch together or asking others for a small favor (both of which risk him to be reprimanded or blamed as “lazy” by institutional staff) and Alden inviting others to
stop being dragged by institutional pace and to listen to his stories – Shinobu at Kapu

Kapu also showed her persistency in inviting and cultivating relationships with others when she approached and greeted one of Kapu Kapu workers’ mothers who had intentionally ignored (due to some relational tensions between her daughter and Shinobu) her greeting the day before. In sum, all the stories I observed and experienced in the field (and hopefully I did a fair job of representing throughout this paper) illuminate subtlety, agency, reflection, and persistent spirit in how the informants interacted with others and how they cultivated a co-vivial community. The complexity revealed by each labeled informant bears little resemblance to the stereotyping pessimism of official definitions to which they have been subject.

Within such communities of idiosyncratic bodies, where all are respected and imagined as “knowledgeable,” embodying idiosyncratic histories, experiences, relationships, competencies, agency, and responsibility to others, the matter of competence and incompetence become resolved as a part of the “chaotic reality of living together” (Takeuchi & Shinhara, 2008, p. 284). Free (albeit not completely) from categorizing labels and pressure to keep an independent outlook, individuals could relate to one another by mutually seeking help and could synergize an interdependent community. The staff-free room at the Farm on one day was such space where Hailey,
who had anxiously presented a competent outlook in response to a skill-testing question posed by one of the staff on another day, was able to casually seek out other women for help on spelling. When Hailey proudly exclaimed “We are too weird!”, which was negated by a consoling staff and yet positively affirmed by another woman informant in the room, her statement sounded as if it were a claim of idiosyncratic knowledgeability of herself as well as of the friendship community.

Another characteristic of the observed communities was that they were hospitable. Warning that “institutionalized systems grow at the expense of communities” (p. 57) and that “[o]ur essential problem is weak communities” (p. 58) much more than the ineffectiveness or insufficiencies of human services, McKnight (1987) advocates for a “community vision” whose goal is “‘recommunalization’ of exiled and labeled individuals” (p. 57). Spending time in the observed communities, I always felt welcomed with genuine hospitality. In fact, I have often felt and feel now that I have been the one who was “recommunalized” into their hospitable, co-vivial community.

Washida (1999), in a book titled (translated in English) *The power of “listening”: A tentative theory of clinical philosophy*, introduces a French philosopher, René Schérer, and cites his idea of “hospitality,” according to which hospitality does not mean hegemonic assimilation of others: Rather, hospitality necessitates that one who
intends to welcome and include idiosyncratic others be challenged, de-stabilized, de-categorized, and vulnerable. That is, “to embrace others is to be embraced by something inconceivable” (Washida, 1999, p. 136); or to express it differently, “to be a guest of the guest” (Washida, 1999, p. 147). When Mary, a young staff of the Farm, replied to Jade with a surprised look on her face, “That was kind of you to ask” after Jade graciously thanked her for taking his request seriously to play his CD in the van (even though the modest request was turned down based on institutional rules), Mary might have sensed that she was challenged, forgiven, and embraced by Jade. Or when Keiko, a soft-spoken worker at Kapu Kapu, cared about a customer at the flea market, who seemed to feel pressured to hurry up and find her purse quickly, and gently told the customer, “Please take your time,” we, the majority oppressors and discriminators of the fast-processing society might have been challenged, forgiven, and embraced by her.

Hanasaki (1993), who urged us to weave each other’s experiences of fighting against various kinds of oppression into the ethics for co-viviality, reveals that to overcome discrimination we each must be self-reflective and self-critical at the moments of discriminating against others (p. 168). Similarly, according to Biklen and Kliwerer (2006), Burton Blatt, who inspired many Americans to act against institutional abuse of people labeled mentally retarded through his publication of *Christmas in Purgatory* (Blatt
Kaplan, 1966), understood and argued that “looking for others to change their ways was not sufficient,” which would be “a kind of artful dodge from personal responsibility” (Biklen & Kliewer, 2006, p. 175). That is, I must be challenged and change in order to work toward a different world. Only when one faces different others with such self-reflective, self-critical hospitality, can one gain what Kurihara Akira, a Japanese political sociologist and a representative of Minamata Forum, calls “active healing” (Kurihara, 1999, p. 176). Kurihara differentiates “active healing” from “passive healing,” which commodifies healing and regenerates pain, suffering, and oppression. In turn, Kurihara (1999) clarifies, active healing “transforms the oppressive structures and relationships” (p. 176), leads to “sustainable relational recovery and emancipation” (p. 177), and moreover, entails “bodily movements to change the self, to change others, and to change the world” (p. 177).

Finally, Ogata Masato, a Japanese fisherman and a survivor of Minamata disease caused by industrial pollution who left the “victims’ movement,” addressed this point as follows:

There is a way of saying that “the experiences of oppressed and discriminated people will make the society better” or that “there is a key to end oppression in the experiences of the oppressed,” but I disagree. Keys are not in the people of
Minamata, nor in the discriminated *buraku* people [descendants of outcast communities of the feudal era in Japan]. Unless you see it *as your own problem* [emphasis added], you won’t find any keys. (Ogata, 1996, p. 187)

In the year of 2014, more than eight years after my first visit to Kapu Kapu, I remain to this day a part of the Kapu Kapu community as a part-time worker. I must not dismiss the fact that Kapu Kapu *is* a social institution that artificially and discriminatory divides community members into two groups based on whether one has a disability label or not; hence, even though the labeled workers of Kapu Kapu seem generally happy to work at Kapu Kapu, it still serves a social organization that segregates and deprives those with a disability label of various life opportunities. No matter how clearly its policy states that Kapu Kapu aims to resist against the traditional and discriminatory concepts around dis/ability and to build an alternative working place where multiple and more just meanings of human worth can be constructed, that does not exempt Kapu Kapu from being an oppressive social organization: There is indeed quite power differences between the labeled workers and non-labeled staff, just like Murphy, the informant in the life history research of Bogdan and Taylor (1982/1994), once stated as “One thing that’s hard is that once you’re in it, you can’t convince them how smart you are…. And you’re so weak you can’t really fight back” (Bogdan & Taylor, 1982/1994, pp. 29-30).”
Thus I do not mean to advocate for “good” or “radical” (albeit segregated) disability-only institutions. Kapu Kapu cannot be “the different world.” As a paid staff of a disability-only institution, it is even more critical for me to be conscious of how it is easy to exert authoritative power on other labeled workers and justify my conducts or interpretations that may undermine their dignity. It is even more critical for me to keep the important lessons from pioneers to my heart, such as Biklen’s (2005) presumption of competence, Goode’s (1992) emic perspective, Bogdan and Taylor’s (1987) sociology of acceptance, Linneman’s (2001) mindedness, Kliwer’s (1998) human reciprocity, Shinohara’s presumption of humanness, and Steeves’ (2006) knowledgeability, and anchor my daily practices to those principles. As Mr. Suzaki (Kapu Kapu’s director) had told me once that he believed “simply by restraining ourselves from judging and problematizing others’ ways of being based on our own narrow conceptions of how things ought to be, we can emancipate oppressed potentials and as a result change the world, little by little,” I too believe that even a disability-only institution can be a site of social change by heightening self-critical attitude and by fighting against my own prejudices that oppress those with “differences that matter” (Kliwer, 1998, p. 3). Working toward “active healing” that Kurihara (1999) clarifies as “transforms the oppressive structures and relationships” (p. 176) and entails “bodily movements to
change the self, to change others, and to change the world” (p. 177), instead of complacent “passive healing,” which commodifies healing and regenerates pain, suffering, and oppression, I do feel that I am a little more able to merge myself within relationships where the concept of intellectual dis/ability has little meaning and relevance and where I share responsibilities to cultivate and maintain the co-vivial, hospitable community by mutually respecting the complexity, subtlety, knowledgeability and agency of each other. In other words, I have developed a stronger feeling that making the society better by developing its competence and habits for co-viviality is now my own problem.

In this dissertation, I have presented my learnings from the experiences of being welcomed into the observed hospitable communities and my analysis on the manner of life toward co-viviality; but hopefully this narrative does so in a way that does not consume and exploit the experiences of informants and end with passive healing. So the keys for hope are in myself, in ourselves. I must act; I must change; I must forgive and be forgiven. Furthermore, I must be committed to overcome the “limited vision of human potential and what the world may become” (Blatt, 1977, p. 5), become an even better observer of myself and others so as to improve my skills of interaction and appreciation, and work as an agent to aim for a different world – a co-vivial world.
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