

Difference, Equality and Disabled People:

Disability Rights and Disability Culture

by Osamu Nagase, December 1995

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To Gan Yoke Ai, with love and respect

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Abbreviations

ADA	Americans with Disabilities Act
DPI	Disabled Peoples' International
I.I.	Inclusion International (formerly ILSMH)
ILSMH	International League of Societies for Persons with Mental Handicap
Standard Rules	Standard Rules on the Equalization of Opportunities for Persons with Disabilities
WBU	World Blind Union
WFD	World Federation of the Deaf
WPA	World Programme of Action Concerning Disabled Persons

Introduction: Dilemma of Difference

I am no more different from you than you are from me.

If we identify the unstated points of comparison necessary to the idea of difference, we will then examine the relationships between people who have and people who lack the power to assign the label of difference.

[W]hen does treating people differently emphasize their differences and stigmatize or hinder them on that basis? and when does treating people the same become insensitive to their difference and likely to stigmatize or hinder them on that basis? I call this question "dilemma of difference."

- Martha Minow, USA

Background

There are men and women with disabilities everywhere in every country, race and class. The number of moderately and severely disabled people is to be 250 to 300 million for 1990 (Helander, 1993). Their life experience is significantly different from their colleagues and counterparts without disabilities.

Disability is a development issue. The causes of many impairments and disabilities are social and economic. While impairments and disabilities are part of normal human experiences, many are created by the unfavourable social, economic and political conditions. Causes of impairments and disabilities include, among others; congenital or prenatal disturbances; communicable diseases, such as poliomyelitis, trachoma, leprosy; non-communicable somatic disease, functional psychiatric disturbances, alcoholism and drug abuse, trauma/injury such as traffic accidents, occupational accidents; malnutrition (Helander, 1993). Impairments and disabilities are linked with disease, malnutrition and war. In USA, the incidence of disability among blacks and native Americans are twice to that of whites (UDNP, 1993). While this aspect is not the focus of this study, any discussion of disability without taking these factors seriously is unrealistic.

Life of people with disabilities is often threatened. Social Darwinism and eugenics have critically devalued life of disabled people. In Germany more than 200,000 people with disabilities were killed during the Second World War. Their life was considered "not worth living". This was extreme but not an isolated one. The challenge is how we can create a society in which everyone including those with disabilities can live, and can live with dignity and have choice.

It should also be noted that disability as an academic discipline is a blossoming area of study. So far most interest in disability has been in medicine, rehabilitation and psychology. But the development of disability

rights movement and the accompanying theoretical developments is turning the focus to social, economic, cultural, historical and political aspects. From 1980's there have been the establishment of Society for Disability Societies (formerly the Society for the Study of Chronic Illness, Impairment, and Disability) and publications of disability study journals, including Disability Studies Quarterly in USA and Disability & Society (formerly Disability, Handicap and Society) in UK. During past few years, research degrees in disability studies have been started in some institutions, including the University of Leeds, the University of Sheffield and Syracuse University. It should be noted that at least some programmes, most notably Leeds, have close working relationship with disability rights movement and involve disabled researchers.

Statement of the Problem

The concept of equality for persons with disabilities and their rights have evolved over time. Equality for disabled people is not a simple non-discrimination, as often perceived, but includes specific measures for particular needs and interests of persons with disabilities. In other words, equality should be disability-conscious. The adoption of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities by UN General Assembly in December 1993 represents the culmination of international efforts to recognize rights of disabled people and to present the new concept of equality.

Traditionally disabilities have been considered as personal and family tragedies. It was persons with disabilities who had problems and who had to adjust themselves to the society. But with the better understanding of the structure of disability, which is based on impairment, disability and handicap, the focus has shifted from individuals with disabilities to the society and the environment. Handicap, which is defined to be the loss or limitation of opportunities to take part in the life of community on an equal level with others, describes the encounter between the person with disability and the environment (Standard Rules). The shortcomings in the environment and socially-organized activities are emphasized.

Objectives

Disability is one distinct "difference". The overall study aims to examine how difference and equality applies to disabled people and how equality concept can be meaningful for disabled people.

The study seeks to trace the historical background in the devaluation of life of disabled people and how ideologies such as Social Darwinism and eugenics have influenced our thinking and practices. The study also analyzes the formation of disability rights movement, a political and social movement, as well as the parallel development of new paradigms and a new theory, which focus on the constraints created by society against disabled people. The study also examines how the development of new paradigms and theory have been reflected in international instruments, focusing on the establishment of disability rights, "reasonable accommodation". The study analyzes the emerging Deaf advocacy of a cultural and linguistic group and its implications to disability, and seeks ways to place it within and beyond disability framework. The study also attempts to create a overall framework of disability culture, in which life with disabilities will be celebrated as difference.

Limitations

This paper is to focus on the development of concept of disabled people's equality mostly at the international level, referring to international instruments such as the World Programme of Action concerning Disabled Persons (1982) and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993). International initiatives, such as International Year of Disabled Persons (1981), have been very successful in raising awareness on disability issues and have made a contribution to the shift from individualistic approach to more social approach. There will be occasional reference to national experiences and developments as appropriate.

As regards the time frame, it only goes back to Social Darwinism in the later 19th century, though an interest in history of disabled people and disability is on the rise.

Another limitation is the more focus given to physical and sensory disability, while this does not mean issues of intellectual disability and mental disability is of less importance.

The focus of this paper is more on "handicap", which is social disadvantages and constrains against disabled people, thus less attention is given to the biological and physical aspects of impairments and disabilities, though as mentioned earlier, many of them are products of social, economic and political conditions.

Research Questions

The focus within disability field is in the process of shifting from the medical orientation, emphasizing impairment and disability, to the social orientation with emphasis on social disadvantages, namely handicap. How this transition contributes to the establishment of equality for disabled people? Are there any implications in this transition? What is the meaning of equality for disabled people and how can they be implemented at the national and international level? When social barriers and constraints are removed, does disability matter at all? How does disability enrich disabled and non-disabled people? Difference, seen through the window of disability, presents a particular challenge. How difference and equality interact with each other?

Analytical Framework

The study listens to the voices of disabled people as much as possible, even though this risks the study being full of quotations. Too often, non-disabled people have been "talking over their head".

The study will use relevant concepts and theories from social theories including a social theory of disability, developed by disabled researchers; poststructuralism; and feminism, which has made much contribution to equality and difference. "Dilemma of difference", presented by Minow (1990) is also utilized to analyze the interaction between equality and difference.

Chapter One: Background: History and Movement

We are ... "an existence which should not exist".

-Hiroshi Yokota, Japan

[I]t seems that killing, say, a chimpanzee is worse than the killing of a gravely defective human who is not a person.

-Peter Singer, Australia

In this chapter, I look into the historic background in which people with disabilities have been devalued. Social Darwinism and eugenics have played major roles in devaluing life of people with disabilities. Though eugenics culminated in Nazi Germany resulting in the murders of more than 200,000 disabled people, eugenicist ideas and practices continue even today in various forms including the selective abortion. Threat to life of disabled people as well as professional control of life of disabled people were major reasons for the formation of disability rights movement. The formation of movements at the national level led to the creation of international movement, most notably represented by Disabled Peoples' International (DPI), founded in 1981. Through these movements disabled people have emerged as active agents of change.

Social Darwinism and Eugenics

Social Darwinism and eugenics, among others, have cast a long dark shadow over disabled people. Both have been particularly influential in devaluing life of disabled people and condemning their life as inferior. As a result, reproductive activities of disabled people have been discouraged and at times banned through forced sterilization.

The publication of "The Origin of Species" in 1859, in which Charles Darwin created an evolution theory in the wake of Malthus, led to the creation of Social Darwinism, the application of theory of evolution to the society. The Social Darwinist idea of "survival of the fittest" and "natural selection" considered that disabled people were human ballasts to be thrown away. Social Darwinism was characterized by laissez-faire attitude. Social Darwinists argued that "[a]ll attempts to reform social processes were efforts to remedy the irremediable, that they interfered with the wisdom of nature, that they could only lead to degeneration" (Hofstadter, 1955: 7) and "positive functions of the state should be kept to barest minimum" (Ibid). Without government interference, they believed, survival of the fittest would emerge out of struggle for existence. Social Darwinists were concerned that an intervention through social policy would only result in the "degradation of the race" (Kelves, 1985, 70).

Eugenics developed out of Social Darwinism. The word "eugenics" was coined in 1883 by Francis Galton, who was a cousin of Charles Darwin. The word is taken from Greek root meaning "good in birth" or "noble in heredity" (Kelves, 1985: ix). Eugenics aims at improving the genetic quality of the humans, based on the idea that careful planning through proper breeding was the key to creating a better society. Unlike Social Darwinism, eugenics advocated an active intervention of governments into human reproduction in order to create a better human breed. Mendel's laws of hereditary, which were only rediscovered in 1900 posthumously, provided a scientific ammunition to eugenics. Initially eugenics was enthusiastically supported by reform-minded people, such as Fabian socialist and feminists as a way to better society (Kelves, 1985).

Eugenics movement has two aspects; positive eugenics, which concentrates on increasing the breeding potential of "good" people and negative eugenics, which emphasizes the restriction on breeding for "unfit" individuals. Increasingly negative eugenics, including compulsory sterilization, was put into practice though today positive eugenics is witnessed in some countries, including Singapore (Correa, 1994).

Eugenics was particularly popular in UK, Germany and USA after around 1910 to the end of the Second World War. In USA, Indiana became the first state to legalize the compulsory sterilization of "feebleminded" and the "hereditary unfit" in 1907. 29 other states followed. Immigration Restriction Act of 1924 was also based on eugenics (Kelves, 1985). Sterilization laws were enacted in Norway, Sweden, Finland, Estonia and Canada (Kuehl, 1994) as well as in Japan.

In Germany, eugenics movement in the name of "racial hygiene" (Proctor, 1988; Hubbard, 1990) culminated under Hitler, who became the prime minister in January 1933. The Law on Preventing Hereditarily Ill Progeny, which had been discussed under the Weimar Government, passed the parliament in July 1933. This law provided that "any person suffering from a hereditary disease may be rendered incapable of begetting children by means of a surgical operation, provided it is established by a scientific medical experience as very highly probable that any children he might beget would inherit some serious physical or mental defect" (Gallagher, 1995, 22). The decision was made by the "hereditary health court" which consisted of judges and doctors (Yonemoto, 1989). Between July 14 1933 and 1 September 1939, 375,000 persons were sterilized (Deuel, 1942 in Gallagher, 1995). This legislation was strongly influenced by USA, particularly by the Californian Sterilization Act of 1909. The collaboration between U.S. and German eugenicists was very strong and a number of U.S. eugenicists praised the German legislation and practice (Kuehl, 1994).

Some consider this legislation as Nazi measure (Saito, 1985) but the Allied did not consider this as a Nazi policy and de-Nazification process did not target it (Yonemoto, 1989, 190). It was not possible to do so unless similar legislation and practice, particularly in USA, were also considered totalitarian and fascist. Over 63,000 persons were involuntarily sterilized in USA from 1921 to 1964 for genetic reasons (Ferser, 1966).

Eugenics was a major factor for T-4 programme, implemented by Nazi Germany, in which more than 20,000 disabled men and women, adults and children in Germany and occupied territories were killed (Kibata 1987, 1989; Proctor, 1988, Gallagher, 1990, 1995; Ambrosselli, 1992; Burleigh, 1994). Hitler signed a secret order in September 1939, which was proclaimed as the year of "the duty to be healthy" (Proctor, 1988, 177), which stated as follows;

Reichsleiter Philip Bowler and Karl Brandt, M.D. are charged with the responsibility of enlarging the authority of certain physicians to be designated by name in such a manner that persons who, according to human judgment, are incurable can, upon a most careful diagnosis of their condition of sickness, be accorded a mercy death. (US Nuremberg War Crimes Trial, 1947, in Gallagher, 1995, 16)

This programme, named after its Headquarters in Tiergartenstrasse 4 in Berlin, which claimed to be an "euthanasia" programme relieving disabled people from their "sufferings", was in fact a mass-termination of disabled people, who were considered "life worth not living", as Binding and Hoche put it in their "Release and Destruction of Lives not Worth Living" in 1920 (Proctor, 1988). It should be stressed that the medical profession, with a few exceptions, in Germany willingly participated in the programme (Gallagher, 1995).

The main target was mental patients who were institutionalized in asylums. Patients were transferred to killing centers equipped with gas chambers, which had been developed for terminating disabled people efficiently. With pressure from churches, this programme was officially called off in August 1941. But doctors continued the mass murder to the end of the war and even beyond (Kibata, 1987, 1989; Gallagher, 1995). After the war, leaders involved in T-4 programmes were found guilty of crimes against humanity

and were executed (Gallagher, 1995). T-4 programme, in retrospect, proved a forerunner of "subsequent destruction of Jews, homosexuals, communists, Gypsies, Slavs, and prisoners of war" (Proctor, 1988: 177). Medicalization and "medical solution" of disabled people run parallel to that of Jewish question (Ibid). It should also be noted that in Vichy France, 40,000 people with mental disability in institutions were starved to death (Ambrosselli, 1992).

Even though eugenics has become a "a word of ugly connotations" (Kelves, 1985: ix), the ideology of better birth dies hard. Some see "an historical continuity from eugenics movement, via Nazi Germany, to the new reproductive technologies" (Mies and Shiva, 1993) and to the "claims of those arguing for a racial basis of intelligence, in certain tenets of sociobiology, and in some proposals for human genetic engineering" (Kelves, 1985: ix).

Even today eugenics legislation exists in a number of countries including Japan and at least nine states in USA (Pfeiffer, 1994; Degener, 1995a). Recently China, which had enacted a regional legislation barring people with mental retardation from having children, introduced eugenics legislation nationally (China's law..., 1994; China Law Will Bar 'Inferiors'..., 1994; Threat to Our Lives, 1994). In fact, with the development of medical science, eugenicist tendencies are spreading. Out of 190 countries research by UN, fetal impairment is allowed as a ground for abortion in 78 countries. (UN DESIPA, 1994). Prenatal screening and amniocentesis provide prospective parents, particularly women, with the power to decide "who should and who should not inhabit the world" (Hubbard, 1990, 179). Yonemoto (1989, 1992) has my support, when he argues that we should not be concerned with superficial similarity with Nazi atrocities. But there is no denying that "a similar eugenic ideology underlies what happened then and the techniques now being developed" (Hubbard, 1990: 192).

Over the issue of "selective abortion", which means abortion on the basis of fetal impairment, disability rights movement and women's movement have had a serious conflict (Kaplan, 1989; Kanai, 1989; Morris, 1991; Tateiwa, 1992a, 1992b). Women's movement, based on the self-determination of women, claims unconditional and total rights of women to have an abortion for whatever reasons. Disability right movement has been against selective abortion (Yokota, 1983; Kaplan, 1989; Yamamoto, 1993). There is a growing awareness that new reproductive technologies do not enhance the choice of women but in fact restrict them. Women will be forced to make the right "choice" in this eugenicist society and be held responsible for their "decision" and "choice" (Kanai, 1989; Hubbard, 1990). In the overall context of the population control by the state (Truong, 1995), which is often both pronatalist and eugenicist, the interests of women and disabled people have been placed at odds with each other. In a way, this has been a proxy war. It also has to do with the lack of disability awareness in women's movement and the parallel lack of feminist awareness within disability movement (Kanai, 1989; UNOV, 1990; Morris, 1991, 1993; Kano, 1993).

The coalition of women and disabled people, realizing this trap, is emerging through movements such as Feminist International Network of Resistance Against Reproductive and Genetic Engineering (FINNRAGE) and "josei to kenko network" in Japan (Degener, 1990; Kanai, 1989, Yamamoto, 1993). Though differences do remain, emerging common goals seem to be (a) the creation of a society in which disabled children and adults can live without social disadvantage and (b) the abolition of state population control. FINNRAGE's 1989 declaration adopted in Comilla, Bangladesh includes the following;

3. Genetic and reproductive engineering are part of an ideology of eugenics which we oppose. In this ideology human beings are viewed as inherently inferior or superior. This leads to degradation, discrimination and elimination of oppressed groups; be they women, disabled, people of certain colors, races, religious, class or caste...

26. We are against any kind of bias and discrimination against disabled people including that of genetic screening and counselling. We particularly oppose human genome project within this context.... Instead we demand elimination of hazardous drugs, radiation, hazardous chemicals at the workplace and in the environment and a solution to the problems of malnutrition and preventable infectious diseases. (Degener, 1990: 76-77).

One area which should be an area of more active coalition of both groups is sexual and reproductive activities of women with disabilities. Women with disabilities have not been expected to be sexual nor to have babies (Finger, 1990; Sakaiya, 1992; Asaka, 1993; Osanai, 1995). "You cannot even take care of yourself" and "You should consider the interest of the baby" have been typical responses. Encouraging is the inclusion of disability aspect into the reproductive rights. The International Campaign on Abortion, Sterilization and Contraception (ICASC, which later changed to Women's Global Network for Reproductive Rights) defined reproductive rights as "women's rights to decide whether, when and how to have children -

regardless of nationality, class, age, religion, disability, sexuality or marital status - in the social, economic and political conditions that make such decisions possible" (emphasis added; Correa, 1994: 60).

Women with disabilities took an active part in the Cairo conference on Population and Development (Fricke, 1994), whose Programme of Action, among others, states "[g]overnments should eliminate specific forms of discrimination that persons with disabilities may face with regard to reproductive rights" (UN 1994, para. 6.31). The Fourth World Conference on Women provided an opportunity for women with and without disabilities to come together (Joneken, 1995; Sara-Serrano, 1995). In the final document (UN, 1995) references to women with disabilities are found in paragraphs on human rights, education and training, health, violence against women, and employment. Women with disabilities have come a long way from Nairobi conference in 1985 which was not "inclusive" (Kiwanuka, 1994) and they were well-prepared. Sydney Manifesto (1995), adopted at the World Congress of DPI in 1994, as demands of women with disabilities, includes, among others, "[t]he right to a full identity as a woman with a disability" as well as the right to live and the right to "define her own health and fertility, including no forced sterilization". Disabled women brought these ideas to Beijing and they were reflected.

The selective non-treatment of babies with impairment is also an issue with serious implications (Weir, 1984). This is often done in the context of "personhood" and quality of life. Tooley (1972, 1979) differentiated "human", physical and biological member of human species, and "person", moral and social being. To qualify as person, following capacities, among others, are proposed as requirements; desires about one's future, concept of a self, self-consciousness, reasoning ability, self-motivated activity, communication (Tooley, 1972; Warren, 1973). Severely disabled people, therefore, are disqualified as "persons".

Singer, an animal rights advocate, defining persons as "rational and self-conscious beings, aware of themselves as distinct entities with a past and future" (1979: 94), states that "it seems that killing, say, a chimpanzee is worse than the killing of a gravely defective human who is not a person" (1979: 97). The concrete implications of these arguments, about the differentiation of "human" and "person", particularly that of Singer, are similar to that of "lives not worth living" in Nazi Germany (Burleigh, 1994). While stating "killing a defective infant is not morally equivalent to killing a person" (1979: 138), Singer claims that "what I was suggesting was entirely different from what the Nazis did. I was not proposing that the state should decide who could live or die, but that parents, in consultation with doctors, should be able to decide when, in the interests of their child, and of their family as a whole, it was better that a severely disabled child should not live" (emphasis added; Singer, 1990: 36). As Burleigh (1994) points out, this is dangerously naive in light of the roles of family members and the medical profession in the T-4 programme as well as children's "euthanasia" programme, which resulted in the killing of at least 5,000 children with disabilities in Nazi Germany (Kibata, 1989). It is important to remember that one of incidents which led to T-4 programme and children's programme was a petition by a father of a disabled child to put his child to death (Burleigh, 1994; Gallagher, 1995). Doctors involved with children's programme found "encouragement and reassurances" from parents, who were "not generally a problem" (Gallagher, 1995: 101).

Some doctors use quality of life indicators of a baby to decide whether to let the baby die or not (Weir, 1984; Wolfensberger, 1994a, 1994b; Gallagher, 1995). Babies whose quality of life is calculated to be lower than a certain figure are "allowed" to die. Withholding treatment on the grounds of impairment is not unusual (Saito, 1985). But the use of particular formula is an attempt to introduce "scientific" criteria. Anthony Shaw, director of the Department of Paediatric Surgery at the City of Hope National Medical Center in USA, created a formula to measure quality of life of babies with spina bifida as follows;

Quality of Life=NEx(H+S)

NE-natural endowment of the child, intellectual and physical

H-the contribution the child is likely to have from home and family, based on emotional stability of the parents' marriage, the educational levels of the parents, and their wealth

S-the quality of social services that will be available to the child from community

(Weir, 1984, 66; Gallagher, 1995, 93)

Shaw used this formula to withhold treatment to twenty-four babies who eventually died in his experiment from 1977 to 1982 (Gallagher, 1995). Wolfensberger (1994a, 1994b) criticizes this kind of practice as "deathmaking" and proposes to discard quality of life concept as hopeless.

The concept of "bio-power" (Foucault, 1978), which aims to achieve "the subjugation of bodies and the

control of populations" (Ibid: 140), could be used to analyze the state-sponsored system of devaluing disabled people, including T-4 programme as its most extreme demonstration. But the overall trend is the shift to the individual convenience which is a deciding factor in today's world. Degener, disabled activist in Germany, analyzes it as follows;

*The paradigm of genetics has shifted. Control over reproductive behaviour is no longer sought by means of invasive state programs but by the establishment of individual self control.

*The improvement of German race or what was called "Volk" is no longer the focus of the population policy. The target is now the individual and his/her economic interest (not to have a disabled child). (1990: 79)

As Beck (1995: 31) states, increasingly we witness "the practice of eugenics without the use of force". With the "neutral" technologies, it is up to each individual to choose and decide. But too often there is no choice left, and "people end up with little, if any, choice" (Hubbard, 1990: 156).

Rights to Live and Rights to Decide: Formation of Movement

"Do we have rights to live?" as well as "Who controls my life, doctors and other medical staff members, family members and staff members of institutions OR myself?" were the questions which led to the formation of disability rights movements in different countries. Turner's analysis of the formation of a social movement, which follows, does seem to apply;

A significant social movement becomes possible when there is a revision in the manner in which a substantial group of people, looking at some misfortune, sees it no longer as a misfortune warranting charitable consideration but as an injustice which is intolerable to society (1969: 391)

Many disabled people have felt and do feel real threat to life. Violence against disabled people in Germany continues today. Recent Neo-Nazi attacks has resulted in a murder ("German Skin Heads Held...", 1993; Handicapped Germans Fear..., 1993; Slapping Spastics, 1993). Physical attacks against disabled people are not confined to Germany. It happens in USA as well (Gallagher, 1995). Up to early 1980's, a murder of disabled child by their parents took place every year in Japan (Namase, 1993). Various forms of actions devaluing lives of disabled people are not difficult to find. Numerous human rights violation of disabled people are reported all over the world (Despouy, 1993).

The threat to life was one major factor for the formation of disability rights movement. The case here is Japan. In Japan Aoi Shiba, the national association of people with Cerebral Palsy (CP) has had a lead role in the modern political movement of disabled people. In 1970, when a mother killed her disabled child and the public was sympathetic to the mother and not to the murdered child, Aoi Shiba protested (Okamura, 1988; Tateiwa, 1990a). Even though these cases happened almost annually, so far there had not been reactions from disabled people. But Aoi Shiba challenged the eugenic ideology of the "able-bodied" society and petitioned the court to judge the mother according to the law when it was common for the neighbours and friends to ask the court for leniency. In 1970, Yokota, a executive member of Aoi Shiba, advanced his ideas into a four-point platform for Aoi Shiba movement as follows;

* We are conscious of ourselves as people with CP.

We are aware of our position which is "an existence which should not exist". Our movement and action should be based on this understanding.

* We assert ourselves aggressively.

When we are conscious of ourselves as people with CP, we will have our will to protect ourselves. We believe that a strong self-assertion is the only way to achieve self-protection and we act on this belief.

* We deny love and justice.

We accuse egoism held by love and justice. Mutual understanding and the accompanied human observation, created by the denial of egoism, is the way to well-being and we act on this belief.

* We do not solve problems.

We have understood from our personal experiences that easy solutions to problems lead to dangerous compromises. We believe that continuous problem finding is the only way for us and we act on this belief. (emphasis added; Tateiwa, 1990a, 179; Okamura, 1988, 204; my translation)

Aoi Shiba has been one of most radical sections of disability rights movement in Japan. It, among others, stopped inaccessible buses, worked against the compulsory education of disabled children at separate schools and organized protest against the inclusion of fetal impairment as a condition for abortion in the Eugenics Protection Law in 1972, 1973 and 1982 (Yamamoto, 1993, 1995). One of the particular characters of Aoi Shiba is its radical critique of "able-bodied culture", claiming the positive aspects of impairments and disabilities. In reaction to prejudice, social barriers and threats to their lives, they have emerged as a social movement. Eugenics has remained its major agenda.

The founding of Disabled Peoples' International (DPI) in 1981, the International Year of Disabled Persons (IYDP), represents the coming together of different national movements at the international level. With its focus on human rights of disabled people, DPI has made a difference.

Before DPI, there were organizations of disabled people according to the category of disability. The World Blind Union (WBU) was founded in 1984, merging the World Council for the Welfare of the Blind (WCWB) and the International Federation of the Blind (IFB) (Driedger, 1989). WBU, as of August 1994, has 158 member organizations in all the regions of the world (WBU, 1994). The World Federation of the Deaf (WFD) was founded in 1951 (WFD, 1991). WFD has member organizations in 109 countries (Zen nihon roa renmei, 1995: 10). Inclusion International (hereafter abbreviated as I.I.; formerly International League of Societies for Persons with Mental Handicap; ILSMH), is an organization of family members of persons with intellectual disability and, increasingly, person with mental disability themselves. In recent years, it has been trying hard to promote the participation of people with intellectual disability themselves, so-called self advocates. Established in 1960, it has 172 member organizations in 102 countries at the end of 1994 (ILSMH, 1994). These organizations, WBU, WFD and I.I., respectively represent the interest of people with disabilities (and their family members in case of I.I.) in each category. Before the foundation of DPI, there was no umbrella organization of disabled people which tried to represent the interest of people with disabilities in general, with particular focus on the human rights of disabled people. In that sense, the founding of DPI was significant.

The process that led to the birth of DPI demonstrates disabled people's aspiration to be masters of their own life and not to let professionals dictate what is best for them. DPI started as breakaway from Rehabilitation International (RI) which is an world-wide organization of professionals. In its World Congress in 1980 in Winnipeg, Canada, just before IYDP, disabled people submitted a resolution which would have mandated that disabled people were equally represented in decision-making body of RI. It did not pass (Driedger, 1989: 28). Reacting to this, participants with disabilities decided to form their own organization, temporarily called "World Coalition of Citizens with Disabilities", which was subsequently changed to Disabled Peoples' International.

The difference between organizations "of" disabled people and organizations "for" disabled people needs a particular attention. And this is a reflection of power relationship between disabled people and professionals in the field of disability, such as medical doctors, social workers, physiotherapists, occupational therapists and staff members of institutions. The professionals have been controlling disabled people. Organizations for disabled people, namely organizations of professionals were the ones which had their voices heard by the government and which had better resources, good organization and memberships. DPI and other organizations of disabled people have been trying to change this power relationship.

The founding meeting of DPI took place in Singapore in 1981 with 400 delegates from 53 countries (DPI, 1991) and adopted its philosophy of "nothing about us without us". For too long disabled people have been excluded from decisions concerning themselves. Its newsletter was entitled "Vox Nostra", meaning "a voice of our own". Disabled people were not listened to nor talked to. People often literally "talk over" disabled people and talk to their personal assistants, their friends and family members as if disabled people do not exist.

The Singapore Declaration of 1981 stated, among others, as follows;

We demand the ending of service providers' permanent domination of all life decisions of disabled people.

We demand the right to make our own decisions and we insist on equality of opportunity. (DPI, 1991, 6)

Kubota (1982) was right to note that different movements at the national level in various countries found the common expressions in the name of "independent living movement" and "disability rights movement", which culminated in the formation of DPI and its later development as a powerful organization. Though the name of "independent living" originates from USA, the global movement of disabled people to be the master of their lives had different roots in different countries, including Aoi Shiba in Japan and Union of Physically Impaired Against Segregation (UPIAS) in UK. Countries were different but in many ways disabled people around the world had been in similar situations, under the strict control in institutions, often being forced to undergo rehabilitation programmes without the consideration of one's whole life (Brisenden, 1986).

With the breakaway of DPI, RI has had to change. Today, RI's president is a wheelchair user. Either a vice president or a deputy vice president for a region should be a person with a disability. What disabled people wanted in 1980 has been happening. In its newsletter, RI used to explain itself as "a federation of 150 organizations in 89 countries conducting programs to assist people with disabilities and all who work for prevention, rehabilitation and integration." (RI, 1993), then it changed to "an international, non-governmental organization of and for people with disabilities" (RI, 1994a). Now it is "a worldwide network of people with disabilities, service providers and government agencies working to improve the quality of life of people with disabilities (RI, 1994b). How much this reflects the change in reality is an open question. But at least the overall direction RI is pursuing now can be understood. The organization has needed transformation for survival.

During its brief history, DPI has made a number of achievements. DPI has provided a catalytic role in the formation of national disability movements particularly in developing countries through the training of national leaders. DPI's influence in international areas has been remarkable. DPI exerted its influence in the elaboration of UN policy documents, such as the World Programme of Action Concerning Disabled Persons, adopted in 1982. DPI lobbied successfully to have the ILO convention concerning Vocational Rehabilitation and Employment (Disabled Persons), No. 159 adopted in 1983 in a record time. In 1984, DPI also was successful in lobbying the Commission on Human Rights to appoint a Special Rapporteur to undertake a study on human rights and disability, whose report was finalized in 1991 (Despouy, 1993). DPI was instrumental in legislative change in Japan. When it was disclosed that mental patients were beaten to death and abused at a Japanese mental hospital DPI brought it up at the Sub-Commission on Prevention of Discrimination and Protection of Minorities, a subsidiary body of Human Rights Commission. In 1985 DPI and two other NGOs sent a fact-finding mission to Japan. With this pressure, the Japanese government revised its Mental Hygiene Law to Mental Health Law in 1987 (Driedger, 1989; Kubota, 1993; Degener, 1995b). DPI put in much efforts to establish a national organization of disabled people in countries without one, and to develop and strength organizations in countries with one. In Asia and the Pacific region, DPI has had a close cooperation with the Economic and Social Commission for Asia and the Pacific (ESCAP) in establishing and supporting organizations of disabled people in developing countries. Many regional leadership training seminars for leaders of national organizations have been organized in different developing regions and have proved useful. Now there are DPI national organizations in more than one hundred countries.

DPI, as part of the disability rights movement, also promoted the political participation of disabled people. Based on the idea of disabled people themselves are experts on disability, it has succeeded in promoting disabled people' participation in decision-making at local, national and international levels. This has been reflected in the representation of DPI and other representatives of disabled people at UN meetings and advisory and representative roles at the national and local levels (Constitution of Republic of Uganda, 1995). DPI as well as the various disability rights movement produced a number of members of parliament at the local and national level and government ministers and officials (Yashiro, 1979; Driedger 1989; Hori, 1995, Nagase, 1995a).

Some Issues of International Disability Movements

The issues discussed here includes the representation and involvement of family members, relationship between organizations, lack of gender awareness and the Western domination.

During the founding meeting of DPI, the participation of family member of disabled people, particularly that of parents was discussed. Some participants were vehemently against the inclusion of family members (Driedger, 1989). Parents are often seen by disabled parents as a major obstacle for their independence (Oka Nakanishi, 1992). But particularly in case of persons with mental retardation or intellectual disability, the role of advocacy in addition to self-determination is essential. Mittler, former President of I.I. (formerly

International League of Societies for Persons with Mental Handicap, ILSMH), states "there is a natural tendency for non-disabled members of the family to represent the interests of their disabled relatives, especially if they are children or have significant difficulties in speaking for themselves" (1994,9). Mittler (1994, 8) observes, "[t]he self-advocacy movement tends to be led by articulate or well-educated people with physical, sensory or invisible impairments", suggesting people with intellectual disability are marginalized in the movement, though admitting "people with intellectual disabilities have started to develop self-advocacy organizations, (e.g. People First)". While I.I. is encouraging people with intellectual disability to be more vocal within the organization and self advocacy organizations such as People First are organizing themselves, the role of family members, particularly of people with severe intellectual disability, continues to be significant. That is why I.I., mainly an organization of family members, has been recognized as an organization of disabled people by DPI, WBU and WFD.

The relationship between DPI and single-disability organizations has been sensitive. While DPI tries to represent all disability groups, single-disability organizations claim DPI only represents physically disabled people and does not represent blind people blind or deaf people. It is true that physically disabled people dominate the world officers of DPI. Between 1981 to 1985, there was one deaf world council member out of 25 (Driedger, 1989) and after that no deaf person was represented at the world council, the decision-making body. When the world council elected officers in 1990, only physically disabled people were elected and there were no blind or deaf officers.

I.I., WBU and WFD have claimed their rights to represent themselves (Andersson, 1992). WBU (1992:38) states that "We have viewed with concern for some time the excessively protagonistic role played by pandisability movements in United Nations' forums, like Disabled People's [sic] International, which aim to represent all categories of disabilities...It is practically unavoidable that the physically disabled are given certain privileges whilst minority disabilities, such as blindness and deafness, are dealt with only superficially". This is echoed by then WFD President, Yerker Andersson, who says "The WFD, the World Blind Union, the International League of Societies for Persons with Mental Handicap and Disabled Peoples' International declared that each of these organizations would have the right to represent on their own behalf at future international meetings" (Andersson, 1993), referring to the special session of the UN General Assembly which marked the end of the UN Decade of Disabled Persons (1983-1992).

While DPI has been claiming that it represents "the voice of disabled people", it has been seen to be representing physically disabled people, as evidenced by the membership of its officers which includes few sensory disabled leaders. Even though it is true in many countries DPI is an umbrella organization which includes different organizations of disabled people, it is not in others. The under-representation of women within the decision-making process of DPI caused controversy at its second World Congress in Bahamas in 1985. Women with disabilities have been marginalized from both feminist movement and disability rights movement (UNOV, 1990; Morris, 1991). Within feminist movement, women with disabilities are seen as "vulnerable" and thus considered to weaken women's movement while in disability movement gender issues have been considered as an side issue. This had to change at the Bahamas. Women protested and threatened to leave the organization unless they were heard (Driedger, 1989). After Bahamas, DPI started to take the issues of women with disabilities more seriously. It organized a number of regional training seminars for women with disabilities. In the Asia-Pacific region, seminars specifically for women with disabilities were held in South Korea in 1986, and in Pakistan in 1987. DPI held its 4th World Congress in Sydney, Australia in December 1994 and elected six world officers for the coming four-year term. The six was equally divided between men and women (Nakanishi, 1995). The issue of gender imbalance is not limited to DPI. For example, WFD has ten officers and only two of them are women (WFD, 1995a).

DPI's strength lies in its equal regional representation in its decision-making body, the world council. The world is divided into five regions of Africa, Asia-Pacific, Europe, Latin America and North America and the Caribbean. Each region nominates five members to the world council. This way regional balance is well-maintained. Among the six world officers, the balance between North and South is well-considered and the majority of them are from developing countries. This is in sharp contrast with other organizations such as WFD. WFD has ten world officers and nine of them are from Europe, North America and Japan, while the remaining one is from Brazil (WFD, 1995a). Within WFD, there is an encouraging trend as well. The British Deaf Association, which normally nominates its member to world officer of WFD, has decided not to do so and to cover the expenses of a representative from developing world (Kauppinen, 1994).

All the headquarters or secretariats of international disability NGOs are located in Europe and North America. DPI is headquartered in Canada, I.I. in Belgium, WBU in Spain, and WFD in Finland. The location of headquarters is closely connected to the funding base of organizations. DPI receives much funding from Canadian International Development Agency. WFD is supported by the Finnish Slot Machine

Association (WFD Hokoku, 1995). WBU receives the strong support from its Spanish member organization, ONCE.

This Western domination of NGOs of disabled people at times creates problems by misrepresenting the views of disabled people (Nagase, 1995b). One example is the Declaration of the Second UN Decade of Disabled Persons. When UN convened the Expert Group Meeting on the Alternative Ways to Mark the end of the UN Decade of Disabled Persons (1983-1992) in 1990, most international organizations of disabled people including DPI and WBU were against the declaration of the second UN Decade saying that the Decade was too weak and ineffective. It was reported that "the idea [of the second Decade] was supported by few participants" (UN, 1990a). This was the Western view. Where civil society is more established, an official umbrella like the UN Decade has less function to play, but in a number of regions including Asia and the Pacific, where more authoritarian tradition is evident, the usefulness of an official proclamation cannot be under-estimated. These official proclamations and endorsements play important roles. That is why in fact DPI Asia-Pacific region took the initiative of and lobbied hard for the declaration of the Asian and Pacific Decade of Disabled Persons (1993-2002), which was declared at the ESCAP Session held in China in 1992 (ESCAP, 1993). DPI Asia-Pacific region lobbied the government of China through its member organization in China, China Disabled Persons Federation (CDPF), headed by Deng Pufang, disabled son of Deng Xiaoping. Asia and the Pacific Decade seems to be enthusiastically supported in the region. The third NGO campaign to support the Decade was held in Indonesia this year, following the first one in Japan in 1993, and the second one in the Philippines in 1994.

Organizations of disabled people in the West have been active in the international field. They have put in much efforts and resources. Their contribution has been immense to the formation of the international movement. But if international organizations of disabled people are to truly represent the interest of disabled people around the world, more equitable representation of views within organizations is needed. In this sense, organizations in non-Western regions are encouraged to be more active and vocal.

Conclusion

In this chapter, I examined the historic devaluation of life of disabled people, manifested in different forms such as Social Darwinism, eugenics and selective abortion. I also examined the development of disability rights movements which emerged against forces controlling lives of disabled people. Some issues of international disability movements were discussed as well. In the next chapter, I will discuss the creation of a social theory of disability against the traditional individual and medical model of disability.

Chapter Two: Towards A Social Theory of Disability and Beyond

The most immediate impression of disability, therefore, is paradoxical. On the one hand there is the appearance of that disability implies a personal tragedy, passivity and dependency. On the other hand disability can be seen as a form of group discrimination, involving constant struggles and independent action.... It [disability] is defined in terms of the special form of discrimination, or social oppression, that is faced by people who are in some way physically impaired.

- Vic Finkelstein, South Africa/UK

When discussing these issues with disabled people who adhere strictly to the definition of disability as 'socially imposed restriction', I am either politely reminded that I am talking about 'impairment' not 'disability'.... This gives rise to feelings of estrangement and alienation.

- Sally French, UK

In this chapter, the development of a new thinking which does not blame individuals with disabilities but locates the problem with the environment and the society is discussed. The traditional medical model of disability ultimately reduced the problem to people who have disabilities. But the social understanding of disability and particularly handicap, social disadvantage, has emerged. The transition, which DeJong described as the shift from "rehabilitation paradigm", whose locus of the problem lies in individuals, to "independent living paradigm" (DeJong, 1979), whose locus of the problem is in the environment, has been phenomenal. The transition has led to the formation of a social theory of disability (Finkelstein, 1980; Abberley, 1987; Oliver, 1990), which places the problem with the society and social organizations. It is essential to note that these theories have been created out of disability rights movement and out of personal

experiences of disabled people.

Personal Tragedy Theory to Social Theory of Disability

For too long disability has been considered as a personal, medical problem. People who have a disability are identified as the problem. They have been seen as "problem people" (Brisenden, 1986: 175). And the problem was considered as medical. Medical interventions are supposed to solve the problem. People with disabilities are therefore considered as medical failures who keep on suffering. They have been targets of pity (Shapiro, 1993). Emotions such as pity and sympathy can serve as a good beginning if they are brought further and deeper. If not, they remains as sources of oppression (Ibid).

DeJong established "the independent living" as an analytic paradigm (1979). In the traditional rehabilitation paradigm, "medical model" was dominant. The medical model led "patients" to assume "sick role", which exempted a sick person from normal social activities and responsibilities, and he or she is not morally accountable for his/her condition so he/she should define being sick as aberrant and undesirable and to do everything possible to facilitate his/her recovery (Ibid: 440). Because a disability is often an irrevocable part of his/her existence, a disabled person, as a result of the sick role, begins to accept not only his/her condition but also as his/her own very personhood as "aberrant" and "undesirable." (Ibid: 441). One variant of the sick role is the "impaired role", which is ascribed to an individual whose condition is not likely to improve and who is unable to meet a requirement of the sick role, the duty to try to get well as soon as possible. Occupants of the impaired role have abandoned the idea of recovery altogether and have come to accept their condition and dependency as permanent.

Many disabled people have been evaluated and at times blamed by professionals for not "adjusting" to and not accepting disability. This has been used even as an evaluation of disabled people. But if the experience of living with a disability entails social exclusion and being discriminated, adjustment includes submission and defeatism. Morris, a disabled feminist, says;

Our anger is not about having 'a chip on your shoulder', our grief is not a 'failure to come to terms with disability'. Our dissatisfaction with our lives is not a personality defect but a sane response to the oppression we experience. (Morris, 1991: 9)

Within the medical model of disability, the environment and the society are taken as given. Individuals are supposed to adjust to disability and to a society which discriminates against them. If they resist, they are cases of maladjustment. They are supposed to try to get well as much as possible and if a complete recovery is not feasible, then they are to adjust to "reality".

Against this dominant medical model, independent living paradigm emerged. Independent living movement in USA, as a social movement started with Ed Roberts (1939-1995), who was the first, severely disabled person to attend the University of Berkeley in 1962 (Levy, 1988, Shapiro, 1993). Ed Roberts, who had polio and used an iron lung, was the main force for the formation of independent living movement in USA, which later had a global impact. In the rehabilitation paradigm, independence meant better ability to carry out tasks. But the independent living movement has radically changed the meaning of independence, which is now defined as one's control over his or her life. DeJong put that "[a]dvocacy, peer counselling, self-help, consumer control, and barrier removal are the trademarks of the IL paradigm" (DeJong, 1979: 443). Within this paradigm, rehabilitation "is seen as part of the problem, not the solution" (Ibid). The self-control and self-determination are the main concept of IL movement.

Table 1: Comparison of Rehabilitation and Independent Living Paradigm

Item	Rehabilitation	Independent Living
	Paradigm	Paradigm
Definition of problem	Physical Impairment/lack of vocational skill	Dependence on professionals, relatives, etc
Locus of problem	In individual	In environment; in the rehab process
Solution to problem	Professional intervention	Peer Counselling
	by physician	physical advocacy
	therapist	occupational self-help
	therapist	voc rehab consumer control
	counsellor, etc	removal of barrier
	Social role	Patient/clientConsumer
Who controls	Professional	Consumer
Desired Outcome	Maximum ADL Independent living	Gainful employment

(DeJong, 1979: 443)

The reaction to the professional control, which was justified by the medical model, was very strong. IL movement was of the factors which led to the formation of the international movement of disabled people, the Disabled Peoples' International (DPI), in 1981, as discussed in chapter one.

In 1960's and 1970's, there were movements in different countries which contributed to the social understanding of disability. In Japan, Aoi Shiba was active, as discussed in the preceding chapter. In UK, the Union of Physically Impaired Against Segregation (UPIAS), a group of physically disabled people, made a significant contribution to the creation of a social theory of disability by the following definition of impairment and disability. UPIAS defined;

Impairment as lacking part of or all of limb, or having a defective limb, organism or mechanism of the body;

Disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities. (UPIAS and Disability Alliance, 1976: 14)

Here disability is clearly defined as social exclusion. Finkelstein, a member of UPIAS and a political refugee from South Africa, further developed this, saying "disability is an oppressive social relationship" (Finkelstein, 1980).

New conception of disability and handicap has emerged against this traditional view. Disability is not seen in the light of personal problems but from the social and political perspective. The change of the focus is significant. Oliver (1990) illustrates this by citing survey of disabled adults by Office of Population Censuses and Surveys (OPCS) of the British government. The interviews included;

Can you tell me what is wrong with you?

Are your difficulties in understanding people mainly due to a hearing problem?

Did you move here because of your health problem/disability?

Does your health problem/disability prevent you from going out as often or as far as you would like? (Martin et al., in Oliver, 1990: 7)

These are compared with the corresponding alternative questions as follows;

Can you tell me what is wrong with society?

Are your difficulties in understanding people mainly due to their inability to communicate with you?

What inadequacies in your housing caused you to move here?

Are there any transport or financial problems which prevent you from going out as often or as far as you would like? (Ibid)

The shift of focus from the individual to the society is dramatic. This tells the importance to turn the focus from the individuals to the society and environment. Thus, "The social theory of disability holds that disability is reducible to the structural features and social forces of society" (Oliver, 1990: 11).

The epoch-making Americans with Disabilities Act (ADA; 1990) the first comprehensive anti-discrimination legislation in the world (Shapiro, 1993; Treanor, 1993), represents this shift. It covers employment, public transportation, public accommodations and telecommunications. ADA has had much influence in different countries, including Australia and UK, which subsequently enacted anti-disability discrimination legislation in 1992 and 1995 respectively, and Japan, which revised the Disabled Persons' Fundamental Law in 1993 (Yashiro and Tomiyasu, 1991; Nagase, 1995a).

Social orientation of ADA is reflected in its definition of disability. ADA's social definition of "disability" includes "a record of such an impairment" and "being regarded as having such an impairment". A person who does not have an impairment at the particular moment is considered to have a disability, for the protection under ADA. This is certainly the reflection of social nature of disability. This is of particular use for people with mental and psychological disability, whose stigma does not always disappear even when the disability is not present any more. UK's Disability Discrimination Bill (1995) also includes past disabilities. Disability Discrimination Act 1992 (1992) of Australia goes even further as follows;

...includes a disability that:

(h) presently exists; or

(i) previously existed but no longer exists; or

(j) may exist in the future; or

(k) is imputed to a person; (para. 4)

This inclusion of "future clause" is significant in light of the development of genetic engineering and the HIV consideration.

Social Theory of Disability and Beyond

The social theory of disability represents the most radical departure from the traditional one. It is also important to note the advocates of the social theory have been disabled people themselves. I do acknowledge the historic significance of the social theory, which helps us understand how our societies have been excluding people with disabilities. But the extreme emphasis on the social aspect leaves some aspects untouched.

One important critique of the social theory has come from Morris, a disabled feminist, who criticizes feminist movement for the lack of disability awareness as well as disability movement for the lack of gender awareness (1991, 1993). Referring to disability rights movement, she says;

Such a perspective is a crucial part of our demand for our needs to be treated as a civil rights issue. However, there is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created. While environmental barriers and social attitudes are crucial part of our experience of disability - and do indeed disable us - to suggest that this is all to it is to deny the personal experience of physical and intellectual restrictions, of illness, of the fear of dying. (Morris, 1991, 10)

French, who has a visual impairment, shares a similar view of Morris and touches upon areas ignored by the social theory. In her article entitled, "Disability, impairment or something in between?" she states;

I believe that some of the most profound problems experienced by people with some impairments are difficult, if not impossible to solve by social manipulation.... Such problems include my inability to recognize people, being nearly blinded when sun comes out, and not being able to read non-verbal cues or emit them correctly. (1993: 17)

French continues;

The difficulty I have described is not entirely due to my impairment, for it involves other people's responses, neither is it easily modified by social or environmental manipulation; it occupies a middle ground. (Ibid: 18)

Morris and French emphasize "the personal is political", which has been the major contribution of feminism. Morris does acknowledge that a social theory has roots in personal experiences of disabled people stating that disabled researchers, including Finkelstein and Oliver;

have been arguing for years against medical model of disability and in so doing they have been making the personal political in the sense that they have insisted that what appears to be an individual experience of disability is in fact socially constructed. However, we also need to hang on to the other sense of making the personal political and that is owning, taking control of, the representation of the personal experience of disability-including the negative parts to the experience. (emphasis added, Morris, 1993: 68)

Socially-created barriers have been taken for granted. Non-disabled people, particularly men, have been the social norm. Those who understand the ideology of personal "adjustment" to a system exclusively created for non-disabled people have created a social theory of disability, rightly blaming the social organizations which are responsible for their exclusion. In that process, the aspect of impairment and disability tends to be ignored. Or it needs not to be focused. Otherwise, the social theory may not have been born. But in the very process, "feelings of estrangement and alienation" (French, 1993: 19) have been created by some disabled people, being told that you "have not quite grasped what disability is" (Ibid). Morris, thus, states;

We can insist that society disables us by its prejudice and by its failure to meet the needs created by disability, but to deny the personal experience of disability is, in the end, to collude in our oppression.

(1991, 183)

French doubts the definition of "disability solely in terms of 'socially imposed restriction'", which "means that many people who define themselves as disabled through symptoms such as pain and vertigo, are not regarded as such by other disabled people" (1993: 19).

What Morris and French point out is that with its exclusive focus on the social aspect, the social theory of disability misses some essential personal aspects such as interaction and pain. French is very much aware that this is a "dangerous line of argument and one which may attract those bent on resisting environmental and social change" (1993: 21). But she argues that "presentation of a complex argument is more effective than a one-sided argument in bringing about change", and "time has now come to broaden and intensify our examination of disability and to develop and deepen our knowledge, to the benefit of all who define themselves as disabled" (1993: 24). Significant contribution of Morris and French is the message that "something in between" the biological/physical and the social should not be ignored.

A similar view is also expressed by Wiman, formerly with disability programme of UN, who does not agree with "an attractive simplification that 'handicaps are created by the environment'" (1992: 2). Advocating adaptation of society to people, Wiman takes people not as passive victims of the environment but as active agents who try to control their lives.

Conclusion

In this chapter I have traced the development of independent living paradigm and the social theory of disability. With these developments, the focus has shifted from the biological/physical to the social. This has been a revolutionary process.

But in that very process, some personal experiences of disability, which lie in-between the biological/physical and the social, are ignored and this may lead to a fresh alienation of some people with disabilities.

In the next chapter, how these theoretical developments have been transformed into international instruments is examined.

Chapter Three: Evolution of International Instruments

[T]he issue of the disabled was one of national solidarity... was not a human rights issue warranting the drafting of further legal instruments. - a representative of the government of France at the 42nd session of UN General Assembly in 1987

I understand that most of you are NGO representatives. My conviction is that the difference between success and failure in implementing the [Standard] Rules lies in your hands.... The Rules represent a unique political opportunity for us to obtain policy development. I promise to do what I can. What about you?

- Bengt Lindqvist, Sweden

In this chapter, the process of the how the transition from the focus on the biological/physical to the social and the emergence of disability as human rights issue, has been reflected in the international instruments. The focus is on the latest United Nations instrument on disability, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules; UN, 1993), which was adopted in 1993.

Developments of UN Instruments on Disability

The overall framework of the international human rights instruments is the Universal Declaration of Human Rights (UN, 1948), which does not specifically refer to disability. The International Covenant on Economic, Social and Cultural Rights (UN, 1966a) and the International Covenant on Civil and Political Rights (UN, 1966b) both embody the rights provided for in the Universal Declaration.

Although the Declaration on Social Progress and Development (UN, 1969), makes reference to disability, the first major instruments in the field of disability was the Declaration of the Rights of Mentally Retarded Persons, adopted 1971 (UN, 1971). This was the first resolution on disability adopted by the United General Assembly of the United Nations (Nakano, 1995). The Declaration was the result of lobbying by the I.I. (then International League of Societies of Persons with Mental Handicap), which is a non-governmental organization of family members of people with intellectual disability and people with intellectual disability (Roehrer, 1982). The article 1 says "The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings." This was a significant achievement at that time since people with mental retardation have been regarded as "abnormal-persons" in the legal context (Minow, 1990, 105). The recognition of their rights was a step forward, But the unfortunate inclusion of the phrase "to the maximum degree of feasibility" as well as the Article 7, which refers to severe restriction of their rights, certainly diminish its value, particularly from today's standpoint (Helander, 1993).

The Declaration of Rights of Disabled Persons followed (UN, 1975) in 1975, International Women's Year. A "disabled person" is defined as;

any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities. (Article 1)

Though this is a typical medical definition, which places the problem with capabilities of individuals, overall, the Declaration is a positive and forceful statement. It addresses social aspects in its Article 2, which says;

Disabled persons are entitled to have their special needs taken into consideration at all stages of economic and social planning.

Equally important is Article 7 which says "Organizations of disabled persons may be usefully consulted in all matters regarding the rights of disabled persons". Though it says "may", it recognizes the role of disabled people themselves through their organizations. It should be added that there is a legitimate criticism of the Declaration since some articles can be interpreted as restrictive (Helander, 1993).

In the following year of 1976, the General Assembly declared 1981 as the International Year for Disabled

Persons (IYDP) with the theme of "full participation". The resolution 31/123 states as one of the objectives of the year as, among others;

(a) Helping disabled persons in their physical and psychological adjustment to society.

For the member states of the United Nations who declared IYDP, it was disabled people that should adjust to society. Overall emphasis was on individuals with disabilities. There was no reference to equal opportunity or equality.

In 1979, the UN General Assembly adopted resolution 34/154, entitled International Year of Disabled Persons. The name of the Year was changed from International Year for Disabled Persons to International Year of Disabled Persons. This was in response to criticisms from disabled people who said the use of "for" reflected paternalistic attitude of non-disabled people, reinforcing "the idea that disabled people should have things done for them" (Oliver, 1990: 115). Incidentally 1979 was the International Year of the Child. The use of "for", however, is not unusual in UN proclamations, such as UN Decade for Women (1976-1985), International Year for the World's Indigenous Peoples (1994), and International Day for the Elderly (1 October).

This change from "for" to "of" signifies the shift from professional control to consumer control and the rehabilitation paradigm to the independent living paradigm. Disabled people's reaction to "for" is a particular reflection of their life controlled by professionals. This also has to do with the conflict between organizations of disabled people and organizations for disabled people, which was discussed in the chapter 1. The same resolution expanded the theme of the Year from "full participation" to "full participation and equality".

IYDP proved very successful, at least in raising awareness on disability issues. The whole process of IYDP made a significant contribution to putting disability on the political agenda at the international and national levels. Oliver gives credit to IYDP since it "gave further impetus to the disability movement, and helped to give it a sense of cohesiveness at national and international levels" (1990, 115). IYDP provided an opportunity for various organizations to get together in order to give influence on IYDP and beyond (Hanada, 1990, Oliver, 1990).

The success of IYDP led the international community to adopt the World Programme of Action concerning Disabled Persons (WPA; UN, 1982a) in 1982 and the declaration of the United Nations Decade of Disabled Persons from 1983 to 1992 as the framework to implement the WPA (UN, 1982b). Enns, the chairperson of DPI from 1985 to 1990, had a very high opinion of WPA (Driedger, 1989). The definition of impairment, disability and handicap adopted by WPA (UN, 1982a) was based on that of the World Health Organization as follows;

Impairment: Any loss or abnormality of psychological, physiological, or anatomical structure or function.
Disability: Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap: A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal, depending on age, sex, social and cultural factors, for that individual. (para. 6)

Since there was a criticism against WHO definitions saying they were too medical and individualistic, WPA further added;

"Handicap is therefore a function of the relationship between disabled persons and their environment. It occurs when they encounter cultural, physical or social barriers which prevent their access to the various systems of society that are available to other citizens. Thus, handicap is the loss or limitation of opportunities to take part in the life of the community on an equal level with others. (para. 7)

Because of this construction, namely WHO definitions and more social definitions, WPA gives a mixed signal. DPI definitions are in the preamble of its Constitution. DPI has revised its Constitution in 1992 but definitions have not been changed.

Whereas disability has too long been viewed as a problem of the individual and not the relationship between an individual and his/her environment, it is necessary to distinguish between;

a) disability is the functional limitation within the individual caused by physical, mental or sensory impairment, and

b) handicap is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers. (DPI Constitution, 1985)

Disabled people, including Henry Enns and Bengt Lindqvist, who become founding members of DPI in December 1981, were involved in the drafting of the WPA. The original draft had more medical orientation and many disabled people did not support it (Driedger, 1989). It had to be re-drafted in 1981, causing the delay for one year.

WPA represents a on-going shift of focus from the medical and individualistic approach to a more social approach. One particular criticism against WPA is its prevention component, which is among the three major components of WPA in addition to rehabilitation and equalization of opportunities. Some aspects of prevention are sensitive issue, as discussed in chapter one. Selective abortion or eugenic policy can be considered as prevention in the broad sense. When a Chinese eugenics legislation which would have banned people with mental retardation from having children was criticized in 1993, the Chinese authorities used WPA as a defense of their position referring to articles on prevention in WPA.

The inclusion of prevention into WPA, has also been criticized as logically inconsistent. WPA refers to "Disabled Persons", people who are already disabled. Sato argues that the title should be changed to "World Programme of Action concerning Disablement" (Sato: 1992, 19). Here disablement is used as an umbrella concept for impairment, disability and handicap though this usage has not been very popular. The action plan for IYDP (UN, 1979a) also had a same problem with the reference to prevention.

I am inclined to support the reference to disabled people since it prevents over-emphasis on prevention aspect particularly at the expense of the equalization of opportunities and also the whole argument is grounded on "people".

Proposed Convention on Disability Discrimination

According to Waesterberg (1993), it was Maria Rita Saulle and Barbro Carlsson, who for the first time raised the issue of convention on rights of persons with disabilities at the European Regional Meeting on Implementation of the World Programme of Action concerning Disabled Persons, Ljubliana, March 1987.

The call for a convention was also recommended by the Global Meeting of Experts to Review the Implementation of the World Programme of Action concerning Disabled Persons at the Mid-Point of the United Nations Decade, Stockholm, 17-22 August, 1987. It said, among others;

The General Assembly should convene a special conference on the human rights of disabled people, with the mandate to elucidate such rights and to draft an international convention on the elimination of all forms of discrimination against disabled persons, to be ratified by States by the end of the Decade. (UNOV, 1987, 6)

This expert group meeting had a special significance since it was the first UN meeting in which majority of experts were disabled (Ibid, 17). The majority of officers were also disabled people as well as members of DPI. It was also the first UN global meeting to provide sign language interpretation, and documentation in Braille and on audio-cassette tapes (Ibid). Their recommendations were very powerful. Some viewed them as "probably too ambitious", as the representative of Japan commented (UN, 1987a, 7).

Bringing this recommendation to the 42nd session of the General Assembly of UN in 1987, the Government of Italy proposed "drafting an international convention on the elimination of all forms of discrimination against disabled persons". (UN, 1987b, 3). Italy, represented by Saulle, stated;

Although there were already a number of international instruments concerning human rights, the provisions of which applied to the disabled, those instruments were general in scope and did not take into account the specific situation and particular needs of the disabled, a very vulnerable group. (Ibid, 3-4)

Referring to previous international actions, it stated that two declarations "were not of a binding nature and

therefore did not provide minimum international standards for the protection of their rights" (Ibid, 4).

This proposal provoked a serious debate though it met mostly negative responses from other governments. With the perennial financial crisis of UN, some were concerned about the financial implications. The government of Australia stated "[d]rafting new instruments was resource-intensive and the implications of such a proposal for progress on substantive programmes would have to be assessed, especially in the current financial climate facing the United Nations" (UN, 1987c, 18). UK also expressed concern saying "[s]ome proposals might require resources which were simply not available..." (UN, 1987d, 4). Unstated but obvious assumption is the low priority given to disability issues. Italy countered this by arguing "[t]he financial implications should be evaluated at the proper time, within a comprehensive framework of priorities, and should not, under any circumstances, prevent an objective evaluation of the merits of a specific initiative." (UN, 1987b, 4).

Some were afraid the convention might duplicate already existing instruments. Lindqvist, speaking on behalf of Nordic countries, stated that they "were not convinced of the need for another convention because the human rights of all persons were already set forth in the Universal Declaration of Human Rights and the International Covenants on Economic, Social and Cultural Rights and on Civil and Political Rights." (UN, 1987e, 4). It was seen that "existing human rights documents seemed to guarantee persons with disabilities the same rights as other persons" (UN, 1993, para. 9). Others simply did not see the significance. Japan "hardly saw the merit of the plan to draft an international convention..."

The Italian proposal brought forth a very pertinent debate regarding disability, whether a specific instrument, such as an convention on disability, was needed or not. In other words, at least part of the debate had to do with whether the establishment of specific disability rights were needed to create "equality" for disabled people.

One typical view was expressed by France which stated that "the issue of the disabled was one of national solidarity...was not a human rights issue warranting the drafting of further legal instruments" (UN, 1987a, 4). This view does not consider disability as a human rights issue.

Others were concerned about "marginalization". Typical was the ILO's view which stated that "the adoption of new international instruments that single out disabled people for special consideration might have the opposite effect - that is, of marginalizing them, and might also undermine existing major human rights instruments" (UN, 1988: 5). This was a surprising and hypocritical statement since the ILO itself had adopted the Convention No. 159, entitled Convention concerning Vocational Rehabilitation and Employment (Disabled Persons) in 1983, which "singled out" disabled people. ILO had been making efforts to make more countries ratify this convention and in fact welcomed the recommendation of the Expert Group Meeting which encouraged more governments to ratify Convention No. 159 (UN, 1987f: 3).

ILO was not the only one which was concerned about marginalization. Though Canada was of the view that "integration of disabled persons should be considered from human rights", it expressed that "International instruments in the field of human rights did not call for "different treatment of disabled persons" on the basis of sex or given impairment, etc (UN, 1988: 13).

Italy, citing the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW; UN, 1979b) as an example, stressed "that the convention would bring about radical changes in living conditions for the disabled both from a practical point of view and in the perception of their role in society" (UN, 1987b: 4)

Italy has my support. CEDAW as well as the Convention on the Rights of Child have made and are making positive impacts. Unless there is a focus on disability, unless disability receives an attention, there is no way forward for the equality for disabled people. The difference should be acknowledged and taken into account.

There was little support to the Italian proposal. Australia, Belgium, France, Japan, and Nordic countries expressed their reservations in the debate. No consensus was reached at the General Assembly. The General Assembly resolution 42/58 requested governments and UN bodies to submit comments on the recommendations of the Expert Meeting. Those who expressed support to the convention, through comments were Byelorussian Soviet Social Republic, Ecuador, Ethiopia, Greece, Kuwait, Luxembourg, Rwanda, Economic and Social Commission for Asia and the Pacific(ESCAP) and UNESCO (UN, 1988). Those who aired reservations were Belgium, Canada, Sweden, the Netherlands, and ILO (Ibid).

In 1989, the convention was brought up again, this time by Sweden. Lindqvist, who had made a statement against the convention two years ago, expressed his disappointment at the lack of implementation of WPA and proposed that "[l]egally binding international regulations must be laid down to guarantee the full implementation of existing international instruments on rights of disabled persons" (UN, 1989a: 4). There was no consensus on this even among Nordic countries since Norway speaking on behalf of Nordic countries had made no reference to the convention (UN, 1989b: 12). This time, Italy was silent on the proposal (UN, 1989a: 9) and only Ukrainian Soviet Socialist Republic (UN, 1989c: 18) expressed its support to the convention. No consensus was reached either in 1989.

It almost looked as though no instrument on disability was to be produced. But Sweden insisted. At the first regular session of Economic and Social Council, Sweden pursued the convention on the rights of disabled people and finally a consensus emerged on the elaboration of an alternative non legally-binding instruments, the Standard Rules (UN, 1990b).

To summarize, those against the convention based their argument on duplication, marginalization, and resource constraint. The issue of marginalization was repeated even after the ECOSOC decision to elaborate the Standard Rules. France, represented by Gillibert himself disabled, reiterated its view stating that "it would not be appropriate to establish specific rights for disabled people since the policy of integration required that disabled should enjoy the same rights as those of all citizens". (UN, 1990c: 13).

Towards the Standard Rules

After three sessions of the Working Group which met in 1991 and 1992, The Standard Rules were adopted by the General Assembly of UN on 20 December 1993. Although Standard Rules are not binding, it is expected "they can become international customary rules" and they "imply a strong moral and political commitment on behalf of States to take action".

Standard Rules clearly address social barriers stating that "[i]n all societies of the world there are still obstacles preventing persons with disabilities from exercising their rights and freedoms..." (para. 15 in Introduction) and makes it clear that "[i]t is the responsibility of States to take appropriate action to remove such obstacles" (Ibid). They also acknowledge that "[p]ersons with disabilities and their organizations should play an active role as partners in this process" (Ibid).

The structure of the Standard Rules is as follows;

Introduction

Preamble

I. Preconditions for Equal Participation

Rule 1. Awareness-raising

Rule 2. Medical Care

Rule 3. Rehabilitation

Rule 4. Support Services

I.I. Target Areas for Equal Participation

Rule 5. Accessibility

Rule 6. Education

Rule 7. Employment

Rule 8. Income maintenance and social security

Rule 9. Family life and personal integrity

Rule 10. Culture

Rule 11. Recreation and sports

Rule 12. Religion

I.I.I. Implementation Measures

Rule 13. Information and research

Rule 14. Policy-making and planning

Rule 15. Legislation

Rule 16. Economic Policies

Rule 17. Coordination of Work

Rule 18. Organizations of persons with disabilities

Rule 19. Personnel training

Rule 20. National monitoring and evaluation of disability programmes in the implementation of the Rules

Rule 21. Technical and economic cooperation

Rule 22. International cooperation

Some more particular aspects of the Standard Rules are examined here. First, the focus is very clear on the equalization of opportunities and this is certainly different from WPA, in which equalization was just one of the three components. Equalization of opportunities is defined as "the process through which the various systems of the society and the environment... are made available to all, particularly to persons with disabilities" (para. 24 in Introduction). It further states that "[t]he principle of equal rights implies that needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies..." (para. 25 in Introduction). In almost two decades from the resolution on IYDP in 1976 (UN, 1976), whose major aim was to help "disabled persons in their physical and psychological adjustment to society," to the Standard Rules in 1993, a revolutionary change in the official discourse has taken place. The focus has shifted from the individual to the society. Second, for the first time "sexual relationships, marriage and parenthood" were recognized as a distinct area of discrimination that needs to be addressed. Rule 9. Family life and personal integrity states;

They [States] should promote their [disabled persons'] right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood".

WPA also refers to this aspect (para. 32 and 74) but only in the Standard Rules it is identified as an distinctive and independent area that needs to be addressed. With the history of eugenics and prejudice against the reproduction of disabled people which die hard, this is ground-breaking. In personal areas such as sexual relationships and marriage, change in attitudes are most difficult. Elimination of legal discrimination is one small but important step.

Third, the stronger monitoring mechanism, consisting of an appointment of a Special Rapporteur and the establishment of the panel of experts of organizations of disabled people, was introduced. WPA's monitoring was based on questionnaires which was done every five-year, 1987 and 1992 respectively. But this system was criticized for the lack of input from disabled people and their organizations. Thus, the issue of monitoring was the one of the most essential parts of the debates of the Standard Rules. The monitoring was all the more important since the Standard Rules were not binding. Without an effective monitoring mechanism, their implementation would not be feasible.

The Special Rapporteur, who needs to have experience in disability issues and in international organizations, is a key position for the promotion and implementation of the Standard Rules. Bengt Lindqvist was appointed as the Special Rapporteur in October 1994 for three years. The background in disability movement, parliament, and government has made Lindqvist probably the best person for the job. He is blind and he has been part of national and international disability rights movement, particularly DPI. He also was the one who proposed the convention in 1989 and the Standard Rules in 1990. The Special Rapporteur is to monitor the Standard Rules by sending questions to governments, UN organs and bodies and NGOs, provide advisory services on the implementation and monitoring of the Standard Rules and report to the

Commission on Social Development.

In addition to the Special Rapporteur, a panel of experts has been formed (Special Rapporteur..., 1995). The panel is formed by non-governmental organizations of and for disabled people. The majority of panel should be organizations of disabled people. The panel includes two representatives each from DPI, I.I., WBU, WFD, and one each from RI and World Federation of Psychiatric Users (WFPU). The Standard Rules encourage the panel to "review, advise and provide feedback and suggestions on the promotion, implementation and monitoring of the Rules". The significance of this panel is that disabled people themselves through their organizations are systematically involved in the monitoring of the Standard Rules. The expertise of disabled people and their organizations is officially acknowledged. Also significant is the participation of psychiatric users who have had a very limited presence within the disability field.

There are some encouraging initiatives from non-governmental organizations for the implementation of the Standard Rules. The Danish Council of Organizations of Disabled People (DSI) has proposed to create a disability index to measure the implementation of the Standard Rules in each country. For this, DSI hosted a one-day International NGO Conference on Disability in Copenhagen on 3 March 1995, immediately before the World Summit for Social Development. At the meeting, DSI circulated a draft index which was later revised and circulated to different countries in September 1995. DSI hopes that this would help NGO's to evaluate the progress being made in each country and facilitate the establishment of global disability index to be included in the UNDP Human Development Report as called for by UN resolutions 47/88 in 1992 and 48/99 in 1993. Disability Awareness in Action, an NGO, has produced an "Information Kit" on Standard Rules (Fletcher, 1995). Japan Council on Disability (JD) has translated the Standard Rules into Japanese and published it (JD, 1995). These NGO initiatives are essential for the promotion and implementation of the Standard Rules.

The support for the convention is alive as well. At the regional level, the Organization of American States (OAS) is considering "the draft Inter-American Convention on the Elimination of All Forms of Discrimination by Reason of Disability" (DPI, 1995). During the preparatory process to the World Conference on Human Rights, Latin American and the Caribbean region identified the need to elaborate "an international convention that will provide, on the basis of equality, for the full exercise and enjoyment of the fundamental rights of disabled people" in its San Jose Declaration (1993, 6). Messages of women with disabilities who participated in the Fourth World Conference on Women in Beijing included that the Standard Rules be "developed into a convention" (Joneken, 1995). Even though there is a general danger that drafting process of a convention "may prompt states, for fear of the binding nature of conventions, to weaken standards" (Stamatopoulou, 1995, 47n), if the implementation of the Standard Rules is not satisfactory, there will be another proposal for a global convention on disability in the future.

"Reasonable Accommodation" as Basis for Equality

The Provision of "reasonable accommodation" is emerging as a part of human rights of disabled people is reflected in national and international instruments.

As a concept to make the overall environment accessible to disabled people, this is an important concept of the Americans with Disabilities Act (ADA) of 1990, a comprehensive anti-discrimination act, which had a global impact. In the employment section of ADA (Sec. 101), reasonable accommodation is defined to include "(a) making existing facilities used by employers readily accessible to and usable by individuals with disabilities, and (b) job restructuring, part-time or modified work schedules...the provision of qualified readers or interpreters, and other similar accommodations for individuals with disabilities."

It is also found in the "General Comment No. 5" (1994, para. 15) to the International Covenant on Economic, Social and Cultural Rights (UN, 1966), adopted by ECOSOC in 1994, which states that;

"disability-based discrimination" may be defined as including any distinction, exclusion, restriction or preference, or denial of reasonable accommodation based on disability which has the effect of nullifying or impairing the recognition, enjoyment or exercise of economic, social or cultural rights. (emphasis added)

The General Comment is not legally binding but "is regarded as an authoritative interpretation" (Degener, 1995b).

In U.K., the Civil Rights (Disabled Persons) Bill (1995), which was supported by organizations of disabled people, including BCODP, defined discrimination against a disabled person as failure to make reasonable

accommodation. The Disability Discrimination Bill (1995) submitted by the government and enacted in November 1995, does not use the term "reasonable accommodation" adopts a similar concept using the term "adjustment".

The adoption of "reasonable accommodation" demonstrates the development of concept of equality for disabled people. Equality has two aspects, sameness and fairness (Lummis, 1992). The formal or absolute equality refers to the former and material equality refers to the latter. Hendriks (1995), tracing the application of these concepts to the development of equality for disabled people, observes the establishment of "reasonable accommodation" as the application of material equality, towards equal results. Lummis argues that "equality of opportunity makes sense in a society organized as a competitive game, which there are winners and losers. What is equal is not the people, but the rules of the game." (1992: 43). On the other hand, if the implication of material equality is "a distribution of goods commensurate with the needs of individuals, instead of a distribution according to merit" (Hendriks, 1995: 49), there is the danger of "dilemma of difference" as Minow (1990) observed. Affirmative actions, including quota systems, which ensures equal results have produced mixed results. In one sense, by focusing on the discriminatory practices, it promotes disadvantaged groups, including disabled people as well racial minorities. For instance, in Japan, there is a legal quota for the employment of disabled people. Ison (1992), however, observes stigma created by this. One Black American (Carter, 1991: 11) says "I got into law school because I am black", referring to the affirmative action in USA. Parallel would be to say "I have got a job with Sony because I am disabled". In fact this happens for people with comparatively less severe disabilities. Some countries, including USA, avoids a quota system for the employment of disabled people (Yasui, 1989). ADA does not enforce quota.

The difficulty of avoiding "dilemma of difference" can be seen in the statement of President Clinton of USA, after referring to 44 political appointees with disabilities in his administration, when he says;

We have not appointed a single, solitary person because of their disability. They have all been appointed because of their ability to serve the American people. (White House, 1994)

Conclusion

The framework of disability within international as well as national instruments have evolved from the personal approach to the social approach. At the international level, this has taken place within two decades, culminating at the adoption of the Standard Rules, whose implementation is crucial.

The concept of equality for disabled people is still being contested in the international arena, even though emerging consensus is that environment should be planned with "all" in mind and "reasonable accommodation" should be made to reflect individual differences, though how to create the material equality without deepening the "dilemma of difference" seems to remain.

In the next chapter, somewhat from a different angle, the advocacy of deaf people as a cultural and linguistic group and its implications for disability framework is examined.

Chapter Four: Different Center of Deaf People

Our life builds on visual means. We use sign language not only to communicate but to build up an identity. Through sign language we learn who we are, gain confidence as Deaf persons and become active members of our communities and of larger communities. It gives us dignity and importance.

- Liisa Kauppinen, Finland

"Do you want to eliminate people like us from the face of the earth?" Rather than prevention, many Deaf parents want to have Deaf children. We are interested in passing on our rich heritage to Deaf children who are just fine, just as we are fine.... we are proud of our language, culture and heritage. Disabled, we are not!

- MJ Bienvenu, USA

Deaf people have been labelled as disabled people. Technically that is correct, of course, and it is important

to accept this. To totally reject this is to collaborate with non-disabled people in oppressing those with disabilities.

- Paddy Ladd, UK

In the previous chapters, I have examined the development of disability movement and accompanying new paradigms, including independent living and the social theory of disability, which squarely address social, economic and political aspects of disability as well as their reflections in international policy instruments, most notably by the Standard Rules.

In this chapter, the emerging cultural and linguistic model of deaf people and their aspiration to linguistic rights, is examined. Bound by a common language of sign language, they form a distinct cultural and linguistic group. Sign language occupies the core of their group identity.

Particular attention is drawn to the assertion that they are not disabled.

Deaf People as a Cultural and Linguistic Group

Deaf people, represented by the World Federation of the Deaf (WFD), which is the global organization of deaf people, are asserting a new identity as a cultural and linguistic group. Liisa Kauppinen, then General Secretary and the incumbent president of WFD (1995-1999), states "we do not differ from other language minorities" (1993b, 3).

The "resolution of XII World Congress of the WFD" (WFD, 1995b: 12), in which 97 countries were represented, includes the following, among others;

The objective [of deaf education and medicine] has been to change a Deaf person to become like a hearing one. This has lead [sic] to "solutions" such as forbidding the use of Sign Language in education and in other interaction.

It continues;

Everywhere in the world Deaf people have proved that Sign Language and the culture, art and traditions of the Deaf Community, and the solutions how to manage as Deaf people, are the resource, the basis for normal language development, access to information, balanced social and emotional development, and control of environment for a Deaf child. (Ibid)

Deaf people are bound by sign language, which occupies the core ground of this group. While most hearing people consider deafness as a serious affliction, many deaf people are proud of their sign language and proud to be part of the signing community.

At this juncture, the distinction between "Deaf" and "deaf" should be made. The capital "Deaf" denotes the cultural and linguistic aspect of Deaf people and small capital "deaf" refers to the audiological condition of not hearing or hearing loss (Markowicz and Woodward, 1978). Padden and Humphries, both Deaf, explains that "Deaf people are both Deaf and deaf, and their discussions, even arguments over issues of identity show that these categories are often interrelated in complex ways" (1988, 3). It should be noted that not all deaf people are Deaf (Gregory and Hartley, 1991; Higgins, 1980). In WFD Manual on How to Establish and Run an Organization of the Deaf, the following definitions are given;

Deaf -refers to a person who uses Sign Language as primary means of communication, identifies him/herself with other Deaf persons and usually does not hear.

deaf -refers to a person who

- 1) was born deaf, i.e. has never heard anything (congenitally deaf)
- 2) has lost hearing in early childhood before learning the spoken language of the environment (prelingually deaf)
- 3) has lost hearing at a later date (Moustgaard, 1994: 15)

The essence is the person's identification with the Deaf community as well as if the person is accepted as a member of the community (Preston, 1994). Preston notes the "dichotomization-there is a Deaf world and there is a Hearing World" (Preston, 1994: 17). Hearing abilities form a continuum, but the distinction between Deaf and hearing, at least for Deaf people, is mutually exclusive. "No one is ever both Deaf and hearing at the same time" (Padden and Humphries, 1988: 13). Hearing children of Deaf parents, who grow up as native signers, are Deaf in the cultural sense and they present a particular problem (Padden and Humphries, 1988; Lucas, 1989). They are culturally Deaf but not audiological or physically deaf.

In this discussion of identity, another reference to the terminology is needed. As seen in the World Federation of the Deaf and the National Association of the Deaf in USA, "the Deaf" or "the deaf" are preferred by people who are members of these organizations. This is in sharp contrast with "the disabled", which is considered dehumanizing and is resented by disabled people (Brisenden, 1986).

Sign language, the core of the Deaf community, is surrounded by many misconceptions. The most typical one is that sign language is universal. Sign language, just like spoken language, differs from country to country and from community to community. Many national and local dialects of sign languages exist. Also it is often considered that sign language is a signed form of spoken language. Sign language does not exist parallel to spoken language or sign language is not based on spoken language. It has its own grammar and syntax. For example, American Sign Language (ASL), which is spoken mainly in USA and Canada, is quite different from British Sign Language since ASL has been heavily influenced by French Sign Language (Padden and Humphries, 1988; Lane, 1992). In Australia, UK and USA, while all are English-speaking countries, their sign languages are different from each other (Preston, 1994: 250n). Japanese Sign Language has had influence on sign languages in Korea and Taiwan because of Japan's colonial rule in these countries.

Sign language in general has been viewed as an inferior means of communication, as a "monkey language" (Bergmann, 1994: 84) or "a kind of primitive prosthesis, a way around the communication impasse caused by deaf people's disability" (Lane, 1992: 184). Lane considers this as "audism", defined as "hearing way of dominating, restructuring, and exercising authority over the deaf community" (1992: 43) and compares the European colonization of Africa to the hearing colonization of the Deaf and views the current advocacy of the cultural and linguistic model of the Deaf as a de-colonization process.

Sign language has a history of oppression (Lane, 1992; Padden and Humphries, 1988). Deaf school children have been prohibited from signing in many schools for the deaf and have been forced to speak (Padden and Humphries, 1988). The International Congress of Educators of the Deaf at Milan in 1880 adopted the oral method as the teaching method of the deaf and banned the use of sign language as a means of instruction (Lane, 1984; Padden and Humphries, 1988; Shapiro, 1993). After this Congress, the use of sign language was suppressed. The rationale was that the use of sign language would hinder the acquisition of the spoken language. This was a typical demonstration of "audism".

Audism has various manifestations. An unidentified number of deaf people were killed in Japan at the time of the Great Tokyo Earthquake in 1923. Proper pronunciation of Japanese was used as test to find out if one is Korean or Chinese, who were rumoured to be poisoning the wells and raping women. More than 6000 Koreans and Chinese were massacred by panicked Japanese. For the protection of their deaf students, schools for the deaf in Tokyo had to produce deaf identity cards for their students (Nishigaki, 1995). Intolerance unable to accept difference caused this tragedy for linguistic groups.

This is in sharp contrast with the case of Martha's Vineyard Island, USA, where because of hereditary deafness there were many deaf people on the island. In "Everyone Here Spoke Sign Language" Groce (1985) describes how hearing people and deaf people were communicating in sign language from 18th century to the early 20th century. Groce argues that during that time, sign language was taken for granted. Though Crouch cautions about "glorification of the past" (1986), this shows the possibility of co-existence of hearing and Deaf/deaf people.

Against historic odds, the recognition of sign languages is growing. In 1981 Sweden officially recognized the Swedish Sign Language as a language of Deaf people in Sweden (Bergman and Wallin, 1990). The Constitution of Finland, in its amendment of 1 August 1995, recognized "the rights of people who use Sign Language" (Ojala, 1995). Uganda's new constitution, adopted and enacted on 22 September 1995, promotes sign language, as one of its cultural objectives. It should be noted this is not in the context of "Social and Economic Objectives", which includes "Recognition of the dignity of persons with disabilities" (Constitution of the Republic of Uganda, 1995).

Andersson, then President of the WFD, says that "I believe that deaf people in most countries will eventually regard themselves as a linguistic minority instead of a disability group, as they become aware of their own mental and physical capacities..." (1994: 10). Bienvenu, prominent Deaf activist in USA, says "[b]ut the meaning of Deaf is not 'cannot hear.' In fact, Deaf people are a distinct minority group with a separate language and culture that has been overlooked and/or oppressed by the hearing majority" (Bienvenu, 1989). A new group in Japan also voices a similar view (Kimura and Yonaiyama, 1995).

A watershed in the awareness among the Deaf community was the Gallaudet revolution in March 1988 (Lucas, 1989). Gallaudet University in USA, the only liberal arts college for the deaf in the world, was established in 1864, and attracts deaf students from all over the world. When the Board of Trustees elected a hearing person who was unable to sign as the new president, deaf students revolted against this decision and demanded a deaf president. After a week of protest, which was publicized nationally, the Board of Trustees elected King Jordan, who became deaf at the age of twenty-one, as the president (Ibid). With its alumni all over the world, this has led to the world-wide heightening of the sense of the deaf community.

Padden and Humphries, both Deaf, cite an example which illustrates the cultural trait of the Deaf (note that American Sign Language is transcribed in upper case) as follows;

...she had many traits of the recognizable characteristics of a person who could hear well, because she was VERY HARD-OF-HEARING. Our friend added that this woman regularly used the telephone to conduct business. (Padden and Humphries, 1988: 39)

Here the expression, HARD-OF-HEARING, in American Sign Language (ASL), means the opposite of the supposedly English counterpart, hard-of-hearing. In the world of ASL, a person who is VERY HARD-OF-HEARING can in fact hear well and is able to use a telephone for business. HARD-OF-HEARING means the deviance from the deaf. The most deviant from the deaf is hearing. Hearing is the "other" in this construction. Another illustration is given by the use of HEARING.

At a football game between two Deaf schools, he saw members of the home team refer to the opposing team HEARING. Even though the name of the opponents' school was prominently displayed on the score-board, the home team had strangely "forgotten" that the opponents were also Deaf. We exchanged laughs. But it occurred to us that this "error" brought out a key concept in defining HEARING: HEARING means the opposite of what we are. (Padden and Humphries, 1988, 41)

There is "different center" (Ibid) which stands in sharp contrast to the hearing center. Kimura has observed the same phenomenon in Japanese Sign Language and Japanese (Kimura, 1995). There is an element of paradigm shift as well as power-shift in this transition from the focus on hearing impairment to the cultural and linguistic aspect. So far, the profoundly deaf people have been viewed as a group very much deviant from the hearing norm. But with the "different center", the more Deaf you are, the more authentic you are. Under "audism", the closer you are to the hearing the better you are, just like in the white-dominated settings, the less black your skin is, the more civilized you are. But "the different center" of the Deaf, in a similar way as "Black is beautiful", turns the table.

The "different center" also represents the empowerment of the Deaf. Nederveen Pieterse (1992, 11) argues that empowerment "is politically neutral. It does not necessarily imply a critical consciousness. Empowerment may relate to emancipation as a necessary but not a sufficient condition: emancipation implies empowerment, but not every form of empowerment is emancipatory". The creation of a "different center" leads to the comparative weakening of the "audist establishment" (Lane, 1992) and to the formation of another power center. In other words, there will be a transition from the world with one center, dominated by the hearing, to the world with two centers, in which power is shared by both the hearing and the Deaf. The creation of an alternative center creates more room for negotiation. It should be remembered, however, that a center creates a periphery. Even with the different center, people who are hard-of-hearing will remain a marginalized group, in between the Deaf and the hearing (Okamoto, 1994). Harris (1995), noting the elitist tendency of Deaf movement in UK, also quotes a Deaf person, who lost hearing later in life, being increasingly marginalized in the British Deaf Association, which is advocating linguistic and cultural model of the Deaf;

You see people like me are becoming to be called 'Not the Real Deaf'.... Well, I spoke to a born deaf person, she said I was a fake - that feeling was not there ten or fifteen years ago. (Harris, 1995: 154-155)
The transition from the deaf organization to the Deaf organization seems to be taking place under the

leadership of those who are close to or even occupies the (different) center.

The alienation of some deaf people within the cultural Deaf construction runs parallel to the argument of Morris and French, discussed in chapter two, concerning impairment and disability within the framework of social theory of disability. With its exclusive focus on the social aspect, French argues, the social theory of disability in fact leaves many people with impairments out. This process of alienation that "a small elite are taking responsibility for the definition of Deafness as socio-political phenomena" (Ibid: 154) is surprisingly similar to what Morris and French describe as "estrangement and alienation" (French, 1993: 19) in their critique of the social theory of disability in chapter two. Both the Deaf argument as well as the social theory of disability have dangers of creation of new alienation. The separation of biological and physical on the one hand and social and cultural, as deaf and Deaf, and impairment, disability and handicap, is also seen in sex and gender; human and person (as discussed in chapter one); black and Black or African; and mixed blood and bi-cultural. At least in the case of deaf and impairment/disability, the transition to "social and cultural" has exclusive dimensions.

Conformity to the group norm and standard is an important qualification within the Deaf community. Padden and Humphries draws the following example;

A friend who uses the telephone "without" effort confided that in the presence of a new Deaf acquaintances she finds herself feigning difficulty on the telephone to avoid being categorized toward the hearing end of the HARD-OF-HEARING continuum. (Padden and Humphries, 1988: 50).

Harris also cites an instance in which a Deaf woman who is a good lip-reader refuses to lip-read and insists on sign language interpretation. Harris (1995: 151) analyses it as an expression of "political allegiance". Those without it may be ostracized, if not expelled from or marginalized within the Deaf community.

Padden says that Deaf "[c]ulture is the glue that binds us together" (1993: 6) and it binds people to "their past and future"(1993: 7). As a linguistic and cultural group, the Deaf community shares many characters, both desirable and undesirable, with other communities. Desirable ones include positive pride and sense of the community while undesirable ones could be ethnocentric attitudes, which has been reinforced in reaction to hearing domination and audism (Preston, 1994).

Unique Aspects of the Deaf Community

Deaf people experience no communication barrier among themselves. It is only when they encounter non-signers, they face communication barrier just as non-signers encounter a language barrier when they come across with Deaf people.

That is why Deaf people prefer to marry among themselves. Over 80 percent of Deaf people marry with Deaf people (Schein, 1989 in Lane, 1995; Aoki and Feldman, 1994). Some call a marriage between a Deaf person and a hearing person a kind of "international marriage" (Kimura and Ichida, 1995: 71). A number of Deaf people are eager to adopt deaf children. Now there is even a free international network of information on deaf adoptions (Susan Brown et al, 1995: 25).

Since approximately 90 percent of deaf children are born into hearing parents, the cultural transmission of sign language takes a unique form. Still, the vertical transmission from a parent to a child is a critical factor for the maintenance of a sign language (Aoki and Feldman, 1994).

Deaf children in hearing family too often have no exposure to Deaf people. They are excluded from family interaction (Harris, 1995). It is only when they go to a school for the deaf or Deaf clubs they encounter other Deaf people. In many schools, sign language is discouraged or oppressed since it is believed it hinders the linguistic development of the child. But children among themselves start to communicate through sign language. There are also some children whose parents are Deaf. This interaction helps deaf children learn sign language.

This is in sharp contrast with Deaf children of Deaf parents. They have a special place in the Deaf Community. They form the core of the Deaf community as native signers who carry on the language heritage to the future generations. Deaf family, in which everyone is Deaf, represents an ideal for the Deaf community.

As mentioned before, Deaf people have a strong sense of independent community. This led to the idea of independent political entity of Deaf people in USA and France (Lane, 1984). Deaf state or deaf township

were proposed. Just like other cultural and linguistic groups, Deaf people considered an independent nation and political self-determination.

As a linguistic group, Deaf people wish to maintain their own language. For this, many Deaf people are against integration and inclusion of their children. They believe schools for the deaf are essential for their children to grow up to be Deaf. That is why Deaf people support separate schools, in which deaf children learn both sign language and spoken language, which is called bilingual education. This is different from other disability groups, most of whom call for inclusion and integration.

The cultural/linguistic view has already been politically recognized, even though in a passing way. The Standard Rules, in its Rule 6 Education supports the principle of integration. But its subsection 9 specifically states that;

owing to the particular communication needs of deaf and deaf/blind persons, their education may be more suitably provided in schools for such persons or special classes and units in mainstream schools. At the initial stage in particular, special attention needs to be focused on culturally sensitive instruction which results in effective communication skills and maximum independence for people who are deaf or deaf/blind" (emphasis added).

This is a recognition of distinct character of Deaf people. This is the first time a UN instrument refers to the cultural aspect of Deaf people. The WFD took an active part in the whole process of the elaboration of the Standard Rules and its efforts are quite visible in the final document as seen here.

Focus on the cultural and linguistic aspect of Deaf people brings in a fresh perspective on a number of issues. Sign language interpretation is one of them. Sign language interpretation is vital. But for who? When a deaf person and a hearing person meet, communication can be difficult. But then is it the deaf person or the hearing person who requires sign language interpretation? The sensible answer is obviously "both of them". A sign language interpreter has been considered as a personal assistant for a deaf person, but in the cultural/linguistic construction, he or she works for both the hearing person and a Deaf person. A communication barrier exists equally for both. Bienvenu, thus points out the difference between sign language interpreters and personal assistants for disabled people by putting it as "[w]hen Gorbachev visited U.S., he used an interpreter to talk to the President," so "[w]as Gorbachev disabled?" (Dolnick, 1993).

This helps one to see the role of personal assistants of disabled people in the wider, social context. While they are called "personal", their roles are clearly social. If a person cannot function without personal assistants, then is it a personal problem or is it an issue which needs the action of a society? If the answer is the latter, "personal" assistants in fact connect disabled people with people and society. A sign language interpreter works for both the hearing person and a deaf person. A personal assistant, who follows the instruction of disabled people, is normally considered to be working for disabled people. But by doing that, they work for the society, which does not exclude disabled people but supports them.

Linguistic Human Rights

Deaf people demand the establishment of linguistic human rights for themselves. (Skutnabb-Kangas, 1994). Article 27 of International Covenant on Civil and Political Rights (1966; UN, 1966b) states that "In those States in which ethnic, religious or linguistic minorities exist, persons belonging to such minorities shall not be denied the right, in community with the other members of their group, to enjoy their own culture, to profess and practice their own religion, or to use their own language. Strengthening the above formulation, the Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities, adopted by the UN in December 1992, in its article 2.1 states that "Persons belonging to national or ethnic, religious and linguistic minorities (hereinafter referred to as persons belonging to minorities) have the right to enjoy their own culture, to profess and practice their own religion, and to use their own language, in private and in public, freely and without interference or any form of discrimination. Its Article 4.3 states "States should, where appropriate, take measures in the field of education, in order to encourage knowledge of the history, traditions, language and culture of the minorities existing within their territory.

Deaf people's alliance with other cultural and linguistic minority groups, such as Kurds in Turkey or Koreans in Japan, may not be easy. Andersson, the former President of WFD, mentions some concern expressed by some leaders about "minority" status in a multi-ethnic country (Andersson, 1994). In a number of countries with ethnic problems, cultural and linguistic presentation of Deaf people may have implications. Linguistic and cultural issues are mostly related to racial and ethnic issues. Also, other

linguistic and cultural groups, unable to grasp the commonality, may not welcome their alliance with Deaf people. As Skutnabb-Kangas (1994) points out, governments have not considered Deaf people as divisive as other ethno-linguistic groups. This brings me back to Uganda, a country full of ethnic tensions. It seems the constitutional amendment to include sign language was possible because of disability discourse. WFD reported that it had materialized as "a result of a systematic advocacy campaign waged by The Uganda National Association of the Deaf and its allies in the disability movement". (WFD, 1994a: 18).

The Deaf community itself seems undecided about its identity. For instance, there was an exchange of views in publications of the deaf in Japan about deafness and disability (Q, 1994: Yamashiro, 1994: Q, 1995). Andersson states that "the World Federation of the Deaf Bureau acknowledged the existence of such contradictory terms in several countries and agreed that the old term [handicap] should be tolerated as long as they meet the needs of deaf people" (Andersson, 1994: 10).

Liisa Kauppinen, the General Secretary of WFD recently is also quoted as saying that "In many countries organizations of Deaf people regard themselves as a linguistic and cultural minority. However, linguistic and cultural minority have neither a strong international network nor any umbrella organization. Taking an active part in disability movements is not inconsistent with being a linguistic and cultural minority" (WFD, 1994b).

According to this view, the lack of strong international network nor any umbrella organization for linguistic and cultural minority justifies the deaf community's participation in disability rights movement. If the deaf community is truly convinced that they do not belong to disability community, this strategy of political convenience may backfire.

Disabled or Not

Some Deaf people as well as some scholars, such as Lane (1992, 1995) claim that Deaf people are not disabled. This has met some critical responses (Ladd, 1990; Finkelstein, 1990; 1993; Nagase, 1995c). Let me now look into this aspect, which I believe shed light on the uniqueness of the Deaf community as well as implications for a social understanding of disability.

Bienvenu, a prominent Deaf leader, says "I cannot agree that Deaf people belong in the disabled group. To me, what lies behind this view is the assumption that there is a defect - a broken-ness" (Bienvenu, 1989: 1). There can be two interpretations of this. First, this view exclusively focuses on the cultural and linguistic aspect. What Bienvenu advocates is the complete separation of deaf, a physical condition, and Deaf, a cultural and linguistic condition. Then logically, all native signers, including hearing children of Deaf people, are Deaf. These people do not have an impairment. Then it is true not all Deaf people have an impairment.

Another interpretation, which is more relevant in the current discussion, is that deaf, not being able to hear, is not an impairment. The difference between deaf and hearing is just like right-handed or left-handed, for example. In other words, being deaf and not being able to hear is "normal". Obviously this line of argument is open to criticisms, most notably expressed by Finkelstein (1990, 1993) One of his article is entitled "'We' are not disabled, 'You' are", indicating this is the attitude of Deaf people (1990). If inability to hear is not an impairment, then similar inability such as an inability to see or to walk, among others, are not impairments. If the argument is to claim deaf is not an impairment, but other inability are impairments, this is a double standard. While demedicalizing hearing impairment, Deaf people medicalize others. Thus, Finkelstein has this to say;

When one group of people with a particular form of impairment (such as hearing impairment) see themselves as fitting into the normal range (for example their language is oppressed but they are not disabled) while at the same time they view people who have different impairments as disabled, they are attributing medical labels to others in exactly the same way that they reject such labels for themselves. (Finkelstein, 1993: 14)

Lane, strong critic of medicalization of deafness, is not immune to the medicalization of disability when he says;

"It is because of the disability construction that organizations for the Deaf are better funded by government than organizations of the Deaf" (1995). Disability rights movement has been trying to change exactly this kind of construction of disability. More correctly, it would have been "It is because of the medical construction of disability that..."

The cultural and linguistic uniqueness of Deaf people has not been fully recognized. That is why the issues

of Deaf people have been largely marginalized with the disability movement. DPI, a cross-disability organization, has had few Deaf/deaf world council members. The provision of sign language has not been sufficient and the communication within the disability movement has been problematic.

Deaf people, represented by WFD, have been part of the forces which have worked hard to shift the focus from physical limitations to the social and cultural barriers and exclusion. For example, WFD's participation in and contribution to the Standard Rules drafting process were excellent. That's why the Standard Rules in a number of ways succeeded in reflecting diversity of different kinds of impairments and disabilities. The new paradigm of disability has been created with the vital contribution from Deaf people. But in their effort to overcome medicalization of deafness, their reference to disability degenerates into the medical model of disability. This is deplorable, to say the least.

Most Deaf people indeed do not consider themselves as "disabled" (Padden and Humphries; 1988; Lane, 1995; Harris, 1995). It has to do with how Deaf people define "disabled". In ASL the sign corresponds to "disability" is "LIMP-BLIND-ETC", which is a typically medical model.

Many Deaf people seem to have a very negative view of disability (Harris, 1995). One Deaf person in UK is quoted as saying;

I don't know if there are positive things about being disabled, that's an interesting point because people have said we have got to have positive images of disabled people-what are they? I mean I'm not sure have they ever actually laid out, this is a positive thing about being disabled, I don't know..that's an awkward question I think. But deaf people do have positive things. We are able to go anywhere and somehow meet people whom we know... So there's number of areas where we can be seen to be positive...but what is positive about being disabled ? (original emphasis; Harris, 1995: 147-148)

Disability label has been so negative, Deaf people are not the only ones who wish to keep distance with it. One prominent blind leader in USA also refuses the inclusion of blind people into the disability category (Levy, 1988).

Though many Deaf people have psychological distance from "disability", most of them have not been hesitant to make use of the disability label when they accept concessions, even though they do so with a disclaimer. Padden and Humphries (1988) cite an example in which a Deaf person, who used a "handicapped" discount when riding a subway, had to defend himself. Harris (1995: 148-149) also describes similar instances. As Bowe (1992) points out, the claim Deaf people are not in the disability category have financial implications as well. If Deaf people truly believe that they are cultural and linguistic minority only and do not belong to disability groups, they may have to choose to discard disability services and funding. Otherwise, they are open to criticisms of hypocrisy. In this respect, when I learnt a leadership member of WFD had not renewed the application to the disability allowance, I saw an honest attempt. On the other hand, with their higher unemployment rate, I am aware that not many Deaf people can afford to do so, even if they honestly believe they don't belong to the disability category.

With the social understanding of disability, Deaf people clearly have disability. Deaf people, who have hearing impairment, experience social disadvantage, manifested in the form of language oppression. But it is not my intention to impose any single identity to Deaf people, who decide who they are.

One particularly unique aspect of Deaf people, rightly pointed out by Lane, is their desire to be and remain Deaf and deaf. On this point, Deaf people are different. Deaf people do "not want to be changed into hearing people" (Harris, 1995: 167). In an interview, when asked if he would take medicine that would restore his hearing, King Jordan, President of the Gallaudet University, answered that he would not take it and the question itself was an insult, suggesting that being deaf means being less than a full human being (Tanuma, 1992). Finkelstein's argument stating "very many disabled people would welcome physical interventions which guarantee elimination of an impairment" does not apply to, at least some of Deaf people.

In my view the core of the debate is an impairment and prevention and its implications for the Deaf community and the maintenance of sign language. Other groups generally do not hope to see more people with same conditions and impairments. People with spinal cord injuries, for instance, do not welcome a policy which leads to more spinal cord injuries. There are disabled people, particularly those with disabilities from the birth, who choose to have children with the knowledge that their children will have disabilities.

The Deaf community, on the other hand, welcome the birth of deaf children (Bienvenu, 1989; Dolnick, 1993; Lane, 1995). One Deaf joke, which is a reaction of newly married Deaf couple to a news of

"discovery of deaf genes" goes as follows;

Husband: Have you read this article?

Wife: Yes, it is ground-breaking.

Husband: Now, we can have babies without worrying.

Wife: That's right. With a little bit of more progress of science and technology, we can avoid having hearing babies.

(D-ko. 1991, 8, my translation)

Referring to Deaf children of Deaf parents, Padden and Humphries acknowledge the "Hearing Construction of Deafness" (Harris, 1995);

outside the group, the notion that parents knowingly gave birth to children when there was a good possibility that the children might be deaf is not an acceptable one. (1988, 48)

Do deaf people have a right to give birth to deaf children? This is a real issue. In some countries, marriages among the deaf are illegal, since there are more chances of deaf babies to be born (Joutsalainen, 1991). Deaf have been the target of eugenics. Now this is a clear violation of the Standard Rules No. 9 which prohibits discrimination regarding marriage, sexual relationships and parenthood.

Deaf people, in their wish to see their own cultural and linguistic community to continue and to see sign language prosper, "have to" deny deaf is an impairment. Otherwise, it is a target of prevention. Sign language as a minority language is "susceptible to extinction" (Aoki and Feldman, 1994: 101). The survival of the community and language in this hearing world is the core of the Deaf community's concern. This leads to another the issue of cochlear implantation among children.

Cochlear Implantation Controversy

There is a heated political debate over the new medical technology called "cochlear implantation", an operation which improves/restores, to a certain extent, hearing ability of a deaf person. Also called "bionic ear", this is an surgical procedure that inserts an device which "converts sound waves into electrical currents that are delivered to a wire implanted in the child's inner ear" (Lane, 1992, 3)

Some, such as hard-of-hearing people as well as deafened people who lost hearing after acquiring spoken language, welcome this as a medical miracle while most of Deaf people don't even consider CI for themselves and oppose CI for young children vehemently and take to the street demonstration (Lane, 1994). There are various aspects to this, including linguistic, educational, social, cultural and perhaps most serious one of all, ethical aspects.

For some Deaf people, CI is seen as the "final solution", threatening their existence as a community. That is why CI for young children has met strong resistance from them. If every new born deaf baby has CI, the Deaf community may disappear. Children, for any community, represent future.

And this invites ethical criticism against CI for young deaf children. Culturally Deaf people argue it is unethical to turn a minority into the majority by an operation. They argue hearing parents of deaf children should not let their children have CI. For them, CI is an operation that turns a black child into a white child. Such an argument goes to say that only with the consent of the child himself/herself, the operation can be done. This means that parents have to wait for a long time. This also shows the confidence of the Deaf community that once grown up being exposed to the Deaf community, say, at the school for the deaf, the child would not choose to have CI, since having CI often indicates unwillingness to be part of the Deaf community and too often it leads to losing Deaf friends (Bienvenu, 1994). Another Deaf argument is that children who have CI will grow up to regret it. One letter from a tenth grader in a U.S. high school testifies to this as follows;

I had a cochlear implant for five years. I stopped wearing the cochlear implant when I was a sophomore in High School. I felt that the cochlear implant was not really part of me. I didn't want to wear one any more. I wanted to be a deaf person, not a hearing person. (Kaftan, 1995, 3)

The issue of parental rights to have the cochlear implantation in their deaf children is debated. When one hearing parent said "... I have a right to want surgery for my child which will make him more like me, a hearing person", Gary Malkowski, then legislator in Ontario, Canada, replied "then presumably you have no objection to deaf parents requesting surgery to make their child deaf."(Lane, 1992: 234). This is the most extreme argument developed from the idea that deafness is not a hearing impairment.

Blume, a sociologist and a hearing father of two deaf children, argues a more realistic approach, partly from a parent's perspective. He proposes that the Deaf community provides hearing parents of deaf children with an alternative , which is to raise their deaf children to be Deaf rather than to try to make them hearing (1995a).

CI's long-term validity for prelingual children is yet to be founded (Lane, 1994). Therefore, the French National Commission on Bioethics, a governmental body in France, has recommended the sign language education to deaf children who are to have CI as well (Blume, 1995b). With the current uncertainty of the effectiveness of CI, this recommendation is based on the understanding that the "successful language acquisition must take place during a critical window of opportunity in childhood" (Pinker, 1994: 38).

Dual Membership Category

The emergence of the cultural and linguistic assertion of Deaf people has clearly shown a unique aspect of the Deaf community. It is a cultural and linguistic group which has a distinct language and culture, so far little known but increasingly conspicuous.

Disabled people are by no means homogeneous. Many disabled people do not have physical disability. Many disabled people do not have intellectual disability. Many disabled people do not have hearing disability. This has been a source of tensions, divisions and misunderstandings within disability movement. Matsukane, a writer with Cerebral Palsy, admits his own sense of prejudice against intellectual disability and points the finger at himself (Matsukane, 1994). On a similar note, Enns, former President of DPI, also cautions the tendency of oppressed people turning into oppressors themselves and appeals not to lose one's own humanity in the fight for liberation (Enns, 1993).

But what they commonly experience is the social disadvantage created by the society, which is designed only for people without disability. Being a linguistic and cultural group does not contradict that Deaf people have much in common with other disability groups in their encounter with and efforts to remove barriers created by the society. Based on the "dual membership category" (Ladd, 1988: 199) of both linguistic/cultural as well as disability group, Deaf people may choose to continue to be an important part of disability rights movement.

Conclusion

The cultural and linguistic identity of Deaf people should be clearly recognized by disability rights movement and the society in general. Everything begins from that point. Any group with this perspective cannot establish a working relationship with Deaf people. The main agenda of Deaf people includes the establishment of linguistic rights and maintenance of their community and its distinct language. Some Deaf people's claim of "we are not disabled", has wider implications. As one way to deal with "dilemma of difference", Minow proposes, is "to take seriously the perspective of those who have not been the norm in the past" (1990: 95) and this applies to the different center of Deaf people.

In the final chapter, I will discuss disability culture, which will be the basis for the establishment of disability rights.

Chapter Five: Disability Rights and Disability Culture

If I am what I am today, you know, deep inside, the way my mind works, it is because of disability. Disability has enriched my life.

-B. Venkatesh, India

[D]isabled people are forming distinct culture based on our own unique life experiences and history.

-Steven Brown, USA

[W]e want something more than integration into mainstream culture.

-Sian Vasey, UK

"Just don't make me walk.... I'll lose my job."

-Ed Roberts, USA

In this chapter, I will discuss disability culture as an emerging movement to "take pride in disability" (Brown, 1994: 10). A disability culture acknowledges life with a disability as a way of life, which means that the life of disabled people is not necessarily tragic or devalued. The creation of a disability culture is a basis for the establishment and implementation of disability rights as a requirement for equality as without creating or deepening "dilemma of difference". This is to say, the establishment of disability as a way of life ensures disability-conscious social organizations. Within this approach, Deaf people, with their distinct culture and language, could make a significant contribution. Disability culture is a creation of new values.

Disability Culture

A disability culture movement (Brown, 1994), which takes pride in disability is emerging. Brown, co-founder of Disability Culture Institute, explains that disability culture is "to exclaim pride in the condition of disability" (1994: 10). In the preceding chapter, a statement by a Deaf person asking "what is positive about being disabled?" (original emphasis, Harris, 1995: 148) was quoted. Indeed this is a soul-searching question. One way to show what disability culture is, is to answer to this question, which is undoubtedly shared by the wider society, which has viewed disability so negatively, as discussed in chapter one. There are a number of disabled people who do answer to this question.

The following is from Venkatesh, a blind director of an NGO in India;

Q: So does that mean that blindness is part of your identity which you feel quite happy with?

[Venkatesh :] If I am what I am today, you know, deep inside, the way my mind works, it is because of disability. Disability has enriched my life as a person.

Q: How has it enriched your life?

[V :] What gives worth to this life? It's not what you have or what you don't. It's the ability to enjoy what you have, no matter what.... Because being disabled is nothing wrong. (Coleridge, 1993: 14)

Brown, who has spoken on topics such as "Why I like my disability", also answers;

The notion of disability being affirming first came to my attention several years ago when a friend exclaimed that losing his leg was the best thing that had ever happened to him. He went on to explain that prior to his accident he was unfocused, joy-seeking person who gave little thought to what he would do with his life or how his actions might impact anyone other than himself. (Brown, 1994: 94)

If I were given the choice of a new life without a disability I would not take it. My disabling condition is one of the many characteristics which has contributed to the person I have become. Without a disability I would be different. And I have no desire to be someone else. I am happy with myself. (Brown, 1994: 96)

Asaka, a disabled activist in Japan, who had been exposed to Aoi Shiba, responds; "My disability is my identity" (Asaka, 1993: 80, my translation) and " I, not only myself I think, don't really care whether I have a disability or not, in my next life, if there is no social disadvantage and if there is no discrimination" (1990: 94, my translation.)

These views might be considered as "compensation", just like a sign language is considered as an inadequate compensation for the hearing loss. A woman with a disability counters this as follows;

Not all of us view our disability as the unmitigated disaster and diminishment that seems expected of us. We know that what hurt, anger and distress we have felt was not generated by the condition itself but by the obstacles and offensive assumptions that society heaps upon it. If we dare express the view that it has brought spiritual, philosophical and psychological benefits, it is suggested that we are making a virtue of necessity, repressing our pain, or glorifying suffering. Such certitudes generally issue from those whose experiences of necessity, pain or suffering is considerably less than our own and who, above all, have no personal experience of our condition. (Morris, 1991: 187)

Morris says;

[T]he emergence of a disability culture is difficult but tremendously liberating. Such a culture enables us to recognize the pressure to pretend to be normal for the oppressive and impossible-to-achieve hurdle which it is. Most importantly, this culture challenges our own prejudices about ourselves, as well as those of the non-disabled culture. (Ibid: 37)

Morris adds "A number of the women I interviewed for this book [Pride against Prejudice] see disability as a positive thing to have happened to them" (Morris, 1991: 187).

For the development of disability culture, history of disabled people has an important role to play. History occupies a significant place in the formation of group identity. However, until recently, history of disabled people has been ignored (Driedger, 1989; Oliver, 1990) or only the medical aspect of disability has received attention. It is, therefore, encouraging to note the growing interest in history of disabled people. For instance, a prominent Japanese author, Hanada, has produced an extensive writings on the history of disabled people in Japan, with particular emphasis on artists with disabilities (1975, 1978, 1980, 1985, 1990). Growing list of literature deals with , among others, independent living movement in USA (Levy, 1988; Treanor, 1993), history of DPI (Driedger, 1989), "medical solutions" to disabled people (Gallagher, 1995). History of deaf people, obviously for their cultural and linguistic aspects, is receiving a particular attention, resulting in the establishment of societies on the history of the deaf in some countries and an international society on deaf history, Deaf History International was founded in 1991.

Heroes, defined as "people who do something out of ordinary" (Brown, 1992: 227) and mythology are essential concepts for all cultures, including disability culture. Brown contends that "almost all people with disabilities have performed heroic activities because of the pervasive discrimination encountered by each individual with a society" (1992: 227). Carrying the argument further, Brown promotes mythology, which is "universal language" and is " a set of symbols placed in a context which anyone can understand" (1992: 232), demonstrated by heroes with disabilities. In fiction, Horwood, a writer and a father of a disabled child, successfully created a legend of a hero with cerebral palsy, who was forced to live in an oppressive institution for decades but never gave up hope (Horwood, 1987).

Artistic activity is also an essential area for the development of disability culture. The cultural representation of disabled people through literature, poetry, music, TV, plays, cinema (Norden, 1994) in the past has been instrumental in creating a powerfully negative imagery of disability and of people with disabilities. Not only metaphor of illness (Sontag, 1977) but metaphor of disability has been powerful and infinitely negative. Disabled people themselves have an essential role to play to change the cultural representation of disability. Morris states that "

we need to explore our own identity as disabled people. We need to explore what physical and intellectual limitations mean to us, what illness and death mean to us. And we need to explore the experience of oppression common to people with all sorts of different physical and intellectual disabilities. (Morris, 1990: 113)

Another woman with disability says;

through the arts we can make discoveries about what we have in common and place the emphasis on those things rather than on our differences, thus countering the traditional charitable model of disability that has historically kept us separate from each other (Vasey, 1989 quoted in Morris, 1991)

Summarizing his own argument as well as developing preceding paradigms, including that of DeJong (1979), Brown has established a disability rights/culture/pride paradigm as follows;

DISABILITY RIGHTS/CULTURE/PRIDE PARADIGM

COMMUNITY ASSISTANCE/MEDICAL/CHARITY PARADIGMS DISABILITY RIGHTS CULTURE/ PRIDE PARADIGM

DEFINITION OF PROBLEMS Physical or mental impairments; lack of socio-economic, political, educational, and cultural skills Dependence on professionals, family members, and others; hostile attitudes and environments; lack of legal protections or recognition of inherent worth of disabled people

LOCUS OF PROBLEMS In individual (who is broken or sick needs fixing and curing) In socio-economic, political, educational environments and perceptions

SOCIAL ROLES Patients, clients, charity recipients, non-existent Family and community members, customers, coworkers, advocates, same as anyone else

SOLUTIONS TO PROBLEMS Professional and volunteer interventions and treatments Equitable socio-economic, political, educational, and cultural options

WHO CONTROLS Professional and/or volunteer Individual or group of individual's choice

DESIRED OUTCOMES Maximum self-care; No social misfits Pride in unique talents and attributes of each individual and positive disability identity

(Brown, 1995b)

Disability Culture and Deaf People

From disability culture perspective, the achievement of Deaf people, including the creation and development of a distinct language and culture, is a blessing and exemplary. While Bienvenu asks "[h]ow can we fight for official recognition of ASL and allow ourselves to be labeled "communication disordered" at the same time?" (Bienvenu, 1989: 13), there is no denying that sign language was born because of deaf people's disability. But that does not mean sign language is "primitive" or it has not developed into a full-fledged language. Disability can be a beginning. It is true, society views impairment and disability very negatively. But that does not mean whatever produced or developed from disability is negative. None other than Deaf people have proved this by their language and culture. And Deaf people are not alone. After all, impairment and disability are natural part of life.

I personally would like to invite Deaf people to be at the forefront of disability culture movement. Deaf people are perhaps most qualified to be the vanguard of this. Within the disability culture framework, Deaf people will have a special place. Deaf people, if they wish and choose to do so, can be leaders in this blossoming new movement. From being deaf and Deaf, they have produced sign language, which is a rich cultural contribution not only to the disability culture but to the overall culture of humans. In this framework, the maintenance of a sign language can be supported by other disability groups. The enhancement and expansion of "normal" will be shared by all, hearing or deaf, disabled or non-disabled.

Deaf people may miss this precious opportunity if they insist they don't belong to disability culture. The selective denial of particular impairment will not lead to a society created for all. The Deaf community can choose to pursue its own path, disclaiming disability, which runs the risk of "collaborat[ing] with non-disabled people in oppressing those with disabilities" (Ladd, 1990: 4). On the other hand, Deaf people may become an integral part of the disability culture movement, which presents a precious opportunity to open up a wholly new path of liberation, in solidarity with other disability groups. It is up to the Deaf community.

Difference, Equality and Disabled People

Our younger daughter, who is two years old, has strabismus (crossed eyes). My wife and I do not want her impairment to develop into eye coordination problem, a disability. We want her to use both eyes properly. She already had one surgery. It seems that she needs to have another one.

Difference, in this instance, disability, is often not desirable from the perspective of the individual concerned as well as their guardians as in the case of children. Historically various social forces have viewed them very negatively with serious consequences for disabled people. Because of particular difference, namely disability, their total existence, even their life was denied.

But we have to be careful and avoid over-generalization. A number of disabled people, including Deaf people, are proving that disability is not necessarily unwelcome. On the other hand, it can be a blessing.

Prevention will never be able to eradicate all impairments and it should not. While there are preventable impairments caused by social, economic and political reasons, many are part of natural human conditions, such as aging. Also, some disabled people, notably Deaf people, decide have children with the knowledge

that their children will have an impairment, as discussed in chapter four. Rehabilitation cannot restore all functions. In consideration of one's overall life, some people choose not to restore certain physical functions. After all, it is up to each individual to decide if it is worthwhile to have rehabilitation (Tsuchiya, 1994).

Asaka (1993) and Brown (1992, 1994, 1995a), among others, say that disability is positive and affirming. At times, it can be true and it is true. But is it necessary to make a value judgement? As Tateiwa (1992b, 1990) argues, disabled people should not be forced to make a judgment if their disability is positive or negative. Disability has been identified as the negative difference by society and by non-disabled people. At times this was also internalized by disabled people themselves. As a reflex, disabled people may be tempted to claim that disability in general is affirming (Tateiwa, 1990). Disability can be affirming and it is at times but not in general. As mentioned earlier, many impairments are caused by political, social and economic reasons (Abberley, 1987; Helander, 1992; UNDP, 1993). Just to think of 150,000 men and women, adults and children, who have survived but have been disabled from mines in Cambodia (UNDP, 1993) suffices.

What is affirming, though not without difficulties, is life with a disability. To live with a disability is not less valuable than to live without it. To live with a disability, can be life-affirming. Many disabled people, including Asaka (1993), Brown (1995, 1994), and Venkatesh (Coleridge, 1993) say it is and there is no reason not to believe them. A number of Deaf people, though differently, testify to this. Their life is NOT life worth not living. But again, disability itself, does not necessarily have to be affirming. In this respect, I find Morris convincing, when she states;

I would still rather walk than not be able to walk. However non-discriminatory the society in which I lived, to be able to walk give more choices and experiences than not being able to walk. This is, however, quite definitely, not to say that my life is not worth living, nor is it to deny that very positive things have happened in my life because I became disabled. I can therefore value my disability, while not denying the difficulties associated with it. (Morris, 1991, 71).

Abberley expresses a similar view;

Impairment must be identified as a bad thing, insofar as it is an undesirable consequences of a distorted social development, at the same time it is held to be a positive attribute of the individual who is impaired. (Abberley, 1987: 9)

There are others such as Hahn (1988), Brown (1992, 1994, 1995) Asaka (1993) and Matsukane (1994), who emphasize enabling aspect of disability. Their overall contribution is a new cultural meaning of disability, which has been fixed as the representation of "the other" and a devalued status.

Though life with a disability is valuable, what makes is difficult is handicap. The priority, therefore, should be on the removal of attitudinal, social, economic, educational, linguistic and cultural barriers and disadvantages our societies have created against disabled people. For too long, these oppressive aspects have not been taken seriously, if not completely ignored. As discussed in earlier chapters, disabled people themselves as agents have taken the bold and historic initiative of changing the paradigm of disability from "the medical", charity and tragedy to rights, culture and pride.

At the international level, the adoption of the Standard Rules is just one small but significant step towards recognitions of these social barriers which prevent disabled people from full participation and equality. Our society has been excluding certain people, including people with disabilities, when we plan and organize our society. The starting point should be the clear recognition that our society has discrimination against disabled people.

The implementation of the Standard Rules at the local, national and international level is an essential factor for the realization of rights of disabled people and the creation of equal society. If their implementation is not satisfactory, disability rights movement may choose to propose an adoption of a more powerful instrument, a convention. If that necessity arises, the disability rights movement should be well prepared, learning from the discussions of the UN General Assembly particularly in 1987. There are a lot of lessons to learn from them. The homework includes the governmental recognition of disability rights, reasonable accommodation, and equality concept for disabled people. Most national governments need to be made aware that social planning and organization which exclude disabled people or which does not provide reasonable accommodation is discriminatory.

Disability presents one of the most fundamental "difference". In other words, successful creation of equality

for disabled people is likely to benefit other socially disadvantaged groups. One of such an attempt is "a society for all" concept, which originates from disabled people's movement (Lindqvist, 1992; Wiman, 1994). The Social Summit in Copenhagen in March 1995 adopted "a society for all" as an umbrella concept for social integration in its final document (UN, 1995b, para. 66), which states that "[t]he aim of social integration is to create "a society for all", in which every individual, each with rights and responsibilities, has an active role to play. Such an inclusive society..." In this paragraph, there is no reference to disability or disabled people.

Difference as Celebration: Disability Culture

Now a mental exercise. It is 2XXX and all the countries in the world have achieved the implementation of the Standard Rules.

Imagine a society without handicap, without social constraints, without prejudice against disabled people. Jobs, schools, support services such as personal assistance, access to information and communication, access to the physical information, opportunities for marriage and the rest are all in place. In that kind of environment, disability and its implications will be quite different from how they are today.

As some argue, it may be true that disability will no longer matter (Shapiro, 1993) in that environment. On the other hand, this kind of "integrationist dream" (Ibid: 103), in which disability does not matter, may never realize and in fact may not be welcome.

Difference is celebration. The purpose of the above exercise is to visualize what we are trying to achieve and where we are going. It is not enough, even though essential, to remove socially-created barriers. A creation of new value is vital. Through the establishment of disability culture, which is a creation of new value, difference emerges as celebration. Without this development, most likely the establishment of disability rights will end up creating or deepening the dilemma of difference.

Also the implementation of disability rights "only" leads to equality, either formal equality or material equality, and not further. As French (1993) and Morris (1991, 1993) argue, middle ground certainly remains.

In this respect, "disabled people are experts on disability" as advocated by disability rights movement, including independent living movement, is an expression of disability culture. The uniqueness of disabled people is their personal experiences of disability. These personal experiences are assets of disabled people. To apply these so far less utilized experiences to disability issues is a creation of a new value.

The precarious situation of human rights of disabled people (Despouy, 1993) presents disabled people paradoxically an opportunity to be socially and politically active. Hahn sees "a unique chance to become involved in a historic struggle to extend and expand the definition of human rights" as well as "greater meaning and purpose in life" (Hahn, 1988: 31). For Hahn, therefore, disability "can also become an important source of empowerment and a major potential for promoting the increased acceptance of human differences" (Ibid). Brown also acknowledges that "my disability have enabled me to play a significant role in one of the greatest human rights movements of my time" (Brown, 1994: 95).

Disability begins as difference, as defined by others (non-disabled people); then goes through equality, with disability rights and reasonable accommodation; and ends as "difference as celebration", this time seen from those with disabilities. In this process, the focus on disability as difference runs the risk of stigmatization. To avoid stigma and to go beyond equality towards emancipation, which is "primarily about social creativity, introducing new values and aims, new forms of cooperation and action" (Nederveen Pieterse, 1992: 13), disability culture is essential. The establishment of disability rights and the parallel development of disability culture are two wheels.

Many voices of disabled people have been quoted in this paper. The following is the final one.

We need courage to say that there are awful things about being disabled, as well as the positive things in which we take pride. If we feel strong enough to do this, we can truly challenge the way non-disabled people make judgements about our lives because in so doing we will take charge of the way in which disability is defined and perceived. (Morris, 1991: 71)

We can celebrate, and take pride in our physical and intellectual differences, asserting the value of our lives. And while confronting the very real difficulties that physical and intellectual differences involve, we can fight against discrimination and insist that the needs created by those differences are met in a way which enhances

the quality, and our control, of our lives. (Ibid, 189)

Disabled people are increasingly more confident and proud of themselves through the development of disability culture. Disabled people are not victims. Disabled people have chosen to be agents of change. The establishment of life with disabilities as a distinct and valuable way of life also provides non-disabled people an alternative vision of life and society in the sense that they do not necessarily take their way of life as given.

This is a truly exciting time to witness this revolutionary change and, if one wishes, to be an active part of it.

Appendix One: Terminology

Terminology in disability field is full of mines. Every now and then, the discussion on the terminology comes up. Same words means different things according to authors and theories. This makes the communication very difficult (Sato, 1992).

In this paper, my terminology is based on the World Programme of Action concerning Disabled Persons and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules). Organizations of disabled people, including DPI, WBU and WFD, were well-represented in the elaboration process of the Standard Rules. Those definitions are basically adopted by DPI as well. I use "disabled people" and "people with disabilities" interchangeably.

The Standard Rules state that;

The term "disability" summarizes a great number of different functional limitations occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature (para. 17).

The term "handicap" means the loss or limitation of opportunities to take part in the life of the community on an equal level with others. It describes the encounter between the person with a disability and the environment. The purpose of the this term is to emphasize the focus on the shortcomings in the environment and in many organized activities in society... (para. 18)

The most major difference in terminology in English is found between UK and others, including DPI and UN. This makes it more difficult since a social theory of disability was created in UK and follows this UK usage. If simplify the difference looks as follows;

UK UN, DPI and others
(social theory of disability)

defective impairment
impairment disability
disability handicap

In UK usage, which is unique, the social aspect is described by "disability" while "handicap" is used elsewhere. In this paper, in order to avoid the confusion, whenever "disability" is used to described social disadvantages and constraints, as defined by the social theory of disability, it is italicized. It should be noted, this is not the most precise way. After all, each author may have different definitions. This is also made more difficult since "disability" is a term which is used to described the overall framework of impairment, disability and handicap. Some use "disablement" for that purpose but it has not received a wide support. (Confusion in other languages than English is also a major issue, but it is not considered here).

Finkelstein, former world council member of DPI and the first chair of British Council of Organization of Disabled People (DPI UK), who was involved with the drafting of DPI definition, providing background, recalls how this situation has arisen;

IMPAIRMENT: is defined as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body.

DISABILITY: is the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

These definitions (which were based upon, but radically altered, definitions proposed by a social scientists in the UK) were adopted by the British Council of Organizations of Disabled People (BCODP) when it was formed in 1981 with myself as Chair. The BCODP sent three delegates to the DPI Congress in 1981 and amongst other things we were mandated to challenge DPI's proposed adoption of the WHO definitions....When the British delegation put forward its definitions, as above, there were serious objections from Scandinavian countries. In the discussions that followed it became clear that the words 'impairment' and 'disability' meant different things to people from different countries. It was agreed that Bengt Lindqvist, from Sweden, Ann Marit Saebonnes from Norway and myself would redraft the DPI definitions...In the end [in Sweden at the third world council of DPI in 1983] we agreed the following[;]

DISABILITY: is the functional limitation within the individual caused by physical, mental or sensory impairment.

HANDICAP: is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.

In our report back to our British members we noted the new DPI definitions and added that in the UK the terms 'impairment' and 'disability' could replace the terms 'disability' and 'handicap' respectively in the DPI definitions. (emphasis added, Finkelstein, 1995)

This, at least partly, has led to the absence of common language and has created a real confusion. For instance, Mittler, former president of Inclusion International from UK, writing for UN in "Families and Disability", states;

Disabled Peoples' International (DPI), a world federation of organizations of disabled persons, have proposed the alterative definitions;

* Impairment is the functional limitation within the individual caused by physical, mental or sensory impairment

* Disability is the loss of limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers

The DPI definition therefore dispenses with the concept of handicap altogether, regarding it as misleading and discriminatory. (Mittler, 1994: 5)

This makes sense in the British context but not in others. The official DPI definition, the original and the revised one, does refer to disability and handicap. It seems the problem is the word, "handicap" and its bad discriminatory connotations, which are not immediately clear to non-UK English speakers.

The editors of "Disability & Society", which was formerly "Disability, Handicap & Society" and a powerful British-based forum promoting a social theory of disability, explains the intent of the change as;

'Disability', therefore, is taken to refer to the complex system of economic and social constraints imposed on people with impairments by the organization of society. And in this view of the overtly negative and oppressive implications of the term 'handicap' when used in relation to disabled people, the Editorial Board have unanimously agreed to omit it from the Journal's title. (Executive Editors, 1993, 110).

Again, this seems to make sense in the British context. But there seems to be little evidence to support the editors' justification of this by stating that this is an "endeavour to reflect the growing international consensus regarding terminology among organizations controlled and run by disabled people" (emphasis added, Executive Editors, 1993, 110). As Barnes (1995) notes the terminology promoted by the social theory has not been adopted widely, and is still far from gaining consensus. After all, DPI, the most major international organization of disabled people, when it revised its Constitution recently in 1992, did not touch its definition of disability and handicap. It was not raised during the Standard Rules process either. This is not to say that the focus has not shifted to the social aspect. Indeed it has, but with different terminology at the international level, at least. The abolition of the term "handicap" may happen in the future. But it seems at least for now

the international consensus, witnessed within organizations of disabled people such as DPI as well as international forums including UN, is to use handicap to represent social disadvantage and constraints, which has not been receiving due attention.

Perhaps the result of the on-going revision of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) of WHO, which is due in 1999, may have some influence on this (Sato, 1995; Keer and Placek, 1995). ICIDH definitions, which have been criticized as "medical model", have had international influence on the terminology. In the 1994 revision meeting, redefinition of "handicap" was proposed as "the result of an interaction between an individual with an impairment or disability and the social, cultural, or physical environment" (Keer and Placek, 1995, 17). With the strong resistance to "handicap" from the school of social theory in UK, it is unlikely that an international consensus on the terminology will be reached in the near future.

Appendix Two: Biological/Physical and Social/Cultural

(biological and physical) (social and cultural)

impairment/disability handicap (UN, DPI)

impairment disability (social theory of disability)

(ex)people with impairments

who don't experience social constraints

deaf Deaf (cultural deafness)

(in)hearing children of Deaf parents

(ex) deafened people and hard-of-hearing people

human person (bioethics, animal rights)

(in)animals (cf. chimpanzees)

(ex)severely disabled persons

sex gender (feminism)

black Black, African

mixed-blood child bi-cultural/bi-lingual child

The above is a preliminary attempt to collect the pair of the biological/physical and the social/cultural. Impairment and disability, deaf/Deaf, and human and person, were discussed in the main text. Please note (ex) stands for exclusion and (in) stands for (inclusion) as seen in the transition from the biological/physical to the social/cultural.

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(Minow, 1990: 22)

(Minow, 1990: 22-23)

(Minow, 1990: 20)

See Appendix 1: Terminology.

See Coleridge (1993) for the examination of "social and political aspects of disability in developing countries" (4).

(Tateiwa, 1990a: 179; Okamura, 1988, 204; my translation)

(Singer, 1979: 97)

Morris, disabled feminist, has discussed feminism and disability in depth. See Morris (1991, 1993).

Lane (1992) applied "bio-power" for the discussion of deaf people.

In this sense, Aoi Shiba is later joined by Deaf culture advocacy, discussed in chapter three and disability culture, discussed in the final chapter. Tateiwa (1990a) analyzes the disability movement in Japan, represented by Aoi Shiba, in the context of modernity, which is oppressive of individual differences, and points out that the experiences of the movement in Japan in some instances have had to go further than their counterparts in the West.

"Disability" in italics indicates it refers to social disadvantages and constraints, as used in the social theory of disability. For more detail, See Appendix one.

(Finkelstein, 1980, 1-2)

(French, 1993: 19)

Ed Roberts, who served as the Director of California's Department of Rehabilitation and a founder of the World Institute on Disability, was also a founding members of DPI (Roberts and Donald, 1982; Driedger, 1989). He visited Japan a couple of times and was a source of inspiration to people with and without disabilities in Japan as well (Yuki, 1995). It was my privilege to meet him during the second Japan-USA Conference of Persons with Disabilities in 1987. He left us on 14 March 1995 (Shapiro, 1995).

(UN, 1987a: 4)

(Lindqvist, 1995: 4)

See Appendix one for the "different" DPI definitions in UK.

I had the privilege to attend this meeting on behalf of the Japan Council on Disability (JD), a non-governmental umbrella organization of and for disabled people in Japan.

(Kauppinen, 1993a: 3)

(Bienvenu, 1989: 1)

(Ladd, 1990: 4)

Bienvenu (1991) has criticized the term "deafness" arguing that just like there is no "Blackness" or "Womanness" it does not make sense. This is based on the view that Deaf people are similar to an ethnic group (Dolnick, 1993)

Parpart (1993) adopted the concept of the 'other' in her analysis of Third World peoples, particularly women, in the context of women and development.

See Appendix two for a table of biological/physical and social/cultural.

The comparison of Deaf culture and women's culture, advocated by cultural feminists, is an interesting area to explore. The disability culture, discussed in the next chapter, might also be considered in this context. For the overview of cultural feminism and second-wave feminism, See Evans (1995).

(Coleridge, 1993: 14)

(Brown, 1995a: 106)

(Vasey, S. in Morris, 1991)

(Shapiro, 1995: 7)

For the role of mythology among Deaf/deaf people, see Harris (1995: 156-157).

Acknowledgement is made to feminist discussions on equality and difference, particular Scott (1988) and Meyers (1994), though they are not referred to in the text.