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The Deafblind and Disability Studies

Satoshi FUKUSHIMA
Research Center for Advanced Science and Technology
The University of Tokyo

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The deafblind and disability studies

Satoshi Fukushima

The issues that disability studies should take up can be described in two categories: contributing to disabled persons and contributing to many kinds of discrimination issues that exist for all people, whether they are disabled or not. There have been two typical strategies in each category. The first is the 'culture theory strategy,' the second, the 'ability theory strategy.' As neither of them is sufficient on its own, I here introduce a third new strategy, the 'ability (difference) culture theory strategy,' which is an approach based on creative communication. Disability studies is a scholarly discipline that aims to have us, whether we be disabled or not, illuminate the world with a new light of recognition.

1. Charles Dickens and the deafblind

Thank you for giving me the opportunity to address you today at this esteemed place. My name is Fukushima Satoshi and I have come from Japan. I was born in 1962. I lost my sight at the age of nine and my hearing at the age of 18 and am a totally deafblind person.

Today I am going to speak on the theme of the deafblind and disability studies and I will first explain something about the deafblind.

Generally the term 'deafblind person' refers to a person with some impairment of both sight and hearing. Although the figure may vary with the country or period, generally speaking, there is approximately one deafblind person in a population of from several to ten thousand people.

It is said that many of the deafblind have become so in midlife and that many of the deafblind are elderly that relatively few are totally deafblind like me, and that most people have sight and hearing to some extent. But for convenience sake, the trend internationally is to group all people who have a combination of sight and hearing impairment, including those with slight or moderate impairment, in the deafblind category. Here, to keep things simple, I will be speaking with the totally deafblind in mind.

Deafblindness is the state of not being able to see and at the same time not being able to hear. This condition leaves the person with the sense, subjectively, of being almost entirely cut off from the outside world. I often use television as an example to explain this, and I will briefly touch on that here.

If you think of 'blindness' in terms of the act that we call 'watching television', and then if you consider what it would be like to watch (or rather, listen to) television with the picture turned off, depending only on the sound, you would get some idea of the sensation that a blind person has. Next, then, comes the situation of deafness. It is just the opposite. In other words, the television speaker is turned off and the person is only seeing the picture. What then would be the situation in the case of deafblindness? In that case both the picture and the sound would be turned off. It would be the same as not

having the TV turned on in the first place. I am using television, a common fixture in our lives, to show what sensation a deafblind person has toward the outside world, but to what extent this has enabled you to understand through actually feeling as the deafblind person does is another question.

Yet, more than 160 years ago the great English writer, Charles Dickens, met a young deafblind girl, was moved by her, and observed the essence of the situation in which she was placed.

Dickens visited Boston in the United States in 1842 and there met a totally deafblind girl, Laura Bridgman, at the Perkins School for the Blind.

He wrote these impressions from that encounter in *American Notes*:

There she was, before me; built up, as it were, in a marble cell, impervious to any ray of light, or particle of sound; with her poor white hand peeping through a chink in the wall, beckoning to some good man for help, that an Immortal soul might be awakened.

Charles Dickens, *American Notes* (New York, 1868), p. 36

I find Dickens' expression, particularly his description of Laura being shut up 'in a marble cell', startling. For in this he has exposed the essence of the condition in which a deafblind person is placed. In essence it is a situation of cognitive asymmetry in which the deafblind person is unable to grasp the presence of the outside world or of the people around her or him, even though the people around can grasp the presence of the deafblind person. The keen imaginative power of the great English writer had in later years a profound effect on education and welfare for the deafblind.

Incidentally, the most well-known deafblind person in the world is probably Helen Keller of the United States. Helen's likewise famous teacher, Anne Sullivan, visited Helen's house and began to teach her in 1887. But the dawn of the history of education of young deafblind children actually goes back half a century from the case of Helen Keller.

One of the earliest and perhaps the first persons in the world to prove the possibility of education of deafblind children was an American, Samuel Howe. In 1837 he succeeded in giving basic language education to a deafblind girl who was seven years old at the time. That was the very Laura whom Dickens met. As a matter of fact, Anne Sullivan had spent time with Laura, who by that time was nearing the end of her life, and that experience was the basis for her being sent to the Keller family as full-time tutor for Helen. In fact, Helen's mother had read Dickens' *American Notes*, and happening to find in it a description of a training session with Laura at Perkins School for the Blind, asked the institution to send a tutor for Helen.

You know what a great contribution Helen Keller made to the twentieth century and to the advancement of social work and welfare for disabled people. Helen even visited Japan no fewer than three times. Recalling how Dickens' encounter with Laura 167 years ago lead, through Helen Keller's mother, to Sullivan coming in contact with Helen, which in turn brought about Helen's development and the worldwide work that she went on to achieve, I cannot but sense the mysterious links that people and history weave.

2. Difficulties the deafblind experience

There are three areas of difficulties brought about by the disability referred to as 'deafblindness': communication, orientation and mobility and obtaining information. Of these, it is, in my opinion, difficulties related to communication that cause the most serious damage to the deafblind.

Twenty-eight years ago I went rather abruptly from a situation of blindness into a situation of total deafblindness. And it was communication that was the hardest for me at that time.

In other words, the hardest thing for me when I became a deafblind person was the great difficulty I had in communicating with other people. I experienced a spiritual isolation as if I had been thrown into a vacuum in outer space. Not being able to see beautiful sights or the stars at night was not really what I missed.

And not being able to play the music that I liked was not the real cause of my loneliness. The essence of the agony that I experienced was an isolation of the spirit that was like the freezing of the core of my heart, cutting me off from relationships of communication with other people.

Later my mother created the original YUBITENJI (meaning 'Finger Braille' in Japanese) method of communication, and I gradually resumed communication with other people and gained the strength to live. But I think that the experience of once having had communication cut off that I had when I first became deafblind had a very big impact on me.

For it gave me the realization that even if one can't see or hear, one can live if one can communicate with others, and at the same time I began to think that if, on the other hand, one cannot communicate well with others even though one is able to see and hear, it is very difficult to live.

3. What I have come to think from having this disability

When I was born I could see and I could hear. Later, at the age of nine, I lost my sight; and at the age of eighteen I lost my hearing and became totally deafblind. I would like to talk about what I have come to feel and think in the course of having these disabilities.

When I lost my sight at nine years of age, I transferred from a regular school to a school for the blind. Yes, I wanted to stay at my old school, and I was sad that I couldn't play with my friends in the neighborhood any more. But losing my sight and transferring to a school for the blind were not in themselves so much of a shock and were not all that hard. This was probably because life at the school for the blind was more fun than that at the regular school I went to before losing my sight, where, because of the eye disease I already had, I had to be absent a lot and thus could not make really close friends.

Becoming a blind child meant many limitations and inconveniences, but the joy of going to school every day and feeling free and happy more than made up for those things. At the school for the blind I made a few, really good friends and got involved in music and sports.

But from about the time I was in junior high school I started thinking seriously about my 'disability'. Once I confronted a totally blind teacher of mine whom I was close to with this problem, and he said to me, 'Satoshi, what do you think is the meaning of being blind?' What he said made me realize something. Of course being

blind means the physical inability to see. But what, in fact, does being blind actually mean? After that I always had this heavy question within me.

When, early in 1981 I lost my hearing at the age of eighteen and became totally deafblind, this question arose again: What does it mean that 'I can't see, and I also can't hear'? I am not talking, of course, about medical definitions or legal standards. Nor am I looking for a list of concrete experiences that one is deprived of by not being able to see and hear.

What I was asking myself and seeking answers about had to do with the existential meaning of the disability experience. That is, in my case, what did it mean for my life that I had become a deafblind person? Again and again I repeatedly asked myself and questioned my fate: 'What is disability?' 'Why did I become a deafblind person?' 'Does this anguish of the soul that comes from having the bottom fall out of this body of mine have any meaning for my life?'

Since then twenty-eight years have gone by. I do not know if I have now really found the existential meaning for me of my disability. But I believe that there is meaning at least in the fact that, by becoming a deafblind person, I have had the chance to keep asking the question: 'What is it that really has value in life?'

Also, because of the disability of deafblindness, although I experienced the anguish of being deprived of communication with others, I have also known the joy of having it restored, through communicating with Finger Braille, literally 'through the hands of others'. And it has been a great blessing for my life to confirm, through this experience, the importance of communication with others, and the fact that it is through our relationships with other people that we human beings truly come alive.

When I consider, based on this experience, ways to approach the issue of 'disability', I think it is not enough to consider only the technical aspects, that is, to deal with 'disability' merely from the medical, educational or social welfare standpoints. I think the importance of approaching the issue on the existential level should not be overlooked. In other words, what meaning can a disabled person find in disability? How does disability relate to the issue of the 'value' of the person's life and way of life?

4. My encounter with disability studies

I had been thinking, then, that there was meaning to be disabled and in thinking about society and life through that experience of disability. And at that time I learned of the existence of the academic field known as 'disability studies'.

Disability studies is said to be theoretical and practical studies that consider, through the phenomenon that is 'disability', the way society and human beings work and which promotes a social movement. What then should we consider as the issues that disability studies should take up now? And what should the direction and framework of these studies be? Here I am thinking in terms of two categories.

The first category is that of contributing to disabled persons; the second category is that of contributing to many kinds of discrimination issues that exist for all people, whether they are disabled or not. For if disability studies is something that is only for disabled people, it will lack the potential to develop. But of course, since it would have no meaning if it did not serve disabled people who suffer discrimination in their lives right now, it must first seek to contribute to disabled people.

Next I consider what kind of 'strategy' can actually fit these categories. Here 'strategy' does not refer to the knowhow involved in addressing particular problems, but

to the theoretical framework of the direction and point of departure for struggling against the reality of discrimination.

There have been two typical strategies in the approach of disability studies heretofore. The first is the 'culture theory strategy', the second, the 'ability theory strategy'. If we consider these in terms of the first category mentioned above, this is what we get.

The 'culture theory strategy' emphasizes the aspect of 'culture' in the struggle against discrimination against disabled people. This strategy would oppose discrimination against disabled people by considering disability as a 'culture'. The 'ability theory strategy' sees discrimination against disabled people as 'discrimination due to ability (difference)' arising from disability, and by analyzing its structure and pointing out how groundless it is, would oppose discrimination against all disabled people.

Next, what would we have if we applied these two strategies to the second category, namely, 'discrimination issues in general that exist in relation to all people'? I think these two strategies can also be applied to the second category.

The 'culture theory strategy' in the context of the first category would oppose discrimination by taking a new look at the attribute that is disability as 'culture'. But one could say that it is a strategy that could just as well fit a range of other discrimination issues that arise from attributes other than disabilities (such as gender, race, age). And the 'ability theory strategy' that would oppose discrimination due to 'ability (difference)' arising from disability can be seen as a strategy that goes beyond the existence or non-existence of disability. It would oppose the discriminatory ranking of the individual (linking the judgment of a person's value with his or her productive capacity) that is based on the productivity-centered meritocracy-based value consciousness' which dominates modern society.

Thus, the 'culture theory strategy' in the context of the first category, by taking a fresh look at the attribute that is disability as culture, can, through the point of aiming to abolish discrimination due to difference in attributes, connect to other discrimination issues. And the 'ability theory strategy', by revising 'abolishing of ability discrimination due to disability' to 'abolishing discrimination due to ability difference in general', can be taken as a strategy for opposing meritocracy-based discrimination in relation to all individuals regardless of whether they are disabled or not.

Are these two strategies good enough as disability studies strategies? Do they form a sufficient theoretical framework to fight against discrimination against disabled people? I think that, although both are important strategies, neither of them can properly function on its own.

5. Combining 'culture' and 'ability' to make a 'creative communication' strategy

Thinking first about 'culture theory strategy', I believe that there is a weak point here. For if value ranking in the attributes of the individual as meritocracy-based discrimination' should permeate into the 'disability as culture' approach, one could not, in principle, resist discrimination according to ability (difference).

Neither, on the other hand, is 'ability theory strategy' sufficient. This is because it is difficult to confront and overcome the problem of abolishing discrimination due to ability (difference) with this strategy alone. For in order to do that it would be necessary to aim for a reform and change in the value system that prevails in modern society,

namely, the mindset that links evaluation of the individual with her/his (productive) ability. But no matter how strongly one may hold it 'inexcusable to discriminate based on ability (difference)', for some reason, the rationale for explaining this ends up being the non-retroactive precept, 'discrimination based on ability should be abolished'.

Let us think a bit more about why these two strategies give rise to these limitations.

First, since meritocracy is a system of value consciousness that would end up ranking ability (difference) on a number line based on the one-dimensional measure of 'productivity', in connection with this, the 'ability theory strategy' that would deny that would also have to be in the nature of something one-dimensional.

The 'culture theory strategy', on the other hand, sees uniqueness and identity in differing ways of behavior and is a value system on the 'quality' dimension that sees irreplaceable value in each culture. In other words, since it is 'quality' that is seen as important in the 'culture theory strategy', superficial advantages and disadvantages don't come into play. But the 'quantitative' measuring rod infiltrates culture. Even if there were no discrimination from differences with other cultures, within the same culture, 'quantitative' discrimination from ability (difference) in 'productivity' could arise, and this in turn could lead to discrimination occurring from differences between cultures.

If this kind of meritocracy-based discrimination structure capable of threatening the 'culture theory strategy' exists, perhaps there should be a counterattack on meritocracy from the side of 'culture theory strategy'. How about, for instance, making, from the 'culture theory strategy' standpoint, the argument that 'ability (difference) is a kind of culture'? This would be an attempt to construct a third new strategy that, going back once more to 'culture theory strategy', works out all over again an 'ability theory strategy' that might well be called an 'ability (difference) culture theory strategy'.

In other words, this concept considers that there are two 'disparities', one 'quantitative' and the other 'qualitative', and finds grounds for inherent value in terms of culture in each of them. It does not deny the existence of 'ability (difference)'. While acknowledging the existence of 'ability (difference)' in the subject, it strips the value-ranking factor from the meritocracy-based discrimination structure that places a value on the individual in 'quantitative' terms. And while acknowledging disparities within ability, it would at the same time introduce a new viewpoint in terms of culture that recognizes an inherent value in those disparities.

Let me put it this way. In the first place, while acknowledging greater or lesser 'ability' or higher or lower productivity by introducing the point of view of culture, value ranking of the individual is not brought in. Secondly, the 'qualitative' disparity that lies in 'ability (difference)', namely, the various qualitative disparities in ability itself, is also seen from the point of view of culture, and the 'culture theory strategy' methodology that 'doesn't attach value ranking to disparity' is applied. This is an attempt to construct a logic that does not bring value ranking into 'ability (difference)' with respect to these two aspects, that is, both 'quantitative' and 'qualitative' disparity'.

Incidentally, if we introduce the 'ability theory strategy' into the 'culture theory strategy' and derive there a third new strategy, the 'ability (difference) culture theory strategy', what characteristics should this third strategy have? I think that this third strategy must be dynamic and evolving. That is, it must be something that can mutually link up with the two categories above and the two strategies that they contain, and it is in essence a 'creative communication' approach.

The 'creative communication' that I have in mind here is not confined to the simple exchange of opinions and information. I see it as a work involving the process of two or more people, through mutual communication, bringing forth and developing new opinions, information and values. Thus the creative communication strategy that I refer to here does not aim to simply combine the 'culture theory' and the 'ability theory' but is a strategy with a dynamic, creative mechanism that, while continuing to look for the possibility of fusions of the various patterns of 'culture theory' and 'ability theory', constantly strives for a new strategy that transcends these two.

Well, of course, I don't expect to get sudden agreement with this idea for a position that not only does not bring discrimination into ability (difference), but even reevaluates ability (difference) from the viewpoint of culture. I believe it is something that will gradually take shape through lively communication among people with ability (difference) disparities, including disabled people, through a power, akin to 'frictional heat', generated by those very disparities. And this is the image that I have of creative communication strategy.

We might also think of it in terms of something like this: if words and information, say, are water, then communication is the flow of water. If you think of it in those terms, an image comes to mind of a very small stream starting to flow and then joining with many other streams to eventually become a great river and finally linking up with the seas that extend throughout the whole earth. This seems to overlap with the image of information and communication in our present day high-tech information society.

And if communication were the flow of water, by the fact of the other being 'different', elements like the differences in the 'height' of the flow of water or changes in its 'speed' would come into play, and just as that would produce great power just like that of the waterfall turning a hydroelectric turbine or a rapids sweeping away a great rock, it would enliven our interrelatedness and give us strength to live and to struggle against discrimination.

From my experience of becoming a deafblind person and having communication with others cut off, I have felt limitless creative possibilities and power hidden in the workings that we call communication. I think that perhaps the desire for creative communication is inherent in all people, disabled or not, and that it will become a new driving force to open up the future.

6. Communication and what disability studies means to me

People live with the support of others. And without the support, tangible and intangible, of others they cannot live. This is something that disabled people, the deafblind, for instance, always themselves experience and show to others. And it is 'language' in the broad sense, communication, that mediate that support of others.

'Communication' derives from the Latin word, 'communicare'. I would like to note that it means not only the 'communication' that we normally use today, but it also contains the meaning, 'to share' and 'to do together'.

What is disability studies?

Disability studies is the field of study that does not turn its eyes from the social and individual realities and phenomena of what is called 'disability', nor from the various difficulties and problems arising from those realities and phenomena.

Disability studies does not turn its eyes from the social mechanisms and structures of this society which we ourselves have created that give rise to the phenomenon of 'disability' and its recognition.

Disability studies does not deny that people have different abilities, nor does it deny that those different abilities make for greater or lesser productivity and greater or lesser efficiency in work. But disability studies does deny any connection between those differences in ability and a person's worth or society's evaluation of the individual.

Disability studies recognizes that while all people have different abilities, they are at the same time all of equal worth. In other words, it sees the solidarity of human beings, beyond the specific attributes and individual characteristics of people, and regards the existence of each person as precious, never to be excluded as an exception.

Disability studies is not only for 'disabled people', nor is it only for the 'non-disabled'.

Disability studies exists not merely for the sake of academic studies, as likewise it is not only for a movement for social change.

Disability studies is not only for the life of a particular individual, as it is also not only for a particular community of disabled people.

And disability studies is a scholarly discipline that aims to have us, whether we be disabled or not, illuminate the world with a new light of recognition.

It is just like our seeing for the first time the pearl-colored brightness of the corona that adorns the circumference of the sun when the moon covers the sun during a total eclipse of the sun. Or like, when a rainbow appears in the sky after the rain, our knowing that the spectra and its infinite gradations of color are contained in light.

In the same way, by passing through the new framework of understanding that is disability studies, we will be able to see this world illuminated by various lights different from those we have hitherto seen. We will discover that our very own existence, regardless of the different characteristics and attributes we may have, or indeed because of them, is in a relationship which involves mutually and unconditionally blessing the fact of our existence.

Disability studies is a field that makes possible that kind of value shift and awakening, and I believe it is a field that gives us a chance to look anew at the world under the light of knowledge with a new brightness.

Let us all learn together. Thank you.