On "the Social Model"

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There is an approach referred to as the "social model of disability". My perspective is one which fundamentally supports what is asserted in this approach. But what is this social model, or what sort of thing should it be considered to be?

It has been described as a way of thinking in which disability (Japanese "shogai") [1] is thought of as having two dimensions, "impairment" and "disability", and an attempt is made to have society take responsibility for socially constructed "disabilities" (Sugino [2007:117]). The following definition is provided by the Union of the Physically Impaired Against Segregation (UPIAS), an organization based in Britain.

"In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society". To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability', of people with such impairment. " (UPIAS [1976: 14]) [2]

Another text which is often cited in explaining the "social model" and is well known to those who have studied this field is a list of questions created by Michael Oliver as an alternative to the list of questions used on surveys conducted by the Office of Population Censuses and Surveys (OPCS).

OPCS "Can you tell me what is wrong with you?"

Oliver "Can you tell me what is wrong with society?"

OPCS "What complaint causes your difficulty in holding, gripping or turning things?"

Oliver "What defects in the design of everyday equipment like jars, bottles and tins causes you difficulty in holding, gripping or turning them?" (Oliver [1990:7-8] [3]

There has been a great deal of debate about this model, quite a lot of which is presented in Sugino [2007] and Hoshika [2007] in Japan. What I will discuss below includes some elements that are a bit different from what is introduced and examined in these two works.

The UPIAS defines impairment as "lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body", and disability as "the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of

social activities". As this was an organization for people with physical impairments these definitions were at first only concerned with physical conditions, but they were later broadened to cover a wider range of situations.

I basically agree with the assertion that society should be seen as the problem, but I also think there are some other things which must be stated and examined in addition to or instead of what is normally discussed in this context.

To begin with, and this is connected to the question of how to interpret the statement "disability is not an illness" (what people are trying to say when they make this claim is right but it is not literally accurate), I would like to establish what kinds of elements exist regarding physical conditions/differences and what aspects of these elements are tied up with disability and illness respectively. In order to give a thorough description of the above we must identify five elements and examine each of them in detail. Reluctantly, I can give only simple accounts in this paper, but in it I will attempt to sketch out the various elements related to physical status and disability and examine which of these are addressed (and not addressed) within the social model. This is also connected to how we should understand criticisms concerning the making light of "impairment". I will examine this question elsewhere.

At Least Five Elements

In what way and to what extent various things exist in the body of each individual is in many cases not known, but these factors are connected to the state of the person in question and their status within society. The element existing in the body which forms the basis of the designation of disability is presumably "impairment", but the range of what exists within each individual body is broader; each body has a particular state of being, these states of being differ, and further effects occur in relation to these differences. These can be divided into at least the following elements, and exist, sometimes simultaneously, in a same person:

(1) differences in function, (2) differences in shape/form of being, (3) pain, and (4) the arrival of death. A fifth element, (5) harmfulness, can also be added. This is not an exhaustive list of everything that can occur in relation to the body. In addition to (3) pain there is also pleasure. But these are the five elements that I think must be considered in connection with disability and illness.

Out of the five elements described above, disability, understood very broadly (there are differences within the everyday use of this term even within a single language, and of course between the way it is used in different languages), exhibits (1) differences in function and (2) differences in shape/form of being, and in addition raises concerns of (5) harmfulness. Regarding illness, while fears of (5) harmfulness resulting from the possibility of infection/contagion have led to it being targeted for the "protection of society", it is also something which causes (3) pain and, in some cases, (4) the arrival of death. This can be viewed independently, but there are also ways in which they can be grouped together and related to each other. For example, there are cases in which (3) pain makes it difficult to perform (1) certain functions [4]. It is possible to distinguish disability and illness in this way, but they can also simultaneously coexist within a single individual or be caused by the same factor [5]. On the

other hand, there are some cases in which the individual in question cannot perform certain (1) functions with his or her own body but he or she suffers no particular hardships as a result.

All of these things are connected to people and to society as a whole. Particular physical conditions actually exist in a very ordinary sense of the phrase, something we can call the "physiological dimension". But these are received, which includes being felt, known, and named, and values are assigned to them. They are then dealt with or handled. It is this state of affairs which differs. Among the five factors listed, (3), the feeling of pain by the person in question, can be said to be in the "physiological dimension". This is something which, to begin with, occurs within the person in question and cannot be moved or transferred to another individual. There are also cases in which this pain cannot be eliminated or lessened. However, or perhaps precisely because of this fact, various "humane" discourses have been offered. As has often been said, (4) death, as something which simply comes, as something which ultimately cannot be prevented by human actions, is not something people experience but something they think about. While thinking about death, or perhaps indeed because of this preoccupation, people normally fear death and fear illness and seek to eliminate or reduce both of these conditions. Let us begin with this extremely straightforward understanding.

Viewed in this way, since the state of affairs referred to as being disabled is quite different from what is positioned as illness it does indeed seem reckless to discuss these two states as though they were the same. In what follows we will discuss what is related to disability, but what the "social model" fundamentally addresses is (1) function. In this regard it has been criticized for ignoring other elements, and this criticism can among other things be seen as an attempt to point out that (2) is being ignored or not given sufficient consideration. In another paper I will examine discussions about the point that elements other than function -- while their existence has not been denied -- have not been addressed or debated within the social model and that this has been seen as problematic. This is a valid issue to raise. While most (1) functions can be substituted or replaced (functions/capabilities used as methods or means employed in living one's life, to the extent that they are methods or means, exist as things which can be substituted or replaced providing no special conditions are applied), (2) the form/shape and the actions/movements of a body normally adhere to the person in question and cannot be separated from them. Are there not various things which arise in connection with this fact, some of them sad and some of them, sometimes, happy? There are those who say this sort of thing. They are no doubt correct. (Moreover, and I will discuss this in a bit more detail later, let me state in advance that it is wrong to assign (1) to "disability" and (2) to "impairment". Something causes an awareness of difference from others or leads to suffering in this regard only to the extent that this difference is taken up by other people, and this must not be thought of as stemming from physiological events and conditions themselves [6]).

Also, for the same reason, when it comes to (1) function it is possible in practice to substitute something other than one's own body and it is possible to say that this kind of substitution must be carried out. This assertion, and the pointing out of instances in which these substitutions or compensations are not made, are both valid as assertions and effective in practice. So it is rightful that disability movements and disability studies target (1) firstly. Here I also examine (1) [7].

Usually (5) harmfulness - while harmfulness can occur as "self injury", it may be possible to include this in (3), here I am referring to harmfulness to others - is not included as part of what stipulates the presence of disability. There is an understanding that it is incorrect and unjust to connect disability, particularly mental disability, with harmfulness/crime, and to a large extent this is right. It is also the case, however, that both historically and at present this issue has been addressed as a social problem, particularly in regard to people with mental disabilities and people with developmental disabilities. These individuals have consistently been targeted for "the protection of society". There is therefore a need to examine this issue. While it is very important, here it is not possible to say anything more about this element than that it exists.[8] All of these elements from (1) to (5) need to be examined, but I will leave this for another time (some of my ideas on this subject have been sketched out in Tateiwa [2008-2010] -- it will become a book in 2011 -- by and in what follows I will examine only (1) function and one of the ways in which it is understood and addressed.

Things Which Need Not Be Understood in the Following Manner

It has been asserted that "impairment" should be resolved at the "individual" level and by "medical treatment" but is rather something which must be addressed at the level of "society". What happens if we examine the implications of this assertion in bit more detail?

First, while it may in some cases be valid to distinguish between physiological and social "causes" of impairment, this cannot be thought of as the true meaning of the individual/society and treatment/society dichotomies found in the social model, or in any case if this is what is asserted it is mistaken. While there are indeed disabilities caused by war or pollution of the environment, it is not claimed (nor should it be) that society only bears responsibility for disabilities which arise in this way.[9]

Second, it is incorrect to think of the "cause" of the disadvantage in question being within either the individual or society. This of course depends on how the word "cause" is understood, but if the cause/factor is seen as that which impedes the elimination/lessening of the disadvantage or that which is effective in eliminating the disadvantage, then in the case of mobility, for example, just as the person in question will be able to move if his or her legs work, he or she will also be able to move if a wheelchair or other device is used. Just as an impairment of the legs may be described as the cause of an inability to move, so too can the lack of a wheelchair or the absence of an environment in which a wheelchair can be used.

Third, there are cases in which "means" of eliminating the disadvantage in question are not specified. To begin with, for any particular state of affairs (or the absence of any particular state of affairs) it is possible to come up with an infinite number of causes/causal factors. From this limitless number of options what we tend to single out as causes are, in most cases, factors which it is possible to create, destroy or modify, and in this sense (our understanding of) cause is connected to methods or means -- we do not tend to count conditions about which nothing can be done as causes.

What we must keep in mind here is that while the problem in question may need to be solved, that does not mean the cause we have identified must be eliminated. It is important to

establish this point at the start. For example, there are cases in which the cause of the problem lies inside the person in question, and removing it - while this may solve the problem being addressed - causes him or her to experience other disadvantages. In reality, however, the practice of finding causes often becomes tied up with the practice of eliminating them. So some disabled people have warned against this, and have been skeptical and even critical of discourse concerning "causes".[10]

To begin with, in the context of what is stated above, I would next like to state that in practice as well interventions directed towards the body itself and other approaches lie along a continuum. For example, devices like hearing aids and cochlear implants -- there has been debate over whether these devices should be seen as good or bad but I will address this issue separately -- and artificial joints are pieces of man-made equipment which are attached to or implanted within the body. It is sometimes difficult to draw a clear line between treating/curing and supplementing or substituting with something else (a person or machine). There is also the fact that various such approaches exist, and it is not always determined ahead of time which is best or better.

Nevertheless, both disability studies and the social model have asserted that rather than focusing on medical treatment and eliminating impairments -- though they do not reject this sort of effort entirely -- we should instead push for society to make the necessary adjustments in terms of providing labor or installing machines/facilities. Why have they taken this approach?

Who Gains or Loses from "What I Can't Do"

Here we must consider what is stated above, namely the question of for whose gains or loses are created.

To begin with, in the case of most disabled people their impairments cannot be cured. Various treatments have been developed and employed, but there remain many people for whom none of them are effective. This is perhaps most clearly evident in the case of people with cerebral palsy. In this case it is pointless to assert that this condition should be cured or if a cure were possible it should be pursued, and there is no practical need to make such assertions. We have no choice but to take other approaches in dealing with this condition and it is important that we actually do so.

Nevertheless, there are also actions which have been carried out as forms of medical treatment/rehabilitation, and there are some people for whom what has been carried out under these auspices has caused pain while providing little benefit. There are people who have been forced to endure pain for these treatments which are of no benefit and have been forced to live their lives under the control of healthcare specialists or institutions.[11] It would therefore not be surprising if these disabled people who have been told to do various things by specialists without their own volition or desires being accommodated spoke out against treatment/rehabilitation, and these sorts of criticisms have in fact been made.

But it is not the case that treatment is never effective. There are instances in which somewhat or even strikingly positive results are achieved. Is there no problem with pursuing treatment in such cases? Here too we must look at what is lost and what is gained. While some

things may be gained, at the same time this may be accompanied by a loss of time, confinement in a particular space, or physical pain. These losses may not easily be perceived by others and in most cases are not included in the calculations performed in research demonstrating the effectiveness of treatments/rehabilitation.[12]

The above pertains to gains and losses when treatment is carried out for the person in question, but what about cases in which the other possibility is considered, i.e. when a comparison is made with "social accommodation"? Not only in cases where efforts are made in order to cure/treat, but in any case where what is done must be carried out by the person in question themselves, most of the time it is easier and more comfortable for the person in question if another approach is taken. This is different from pain or death. Pain and life are things which cannot be transferred form one person to another, while function on the other hand can for the most part be augmented by another person or device, with the result in many cases being close to what would be experienced if the individual could perform the function on their own. These things which can be substituted may also be considered means. If so, in cases where this kind of supplement or augmentation is employed, for the person in question there is nothing negative about the situation.

There are, however, some functions which cannot be performed by a substitute. There are also cases in which this approach requires the person in question be in close contact with other people in ways that may cause them to feel shame or embarrassment. This embarrassment may to some extent fade as the person in question gets used to the situation, but it cannot be said that all such negative emotions will necessarily disappear over time. [13] This is not something which can be ignored, and must often be taken into account on a case by case basis. But it is also a fact that there are some disabilities, people, and situations where these problems do not arise.

This may also provide one answer to the question of "would it be better if disabilities did not exist" [14] -- although as I have mentioned when asking this question it is difficult to translate disability [Japanese "shogai"] as either "impairment" or "disability" as these terms are used in British disability studies. Looking at only these sorts of cases it cannot be said that it is better for disability (things which they cannot do for themselves) not to exist. Put simply, there are cases in which rather than performing an action themselves it is easier for the person in question to use an alternative means such as having someone else perform the action on their behalf.

But what about the other people involved? In order to facilitate the daily life of the person in question they must suffer the disadvantages of having to carry out various caregiving activities and/or bear various economic burdens. It would be better if the person in question could do these things for themselves.

In contrast to this sort of situation, in the case of illnesses which cause (3) pain and (4) the possibility of impending death, usually -- I say usually because, there are cases in which it is not that simple (eg. the use of morphine as "palliative care" makes carer's works easier and carers better off, cf. Tateiwa [2010g]) -- the people in question themselves want to avoid this state of affairs. (And also, particularly in the case of others who are not close to the person in question, there is little concern about the person in question's burden becoming other people's burden. In a straightforward sense the death of the person in question does not mean the death of anyone else and their pain cannot be felt directly by other people). Here too disability and illness differ.

This is another way in which the assertion that disability and illness should not be lumped together can be seen to be correct (although, as I have already stated, we should note that there are many cases in which both occur at the same time).

In summary, contrary to what is generally believed, there are cases in which a lack of ability to perform (1) does not detract from the wellbeing of the person in question but instead places a burden on society. It is a mistake to overlook this and assert that these states of affairs are always disadvantageous for the person in question. Both disability studies and the social model can be thought of as making this point.

Divergence Exists in the Standards of Norms

When the issue is considered in this way, what should be done? As I have stated, there are some cases in which all we can do is say that the person in question cannot do what he or she cannot do. Here there would seem to be no need for argument. We must do what is needed for the sake of, and in the place of, the person in question. But there are those who reject even this. There are also cases where the person in question can do certain things or become able to do certain things only with some difficulty or with great difficulty. What are we to think about such cases? This is a fundamental issue concerning justice and "distributive justice".

One approach is that of self determination in which the person in question chooses what is best for oneself. Self determination and autonomy are of course very important. But they are not enough on their own. It is because - and this is something recognized within disability studies - determination or making choices is something which is carried out within a society. If two options are presented but the actual circumstances are such that one of the two choices offered would be extremely difficult or impossible to carry out in practice then it is meaningless to present the individual in question with these options and tell them they can choose whichever they like.

So is everything fine if the two options are presented as "equivalent"? But what does equivalence mean in this case? And even if they are not equivalent, what sort of options should be presented as the objects of determination? The problem is indeed a normative one.[15]

In other words the question is what sort of norms are put in place, and on the basis of these norms in what ways do options - stated by people who say that options and choice are important - exist, and how are they evaluated?[16]

To put things very simply, let us begin with the assumption that what must be fundamentally established is equality/fairness. Of course there are various detailed arguments which arise here, and I myself have participated in some of these debates (I have criticized certain approaches to introducing equality and dealing with disparity), but here I will omit such details and assume that everyone, regardless of whether or not they have a disability, should be able to receive the resources needed to live a normal life, including all of the extra resources required to do so in this society. (See Tateiwa [1997][2004a]. For a simpler version of what is discussed in these texts see Tateiwa [2010e]).

Different people may want to do different things, however, and this is something which must be acknowledged. And it goes without saying that the condition of people's bodies differ.

This being the case, how much are people able to do? How much should people receive?

A brief outline of my thoughts on this is below (see Tateiwa [2010a] in detail). To begin with, in addition to what is added as compensation for labor, each person should be able to receive as income what is needed to have the same level of live with the same concrete income. Here there is no calculation of the presence or absence of disability. Each person is free to use what they receive in whatever way they like. In addition, regarding this use within the context of our society, additional costs associated with disability should be born by society, or in other words paid for using revenue collected through taxation. For example, if an individual wants to travel overseas two times using their annual income (by reducing consumption in other areas), they should receive support funded by taxation for any additional costs related to their physical condition they would incur in doing so. So what about burdens/labor? I discussed my fundamental views on this issue elsewhere (Tateiwa et al. [2008] etc.), so I will omit discussion of them here.

This is what can be said from my perspective -- and I think it is also supported by the advocates of the social model. So what about the issue discussed earlier? In other words, what about the relationship between medical treatment/cures and substitution/supplementation under the kind of system described above? In the situation I have described there are indeed additional burdens born by society. It is not plausible, however, that this should lead to problems concerning resources. Regarding human resources in particular there should be enough to easily provide the additional labor required. Doubts have been raised about whether it is possible to justify considerable additional support provided by society in cases where an equivalent state of affairs could be reached through relatively small effort on the part of the individual in question. In other words, based on the same standard of fairness we have employed in advocating this system, it has been asserted that there is a need for fairness concerning the burden born by others and the burden born by the individual in question.

I admit that in theory it is possible to make demands of the person in question. While training/rehabilitation may be long and difficult, it is not always the case that nothing can be gained by it. There are also cases in which a short and relatively painless rehabilitation can enable the individual in question to do more on their own and thereby reduce the burden born by society. People should be made aware of these kinds of treatments where they exist and encouraged to undergo them.

But there are several points which can be raised here. First, there are many cases in which the effects on the individual of trying to restore or improve their capability are not known. These efforts may or may not be successful. Second, the hardship and struggle involved is that of the person in question. The extent of this hardship cannot be directly experienced by other people. Third, in many cases in which these sorts of programs are carried out the person in question stops without having achieved a sufficient standard in comparison to those who already possessed the capability in question or those who are able to attain it quickly. Fourth, this leads to the person in question being viewed negatively by other people and by themselves to the extent that they internalize the values of others. On the other hand, if the person in question thinks that after considering the realities of treatment briefly laid out above and the costs involved it is still to their advantage to recover/improve the functioning of their own body, even

if society is prepared to sufficiently augment or substitute their functioning they will presumably choose to attempt the treatment/rehabilitation in question.

Considering all of the above the assertion that it is society that must change/be changed has both sufficient grounds and rationality.

The Essential Meaning of the Social Model

Based on the above it is possible to give a fundamental account of how the social model can or should be understood in contrast to the medical/individual model.

The reason the social model is meaningful is not that it places the "cause" of the hardships and disadvantages suffered by the individual in question in society and not in the person in question themselves. This is, at least, inaccurate. In response to the medical/individual model saying "he or she cannot go there because he or she does not have legs" the social model offers a contrasting explanation, "he or she cannot go there because there is no wheelchair-accessible path", which seems easy to understand but is in fact incorrect and confusing. Either condition [i.e. having working legs or having a wheelchair-accessible path] would be sufficient to allow the person in question to reach their destination. The problem is not the relationship between cause and effect. Nor need it be seen as the assertion, regarding the question of whether the person in question should undergo medical treatment/rehabilitation or whether their capability should be supplemented by other means, that the former option should always be taken.

The meaningful difference between the two models, the contrast which must be drawn, is related to society's fundamental attitude towards ownership and distribution. Here the models diverge. One views what an individual can and cannot do as fundamentally distinct from that individual's living, and holds that to the extent implementable and effective means exist -- it is impossible to completely eliminate disparity no matter what methods are used -- these means should be employed in allowing people to live their lives. The other holds that people who produce and contribute should fundamentally own what is produced and receive resources in accordance with their contributions.

The latter perspective has been fundamentally affirmed and maintained until now, albeit in various forms and with various attempts to correct the unfairness it produces, within political philosophy and welfare economics -- pointing out the inadequacies of these approaches, justifying the former and showing the ways to realize it have been main part of my work since Tateiwa [1997].

In regard to this, and if we take the point of view described above, I think that the assertions of disability studies and the social model should be seen as rejecting the fundamental aspects of this latter perspective and asserting that we must not accept as a matter of course or as something which cannot be helped the disadvantages created by this society which are connected to the differences between the bodies of different individuals. When this is what is asserted this becomes the position which is most consistent and can be most effectively defended against possible criticisms. This is my position as well, and there are fundamental commonalities between what has formed the foundation of this field of study called disability studies and what I have seen -- disability movements and its thinking in Japan gave me much --

and taken as starting points.

Both criticism of medicine and specialists and the assertion that society should be placed in contrast to the individual are things which have appeared and must inevitably appear when this society is the society which we have criticized. In this kind of society it is assumed that individuals will maintain, increase, and recover their own functional capabilities and live by doing so. Since life is difficult if this approach is not followed individuals will give priority to restoring and seeking to increase their own capabilities, viewing this prioritization as unavoidable even if they are given the option of self determination, and a lot of power will presumably be given to people whose work is related to this restoring and maintaining of function. Society does not have to be this way. There are things which can and should be done to create a different kind of society. I think this is what assertions of the social model are saying.

The above has been a very brief outline, and limited to the dimension of (1) function, of what can be said about these issues. There are many points which must be examined in more detail. And there are other things which must be examined concerning at least the five elements I described; we should examine at least some of these five. I will also undertake the task in other writings.

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Notes

[1] Disability is translated into Japanese term "shogai(障害)". But "shogai" includes both impairment and disability. And generally it means the former, and the latter is expressed as (unjustified) disadvantages concerning "shogai". And this usage itself does not deny the assertion of the social model. (When we accept the terminology of impairment and disability in disability studies, impairment is sometime translated into "functional shogai (機能障害)", "欠損(defect)", "インペアメント"(English pronunciation to Japanese letter) etc.

[2] Oliver [1983:24] is quoted in Sugino [2007:117] (written in Japanese). The following explanations given:

"The social model approach taken in British disability studies, in which "disability (shogai)" is thought of as being divided into two dimensions called impairment and disability, with social responsibility being pursued regarding disability which is socially created, has been developed based on the original definition of disability employed by the Union of the Physically Impaired Against Segregation (UPIAS). In this sense the British social model is a concept formed within the actual practice of the disability movement, and its central aim is to shift the thinking of people with disabilities and able-bodied society as a whole towards acknowledging that problems should not be attributed to individual people with disabilities and that social solutions should be sought to the various problems caused by impairment" (Sugino [2007:117]).

Regarding UPIAS he writes as follows:

"In the second half of the 1960s, at Le Court, one of the "Cheshire home" that was viewed as "progressive" among British institutions for disabled people, self-governing activities undertaken by residents developed into criticism of the institution, and eventually an "abnormal state" of "autonomous management" by residents ensued. At the center of this movement was a resident of the institution named Paul Hunt. In 1972 he put forward his criticism of the institution in The Guardian, a national newspaper, and regarding people with disabilities who had entered it called for the formation of a user sovereignty movement. The organization formed by those responding to Hunt's call came to be called "Union of the Physically Impaired Against Segregation (UPIAS)" (Sugino [2007:155]. Here he also refers readers to Sugino [2000]).

Regarding Fundamental Principles of Disability, sections of which are cited in the main text: "The historic Fundamental Principles of Disability text published by UPIAS in 1976 was a version edited by Oliver, and a section of it was reprinted in Oliver [1996:21-28]. The full text can be downloaded from the website of Leeds University's Centre for Disability Studies" (Sugino [2007:155]).

Almost exactly the same section is quoted in Shakespeare [2010:267] and the URL for the website of Leeds University's Centre for Disability Studies is given. But in the Shakespeare's paper this is cited as UPIAS [1975]. This is presumably in light of the fact that these "fundamental principles" were presented in a debate with the Disability Alliance (published in 1976) that took place in 1975. Shakespeare quotes this section as "the Fundamental Principles of Disability discussion with the reformist Disability Alliance, went Further:"

In the same text introducing the social model and the debate that surrounds it Shakespeare also quotes the first part of the "Aims" section of UPIAS' 1974 policy statement. "We find ourselves isolated and excluded by such things as flights of steps, inadequate public and personal transport, unsuitable housing, rigid work routines in factories and offices, and a lack of up-to-date aids and equipment. (Shakespeare [2010:267]. By the way I cannot agree to some arguments of Shakespeare [2006]. I will discuss these in another paper.)

In Japan "Platform for Aoi Shiba Movement" (1970) by "Aoi Shiba no Kai" (cf. Kohichi Yokozuka (1935-1978) -- great leader of this group -- [1975 1981 2007], my commentary on this book (Tateiwa [2007] and one of our member (PD)'s new book, Sadato [2011] etc.) "We identify ourselves as people with Cerebral Palsy (CP). "We recognize our position as "an existence which should not exist", in modern society. We believe that this recognition should be the starting point of our whole movement, and we act on this belief. "(cited in Nagase [1995] etc., the full test in our website: http://www.arsvi.com/o/a01-e.htm)

I think it is interesting to examine common and different features of these texts in Britain and Japan.

- [3] Nagase [1999], Hoshika [2007:47-48], Barnes & Mercer [2010:32], etc.
- [4] It is therefore entirely reasonable to assert that to the extent that an individual's activities or lifestyle requires assistance they may be considered disabled, even if their body does not have any (outwardly apparent) injuries or damage. On the lives of people with complex regional pain syndrome (CRPS) see Ohno (our graduate student) [2009].
- [5] If disability studies and its research are concerned with people in these sorts of circumstances, we (who participate in the project of "Ars Vivendi: Forms of Human Life and Survival") take the position of speaking and writing about a range of phenomena including those we recognize or are generally recognized as illnesses. Here the question of how to think about both disabilities and illnesses arises.

"Is ALS an illness or a disability? Are people with ALS ill or disabled? Of course, since words can be used with a variety of meanings and the scope of what they refer to can be altered, the answer will depend on how this done. Generally speaking, illness is something that is contrasted with health and causes suffering. Illnesses can also lead to death, and are viewed as undesirable. Disabilities exist when there is some hindrance or inconvenience related to the state of the body of the person in question. Since illnesses can lead to disabilities, there are instances in which both arise in combination. ALS is an illness. At the same time, it also leads to the impairment of abilities. People with ALS are both people with an illness and people with a disability. To begin with, this is a simple answer to this question. […] And people with ALS are also both in relation to social services." (Tateiwa [2004b])

While ALS can indeed lead to considerable discomfort, if this can be eliminated or reduced, and since with proper treatment it need not be fatal, it seems best to treat this condition as a severe and progressive disability. (Nonetheless, these individuals want to be cured, and there are good reasons for this).

This does not, of course, contradict in any way these individuals' need for what is referred to as "medical treatment" and "medical care". These techniques and procedures are needed to maintain the condition of their bodies, and there are instances in which they can (only) be carried out by medical professionals. If so this kind of care is required. On the other hand, there are also cases in which appropriate care can be provided by people without medical or nursing qualifications if they have learned how to perform the necessary actions. When such activities are nevertheless restricted by the need for qualifications or attempts are being made to impose such restrictions, It is something that must be opposed, and in practice opposition movements against qualification and monopoly often have occurred also in Japan (cf. Tateiwa [1999]).

[6] The "affirmation" of inability ("shogai") is something which has been spoken of in the past and continues to be spoken of today, but, even regarding only that which is related to dimension (2), it is not impairment which is being affirmed. The claim is that there are things which arise because of impairments that are not found in people who are not impaired, and that some of these things are good. Regarding (1) the dimension of function, too, it is not a lack of ability to perform certain functions that is being affirmed. What is asserted is that there are some good things which can arise as a result of an inability to do certain things. Several points relating to this issue are also discussed in Tateiwa [2010e].

[7] This is also the approach that I myself have taken -- to think about ownership and distribution concerning that which can or must be moved around and distributed. Here we are immediately faced with the question of what sorts of things should not be reallocated or distributed even though to do so would be possible in practice, and the related question of why we think distribution would be wrong in these cases. I discussed my fundamental views on these issues in Tateiwa [1997:chap.4]. But regarding that which cannot or should not be substituted or exchanged, if we do not simply give up and conclude there is nothing to be done, we are inevitably left with the question of how to think about these problems and how to approach solving them. While acknowledging that such problems exist, we can put them aside if they are too difficult and return to them later when we think have something useful to say about them. This is what I have written concerning these issues in the past (see Tateiwa [2002]). In this way I have avoided dealing with these problems and have not been able to make any progress since then. I have also not yet been able to write a follow-up to Tateiwa [2002]. The same can be said of Tateiwa [2010e], and I have understandably been criticized for not including in this work examination of not only (1) "lack of ability" but also of (2) "shape/form". I hope I can make some progress on these issues after this paper.

[8] There are many writings on "measures to preserve law and order" and "legally mandated medical supervision". These are of course necessary, while at the same time some of them are quite dangerous. But I think that there have been few attempts to address this topic on the basis of the question "what is (or is considered to be) a disability?" For related works see Teramoto [2002a] and [2002b]. In my own writings I have done little more than point out that this is a difficult problem (see Tateiwa [2003]).

[9] Is it possible to reconcile the assertion that there are things in society which lead to impairment, and, as such, should be criticized and ultimately reformed, with the assertion that it is wrong to view "shogai" negatively? If such reconciliation is possible, what form might it take?

Regarding war, for example, it has been pointed out that even after the fighting has ended large numbers of people continue to be rendered disable by landmines and conditions of poverty that armed conflict leaves in its wake. This observation is indeed correct. In particular, this issue is often raised regarding disability as it occurs in "underdeveloped" countries/regions. This is, I think, quite natural. But how does this kind of assertion relate to the claim that "we should not reject "shogai""? In Japan this question arises as one of how would people with Minamata disease view or depict this kind of assertion? How might we reconcile the denouncing of Minamata disease with a reluctance to characterize people with this disease as pathetic or miserable? I discuss this briefly in chapter 2 of Tateiwa [2008]. Questions were later raised about to what extent it should be acceptable for the anti nuclear reactor movement to use images of the victims of the Chernobyl disaster in the course of advocating for their cause -- I touch on this in cited papers of Aiko Tsutsumi (Tsutsumi [1988] and [1989], she has cerebral palsy and is peer consultor and a member of Women's Network of DPI Japan, cf. Tsutsumi et al. [2009] as English paper on website) in Tateiwa [2002]. (Some of these texts of Tsutumi and others are translated into English and Korean and cited in our website. See "Discourses on Disability": http://www.arsvi.com/d/d00d-e.htm, http://www.arsvi.com/d/d00d-k.htm). I do not think there is a fundamental contradiction between denunciation/accusation and affirmation (or at least a refusal to reject) in this case. The question is thus how to articulate these assertions that I do not think ought to contradict each other. This is one of the things I have attempted to do by writing this article.

There is, for example, an organization called the "Association of parents of children with congenital limb defects (APCCLD)". It was established in 1975 as an organization for the parents of children born with missing limbs or fingers. The causes of these impairments were not known, but many problems concerning environmental pollution were uncovered around that time. A connection between this kind of pollution and these impairments was suspected, and part of what this organization engaged in was a movement to demand an "investigation of causes". One of their aims in doing so was to eradicate these sorts of impairments.

But is it right to view impairments (rather (2) differences in shape/form) negatively when there are already children living with them? Over time this sort of question began to be given consideration. What is written in APCCLD eds.[1982a], [1982b], for example, is not the same as what is asserted in APCCLD [1999], [2003]. Differences can also be seen between what is said in Nobe [1982] and Nobe [1993] -- two texts by Akiko Nobe, someone who has been involved with this organization for many years. For a description and analysis of this organization's history see Hori (our post doctoral fellow in 2011) [2007] and [2008].

[10] This is one of the reasons there are instances in which it is not appropriate to speak in terms of the contrast between impairment and disability. Assertions of the social model do not emphasize impairment, and it would presumably be acceptable for there to be some cases in which it is not specified, but impairment is nevertheless essential to the construction of these arguments. There are cases, however, where no explicit specification is made, and perhaps it is not always needed. In any case, the argument is made that if an individual cannot do something we ought to seek ways to make up for this lack of ability without rooting around for its cause. If so, it may be suggested that we should view cases in which an individual cannot do something — within this society — and suffers a disadvantage as a result, presumably in connection with some aspect of the body of the individual in question, as instances of disability. I basically support this view.

This is also connected to what was discussed in the previous note. Individuals are required to prove certain things about the current condition of their bodies in order to receive compensation/support. They may also be required to describe how pitiful or miserable their own condition is, which can then lead to their being suspected of exaggerating their suffering in order to receive more benefits.

On the other hand, individuals do in fact benefit from having the situation they find themselves in described and given a name. So what is the nature of these benefits they receive? And what sorts of things can be said about "understanding" based on taking this into consideration? Quoting from the writings of people who have stated that they benefitted from understanding that they are "autistic", I considered this issue further in serial articles (Tateiwa [2008-2010], they will become a book in 2011).

[11] See Furui [2003] (He is a physiotherapist and also has lived as partner of an activist of disability movement), and also the section on the history of (the failures of) treatment of cerebral palsy in Sugimoto and Tateiwa [2010], an interview to Dr. Sugimoto.

[12] I first discussed this in Tateiwa [2001]. At the time I wrote this text I was in charge of a course for students aiming to become physiotherapists. Eg. for them, the first thing to be done is to give medical

treatment, and once a certain level has been reached rehabilitation (in the normal, narrow sense of the term) is carried out. Even after this process has been completed some aspects of the patient's condition may remain unrecovered. Here "social welfare" comes into play. This is considered an obvious and natural state of affairs, and in practice this process is carried out smoothly. I do not deny that in some cases this is a valid approach. But it is surely not correct to always think in this way. I have talked and written about this.

[13] There are cases in which the body is touched and seen. There are excretions. There are sexual issues that arise when care is administered, and care in the form of sexual activity. This is discussed in Kusayama [2005] and Maeda [2005], both of which were published in Kuramoto ed. [2005]. Related discussion/analysis also appears in Maeda [2009]. In one of my other works (Tateiwa [2010e:51-58]) I quoted from a letter by Kinuko Mitsui (in Mitsui [2006]) -- she has cerebral palsy and is one of those who left institutions and began independent living in the early 1970's in Japan -- in which, responding to the head nurse at the institution where she lived saying that regarding assisting inmates when they use the toilet "you should get beyond the distinction between men and women", she writes "if that is the case, why do we have separate washrooms for men and women?". Next I cited from Yuho Asaka's book -- she has dysosteogenesis and who introduced peer counseling into Japan first, lived with a daughter who also has dysosteogenesis, and is representative of a CIL (Center for Independent Living). "Our immovable limbs are a fact of our existence, so openly putting our bottoms in the care of others for us constitutes independence. ...thinking in terms of "privacy" and "personal territory" serves no useful purpose when it comes to the actual circumstances of disabled people, and in some cases this way of thinking may in fact be harmful" (Asaka [2010]). Both Mitsui and Asaka are no doubt correct in what they assert. The question then becomes how this can best be articulated. Some aspects of these issues are discussed in Tateiwa [2010e:56-58]. (Their lives and activities are introduced in "Disability Movement / Studies in Japan 9: http://www.arsvi.com/ts2000/20100099-e.htm Women" site. See (English), http://www.arsvi.com/ts2000/20100099-k.htm (Korean)).

[14] For example Peter Singer says the following (quoted these passages in Tateiwa [2002]).

"If disabled people who must use wheelchairs to get around were suddenly offered a miracle drug that would, with no side effects, give them full use of their legs, how many of them would refuse to take it on the grounds that life with a disability is in no way inferior to life without a disability? In seeking medical assistance to overcome and eliminate disability, when it is available, disabled people themselves show that the preference for a life without disability is no mere prejudice. [...]

To be able to walk, to see, to hear, to be relatively free from pain and discomfort, communicate effectively--all these are, under virtually any social condition, genuine benefits. To say this is not to deny that people lacking these abilities may triumph over their disabilities and have lives of astonishing richness and diversity. Nevertheless, we show no prejudice against disabled people if we prefer, whether for ourselves or for our children, not to be faced with hurdles so great that to surmount them is in itself a triumph." (Singer [1993:54 = 1999:65])

This section is translated into Japanese and examined in Tsuchiya [1994a] (see also Tsuchiya [1993] [1994b][1994c]). Attention should be paid to the assertion in the cited text that there are no disadvantages to what is gained -- "with no side effects" -- and the fact that several factors "to be able to walk, to see, to hear, to be relatively free from pain and discomfort" that I have attempted to separate in this paper are

enumerated and stapled.

[15] This is correctly pointed out in Hoshika [2007]. Hoshika asserts, as I do, that the problem is not one of standards regarding matters of fact or of standards regarding the facts of causation, and that errors are sometimes made regarding this point. In this text I have stated that I fundamentally share Hoshika's perspective. It would seem that when the English phrase "due to" is used what is referred to is not only causes/factors that bring about (or do not bring about) certain phenomena; it is also used in instances when various things occur which should not (or fail to occur when they should). We can interpret Oliver's example which I cited at the beginning of this paper. But I (too) think it is right to address as problematic writings/approaches that maintain a certain vagueness regarding what the core of the issue is.

At the same time, Hoshika has criticized the understanding of the social model presented in Tateiwa [2002]. What I state in this text is also meant to serve as a reply to these criticisms. I intend to carry out an introduction and examination of Hoshika's arguments in a separate work.

[16] I do not think it wrong itself that reformist and conscientious leaders of rehabilitation assert that both medical treatment/rehabilitation (in a narrow sense) and social support are required and that it is wrong to advocate for only the latter. One issue that should be addressed, however, is why such "extreme" assertions have been made by some disabled people. Another important question is what actually follows from related assertions such as that since both are important they should be used in combination, and that decisions should be made by the person in question. Problems will result if this issue is not given sufficient consideration. If this point is not clearly addressed, or indeed even if sufficiently correct and precise statements are made in the discourse, when it comes to putting these ideas into practice or implementing them as public policy what is said or done "on site" could very well become something different (and not simply by accident).

Tateiwa [2010d] addressing the movement in opposition to the termination of rehabilitation (by the national government since 2006) advocated by Tomio Tada -- he was famous biologist and had fit of apoplexy and had received rehabilitation -- and others (and its complicated connection to the rehabilitation industry and its academic world and those who promote these) addresses this, and should lead to a clearer, more concrete exposition of this issue. And I think that it is necessary to examine the relationship between their assertion and the assertion by eg. DPI that the term of rehabilitation should be limited (cf.Tateiwa [2000:254-255, 335]). Tateiwa [2010c] takes up this topic, and will presumably clarify some of the confused or confusing statements which have been made regarding excessive/insufficient medical treatment, rehabilitation, and social services at large and ultimately delineate what sorts of things can validly be said on this topic.

[17] My criticism of Van Parijs's "undominated diversity" solution (Van Parijs [1995 = 2009]) -- here too various other factors in addition to functional differences are addressed together; differences related to physical beauty are raised as an example, and it is proposed that regarding those who are (deemed to be) inferior in this regard, supplementary funds be provided (separately from the basic income) up to the point a single individual emerges who would accept the situation in question in exchange for the supplementary funds provided -- is in Tateiwa [2010a]. I make several additional points on this topic in Tateiwa [2010a].

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