

Creating a Society for All: **Disability and Economy**

Proceedings of the forum *Disability and Economy: Creating a Society for All* hosted by Research on Economy and Disability (READ), the University of Tokyo (Todai) in association with Manchester Metropolitan University (MMU)

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The Disability Press

The Disability Press aims to provide an alternative outlet for work in the field of ‘disability studies’. It draws inspiration from the work of all those countless disabled individuals and their allies who have, over the years, struggled to place ‘disability’ onto the political agenda. The establishment of The Disability Press is a testament to the growing recognition of ‘disability’ as an equal opportunities and human rights issue within the social sciences and more widely in society.

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Colin Barnes and Alison Sheldon, 2012

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INTRODUCTION

Creating a society for all: Towards an emancipatory economics of disability

Dan Goodley, Yasuyuki Sawada and Alison Sheldon

Introduction

This book brings together the proceedings of the conference *Disability and Economy: Creating a Society for All* hosted by Research on Economy and Disability (READ), the University of Tokyo (Todai) in association with Manchester Metropolitan University (MMU), held in Manchester in April 2009. This conference, funded and supported by both universities, allowed opportunities for the sharing of research in the areas of disability studies and economics. Delegates representing numerous countries including Britain, India, Malaysia, Nepal, Japan and the United States came together over two days to discuss the interconnections of disability and the economy (Scullian, 2009). As the contributions to this book demonstrate, these connections are complex but necessary. In April 2009 the world was entering increasingly uncertain economic times. We know from history that when societies struggle to maintain their wealth then disabled people are among the first to suffer (Ainsworth, 2009; Sheldon, 2009). The conference was therefore timely and as delegates we were reminded (as if we need to be reminded) that there remains a paramount duty to develop *social* theories of disability that address the socio-economic, cultural and political conditions of disabled people's exclusion in order that that their disadvantage might be alleviated. This then is the continuing challenge for disability studies.

As chapters in this collection demonstrate, disability studies has developed in nuanced, 'glocal' ways reflecting distinct regional contexts (Goodley, 2011). As disability studies develops across the globe this raises interesting questions about how theory, research and practice to respond to these global and local challenges (Shakespeare, 2006; Goodley, 2011) of disability studies theory. Like women's and black Studies, it has also developed into a new interdisciplinary sphere of scholarly work (Meekosha, 2004). More and more collections of Disability Studies writings transcend both trans-national contexts and disciplinary perspectives (eg: Albrecht *et al.*,

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2001; Barnes *et al.*, 1999). Increasingly, researchers work across disciplines, such as the social sciences and humanities (Riddell and Watson, 2003). This collection continues in this pan-national and trans-disciplinary vein by bringing together scholars from Britain and Japan from the disciplines of sociology, social policy, psychology and economics. What is very clear from all of the contributions is that the economic position of disabled people threatens to create conditions of marginalisation, cultures of exclusion and psychological experiences of disablism.

Materialist disability studies writings have long been concerned with the economy as the root cause of disabled people's disadvantage (eg: Finkelstein, 1980; Gleeson, 1999; Russell, 2002), although this strand of scholarship remains woefully underdeveloped (Sheldon, 2009). In economics – one of the established fields in the social sciences – researchers investigate the allocation mechanisms of economic and non-economic resources and the resulting welfare and well-being of people. However, while the disabled population comprises one of the poorest and most marginalized segments of global society (World Bank, 2005), suffering from considerable welfare losses under social and economic turmoil such as the current global financial crisis; economics has more or less ignored issues specific to disability. There are at least two possible reasons for this neglect.

Firstly, first-generation modern economics in the 1950s and 1960s, (a.k.a. neoclassical economics) investigated price mechanisms in 'frictionless' markets (Arrow and Debreu, 1954). In such an imaginary world, market allocation can achieve a unique desirable outcome, and therefore, there would be no need to analyze disability-specific issues. In reality, however, the existence of market frictions hinders the functioning of price mechanisms. In the real world, multiple outcomes – some of which are better than others – may arise. Indeed, second-generation economics has explicitly investigated such market failures. One of the most powerful tools has been 'game theory' – a mathematical framework to formalize decisions and allocations under strategic environments (Fudenberg and Tirole, 1991). With this new tool, economists have studied diverse issues, ranging from firm entry to social discrimination. Hence, it appears natural for economists to proceed to study disability issues.

Secondly however, there still seems to be a serious lack of rigorous evidence to identify the socioeconomic, cultural, and political underpinnings of disabled people's exclusion, especially in 'developing' countries (Eide and Loeb, 2006). This lack of information and data may have prevented most

empirical economists from studying disability and related issues. Hence, gathering detailed evidence is an indispensable component of the economics of disability. While a global- or macro-level analysis is indispensable, micro-level – individual, household, or community level – evidence would also be crucial to developing evidence-based economic analyses of disability. In sum, there is a large space in which we can facilitate mutually-complementary collaborations between disability studies and economics. This book is an attempt to bridge these two divided fields, together with other related disciplines, by evidence-based research from different countries. As will now be outlined, the various chapters in this volume represent an important step toward an emancipatory economics of disability.

Overview of chapters

This collection is in two parts. The chapters in *Part One* are based on conference presentations delivered by established British and Japanese scholars in April 2009. The shorter chapters in *Part Two* are based on poster presentation and additional material by Japanese researchers. Whilst language and terminology can be a very sensitive issue within disability studies, it is also the case that what is and is not acceptable language to describe disabled people varies both historically and culturally. The chapters have therefore not been subject to editorial amendments in this area.

Part one: conference papers

In *Chapter 1*, Akihiko Matsui argues that disability studies can provide mainstream economics with new insights that facilitate the formation of better economic and social theories and policies. He bases this argument on the results of empirical analyses of Japanese data in which the perceptions of homogeneity, which affect people's attitudes toward disabled people and thereby induce stigma and prejudice, are directly observed and significantly related to economic variables.

Disability is intimately related to global poverty – an issue examined by Colin Barnes in *Chapter 2*. Rooting his analysis in a social model of disability, Barnes provides a materialist analysis of the production and perpetuation of both disability and global poverty and charts the emergence and achievements of disabled people's movements across the globe. In conclusion he proposes that the current emphasis on rights-based solutions is insufficient to eradicate the global problems of disability and underdevelopment. Instead, disabled

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people's movements and other like-minded groups should work together to challenge the root causes of all forms of global oppression.

Chapter 3 by Dan Goodley and Rebecca Lawthom employs a study of disablism in and across the UK and Malaysia in order to investigate some initial findings on the economics, psychology and disability nexus. This chapter discusses inter-connections between biopower, economic power and the hybrid nature of all local contexts with reference to the concept of 'Empire', which can be defined as a globalised biopolitical machine, that is, the means through which theories of psychology spread, infecting or affecting people in every corner of the world. The authors find a complex mix of local and global disability discourses and highlight the possibilities these allow for working in enabling ways with disabled people.

The nexus between disability, impairment and economics is discussed further in *Chapter 4* by Tom Shakespeare, who argues for the relevance of class and inequality in both causal and consequential terms. This chapter also emphasizes the need for a deeper theoretical understanding of the relationship of disability to economics in the contexts of capitalism or other economic systems, social inequality and deprivation, class-specific barriers, labour market and employment experience, and consumption.

Chapter 5 by Satoshi Fukushima attempts to characterise disability studies on the basis of the author's own experience as a deafblind person. For Fukushima, disability studies is an interdisciplinary research field in which – through the phenomenon of disability – the way both society and human beings work is investigated. Two primary tasks of disability studies are to make a positive contribution to disabled people's lives and to tackle issues relating to discrimination for both disabled and non-disabled people.

In *Chapter 6*, Ryoji Hoshika investigates whether a quota system for the employment of disabled people can be justified in a normative manner from the perspective of equality of opportunity. The research results indicate that within the 'equality-of-opportunity' philosophies based on the 'level-the-playing-field' principle, quota employment systems can be justified. In the case of Japan's quota employment system for disabled persons, the system can at least be partially justified from an equal opportunity policy perspective, although this perspective would not be fully adequate to defend the system. If these findings are disseminated among many disabled and non-disabled people, we can expect that the negative effects of the policy will be mitigated or prevented.

Part two: poster presentations and additional material

We begin *Part Two* of this collection with *Chapter 7* by Machiko Kawamura, who examines the problems faced by siblings of persons with ‘intellectual and developmental disabilities’. The chapter emphasizes the view of disability as a social obstacle and the integrated view of the characteristics of a society and the characteristics of siblings of persons with ‘intellectual and developmental disabilities’ as non-separable attributes. Such a view is based on the conceptualisation of an individual’s various psychological processes as one part of the socio-cultural system.

In *Chapter 8*, Satoshi Kawashima explores through the use of different models of disability, how disability should be defined and conceptualized in the context of the judicial and legislative process of discrimination law. The chapter explores disability law in light of the recent United Nation Convention on the Rights of Persons with Disabilities. This chapter raises some difficult but important questions about the impact of definitions of impairment and disability on anti-discriminatory law, reminding us that the potency of disability studies theory is often assessed in terms of how it is applied in the social world.

Chapter 9 provides an exploration of disability activism by Osamu Nagase. His focus on *Aoi Shiba* – a group of disabled people in Japan, which formed in 1957 – raises fundamental issues about self-identity, self-assertion and paternalism in the lives of disabled people. This organisation initiated what has now come to form the modern disability rights movement in Japan and has been instrumental in the development of disability studies. The aims of the group capture some of the nuanced foci of disability activists – particularly the relationships between disabled and non-disabled people – captured powerfully in one of their assertions:

We deny love and justice: We condemn egoism held by love and justice. We believe that mutual understanding, accompanying the human observation which arises from the denial of love and justice, means the true well-being, and we act on this belief.

Furthermore, this chapter draws our attention to the varying forms of disability activism that have emerged in specific times and places in response to national, as well as global, discourses around disability.

Chapter 10, by Miki Nishikura, explores an issue often ignored by mainstream disability studies: the experiences of people with facial

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disfigurements. The chapter considers the various difficulties that people with visible differences experience in terms of employment, with a specific focus on the time just before applying for work. This is another welcome contribution to disability studies because it recognises that perceptions of impairment hugely influence how non-disabled others react to the phenomenon of disability. Furthermore, the use of psychological literature in this chapter indicates that much can be gained by disability studies colonising disciplines in order to expose the conditions of disablism.

A social psychological and economics analysis is taken further by Kiri Sakahara and Takashi Sato in *Chapter 11*, who employ ideas from channel theory to unpack some of the inter-subjective relationships between disabled and non-disabled people. A key application of their work, the authors suggest, is to promote understandings of disability and impairment at the level of relationships between people. Hence, the very meaning of disability and impairment do not reside within individuals but between individuals. Disability and impairment are thus relational phenomena, requiring sustained analysis and application.

In *Chapter 12*, Yohei Sekiguchi explores the ethics of societal responses to disability. Welfare states often respond to disabled people through offering some kind of compensation. The arguments developed in this chapter suggest that there is no satisfactory way to aggregate individuals' opinions about various compensation schemes. Through a specific exploration of social insurance for disabled people, the author concludes that, based on the social choice theory and their empirical analyses, there are huge problems with monetary compensation for disabled people.

Yuriko Iino's analysis in *Chapter 13* continues the trans-disciplinary nature of the contributions of the book by synthesising feminist and disability activist agendas in an analysis of 'productivity' and 'work'. The contributions of *Lotta Feminista* (an Italian feminist group known for its argument on wages for household work), and *Aoi Shiba* (the Japanese disabled people's organisation, also introduced in chapter 9 of this book) are compared and contrasted. It is concluded that 'A society for all' must be a society that allows all members to live dignified lives. We are urged to create a society that includes the perspective of those who have difficulty sustaining their lives either through dependence on the labour market or on any 'productive' work. This finding reminds us that material labour – particularly as it is conceptualised in capitalist societies – should not be seen 'as the be all and end all' of citizenship.

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Our examination of the intersections of gender and disability continues in *Chapter 14* through Noriko Seyama and Kumiko Usui's analysis of the current socioeconomic situation of disabled women in Japan. Their research reveals an all-too-common global finding: disabled women are placed in a position of high instability and poverty. It is possible perhaps to read this chapter as defining the problem and *Chapter 13* as providing some responses to the exclusion of disabled women. For, as Seyama and Usui conclude:

the challenges surrounding the existence of women with disabilities raise issues regarding the need to connect the ideas of work with the idea of 'living with dignity as a member of society', from a position where two perspectives intersect: the perspective of efforts by women bringing gender discrimination structurally-embedded in our society out into the open, and the disabled people's rights movement, which has prompted a shift in the definition of the right to live and to be independent.

Finally, *Chapter 15* by Kamal Lamichhane explores educational provision and parental perspectives in the lives of disabled children in Nepal. Considering data on the educational exclusion of disabled children, Lamichhane concludes that in light of the complex interrelations of various barriers to education, it is imperative that efforts be made to ensure that disabled people in South Asian 'developing' nations like Nepal are included in disability studies research on education. This last chapter acts as a healthy reminder that disability is a global and local phenomenon. While disability studies has been largely conceived in Anglo-Nordic-North-American contexts (Goodley, 2011), this chapter – along with the other contributions to this book – clearly indicates that disability studies is, and should be, responding to both the global and local concerns of disabled people.

Summary

What is very clear from all of the contributions in this volume, is that the economic position of disabled people threatens to create conditions of marginalisation, cultures of exclusion and psychological experiences of disablism. Thankfully, the global rise of disability studies attends not simply to oppression but also to possibilities for resistance. Disability studies are testimony to the politicisation of disabled people and their representative

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movements. The onus is on disability studies scholars to engage in research that assists disabled people in their fight for full equality (Thomas, 2004). An emancipatory economics of disability could play a crucial role in disabled people's struggles to create a society for all.

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Part One:

Conference presentations

Disability and economy in Japan

Akihiko Matsui

This paper shows that, at least in Japan, the perception of homogeneity affects people's attitudes toward disabled people, inducing prejudices and stigma, and that these attitudes are not only real, but are also related to economic variables. Through this work, we argue that disability studies can provide mainstream economics consisting of price theory and game theory – that have developed tools to study not only markets, but also customs and institutions as endogenous and integral parts of economies and societies – with new insights and can in turn make use of their methods in forming economic and social policies.

Introduction

Japanese society has been perceived as one consisting of a homogenous population by the Japanese themselves. This perception is not completely groundless. Although the *Ainu* have been recognized as a minority, they are far out-numbered by the majority of the population (according to *Hokkaido Kankyo Seikatsu-bu* (2006), only about 24,000 people, or 0.02% of the total population, have been identified as *Ainu* people). Unlike many other developed countries, Japan does not accept a substantial number of immigrants (according to the United Nations (2006), migrant stocks are 9.1% of the total population or 14th among 30 OECD countries for the U.K., for example, while 1.6% or 28th for Japan). Still, there are certainly groups of people in Japan who are not regarded as 'ordinary' Japanese. Six and a half million disabled people, or 5% of the total population, constitute the most significant among such groups, though this number itself is much lower than the corresponding numbers in other developed countries. For example, the fraction of people with LSHPD (longstanding health problem or disability) between 16 and 64 are 32.2% in Finland (the highest), 27.2% in U.K. (EUROSTAT, 2003). On the other hand, People registered as disabled between 18 and 64 is 4% in Japan, which makes a strict distinction between

disabled people from those who suffer from longstanding health problems (Ministry of Health, Labour and Welfare, 2005, and National census, 2005).

As a matter of course, the various systems that make up society, including the height of each step of a flight of stairs, and the tax and social security systems, are designed to meet the needs of ‘ordinary’ people. As a result, those who are not ‘ordinary’ have difficulties in living with these systems. This is true not only in Japan but also in the United Kingdom and many other countries. Since, however, the Japanese perceive their country as consisting of a homogeneous group of people, there is a possibility that Japan disables some people more than other developed countries do. Indeed, some of these people are considered exceptional and are classified into groups like homeless people, single mothers, disabled people, and so on. Their basic needs are determined by the government, each individual need is labelled a ‘luxury’, and they are obliged to lead their lives as a social burden.

The purpose of the present paper is twofold. First, it shows that, at least in Japan, the perception of homogeneity affects people’s attitudes toward disabled people, inducing prejudices and stigma, and that these attitudes are not only real but are also related to economic variables.

The second purpose is related to the scope of our entire research project – rather than that of the present paper *per se* – which is to develop a new field of study on barriers in socio-economic contexts through the interaction between disability studies and economics. Disability studies as a discipline is said to have begun in the United Kingdom in the 1970s as an interdisciplinary field of research, to which political science, history, and sociology have contributed. These differentiate socially constructed disabilities from physical impairments and focus on the former.

In spite of its rich contents, disability studies has not adequately reached mainstream economists who study price theory and game theory, and therefore, has not satisfactorily influenced economic policies. This is unfortunate, since price theory and game theory have developed tools to study not only markets but also customs and institutions as endogenous and integral parts of economies and societies. Disability studies can thus provide price theory and game theory with new insights, and can in turn make use of their methods in forming economic and social policies.

The remainder of this paper is organized as follows. Section 2 introduces two key related concepts in economics, complementarity and externality. In the presence of complementarity and network externality in an economy, Adam Smith’s invisible hand may not work, and the economy may

be trapped in a poor equilibrium, i.e., a stable situation. Section 3 presents a formal theory of inductive game theory, which gives rise to social perceptions that do not necessarily reflect the underlying structure of the society. Section 4 shows that such perceptions are not only real, but are also related to economic variables such as income. Section 5 argues that such perceptions may affect a welfare regime. Section 6 concludes the paper.

Complementarity and network externality

This section introduces two key related concepts in economics, complementarity and network externality. Network externality can be explained by using a public transport system as an example, say, an underground railway system. If only one station, say, *A*, is accessible by wheelchairs, the system is useless for people using wheelchairs since the purpose of using the underground is to go to another station. Therefore, we need at least two stations to be accessible by wheelchairs. But again, unless one uses these two particular stations, say, *A* and *B*, the system is still useless. Only one pattern of movement, going between *A* and *B* can be accommodated. What happens if three stations, *A*, *B* and *C* become accessible? There are now three patterns that can be accommodated. In general, if n stations become accessible by wheelchairs, $n(n-1)/2$ patterns of movements are accommodated. In other words, the accessibility of the underground increases at a faster rate than the number of stations with wheelchair access.

One may correctly point out that the accessibility of underground railways is not enough for those who wish to move around by themselves. We need more, of course. We need accessibility for buildings, streets, buses, and so on. Some economists call such a situation institutional complementarity (Aoki, 2001).

Another notable example can be found in the New York (NY) subway system. In the 1980s, it was considered dangerous to travel on the NY subway. Robberies were common, and the train cars were covered with graffiti. In the late 80s and early 90s, there was a dramatic change. In order to make the subway safe, NYC increased the number of policemen on board the trains. It also changed the materials used for train car bodies to make it easy to erase graffiti. As a result, the NY subway became a fairly safe means of transportation.

The implication is significant. Unlike simple externality, which can be corrected through, say, Pigouvian taxation (see a standard textbook, say,

Mankiw (1998)), the network externality and complementarity pose an immense challenge to a market economy: Adam Smith's invisible hand does not necessarily work. Examples other than the above anecdotes are abundant. The financial crisis is one of the latest and severest examples. If many investors want to take their money out of an investment bank, then people rush into this conduct since the swifter one moves, the higher is the chance of securing one's investment money (see Diamond and Dybvig (1983)). This leads to a so-called bank run. What happened in 2008 was this fear of a bank run in non-commercial-bank financial institutions, which were not regulated as stringently as commercial banks. This 'bank run' corresponds to one equilibrium, while 'no bank run' corresponds to another. What the governments and central banks have been trying to do is to avoid the bank run equilibrium by injecting trillions of dollars into financial sectors.

As is mentioned already, in the realm of disability, a similar phenomenon can be seen in terms of accessibility. If all disabled people stay in their domicile and do not go outside, then there is no need to accommodate them, and therefore, no action is taken, say, by the government. Thus, we need a critical mass to obtain a different equilibrium where the needs of disabled people are properly accommodated.

As we have seen above, complementarity often creates multiple equilibria, some of which are better than others. This multiplicity sometimes gives rise to unnecessary but persistent discrimination and stigma, to which we now turn.

The emergence of stigma from discrimination

While stigma has been a key concept in sociology since Goffman (1963), it has never been a key concept in economics. One reason for this is that stigma is a mental attachment, and there has been little attempt to relate it to economic variables (Note: One exception is Becker (1971), but his analysis assumes stigma at the outset, while the purpose of our analysis is to endogenize it). Kaneko and Matsui (1999) studied stigma in a game theoretic context, constructing a two-stage game called the festival game. In the first stage of this game, a population, which is divided into two ethnic groups, *A* and *B*, simultaneously choose a location, 1 or 2, to visit. Let group *A* be the majority and group *B* the minority. In the second stage, upon observing the ethnic composition of the participants at one's own location, each person decides whether he/she will play in a friendly or an unfriendly manner. If a

person takes unfriendly action, then his/her level of satisfaction (payoff, henceforth) is at the default level of zero. On the other hand, if the person takes friendly action, then--since this is a 'festival'--his/her payoff depends upon the number of friendly people in the same location. The greater the number of friendly people, the higher the payoff to the person who takes friendly action. In other words, the festival game exhibits complementarity. If no other people take friendly action, the payoff from taking friendly action is less than that from taking unfriendly action. Here, we assume that even the smaller ethnic group is so large that the group by itself can reach a critical mass beyond which people taking friendly action receive a positive payoff. In order to obtain a clear result, it is assumed that their payoffs do not depend, among other things, upon the demographic composition.

Kaneko and Matsui decomposed the analysis of this game into two parts, the standard equilibrium analysis and a new analysis, called inductive game theory. First, the simplest equilibrium is the one in which everyone goes to the same location and takes friendly action. This is a unification equilibrium. Another simple equilibrium is the one in which people choose a location randomly, and wherever they may go, they take unfriendly action. These are equilibria since people would like to take friendly action if many others do, and vice versa.

Yet, there is another equilibrium, which may be called a segregation equilibrium. In this equilibrium, the two groups of people go to different locations: group *A* people go to, say, location 1, while group *B* people go to location 2. They take friendly action as long as they observe only people from their own ethnic group. In order for this situation to be an equilibrium, each individual in group *B* must have no incentive to deviate to location 1, which is physically more attractive than location 2 since more people gather there and a higher payoff is obtained there than at location 2. This is made possible if group *A* people discriminate against group *B* people. Technically, this can be done if when group *A* people see a group *B* person they suddenly take unfriendly action. This way, segregation is maintained through discrimination.

Kaneko and Matsui continued on to the development of inductive game theory. In this theory, people try to 'explain' their experiences by constructing a model. Suppose, for this purpose, that people do not know the actual structure of the game, or in particular, how their payoffs are determined. Suppose further that they play the game according to the segregation equilibrium described above.

In this equilibrium, people who wish to ‘explain’ the discriminatory behaviour may come up with the following story. For some reason, group *A* people are happy in general, but they become unhappy from time to time. When one closely monitors what happens when their payoff drops, one may realize that a decrease in payoff is observed whenever there is a group *B* person in location 1. Thus, this group *A* observer may conclude that group *A* people become unhappy when a group *B* person joins them. This is a false model since the objective game says that what matters is the number of friendly people. However, this prejudicial model may well explain one’s experiences. Prejudices emerge.

Intellectual disability and stigma

It is in this way that stigma may be attached to disabled people. This section constructs a very simple model in which stigma and income act as arguments of the utility function of the decision maker, and compares it with other alternative models via regression analysis. Moffitt (1983) presented a model of welfare stigma where participation in a welfare program causes utility reduction. The analysis of this section uses Japan’s prefectural data to see if there is stigma attached to disability registration, and if so, in which category we observe it.

Facts

What this section focuses on is the relationship between per capita prefectural income and the fraction of people registered as disabled. Samples are 47 prefectures of Japan. Summary statistics and their sources are listed in *Table 1*.

Table 2 (below) shows this relationship. As shown in the table, there is a strong negative correlation between per capita prefectural income and the fraction of people registered as mildly intellectually disabled, while per capita income has no significant correlation with the fraction of people registered as severely intellectually disabled, or physically disabled. These relations do not change in various other tests using different explanatory variables. In short, the higher the per capita prefectural income becomes, the lower the fraction of people registered as mildly intellectually disabled. This observation gives rise to several competing hypotheses, which we may classify into two classes. The first is where the actual number of mildly intellectually disabled people affects

the per capita income, and the second is where the number of registrations is affected by the per capita income.

Table 1

	Simple average across prefectures	Standard deviation	Source
Fraction of severely intellectually disabled people (per 10,000)	26.04	7.45	' <i>Fukushi-gyosei houkokurei</i> ' (2006) and 'Statistical observations of prefectures' (2005)
Fraction of mildly intellectually disabled people (per 10,000)	30.91	9.09	same as above
Per capita prefectural income (in thousand yen)	2623	327	'Statistical observations of prefectures' (2004)
Rate of continuation onto colleges (%)	47.30	6.668	'School basic survey' (2006)
Average number of people per household	2.670	0.202	'Statistical observations of prefectures' (2005)
Net social increase rate (%)	-0.173	0.250	'Statistical observations of prefectures' (2006)
Fraction of people at 65 and over (%)	22.44	2.74	'Statistical observations of prefectures' (2005)

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Table 2

	Fraction of severely intellectually disabled people (per 10,000)		Fraction of mildly intellectually disabled people (per 10,000)		
	Coefficient	t-value	Coefficient	t-value	
<i>Per capita prefectural income (in thousand yen)</i>	-0.0033	-0.80	-0.013	-2.73	**
<i>Rate of continuation onto colleges (%)</i>	-0.11	-0.63	-0.42	-2.07	*
<i>Average no. people per household</i>	0.80	0.18	15.17	2.92	**
<i>Net social increase rate (%)</i>	-6.57	-1.06	17.20	2.34	*
<i>Fraction 65 and over (%)</i>	1.05	2.43	1.36	2.65	*
<i>Constant</i>	13.09	0.78	18.73	0.94	
	R ² = 0.54		R ² = 0.57		

** Significance at the 1% level

* Significance at the 5% level

Another notable fact is that a very rough benchmark for intellectual disability is an IQ of below 75. Even if we set the threshold at 70, around 2.2% of the population should be intellectually disabled. However, even in the prefectures with higher numbers of registrations (Saga and Kagoshima), we observe that only 0.82% are registered (the lowest is Kanagawa, at 0.21%).

Competing hypotheses

This subsection considers several competing hypotheses that might explain the above facts. We divide the various hypotheses into two classes, based on whether the difference in the number of people registered as disabled reflects the actual number or not.

Hypothesis group 1: The actual number of disabled people and economic conditions

According to this hypothesis, economic conditions affect the distribution of intellectual level. There is some research that claims that children raised in a barren intellectual environment perform poorly on the standard IQ test. Among earlier works, Gordon (1923) conducted the Binet-Simon tests on different children to obtain several findings. For example, 76 children in England who live on canal boats and attend school only 5% of the requirement scored an IQ of 69.6. Moreover, the older they were, the lower were their IQ levels (the average IQ was 90 for children aged 4-6 years, while it was 60 for children aged 12-22 years). 82 Gipsy children scored 74.5 (their school attendance was 34.9%). In Japan, Hiroshima University (1965) and Takemura *et al.* (1965) conducted the Tanaka-Binet tests on 152 elementary school students. The average IQ was 87 (boys: 92, girls: 80).

If the rate of registration is higher for lower average IQs, then the suitable variables that explain this are measurements of intellectual level. There are some measurements of intellectual level that are available for all prefectures. One is the rate of higher education, and another is the average score in nation-wide examinations.

Table 2 shows that the percentage of high school students continuing on to colleges is significant at the 5% level, which shows the importance of the general educational level on the fraction of mildly intellectually disabled people. Still, notice that per capita prefectural income is significant at the 1% level.

Hypothesis group 2: Number of people registered as disabled and economic conditions

As we have already seen, there is a wide discrepancy between the statistically estimated number of intellectually disabled people and the registered number. This fact itself suggests that there is a possibility that registration is affected by factors other than IQ. One can think of two major competing hypotheses. The first is that it is the local government that decides whether or not to accept the application based upon its own merit. The second hypothesis is that each applicant for registration chooses whether or not to apply for registration in order to maximize his/her payoff. If the former is the case, then the richer the local government, the higher the fraction of disabled people becomes, since the local government has enough ‘pocket money’ to distribute to the public. Note that the index of the strength of local governments in terms of fiscal budget is strongly correlated with per capita prefectural income. The first hypothesis is therefore rejected at the 1% level as the sign is reversed and significant.

The second hypothesis is based upon a very simple economic model involving stigma. Suppose that one’s payoff is based, among other things, upon income and whether or not a stigma is attached. Let the payoff function u be of the form:

$$u(t,y,e) = t y^{ae} ,$$

where t is either one or a number s less than one, y is income, e is an idiosyncratic characteristic of the person in question, and a is a parameter less than one.

Suppose now that if one were registered as a person with an intellectual disability, a stigma is attached so that one’s payoff decreases, while at the same time one can obtain certain monetary benefits such as tax reductions and discounts for public transportation. Then, for the same monetary benefit z , one has an incentive to register if, and only if

$$u(s,y+z,e) > u(1,y,e),$$

or

$$y < z/[s^{-1/(ae)}-1].$$

Thus, the lower the person’s income, the higher the likelihood that the person will register. If the standard deviation of income distribution is the same

across prefectures, then the above formula is translated into a negative relationship between the rate of registration and per capita prefectural income. Note that we cannot do a similar analysis if we use an additive separable utility function as in Moffitt.

Table 2 shows this relation. The coefficient for per capita prefectural income is -0.013 and is significant at the 1% level. This tendency does not change even if we remove or add other variables except for a local government budget index which induces multicollinearity with per capita prefectural income.

For the moment, let us ignore the significance interval and look at the magnitude of the effect of per capita income. The coefficient of -0.013 implies that as per capita income increases by one million yen, the number of registrations for mild intellectual disability decreases by 13 per 10,000. This is a significant number when the numbers of registrations for this class across prefectures vary from 11 (Kanagawa) to 50 (Okinawa) per 10,000.

This hypothesis is consistent not only with the fact that there is a strong negative correlation between the number of registrations and the per capita prefectural income, but also with the fact that this correlation is seen only for mildly intellectually disabled people and not for severely intellectually disabled people. The reason that this correlation is not seen for severely intellectually disabled people is twofold. First, they are recognized irrespective of registration, and therefore, there is little disincentive to register. Second, their compensation level is much higher than that of mildly intellectually disabled people so that the effect of stigma is outweighed by this benefit. At this moment, we do not have data to differentiate these two reasons.

As can be seen from *Table 2*, there are other significant factors for the number of people registered as mildly intellectually disabled. The coefficient of the average number of people per household is positive and significant at the 1% level. As the number of people per household increases by one, the registered number increases by 15 per 10,000. Roughly speaking, the more children there are in a household, the more likely the household will tend towards registration, or a three-generation family will tend towards registration. One bold hypothesis is that if a family can compare one child with another child – either a sibling or a child of the grandparents, i.e., a parent when he/she was a child, then it is more likely to detect that the child in question is different from others than if they were not able to make the comparison.

Net social increase rate is also positive and significant. Given that urban area tends to attract people from rural area, this may mean that families with mildly intellectually disabled children move to urban area, seeking for better opportunities for special education and work opportunities.

An additional factor that may explain the decision to register is an employment quota for disabled people. Japan has an employment quota for disabled people: 1.8% for private firms, and 2.1% for many organizations in the public sector. The quota comes into effect when a firm has 56 or more employees. Moreover, if a firm has 300 or more employees, then it has to pay the government 50,000 yen or £400 per month for each person below the threshold (if a firm with more than 55 employees exceeds the threshold, it obtains a benefit from the government amounting to 25,000 yen or £200 per month for each extra person). On June 1, 2008, the rate of employment – the fraction of disabled people among the entire employees – was 1.59% (the actual rate is much smaller than this rate since there are exemptions, and a person with a severe disability is counted as two (double count)). Because organizations can count a worker only if the worker is registered as disabled, people have an additional incentive to register as disabled in order to make use of this system. The result indicates that people refrain from registering in the presence of prejudices and stigma even for the sake of such a non-negligible benefit.

Discussion – Diversity and welfare capitalism

Esping-Andersen (1990) argued that a key factor in the measurement of welfare capitalism is the degree of de-commodification. According to his analysis, ‘De-commodification occurs when a service is rendered as a matter of right, and when a person can maintain a livelihood without reliance on the market’ (*ibid*: 21-22). Based on this observation, he identified three different welfare regimes: 1) liberal; 2) conservative; and 3) social democratic. The United Kingdom and the United States are classified as liberal, Germany and many continental European countries as conservative, and Scandinavian countries as social democratic.

In the liberal regime, ‘rights are not so much attached to work performance as to demonstrable need. Needs-tests and typically meagre benefits, however, serve to curtail the de-commodifying effect’ (*ibid*: 22).

The conservative regime ‘espouses compulsory state social insurance with fairly strong entitlements. But again, this may not automatically secure

substantial de-commodification, since this hinges very much on the fabric eligibility and benefit rules' (*ibid*: 22).

Among these three, he considered the social democratic regime as the most advanced of the three in terms of de-commodification. 'It offers a basic, equal benefit to all, irrespective of prior earnings, contributions, or performance' (*ibid*: 23).

While Watanabe (2004), looking into Japanese social security system in general, stated that the Japanese regime was classified as a conservative regime in Esping-Andersen's context, Nakanishi (2008), who gears more toward a system for disabled people than a general one, claimed that the overall tendency of Japan is toward the liberal regime, especially after 1990.

This discrepancy can be explained by the factor of perceived homogeneity that characterizes Japanese society. In fact, Japan's system is twofold and somewhat skewed. On one hand, Japan's pension and medical systems are close to what the conservative regime prescribes in the sense that everyone is supposed to join the national health insurance program, though in reality we are facing a serious problem of non-registration. On the other hand, the programs for people with 'special' needs, including disabled people, look more similar to those in the liberal regime than in the conservative regime. Japan's *seikatsu-hogo* or livelihood protection system is best understood as similar to that under the liberal regime, as is the registration system for disabled people.

This double-standard is well reflected in the statistics on public expenditures. The public social expenditures of Japan in 2007 was 18.6% of GDP while the OECD average was 20.5%, and the incapacity related expenditures of Japan in 2007 were only 0.7% when the OECD average amounts to 2.3%. In fact, Japan is an outlier in the sense that incapacity related expenditures are disproportionately low when compared to total public social expenditures. An increase in incapacity related expenditure, especially in the form of direct payment, would increase benefits discussed in Section 4, which would in turn enhance registration of intellectually disabled people. It would then improve their living conditions.

Conclusion

This paper has shown that, at least in Japan, the perception of homogeneity affects people's awareness (or lack of awareness) of, and their attitudes towards, disabled people, which may lead to prejudices and stigma, and that

the consequences of this are real and related to economic variables. If the reader feels the importance of disability studies and economics proceeding hand in hand, half of the goal of this paper will have been achieved.

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CHAPTER 2

Disability in a Majority World Context: A materialist account

Colin Barnes

..the politics of disablement is about far more than disabled people, it is about challenging oppression in all its forms... Like racism, sexism, heterosexism and all other forms of social oppression, it is a human creation. It is impossible, therefore, to confront one type of oppression without confronting them all and, of course, the cultural values that created and sustain them. (Barnes, 1996: ix)

Introduction

Since the emergence of disability studies in the 1970s, most of the theorising produced by disability scholars has centred on the economic, political and cultural deprivations encountered by disabled people in wealthy states. With few notable exceptions, little attention has been paid to disability in the poorer countries of what is generally referred to as the ‘developing’, ‘third’ or, more recently, ‘majority’ world: nations outside Europe, North America, Australia and New Zealand. Yet it is increasingly evident that as globalisation intensifies all countries, whether rich or poor, are ever more economically, technologically and socially interdependent, and that the gap between high and low income countries has increased substantially. Also that the individualisation and medicalisation of disability that accompanied capitalist development in wealthy states is now commonplace across the world and that disabled people are the ‘poorest of the poor’ in all societies (Hurst and Albert, 2006: 24).

By employing a *social model* inspired analysis (Oliver, 2009) this paper offers a materialist exploration of the production and politics of poverty and disability in poorer countries. A materialist analysis is rooted in the belief that there is no life without material resources and that human history is nothing less than a protracted struggle for access to and control of these resources; namely, the economy. Also, that those who control the economy have a

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disproportionate influence on the politics and culture of everyday life. It is divided into three parts. The first part focuses on globalisation and inequality. The second section centres on poverty and disability. This is followed by a discussion of disability politics and the struggle for change. It is argued that both poverty and disablement are socially created problems that are exacerbated by the escalating processes of globalisation. Further, that proposed solutions to the problems encountered by disabled people in the developing world are unlikely to achieve success without radical change in terms of ideology, policy and practice at both national and international levels.

Globalisation and inequality

To understand poverty and disability in poor countries analyses must be set within a global context. Since the mid 20th century there has been a significant escalation of globalisation (encompassing the interconnectedness of individuals, groups and communities within world-wide economic, political and cultural networks) and an acceleration in the imposition of a capitalist world order (Held *et al.*, 1999). Consequentially the disabling tendencies associated with western influenced economic and cultural development: industrialisation, urbanisation, self reliance and ‘able bodied’ normality, are replicated across the globe. This has led to the erosion of diverse responses to impairment and in many cases the exclusion of people with impairments from communal life. Disabled women and children are especially vulnerable (Miles, 1995).

Whether global inequality has accelerated as a result of globalisation is a contested issue. Advocates argue that it is a positive, levelling process that undermines the disparity between rich and poor. They argue that during recent decades standards of living have improved across the world, illiteracy is declining, infant mortality and malnutrition is falling, and life expectancy has increased. Critics maintain that globalisation has generated greater inequality. They point to the 1990 *United Nations’ Development Report*, which notes that in 1960 twenty percent of the population in rich countries had thirty times more income than the poorest 20 per cent. By 1997 this disparity had risen to seventy four percent (Giddens, 2006: 392).

There are several ways of explaining global inequality. Modernisation and neo-liberal theories explain the disparity of wealth amongst nation states in terms of the failure of some countries to embrace free market forces. Thus, unfettered capitalism is the key to national and international prosperity. It is

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argued that adherence to traditional cultural values and institutions and the failure to adopt free market policies and values are responsible for the poor economic performance of poor countries (Rostow, 1978). Such arguments ignore or downplay the often long standing economic and political ties between rich and poor nations; ties that in many ways enable the former to sustain economic growth and prosperity at the expense of the latter (Hoogvelt, 2001).

Taking their lead from Karl Marx, dependency and world systems theorists argue that the spread of world capitalism has created a class like structure in which a core group of powerful states manipulate and exploit less powerful economies, in the same way that capitalists within nations create and exploit the working classes. Therefore the poverty of poor countries is explained as a direct consequence of their exploitation by wealthy nations and trans-national corporations that usually have their headquarters in one or more core states. Dependency theorists argue that exploitation began with colonisation; a political, economic system whereby powerful states colonise and rule over weaker societies to generate profit. This usually means the systematic acquisition and exploitation of the colonised nation's natural resources such as oil, metals, agricultural products and labour by and for the benefit of the colonial power. Although colonisation is generally associated with European nations colonising parts of Africa, Asia and South America; other states such as Japan were colonial powers too (Hout, 1993).

Although the spread of colonisation declined significantly during the last century, the exploitation of poor countries by trans-national corporations and wealthy states continues. Global corporate bodies, international banks and governments of rich countries exploit cheap labour by establishing factories and exploiting raw materials in poor nations to maximise profits with minimum government intervention. Additionally, the low prices set for local labour and natural resources prevent these countries from developing their own economies. They then have little choice but to borrow from international corporations and wealthy nations resulting in a spiral of debt which ensures their continued economic dependence (Hout, 1993).

World systems theorists argue that global inequality is best understood as a unified whole. Immanuel Wallerstein (1990), for example, argues that the world system is rooted in the expansion of markets and international trade in the fifteenth and sixteenth centuries. It encompasses an international market for goods and labour, a division of labour along class lines, formal and informal cooperation amongst powerful rich countries, and the structuring of

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the world economy into three economic zones: core, peripheral and semi peripheral. Core states are rich, industrially advanced countries like the USA, Japan and western European states that take most of the profit from the world economy. Semi peripheral nations are semi industrialised ‘middle income’ countries that yield profit to core nations, but also extract wealth from poorer peripheral states. Examples include Brazil, Chile, Mexico and the newly industrialised nations of East Asia such as South Korea.

Peripheral countries are mainly agricultural economies often rich in natural resources but the poorest in the world. Examples include Chad, Ethiopia, Nigeria, and Sudan in central Africa, and Columbia and Ecuador in South America. Their continued poverty is the result of systematic and ongoing exploitation by the core, and to a lesser degree, semi peripheral states. Notably, the apparent success of the semi periphery holds out the promise of similar development to periphery states. The structure of the world system has changed significantly over time. In the fifteenth and sixteenth centuries it was dominated by Italian city states such as Genoa and Venice. As their power waned they were superseded by Holland, then the UK and now the USA (Wallerstein, 1990).

However, the role of ‘free’ market economics as the main driver of wealth creation has been undermined further by recent research suggesting that sustained economic development is achievable by firm government action. Strategies include the state making low cost loans and tax breaks available to favoured industries, keeping tight controls on wages and the aggressive maintenance of political stability (World Bank, 1997). However, this form of state sponsored capitalism often results in the negation and suppression of basic human rights and freedoms. In countries like China, Taiwan and Singapore, for example, this has involved outlawing trade unions, banning strikes and jailing union leaders and political dissidents (Giddens, 2006).

Poverty and disability

In 1999 the World Bank estimated that 20 percent of people living on or below the poverty line in developing countries are disabled. A poverty line specifies a society’s minimum standard of living to which everybody should be entitled (Levinsohn, 2002). Poverty lines are country specific and most countries have different ideas of what constitutes a minimum standard of living. Nevertheless recent research using revised poverty line measures at

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\$1.25 based on the average poverty lines of the world's 10 to 20 poorest states, suggest that 1.4 billion people (one in four) in the 'developing' world were living on less than \$1.25 in 2005 (Chen and Ravallion, 2008).

Poverty however is best understood as a complex matrix of social exclusion that extends beyond income to encompass access to education, employment, housing, transport and the built environment, leisure, family life and social relationships (Coleridge, 2006). But disabled people's poverty cannot be explained simply in terms of disabling attitudes and prejudice. Rather it is rooted in structural inequalities and social processes. For instance, almost a third of the world's 'absolute poor' live in India. This level of poverty applies where people do not have enough resources to support a minimum of health and efficiency. Furthermore,

while 46 per cent of India's people survive in absolute poverty... about two thirds are "capability poor" i.e. they do not receive the minimum level of education and health care necessary for functioning human capabilities. (Sharif, 1999 quoted by Ghai, 2001: 28)

The marginalisation and powerlessness experienced by disabled people living in isolated rural areas and urban slums across Africa, Asia and Latin America are often overlooked. They are disproportionately unemployed, underemployed and underpaid. Moreover, poor societies rarely have the resources to sustain an adequate welfare safety net for those worst off. For example, between 65 and 80 percent of India's estimated 60 million disabled people live in areas where public amenities such as clean water, electricity and sanitation are almost non-existent. When juxtaposed with the lack of the most basic medical treatments and services, 'the problems of inequality and injustice are so massive as to appear unmanageable'. Disabled women and children experience particularly high levels of poverty, leading to chronic malnutrition and difficulty in resisting debilitating sickness (Ghai, 2001).

Education is frequently presented as a means of overcoming poverty and a necessary route to social inclusion. It also has a role to play in promoting the ideals of peace, freedom and justice (UNESCO, 1996: ii). Yet the export of western type schooling and skills often prove exclusionary or less relevant to local needs (Miles, 1996). The emphasis on specific skills such as literacy and numeracy, for example, may lead to the labelling of some children as 'educationally backward', or with 'learning difficulties' resulting

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in their marginalisation even in contexts where these skills are not vital to an individual's life chances (Ingstad, 2001).

Nevertheless in most developing countries education is viewed as the key to national reconstruction and prosperity. Henceforth international efforts to promote *Education for All* (EFA) have intensified since the first EFA conference in Jomtien, Thailand in 1990. The primary aim was to ensure that all children should complete at least five years of primary education by the year 2015). Yet despite successive initiatives since the *Salamanca Statement and Framework for Action* of 1994 to ensure that children with impairments are included in mainstream schools, recent research suggests that only 10 percent of *all* disabled children are in school (UNESCO, 2007). Also, there remains a divergence of views on the meaning of inclusion. Consequently despite some notable successes (Rieser, 2008), many disabled children are educated in segregated special schools (Miles and Singal, 2008).

In poor countries disability support systems (examples include peer support services, personal assistance schemes and assistive technologies) are severely under resourced or non-existent. Where basic services are available most disabled people cannot afford to pay for them. Recent estimates suggest that only two percent of disabled people in 'low and middle income states' have access to any kind of health/disability related support thus justifying the contention that disabled people in poorer societies are ignored by both 'governments and the international communities' (Katsui, 2006: 2). These problems are complemented by inaccessible transport systems and built environments. Moreover, there is little short-term prospect of moving significantly towards satisfying accessible housing or transport needs when overall standards are low. Environmental access appears to be of little concern in the densely populated and rapidly expanding cities of the developing world (Charlton, 1998).

As poverty is a consistent feature of disabled people's lives the world over, it is a major concern for most user led disability organisations in rich and poor countries alike. Yet although the link between disability and poverty is unequivocal and internationally recognised, recent attempts by agencies such as the United Nations (UN), the World Bank and the International Monetary Fund (IMF) have largely failed to address this issue in their attempts to eliminate poverty. The UN's *Millennium Development Goals* (2000), for example, have eight primary aims. These are universally desirable and ambitious goals, but they are rather vague and in concert with previous international initiatives are not accompanied by detailed, well planned

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participatory programmes. Moreover, whilst these aims were intended to be inclusive they were heavily criticised for their failure to address disability and disabled people (Albert, 2006: Coleridge, 2006).

Further, the World Bank and IMFs *Poverty Reduction Strategy Papers* (PRSP) approach launched in 1999 is widely touted as a major tool for tackling poverty and features in the planning documents of many low income states. Participation of poor people is encouraged at all stages of the PRSP process: formulation, implementation, monitoring and evaluation. This is in marked contrast to the top-down externally-imposed planning procedures of previous initiatives favoured by the IMF which were largely ineffectual. But whilst the PRSP approach may appear to represent an historic departure from earlier strategies, it does not include participation by disabled people. Indeed, the PRSP initiative presented disabled people, along with 'old' people, children and the 'chronically sick', as not 'economically active', but dependent on the community for 'special care and welfare' or as Coleridge points out 'objects of charity' (2006: 22).

Recently however the World Bank has undergone something of a sea change in its response to disability, largely due to the critique of its activities by disabled people and their organisation (Hurst and Albert, 2006; Coleridge, 2006). It has since adopted a policy of mainstreaming disability in all its programmes. In 2007 it published its *Social Analysis and Disability: A Guidance Note* which 'offers a practical guide to integrating social analysis and disability inclusive development into sector and thematic projects and programs of the World Bank' (World Bank, 2007: 1) including examples of linkage between disabled people and the UN's *Millennium Development Goals* mentioned above (*ibid*: 4).

But whilst this document highlights the importance of disability rights and institutional change the guidelines therein are not binding. Hence their impact depends on a variety of factors including: the project or programme, local context and, most importantly, 'available resources' (*ibid*: 2). These must come from other sources as the Bank is not a charity or a human rights organisation. Its policies are founded on neo-liberal/capitalist principles that support the interests of big business and trans-national corporations. Its primary function is to provide loans for economic development that have to be repaid. Its policies are determined by shareholders votes. The USA is its largest shareholder followed by Japan, Germany, the UK and France. 'The poorer the country the fewer votes it has and the less influence over the Bank's agenda' (Yeo, 2006: 75-76). Despite the apparent inclusion of

disability into the UN's *Millennium Development Goals*, the Bank has yet to allocate substantial funding into low income countries with an overtly disability inclusive philosophy and policy programme such as South Africa and Uganda.

Disability politics and the struggle for change

Since the 1970s a key stimulus for the politicisation of grass roots disability organisations the world over has been the increasingly high profile of disabled activists and their organisations in international politics. A major catalyst for change was the formation in 1981 of *Disabled Peoples' International* (DPI). As in rich countries, the experience of social exclusion had stimulated a growing radicalisation amongst disabled people in poor nations. The conflict between 'old' and 'new' disability politics surfaced at the meeting of *Rehabilitation International* (RI), an organisation led by non-disabled professionals wedded to traditional 'apolitical' medical interpretations of disability in Winnipeg, Canada, in 1980. Because of their exclusion from RI's controlling body dissident disabled delegates left to set up DPI, an international umbrella for national organisations *controlled and run* by disabled people (Driedger, 1989). The formation of DPI:

sent a clear message to bodies such as RI that never again would it be acceptable for discussions about disabled people to take place without our full and equal participation. (Flood, 2005: 184)

The growing international interest in disability is also evident in the UN's *Declaration on the Rights of Mentally Retarded Persons* (1971) followed by the *Declaration of the Rights of Disabled Persons* (1975). These were deemed necessary as previous conventions such as the *Universal Declaration of Human Rights* (1948), intended to include all sections of the community, had failed to address the particular needs of disabled people who were 'buried in the general category of vulnerable groups' (Coleridge, 2006: 23). Furthermore, 1981 was designated the *International Year of Disabled Persons* and 1983-92 the *Decade for Disabled Persons*. But the apparent radical thrust of these initiatives cannot obscure their foundation on individualistic, medical notions of disability and rehabilitation. But whilst the UN Decade achieved some successes, these were largely viewed as benefiting those in rich states by activists in poor nations. Thereafter followed a series of

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similar initiatives including the first and second *Asian and Pacific Decade of Disabled Persons* (1993-2002 and 2003-2012), the *African Decade of Disabled Persons* (2000-2009) and the *Arab Decade of Disabled Persons* (2003 - 2012), largely as a result of lobbying by disability activists and their organisations located in these regions. Subsequently local, national and international organisations have taken a more prominent and assertive role in promoting social change based on their own interpretations of disability and disability rights (Barnes and Mercer, 2005; Albert, 2006).

The activities of disabled activists in Uganda and South Africa illustrate the point well. In 1987 the *National Union of Disabled Persons of Uganda* (NUDIPU) was formed by 17 disabled people's groups as an umbrella organisation representing Uganda's disabled population. A cross impairment body its express aim is to fight discriminatory attitudes and practices, improve the welfare of disabled people, advocate for equal opportunities through involvement in policy planning and implementation with government and non-government organisations. As a consequence of NUDIPUs activities disability issues were embedded in the Ugandan Constitution in 1995. Disabled people are involved at all levels of the political process in Uganda including a Minister and five members of parliament and at least two officials in every regional and local governing body. A whole raft of legislation specifically addressing the needs and rights of disabled Ugandans has been introduced with the avowed aim of mainstreaming disability issues and access (Dube, 2006a).

Disability activism in South Africa is rooted in the 1980s and the opposition to apartheid (Finkelstein, 2005). So when the democratically elected *African National Congress* came to power in 1994 it established a *Constitutional Assembly* that introduced a *Bill of Rights* on May 8th 1996 which prohibits unfair discrimination against various categories of people including disabled people. Disability has a strong parliamentary presence in South Africa with an Office on the Status of Disabled Persons and staffed entirely by disabled people. In 1997 an *Integrated National Disability Strategy* was introduced which provided government and society as a whole with guidance to promote non-discriminatory development planning, policy and practice. This was accompanied by several initiatives with a strong disability element such as the *South African Schools Act* and the *Employment Equality Act 1998* (Dube, 2006b: 126).

The policy environment in both Uganda and South Africa should have stimulated a general awareness of the needs of disabled people and an

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unprecedented opportunity to bring about meaningful change in both countries. Yet implementation has been seriously hampered by several factors. These include a chronic lack of funding and capacity resulting in limited understanding and championing of key issues. This resulted in inadequate and inappropriate institutional arrangements across all levels of government. Uganda's NUDIPU was deeply involved in the country's poverty reduction strategy *The Poverty Elimination Action Plan* (PEAPS). But whilst some progress was made in linking disability issues to Uganda's *Medium Term Expenditure Framework*, there is nothing in the 2005 PEAP document to mainstream disability as proposed by the NUDIPU (Dube, 2006a).

In South Africa implementing the Schools and Employment Equality Acts encountered many difficulties. For education the most obvious is an absence of financial and human resources, particularly the lack of trained teachers. Hence, disabled children are still not fully integrated into mainstream schools. Also despite positive intentions disabled workers continue to remain disproportionately unemployed. Department of Labour figures suggest that only 1 percent of disabled people are employed in the formal sector of the economy (Dube, 2006b). Sadly, similar examples are all too common in all poor societies, well meaning policies are rarely implemented as intended. This poses an ongoing challenge to disabled people's organisations at both the national and international level (Hurst and Albert, 2006).

In response disabled activists were mainly responsible for producing the UN's *Standard Rules on the Equalisation of Opportunities for People with Disabilities* (UN, 1993). This initiative comprises 23 standard rules to facilitate full participation and equality including awareness raising, medical and support services, education, employment, leisure and cultural activities. Disabled people's organisations working together as the *International Disability Caucus* (IDC) were an active partner in developing and promoting the *Convention on the Rights of Persons with Disabilities* (Hurst and Albert, 2006) adopted by the UN general Assembly in December 2006. With 50 articles covering all aspects of daily living, the Convention is the most comprehensive document yet produced on the rights of disabled people (UN Enable, 2008, unpagged). Designed within in an international law context the Convention sets out the duty of nation states to protect disabled people's human rights. Once in force, it is legally binding on any country that ratifies it. The Convention came into force in April 2008. In September 2009 it had been signed by 142 countries, but ratified by only 66 (UN Enable, 2009).

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Despite considerable enthusiasm among disabled people's groups there is growing concern that the legal route to social change is limited. Hitherto, securing human and civil rights through existing legal frameworks has not brought about equality for either the overwhelming majority of disabled people or other oppressed groups. Pursuing protection through established legal frameworks does not challenge directly the current economic and political system and therefore will not bring about the radical changes needed to eradicate structural inequality at either the national or international level (Oliver and Barnes, 1998).

This has important implications for disabled people, their families and indeed the population as a whole in both rich and poor countries alike. Global stability and future prosperity seem ever less secure as we move further into the 21st century. Constraints on the fiscal policies of national governments and international financial institutions are likely to intensify even further as a consequence of the recent global economic downturn which began in 2008 (Dunphy, 2008) and other world-wide problems that remain unresolved. Longstanding concern about environmental decay has escalated significantly over recent years as a result of mounting evidence of the detrimental impact of industrial development on the earth's finite resources (Dobson, 2000). Also demand will intensify further due to unprecedented population growth in future decades, especially in poor nations (UN, 2003). Since the turn of the millennium cultural opposition to the spread of western values and lifestyles has stimulated new forms of international terrorism prompting a costly international 'war on terror' by the USA and wealthy European states including the UK (Coates and Krieger, 2008).

Conclusion

As we move ever further into the 21st century it is increasingly evident that the spread of free market economics throughout the world has generated unprecedented inequalities within and between nation states. Western notions of impairment and disability are now commonplace across much of the developing world. This has led to the systematic exclusion of people with perceived impairments from the mainstream of community life in almost all societies, the generation of an international disabled people's movement, and their demand for legal frameworks with which to address the multiple deprivations encountered by people viewed as 'disabled'.

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But whilst the growing emphasis on human and legal rights, as exemplified in the UN Convention, may provide valuable insights into the extent of the abject poverty experienced by disabled people in a majority world context, it does not overtly challenge its cause: an overtly inequitable and unjust world system. There is therefore an urgent need for the establishment of a new world view and value system that does not obscure the 'structures of exploitation and oppression' (Leys, 1975: 275) but, instead, warrants a retreat from unregulated economic growth in favour of a redistribution of material resources and the propagation of meaningful social justice across and within all nation states (Charlton, 1998; Oliver and Barnes, 1998). To bring about such a change the international disabled people's movement must forge links with other political and oppressed groups working toward a similar goal: the creation of a world in which disability and uneven economic and social development are of historical interest only (Sheldon, 2005: 126).

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Disability and Empire: Making sense of disability in changing economic times

Dan Goodley and Rebecca Lawthom

How do economics, psychology and dis/ability intersect? In what ways are dominant – or Western European and North American (WENA) – models of psychology being rolled out across the world? What are the potentials and pitfalls of this rolling out of a psychology of the Global North on disabled people? To what extent do majority and minority world contexts boast complexities that allow them to adapt WENA perspectives? This chapter explores some initial findings emerging from a study of disablism in and across the UK and Malaysia. We are interested in the complex mix of local and global disability discourses and the possibilities they allow for working in enabling ways with disabled people. We make reference to the concept of *Empire* (Hardt and Negri, 2000). This concept acknowledges inter-connections between *biopower* (techniques, practices, professionals and discourses which are used to make sense of the dis/abled self), the *economic power* of WENA and their chosen forms of biopower (played out through, for example, the demands made of majority world nations of minority world contexts) and the *hybrid* nature of all local contexts (which have the potential to use and refuse the ideas of Empire).

Background

The chapter comes out of a project (RIHSC, 2008). This Prime Minister's Initiative 2 (PMI2) Project funded by the UK Department for Innovation, Universities and Skills (DIUS) is directed by Dan Goodley and Rebecca Lawthom (MMU) and How Kee Ling at Universiti Malaysia Sarawak (UNIMAS). The project started in 2008 and ends in 2010 and addresses a number of aims:

- develop understandings of the barriers facing disabled people in and across the UK and Malaysia;

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- explore these different national perspectives on disability and to see how they can be applied in the other's country;
- develop our international perspectives through the sharing of theory, research findings, practice and policy in relation to the promotion of disabled people in mainstream society;
- establish effective and sustainable partnerships that provide the foundation for future collaboration including submission of research bids between the UK and Malaysia.

Our research team includes educators, psychologists, nurses, sociologists, social workers, Non-Government Organisation workers (NGOs) and parents of disabled children. By September 2009, the Manchester team had visited and implemented research in Sarawak (a Malaysian state on the Island of Borneo) which (i) examined disability politics in Sarawak (researcher, Tsitsi Chataika) and (ii) explored indigenous and rural knowledge around disability (researchers, Anne Kellock and Shaun Grech) and (iii) garnered the views of NGOs, community-based rehabilitation centres, professionals and representatives of government organisations (including Women, Community and Family; Education; Social Welfare). The Malaysian team visited Britain in April 2009 and implemented a number of projects including (i) a study of self-advocacy in special schools; (ii) an early intervention and special education; (iii) an exploration of the experiences of parents of disabled children and (iv) a critical policy analysis of disability and childhood. This chapter reflects on the first trip to Malaysia, with a specific focus on disabled children, their families, professionals and community.

Sarawak is a fascinating context displaying a rich mix of new/traditional; Global North/Global South; minority/majority. Malaysia is a rapidly developing, industrialised country (Global North) in a geographical location often associated with the Global South. Malaysia has huge natural, economic, educational and cultural resources and might be sensibly viewed as a *postcolonial context*, displaying a hybrid mix of pre/colonial/post aspects of social and economic life (Muhd Salleh and Dhevan Meyanathan, 1997; Lal, 2006). The nation state of Malaysia boasts a multicultural population. Malays constitute nearly 54 per cent of the population, 26 per cent are Chinese Malaysians and 8 per cent are Indians. (Lal, 2006). In Sarawak, things become even more mixed. There are over 30 indigenous groups each with their own distinct language, culture and lifestyle. Indeed, one of these groups, the Ibans, make up the majority in Sarawak, followed by the Chinese, Malays, Bidayuh

and Melanau.

The rights of these indigenous groups have been threatened by land ownership, logging and rapid industrialization (see Borneo Project, n.d.). At the time of visiting Sarawak, the Federal government had just introduced the first piece of anti-discriminatory legislation – the Persons with Disabilities (PWD) Act (late 2008). A number of disabled writers (e.g. Tan, n.d.) and organizations (Disability Equality Training (DET) Forum, n.d.) were questioning whether or not the PWD would meaningfully impact upon the social inclusion of disabled people. The complex cultural mix of Sarawak raises fascinating questions about disabling society. With these complexities in mind, the Manchester research team aimed to work with professionals, families and disabled people in Sarawak to explore their understandings of community, culture and disability. As a consequence of this work, we became ever more mindful of the presence of WENA/Global North ideas on the Global South context. Simultaneously, we were alerted to the complex ways in which Sarawakian culture dealt with disability through a host of hybridised cultural practices. This mixing of North/South is captured well by the concept of *Empire*.

Empire: Political economy, psychology and biopower

Hardt and Negri's (2000) *Empire* provides a means of bringing together analyses of globalisation, economic expansion of late capitalism, rapid developments in communication and the impact on the psychology of the 'global citizen'. Following Goodley (2011), *Empire* is conceived of as a post-colonial and post-modern process, in which knowledge, particularly from the Global North, spreads across the globe in ways that are, potentially, imposed on, taken up or resisted by citizens in their local contexts. Hardt and Negri aim to synthesis a Marxist attention to economics with a postmodernist sensitivity to culture and knowledge. While interested in the ways in which powerful WENA nations police the global economic and cultural stage – through the workings of supranational organisations such as the *World Bank*, the *United Nations*, and the *International Monetary Fund* – they are also mindful of the ways in which less powerful nations, collectives and groups resist and engage with this governance. Their ideas allow us to consider the ways in which global citizens are subjected to big modern ideas (such as choice, competition and science) while, also, holding on to more local concerns (such as community and tradition). Hardt and Negri are clear that powerful nation

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states and WENA ideas hold sway over less powerful nations and the concerns of local communities. But, following Goodley (2011), their analysis can also be viewed as an account of the human experiences and community response that transpire in direct response to Empire. At the core of the 21st Century economic and knowledge society is Foucault's notion of *biopower*: those ever-increasing and rapidly developing forms of knowledge and practices through which the human subject comes to understand themselves. Biopower is re/produced in the institutional regimes of work, school, healthcare, home and welfare. Biopower draws in discourses that we used to create a sense of who we and others are: our psychologies:

Subjectivity is a constant social process of generation ... the material practices set out for the subject in the context of the institution (be they kneeling down to pray or changing hundreds of diapers) are the production processes of subjectivity ... the institutions provide above all a discrete place (the home, the chapel, the classroom, the shop floor) where the production of subjectivity is enacted. (Hardt and Negri, 2000: 190)

Following Goodley (2011) underpinning these goals is the big lie of modern civilisation: your self is free. For Foucault, *you are free only to govern yourself*, and discourse and practices of institutions aid in this 'freedom'. The ever-growing discourses of criminal psychology, psychiatry, liberal education and the judicial systems produce specific techniques of *biopower*. Psychiatry, psychology, medicine, social policy and education all come to occupy leading roles in the biopower of the self or, what Hardt and Negri (2000) term, emotional labour. The deregulation of the global market means that citizens of the world are more and more likely to come into contact with biopower. Ideas from psychology, for example, know no fixed boundaries as they are caught up in plural exchanges of information and communication. Stock concepts of North American social psychologists such as 'personality' and 'attitude' are readily transferred across the globe and used to measure, for example, the dispositions of children in non-WENA contexts. This is what Hardt and Negri (2000: 40) mean when they define Empire as a *globalised biopolitical machine* (Hardt and Negri, 2000: 40): the means through which theories of psychology spread, infecting or affecting people in every corner of the world. But biopower has a preferred psychology and version of humanity in mind – and one that fits the aims of WENA societies and their economies – namely

the healthy, rational, autonomous, educated, economically viable, self-governing and able (Goodley, 2011). And if you don't fit: then Empire is ready to fix you. That said, as we shall see in this paper, Hardt and Negri (2000) are mindful of the ways in which global citizens envisage other ways of being – through and against the practices of biopower – that are enabling to them.

In terms of our research in Sarawak – a rich multicultural context of Global North/South, with deeply held traditions and rapidly changing identities – we found ourselves asking questions about the psychological (or bio-political) impact of *Empire*. Moreover, we were concerned with the extent to which Empire, and responses to it, were influencing the ways in which disability was understood in the Sarawakian context. This highlighted how our research is engaged with the intersections of economics, culture and psychology, which we will come to below, but first a few words about our research.

A story from Sarawak

In order to explore these intersections we turn in this paper to a story (an account which we explore further still in Goodley and Lawthom, 2011). The piece can be defined as the product of an auto-ethnographic approach to the collection of qualitative material from a context new to us (see Goodley *et al.*, 2004). In this paper we tell a story of a particular organisation. Names have been changed but we retain the meaning of their stories. The story we present is a subjective and personally driven account. Our partisan affiliation with disability politics and disabled children will ensure that we not only interpret but no doubt re-present the story in particularly skewed ways. That said, we have learnt much from poststructuralist and cultural theorists of disability studies (e.g. Wendell, 1996; Corker and French, 1999; Davis, 1995), who urge disability studies researchers to unravel not only the disabling dynamics of culture but also to attend to the subjectivities of the researcher. We would probably accept the claim that our analyses are always biased, always Anglocentric and, therefore, tinged with colonialism of the research contexts in which we usually work. That said, as we explore in Goodley and Lawthom (2011), we hope that openness to the experiences we have had has made us, at the very least, engage with a postcolonial positionality which has deep resonance with disability studies (see Sherry, 2006, 2007 for excellent discussions of these intersections).

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During our research in Sarawak in 2008, as detailed in Goodley and Lawthom (2011), we were fortunate to meet with a number of community-based rehabilitation groups. One of these, a very unique organisation funded and managed by parents of disabled children, provided a host of services to children ranging from physiotherapy, education, life skills and vocational training and leisure and self-advocacy skills for young disabled people. This organisation filled us with hope and positivity, as it was one of the few places in Sarawak, run by parents, which aimed to bring together medical, social and educational needs for disabled children. As one parent told us, the organisation 'had saved her child'. A number of key players such as professionals and parents, brought attention not only to different understandings of disability but also to cultural conventions and assumptions that underpinned these understandings. We provide a short story from the centre:

In the physical therapy centre of the organisation (where children and parents attend) the supervisor notes that staff selection 'Is based on love and affection for the children. This is key to effectiveness'. We were told of families who had adopted disabled children from abroad. We were introduced to a father who spent most the day aiding the physiotherapy of his son. We were reminded of the importance of family and the support that could be offered through extended family networks. At the same centre, we find ourselves drawn to the white board. On it we read the label of each child, including Angelman, Williams Syndrome, Down Syndrome, Cerebral Palsy. The head physiotherapist shows us the book from which the diagnoses are drawn: a weighty book, written by a British expert, which provides signs, symptoms, prognoses and cross-references documents from the World Health Organisation, Diagnostic Statistical Manual IV (DSM IV). The author of the book is held up as a brilliant mind, an expert from which professionals of the centre can learn. Over noodles for lunch, we are then reminded of the personalities of the children. We are told how well they are doing. A parent pops in to tell us about how her child is developing with help of the organisation.

This story demonstrates some of the fascinating qualities of the organisation. On one level, the organisation is managed and funded through the activities of parents of disabled children. In contrast to the many service and professionally led organisations we are used to encountering in Britain, this organisation drew heavily upon the close-knit community and kinship networks of the parents. On a further dimension, the organisation was developing its professionalism, through the work of the physiotherapist and

other professions. As we elaborate in Goodley and Lawthom, (2011), while these interventions were clearly helpful to children and their families, the growing prominence of the use of WENA-originating diagnostic classifications of the children, sit uneasily with our more positive feelings around the community/familial-based aspects of the organisation. The complexity of the organisation can be understood through reference to the workings of Empire.

Empire: Mixing indigenous psychologies

The story from Sarawak is, we would argue, symptomatic of a contemporaneous political economy through which the spread of bio-power is felt, adapted and resisted. In the story we read accounts of community and family alongside those of biopower and professionalism. In this sense, the story is a hybridised account; a quintessential narrative of Empire, the blurring of North/South, or new/old, Global/local. This becomes particularly apparent when we read the ways in which disabled children are conceptualised by the organisation. Put simply, the ‘self’ of the child is read in different though mixed ways. First, for some contexts, such as Global South/ East Asian countries such as Malaysia, self and other have been historically fused together. This might be seen in the constitution of oneself in relation to family and kinship. For others it might be found in religious ways of life. Second, in Global North countries, the distinction between self and others has been traditionally maintained by strict, demarcated boundaries, to the extent that the self becomes clearly marked and made as distinct and separate from others (including other people and communities). We can detect these different readings of the self in the story presented above. Sampson (1988) provides a useful starting point for teasing out North/South; Global/local distinctions. Sampson contrasts two different ‘indigenous psychologies’ that influence how we understand the individual (see *Table 1*: overleaf).

While Sampson’s (1988) preference for indigenous psychology is with type 2, we can draw on both types to make sense of our story of Empire. Our story is clearly a complex *hybrid* of both psychologies of individualism described above; where ensembled and self-contained notions of the disabled child and the community are drawn upon. Hybrid is a postcolonial term and refers to the mixing of local and global discourses. Bhabha’s work on hybrids (e.g. Bhabha, 1985) is drawn on by Hardt and Negri (2000) to make sense of the fusing together of pre/present/postcolonial practices that at their most

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radical destabilise the signs of imperialist authority. Following Goodley (2011: 213) examples might include, ‘the Indianized gospel, a British-born Pakistan identity, the glocalisation of a South East Asian youth, where there is an appropriation of and resistance to the signifiers of colonial and traditional cultural practices’. It is possible to see the works of hybridisation in everyday cultural and community life: where the ‘glocal’ captures the folding into one another of global and local ideas.

Table 1: Self-contained and ensembled individualism: Adapted version of Sampson’s (1988: 16) two indigenous psychologies of individualism

	Type 1: Self-contained individualism	Type 2 Ensembled individualism
Self/other boundary	Firm self and definite other – to be found in hyper- capitalist communities	Fluid and blurred self and other – to be found in ‘majority world’ contexts such as Maori (New Zealand/ Aotearoa) and Chewong (Malaysia)
Control	Personal – based on egocentric models of psychology; related to personal achievement of atomistic individuals; qualities of character	Field – based on sociocentric models; related to relational actions of communities of individuals; community cohesion
Conceptions of person/self	Excluding – an ontology of exclusion; internally directed subjectivism; atomistic strangers; independent and separated	Including – an ontology of inclusion; self defined in relation to others; ‘I am who I am through my relations with other’; interdependent and connected

Our story locates a service for disabled children firmly within the community supported by the extended networks of parents of disabled children. One of our colleagues on the project, Ling (2007), has analysed the meaning of care/helping in indigenous Sarawak culture. She found that care was often understood in ensembled ways. *Gotong-royong* refers to the practice of mutual helping, aid and pooling of resources. This approach to care draws on resources of kinship and the love of families. We can read this approach to care in our story where the status of professionalism is considered primarily in terms of their abilities to love and respect children and to work in terms of *gotong-royong*. Indeed, Ling (2007) argues that previous attempts to import WENA approaches to care practices – such as individualised one-to-one forms of social work (self-contained individualism) – have failed in the Sarawakian context because they jar with the preference for community responses (ensembled individualism). Here is a case of the preferred practices of biopower of WENA contexts failing to match up with local context. Instead, following Hardt and Negri (2000), preferred methods of community and professional intervention, emerge as *imminent* local practices in response to the needs of disabled children and their families. That the centre has been set up by parents says much about the alliance of welfare and the family; an ensembled relationships between the service, professionals, parents and children. Local manifestations of culture – which celebrate the community-located self, the place of the disabled child in the community and the power of collectivism among parents – are necessarily drawn on to make the organisation work.

Later on in the story, we find the spectre of powerful individualising discourses of the biopolitical machine of Empire. The assessment of children through the categories of the DSM IV rip the child out of her relations with kin and re-site her as a solitary, lacking, deficient individual through recourse to these bio-political texts. What would the child have been conceptualised as prior to the appropriation of these schemas? Would the child have remained enmeshed in an ensembled relationship with others? Has the rolling out of one aspect of Empire's psychology reduced the child to nothing more than a label (Goodley and Lawthom, 2011)? Our colleague Ling (2007: 82) has expressed similar concerns in her attempts to promote indigenous social work practice. She observes that as the social work profession grows in Sarawak, families:

are more aware of the hereditary aspects of certain disabilities. They are

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becoming more questioning and look towards workers to provide answers as to whether it is their fault.

Such growing awareness – typical of the ‘global citizen’ of Empire – challenges a previous reliance on clan, religious or village level associations for day-to-day support and embedded forms of assistance (Ling, 2007: 115). The use of the DSM-IV exemplifies an adoption of powerful biopolitical discourses of psychiatry and psychology, which have their potential pitfalls and problems: not least in reducing complex humanities to the level of simplistic psychological markers. However, our encounters in Sarawak, have reminded us that Empire can be *both* pacifying *and* productive (Hardt and Negri, 2000). The pacifying effects, as we described above, are related to the unproblematic rolling out of biopower which threatens to instill a deficient understandings of disabled children (based on the WENA DSM IV) and eradicate local enabling community practices (founded on the mutuality of *gotong-royong*). We can trace other pacifying effects. Goodley (2011) notes that the UN convention of the rights of the child aims to extend children’s welfare, cultural and political rights but also instills a culturally specific notion of idealised child subjects and family forms (Burman, 2008: 53). The Indian Human Development report smuggles in archetypal medicalised Global North conceptions of impairment that might not fit readily with the Indian context (Ghai, 2006). The extent to which disabled children are included in schools in the majority world, is framed by bilateral and multinational donors from the minority world who fund and monitor the progress of the nations they patronise (see Gabel and Danforth, 2008). One of the *International Monetary Fund’s* loan requirements of Argentina has been the reduction to pensions and programs for elderly people, many of whom are disabled (McRuer and Wilkerson, 2003: 3). Empire can damage local contexts. The productive impacts are to be found when the self-contained individualism of Empire is used politically towards specific ends. Examples from Malaysia (and South East Asia) provided by Goodley (2011) include:

- The development of self-advocacy and Independent Living principles in Malaysia (United Voice, undated)
- The delivery of Disability Equality Training (devised in the UK) in the Asia Pacific (Carr *et al.*, 2008);
- A Balinese organisation of disabled people declares its ambitions as moving from ‘isolation to integration’. Funded by donors from

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Malaysia, Singapore and Europe, this registered charity provides an accessible village for disabled people to live and work in and has campaigned against the lack of physical access in Bali. The only non-disabled person employed by the organisation is the driver (Senang Hati Foundation, n.d.).

These organisations use the language of self-contained individualism: of individual human rights; educational achievement through inclusion; independence, self-help. Understanding disability requires us to think carefully about the hybridisation of local and global meanings, of tradition and Empire, of new forms of welfare, social services, politics, social class and social capital. For example, the ‘social model of disability’ makes complete sense to indigenous Malaysian families because they *already* think about disability as a predicament not of the individual but of the whole community (Ling, 2007). Following Hardt and Negri (2000), effective politics such as those displayed in South Africa combine a call on the truth and rights discourse of Empire while also celebrating cultural specifics of distinct national communities.

Conclusions

In this chapter we have aimed to tease out some of the cultural and psychological impacts of the late capitalist economy on the lives of disabled children and their families. We believe that the notion of Empire brings together an analysis of disability studies, economics and (critical) psychology that can be used to promote cultural and economic modes of organisation that have at their heart the promotion of a society for all.

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CHAPTER 4

It's the Economy, Stupid! The ironic absence of class analysis in British disability studies

Tom Shakespeare

In this paper, I want to look at the relationship between disability, impairment and economics, arguing for the relevance of inequality to understanding disability, in both causal and consequential terms. The secondary argument of the paper is that there is a need for a deeper theoretical understanding of the relationship of disability to economics. There are many different economic questions which could be asked about disability:

1. What role do different versions of capitalism or other economic systems play in the creation of disability as a form of inequality?
2. What relationship does the distribution of impairment and long term illness have to the distribution of social inequality and deprivation?
3. How do people from different socioeconomic groups experience impairment and disabling barriers?
4. What impact does impairment and disability have on labour market participation and employment experience?
5. What are the implications of impairment and disability for consumption?

With such a broad field of enquiry, this paper cannot even begin to address all these questions. The purpose here is to introduce several economic questions and to explore the general issue of the relationship of class and inequality to disability. First, I will claim that the materialist tradition in UK disability studies has failed adequately to address class differences in the experiences of disabled people. Second, I will explore the social determinants of illness and impairment. Third, I will explore social differences in the social impact of illness and impairment, focusing particularly on employment. Finally, I will explore inequalities within the disability population itself. Throughout, I will support my discussion with empirical evidence wherever possible.

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I have previously argued that it is important to take impairment into account when exploring the lives of disabled people (Shakespeare, 2006). While accepting that definitions of impairment, as Irving Zola (1993) argued, are not fixed and dichotomous in terms of culture and social usage, I do not want to endorse any postmodern undermining of the materiality of disability, and therefore for the purposes of this paper I take impairment to be adequately conceptualised by the International Classification of Functioning, Disability and Health (WHO, 2001). The ICF takes a universal approach, which does not discriminate between causes and types of impairment: unlike some disability studies approaches, it does not draw distinctions between 'chronic illness' and 'disability' or 'illness' and 'impairment'. Impairment might therefore include epilepsy, dyslexia, depression or multiple sclerosis, as well as spinal cord injury, blindness and deafness. Within the ICF, disability is regarded as a universal experience, arising from decrements in health, but this experience is understood in the context of physical and social environments which hinder or facilitate participation.

The ironic absence of class

British disability studies, in the dominant tradition epitomized by the work of Finkelstein (1980), Oliver (1990) and Barnes (1991, 1997), has taken a materialist approach to understanding disability, heavily influenced by Marxist understandings. While in *Capital*, Marx and Engels revealed capital to be not a thing (accumulated wealth), but a relationship (congealed labour or exploitation), the materialist tradition in disability studies has identified disability not as a biological difference but as a social relationship based on oppression and exploitation. Incidentally, this move has always contained within it an implicit requirement, namely that for disability to be conceptualized as a form of exploitation, it has to be explained whose interests it serves, and in which ways it can be conceived to be economic (Abberley, 1987).

Finkelstein (1980) was one of the earlier writers to suggest that the disability category originates as an outcome of industrial capitalism, a theme continued by Oliver (1990) and Barnes (1997). In this move, they highlight the role of industrial production in excluding formerly productive people with impairments and promoting segregation. Gleeson (1999) offered the most extensive account of how capitalism excluded disabled people from the mainstream, contrasting feudalism to market relations. Oliver also accounts for disability in terms of ideology, generating what he calls the personal

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tragedy theory of disability. Answering the critique that disability predates capitalism, Barnes (1997) describes a value system, originating from ancient Greek and Rome: unlike Finkelstein and Oliver, he does not account for disability in terms of the transition to industrial capitalism alone, although he does root culture in underlying material relations, as a determinist Marxist account requires.

If class struggle has the proletariat as the agent of history, so materialist disability studies stresses the transformative role of the disabled people's movements as a common theme (Campbell and Oliver, 1995). In successive publications (e.g. Oliver, 2009) and with the aid of renewed doses of Bob Dylan, Oliver looks forward to the day when the disabled people's movement will help transform capitalism and build an egalitarian society. This endearingly nostalgic Marxist rhetoric seems at odds with the success of revolutionary socialist groups in contemporary politics. Oliver's optimism also overlooks evidence that the disabled people's movement has never played a significant role in the UK anti-capitalist movement, a fact that at least one Leeds postgraduate blamed on not just disability separatism, but also the corrupting role of post-modernist conceptions of disability (Horsler, 2003).

However, more importantly, it appears that the materialist approach has never adequately and fully explored the economic dimension of the exclusion of disabled people. At least in the published literature of British disability studies, the economic inequalities between different peoples, inequalities which explain why some people are more likely to be impaired than others, and why some people with impairment are more likely to be excluded than others, have not been a major area of research or analysis (though note Vernon, 1999). I believe this is at least partly because for materialist disability studies, disability has been a master status: exploring differences between disabled people would detract from this.

The relevance of inequality

Whereas materialist disability studies has largely neglected inequality and class as a factor in disability, these issues have been central to mainstream medical sociology and social policy. Since the 1970s, the social determinants of health have been a well known story, for example the Black report linking health and deprivation, and the two Whitehall studies. The Whitehall studies of civil servants showed that it was inequality, rather than absolute deprivation, which caused most ill-health. Men in the lowest grade of the civil

service had a mortality rate three times higher than the highest grade. This was partly due to risk factors such as diet and smoking, but even after allowing for these risk factors, lower grade staff still had more than twice the mortality, which may be accountable by the role of stress (Marmot *et al.*, 1991).

Many commentators such as Albrecht (1992) have shown that the type of society in which people live produces particular illnesses and impairments. To give a more up to date example, a recent report (Australian Institute of Health and Welfare, 2009) presented data from the 2006 Australian census on severe disability among people under 65 years of age. It showed that severe disability (impairment) was more common in more socially excluded areas: 3.1% of people living in the most disadvantaged fifth of local areas had severe disability compared to 1.3% in the most advantaged fifth. Similar data is available from many countries (Minkler *et al.*, 2006; Rogenrud *et al.*, 1998; Schoeni *et al.*, 2005)

For example, evidence shows that many hazards, such as smoking, accidents, workplace disability and poor diet are commoner in lower socio economic groups. Pagano *et al.* (2009) show that people from deprived backgrounds were not only more likely to have heart disease, due to risk factors such as diet, obesity and smoking, but also had poorer survival rates after surgery (n=44902). Even after removing obesity, diabetes and smoking, deprivation had an independent impact on survival rates.

The impact of inequality is not limited to acquired impairments and illnesses. For example, several studies have highlighted low socioeconomic status as a risk factor for epilepsy, due to higher alcohol intake, poorer nutrition and increased risk of trauma and birth defects (Hesdorffer *et al.* 2005, Li *et al.* 2008). Bushby *et al.* (2001) showed that as a group, patients with Duchenne muscular dystrophy have significantly greater material deprivation at diagnosis than the average of the population from which they are drawn. This is evident even in families where the disease is known to be the result of a new mutation. They could find no simple explanation for this effect, but it seems that new mutations in the dystrophin gene do not occur randomly in the population.

While Bushby *et al.* did not hypothesise a mechanism, it might be suggested that diet may play a role. Not only are micronutrients essential in the development of the human brain, they can also be protective against genetic and developmental abnormalities. For example, a diet with adequate folate is protective against neural tube defects such as spina bifida. For similar reasons, higher than average genetic mutation may be connected to poorer

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than average diet, as well as to exposure to toxins and environmental pollution.

Another mechanism was identified by Evans and Schamberg (2009) in a paper in the Proceedings of the National Academy of Sciences which showed an association between the duration of childhood poverty and adult working memory, which they explained by the impact of elevated stress during childhood. In other words, that people who experience deprivation may have reduced memory capacity as a result of stress affecting the way that children's brains develop.

Disability studies academics such as Colin Barnes, Paul Abberley and others have certainly cited socio-economic factors in the generation of impairment. However, I contend that this issue has never been adequately analyzed, and nor have the class differences in the origins of impairment been fully acknowledged, within disability studies literature.

Class and the social response to impairment

Stephen Macdonald's doctoral research with people with dyslexia highlighted differences between people from working class and middle class backgrounds (Macdonald, 2009; Macdonald, 2009a; Macdonald, 2009b). Middle class children who are failing in school are more likely to be tested for dyslexia, due to the expectations and pressure from parents, and perhaps consequently heightened awareness by teachers. Working class children who are failing in school are less likely to be tested or diagnosed with dyslexia, due to the lower involvement of parents in education, and the lower expectations of achievement. Diagnosis with dyslexia is important both in promoting self esteem among previously failing pupils, and in gaining access to extra educational resources, in the form of remedial or special education, as well as computer software and hardware than can mitigate the impact of dyslexia. In the absence of diagnosis and treatment, working class boys with dyslexia are likely not just to underperform educationally, but also to become bored and alienated. Leaving school with no qualifications and a tendency to behave badly, it is perhaps unsurprising that some studies have found around 50% of people in prison to be dyslexic (Reid and Kirk, 2001). Middle class people, who are diagnosed early, who are supported in school, and who can develop coping strategies and access assistive information technologies, are less disadvantaged in gaining employment.

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It is widely known that disability is associated with poverty, and with social and economic problems. People with impairment are less likely to be employed and more likely to be on low income. Families with disabled children are poorer (Gordon *et al.*, 2000), often because one parent has to give up work to support the disabled child. Secondary research by Eric Emerson (2003) showed that families supporting a child with intellectual impairment were significantly economically disadvantaged when compared with families supporting a child who did not have impairment, and that mothers of children who had intellectual impairment reported that their child's difficulties resulted in greater social and psychological impact, compared to those with non-disabled children. Conversely, middle class families would not be so disadvantaged if one parent had to give up work. Alternatively, such families would be more likely to be able to afford to pay for the support needed to make life easier with a disabled family member. With money, life with impairment becomes much easier.

Employment and disability

As of spring 2005, the Labour Force Survey indicated that the employment rate of people with current disability was 48.2%, whereas the employment rate of people without disability was 79.9%. However, this headline conceals considerable variation. Examining the Labour Force Survey (2001) shows significant differences according to impairment (see *figure 1* – below). There would of course be differences again with the employment rate of people with mental illness (estimated at 10%) or intellectual impairment (estimated at less than 20%). If you are from a Pakistani background and also disabled, the employment rate is less than 25% (Labour Force Survey, 2007). It is interesting to note that the otherwise excellent collection *Working Futures? Disabled people, policy and social inclusion* (Roulstone and Barnes, 2005) does not explore differences between impairment groups in any depth, nor does it explore the role of impairment in achieving employment, although it does contain chapters on people with mental illness, people with intellectual impairment, and people with visual and hearing impairment, and it does report that severity of disability does have an impact on employment rates. I believe we need more information on the specific impact of different impairments on employment, as well as on the intersection between impairment, gender and employment, or impairment, ethnicity and employment, rather than

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aggregating impairment groups and assuming that disability is a universal experience.

Figure 1: Employment – People in Employment by Physical Disability (UK)

<i>Type of Long-Term Health Problem</i>	<i>Employment Rate (%)</i>
Skin conditions, allergies	69.3
Difficulty in hearing	68.1
Diabetes	65.1
Chest, breathing problems	64.0
Other problems, disabilities	52.9
Stomach, liver, kidney, digestion	52.0
Heart, blood pressure, circulation	50.3
Arms, hands	48.4
Back or neck	46.1
Musculoskeletal	45.6
Epilepsy	44.0
Difficulty in seeing	44.3
Legs or feet	43.5
Progressive illness	39.0

(Source: Labour Force Survey, 2001)

The LFS statistics show the importance of considering specific groups, rather than disabled people as a collective. For example, when my team conducted research with the restricted growth community, we found that there was not a huge disparity in the employment rate: 57% of our sample were in paid work, while the 2001 UK Census found 61% of the general population

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were in paid work. However, we did find that respondents were concentrated in lower occupational roles. They were twice as likely to be found in lower supervisory and technical or routine occupations than non-disabled people. They were half as likely to be in higher managerial/professional roles, and a third as likely to be in lower managerial/professional roles. Given that they generally had educational qualifications as good as or even better than the average population, it was common for respondents to feel over-qualified for their jobs (Shakespeare, Thompson and Wright, 2010). I speculate that this 'glass ceiling', or perhaps more appropriately 'glass staircase', may apply to people with other impairments: where they get jobs, they don't get promoted, or choose not to opt for promotion. Evidence suggests that this is the case for Deaf people (Harris and Thornton, 2005). With restricted growth at least, it is not just a matter of discrimination: it is also a matter of disabled people preferring to stay in a role or a workplace where they fit in, are accepted, and can manage, rather than risking promotion to another situation where they may be rejected or fail to cope.

Holland *et al.* (2008) show that people with epilepsy have significantly lower employment rates than the general population: male employment rate was 26.5% points lower than general population. There was evidence in the study (n=350) of some downward mobility consequent on diagnosis. Manual workers with epilepsy may be at particular disadvantage, as they may need to drive or operate machinery for their jobs, which would be prohibited after seizure: they were significantly less likely to be employed than professional workers. People who experienced remission over the four year follow up period regained employment, though overall the employment rate remained lower than the general population. The more seizures that respondents had, the less likely they were to be working. In other words, both impairment and occupational role have important effects on disability outcomes. We could hypothesize that many impairments are much easier to manage in a white collar role than they would be in manual work, where there may be less flexibility and more physically demanding tasks.

Impact of inequality varies between countries, as well as between impairment groups. Burström *et al.* (2003) compared employment experiences of women with chronic illness in Sweden and Britain, finding that British women with chronic illness in the 1990s had less than half the employment rates of healthy women, whereas these inequalities were less accentuated in Sweden. OECD figures quotes by Pearson and Prinz (2005) suggest that the employment rate of disabled people varies from 22.1% in Spain or 20.8% in

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Poland to 56.3% in Canada and 61.7% in Norway and 62.2% in Switzerland: UK is 38.9%. Some countries will have extensive employment schemes and expectations that people with particular impairments will work, whereas others will segregate and/or expect people to live on the disability pension. OECD (2003) noted major improvements in employment integration policy between 1985 and 2000. However, still every year only about 1% of the incapacity caseload exits to work, despite all these efforts (Pearson and Prinz, 2005), although this figure is 2% in UK (Labour Force Survey 2007).

Contributors to the *Working Futures?* collection espouse the social model of disability, disabled-controlled employment services, and challenge the prejudice, ignorance and discrimination of employers. They propose many important practical steps to reduce the exclusion of disabled people from employment, all of which I support. But there is an underlying question which is not answered: what would be an acceptable and achievable employment rate for disabled people? Nowhere has exceeded 70%: is this due to a lack of imagination and effort, or is that the highest feasible employment of disabled people in a modern knowledge economy? Only one in three disabled people now unemployed would like to find work (Labour Force Survey, 2007).

Disability, difference and inequality

It seems clear that class or inequality are very significant factors in disability. Why, then, have they not adequately been addressed in UK disability studies?

One factor may be an unwillingness to engage with impairment. Materialist disability studies has bracketed the issue of impairment, preferring to analyze disabling barriers. An honourable exception is the seminal paper of Paul Abberley (1987) on the concept of social oppression, where he argued that more work needed to be done on the material basis of disability, and on the role of impairment in the lives of disabled people. If impairment is not regarded as an important variable or influence on disability, then it is hard to capture the social basis of impairment, or its distribution by social class.

Another factor maybe an unwillingness to consider differences between disabled people, the sort of differences which were revealed in the LFS employment rate table. Like the radical feminists before them (Seidman 2008), the materialist tradition in UK disability studies have seen disabled people as a coherent class of people, in distinction to the non-disabled majority. Disablism as a form of oppression, in this approach, has created disabled people as a legion of the dispossessed: disability becomes a master

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status. In this way the differences between disabled people, just like the differences between women, are obscured. It becomes intellectually desirable and politically expedient to claim that disability forms the great divide.

Yet disabled people are a hugely diverse population. Not only are poor people more likely to become ill or impaired, they are less likely to receive adequate medical treatment, and more likely to be socially excluded as a result of impairment. Moreover, as well as this social class gradient in the experience of health conditions and disabling environmental factors, there are also significant differences between people with particular health conditions. For example, those who are able to compete effectively in a market economy, given certain basic protections and welfare services, flourish in a way impossible for those who cannot work the same hours as non-disabled people.

While the determinants of productive labour are partly to do with social barriers, this does not fully explain these differences. In knowledge economies, those who have difficulties with communication or cognitive functioning are substantially disadvantaged. Thus while people with physical or sensory impairments begin to enter the mainstream and enjoy better quality of life, those with intellectual impairments or mental health conditions and also those whose impairments cause speech or communication difficulties remain excluded from the labour market and disproportionately poor. Technology and social support can overcome many of the innate limitations of disability, but cannot currently compensate as effectively for cognitive deficits or psycho emotional disturbances. As Abberley (2002) argued, even when all barriers are removed, some disabled people will not be able to work.

Thus inequality becomes relevant in a final and devastating way. The very success of the disabled people's movement has created and exacerbated inequalities between people with different impairments. While it may once have been true to say that to be disabled was to be poor and excluded, that judgment now has to be qualified. Some disabled people are moving ahead in the race, while others remain at the starting gate. For people with some impairments, a level playing field achieved through civil rights helps achieve increasing equality and participation. For others, barrier removal is not enough. Different interventions, and a more radical social philosophy, are required to achieve the emancipation of all.

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CHAPTER 5

The deafblind and disability studies

Satoshi Fukushima

Summary

Based on my own experience as a deafblind person, I had the thought that there is some meaning in being disabled and in thinking about society and life from the experience of disability. It was around that time that I learned of the existence of the academic field known as ‘disability studies’. Disability studies is said to consist of theoretical and practical studies that consider, through the phenomenon of ‘disability’, the way society and human beings work, and which also promote a social movement.

The issues that disability studies should take up can be divided into two categories; those contributing to disabled persons and those contributing to a large number 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 introduce here a third, new strategy, the ‘(differences in) ability culture theory strategy’, which is an approach based on creative communication. This strategy may also be called the ‘creative communication strategy’.

Disability studies is a scholarly discipline that aims to have all people, whether disabled or not, illuminate the world with a new light of recognition.

Charles Dickens and the deafblind

I was born in Japan in 1962. I lost my sight at the age of 9 and my hearing at the age of 18 and am a totally deafblind person.

I would like to discuss here the theme of the deafblind and disability studies and I will first explain 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 according

to the country or period, generally speaking, there is approximately one deafblind person in a population of from several thousand to 10,000 people.

It is said that many of the deafblind have become so in midlife, that many of them are elderly, that relatively few are totally deafblind as I am, and that most of them have sight and hearing to some extent. For the sake of convenience, however, the trend internationally is to group all people who have a combination of sight and hearing impairments, 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 notion here.

If you think of 'blindness' in terms of the act 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 sees only 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 indicate the 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 met there a totally deafblind girl, Laura Bridgman, at the Perkins School for the Blind.

He wrote these impressions from that encounter in his *American Notes for General Circulation*:

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. (Dickens 1842: 73)

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 the education of young deafblind children actually goes back more than half a century before the case of Helen Keller.

One of the earliest, and perhaps the first person in the world, to prove the possibility of the education of deafblind children was an American, Samuel Howe. In 1837 he succeeded in giving basic language education to a deafblind girl who was 7 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 a 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.

The great contribution made by Helen Keller to the twentieth century and to the advancement of social work and welfare for disabled people is well known. 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 into 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.

Difficulties experienced by the deafblind

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

28 years ago, I went rather abruptly from a situation of blindness into a situation of total deafblindness, and at that time it was communication that was the hardest problem for me.

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.

Neither was not being able to play the music that I liked 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 communicative relationships with other people.

Later, my mother created the original *yubitenji* (the Japanese for ‘finger braille’) method of communication. I was thus able gradually to resume the ability to communicate with other people and gained the strength to live. However, I think the experience of having had communication cut off that I had when I first became deafblind had a very big impact on me. It gave me the realization that even if one cannot 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 could not communicate well with others even though one is able to see and hear, it would be very difficult to live.

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 9, I lost my sight; and at the age of 18 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 9 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 could not play with my friends in the neighbourhood 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 had attended 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.

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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.

From about the time I was in junior high school, however, I started thinking seriously about my 'disability'. I once confronted a totally blind teacher whom I was close to with this problem. 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 carried 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 also I 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 28 years have gone by. I do not know if I have now really found the personal existential meaning 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?'

In addition, 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 by Finger Braille, literally 'through the hands of others'. Moreover, 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 standpoints of medical, educational or social welfare. 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?

My encounter with disability studies

I had been thinking, then, that there was meaning in being disabled and in thinking about society and life from the experience of disability. It was around that time that I learned of the existence of the academic field known as ‘disability studies’.

Disability studies is said to consist of theoretical and practical studies that consider, through the phenomenon of ‘disability’, the way society and human beings work and which promote a social movement. What then should we consider as the issues that disability studies should take up, 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 the large numbers of discrimination issues that exist for all people, whether they are disabled or not. If disability studies were a discipline that was only for disabled people, it would lack the potential to develop. However, 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 the lives of 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 thus far been two typical strategies in the approach of disability studies. The first is the ‘culture theory strategy’, and the second, the ‘ability theory strategy’. If we consider these in terms of the first category mentioned above, the result will be as follows.

The ‘culture theory strategy’ emphasizes the aspect of ‘culture’ in the struggle for the elimination of 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 (differences in) ability’

arising from disability, and by analyzing the structure of this discrimination and pointing out how groundless it is, opposes discrimination against all disabled people.

Next, what would we find if we applied these two strategies to the second category, '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 of disability as 'culture'. One could also say that this 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, and age). Further, the 'ability theory strategy' that would oppose discrimination due to '(differences in) ability' 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-centred 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 of disability as culture, can, through the point of aiming to abolish discrimination due to differences in attributes, connect to other discrimination issues (Padden and Humphries 1988; Benedict and Reynolds 1995). Moreover, the 'ability theory strategy', by revising 'abolition of ability discrimination due to disability' to 'abolition of discrimination due to ability differences 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 (Oliver 1990; Sen 1992; Tateiwa 1997).

Are these two strategies good enough as disability studies strategies? Do they form a sufficient theoretical framework for the fight against disability discrimination?

I think that, although both are important strategies, neither of them can function properly on its own.

Combining ‘culture’ and ‘ability’ to make a ‘creative communication’ strategy

Thinking first about the ‘culture theory strategy’, I believe that there is a weak point here. For if value ranking of 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 (differences in) ability.

Neither, on the other hand, is the ‘ability theory strategy’ sufficient. This is because it is difficult to confront and overcome the problem of abolishing discrimination due to (differences in) ability with this strategy alone. 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. However, no matter how strongly one may hold it ‘inexcusable to discriminate on the basis of (differences in) ability’, for some reason the rationale for explaining this ends up becoming 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 ends up ranking (differences in) ability on a scale based on the one-dimensional measure of ‘productivity’, in connection with this, the ‘ability theory strategy’ that would deny such discrimination would also have to be of a one-dimensional nature.

The ‘culture theory strategy’, on the other hand, sees uniqueness and identity in differing ways of behaviour and is a value system based 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 do not 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 (differences in) ability in ‘productivity’ could arise, and this in turn could lead to discrimination occurring from the differences between cultures.

If this kind of structure of meritocracy-based discrimination capable of threatening the ‘culture theory strategy’ exists, perhaps there should be a counterattack on meritocracy from the side of the ‘culture theory strategy’. How about, for instance, formulating, from the ‘culture theory strategy’

standpoint, the argument that '(differences in) ability 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 a '(differences in) ability 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 '(differences in) ability'. While acknowledging the existence of '(differences in) ability' in the subject, it strips the value-ranking factor from the 'structure of meritocracy-based discrimination' that places a value on the individual in 'quantitative' terms. Further, 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 avoided. Secondly, the 'qualitative' disparity that lies in '(differences in) ability', namely, the various qualitative disparities in ability itself, is also seen from the point of view of culture, and it is possible to apply the 'culture theory strategy' methodology that 'does not attach value ranking to disparity'.

This is an attempt to construct a logic that does not bring value ranking to '(differences in) ability' with regard to the two aspects of 'quantitative' and 'qualitative' disparity.

Incidentally, if we introduce the 'ability theory strategy' into the 'culture theory strategy' and thereby derive a third, new strategy, the '(differences in) ability 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 this strategy that I refer to here does not aim to simply combine the 'culture theory strategy' and the 'ability theory strategy', 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 both.

Naturally, I do not expect to obtain immediate agreement with this idea for a position that not only condemns discrimination in (differences in) ability, but even re-evaluates (differences in) ability from the viewpoint of culture. I believe it is something that will gradually take shape through lively communication among people with ability disparities, including disabled people, through a power, akin to 'frictional heat', generated by those very disparities. Moreover, this is the image that I have of the '(differences in) ability culture theory strategy'. That is to say, the '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 around the whole earth. This seems to overlap with the image of information and communication in our present day high-tech information society.

Further, if we liken communication to the flow of water, the fact that people are all 'different' could be represented by elements such as the differences in the 'height' of the flow of water or changes in its 'speed' coming into play, and just as that would produce great power, such as that of a waterfall turning a hydroelectric turbine or 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 opening up the future.

Communication and what disability studies means to me

People live with the support of others, and without the support, tangible and intangible, of others their lives may not be possible. This is something that disabled people, the deafblind, for instance, always experience themselves and

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show to others. Further it is 'language' in the broad sense, communication, that mediates 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. Disability studies does, however, 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 does not exist only for the purposes of 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.

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

It is just like our seeing for the first time the pearl-colour 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 colour 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 seen thus far. 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 mutual and unconditional blessing for the fact of our existence.

Disability studies is a field that makes possible these kinds of value shifts and awakenings, and I believe it is a field that gives us a chance to look anew at the world under a new bright light of knowledge.

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CHAPTER 6

Appraisal of the justifiability of the Japanese employment quota system for disabled people

Ryoji Hoshika

The aim of this article is to investigate whether a quota system for the employment of disabled persons can be justified in a normative manner from the perspective of equality of opportunity. We focus on the possibility of normative justification in consideration of the possible negative effects such a system could potentially have; specifically, if the system were actually put into practice and perceived as deviating from the norms of society, then it could result in stigma being attached to those subject to the quota policy.

The results of the investigation indicate that within the equality-of-opportunity philosophies based on the level-the-playing-field principle, it is possible to justify quota employment systems, drawing on a basis in the conception of Roemer, who adopts a strict position of luck egalitarianism. The case of Japan's quota employment system is basically the same, while there are several points that must be revised. Through sharing these findings with disabled and non-disabled people, we can expect that any negative effects of the policy will be mitigated or prevented.

Introduction

Modern capitalist production processes focus on individuals acting as a workforce, and the human body (in a medical sense) that fit this type of production process has been accepted as the norm. The thesis (Oliver, 1990; 1996) that the concept of disability was produced in a medicalized and individualized form as a consequence of this 'normalizing' process is one of the most important ideas in the field of disability studies. This thesis suggests that 'disabled people' are a group whose core characteristic is inadequateness for labour in a market economy. Considering this, issues related to the labour market have special significance for disability studies. In seeking to reincorporate disabled persons into a labour market from which they have been historically excluded, to what degree and how can the labour market be

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reorganized, revised, and regulated? In addition, to what degree is it possible, within the labour market, or within a system that is relatively independent of this market, to seek the 'distribution of goods, rights and dignity' (Ishikawa, 2002) that disabled people need? Even today, these questions remain central themes in issues of disability.

In this article, we focus on quota systems in employment, especially on the Japanese use of these systems, as one possible means of including disabled persons in the labour market. We also explore the possibility of normative justification for the quota system. Thereafter, we focus on the possibility of normative justification because it is not sufficient to simply put the quota system into practice. This is because the system could generate rather negative effects if it were perceived as deviating from the norms of society, that is, if the subjects of such a policy were regarded as receiving 'unreasonable' benefits. These effects include the fostering of stereotypes and stigma toward disabled persons and the triggering of self-contempt or feelings of guilt in disabled persons themselves. Considering this point, we must consider the importance of quota employment being rooted in powerful and widely shared social norms.

Confirming the significance of this consideration, the normative justifiability of the policy is one of determinants of whether it succeeds or fails. From this perspective, we explore the justifiability of the quota system using the philosophy of equal opportunity, which is one prominent representation of a powerful and widely shared norm.

Quota employment system in Japan

We begin the discussion by outlining Japan's quota employment system for disabled persons. The quota employment system in Japan is regulated according to the Law for Employment Promotion, etc. of Persons with Disabilities. This law stipulates that the number of disabled persons hired by employers must exceed a certain minimum proportion of employees, with private corporations currently required to achieve a legally designated employment rate of 1.8 per cent, and national and local governments required to achieve the rate of 2.1 per cent. This legally designated rate is calculated based on the ratio of the number of regularly employed and unemployed people with impairments out of the total number of regular employed and unemployed people. Unemployed people here indicates people without work who are hunting for jobs, and, thus, this figure ultimately denotes the

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proportion of disabled persons among the entire population of people currently willing to work (regardless of whether they are actually working or searching for work). Seen in this way, the fundamental policy objective of this system can be understood as the realization of a situation in which those who are willing to work will be employed at the same rate, regardless of whether they are disabled or not. In reality, even if the actual employment rate were to reach the legally designated rate, this would not strictly ensure that employment rates were implemented at the same level, for several reasons. Professional jobs are excluded from basic calculations, a double-count system is used that counts the employment of a single severely disabled person as the employment of two persons, and the number of mentally disabled persons is added only to the calculation of the actual employment rate. However, the primary objective of this measure can be regarded as stated above.

While there are no penal regulations established for punishing employers who fail to satisfy this obligation, incentives have been offered to encourage fulfilment of employment obligations as a way to realize the policy objective mentioned above. These incentives take two forms. One is the form of a fixed-fee scheme under which money is collected from employers who do not achieve the legally designated employment rate. Concretely, firms with more than 200 employees have to pay 50,000 yen per month for each person below this threshold and receive 27,000 yen per month is awarded for each above it. The other is a mechanism by which the names of companies failing to attain this minimum level of achievement are released to the public.

Despite these incentives and sanctions, the actual employment rate of disabled persons at private corporations in 2009 remained at 1.63 per cent, with more than 50 per cent of corporations falling short of achieving the legally designated employment rate. Therefore, it is clear that the objective of this policy has not yet been attained. Moreover, the basis justifying the policy, that it is a special preferential treatment for a particular minority group, is weak. For example, in the Law for Employment Promotion, etc. of Persons with Disabilities mentioned above, what is actually set forth is the ‘obligation to cooperate in efforts of disabled workers to achieve independence as capable professionals based on the principle of social solidarity’; no reference is made to the principle of implementing the guarantee of rights or equal treatment. In addition, there are many who argue that such measures as creating an ‘equitable’ result go beyond, or do not conform to, the idea of equality of opportunity that is the legal basis of equal employment (Sekikawa, 1999; Hasegawa, 2008).

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Certainly, the International Labour Organization (ILO) Recommendation R071, which is regarded as endorsing the quota employment system in Japan, states that, for the purpose of ‘insuring equality of employment opportunity’, it is reasonable to require corporations to employ a certain proportion of disabled workers. In this light, the quota system seems to be justified by philosophies of equal opportunity. However, in an interpretation by the ILO itself, such special measures were identified as contemporary means (Matsui, 2008). Therefore, the quota system may be step toward realizing ‘true’ equality of opportunity, rather than an embodiment of philosophies of equal opportunity. Therefore, the philosophies of equal opportunity are only considered to have an indirect link to the quota system.

If these views are accepted, then the quota employment system loses one powerful basis for its justification. Is it, then, actually impossible to situate the quota employment system in the context of equal opportunity policy?

Variation in Equality of Opportunity

In considering this question, it is necessary to articulate the concept of equality of opportunity. There are considerable variations in the meaning of equality of opportunity, and corresponding differences in the normative evaluation of concrete policy. There is, therefore, a need to articulate the concept of equality of opportunity in more detail, prior to arguing about the possibility of justifications based on this philosophy.

In a very rough sense, equality of opportunity may be described as the demand that people be treated equally in terms of their individual willingness and abilities. A distinction can be drawn, however, between the two following interpretations:

I: In competition for positions, people should be evaluated in the same way, based on their attributes relevant to the performance demanded. Nothing other than these attributes should be considered in assessment.

II: In competition for positions, competitive conditions should be levelled between individuals in such a way that those who have similar potential will eventually be treated in the same way.

We refer to the former as the ‘merit principle’, and the latter as the ‘level-the-playing-field principle’, using John E. Roemer’s phrases (Roemer 2000). We

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would like to stress here that, whereas in the merit principle the emphasis is placed on 'performance', in the level-the-playing-field principle it is 'potential' that is the focus. In other words, whereas in the former case only abilities that have actually been realized are considered targets of evaluation, in the latter case the overall capacity that the individual may potentially exhibit under certain conditions, including those that for whatever reason are latent but not yet actualized, are evaluated.

To think about the normative justification of quota employment systems for disabled persons based on this articulation, the merit principle is not necessarily effective. Certainly, the equal opportunity philosophies based on the merit principle have played an important role in historical terms. The demand for equal opportunity in this sense has been an effective approach in cases of direct discrimination, where employment has been denied on the basis of disabilities alone, regardless of a person having the abilities needed for a particular job. Work environments and employment practices regarded as 'neutral', however, may in fact be difficult for disabled persons to adapt to. Disabled persons who are required to exhibit their abilities in these environments may be unable to sufficiently make use of their potential, resulting in a significant disadvantage. Thus, disabled persons actually placed in such environments are unable to actualize their abilities, and are regarded as inferior in the performance required. The pure merit principle is ineffective in this type of situation.

However, according to the social model of disability, this 'neutral' environment was created based on the assumption that it would be used by non-disabled persons, and in this sense it is biased and imposes unfair conditions. Since the disadvantages that disabled persons face are emerging from unfair settings, these should be redressed by society. Today, this type of understanding constitutes a major current in discussions of anti-discrimination legislation. In addition, as the development and use of technology have advanced, the room for technological modification of such unfair working conditions has expanded, and the social understanding that equivalent competitive conditions are needed to some extent for those with and without disabilities has also gradually broadened. The 'reasonable adjustment (or accommodation)' approach is part in this tendency. Reasonable adjustment or accommodation is stipulated in the Convention on the Rights of Persons with Disabilities and in the anti-discrimination legislation of various countries. As is well known, this means that necessary accommodation that does not impose an undue burden on the employer is required in order to enable the exercise of

equal rights. In the context of our argument, the significance of this approach lies in that it aims to realize equality of opportunity based on the level-the-playing-field principle.

However, the provision of reasonable adjustment is not in fact necessarily sufficient in light of the demands of the level-the-playing-field principle, which stipulates that individuals with the same potential should be treated equally. The approach of reasonable adjustment draws attention to potential that has already been formed but is not able to be used due to unfair conditions in the setting of competition. It is assumed, in other words, that equal performance can be expected if temporarily latent abilities can be drawn out. What happens, however, in cases where potential has not been sufficiently developed, due to factors occurring in the ability formation period? Regardless of the degree to which reasonable accommodation is offered in the examination or workplace, in such cases, there is no way to demonstrate the required ability, and, as a result, individuals have no choice but to give up and lament their misfortune. Many advocates, in fact, treat this as an area that goes beyond the range of the equal opportunity approach in employment.

Does this then mean, then, that measures requiring reasonable accommodation constitute a critical point in justifications based on the equal opportunity philosophy?

Radical Interpretation of Equality of Opportunity: Roemer's Luck Egalitarianism

Arguments that draw attention to potential based on the level-the-playing-field principle are not monolithic. In fact, some equality-of-opportunity arguments treat certain types of inequality in ability formation as areas to be redressed.

In the field of political philosophy, various concepts have been suggested regarding standards for distinguishing between domains that demand compensation, and domains that do not. One influential standpoint in this context is the idea of 'luck egalitarianism' (Dworkin, 2000; Cohen, 1989; Roemer, 1998). Luck egalitarianism is the normative standpoint according to which advantages and disadvantages ethically arising from arbitrary luck should not be ascribed to the accountability of the individual, and should therefore be equalized. While there is no need to intervene in any way regarding disadvantages associated with the individual's accountability, redress is required in cases of disadvantages arising from areas that go beyond individual accountability.

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John E. Roemer adopts a strict position of luck egalitarianism (Roemer, 1998; 2000), drawing a distinction between circumstances outside the control of the individual, and autonomous choices and efforts of the individual, insisting that the scope of individual accountability is limited to the latter. Differences in circumstances come about, in an ethical sense, through arbitrary luck, and hence it is unfair for individuals to be made to put up with disadvantages that arise as a result of circumstances. These circumstances include not only the physical environment and social system, but also one's genes, family background, and culture. In other words, all aspects over which the individual does not have autonomous control are treated as belonging to the circumstances. Having configured the scope of these circumstances in broad terms, the scope of individual accountability, with the influence of circumstances removed from achievement, is limited to efforts chosen freely by individuals. What should be emphasized here is that the amount of effort actually expended is not what should be considered. The issue of whether effort has been expended or not is also partly affected by the individual's circumstances, and thus this part should be removed, and only effort resulting purely from individual decisions should be assessed. The conception of equality of opportunity presented here is based on a level-the-playing-field principle that demands a form of competition in which the influence of the circumstances is completely excluded, and in which expected level of achievement of the individual in question should be decided exclusively on the basis of efforts freely chosen by the individual.

With this concept as his premise, Roemer proposes an equal opportunity implementation using the following method. First, based on the ways in which the achievement of individuals is influenced, the circumstances of various individuals are categorized into several different types, and each individual's circumstances are then specified as belonging to a particular type. Based on this definition, individuals who belong to the same type are considered to be affected by their circumstances in the same way, and those who belong to different types are considered to be affected differently by their circumstances. Under these conditions, no active intervention is introduced in competitions within the same type, and disparities in achievement arising as a result are permitted. The reason for this is that these differences arise solely from the autonomous efforts of the individuals. On the other hand, in competitions between individuals belonging to different types, achievement is specified using the centile of the effort distribution in the type as a measure. In other words, if relative positions within the types are the same, then the same results

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are realized even if the apparent achievement level and amount of effort expended are clearly different. This kind of policy is justified for the reason that differences between individuals of different types in apparent achievement levels are regarded as being produced through the influence of the circumstances. In reality, it would appear that there may be differences between types at the level of autonomous effort. If we assume, however, that there are sufficient numbers of individuals in each type, then in cases in which centiles are the same, it is logically reasonable to expect that the same degree of autonomous effort will be exerted.

For instance, suppose that there are four persons (A, B, C, D) located in relatively advantageous circumstances (type α), and another four persons (E, F, G, H) located in relatively disadvantageous circumstances (type β). Suppose further that an examination is administered to evaluate individuals according to a ranking, and that the scores of the eight persons are: A: 80 points, B: 70 points, C: 60 points, D: 50 points, E: 50 points, F: 40 points, G: 30 points, H: 20 points. In this case, B and F both sit at the 75th centile within their types, so these two will obtain the same result. On the other hand, while D and E have the same score, their centiles in their types are different (D has the 25th centile, whereas E has the 100th centile), and thus D and E will obtain different results.

This conception of equality of opportunity has been criticized for being associated with stigmas attached to people assumed to belong to a relatively disadvantageous type, and for hurting such individuals' self-esteem (Anderson, 1999). In addition, in cases in which employees are selected using the centile within types, it is quickly noticed that screening invariably ends up resulting in a reduction of labour productivity, at least for a short period of time. What Roemer is doing here, however, is setting up an algorithm for implementing a policy based on a certain kind of norm of equal opportunity. There is no implication that this is the only model, or that such a norm should be preferred over all others. Roemer himself admitted that the proper scope of application of equal opportunity policy should be determined in a given society, considering the balance among various social values, including efficiency. Given that he is not denying the need to restrict applicability of equal opportunity policy relative to other values or models, these points do not constitute intrinsic criticisms. We would like to emphasize here that at the very least, in cases based on Roemer's conception of equality of opportunity, the measures stated above are justified. Even if, hypothetically, there are difficult aspects of actual implementation, this is not because there is any

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conflict with the philosophy of equal opportunity, but rather because implementation of equal opportunity must be abandoned due to the requisite of different social norms.

Justifiability of the Quota Employment System

Given the above, if we take Roemer's conception as a starting point, the interpretations of what constitutes a radical type of positive action, such as the 'quota model' and the 'preferential model' (Oppenheimer, 1988), are varied. At present, whether or not these types of positive action conflict with the equal opportunity principle has been a contentious subject. However, according to Roemer's conception, not only is there no problem at all with treating people from different type of circumstances differently, but, on the contrary, this is precisely what is required of equal opportunity policy. The focal point thus must be shifted from the problem of justifying the implementation of specific preferential treatment itself, to the question of whether a person receiving such treatment really belongs to a group subject to disadvantageous circumstances or not, and whether conditions being realized through preferable treatment are excessive or not.

It may be possible that this point of view is basically valid in the context of the equal opportunity principle and the quota employment system of disabled people. That is, it is possible to justify the quota employment system from the perspective of equal opportunity policy, if the following requirements are met. These are:

- (1) 'Disabled people' who are subject to the policy must belong to the same type, where the circumstances limit the potential of those people to the same degree.
- (2) The target employment rate must be appropriate.

If these prerequisites are satisfied, then radical measures attempting to raise the actual employment rate of disabled people to the legally designated employment rate become part of the overall equality-of-opportunity measures needed to level the playing field in differing circumstances (according to which, individuals of the same centile receive identical treatment).

The question, then, is this: Are prerequisites (1) and (2) satisfied? Prerequisite (1) is intuitively unrealistic. In the Japanese quota employment

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system, all 'disabled persons' are treated together as a group, and this group is not divided into subgroups at all. In addition, there are no established distinctions other than the one between 'disabled person' and 'non-disabled person'. This implies that all disabled persons are affected by their circumstances in the same way, and that variations in circumstances in Japan are distinguished only in terms of this one point of whether or not someone is disabled. In order to adequately justify the Japanese quota employment system from the perspective of equal opportunity policy, there is a need to appropriately divide the group 'disabled persons' into several subgroups, considering various factors (including differences in impairments). In the actual Japanese system, however, the degree of disability may be defined by one's achievement (not by one's circumstances), especially in the case of intellectual disability. Therefore, it is impossible to use disability ranking for division into subgroups.

Next, we turn to point (2). As seen above, considering the political objective of the approach used to calculate the legal employment rate adopted in Japan's quota employment system, the policy aim may be interpreted as one of realizing a situation in which people presently willing to work are hired at a similar rate, regardless of whether they are disabled or non-disabled. If this interpretation is correct, then this would seem to be precisely the type of system that satisfies the demands of Roemer's conception of equality of opportunity. Considered in more detail, however, this goal is clearly not sufficient. There are a number of reasons for this (for example, many problems regarding the calculation method for the employment rate referred to in Section 2), but let us focus on the condition that a person must be 'presently willing to work'. Because of this condition, people not currently job hunting, regardless of whether they have the desire to work (or once had the desire to work), are not included at the base of calculations. Of course, people who fit this description exist both among the disabled and among the non-disabled, but considering differences in circumstances such as social environments and impairments, one may assume that the rate is higher among the former group than among the latter group. If this is the case, then in the calculation of the legally designated employment rate, one can expect that estimates of the number of disabled people with the willingness to work will be relatively low, with the result that the policy objective is not fulfilled. From the perspective of equality of opportunity, therefore, there would appear to be a need for policy aiming to achieve an even higher employment rate.

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Furthermore, Roemer's conception as a basis of the arguments above will invoke a more fundamental problem. This is the fact that if the attempt is made to exclude the influence of circumstances, including impairment, then the meaning of the concept of 'potential', which is the focus of the level-the-playing-field principle, is weakened. To repeat what was mentioned earlier, what is required in the level-the-playing-field principle is a situation in which 'people with relevant potential end up being treated in the same way'. Generally, the 'potential' mentioned in cases like this indicates ability that can be actualized as long as the appropriate conditions are in place. In fact, even in justifications based on equal opportunity philosophies from positive action in various fields, the potential of individuals is assumed to be essentially equal, either explicitly or implicitly supporting the hypothesis that such potential is actualized through some sort of social action (Salinas, 2003).

However, as a result of circumstances involving impairment and other genetic attributes, it is generally impossible, through later activity, to actualize abilities that have 'become latent'. Roemer's conception does not regard such aspects as differences in potential, but rather narrows the concept of potential to the meaning of 'ability to make autonomous efforts'. Of course, one can think of the concept of potential in this way. However, if policies are justified through an equality-of-opportunity philosophy based on this type of limiting understanding of potential, then there is the danger that the normative power inherent in equality of opportunity will be lost.

Conclusion

Based on this study, we conclude that Japan's quota employment system for disabled persons can at least be partially justified from an equal opportunity policy perspective, while this perspective would not be fully adequate to defend the system. If these findings are shared among many people, especially among those who are subject to the policy, then it can be expected that the negative effects of the policy will be mitigated or prevented.

In addition, it can be said that, while the quota employment system contributes to the substantial expansion (or in Roemer's conception, 'equalization') of employment opportunities for disabled persons, there is nonetheless a need to establish political measures striking a balance in maintaining the appeal of social norms of equal opportunity.

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Part Two:

Poster presentations and additional material

Cultural effects of disability on siblings of persons with intellectual and developmental disabilities: from the perspective of cultural psychology

Machiko Kawamura

When researching disability by examining the problems faced by siblings of persons with intellectual and developmental disabilities, it is essential to present disability as a social obstacle. One must not distinguish the characteristics of a society and the characteristics of siblings of persons with intellectual and developmental disabilities as separate attributes. Rather, we must redefine this relationship as different facets of a single complex; it is the conceptualization of an individual's various psychological processes as one part of the socio-cultural system. From this cultural viewpoint, we delve into the social obstacle of disability.

Introduction

Numerous studies have looked at siblings of persons with intellectual and developmental disabilities from the perspective of family system theory. Several obstacles are faced in bringing the experiences of siblings of persons with IDD into focus, and siblings of persons with IDDs or sicknesses respond with considerable variability: some siblings benefit from their experiences, others remain unaffected, and some are worse off (McHale and Gamble, 1989; Meyer and Vadasy 2000). Recent approaches have added other qualifications such as peer relationships and sibling support (Meyer and Vadasy, 1994; Fujii, 2006; Nishimura, 2006), but the position of the siblings remains largely unchanged. A deeper analysis into the underlying problems is essential.

Problems facing the siblings of persons with IDDs do not exist in a vacuum. Rather, the very nature of the public sphere contributes to the formation of these problems, or at the very least, acts as a significant element in its construction. Thus, any resolution to these problems must take this state into careful consideration. The purpose of this article is to delve into the experiences of siblings of persons with IDDs from the viewpoint of cultural

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psychology. Using this approach, it might seem that this discussion is natural and does not require clarification, but we hope to reveal what often goes unseen and to explain in detail certain social aspects related to the issue.

The cultural construals of the self: independent and interdependent models of being

In cultural psychology, a concept known as the cultural construals of the self, which focuses on the cultural differences in one's makeup from the perspective of self schemata, was recently developed. Markus (1977) describes self-schemata as experience-based cognitive generalizations of the self that process self-related information. Kitayama (1998) defines the cultural construals of the self as a generally accepted idea about the tacitly shared dominant nature of a person historically created within a culture. In other words, it is the centre point of mutual effect processes between culture and psychology.

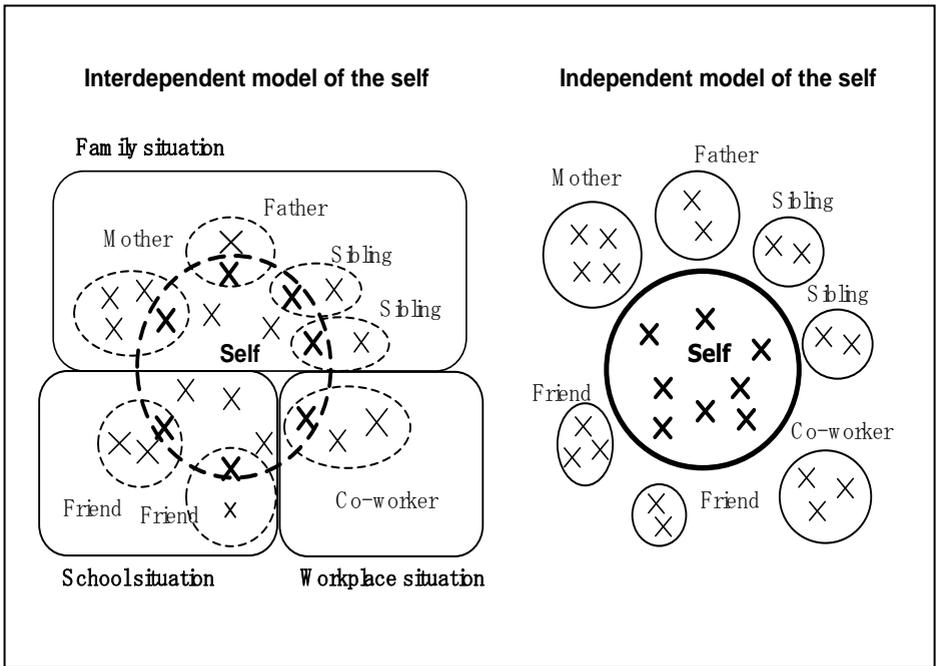
The two types distinguish cultural construals of the self as independent or interdependent and the form of each individual self as independent or interdependent. Within the framework of everyday Western customs, social systems, and various other common understandings, we know that: (1) individuals are independent from their surroundings; (2) their existence is defined by internal attributes such as opinion, attitude, ability, motivation, and personality traits; (3) the behaviours influenced by these internal attributes affect their surroundings. This independent model of the self is accepted as the norm. However, in Eastern societies, other cultural elements are seen, such as: (1) individuals are closely tied to their surroundings; (2) their existence is defined by the social relationships that result from these connections; (3) individual behaviours are influenced by these connections. This interdependent model of the self seems to be the norm in this case. Numerous cross-cultural studies have indicated that cultural models of the self are associated with analogous psychological forms and functions of the self in respective communities (Markus and Kitayama, 1991a). This is illustrated in *figure 1*.

The cultural models of the self that are reflected in practices on a cultural level can also be seen in behavioural tendencies on a personal level. This is because individual differences in behaviour are influenced by the relevant cultural and common practices. According to such input, certain behaviours are taken, or not taken, and individuals who behave counter to this

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input distance themselves from the norm. Depending on which of the two cultural models of the self is dominant, there will be a difference in the psychological processes resulting in individual behaviour (Markus and Kitayama, 1991a, 1991b).

Figure 1: Conceptual representation of cultural models of the self



(Based on Markus and Kitayama, 1991a)

Thus, cultural models of the self can be used as analytical models to compare the differences in individual behaviour within a country (Kurokawa, 1994; Kiuchi, 1995; Takata *et al.*, 1996). Research has also been done on how independent and interdependent self-construals are incorporated into the self-schemata and the relationships between these and social and cultural formative factors (Singelis, 1994; Takata, 1994a, 1994b, 1999a, 1999b; Kiuchi, 1995, 1996, 1997; Takata and Matsumoto, 1995).

CULTURAL EFFECTS OF DISABILITY ON SIBLINGS OF PERSONS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

In the literature, it is assumed that people in different cultural contexts tend to internalize and believe the respective models and psychological systems. All major attempts to measure self-construal at the individual level and then to relate individual differences in the sense of self to differences in psychological functions in other domains have been grounded in the assumption that cultural views of the self must be internalized in order for them to have any significant influence on psychological processes.

The above rationale focuses on how cognitive symbols are developed within the individual. On the other hand, Kitayama *et al.* (1997) assert that the transformation of cultural models to individual psychological and interpersonal systems is mediated collectively by the way in which situational scripts are accumulated and thus available in the respective cultural context. They point out that a complex of psychological and social elements should serve as the unit for analysis. Cognitive models of the self are fundamentally social, and have roots in the nature of society while also representing an element in the make-up of society. This does not deny the involvement of internalized cognitive models of the self in mediating psychological responses. In other words, it emphasizes the role of collectively constructed social situations in the analysis of culture's influence on psychological processes.

Furthermore, examinations of various cultures to see if their values and beliefs are predominantly independent or interdependent find significant overlapping among these different cultures. Judging from this research, many individuals resist the predominant values and behavioural norms of their society, regardless of country or culture. However, there is a tendency to accept these at face value. Kitayama *et al.* (1997) believes this complex to be a very dynamic unit.

Cultural participation and siblings of persons with IDDs

According to the theoretical framework of cultural psychology, the approach taken by siblings of persons with IDD's in their effort to adapt may not simply be a psychological product of each individual. It may, in fact, be afforded through various social and cultural processes.

A study by Hara and Nishimura (1998) suggests that differences in cultural background lead to differences in how siblings of persons with IDD's adapt to their social environments. They find that the developmental processes of siblings with brothers or sisters with IDD's differ from those who do not. With the aim of determining the process of self-awareness and social

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adaptability of siblings of persons with IDD, 180 siblings with brothers or sisters with IDD and their mothers and a 180-person control group of siblings who did not have brothers or sisters with IDD and their mothers were given a questionnaire. The results show that the self-awareness and social adaptability of siblings of children with IDD are in fact affected. Compared to the control group, it became clear that siblings with brothers or sisters with IDD have a compromised cognitive ability with relation to self-awareness. Furthermore, similar, earlier research in the United States finds that one great difference between the two groups manifests itself in a combination of social and physical ways.

Comparing Japan and the United States, because Japanese people tend to place a high value on academic achievement, social and physical factors become less important. As a result of Japan's rigorous educational culture, junior high school students have less self-awareness and lower self-esteem than their U.S. counterparts. Against this backdrop, Hara and Nishimura (1998) assume that siblings of those with IDD are more affected by the educational environment than those without brothers or sisters with IDD, showing that self-esteem is affected by educational circumstances. Although individuals without brothers or sisters with IDD are also affected by these circumstances, they clearly find that siblings of children with IDD look for values in areas other than academics to maintain their self-esteem and self-respect. In one instance, they point out that these siblings mature faster.

According to cultural psychology, self-esteem differs according to culture. Influencing behaviours are more culturally accepted in independent cultures (North America) than in interdependent cultures (Japan), and the effects of acts of influence on self-esteem may be more conspicuous in North America than in Japan. Another relevant aspect of self-esteem concerns the sense of connectedness to others in interdependent cultures (Japan). Adjustment is an expression of one's commitment to a relationship and the value one attaches to it, and individuals are thought to feel more connected when they engage in acts of adjustment. Moreover, because adjustment is more culturally accepted in Japan than in North America, the effects of adjustment on the perceived connectedness of the self are predictably greater in Japan than in North America (Heine *et al.*, 1999).

Kitayama and Markus (2000) assume that the psychological processes that result from efforts at cultural and social adaptation are conceptualized as the intra-individual phase of the relevant cultural complex. Thus, cultural

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models of the self can be used as analytical models to compare the differences in individual behaviour within a country.

Kawamura (2005, 2007) focused on the cultural construal of the self of the sibling. She investigated six factors that influence the acquirement process of the cultural rules of interpersonal relationships and siblings' cultural self-construals of the self: (1) family environment, (2) high school and college life, (3) relationships with friends, (4) living in a foreign country, (5) problems and worries due to the disability (6) valuable experience gained from the disability. She found that among siblings belonging to the independent model of the self group there was a strong connection between 'family' ($p < .01$) and 'valuable experience gained from the disability' ($p < .01$). On the other hand, 'high school and college life' ($p < .01$) and 'problems and worries due to the disability' ($p < .01$) were related to siblings of the interdependent model of the self group.

The transmission of cultural meaning requires interpersonal interaction in the formative years between the ages of 9 and 15 and the quantity and quality of interaction are related (Minoura, 1984, 2003). Kawamura (2009) examined if the siblings lived with brothers or sisters with disabilities during this period to measure the amount of interactions. She discovered five factors influencing the siblings' cultural construal of the self. The five factors are below.

- (1) Parents emphasizing independency
- (2) Intercultural experiences
- (3) The circumstances surrounding interaction with persons with disabilities
- (4) Relationships with high school and college friends and the present organization/community
- (5) The atmosphere of the high school and college, teachers and mothers raising children interdependently

In addition, in the case where siblings live with persons with disabilities during this period between 9 and 15 years of age, high levels of both the independent and interdependent models of the self appear possible.

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Conclusion and future directions

For some time, research on siblings of persons with IDD has been concerned exclusively with their negative emotional states such as frustration, stress, burnout, anxiety, shame, and guilt. The focus has been put on siblings of persons with IDD who are placed in a stressful environment and trying to adapt to their brothers or sisters with IDD as a family unit. Most studies on sibling relationships are devised with the intent of improving sibling relationships. Therefore, while investigating various factors, researchers have concentrated on helping siblings transform any negative feelings they might have toward their brothers or sisters with IDD into positive ones.

However, the mind is a social entity. If we assume that all attributes of the mind are grounded in the nature of society, there is no good reason to conclude that one set of relationships is good and that another is bad. To interpret differences and variations in the nature of these relationships within the framework of 'evolution' entails difficulties. How siblings adapt to their brothers or sisters with IDD is a psychological process resulting from social adaptation to the relevant cultural community, and it results from the conceptualisation of the intra-individual phase of the relevant cultural complex.

The cultural psychological approach assumes from the outset that situations may be different from what is typical. Details previously thought to be insignificant become noteworthy and social aspects receive more focus. Applying this method to research on sickness and disability will lead to further studies on how disability is influenced by cultural relationships.

More often than not, the experience of siblings of persons with IDD is marginalized in the research of problems stemming from disability. But the cultural psychology grounded approach to disability can nicely supplement earlier research on siblings of persons with IDD. This will produce a fuller account of human emotional experience and its socio-cultural and individual dynamics. The cultural perspective offers a number of useful directions for future research in this area.

First, it should be recognized that problems of siblings of persons with IDD are conceptualised as a tuning between an individual and his or her socio-cultural context. This should be taken more seriously in studies on the problems associated with siblings of persons with IDD and social relations.

Second, the notion that each sibling of persons with IDD has a social function, which is to increase the good and decrease the bad by internalizing

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cultural models, may itself be cultural. This idea may be grounded in the different ideological bases of those siblings who have lived with persons with IDD's from infancy. Diverse as they might be at first glance, different ideological bases are all rooted in a holistic conception of the universe and a world where everything is interconnected.

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The term ‘disability’ in discrimination law

Satoshi Kawashima

Introduction

The Convention on the Rights of Persons with Disabilities was adopted on 13 December 2006 and opened for signature on 30 March 2007. As of October 24 2009 there were 71 States Parties to the Convention (see UN n.d.). The Japanese government and NGOs – especially the Japan Disability Forum – participated actively in the elaboration process of the Convention. Japan has not yet ratified the Convention, but is making an effort to do so now.

It is not clear whether Japan will enact a new municipal law to prohibit discrimination based on disability in order to ratify the convention, but consideration of such a law will certainly be useful for the future possible and necessary reform of the Japanese disability law system. There are various issues related to disability discrimination law that have to be considered, one of which is the legal definition of disability. In this brief essay I explore, through the use of some models of disability, how disability should be defined and conceptualized in the context of the judicial and legislative process of the discrimination law.

Two features of the social model of disability

In identifying some features of the social model of disability, it is important to take note of the statement of UPIAS, which is articulated in the following manner.

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. (UPIAS, 1976: 14)

Strongly influenced by this definition of disability and historical materialism, Michael Oliver (1990) explains why and how disabled people were produced

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and categorized as unproductive and dependent persons, and excluded from mainstream society with the rise of capitalism.

One of the distinguished characteristics of this UK social model is that it adopts the distinction between 'impairment' and 'disability' as proposed by UPIAS (Oliver, 1996: 33). Vic Finkelstein (2001: 2), who founded UPIAS with Paul Hunt, states,

The agreed UPIAS interpretation was that, although it may be a *tragedy* to have an impairment, it is *oppression* that characterises the way our society is organised so that we are prevented from functioning.

Recently Alison Sheldon (2007: 210) has said, in the context of criticizing an influential article written by Shakespeare and Watson (2002),

Disability and impairment are of course interconnected and the distinction between them less than clear, but in order to identify political strategies it makes sense to separate the two analytically, treating them not as concrete objects but as abstractions.

The well-known slogan of the UK social model, 'People are disabled by society not by their bodies' (Shakespeare, 2006: 200) implies that we should focus not on the impairment, but on the inappropriate and negative reactions to persons with impairments which have caused them to be disadvantaged. On this point, the UK social model is similar to the US social model articulated in various legal articles, including one by Adam Samaha. According to him,

The social model defines 'disability' as disadvantage caused by the confluence of (1) personal impairment and (2) a social setting comprising architecture, economics, politics, culture, social norms, aesthetic values, and assumptions about ability. Different scholars stress different social factors: some American disability scholars have emphasized stigma and role theory, while some British writers concentrate on the mode of production. But their messages are similar. (Samaha, 2007: 1257 citations omitted)

As Carol Thomas (1999: 14) has explained,

(t)he social model asserts that it is not the individual's impairment which causes disability (Impairment→Disability), or which is the disability (Impairment=Disability).

This statement implies that there are no less than two distinctive features of the social model: one is causation and the other is terminology. Although these two features are closely interrelated, it is analytically useful not to adopt the terminology aspect in the context of defining the legal (or judicial) term 'disability' in the discrimination law.

Legal and socio-political terminology of disability

The socio-political (or disability studies) terminology of the UK social model, which makes a firm distinction between impairment and disability, may often cause confusion from the legal perspective and prevent effective realization of the object and purpose of the discrimination law (i.e. providing corrective justice for those who have suffered disability discrimination). In this regard, I will explain why there is a need not to adopt the socio-political definition in disability discrimination law through a comparison of the Japanese and US experience.

According to the Basic Law for Persons with Disabilities (Law No. 84 of 1970) in Japan,

The term 'persons with disabilities (shogai-sha)' means individuals whose daily or social life is substantially and continuously limited due to physical, intellectual or mental impairments (shogai).

Strongly influenced by this definition, the Ordinance on Disability Discrimination in Chiba Prefecture (Ordinance No. 52 of 2006) defines 'disability (shogai)' as 'physical, intellectual or mental impairments (shogai) which substantially and continuously limit individual daily or social life'. In these definitions the legal or juridical term 'shogai' (in Japanese) is used with two different meanings: 'impairments which do not limit individual daily or social life' and 'impairments which limit such life (= disability)'. The latter is legally protected by the Ordinance and the former is not.

Some leading disability activists in Japan, who are influenced by the idea of the social model, insist that the legal definition should reflect the social model. As is often the case, these activists strongly urge that we should

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incorporate the term 'environmental aspects' in the legal definition of 'disability' in discrimination laws. This, however, is not a good approach in terms of the effectiveness of discrimination laws. Regrettably, these activists are confused with legal and non-legal definitions of 'disability'. As the US experience shows, the legal definition of 'disability' under the Americans with Disabilities Act of 1990 (ADA) has been narrowly construed by Courts. A large number of persons with impairments have thus not been protected by the Act. The ADA Amendments Act of 2008 (ADAAA) was passed in order to restore the original intent of – to extend the scope of persons protected under – the ADA.

Under the ADA, the legal (juridical) term 'disability' means 'a physical or mental impairment that substantially limits one or more major life activities of such individual; a record of such an impairment; or being regarded as having such an impairment'. This definition of 'disability' is a legal one, not a socio-political one. Although there is a huge difference between the legal or judicial term 'disability' and the socio-political or sociological term 'disability', these terms are often used interchangeably in the context of discrimination law, which makes fruitful policy discussion almost impossible.

As Theresia Degener rightly proposes,

the solution might not be to refrain from using medical terms or impairment terminology [in the legal definition of disability]. Rather the opposite is true if we think about how disability discrimination actually works. (2004: 5. Cf. Hendriks, 2002: 210)

This insight implies that we should not reflect the terminology aspect of the social model in the context of discrimination law. Rather, we need to take the causation aspect of the social model seriously, focusing not on personal impairment but on the inappropriate reaction (i.e. discrimination) to persons with impairments which causes them to be at a disadvantage.

In this regard, the ADAAA reflects not the terminology aspect but the causation aspect of the social model, stating that 'the question of whether an individual's impairment is a disability under the ADA should not demand extensive analysis'. This statement means that the ADAAA shifts the focus of the analysis in courts from the question of whether a personal impairment is a legally protected trait (the legal definition of 'disability'), to the question of whether discrimination has occurred.

In the pre-ADAAA era, the court deprived the plaintiff of the status of legal protection by accounting for the effects of mitigating measures, one of the environmental aspects (e.g. *Sutton v. United Airlines, Inc.*, 527 U.S. 471 (1999)). This US experience has important implications for elaborating the legal definition of 'disability' in Japan. It is critical to focus on discrimination not on impairments in the application of the law. This is a central message of the social model of disability. In elaborating the definition of 'disability' in the discrimination law framework in Japan, the legal or juridical term 'disability' ought to be defined as 'personal trait' or 'impairment' not as 'social barrier' or 'social oppression.'

As mentioned above, if competent courts and other authorities have narrowly construed the term 'impairments which limit individual daily or social life (=disability)', certain 'persons with disabilities' might not be protected under the Ordinance. For this reason, the definition of 'disability' or 'persons with disabilities' in future disability discrimination law in Japan should be broadened as far as it is possible to do so.

Minority and universal model of disability

How then should we define disability (impairment) in discrimination law in terms of the causation aspect of the social model? Degener (2004: 11) has argued that 'the definition should describe the term 'disability-based', rather than the term 'disabled person''. We ought to focus on 'discrimination based on disability (impairment)' and prohibit it as broadly as possible under the law. We should also take note of the following statement by Robert C. Burgdorf (1997: 528):

The term 'individuals with disabilities' also underscores the critical difference between laws that provide services and benefits, on the one hand, and nondiscrimination laws, on the other. The benefit laws aim to give something to one group of people that is not made available to others. This necessitates a definite, circumscribed standard for determining who can get the services or benefits – an eligibility class. A nondiscrimination law, on the other hand, aims to provide a remedy for a much less confined class – anyone who has been subjected to discrimination.

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Degener (2004: 11), who recognizes that the distinction of the purposes of law is crucial for elaborating the legal definition of disability, points out that

(t)he medical model of disability is perpetuated if the definition of disability only covers a certain group of 'truly disabled persons' or – more generally speaking – if not all persons affected by disability discrimination are protected.

She also insists that in order to avoid the medical model the legal definition of disability should be tailored according to the following guidelines. The definition (1) should be related to impairment, chronic illness or malfunctions; (2) should not be based on a certain severity of disability; (3) should cover past, present, future and imputed impairments or chronic diseases and associates. According to Degener, 'the Irish definition follows most of these guidelines'.

In her view, the social model focuses on the discrimination; inappropriate or negative reactions to disability (impairment). The court should focus on 'discrimination based on disability (impairment)', which is line with the ADAAA mentioned above. In this sense discrimination law should forbid 'discrimination based on disability (impairment)' as broadly as possible. In order to broaden it we have two choices: to broaden the definition of discrimination or to broaden the definition of disability (impairment).

I focus here on the latter choice (broadening the definition of disability) in light of the object of this essay. Recently, I have proposed that instead of the US minority group model a universal model of disability can and should underpin discrimination law (Kawashima, 2008). Some people may doubt the idea that the minority group model could be replaced by universal model, because of American culture (e.g. Bagenstos, 2009). But we should not deny the theoretical possibility that the legal definition of disability (impairment) can be broadened if we view disability (impairment) as 'an infinitely various but universal feature of the human condition' (Bickenbach *et al.*, 1999: 1182), not as traits of members of a minority group.

Here it is important to note that the concept of the US minority model of disability has some unfortunate consequences. Although the US minority model has underpinned disability discrimination law, the implication it carries has prevented the very purpose of the law that all persons discriminated against based on disability should be protected. This model may define

persons with certain impairments as a minority group consisting of 'truly disabled persons' (see Degener, 2004). This concept of 'truly disabled persons' strongly reflects a dichotomous rather than a fluid conception of disability.

This dichotomous conception tends to force courts to focus not on discrimination but on a group characteristic (impairment) and may restrict legal protection to persons with certain impairments. In the process of interpretation and application of the discrimination law it is critical for courts to consider whether a person has experienced disability discrimination, not whether persons with some particular kind of impairments should be legally protected. The dichotomy-driven minority model may permit theoretically deprivation of the legal protection against disability discrimination in the case of persons with certain impairments.

Cass R. Sunstein (1994: 2428-33) notes that it is the underlying principle in American society that no members of any one group should be treated as second-class citizens. By analogy to civil rights movements, such as racial minorities' and women's movements, disability discrimination law has come to be linked closely with the minority model of disability, but in terms of logical perspective this link cannot be a necessary one. As Jerome Bickenbach (1999: 106) notes,

minority group analysis is based upon a forced analogy between racial minorities and disabled people that breaks down at many important points.

The following statement by the US National Council on Disability could be understood as endorsing the universal model of disability which recognizes 'that the entire population is 'at risk' for the concomitants of chronic illness and disability' (Zola, 1989: 405).

Most Americans will experience disability at some point during their lives, either themselves or within their families. Disability is not the experience of a minority of Americans. Rather, like aging, it is an experience that will touch every American family. (National Council on Disability, 1996: 4)

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In a similar vein, the US Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6000 et seq.) states that '(d)isability is a natural part of the human condition'.

In this regard, we should also take note of the Sutton case, in which the Supreme Court based its narrow construance of the definition of disability partly on the ADA's findings that 'some 43,000,000 Americans have one or more physical or mental disabilities' and that 'individuals with disabilities are a discrete and insular minority' (Sutton, 527 U.S. at 484; 494). These phrases in the ADA have now been deleted by the ADAAA. This case shows that the minority group model could restrict the scope of protection of the discrimination law. In order to broaden the scope of the juridical (legal) term 'disability' we should recognize the important contribution of the universal model of disability.

Conclusion

The findings in this essay are as follows. From the analytical perspective, there are two aspects of the social model of disability: Terminology and causation. In the context of disability discrimination law, we should not reflect the terminology aspect of the model, the socio-political term 'disability' denoting social oppression or disadvantage. The legal definition of disability should mean an individual trait (impairment) in the context of discrimination law. On the other hand, we need to take the causation aspect of the social model seriously, since one of the causes of the disadvantages that persons with impairments experience is discrimination (unequal treatment) based on their impairments.

The causation aspect has the effect of focusing not on impairment but on discrimination based on impairment, and forbidding such discrimination as broadly as possible in the judicial and legislative process of the law. For this purpose the juridical (legal) term of 'disability (impairment)', which is one component of the legal definition of 'discrimination based on disability (impairment)', should be defined as broadly as possible. If some particular kinds of impairments are not included in the legal definition of disability, then discrimination based on such impairments cannot be protected under the law.

In this regard, the minority model of disability based on the dichotomous conception of disability, theoretically, tends not to protect persons with some particular kinds of impairments in discrimination law. This model has the effect of forcing courts to focus more on impairment than

discrimination. Whether an individual's impairment is a legally protected trait (disability) or not demands extensive analysis in the judicial process under this model.

On the other hand, the universal model of disability, theoretically, tends to protect those persons who are not protected under the minority model in the context of discrimination law because the former model presupposes that almost all impairments are legally protected traits. As a result the universal model has the effect of focusing more on discrimination than impairment in the judicial process. In this sense the universal model, being in line with the social model, is preferred to the minority model in the context of discrimination law.

This does not mean that the universal model is better than the minority model in any aspects of the discrimination law. We should further consider various theoretical issues concerning such a law, including tensions between the minority and universal models.

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***Aoi Shiba* and fundamental issues of family and productivity**

Osamu Nagase

When a mother murdered her disabled child in 1970, *Aoi Shiba*, a group of disabled people in Japan, declared their stance. Their platform, quoted in full, raised fundamental issues including self-identity, self-assertion, and the rejection of family members' over-protective love. This initiated the modern disability rights movement and led to disability studies. These issues raised by *Aoi Shiba*, including family and productivity, still present major challenges today.

We deny love and justice.
Aoi Shiba, 1970

Introduction

Aoi Shiba no Kai (hereafter referred to as *Aoi Shiba*, meaning 'green grass') was a group of disabled people in Japan that was particularly active in the 1970s and 1980s. They raised fundamental questions about their very existence, society and values, and objected to the dominant ablist and paternalistic society. This paper tries to shed some light on this group and their ideas, which have had a lasting impact on disability thinking and beyond.

***Aoi Shiba* and its platform**

Aoi Shiba is a group of people with cerebral palsy (CP), and was initially started in 1957 as a social group, becoming increasingly politicized during the 1960s. Terada (1990), one of the founding members of *Aoi Shiba*, has recalled that when the economy was rapidly expanding in the 1960s and 1970s, society adopted the attitude 'If man will not work, he shall not eat', and *Aoi Shiba*

started with the self-awareness that they had no income generation capacity and established that they had to resist dependency on family members.

Lack of community support services forced family members to provide support and care to disabled people. Occasionally, this led to murders of disabled people by their parents. Even today, murders of disabled children, including those who are grown-up, happen almost every year in Japan. Some parents even commit suicide after killing their disabled children. Some of these cases are reported, but not all.

In 1970, another murder of a disabled child happened in Yokohama. As usual, the public expressed sympathy for the mother who had killed her child. Parents' groups petitioned the local court for lenient sentencing, claiming that the mother had to take care of another child, and that other parents shared the feelings of the mother (Asahi Shimbun, 1970). What was different this time was that *Aoi Shiba* members publicly criticized these sympathies expressed by the community and parents' groups for the mother who had killed her disabled child.

Yokoduka (1975: 108), a leading and vocal member of *Aoi Shiba*, condemned the Eugenics Protection Law of 1948, which provided for the forced sterilization of disabled people, and stated as follows:

In a society that gives supremacy to production, disabled people, who have low productivity, have been treated as a burden and an existence that should not exist. This law literally protects those who are superior (productive) and eliminates those who are inferior (lesser). This law determines that those without productivity are 'evil'.

Against this background, *Aoi Shiba* announced its four-point platform in its newsletter in 1970, which reads as follows (Ayumi, 1970):

*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 for our whole movement, and we act on this belief.

* We assert ourselves aggressively.

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

* We deny love and justice.

We condemn the egoism held by love and justice. We believe that mutual understanding, accompanying the human observation arising from the denial of love and justice, means true wellbeing, and we act on this belief.

* We do not choose the way of problem solving.

We have learnt from personal experience that easy solutions to problems lead to dangerous compromises. We believe that an endless confrontation is the only course of action possible for us, and we act on this belief.

The following fifth point was added later.

*We deny an able-bodied civilization.

We recognize that modern civilization has managed to sustain itself only by excluding us, people with CP. We believe that the creation of our own culture through our movement and daily life leads to the condemnation of modern civilization, and we act on this belief.

(I take this opportunity to express my appreciation to members of the disability-research discussion list, including Ron Amundsen of the University of Hawaii at Hilo, who kindly helped me with the English translation of this platform. This discussion list is managed by the Centre for Disability Studies of the University of Leeds).

This often quoted platform signalled the formation of the modern disability rights movement and led to disability studies. Before *Aoi Shiba*, disability movements were more focused on the lack of services and policies, and many activists were family members of disabled people (Yamashita, 2008).

Aoi Shiba organized demonstrations and sit-ins against inaccessible public transportation and successfully lobbied against the addition of impairment of the foetus as a justification for abortion in the notorious Eugenics Protection Law during 1970s and 1980s.

In 1990, Tateiwa (1990) broke new ground by analyzing the independent living movement in Japan, including *Aoi Shiba*, and this is when disability studies truly came to exist in Japan, though not named as such. That had to wait until 1999, when Ishikawa and Nagase (1999) published *Invitation to Disability Studies*.

‘Fundamental questions and uncompromising positions’ are the constant characteristics of *Aoi Shiba* (Kuramoto, 1999: 224) and their ideas remain radical and fundamental. *Mothers, Do Not Kill* by Yokoduka, which elaborates *Aoi Shiba*’s philosophy, was published again in 2007 together with his unpublished papers, eulogies of the author (who had passed away in 1978), and Tateiwa’s commentary, which stated, ‘this is one of the most important books published last century’ (In Yokoduka, 2007: 392). Now, I focus on two major issues raised by *Aoi Shiba*, namely family and productivity.

Love that kills, supported by justice

Aoi Shiba denied the love of the family that killed them. The lack of support services in the community forced family members, and parents in particular, to become the main providers of support and care, and many disabled people had to depend on family members. This created a situation in which disabled people had, on the one hand, no other choice but to rely on family members and, on the other, fear that the very family members who provided them with care and support might murder them one day. Parents loved their disabled children so much and were so concerned about their future, including those who had grown-up, who they could not leave them behind. It is interesting to note that in his analysis of British disability studies, Sugino (2007) points out common elements between Yokoduka and Jenny Morris (1991) when the latter discusses lives not worth living and chances of life.

Aoi Shiba’s anti-family position was a factor in the discussions for the formation of Disabled Peoples’ International (DPI), an international cross disability organization. Some *Aoi Shiba* members joined DPI’s founding meeting in Singapore in 1981 and strongly advocated against the participation of parents, claiming that ‘parents tended to over-protect their disabled children and wanted to keep them dependent’, whereas ‘disabled people wanted to be adults, not protected children all their lives’ (Driedger, 1989: 54).

Parents and their organizations do not have to be over-protective and can develop to include persons with disabilities as equal partners. For instance, the Canadian Association for Community Living (CACL: originally Canadian

Association for Retarded Children when it was founded in 1958) began as an organization of parents but now has at least eight self-advocates among its 22 directors on the board. It has been very actively promoting deinstitutionalization (Panitch, 2008).

On the other hand, CACL's counterpart, Inclusion Japan, a leading organization of people with intellectual disabilities and their family members, does not have a single self-advocate on its board, though it promotes self-advocacy. In response to proposals to have self-advocates on the board of directors, some members expressed the view that it was problematic to 'overburden' self-advocates (Fukuoka, 2007, 5). This is just another example of the paternalistic attitude toward disabled people in general, and, in particular, the more common attitude toward people with intellectual disabilities. It is in this context that Nakanishi, leader of the Japan Council on Independent Living Centers and a world council member of DPI, stated, 'family members are the major enemy' (Motohashi, 2009, 65).

An alliance between disabled people and their family members is yet to emerge in most countries. A self-advocacy movement of persons with intellectual disabilities, for instance, does not exist at all in many places, or is very weak. Empowerment of persons with intellectual disabilities is hard when many are excluded from education. There are encouraging signs as well. People First of Canada, an organization of persons with intellectual disabilities, joined Inclusion International in 2008. Inclusion International, which began as an organization of parents of persons with intellectual disabilities in 1960, now has five self-advocates among its 14 council members.

Productivity and work

Another fundamental question relates to the values attached to the work and productivity of disabled people, as well as the assumed low productivity of some disabled people because of their impairments. *Aoi Shiba's* basic philosophy was to separate productivity from the meaning of their existence, which was denied based on their low productivity, real or imagined.

This was expressed by some of the responses to the passage of the Americans with Disabilities Act (ADA) of 1990, a comprehensive anti-disability discrimination in the United States of America. The ADA had much impact on and was generally well received by the disability community in

Japan, but there were some minority views expressed from the perspective of *Aoi Shiba*.

Stating that as long as economic efficiency was valued, there was no way out for people with severe impairments, Hanada (1990: 130), a long-time activist who also worked with *Aoi Shiba*, criticized the elitist nature of the ADA, writing that

If the logic of ‘it pays’ is imported now after all these years, we will have to do our movement such as *Aoi Shiba* all over again.

This kind of scepticism of meritocracy, which Hanada suspected was the basis for the ADA, was shared by others, including Terada (1990), a member of *Aoi Shiba*.

Inspired by *Aoi Shiba*, Tateiwa (1997, 2004, 2009) developed his thinking regarding the relationship between what one produces and ownership. In current discussions about the meaning of work in the context of basic income, *Aoi Shiba*’s claim that just moving one’s body to help his/her assistant was already hard work for people with severe physical impairment is recalled. *Aoi Shiba* even claimed that for disabled people, ‘living itself was work’ (Yamamori, 2009).

The disability rights movement and disability studies: the legacy of *Aoi Shiba*

Some of the legacies of *Aoi Shiba* are still evident. For instance, even today’s abortion law – Mother’s Body Protection Law – which was revised from the Eugenics Protection Law in 1996, does not allow abortion based on impairment of the foetus largely thanks to activities initiated by *Aoi Shiba*. In fact, the official policy does not encourage prenatal screening. For instance, in Japan, the percentage of pregnant women who undergo triple marker screening, which identifies foetuses with Down Syndrome, has been quite low compared to South Korea, the UK and the USA where the majority of pregnant women consent to screening (Mori, 2001). This is partly because the Health Sciences Council on the evaluation of advanced medicine under the Ministry of Health and Welfare issued a directive in June 1999 that did not recommend this screening. This process was influenced by *Aoi Shiba* and the disability rights movement.

This brief paper presents the message of *Aoi Shiba*, symbolized by its platform, focusing on its anti-family stance and resistance to the production-oriented society. Sugino (2007) identified the following major challenges facing disability studies in Japan from an international perspective: (1) the family as a barrier, (2) meritocracy and anti-discrimination law, (3) feminist theory and disability studies – equality versus difference, (4) putting disability studies into practice – the social model and its application, (5) users' sovereignty and stakeholders' sovereignty – reform of the individual model and its application. A number of these points originate from *Aoi Shiba*.

What is needed is a comparative analysis of disability rights movements and the development of disability studies in different countries, including *Aoi Shiba* in Japan, represented by its platform in 1970, and the Union of the Physically Impaired Against Segregation (UPIAS), represented by its historic *Fundamental Principles of Disability* in 1976, as well as the independent living movement in the USA, among others.

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Three employment-related difficulties: understanding the experiences of people with visible differences

Miki Nishikura

Since the 1980s, and in contrast to Japan, many researchers in the UK have revealed that facial disfigurement can disturb social interactions and have a great psychological impact upon the people affected. Despite the known psychological and social consequences associated with facial disfigurement, little is understood of the economic difficulties confronting people with visible differences. The aim of this paper is to explore the various difficulties that people with visible differences experience in terms of employment. Fourteen people with visible differences participated in this small qualitative study. This paper argues that research on the difficulties for people with visible differences in terms of employment has to pay attention to the stage ‘before applying for a job’.

Introduction

The charity *Changing Faces* (n.d.) estimated that 542,000 (or one in 111) people in the UK have a significant facial disfigurement. It is not easy to draw a boundary between what is and is not facial disfigurement, so several researchers define disfigurement as ‘a difference from a culturally defined norm which is visible to others’ (Rumsey *and* Harcourt, 2005: 88). The causes of facial disfigurement include congenital malformations, such as birthmarks, cleft lips and/or palates and haemangiomas, and acquired conditions, such as burns, scars from traffic accidents and dermatological disease.

When one considers the high specificity of the face when compared with any other part of the body, it is not surprising to find that people with facial disfigurements encounter serious psychological and social problems. In Japan, however, until very recently, they have received little attention. Since the establishment of a nation-wide self-help group *Unique Face* in 1999, research on the problems related to facial disfigurement have only just started (e.g. Matsumoto, 1999; Kondo and Yamazaki, 2005; Nishikura, 2009). Thirty

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years ago, Macgregor (1979: 116) suggested that people with facial disfigurements seemed to be ‘the forgotten people’, and this is still the case as far as Japan is concerned.

In contrast to Japan, many researchers in the UK from a variety of academic backgrounds, have, since the 1980s, studied the serious problems that people with facial disfigurements have to deal with. The problems most frequently reported are negative self-perceptions and difficulties with social interactions (e.g. Bull and Rumsey, 1988; Rumsey and Bull, 1986; Robinson, 1997). While studies to date in the UK are of significance to researchers in Japan, very little research has focused on the difficulties that people with facial disfigurements encounter in the labour market. Exceptions have been Bradbury (1997) and Stevenage and McKey (1999). Bradbury pointed out that people with facial disfigurements consciously tend to choose a low-profile career and are reluctant to seek advancement in their careers. Stevenage and McKey found that having a facial disfigurement had a markedly negative effect in the recruitment and selection process. In the US, Tartaglia *et al.* (2005) documented the experience of discrimination in the workplace for Americans with facial disfigurements. Using data from the Equal Employment Opportunity Commission, they showed that allegations from people with facial disfigurements were significantly higher for the retail and service industries and lower for the construction and manufacturing industries where employers could more easily ‘hide’ employees. Although research on employment to date has addressed the problems people with facial disfigurement confront both in the recruitment and selection process and in the workplace, these are not the only problems that people with visible differences in Japan have reported in the area of employment (e.g. Ishii *et al.*, 2001). This study, based on accounts given by the people concerned, aims to explore the various difficulties that people with visible differences experience in the area of employment.

Methods

This qualitative study constitutes preliminary research to help create a draft questionnaire for quantitative data collection and analysis. Using qualitative methods, the focus of this study is an in-depth understanding of the lived experiences of those who have visible differences.

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The primary research questions were: ‘How has visible difference affected the participants’ work and occupation?’ and ‘With what thoughts or attitudes have they sought employment?’

Participants

The participants consisted of fourteen people who have lived with a visible difference in their face, hair or skin on almost every part of their body. One half of the participants were members of three self-help groups that support individuals who have a visible difference and their families in Japan. The other half were recruited either from the community site of a social networking service in which people with visible differences exchanged medical information or talked about their troubles in everyday life with each other or through the private friendships.

Of the fourteen participants, there were six men and eight women, ten people who had congenital disfigurements and four people who had acquired conditions. At the time of the interviews, the participants ranged from 21 to 59 years of age. The educational level of three participants was high school, five had graduated from a vocational school or junior college and six had university degrees. Seven participants were permanent employees and three were employed as part-timers or as temporary staff. Four were unemployed. Apart from four women, all the participants had contact with a self-help group and, to varying degrees, were committed to social issues concerning visible difference. In addition, to gather as much information about people with visible differences in a clinical setting as possible, I interviewed a plastic surgeon who specializes in congenital disfigurements and a dermatologist who has assisted a patient support group for people with alopecia areata.

Interviews and data analysis

The collection and production of data occurred through fourteen interviews that took place over a three-month period. Each interview was approximately two hours in length. Influenced by Flick (1998), I used focused interviews with a semi-structured format to discover the difficulties that people with visible differences encounter with employment. Flick explains that focused interviews enable us both to explore the ways of thinking that are specific to various social groups and to set up a hypothesis for subsequent quantitative research. Interviews were recorded and transcribed verbatim. The transcripts were systematically analyzed by means of coding, categorizing and interpreting the transcripts.

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Findings

Although earlier studies on facial disfigurement and employment have focused entirely on the discrimination experienced by people with visible differences in the recruitment and selection process or in the workplace, it seems that the participants in this study encountered more diverse and complex difficulties when it came to their employment. These can be roughly classified into three types: (1) difficulties before applying for employment; (2) difficulties while applying for a job and during the recruitment and selection process; and (3) difficulties in the workplace.

Difficulties before applying for a job

Some participants reported that it is not easy to make up their mind to apply for work. As many researchers have revealed, people with visible differences feel that they are avoided and rejected by others. The fear of these negative reactions is so great that withdrawal from social situations involving an avoidance of occupational activities is frequently chosen as a way to deal with the difficulties and protect themselves. A man heading a parent support group for people with a cleft lip and/or palate indicated that there were not a few people with the condition who became preoccupied with their appearance and withdrew from the world of work. Furthermore, psychological problems such as feelings of isolation and low levels of self-esteem can result in a person avoiding employment. A 35-year-old man who had alopecia areata at the age of six months could not bring himself to find work when he was a university student:

I felt alone. There were no role models who showed me how to live with alopecia areata because I did not know anyone who had the same disease as me. While I only had to run on rails from elementary school to university, I could not have the confidence to start work after finishing university and withdrew into my own world when I was a senior.

He needed seven extra years to graduate from university. It was not until he took part in a self-help group that aimed to provide information and support to individuals with alopecia areata and got to know many people with the disease that he made up his mind to look for work.

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Difficulties with applications and during the recruitment and selection process

Some participants said that they chose to seek work in industries with limited public interaction and exposure. The man with alopecia areata mentioned above remarked that people who lost their hair because of the disease and wore a wig consciously tended to choose a job that minimizes the chance of exposure. They tend to work as part-timers, temporary staff or on short-term contracts, avoid developing close and long-term relationships in the workplace and change jobs frequently for fear that their visible difference may be noticed by colleagues. A 31-year-old woman who had congenital ichthyosiform erythroderma avoided looking for jobs in such industries as the retail and service sectors when she was a junior college student:

I knew it was completely impossible for me to get a job with customer contact. Even if I was employed in these industries, I would be exposed to negative reactions from customers, including invasive comments and staring. In addition, I thought I could never gain employment that involved the handling of foods because of my turned-up skin.

In addition, persons close to the participants also played an important role in preventing them from pursuing employment that made them more noticed by others. For example, a 21-year-old woman who had a port-wine stain and does not use cosmetic camouflage was told by a guidance counselor in her high school that it would be better to avoid seeking employment in situations involving extensive customer contact. The teacher counseled that she should choose a job with little or no customer contact so that her facial disfigurement would not cause discomfort to anyone. A 37-year-old man with cavernous haemangioma on one side of his face was forced by his father to seek employment in industries with little or no customer contact. He was going to take a humanities course in college and wanted to become a businessman when he was a high school student. His father, however, told him that it was impossible for him to become a businessman because of the severe disfigurement of his face and advised him to take a science course in college to get employment in the construction or manufacturing industries, where there was limited public interaction and his condition would not be so visible.

Some participants tended to choose to look for work in industries with limited public interaction and exposure, as mentioned above, but others did not. Nevertheless, in the recruitment and selection process, they were rejected

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as ‘unqualified’ because of their appearance. One of the worst types of recruitment discrimination occurred when people with visible differences were denied employment because of the unjustified belief that customers would be offended simply by seeing them. A 24-year-old woman has very fair skin and light-coloured hair as a result of albinism, which is quite different from the ‘normal’ appearance of the Japanese. Since high school, she had tried to work part-time at a supermarket or store. One day, she made an appointment for a job interview by phone but as soon as the store manager saw her he told her that the store could not hire her because of her ‘unusual’ hair colour. She remarked:

Few people know that there are those who live with albinism and have light-coloured hair in Japan. Consequently, employers fear the negative reactions of customers to my light-coloured hair and I have been denied employment.

A woman in her forties with a port-wine stain covering one side of her face was told at a job interview with a restaurant that she had to conceal her facial disfigurement by wearing a cotton mask for fear that co-workers as well as customers would feel uncomfortable when they saw her face.

Difficulties in the workplace

Even if people with visible differences are able to find work, some difficulties still lie ahead. Some participants described that they had been exposed to workplace harassment that was related to their visible difference. The harassment included teasing, ridiculing, bullying, verbal abuse, and arbitrary changes in their jobs or their assignments. A woman with a severe facial disfigurement as a result of von Recklinghausen disease got a clerical position in a small company after graduating from vocational school:

One day, I served tea to a client as usual but a co-worker said to me ‘How dare you do that? What would clients feel if they see your face?’ That was what I had to do at the office and the client didn’t look offended. I was deeply shocked to hear her say such a thing.

People with visible differences were targeted for harassment not only because of the visible difference itself but also because of the concealment of it. A member of a self-help group for people with alopecia areata said that those

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who had the disease and covered up their hair loss with a wig were frequently teased by their colleagues by being called, for instance, 'baldie' and 'wiggy'. According to a dermatologist who assisted a patient support group for people with alopecia areata, those who developed the disease tended to be assigned against their wishes to positions with little or no customer contact because of the changes in their appearance. To make matters worse, people who were subjected to harassment in the workplace remarked that they had no one and nowhere to turn to for help or redress.

Discussion

Although research on this topic to date has mainly addressed the discrimination people with facial disfigurements experience in the recruitment and selection process and in the workplace, some participants in this study remarked that they had already encountered difficulties before 'being an applicant' and cannot make up their mind to look for work. Frequent exposure to such negative reactions as avoidance and rejection by others since childhood can result in withdrawal from social situations and avoidance of occupational activities. Unfortunately, people with visible differences tend to be isolated because they do not have people with the same disease or medical condition around them. It is very hard for them to know how to live with a visible difference and thus have the confidence to enter the world of work. For some people, moreover, the work that they could try to get was largely limited by persons close to them, such as their family or teachers, to industries with little or no customer contact. Accordingly, it is necessary to pay attention to the difficulties before someone applies for a job. Figuratively speaking, we need to expand our interest toward an 'earlier' point in time.

Until recently, most research on visible difference has employed quantitative methods of data collection and analysis. The methodology used in these studies has enabled some meaningful comparisons to be made between studies that share the same quantitative measures, but little is known about the complexity of the psychological and social effects of visible difference. This qualitative study, based on accounts given by people with visible differences, is different from others in that it attempts to offer an in-depth understanding of the experiences of people living with visible differences. However, this research has several limitations. First, as in many qualitative studies, the number of participants interviewed was relatively small. The descriptions given here may not be typical of the experiences of all people with visible

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differences. It may be that the participants (members of self-help groups and those interested in the social issues surrounding visible difference) and the types of question asked (about how visible difference has affected their employment) may have biased the responses toward a recounting of more negative experiences. Second, this study could not compare the difficulties for people who have a certain condition with people who have another condition, although we did interview people with a variety of conditions. It seems likely that there are significant differences between people with congenital visible differences and people with acquired differences, between people with concealable visible differences and people with non-concealable differences, between people with more severe visible differences and people with milder differences, and so on. I will explore the experiences of a larger sample of people who are living with visible differences using a questionnaire employing quantitative methods of data collection and analysis. In addition, I will examine the difficulties people with visible differences experience with employment by focusing on the type, severity and concealability of a visible difference as well as on demographic and social factors such as age, gender and socio-economic status.

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CHAPTER 11

On understanding experiences of disability

Kiri Sakahara and Takashi Sato

Grasping an experience as a disability: it is this simple cognition process that we explore in this article. Stated more generally, we explore the ability to cognize an object as a being with an attribution. We could say that this is an ability which we (have to) presuppose as obvious when we cognize the world. At the same time, it is undeniable that it is an ability with a certain kind of indefiniteness. In fact, the judgement of what experience can (or should) be deemed a disability varies according to the context and situation, or even the person who judges it. The aim of this article is to clarify what creates this indefiniteness and to highlight a creative aspect of cognition by formalizing the schematic of this ability.

Introduction

We begin by presenting an example which the authors actually experienced in order to specify this problem concretely. It was an ordinary event, but forced us to rethink our understanding of the concept of ‘disability’.

It was early spring when S was waiting for a lift to go down to the floor where a research forum was going to be held. N , a research colleague who attends the forum, was also there. A minute later, the lift stopped on the floor. Then the door opened and N asked S , looking at the mirror set up in the lift, what really troubles him when it’s missing from a lift. S began to think and kept silence for a while, but could not get it. The answer was a mirror.

Some explanation is needed to interpret this example. N requires a wheelchair for everyday life. As is well known, he needs the mirror to confirm the safety of the rear side of his wheelchair, particularly when getting off the lift.

N would have been made conscious of this ‘disability’ whenever he rode in a lift. Anybody who has ever ridden in a lift with a wheelchair must be conscious of this. However, S wasn’t aware of this obvious fact at that time.

This made S ponder. There are experiences that we can be unaware of being a disability but also that we can be aware of and cognize it as a disability. What makes this experience possible or what happened in this experience?

Let us first confirm that S didn’t change his syntactic structure of ‘disability’ from this experience. He understands the concept of ‘disability’ as ‘an experience which is brought about by a certain type of barrier’. It was a change of the correspondence between ‘disability’ and its referent that S went through from that event, i.e., ‘the barrier of getting off a lift without a mirror in a wheelchair’ is a ‘disability’.

It is more important that S didn’t experience the ‘barrier’ directly himself. S was only made aware by N of a troublesome situation that he had ever seen. Or, S changed the correspondence between his concept of ‘disability’ and its referent only due to the indication that the ‘experience’ which he had witnessed was a ‘barrier’ (and by exercising his imagination). Therefore, this change must have been brought about by N ’s utterance alone.

We present a model of the schematic which makes this change possible. The model captures at least one aspect of our cognition, that agents can be both unaware of some experience being a disability and, at the same time, be aware of it as a disability, and highlights the function of the concept of ‘disability’ which sets off this change.

Preliminaries

In this section we introduce the basic concepts constituting the framework of channel theory. Channel theory is a formal framework established by Barwise and Seligman (1997) to model information flows. We apply it to model an agent’s cognition.

Classifications

One of the most fundamental concepts of channel theory is *classification*. First we define it as follows.

Definition 1. A *classification* $A = \langle \text{tok}(A), \text{typ}(A), \vDash_A \rangle$ consists of

1. a set, $\text{tok}(A)$, of objects to be classified, called the *tokens* of A ,
2. a set, $\text{typ}(A)$, of objects used to classify the tokens, called *type* of A , and
3. a binary relation, \vDash_A , between $\text{tok}(A)$ and $\text{typ}(A)$.

If $a \vDash_A \alpha$, then a is said to be *of type* α in A .

Below we describe an agent's *observation* as a classification, i.e., the tokens are the subjects of the observation and the types are the observed attributions.

Infomorphisms and channels

Next we introduce *infomorphism* which detects a certain kind of sameness of classifications.

Definition 2. An *infomorphism* $f : A \rightleftarrows B$ from A to B is a contravariant pair of functions $f = \langle f^\wedge, f^\vee \rangle$ satisfying the following *Fundamental Property of Infomorphisms*:

$$f^\vee(b) \vDash_A \alpha \quad \text{iff} \quad b \vDash_B f^\wedge(\alpha)$$

for each token $b \in \text{tok}(B)$ and each type $\alpha \in \text{typ}(A)$. Classification A is called the *domain* of f and classification B is called the *codomain* of f .

If a family of infomorphisms has a classification as a common codomain, the family of infomorphisms is called a *channel* and the classification a *core*. The definitions are as follows.

Definition 3. A *channel* C is an indexed family $\{f_i : A_i \rightleftarrows C\}_{i \in I}$ of infomorphisms with a common codomain C , called the *core* of C . The tokens of C are called *connections*; a connection c is said to *connect* the tokens $f_i(c)$ for $i \in I$. A channel with index set $\{0, \dots, n-1\}$ is called an *n-ary* channel.

In this article, we describe an agent's cognition as a binary channel. The channel describes the function of making a connection between the left-hand-

side classification (called the *source*) and the right-hand-side classification (called the *target*).

Theories

Next we bring up a concept of *theory* to model the agent's knowledge and inference process. We assume in this article that all agents make an inference according only to the knowledge expressed by this theory.

Definition 4. Let Σ be an arbitrary set. A binary relation \vdash between the subsets of Σ is called a (*Gentzen*) *consequence relation on Σ* . A *sequent* is a pair $\langle \Gamma, \Delta \rangle$ of subsets of Σ and a sequent is called a *partition* of a set Σ' if $\Gamma \cup \Delta = \Sigma'$ and $\Gamma \cap \Delta = \emptyset$. A *theory* is a pair $T = \langle \Sigma, \vdash_T \rangle$, where \vdash_T is a consequence relation on Σ of theory T . A *constraint* of the theory T is a sequent $\langle \Gamma, \Delta \rangle$ of Σ for which, $\Gamma \vdash_T \Delta$.

We assume regularity below as a property of the theory.

Definition 5. A *theory* is *regular* if it satisfies the following for all types and all sets $\Gamma, \Gamma', \Delta, \Delta', \Sigma', \Sigma_0, \Sigma_1$ of types:

Identity: $\alpha \vdash_T \alpha$.

Weakening: If $\Gamma \vdash_T \Delta$, then $\Gamma, \Gamma' \vdash_T \Delta, \Delta'$.

Global Cut: If $\Gamma, \Sigma_0 \vdash_T \Delta, \Sigma_1$ for each partition $\langle \Sigma_0, \Sigma_1 \rangle$ of Σ' , then $\Gamma \vdash_T \Delta$.

Furthermore, when an arbitrary theory T is given, we define the *regular closure* of theory T as the theory which includes all the constraints derived from the constraints of theory T by the regular operations above.

Definition 6. Let arbitrary theory $T = \langle \Sigma, \vdash_T \rangle$ be given. The smallest theory whose constraints are comprised of the constraints of theory T and all the constraints derived from the constraints of theory T is called the *regular closure* of theory T and is denoted as $\bar{T} = \langle \Sigma, \vdash_{\bar{T}} \rangle$.

Cognizance Classification

The essential notion for describing an agent’s cognition is the *cognizance classification*. It is a classification which reflects not only the structure of source and target but the agent’s own knowledge.

Definition 7 (Barwise 1997; Sakahara and Sato 2008). Let A be a source, B be a target classification, and T be a regular theory. Firstly, the set of all partitions of $\text{typ}(A) \cup \text{typ}(B)$ is said to be the set of *states* generated by A and B , written $\Omega_{\langle A, B \rangle}$. Secondly, the set

$$\Omega_{\langle A, B \rangle}^R = \{ \langle \Theta, \Lambda \rangle \in \Omega_{\langle A, B \rangle} \mid \exists a \in A, \text{typ}(a) \subseteq \Theta \text{ and } \text{typ}^c(a) \subseteq \Lambda \}$$

is said to be the set of *realizable states* generated by A and B under the tokens of A . Thirdly, the set

$$\Omega_{\langle A, B | T \rangle}^{IP} = \{ \langle \Theta, \Lambda \rangle \in \Omega_{\langle A, B \rangle} \mid \langle \Theta, \Lambda \rangle \notin_T \}$$

is said to be the set of *impossible states* under the theory T . Fourthly, the set

$$\Omega_{\langle A, B | T \rangle}^P = \Omega_{\langle A, B \rangle} \setminus \Omega_{\langle A, B | T \rangle}^{IP}$$

is said to be the set of *possible states* under the theory T , which are not impossible under T . Finally, the set

$$\Omega_{\langle A, B | T \rangle}^{PR} = \Omega_{\langle A, B | T \rangle}^P \cap \Omega_{\langle A, B \rangle}^R$$

is said to be the set of *possible and realizable states* under the theory T and the tokens of A .

Then we define a cognizance classification whose tokens are the possible and realizable states under the theory T .

Definition 8. Given a source A , a target B , and a regular theory T , the *cognizance classification* $C_{\langle A, B, T \rangle}$ is the classification generated by A , B , and T such that:

$$C_{\langle A,B,T \rangle} = \left\langle \Omega_{\langle A,B|T \rangle}^{PR}, \text{typ}(A) \cup \text{typ}(B), \models_{C_{\langle A,B,T \rangle}} \right\rangle$$

where $\models_{C_{\langle A,B,T \rangle}}$ is defined as:

$$\langle \Theta, \Lambda \rangle \models_{C_{\langle A,B,T \rangle}} \alpha \quad \text{iff} \quad \alpha \in \Theta.$$

Formulation

In this section we give a formal expression of the function of cognition under which an agent deems an experience to be a ‘disability’.

First we consider a society consisting of N agents $I = \{1, \dots, N\}$. Then picking an *observer* agent $i \in I$, we investigate observations from the viewpoint of i .

The observer i observes certain experiences $\{e_1, \dots\}$. We denote this observation O^E . The token observed is an intentional object common to all agents and the type observed consists of Db and Bar, with the former indicating *disability* and the latter *barrier*.

At the same time, i makes an observation of the society I . We denote this observation O^I . The token observed is I . The type observed consists of Chr and $\langle e_m, \alpha \rangle$ where $\alpha \in \{\text{Db}, \text{Bar}\}$. The former Chr indicates that the agent whose experience is observed by i has physical (we mean by this word both material and bodily) characteristics and the latter $\langle e_m, \alpha \rangle$ indicates how each agent whose experience is observed deems her own experience. For example, the type $\langle e_m, \text{Bar} \rangle$ indicates that the experience e_m is a barrier and the type $\langle e_m, \text{Db} \rangle$ that the experience e_m is a disability.

Next we formulate observer i 's knowledge on the types defined above. We define that i deems an experience e_m to be a disability Db if and only if (1) e_m is experienced by agents with physical characteristics Chr, and (2) e_m relates (or seems to relate) the environmental or institutional barrier Bar. We can express the fact that i 's knowledge includes the type $\langle e_m, \text{Db} \rangle$ as the following constraints:

$$\begin{array}{l} \text{Chr, } \langle e_m, \text{Bar} \rangle \vdash_K \langle e_m, \text{Db} \rangle, \\ (1) \qquad (2) \end{array}$$

and

$$\begin{array}{l} \langle e_m, \text{Db} \rangle \vdash_K \text{Chr}, \qquad (1) \\ \langle e_m, \text{Db} \rangle \vdash_K \langle e_m, \text{Bar} \rangle. \qquad (2) \end{array}$$

We assume $\text{typ}(O^E) \cup \text{typ}(O^I) \subseteq \text{typ}(K)$, i.e., the knowledge K includes the types of observation both on i 's experience and on society.

Finally, under the above settings, we define an agent i as being able to understand an experience of disability of an agent $j \in I$ as follows.

Definition 9. Suppose an agent $j \in I$ with a physical characteristic Chr deems her own experience e to be a disability Db, i.e., $j \models_{O^j} \text{Chr}$ and $j \models_{O^j} \langle e, \text{Db} \rangle$. Then i can understand that j deems her experience e to be a disability if the token of which type is only Chr is connected only to the token of which type is $\langle e, \text{Db} \rangle$ under a channel with the cognizance classification with respect to i 's knowledge as a core.

In other words, if i can imagine a barrier with j 's experience by a physical characteristic and take it as a disability according to i 's knowledge, we say that i can understand that j deems her experience to be a 'disability'. We call this condition 'understandability (of disability)' hereafter.

The example

In this section, we give a formal expression to the example which we presented at the beginning. Specifically, we consider a society consisting of $I = \{S, N\}$ with the observer S . We also consider only one token y , an experience of *getting-on-a-lift-without-a-mirror*. Moreover, we set Chr as the type of a specific physical characteristic *needing-a-wheelchair*. As knowledge, S only has the constraints presented in the previous section.

How we fail to understand experiences of disability

To model S 's cognition, we consider the observation O' of an imaginary society I' in which the observer S himself 'needs a wheelchair'. That is, we verify whether we can imagine that a certain experience is a barrier and a disability or not by imagining a society in which we ourselves 'need wheelchairs'. We first consider a classification B based on an image of a society comprised of X and Y , the former being an agent who deems a lift without a mirror to be a barrier and the latter an agent who doesn't. The classification tables of O' and B are in *Table 1*.

Table 1: Classification tables of O' and B

$\models_{O'}$	Chr	\models_B	$\langle y, \text{Bar} \rangle$
S'	1	X	1
		Y	0

Considering a channel of which the source is the observation O' and the target is the observation B , we can see the relationship with respect to S 's cognition between an agent who needs a wheelchair and an agent who perceives an experience of getting on a lift without a mirror as a disability. In order to construct this channel, we compose a cognizance classification $C_0 = C_{\langle O', B, \bar{K} \rangle}$ as a core of this channel using observer S 's own knowledge K . In accordance with definition 7 and definition 8, we can derive this cognizance classification C_0 as in *Table 2*.

Table 2: Classification table of $C_0 = C_{\langle O', B, \bar{K} \rangle}$

\models_{C_0}	Chr $\langle y, \text{Bar} \rangle$	
X	1	1
Y	1	0

Adopting this classification C_0 as a core, we can construct a channel $\mathcal{C}_0 = \langle f_0, g_0 \rangle$ between the classification $O^{I'}$ and B .

There are connections of S' not only to X but also to Y . We interpret this as a situation where S cannot detect any relation between *needing-a-wheelchair* and *perceiving-a-lift-without-a-mirror-as-a-barrier*.

By the above we have confirmed that a lack of proper knowledge can be a restraint of understanding disability.

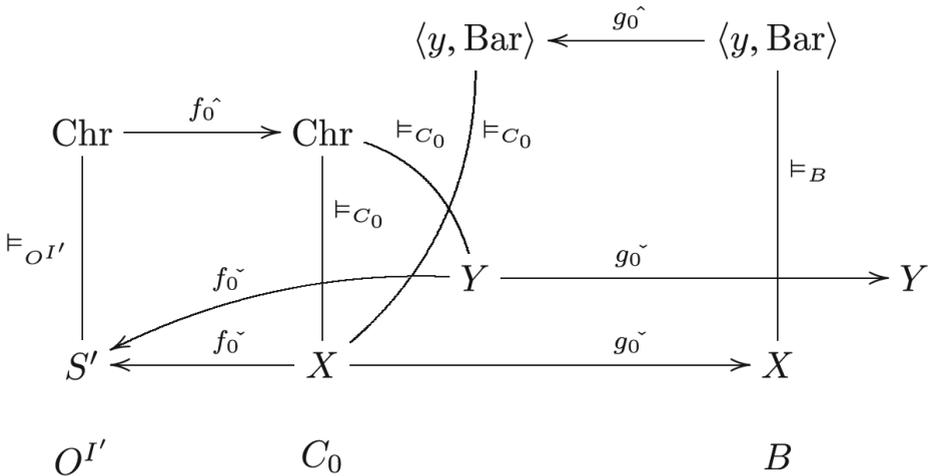


Figure 1: Channel \mathcal{C}_0 and its core C_0

How we do understand experiences of disability?

In this subsection we consider S 's observation of the society after hearing N 's words that getting on a lift without a mirror is troublesome. At this moment, S can observe that N deems the token y to be a barrier. So we can express S 's observation O_1^I of the society as follows.

Table 3: Classification table of O_1^l

$\models_{O_1^l}$	Chr $\langle y, \text{Bar} \rangle$	
N	1	1
S	0	0

Let us recall what N said. N asked S to imagine factors that might act as a barrier to moving his wheelchair beforehand, and gave the answer ‘a mirror’. According to this guidance, S received a hint for understanding why ‘a lift without a mirror’ could be a barrier.

We can simplify this inference process by a proof figure consisting of the following two constraints.

$$\text{Chr} \vdash_{Ab} \langle y, \alpha \rangle \quad \text{and} \quad \langle y, \alpha \rangle \vdash_{Ab} \langle y, \text{Bar} \rangle,$$

where α indicates *cannot-view-the-rear-side*. Then we can interpret the first constraint as ‘if one *needs-a-wheelchair*, then one *cannot-view-the-rear-side-in-a-lift-without-a-mirror*’ and the second as ‘if one *cannot-view-the-rear-side-in-a-lift-without-a-mirror*, then the lift is a *barrier*’. These constraints enable us to infer that ‘if one *needs-a-wheelchair*, then *a-lift-without-a-mirror-is-a-barrier*’. The following proof figure depicts this inference process.

$$\frac{\text{Chr} \vdash_{\bar{Ab}} \langle y, \alpha \rangle}{\text{Chr} \vdash_{\bar{Ab}} \langle y, \alpha \rangle, \langle y, \text{Bar} \rangle} \text{ (Weakening)} \quad \frac{\langle y, \alpha \rangle \vdash_{\bar{Ab}} \langle y, \text{Bar} \rangle}{\text{Chr}, \langle y, \alpha \rangle \vdash_{\bar{Ab}} \langle y, \text{Bar} \rangle} \text{ (Weakening)}$$

$$\frac{}{\text{Chr} \vdash_{\bar{Ab}} \langle y, \text{Bar} \rangle} \text{ (Global Cut)}$$

Let these two constraints add to the knowledge K , and let it be written $K' = \langle \text{typ}(K) \cup \text{typ}(Ab), \vdash_K \cup \vdash_{Ab} \rangle$ where Ab is a theory consisting of only the two constraints above. Then, by using the revised knowledge K' , we can compose a cognizance classification $C_1 = C_{\langle O', B, \bar{K}' \rangle}$ between two images of society previously discussed O' and B .

Table 4: Classification table of $C_1 = C_{\langle O', B, \bar{K}' \rangle}$

\vDash_{C_1}	$\text{Chr} \langle y, \text{Bar} \rangle$	
X	1	1

By letting this classification C_1 be a core, we can construct a channel $C_1 = \langle f_1, g_1 \rangle$ between O' and B , as shown in Figure 2.

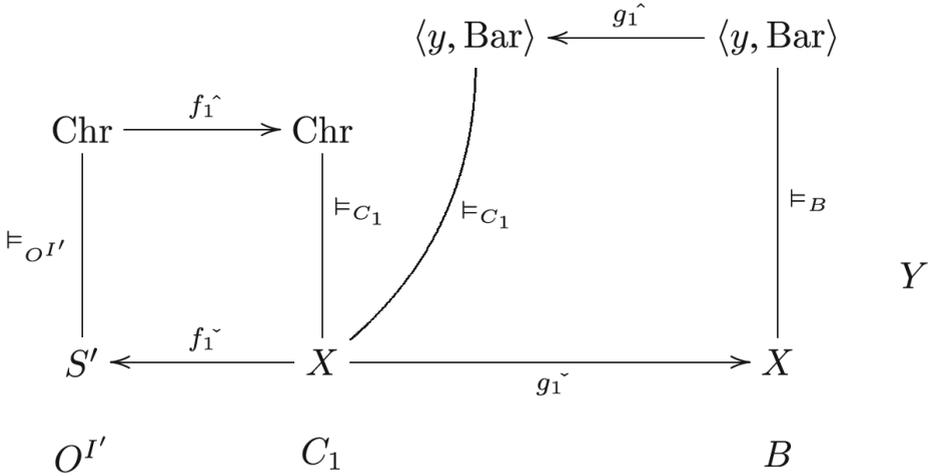


Figure 2: Channel C_1 and its core C_1

Next, we consider a classification D which describes a society consisting of P and Q , the former being an agent who deems the experience y of getting on a lift without a mirror to be a disability and the latter being one who does not. Then we investigate a channel where the source is O' and the target D . We can depict D as in the following classification table.

Table 5: Classification table of D

\models_D	$\langle y, Db \rangle$
P	1
Q	0

By using the definition of disability which the knowledge K originally includes, we can compose a cognizance classification $C_2 = C_{\langle C_1, D, \bar{K}' \rangle}$ between C_1 and D as follows.

Table 6: Classification table of $C_2 = C_{\langle C_1, D, \bar{K}' \rangle}$

\models_{C_2}	Chr $\langle y, Bar \rangle \langle y, Db \rangle$		
P	1	1	1

By way of C_1 , and letting C_2 be a core, we can construct a channel $C_2 = \langle m_2, \ell_2 \rangle$ in which $m_2 = h_2 \circ f_1$. This channel is shown in *Figure 3*.

Under this channel C_2 , S can come to understand a *disability*, which he himself cannot experience directly, involved in *getting-on-a-lift-without-a-mirror*. And S doesn't connect *needing-a-wheelchair* to *not-perceiving-the-experience-of-getting-on-a-lift-without-a-mirror-as-a-disability*. Thus we can say that S understands N 's disability in the light of the definition of understandability.

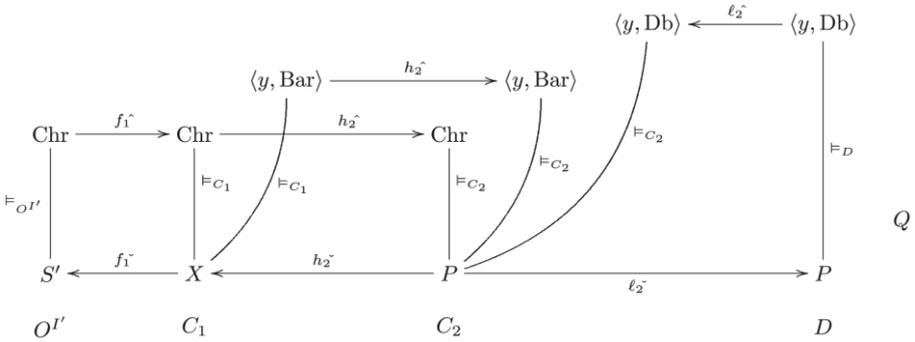


Figure 3: Channel C_2 and its core C_2

Conclusion

The last example can be summarized as follows. At first, S didn't understand the disability N experienced. This was because S lacked knowledge about the relation between *needing-a-wheelchair* and *a-lift-without-a-mirror-is-a-barrier*. This inability to understand was resolved by S imagining a link between them by himself. In other words, he came to infer a relation between them by imagining two constraints, 'if one *needs-a-wheelchair* then one *cannot-view-the-rear-side-in-a-lift-without-a-mirror*', and 'if one *cannot-view-the-rear-side-in-a-lift-without-a-mirror* then the lift is a *barrier*'.

It is noteworthy that it isn't necessary to confine the constraints leading S to deem N 's experience to be a disability to the ones outlined above. They are not the only way in which N can come to deem his experience to be a disability, too. The basis and validity of S 's imagination doesn't go beyond the fact that its consequence is consistent with S 's experience and N 's utterance. In fact, many of our imagining in everyday life takes place in a similar way. It isn't claiming objective validity that we do when we take an experience to be a disability. Rather, it is the expression of subjective or intersubjective understanding which makes us highlight the barrier which is brought to light in the experience of the agent, and interpret a friction with the environment or society in a comprehensible way for ourselves. And since this

way of understanding is defined by our relationship with the partners, the environment, or society, it becomes a kind of judgement of which way of understanding defines the relationship between the interpreter and the partner, environment or society. So we can see that, by imagining something and making a judgment, S creates the society itself, in which he appears as an agent, made up between N , S himself and the reader reading this text.

This leads to two implications. One implication is for disability studies. One of the most important role of disability studies is to give people like S , who don't experience and are not aware of disabilities, proper knowledge and to get them to understand disabilities by accumulating simple imaginatings and inferences. By doing that, making disability into an intersubjective existence we can create such a world.

Another implication is for economics. When economists attempt to analyze society objectively, they do so using models in which everything is defined by the economists themselves. How an agent's cognition functions isn't defined, because it cannot be defined objectively. However, in order to analyze disability, a framework which can formally handle the cognition of an agent who interprets and, at the same time, creates the world, is essential. We believe the approach presented in this paper has the potential to do that.

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CHAPTER 12

Compensation for disabilities

Yohei Sekiguchi

Introduction

In society, individuals face different circumstances which are beyond their control, e.g. race, gender, or disability, etc. The heterogeneity of circumstances sometimes gives rise to a fatal disproportion of well-being among individuals, and hence compensating transfers are necessary to offset welfare losses due to unequal circumstances. In fact, several social security regimes are employed to protect individuals against poverty, disability, unemployment and others.

Two kinds of ethics are known to be of concern when we consider fair compensation problems. One is the ‘compensation principle’, which states that inequalities due to differential circumstances for which individuals are not responsible are illegitimate and should be suppressed (Fleurbaey, 2008: 25), and the other is the ‘liberal reward principle’, which states that one should not advocate any ‘artificial’ reward favouring the agents who exercise their responsibility in a particular way (Fleurbaey and Maniquet, 2005: 5). However, as is by now well-known, these two principles are, in general, incompatible, even if we adopt an extremely weak interpretation (e.g. Fleurbaey 1994). This observation is important when we consider compensation for disabilities.

Concerning compensation schemes for disabilities, another important issue is the so-called ‘preference aggregation problem’. That is, there is no satisfactory way to aggregate individuals’ opinions about compensation schemes. In this paper, we analyze social insurance for disabilities based on the social choice theory, and we show the limitations of monetary compensation schemes for disabilities.

Compensation problem

We consider the problem of compensation for disabilities in the following general framework, which is standard in the literature (Fleurbaey 1994;

Bossert 1995; Fleurbaey 1995; etc), as follows. The society consists of heterogeneous individuals. Each individual in the society is identified by the two characteristics, (i) disability, and (ii) preference relation defined over disabilities. The well-being of each individual is determined by these two characteristics and monetary transfer for herself. Through monetary transfer among individuals, the social planner is willing to equate the difference of well-being due to disabilities among individuals. Then, what is a fair rule?

Concerning with our formulation, three remarks should be noted. First, people can evaluate not only her own disability but also those of others. Note that it does not mean that people can evaluate disabilities objectively. It only means that people can compare several disabilities subjectively. That is, we assume that one can consider, for example, ‘her disability is serious than mine’, or ‘Alice’s disability is the same level as Bob’s’. This assumption is based on the premise that people are able to empathize with others’ disabilities. Otherwise, no one consider that compensation for disabilities is necessary. Second, we do not impose any restriction on individuals’ preferences over disabilities. This assumption, called unrestricted domain condition, is a standard one in the social choice theory.

Third, the preferences on disabilities are made by considering all available information, such as ex ante income, but the disability characteristic itself. That is, each one’s disability characteristics represent her own objective disability, for example, ‘one cannot read books’, and how one feels her own disability is represented by her preference. This implies that if some disability causes her to have low well-being, then she considers this disability is serious.

A compensation rule determines transfers for individuals, given a list of characteristics of individuals. One trivial example of compensation rules is the no-transfer rule, in which no transfers are made always. Another example is the egalitarian rule, in which transfers are determined such that each individual’s well-being becomes the same. These two are simple but too extreme: it is difficult to say that these are best in the normative sense. As sequel, we will consider compensation rules based on classes of disabilities, and will show the limit of them.

Compensation rules

In Japan, the pension for disabilities (*Shougai-nenkin*) is determined by each individual’s rank of disability called *Tokyu*. In this section, we consider compensation rules such that monetary transfers are determined by the ranks

of disabilities. Note that such a process defines one-to-one correspondence between the ranks and the order of monetary payments. That is, if someone receives more payment than another, then the former is thought to be with more serious disability than the latter, and vice versa.

Compensation rules based on ranks implicitly assume the following two properties. First, for any pair of individuals, the order of transfer for them is independent from others' disabilities. For instance, transfers for some disability are unchanged even if the number of individuals with this disability increases.

Axiom 1 (Independence from Others' Disabilities): For any pair of individuals, the order of transfer for them is independent from others' disabilities (provided that preferences are unchanged).

This axiom is important in the normative sense: If this axiom is violated, then it may occur that some disability is treated favourably since there are large numbers of individuals with this disability.

Second, each individual's rank of disability is determined only by her own disability, and does not depend on other characteristics such as gender, age, or social position. It implies that if Alice's disability and Bob's disability are exchanged, then their ranks are also interchanged.

Axiom 2 (Anonymity on Disabilities): The order of transfer for individuals is invariant w.r.t. any permutation of disabilities (provided that preferences are unchanged).

This axiom states that the order of transfer for individuals is invariant w.r.t. any permutation of their disabilities. If this axiom is violated, then it may occur that someone receives more pension than another with the same disability.

Thus, compensation rules based on ranks implicitly assume these two axioms, and these axioms are desirable in the view of fairness.

Impossibility theorem

In the previous section, we provided two axioms, which are necessarily satisfied by any compensation rule based on ranks. In this section, we add two more axioms concerning to determination of ranks. Unfortunately, however,

Arrow's impossibility theorem implies that any compensation rule satisfying those four axioms must be dictatorial.

The third axiom is simple and there may be no objection.

Axiom 3 (Strong Protection of Disability): An individual unanimously considered as with more serious disability than another should receive more transfer.

This axiom requires that if all individuals in the society consider that Alice's disability is more serious than Bob's, then Alice should receive more payment than Bob.

The last axiom is 'Independence of Irrelevant Alternatives', which is standard in the literature.

Axiom 4 (Independence of Irrelevant Alternatives): For any pair of individuals, the order of transfers between them depends only on members' preferences on them.

This axiom requires that for any pair of individuals, the order of transfers between them is independent from members' preferences on other disabilities.

Sekiguchi (2009a) showed that any compensation rule satisfying our four axioms is dictatorial, that is, there is a dictator in the sense that Alice obtains more than Bob if and only if the dictator considers that Alice's disability is more serious than Bob's.

Theorem 1

Any rule satisfying Axiom 1-4 is dictatorial.

Possibility results

In the previous section we consider the case where only the ordinal preferences are available for an informational basis to execute the compensation policy. In this section, we consider the case where interpersonal-comparable cardinal utilities are available. It is well-known that in the standard preference aggregation problem, Arrovian impossibility is escapable if the social planner can use information about interpersonal-comparable cardinal utilities (see Sen, 1971). In a similar manner, such a possibility is also valid in our settings. Sekiguchi (2009a) showed that

COMPENSATION FOR DISABILITIES

compensation rules are exactly Phi-conditional equality rules defined by Fleurbaey (1995).

Roughly speaking, Phi-conditional equality rules are as follows. First, define some reference-preference. Then, the transfer for an individual is determined by the sum of ‘the loss of her well-being evaluated by the reference-preference’ and ‘the constant determined by the feasibility constraint’. A matter of concern w.r.t. Conditional Equality rules is what reference should be adopted.

One of the most important one is the Average Conditional Equality rule (Fleurbaey, 1995), in which the reference is equal to the average of utility functions of individuals in the society. This rule has several desirable properties in the normative sense. In particular, this rule satisfies Axiom 1, 2, 3 and the cardinal version of IIA axiom. In Sekiguchi (2009a), several important rules including the Average Conditional Equality rule, discussed in the literature, are characterized.

Weak social consensus

So far, we consider the general framework, in which no restriction is imposed on each individual’s preference, that is, the domain of preference is universal. This assumption is natural when we consider general compensation schemes comparing among different sorts of disabilities. However, it may not be reasonable if we restrict our attention to comparing the extent of some specific disability. For example, no one consider that an individual with good eyesight has more serious disability than an individual with poor eyesight. In this section, we consider the classification of disabilities under weak social consensus, that is, each individual has a common weakly ordered preference on disabilities. (It is well known that Arrovian impossibility can be escapable if we assume that the preference domain is restricted to some sub domain, e.g. single-peaked preferences or single-crossing preferences (see Gaetner 2002)). Unfortunately, however, Arrovian impossibility is valid even if we consider such a domain restriction.

For instance, consider the classification of visual impairments according to the value of eyesight, in order to determine the monetary transfer scheme. In particular, defining the boundaries, which partitions eyesight into different classes, is the case. If all member of the society have the same opinion w.r.t. boundaries, then the social planner should set boundaries according to this opinion. However, it is natural to consider that individuals have different

opinions, and hence the social planner need determine the way of aggregating members' opinions to decide boundaries. To determine the aggregation rule which is desirable in the normative sense, we should impose the following three conditions on the aggregation rule. First, it may be possible that the social planner never define boundaries, that is, all visual impairments are considered to be socially indifferent. However, we prohibit this rule since it is equivalent to 'no compensation'. Second, it should be avoided that the social planner always adopt some scheme independent from members' opinions, which implies that the social planner is a dictator. Third, the rule should satisfy the 'Independence of Irrelevant Alternatives' condition, that is, for any pair of values of eyesight, whether or not they are in the same class is determined only on members' opinions about it. Sekiguchi (2009b) showed that even in the case of weak social consensus, the following negative result is valid.

Theorem 2

Under weak social consensus, any rule satisfying the above three conditions is dictatorial.

Conclusion

In this paper, we have considered the compensation problem for disabilities. We have shown a limitation of compensation, by showing Arrowian impossibility theorem (*Theorem 1*). This impossibility can be escapable if the social planner can use the interpersonal-comparable cardinal utilities as an informational basis. However, our impossibility result is valid even if there is weak social consensus on disabilities, whenever only ordinal preferences are informational sources to execute the compensation scheme for disabilities (*Theorem 2*).

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Separating the concepts of income and work: The arguments of *Lotta Feminista* and *Aoi Shiba no Kai*

Yuriko Iino

It is well-known that many social movements that emerged in the 1960s and '70s strived towards guaranteeing income. It is important to note that these movements, in many ways, critically questioned the idea that 'income should be guaranteed by employment'. Among these movements were *Lotta Feminista*, an Italian feminist group known for its argument on wages for household work, and *Aoi Shiba no Kai*, a group of people with cerebral palsy who helped pioneer the disability movement in Japan. By exploring the arguments of Mariarosa Dalla Costa, a *Lotta Feminista* leader, and Koichi Yokozuka, a leader of *Aoi Shiba no Kai*, this paper found that the major issues to be resolved invoked significantly different arguments and ways of understanding the link between 'work' and 'productivity'.

Preface

Recently in Japan, the appearance of poverty as a 'new' problem has stimulated interest in basic income, that is, an income unconditionally granted to all on an individual basis, without a means test or work requirement. In such circumstances, Toru Yamamori, one of the leading researchers of basic income, asserts that the idea of basic income is more than 200 years old. According to him, we can find similar ideas in the historical writings of thinkers such as Thomas Paine, John Stuart Mill, James Edward Meade, and Milton Friedman, as well as in the arguments of social movements that emerged in the 1960s and '70s. For example, the Claimants' Union, established in Birmingham, England, between 1968 and '69, argued that proper income should be guaranteed to everyone without subjecting anyone to a means test in ensure that they maintain dignified lives regardless of their employment status. Yamamori postulates that the claimants union was able to make such a claim because they placed priority on protecting people's lives and dignity while assuming that there were people who could not sustain their

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lives by solely depending on the labour market. According to him, we can also find opposition to the idea that ‘income should be guaranteed by employment’ in other social movements: the Welfare Rights Movement in the United States, *Lotta Feminista* in Italy, and *Aoi Shiba no Kai* in Japan (Yamamori 2009a, 2009b).

Yamamori aims to show that these social movements are quite similar in that they separate the concept of income from work. However, it is important to note that each movement had its individual goals; as a result, they might have understood the concept of ‘work’ differently. In order to clarify this point, this paper focuses on *Lotta Feminista*, an Italian feminist group famous for its argument on wages for household work, and *Aoi Shiba no Kai*, a group of people with cerebral palsy (CP) who helped pioneer the disability movement in Japan. Unlike Yamamori’s postulation, this paper will show that there is a serious gulf between the two movements in terms of their understanding of a link between ‘work’ and ‘productivity’.

Short hours of work and substantial income – Goals of *Lotta Feminista*

Feminism began to concern itself with the concept of household work around the late 1960s to ‘70s. The number of women in the labour market began increasing during this period. As a result, people became aware that female workers were unfavourably compensated in comparison to their male counterparts. Further, women had to assume responsibility for the double work of waged employment and unwaged household chores. This era witnessed the emergence of Marxist feminists. They pointed out that the roles of women performing household chores and those in the labour market as peripheral workers were closely related to each other; they insisted that the household chores that women performed were advantageous not only to individual men but to the continuation of capitalism.

As with many Marxist feminists, Mariarosa Dalla Costa, a member of *Lotta Feminista*, argued that capitalist societies are based on the separation of paid work and household work, and women are in a disadvantageous position in the labour market because they are assumed to be responsible for household work. The uniqueness of her theory – expanded in her book *Wages for Housework* (1986) – lies in its interpretation of second-wave feminism – the collective resistance of women in the 1970s – as a rejection of household/reproductive work. It is well-known that second-wave feminism regarded the biological differences between men and women and the meaning

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of the female body as the main areas of contention. In this regard, Dalla Costa's interpretation significantly restricts the scope of this movement and is therefore problematic. However, instead of further criticizing this point, this paper moves on to discuss why Dalla Costa insisted that wages should be provided for household work.

As discussed so far, Dalla Costa interpreted the second-wave feminism as a rejection of household/reproductive work. On the basis of this notion, she argued that if it is true that women's rejection of household/reproductive work further evolved through the '70s and if it is the matter of reproduction that aroused public interest in their rejection of work, then it is necessary to address the issue summarized below:

In other words, the problem is what the rejection of work with regard to reproduction coaxed from the nations in response to the rejection. (1986: 33; originally written in 1981)

One response to this issue is that, after the '70s, women began to demand improvements in social services for childcare and nursing, and reproductive work shifted from housewives to workers in social facilities such as day care centres, schools, and nursing homes. However, Dalla Costa argued that such social services provided as social investments constituted only a nation's minimum level of work; consequently, improvements in social services do not necessarily result in a drastic reduction in women's work hours in the domestic sphere.

Of course, it is possible to argue that this is the reason for further improvements in social services. However, Dalla Costa argues that there will be no reduction in the total hours that women work if they have to put in longer hours in the labour market in order to earn the money necessary to purchase social services – such as childcare and nursing services – to reduce their domestic work hours. She then argues that it is necessary to find other means, besides improving social services, to stop the negative feedback loop. In other words, she suggests that we return to the fact that 'it is impossible to have free time unless she earns higher salaries' (*ibid*: 74; originally written in 1982) and claims that the overall income of women should be increased. Payment for household work is thus an effective means of accomplishing that goal. She expands on these arguments as seen in the quote given below:

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In this regard, the struggle to demand wages for household work potentially has the possibility to gain the new power to release women from the condition in which they have no need to leave their homes because of their weaknesses, in other words, the condition in which they are forced to accept ‘any kind of work’ to earn a ‘small amount of money’, and they also have to accept ‘any kind of services’ because they are in a hurry to work. (*ibid*: 115; originally written in 1974)

As the discussion so far indicates, Dalla Costa’s aim was to shorten the working hours and increase the wages that women earn for their work—the work for which women are typically responsible under an economic system based on a gendered division of work. Because household work is ‘reproductive work’ (*ibid*: 20) which produces ‘life itself’ (*ibid*: 21), according to her, wages should be paid for household work as is the case with work done in the labour market.

Dalla Costa’s claim that household work is also productive work seeks to reconsider activities that have been placed outside the labour market as ‘work’ while maintaining, and even extending, the concept of ‘productivity’. This viewpoint stresses that, among social necessities, certain work is emphasized as paid work, while other work is regarded as having lower social value. Nonetheless, the argument retains a link between ‘work’ and ‘productivity’ and is unfavourable to those who cannot engage in ‘productive’ activities. This is precisely what *Aoi Shiba no Kai* questioned. In the next chapter, we will see how and why *Aoi Shiba no Kai* tried to unlink the concepts of ‘work’ and ‘productivity’.

Escape from the norms – Goals of *Aoi Shiba no Kai*

On 29 May 1970, a mother killed her two-year-old child with CP by strangling her with an apron cord. When this incident was reported, the mother gained much of the sympathy. Local town associations and groups of parents of disabled children started a movement for the commutation of the mother’s penalty. They insisted that this incident would not have happened if there were more facilities available for disabled children. In this case, the one deserving sympathy is the mother and not the child. Moreover, it is necessary to judge the nation and not the mother.

It is strange that many people sympathized with the perpetrator and not the victim. Did our society think that the perpetrator should not be held

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responsible for such a serious crime since the victim was severely disabled? If so, then why?

Aoi Shiba no Kai had its own answer. Members of this group did not hail from the academic field; however, they published many essays under the leadership of Koichi Yokozuka and Hiroshi Yokota, the philosophical leaders of the movement for independent living at the time. More importantly, their essays disclosed the ideology of able-bodiedness behind such mercy killings. For example, in his book, *Do NOT Kill, Mother!* (2007), a collection of essays written in the first half of the 1970s, Yokozuka asserts that the movement for the commutation of the mother's penalty was a 'movement from the standpoint of the mothers or of able-bodied people', (38) and it 'had overlooked the existence of the very person (the disabled) who must be the most important one in this case'. (*ibid*: 97) Thus, he tries to view the situation from the standpoint of the disabled person.

As the mother described it, she thought, 'This child will never be cured. She is better off dead than alive in such a state.' The problem is a value system that seeks to determine human happiness based on whether a person can be cured or not or whether a person can work or not. Because this value system regards people who cannot work as non-human, people believe that disabled people should not exist in the first place, and disabled people are continuously oppressed day and night. (*ibid*: 42; originally written in 1972)

In a society that strictly follows the norm 'If a man will not work, he shall not eat', those who are not capable of carrying out productive work are at risk of being abandoned as someone who 'should not exist in the first place'. An even more grave issue is that disabled people strongly internalize 'the sense of values of the world that better workers and stronger, faster, and more beautiful people are right and great' (*ibid*: 138) and get caught up in 'a psychological structure of wanting to be more like able-bodied people' (*ibid*: 65); as a result, they fall into a state where they negate their own existence. The following quotes point out several problems caused by such self-negation.

Disabled people have negated their existences up until now, and doing so has been regarded as a virtue. They have always been placed at the bottom of society and forced to live in hiding. (*ibid*: 29-30; originally written in 1972)

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Disabled people are always handled. Society is founded on the idea of how to handle disabled people, as seen in measures for disabled people and issues of infrastructures and health care. Even when disabled people speak up, they cannot get rid of the psychological structure in which they explore how they ask society to understand, as in how they ask society to increase their pensions or to give them discounts on fees for public services. (*ibid*: 59; originally written in 1972)

Of course, there are many disabled people who are able to find jobs and become financially independent. However, in the case of people with CP, most of them are in a ‘condition that cannot be involved in productive activities’ (*ibid*: 94). Because of this, Yokozuka refuses the idea that we need to make efforts to become more productive:

In conversations with other disabled people, they (polio patients, amputees etc.) attack us by saying something like, ‘You guys are not even trying. Everyone is working hard. Even if we cannot make money, working itself is a noble thing.’ I would never want to make things that wouldn’t be sold by getting scratches on my hands and legs. (*ibid*: 89; originally written in 1970)

The independence that we, *Aoi Shiba no Kai*, aim to achieve is not to create a condition where disabled people work and make ends meet. Rather, we aim to facilitate a complete overhaul of the conventional idea of isolating and killing disabled people who cannot do so as a good-for-nothing nuisance while treating only those who are capable of financial independence as humans. (*ibid*: 304; originally written in 1978)

The similarity with the argument of Dalla Costa is evident in this quote. Both Dalla Costa and Yokozuka criticize the situation in which women and people with CP have to participate in the labour market in order to earn meagre salaries. However, while Dalla Costa demands payment for the productive activities that produce ‘life itself’, Yokozuka does not demand monetary compensation. Rather, he demands a different possibility of life for people with CP who ‘have negated their own existences wishing they never had impairments’ (*ibid*: 177). In fact, Yokozuka argues as follows:

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I must say that negating the existence of a human being just because the person does not fit in the traditional sense is mistaking the means for the end. It is absurd to force a foot into an already manufactured shoe, even if one has to cut and scrape the foot. Social participation (I intentionally use the word ‘participation’ rather than resuming social activities) does not mean to blend in with the world; it means to proudly claim our natural conditions to the society – our inefficient existences without social capabilities. (*ibid*: 91; originally written in 1970)

Why do we have to resume social activities after trying so hard to live to be alive today? Is it that those who cannot be involved in productive activities (those who are in institutions and disabled people at home) are not part of society because it is a production-oriented society? (*ibid*: 147; originally written in 1974)

Even those who cannot participate in productive activities comprise a part of society by ‘actually being alive here’; thus, people with CP deserve to have ‘undisguised existences’ and be accepted as a part of society. Through such a ‘daring attitude’, they can experience a sense of fulfilment in their own lives (*ibid*: 230). In such circumstances, the negation of the norm relating to ‘work’ holds out for people with CP the possibility of a different life, unlike the present situation where they are downgraded in a society that values paid work and productive activities. In other words, Yokozuka was concerned with constructing a logical argument that secures the existence of people with CP; in order to do so, it was necessary for him to unlink ‘work’ and ‘productivity’. This approach is understandable when we consider that *Aoi Shiba no Kai* originated as a reaction to those who justified the crime of murdering a seriously ill child.

Conclusion

This paper explored the arguments of Mariarosa Dalla Costa, who led *Lotta Femminista*, and Koichi Yokozuka, one of the leaders of *Aoi Shiba no Kai*. As a result, it found that the major issues to be resolved invoked different arguments and different ways of considering a link between ‘work’ and ‘productivity’.

The major issue for Dalla Costa was to reduce the burden on women at home and in the labour market while increasing their actual income. For such purposes, she demanded payment for household work by arguing that

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household work was a productive activity because it produces ‘life itself’. Among the many concepts of basic income, her argument is closer to the idea of participation income, that is, the idea that all activities that contribute, in some way, to society are ‘work’, and thus, such ‘work’ should be compensated. Furthermore, if ‘actually being alive here’ is to be regarded as social participation as Yokozuka states, then everyone, including people with CP, is entitled to receive a basic income under the framework of participation income.

Nevertheless, in Yokozuka’s argument, he never discussed ‘actually being alive here’ as justification for receiving any guaranteed income; rather, he extended his argument to refusal to work. This reflects that for Yokozuka, the most important issue was the self-affirmation of people with CP. Because he recognized that social norms relating to ‘work’ and ‘productivity’ have downgraded the existence of people with CP on multiple levels, he thought that the negation of such norms would provide the foundation for political activities in which they are involved.

Such political activities should not be underestimated in the sense that they would enable people with CP to actively resist social discrimination. Nonetheless, though it may be a requirement, it may not be a sufficient condition for ‘creating a society for all’. Thus, this level of change must be followed by a change in the socio-economic status of those with CP. In order to initiate such change, what kind of policies and actions do we need to implement? How is the idea of basic income positioned in this process? ‘A society for all’ must be a society that allows all members to live dignified lives. Our project for creating such a society must therefore include the perspective of those who have difficulty sustaining their lives either through dependence on the labour market or on any ‘productive’ work.

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The Current Socioeconomic Situation of Women with Disabilities in Japan

Noriko Seyama and Kumiko Usui

The purpose of this paper is to attempt to clarify the situation of women with disabilities in Japan. Demographic statistics on disabled persons published by the Japanese government are categorized according to disability, with no data or analysis focusing specifically on gender. Given that the original data is not provided, it is impossible even to attempt to gather gender-specific data. Although it has been recognized with respect to disabled persons that there are ‘type’-related issues, no such issues have been raised in relation to gender.

Thus we have used survey statistics from two papers, *Shogaisha seikatsu jittai chosa* (Survey on the Living Conditions of Persons with Disabilities) and *Nihon no shogaisha koyo no genjo* (Current Status of Employment of Disabled Persons in Japan).

Using this limited data we were able to confirm that gender-specific issues do exist and that women with disabilities are placed in a position of high instability and poverty.

Revealing the socioeconomic situation of Japanese women with disabilities

Making sense of the socioeconomic situation faced by women with disabilities is in itself a challenge. Demographic statistics on disabled persons published by the Japanese government are categorized according to disability, with no data or analysis focusing specifically on gender. Given that the original data is not provided, it is impossible even to attempt to gather gender-specific data. Although it has been recognized with respect to disabled persons that there are ‘type’-related issues, no such issues have been raised in relation to gender. In this situation, we cannot even know whether or not gender-based issues exist.

To rectify this situation we examined two surveys in an attempt to clarify the socioeconomic situation of Japanese women with disabilities.

Survey statistics were obtained from a paper entitled *Shogaisha seikatsu*

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jittai chosa (Survey on the Living Conditions of Disabled Persons), published by the National Institute of Population and Social Security Research, the survey being headed by Yukiko Katsumata and conducted in fiscal year 2005-2006 in two cities, Inagi City, located in the Tokyo Metropolitan area with a population of about 80,000 people, and Fuji City, Shizuoka Prefecture, located in the Chubu Tokai region with a population of about 260,000 people. One further source of statistical data was a paper entitled *Nihon no shogaisha koyo no genjo* (Current Status of Employment of Disabled Persons in Japan), published by the National Institute of Vocational Rehabilitation. This paper is a recalculation of a paper entitled *Shogaisha koyo jittai chosa* (Survey on the Employment Conditions of Disabled Persons) (Ministry of Health, Labour, and Welfare 2003).

Survey on the living conditions of disabled persons in two cities

The aim of the paper entitled *Survey on the Living Conditions of Disabled Persons* is stated as being:

...to collect basic data in order to investigate the kinds of support required for persons with disabilities to be able to live comfortably in their own community with dignity regardless of type or degree of disability, age, family structure, or the neighbourhood they live in, and the kind of system required to continue that support. (Katsumata *et al.* 2008: 3-4)

The survey's analysis:

...focuses on the three categories of employment, household budget and time-budget, with comparisons with the general population in mind. (Katsumata *et al.* 2008: 3-4)

This survey is unusual in that it includes gender-specific data as well as an analysis from the perspective of gender.

Employment and income

The survey described here was conducted in Inagi City in fiscal year 2005 and in Fuji City in fiscal year 2006. A total of 159 persons were surveyed (87 with physical disabilities, 23 with intellectual disabilities, 40 with mental disabilities, and nine with overlapping disabilities). Of these, 67 (42.1 per cent

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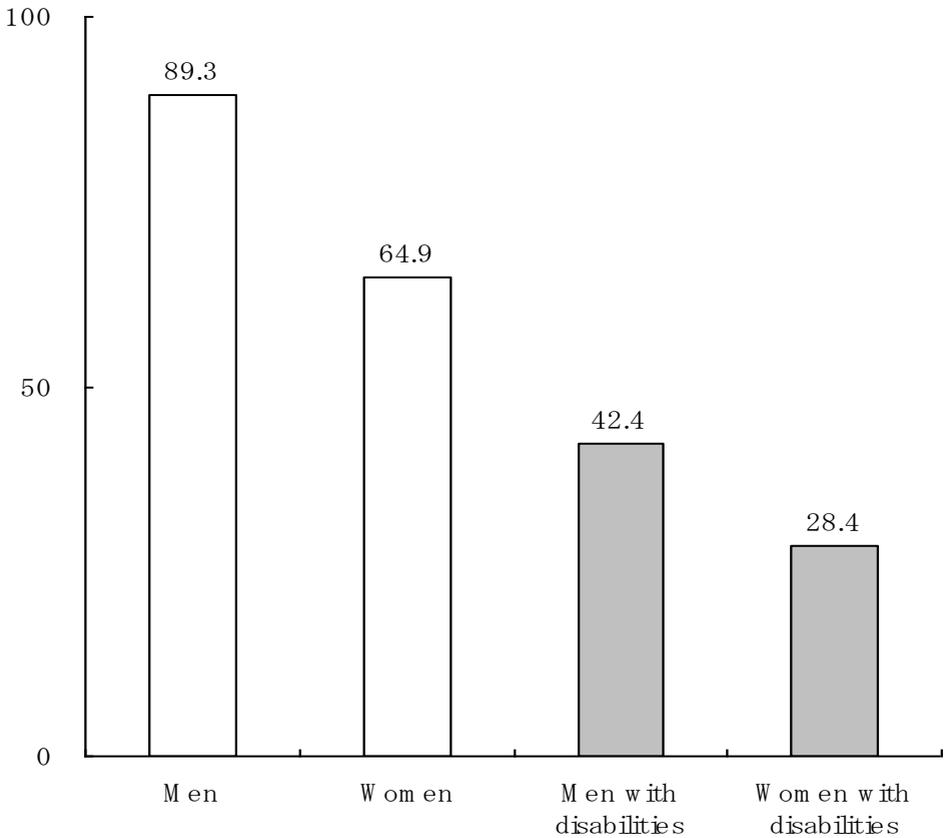
of the total) were women. The ages of subjects vary between 18 and 64. Subjects were persons holding ID booklets for disabled persons and users of services provided by social welfare councils and work centres who agreed to participate in the study. Data representing 'the general population', used for drawing comparisons, was taken from *Shugyo kozo kihon chosa 2002 jisshi ban* (2002 Employment Status Survey) (Ministry of Internal Affairs and Communications). The surveyor was Ms. Masayo Toyama, and the head researcher was Ms. Yukiko Katsumata.

Figure 1 below shows the percentage of employment for different groups, excluding welfare-like employment. The percentages are as follows: Men 89.3 per cent, women 64.9 per cent, men with disabilities 42.2 per cent, women with disabilities 28.4 per cent. While employment percentages for both men and women with disabilities are low, they are particularly low in the latter group. Among the 'employed' group, the percentages of people engaged in 'long-term contract employment' were as follows: Men 77.8 per cent, women 66.8 per cent, men with disabilities 51.4 per cent, women with disabilities 33.3 per cent. It is evident from these figures that there is a disproportionately high percentage of women with disabilities engaged in non-standard employment.

Many disabled persons fall under the category of 'welfare-like employment', a type of employment that is considered to be separate from 'regular employment', with disabled people in this type of work treated as trainees or users of services. These disabled people have no rights as workers, and although actual work takes place, labour laws are not applied. There are various forms of welfare-like employment, including 'vocational aid centres', 'welfare factories' and 'work centres'. The number of employees at these centres is twice that of those hired in the context of 'regular employment'. 'Welfare-like employment' is excluded from the 'employed' category in order to draw comparisons with data on the general public, where there is no such category as 'welfare-like employment'. The category of 'employed' includes sub-categories such as 'long-term contract employment', 'business owner' and 'day, temporary worker'. These sub-categories are, however, omitted in the figure below.

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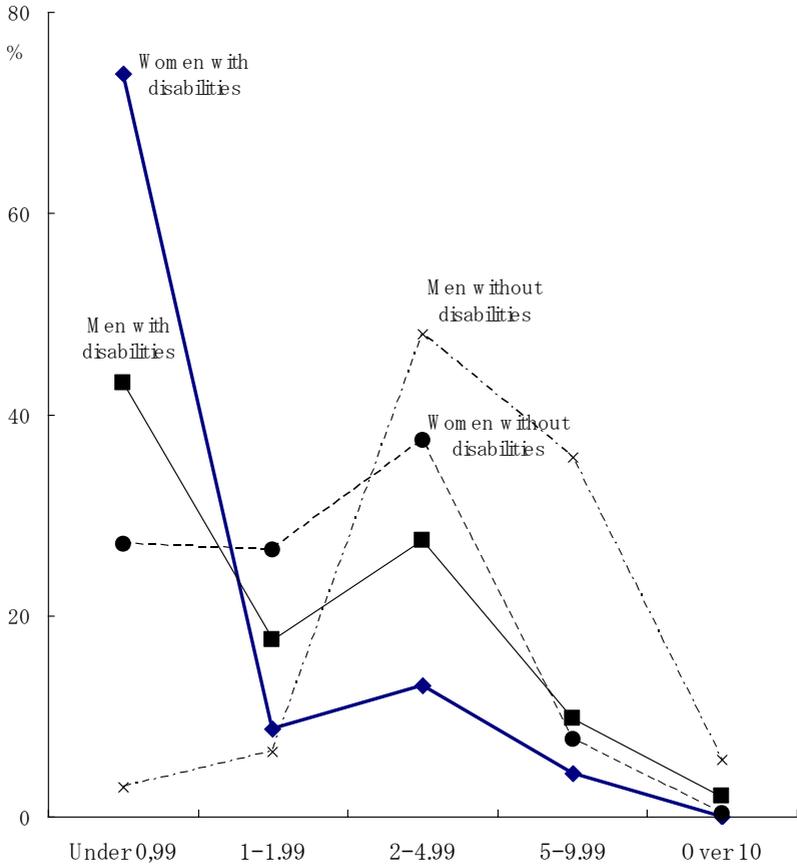
**Figure 1: Percentage of 'employed', excluding welfare-like employment
(Unit: %)**



(Compiled using data extracted from Table 5, p. 37 and Table 10, p. 39 of the Survey Report)

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Figure 2: Annual income from labour (including welfare-like employment for disabled persons) (Unit: %, million yen)



Unit: % & million yen

	Under 0.99	1-1.99	2-4.99	5-9.99	Over 10
Women with disabilities	73.9	8.7	13.0	4.3	0.0
Men with disabilities	43.1	17.6	27.5	9.8	2.0
Women without disabilities	27.1	26.5	37.5	7.7	0.3
Men without disabilities	3.0	6.5	48.0	35.7	5.7

(Compiled using data extracted and partly summed from Table 15, p. 41 of the Survey Report)

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Annual earned income is plotted in *Figure 2* (above). Income earned through welfare-like employment is included in this income. As indicated in the figure, whereas a majority of men (89.4 per cent) earn two million yen or more per year, nearly half of all women with disabilities (52.2 per cent) earn less than five million yen per year, and roughly 70 per cent earn less than 990,000 yen. Among men with disabilities, however, 35.3 per cent earn less than 500,000 yen per year, and one quarter of women (27.1 per cent) earn less than 990,000 yen per year.

Covering basic expenses such as rent and cost of minimum living expenses (electricity bills, meals, transportation costs, etc.) is nearly impossible at this level of income. While one can assume that disabled persons receive extra income through pensions and benefits, even with these sources there are some whose income does not add up to one million yen per year. This means that such people are unable to meet their livelihood needs without a provider, such as a husband or parents, to supplement their income and provide a place to live. It should also be noted that the average annual income for welfare-like employment is very low: 119,000 yen in the case of both men and women.

Income and family structure

Next we consider the survey results on income and family structure. The region and fiscal year of these results are the same as those described in 2.1. Data for 203 subjects was sampled from the total set, excluding high-income earners. Roughly 44 per cent of subjects were women. Salary, wages, pension, benefits and so on are all included in income. There are two public pension plans directly connected to disabilities in Japan: The disability basic pension of the national pension plan, and disability employee basic insurance. People with 'severe' disabilities (grade 1) are paid an additional 82,000 yen per month, while those people who have had a child before the age of 20 are paid an additional amount. The disability employee basic insurance is based on a wage-proportionate calculation with an additional amount paid if the recipient has a spouse. However, the range of groups that are eligible for pensions is very small, an issue that has been a continual problem.

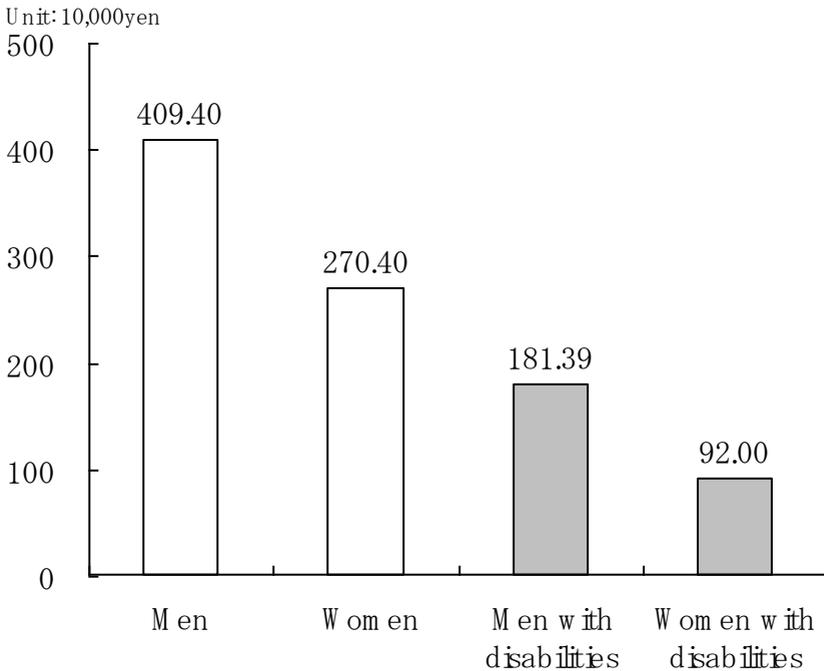
In addition, half of all subjects receive a disability basic pension. Regarding family types, about half of all subjects belong to families of procreation (families created mainly to bear and raise children), about a quarter belong to families of orientation (families that they were born into) and 15 per cent belong to single-person households. Data on the general public

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were taken from *Zenkoku shohi jittai chosa 2004* (2004 National Survey of Family Income and Expenditure) (Ministry of Internal Affairs and Communications). The surveyor for this study was Ms. You Tsuchiya, and the head researcher was Ms. Yukiko Katsumata.

Figure 3 shows average annual incomes of single-person households. The average annual income for men was 4,094,000 yen, for women 2,704,000 yen, for men with disabilities 1,813,900 yen, and for women with disabilities 920,000 yen. Women with disabilities earn only about half as much as men with disabilities.

Figure 3: Average annual income of a single-person household (Unit: 10,000 yen)



(Compiled using data extracted from Table 18, p. 81 of the Survey Report)

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Table 1 shows the average annual income of men and women with disabilities. Annual income for men with disabilities is 2,194,000 yen, whereas for women with disabilities it is 1,117,000 yen. Here too, women earn only half as much as men.

Table 1: Average annual income of men and women with disabilities

Men with disabilities	2,194,000 yen
Women with disabilities	1,117,000 yen

(Compiled using data extracted from Table 13, p. 75 of the Survey Report)

Table 2 indicates the annual income of men and women with disabilities in families of orientation. The annual income for men with disabilities is 1,081,200 yen, whereas for women with disabilities it is 900,000 yen. The difference in this case is small, but there is nonetheless a gap between genders.

Table 2: Annual income of men and women with disabilities in families of orientation

Men with disabilities	1,081,200 yen
Women with disabilities	900,000 yen

(Compiled using data extracted from Table 16, p. 77 of the Survey Report)

Table 3 shows the annual income of men and women with disabilities in families of procreation. Annual income for men with disabilities is 3,422,600 yen, whereas for women with disabilities it is 1,207,000 yen. One may thus observe that in a family of procreation, women with disabilities earn 35.3 per cent of the amount earned by men with disabilities.

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Table 3: Annual income of men and women with disabilities in families of procreation

Men with disabilities	3,422,600 yen	
Women with disabilities	1,207,000 yen	← Income of women is 35.3% that of the income of men

(Compiled using data extracted from Table 16, p. 77 of the Survey Report)

Employment statistics from the recalculation of the survey by the Ministry of Health, Labour and Welfare

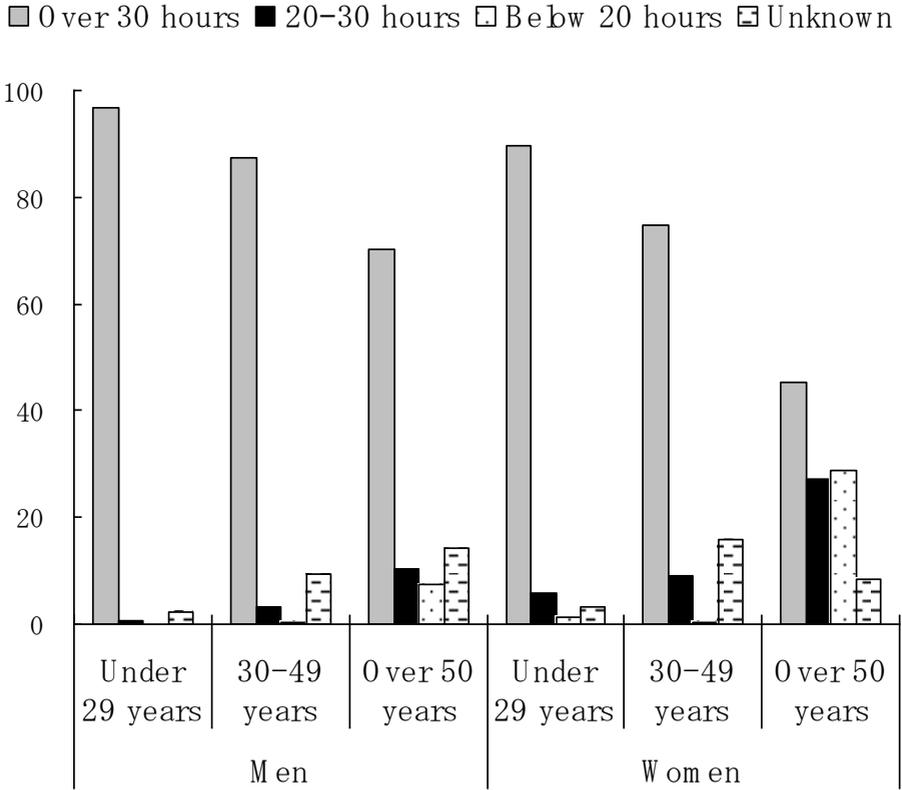
In this section, we extract data related to gender gaps from the paper entitled *Current Status of Employment of Disabled Persons in Japan* (abbreviated to: NIVR38), which is a recalculation of the 2003 *Survey on the Employment Conditions of Disabled Persons*, published by the Ministry of Health, Labour and Welfare. No gender data was given in the latter paper, and it was only in NIVR38 that gender-specific data was revealed for the first time. Focusing in particular on classification by gender and age, we chart here the averages for three classes of disabilities; physical, intellectual and mental.

In addition, in the *Survey on the Employment Condition of Disabled Persons*, 7,000 enterprises having more than five employees (71.5 per cent response rate) were surveyed, about 15 per cent of the enterprises responding to the survey reporting that they employ persons with disabilities on long-term contracts. Among those employed on a long-term basis, 37 per cent were reported to be women. Of enterprises that responded to the survey, 84.9 per cent employ less than 30 workers, indicating that the enterprises are relatively small. Given, however, that the survey includes only enterprises that employ more than five employees on long-term contracts, and that it excludes those which do not hire long-term contract employees, as well as small enterprises and ‘welfare-like employment’, results cannot be taken to reflect the overall state of affairs in employment among persons with disabilities.

The first result, shown in *Figure 4*, indicates overall accumulation of working hours. It is evident from this figure that for subjects under 49 years of age, there is not a great deal of difference between genders in working hours.

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Figure 4: Hours of work (per week) (Unit: %)

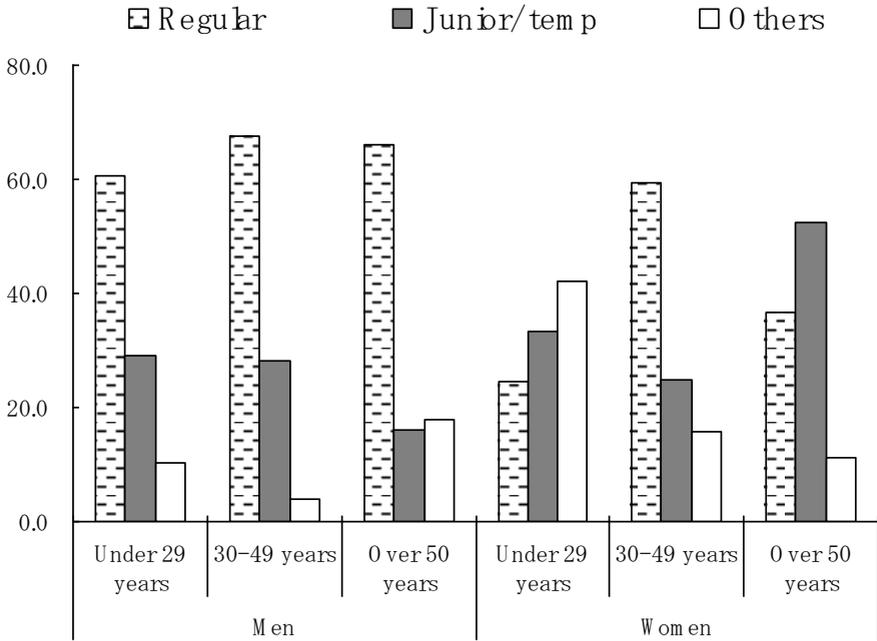


		Unit: %			
		Over 30 hours	20-30 hours	Below 20	Unknown
Men	Under 29 years	96.9	0.8	0.2	2.2
	30-49 years	87.3	3.1	0.2	9.4
	Over 50 years	70.2	10.4	7.6	14.3
Women	Under 29 years	89.5	6.0	1.2	3.3
	30-49 years	74.8	8.9	0.4	15.9
	Over 50 years	45.4	27.1	28.9	8.3

(Compiled using data extracted and then averaged from Table 5, p. 124, Table 2, p. 186, Table 2, p. 210 of NIVR38)

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Figure 5: Employment status (Unit: %)



		Unit: %		
		Regular employee	Junior/temp employee	Others
Men	Under 29 years	60.5	29.1	10.4
	30-49 years	67.6	28.3	4.1
	Over 50 years	66.1	15.9	18.0
Women	Under 29 years	24.5	33.5	42.0
	30-49 years	59.3	24.9	15.8
	Over 50 years	36.6	52.4	11.1
	Over 51 years	37.6	53.4	12.1

(Compiled using data extracted and then averaged from Table 5, p. 124, Table 2, p. 186, Table 2, p. 210 of NIVR38)

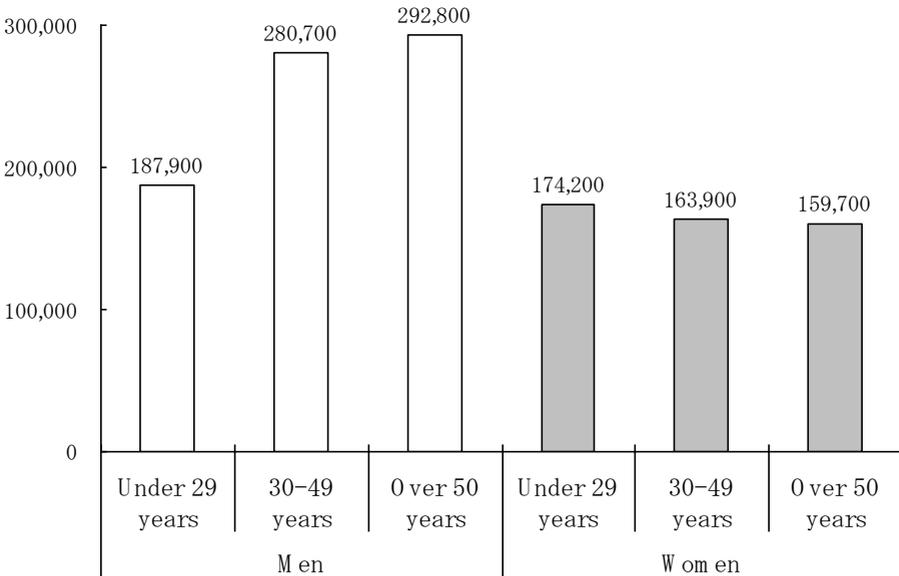
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Next we consider status of employment (*Figure 5*). In this case it is evident that, regardless of age group, the rate of full-time employment for women with disabilities is lower than that for men with disabilities. A significant gender gap is particularly evident in the age group of subjects under 29 years of age, where the rate of full-time employment for men with disabilities is 60.5 per cent, compared to a rate of full-time employment for women with disabilities of 24.5 per cent.

‘Junior/temp employee’ is a term that refers to those people employed on a fixed term, and is used in enterprises to differentiate this group from regular employees.

Finally, results on average wage (for November 2003) in *Figure 6* indicate that the average wage for women with disabilities is 73 per cent of the average wage for men with disabilities, and whereas wages for men increase rapidly with age, the opposite is true for women, where wages decline with age.

Figure 6: Average wage (physical disabilities) (Unit: yen)



(Compiled using data from Table 5 (physical disabilities), p. 124 of NIVR38.)

Conclusion

We have examined survey data to answer the question of whether or not there are disability-related issues based on gender. Using the limited data, we have confirmed that there are gender-specific issues and that women with disabilities are placed in a position of high instability and poverty.

The data demonstrates that the income of women with disabilities is disproportionately low compared to both non-disabled men and women, as well as being low compared to men with disabilities. Among regular employees, moreover, the proportion of women with disabilities engaged in full-time employment is low, and with the exception of the higher-age group, working hours are just as long as regular full-time employees.

This data points to the fact that women with disabilities, being both ‘women’ and ‘disabled’, are placed in a structurally unstable position in society. It is evident from this situation that women with disabilities live lives in which they are either financially dependent on other people, such as family members, or that are unstable as a result of low income.

As Article 6 of the Convention on the Rights of Persons with Disabilities expresses a clear recognition that women and girls with disabilities are subject to multiple discrimination and calls for appropriate measures to guarantee them the exercise and enjoyment of human rights, it is necessary to have more precise information concerning the actual situation faced by women with disabilities. We therefore demand that the government compile basic data disaggregated by gender.

Challenges surrounding the existence of women with disabilities raise issues regarding the need to connect the ideas of work with the idea of ‘living with dignity as a member of society’, from a position where two perspectives intersect; the perspective of efforts by women bringing structurally-embedded gender discrimination in our society out into the open, and the disabled people’s rights movement, which has prompted a shift in the definition of the right to live and to be independent.

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Barriers associated with the educational dropouts of persons with disabilities in a developing economy, Nepal

Kamal Lamichhane

Introduction

Access to education by persons with disabilities in developing countries is still often elusive. It is estimated that more than 90 percent of children with disabilities in developing countries do not attend school (UNESCO 2009), compared with 18 percent of primary school age children worldwide who are excluded from education, and an overall rate of 25 percent of primary school age children in South Asia in particular. Meanwhile, in industrialized countries, plus East Asia and the Pacific, and Latin America and the Caribbean, only around six percent of children are out of school (UNESCO Institute for Statistics 2005). In the case of Nepal, persons with disabilities' rights to equal access to education, employment and health, which are some of the important indicators of socio-economic status, have not been properly reflected in the policy and legislation of the country. Due to the poor socio-economic status of this group, they are neither socially included nor economically independent. Expectations of equal access are, for them, still wishful thinking.

While no precise statistics are available on how many children with disabilities attend school, the National Planning Commission and UNICEF have stated that 68.2 percent of people with all kinds of disabilities lacked any formal education (UNICEF/Nepal 2001). This percentage is significantly higher compared with the national estimate for those with no education, about 43.9 percent (UNICEF/Nepal 2001). Moreover, research in Nepal has empirically shown that education has a positive impact on increased income for persons with disabilities. According to Lamichhane and Sawada (2009), the estimated rate of returns to the investment in education is very high among persons with disabilities in Nepal, ranging from 19.4 to 32.2 percent. This is significantly higher than those for persons without disabilities in developing countries, as reported in Psacharopoulos and Patrinos (2004),

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according to whom returns differ from country to country, but remain around or less than ten percent.

Even without using any specific econometric models, simply calculating the median of income, levels of education, job situation and types of impairments shows a positive relationship between education and income. Those who obtain a School Leaving Certificate (SLC – 10 years of schooling), for example, have higher incomes than those who do not reach the SLC level (See *Table 1*). Regardless of types of impairments, part time workers who have graduated from the SLC level will have income levels four times higher than those who do not, while, for fulltime workers, SLC graduates’ incomes are about 1.5 times higher. One exception, however, is that full-time workers with hearing impairments have no income difference according to their education level. This may be due to the limited opportunities on labour market because of the lack of facilities such as sign language or other communications tools. On the other hand, it could also be due to the problem of the quality of education itself. Despite the significant impact of education, however, the research which will be described here reveals that persons with disabilities in Nepal often miss out on these benefits by dropping out fairly early in their education. In the following, we will discuss some of the factors – economic, social, attitudinal and physical which are associated with early dropout.

Table 1: Median of income per month according to educational background, job status and type of impairment

	<i>Educational Background</i>	<i>Visual Impairment</i>	<i>Hearing Impairment</i>	<i>Physical Impairment</i>
<i>Part-time</i>	<i>Without SLC(part-time)</i>	1100	200	250
	<i>With SLC(full-time)</i>	3000	1000	3000
<i>Full-time</i>	<i>Without SLC</i>	5500	5500	3650
	<i>With SLC</i>	7300	5500	7250

SLC (School Leaving Certificate) is given to those who graduated from 10 years of education.

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Data collection and analysis

The author has collected unique data through direct interview, using carefully-structured questionnaires, from 421 persons with disabilities, covering hearing, physical and visual impairments. All participants were living in Nepal's Kathmandu valley (inclusive of the three districts: Kathmandu, Lalitpur and Bhaktapur) at the time of the survey. The size and the coverage of this survey are large for Nepal; it is essentially the first of its kind, given the general lack of studies on disability issues in Nepal. Socio-demographic characteristics and educational information of the participants are presented in percentage points. The average has been calculated wherever necessary.

In this study, participants from 16 to 65 years of age were selected. Although the interview was conducted with 421 participants, 11 of them had to be excluded as their age exceeded 65 years. On the whole, we have analyzed 409 participants; however, in terms of educational information, only 399 provided their information and, among them, 37 were illiterate. Another 10 participants had received some form of literacy training from an adult education program. As these 47 participants never attended primary school to begin with, they have been excluded from the discussion of educational dropouts.

Socio-demographic characteristics of the participants

The 409 participants in this study ranged from ages 16 to 65 years, with an average age of 31.48 years. The majority of the participants (57.7 percent) were male, and the remaining 42.2 percent were female. Participants were asked to classify their disability; among the respondents, 36 percent had hearing impairments, 32 percent had visual impairments, and 31.5 percent had physical impairments. These statistics are summarized in *Table 2*.

Table 2: Descriptive statistics

<i>Variable name</i>	<i>Percentage</i>
Female	42.0
Persons with visual impairments	30.2
Persons with hearing impairments	37.9
Persons with physical impairments	31.9

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Average years of schooling and type of disability

Irrespective of disability, the participants had an average of 8.81 years of schooling. Disability-specific averages for years-of-schooling were, respectively, 6.9 years for participants with hearing impairments, 8.78 years for participants with visual impairments, and a significantly higher 11.03 years for participants with physical impairments.

Type of school (Table 3)

Irrespective of the type of disability, 34.5 percent of the total participants had received education in integrated schools, that is, schools for persons both with and without disabilities which are able to offer specific resources and facilities to their students with disabilities. In contrast, 24.16 percent of participants obtained their education from special schools for persons with disabilities. The highest number of participants, 39 percent, had received education through local schools which had no specific facilities or resources (henceforth referred to as 'local schools'). Another 2.2 percent of participants had received adult education informally.

Table 3: Education and type of disability

	<i>Total</i>	<i>Visual impairment</i>	<i>Hearing Impairment</i>	<i>Physical Impairment</i>
<i>Average Years of Schooling</i>	8.8	6.9	8.7	11.03
<i>Integrated School</i>	34.5%	56.1%	13.1%	42.6%
<i>Special School</i>	24.1%	6.7%	56.9%	1.5%
<i>Local School</i>	39%	33.7%	26.2%	55.8%

Integrated educational programs are generally targeted to those with visual impairments, and our findings corroborate this, as the majority of the participants with visual impairments (56.1 percent) had received education in

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integrated schools. Only 6 percent of the participants with visual impairments had received education from special schools, whereas there were 30 percent of the participants who had received education from local schools. As there is only one special school for students with visual impairments in Nepal, this finding is unsurprising.

Contrastingly, 13.1 percent of participants with hearing impairments received their education in integrated schools, while the majority (56.93 percent) obtained it from hearing-impairment oriented special schools. Again, some students with hearing impairments simply could not access education which provided for their specific needs, with 26.2 percent of respondents having studied in local schools.

Compared with the participants with visual and hearing impairments, the educational status of respondents with physical impairments encourages optimism. 42.6 percent of the participants with physical impairments studied in integrated schools, while 55.8 percent had studied in local schools.

It is important to note that the choice of some students with visual or hearing impairments to get their education from local schools cannot be used to justify politicized claims of supporting inclusion – a conclusion also drawn by Anastasia Vlachou in her study of support teachers in Greek primary schools (Vlachou 2006). Rather, it might be mainly due to circumstance, for example the unavailability of seats in integrated schools, or schools being located far from students' homes. A look at the availability of special schools in one area of the country makes this problem clear: as there are only three integrated schools for students with visual impairments - one in each of the three districts of Kathmandu Valley (Kathmandu, Lalitpur and Bhaktapur) – and only one special school for students with hearing impairments, the number of seats available for admission is severely limited. Thus, it would appear that students with hearing and visual impairments often join local schools simply because flawed education is better than none.

By contrast, there are no special schools for students with physical impairments in Nepal. No matter whether they chose integrated or local schools, students with physical impairments largely receive their education in the same manner as people without disabilities; therefore, the primary obstacle they must confront is accessibility.

Disability and dropout (Table 4)

Regardless of the type of disability, nearly one in five participants 21.8 percent dropped out after only completing primary education up to grade five. Similarly, 23 percent of participants continued only as far as eight years of schooling. In total, 48.9 percent of participants did not continue to the end of their secondary education of ten years. Ten years is formally the end of secondary school education in Nepal, after which graduating students are qualified to enter college. Comparatively, among students without disabilities, national dropout rates in local schools are: a 9.2 percent dropout rate after five years; and a rate of 18.6 percent dropping out after 10 years (Nepal Department of Education 2008). 14.67 percent of participants graduated from a higher secondary level of 12 years of schooling, while 15.89 percent graduated at the bachelor level (15 years), and 4.40 percent completed a Master's program. The results clearly indicate that, mostly, participants' dropout rates were higher at the primary and lower secondary levels.

Dropout rate and type of impairments

Looking at the dropout rate according to the type of disability, persons with hearing impairments have the highest dropout rates. The majority of the participants with hearing impairments had not completed their full school education of 10 years – 34 percent dropped out after completing primary education up to grade five. This figure is even higher for dropouts following grade eight, rising to 42.9 percent of respondents giving up their education after eight years. Only 17 percent of participants with hearing impairments had completed ten full years of schooling.

Compared to the high dropout rates of persons with hearing impairments, the dropout rates of participants with visual and physical impairments were significantly lower. For example, only 16.6 percent of participants with visual impairments had given up their education after five years. This figure decreases to 6.6 percent when we look at the percentage of dropout after grade eight. The number of students with visual impairments who did not continue to higher education after graduating from secondary school was also low, at 6.6 percent. Also, fewer participants with physical impairments discontinued their education when compared to their counterparts with hearing impairments, but, compared to the respondents with visual impairments, their dropout rates were slightly higher. Respectively, 11.9 percent, 13.4 percent, and 3.1 percent did not continue their education after graduating from the primary, lower secondary and secondary levels. In terms

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of college education, participants with physical and visual impairments showed similar rates of attendance: 67.7 percent and 51 percent of participants with physical and visual impairments, respectively, had had some college education. Compared to this, only 9.6 percent of participants with hearing impairments had obtained college education.

Table 4: Share of education level and type of disability

	<i>Visual Impairment</i>	<i>Hearing Impairment</i>	<i>Physical Impairment</i>	<i>TOTAL</i>
<i>Primary</i>	16.7%	34.1%	11.9%	21.9%
<i>Lower Secondary</i>	6.7%	43.0%	13.5%	23.0%
<i>Secondary</i>	2.2%	5.9%	3.2%	4.0%
<i>School Leaving Certificate</i>	6.7%	7.4 %	20.6%	11.9%
<i>Intermediate</i>	21.1%	6.7 %	23.8%	16.5%
<i>Bachelor</i>	34.4%	2.2%	22.2%	17.6%
<i>Master</i>	12.2%	0.7%	4.8%	5.1%
<i>College Level</i>	67.8%	9.6%	50.8%	39.2%
<i>TOTAL</i>	100.0%	100.0%	100.0%	100.0%

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Factors contributing to dropout rates

The kinds of factors associated with the dropouts of persons with disabilities are many: economic, social, attitudinal and physical. Some of these factors are described below in detail.

Lack of support in schools

Participants have cited many different factors as contributing to their decision to discontinue their education. Lack of support on the part of institutions was overwhelmingly cited by 29.8 percent of participants with hearing impairments, as opposed to comparatively small percentages of 4.62 and 2.3 percent of participants with visual and physical impairments, respectively.

In this study, it appeared that participants with hearing impairments were the most likely to find themselves at a disadvantage due to inadequate support systems. The large number of respondents noting this as a problem makes it clear that there are significant institutional barriers undermining their education in Nepal. By support systems, it is meant such things as sign language facilities, appropriate teaching methods, an understanding of the challenges faced by hearing impaired students on the part of the schools' administrators and teachers, and various other adjustments which address students' educational needs. Ultimately, the likely problem is the dominance of spoken language in mainstream teaching. Unless the problem of this language barrier is addressed, students with hearing impairments cannot fully participate in classroom study. The greater likelihood for individuals with hearing impairments to give up their education, their overall fewer years of schooling, and the general majority of participants citing the lack of support systems as a problem – as demonstrated by this study's data – all make for clear evidence of this fact.

Unavailability of school

In addition to this serious problem of inadequate support within schools, participants from all groups said that they had faced significant challenges in finding schools at all. The unavailability of schools was cited by 15.17 percent of the total respondents, with 21.49 percent of persons with hearing impairments, 7.14 percent of those with visual impairments, and 6.45 percent of those with physical impairments claiming it as a barrier. It was once again found that participants with hearing impairments were the most likely to have been negatively affected.

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Parents' financial difficulties

Irrespective of the type of disability, the cost of education was a major concern. 40.76 percent of all participants cited financial difficulties as preventing them from continuing their education. Among participants with visual impairments who had dropped out of school at some point before completing ten years, 53.57 percent had encountered serious financial difficulties. This figure is only slightly lower for participants with physical impairments, 51.61 percent of whom indicated that this had been a serious problem, while a much lower 32.3 percent of hearing impaired respondents cited the same reason as one of the main causes.

Without financial certainty, families cannot send their children to school, even when they know well the potential benefits of doing so. Poverty is widespread, and moreover discriminatory attitudes contribute to a pattern of non-disabled children being favoured when a family is so disadvantaged that they are obliged to choose who gets to go to school.

Parents' attitudes

It was found by this study that parents' attitudes toward their children with disabilities can be a major determining factor in students with disabilities' quest for education. No matter whether a child is disabled or not, parents play a crucial role by enrolling their children in school, and rendering other support. The hypothesis is that if parents are understanding of their children's disabilities – that is, if they believe that being disabled doesn't mean being *unable* – they are likely to have a positive impact on their children's education.

We examined parents' attitudes towards their children with disabilities through survey questions. Participants with disabilities were asked to rate their parents' attitudes toward them; specifically, they were asked how well their parents understood disability issues, and whether or not their parents' attitudes toward their disabled children's potential for personal advancement were positive. We then investigated whether there was any correlation between parents' perceived attitudes and respondents' education levels.

The results, presented in *Table 5* indicate that, the more positive their parents' perceived attitudes, the greater was the average number of the respondents' years of schooling. Contrastingly, less positive parental attitudes were associated with significantly fewer years of schooling.

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Table 5: Average number of years of schooling by rating of parents' attitudes – question: 'My family understands the issues of disability'

<i>Answer to the question</i>	<i>Average Years of Schooling</i>
<i>Very high</i>	10.33
<i>High</i>	9.73
<i>Moderate</i>	8.3
<i>Low</i>	7.65
<i>Not at all</i>	5.66

Our data results indicate that parents do enrol their children quite readily if they have a positive understanding of their children's disability. As Seamus Hegarty (1998) points out, attitudes toward people with disabilities are centrally important to any effort to reform education provisions. Our findings suggest that further programs on awareness-raising among parents of those with disabilities are in order.

Conclusion

We have discussed different barriers faced by persons with disabilities in relation to their school education. Overall, it seems that raising awareness, in families, communities, and at the government level alike, is potentially the strongest tool for working towards better education and more opportunities for persons with disabilities. Hegarty has suggested that educational policies which disregard social and cultural realities (such as social stigma) are 'likely to be ineffectual, and indeed to waste resources' (1998: 114): this is why raising awareness is key. Neither policy interventions nor community-based solutions can work to their full potential without the cooperation of the other, i.e. government, and family and community both can only do so much unless they support one another. Understanding an issue is the first step toward solving it; in this sense, awareness at all levels is the first step towards implementing policies to combat other barriers like poverty and the lack of resources. In 1995, a paper by Ahuja and Filmer projected that South Asia, 'which is currently the least educated region, is expected to substantially augment its stock of human capital by the year 2020' (1995: 21) Considering our findings regarding the complex interrelations of various barriers

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education, it is imperative that efforts be made to ensure that persons with disabilities in South Asian developing nations like Nepal are included in this projected development.

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