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## **Human Rights of Disabled People in the South**

**By Hisayo Katsui<sup>1</sup>**

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### **Introduction**

This paper focuses on human rights of disabled people in the South. This superficially remote topic is actually relevant to every reader. This article explains that our ignorance has led to the global disparity between rich and poor people and reinforced particularly the vulnerability of disabled people in the South. Thus the aim of this article is to bring the consciousness and ownership of the wide readers towards disability issues in the South.

In this article, **human rights** refer to universal rights held to belong to individuals by virtue of their being human. I use **South** as so-called "developing countries" and recipients of development cooperation, while **North** as "developed countries". The concept of "development" is not universal and thus I believe that countries cannot fit into this simple dichotomy between "developed" and "developing." For instance, many "developed countries" do not necessarily fit into the category when human rights perspective is applied. This North-South solution is to politicise "development" rather than to capture the world in a geographic specificity (e.g. Australia). The border line between the North and the South has been blurred in disability discourse because no country has achieved equality to disabled people. For instance, first countries that acknowledged sign language as the official language for Deaf people in Constitutions were Slovak Republic, Uganda, and Finland in 1995, Czech in 1998, and Thailand and Venezuela in 1999 (Lapiak, 2003). Another example is Mexico which vigorously addressed the need to stress human rights of disabled people in United Nations Assembly in 2001, which led to the process to make a new convention on this issue. In other words, both the North and the South started to pay attention to disability issues only recently.

At present, the number of disabled people around the world is estimated 600 million, (WHO, 2003; UN/Division, 1999), which occupies 10% of the total population. However, national statistics vary from 4 % to 20% (WHO, 2001) due to the different definition and conditions in each country. More developed countries tend to have a higher number due to 1) longer longevity, 2) developed medical technologies, 3) inclusion of newly diagnosed and mental disabilities and 4) better statistical systems to cover the whole population (Katsui, 2005:24). The second factor prolonged life expectancy especially of those severely disabled people who could have died when certain medical technology had not been developed yet. The increasing number of conflicts and HIV/AIDS epidemics, on the other hand, affected the number of disabled people in many other countries. For instance in Cambodia, the ratio of disabled people is as high as 20% after the conflict (Wiman, 2004), while 95% of new HIV infections occur in the South (UNCDF/SUM, 2003). At the same time, 20% of the cause of impairment is malnutrition (UNESCO, 1995), while only 10% of people living with AIDS in Africa receive some treatment (Mainichi-, 2005). In this regard, cultural relativism becomes an important dimension in disability discourse. Especially the concept of

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“disability” is diverse. However, disability discourse is largely North-oriented. How then disabled people in the South are connected to North-oriented discourse?

80% of the world disabled people are estimated to live in the South (WHO, 2003; UN/Division, 1999). Despite the significant number in the South, only 2% of them receive some kind of support (United Nations, 2000; San, 1999). This explains the next statistics: 17% of the poor people are occupied by disabled people according to the World Bank (Haar, 2005). That is, disabled people in the South are largely ignored both by the governments and international communities. Human rights approach of disability connects these largely neglected part of the world population into the discourse.

Theories of disability studies developed rapidly over the last few decades to challenge the social values against disabled people. The theoretical framework of this study is human rights approach of disability (Bickenbach, 2001; Katsui, 2005). Under the **medical approach**<sup>2</sup> of disability, disability is the direct consequence of the individual impairment. Therefore, medical cure or rehabilitation is the natural solution for disabled people from the viewpoint of scientific authenticity. Disability activists themselves established the **social approach** of disability that challenged the very assumption of "normality" and re-defined disability as social oppression (French, 1994). In other words, the problems are not within the individual disabled person but within society (Oliver, 1990). **Human rights approach** conceptualises disability as violation of human rights. This approach challenges the fundamental inequality. This approach and social approach are continuum and mutually reinforcing (Bickenbach, 2001; Katsui, 2005). Human rights ideology has three significances: 1) intervention has to be rights-focused rather than charity, 2) legal obligation of the government is required and 3) transnational obligation gives legitimacy to interventions beyond country borders (Khan, 2005). Human rights approach has become important towards equality of socially marginalised groups of people beyond national borders.

The most explicit Northern efforts for disabled people in the South have been taking place in development cooperation activities, which is the next theme. This chapter gives background information to the readers to understand the context of this article. Important concepts such as poverty, partnership and ownership are introduced. Secondly, development cooperation activities in the field of disability are focused. This part argues that this sector has been marginalised without enough attention of different actors. Particularly human rights approach is rare. Third part elaborates why activities with human rights approach are challenging. Fourth part introduces a case study of development cooperation activities of one Finnish non-governmental organisation (NGO) in Central Asian countries. This part explains the challenges of this approach on the ground of Southern contexts. Subsequently, lack of public awareness in the North partially explains why human rights of disabled people in the South have attracted little attention. Deficiency of research works in the South also contributes to reinforce the status quo. In conclusion, all the arguments are summarised to highlight how ignorant North has been to human rights of disabled people in the South. I pose a question to each reader: how we can support the Southern peers?

## **Development Cooperation Activities at a Glance**

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<sup>2</sup> In literature of disability studies, medical “model” or social “model” are more common names to distinguish the theoretical differences. In this article, I deliberately use “approach” rather than “model” because different approaches as means are important in conceptualising the relationship between North and South rather than fixed model as such. Furthermore, my academic background is both Disability Studies and Development Studies, the latter of which use human rights-based approach as one integral strategy of development. Thus “approach” synchronises both disability and development discourses better in this article.

## **From Charity to Human Rights**

Development cooperation is currently understood as “an investment as well as a moral imperative – an investment in shared prosperity, collective security and a common future” (UNDP, 2005:7). At present, Northern countries allocate 0.25% of their Gross National Income (GNI) on it, which lags far behind the UN target of 0.7% allocation. The development cooperation used to be more a charity of rich countries. The notion has changed with the introduction of human rights approach:

*In the past, the terms used were aid or development assistance, or that Sweden sent money to the poor. Today, the term used is development cooperation since it is a matter of cooperation rather than providing money: cooperation between people, between international bodies such as the UN and EU, and between the peoples and governments of countries. It is not a matter of charity, but a matter of the right of people to avoid being poor (SIDA, 2005).*

The above statement of Swedish Agency for International Development is illustrative to show the deep interconnection between human rights approach and development cooperation. Not only Swedish government but many Northern countries currently mention human rights as the essential approach. In this way, human rights approach started to motivate Northern countries to increase the quantity and improve the quality of their development cooperation activities. For instance, the world governments signed the Millennium Declaration (commonly known as Millennium Development Goals<sup>3</sup>) to tackle with the increasing inequality between the rich and the poor and to halve the extreme poverty by 2015. Development cooperation has become important aspect of globalisation at least in theory.

Despite the increasing recognition of human rights in international policy and recommendations, the actual implementation is not as impressive. For instance, “Since 1990 increased prosperity in rich countries has done little to enhance generosity: per capita income has increased by \$6,070, while per capita aid has fallen by \$1” (UNDP, 2005:8). Another example proves the priority of military security over human security: “for every \$1 that rich countries spend on aid they allocate another \$10 to military budgets” (ibid.). If the same tendency continues, shortfall for achieving Millennium Development Goals (MDGs) is expected to increase from \$46 billion in 2006 to \$52 billion in 2010. This is a scandal.

## **What Is “Poverty”?**

Prior to the specific focus on disability field, concept of “poverty” has to be understood because poverty is deeply interrelated to disability in the South (Yeo, 2003: Katsui, 2005). This central concept of “poverty” has developed overtime. Poverty had long been understood primarily as income poverty in terms of daily income. This poverty line was the predominant measuring indicator for identifying the poor population in the world. Thus economic solution was naturally the mainstream poverty reduction policy and practice. The economic solution included introduction of the market economy and free trade so as to expect trickle down effect toward the majority of poor people by benefiting directly the minority of rich people. This free development solution has succeeded in increasing some countries’ GDP. In early capitalism, development was natural result of production and competition. Therefore, some negative effects such as under-development and

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<sup>3</sup> The 8 goals are the following: 1) Eradication of extreme poverty and hunger, 2) Achievement of universal primary education, 3) Promotion of gender equality and empowerment of women, 4) Reduction of child mortality, 5) Improvement in maternal health, 6) Combating HIV/AIDS, malaria and other diseases, 7) Ensuring environmental sustainability, and 8) Developing a global partnership for development. More detailed information on MDGs can be found on [www.un.org/millenniumgoals/](http://www.un.org/millenniumgoals/)

disorder were included in the simultaneous part of the process of development and not paid much attention due to the focus on productivity.

In more matured period of capitalism, however, development became intentional act without final end when surplus population was recognised as a big problem and side effect of capitalism that needs intervention. Poverty concept was then unemployment. When capitalism started to involve more and more countries and be globalised, two new issues came up: 1) free development and/or doctrines of development increased the gaps between poor and rich people and 2) income is not the only way to measure a “good life” in another local context outside of the North. These unintended or intended changes shed light on the mechanism of free development and wrongly interpreted doctrines of development. This phenomenon drew attention to the existing poverty concept and questioned it because the existing combination of free development and development intervention did not properly work. As the Nobel Prize winner Amartya Sen argued since early 1980s, poverty was too simply understood and thus the solution was also too simplistic.

In 1990, United Nations (UN) introduced Human Development Index (HDI) that included new indicators such as life expectancy at birth and adult literacy rate in addition to income per capita for measuring achievements in basic human development. This effort helped to enlarge the concept of poverty. In 1997, UN further elaborated the concept of poverty by introducing Human Poverty Index (HPI). HPI considers poverty as deprivation and tries to measure it, while HDI measures achievements. This HPI was one of the clear paradigm changes: poverty is not what you have not achieved but is denial of choices and deprivation of opportunities to live a tolerant life. Moreover, in 2000 UN differentiated HDI into two categories so that poverty is measured more in context specific ways. For instance, poverty in the North is taken into account in this new HDI-2, while HDI-1 deals with poverty in the South. Unequal distribution in each country has become much clearer with this effort. For instance, the gaps between urban and rural population and gender imbalance were clarified. At the same time, the most disadvantaged group of people were identified with this new indicator. In this way, the poverty concept has developed in the way to pin point the most deprived groups of population within a country, which goes beyond the aggregated number attached to each country. In this way, the poverty concept as multidimensional phenomenon of deprivation has become the consensus among the main international institutions at least at policy level.

### **Poverty and Disability**

Both disability and development theories changed over time from a positivist paradigm to an interpretive paradigm, and further into an emancipatory one in terms of their central concepts of disability and poverty. Traditionally, poverty and disability were considered as a personal problem or the problem of the country in the positivist paradigm, and so the problem carriers had to deal with their “own problems.” Poverty was measured solely in term of income, while disability in terms of medical normalcy. At this stage, the vulnerable group of people was excluded from the mainstream when the concept of “normality” labelled them as “abnormal.” Subsequently, more contextual, social conditions and environments are taken into account in the interpretive paradigm. That is, the social solution has replaced the individual solution. At this stage, the vulnerable groups of people are included in the contextual framework of the mainstream where rich and non-disabled people are also responsible in reducing inequality by changing the mainstream structure. The concepts are now multi-dimensional when context-specificity and individual diversity are also taken into account. Therefore, the solutions also need to be multi-dimensional to meet the context-specific differences and variety of different persons.

Development of concepts is not the only common features between poverty and disability. They have mutual relationship of cause and effect (Yeo, 2003; Katsui, 2005). In other words, disability tends to lead to poverty, and vice versa, which creates a vicious circle to worsen the quality of life of those trapped in the vicious circle<sup>4</sup>. Due to disability and discrimination, an impaired person tends to have difficulties in increasing her/his position. As a result of systematic exclusion, their financial position is in jeopardy. It then leads to poverty in many other senses in addition to the financial one and consequently ends up in further exclusion from society. At the same time, poverty also tends to lead to disability. Poor people are often excluded from different levels of the system, and thus their living condition is worsened as well as the voice is not heard. As a result, a poor person has a much higher risk to gain impairment compared with non-poor peers. That is, those who are poor and disabled people have difficulty in escaping from the degrading system if no intervention is made.

### **Partnership and Ownership**

Partnership has become important goal and means in development cooperation because poverty reduction and ultimately equality require changes at all levels. For instance, the aforementioned Millennium Development Goals include global partnership as its 8<sup>th</sup> goal, while partnership as a means reflect the ineffectiveness of development cooperation (Kontinen, forthcoming). The development cooperation as a social system has peculiar donor-recipient culture in favour of the donor (Tvedt, 1998; Hoksbergen, 2005), even though the philosophy of human rights has been introduced at policy level. That is, donors are more powerful than recipients because the donors hold the strategic decision making power that the recipients have to follow to receive various resources. As a result, this asymmetrical power relationship caused dependency of the Southern counterparts (Katsui, forthcoming).

The criticism naturally and gradually followed another concept of ownership of the South. The priority is placed more on the actual ownership of Southern “partners”. This ownership concept became important since mid-1990s (Helleiner, 2002). Partnership discourse allows ownership to both Northern and Southern actors with interdependent relationship represented in reciprocity, trust and equality, whereas ownership discourse aims at ownership of the Southern actors that has been marginalised. That is, partnership and ownership are potentially contradictory concepts to promote at the same time because their priorities are different. Regardless of this priority gap, both concepts have gained visibility in development cooperation both as means and goals.

Human rights approach of disability is relevant to these two concepts: partnership is necessary to tackle the violation of human rights at all levels, while ownership is the very reason what disability movement fights for. Both are important means and goals in this paper.

### **Development Cooperation Activities in the Field of Disability**

When it comes to disability in development cooperation, the amount allocated is obviously even more scarce in already scarce development cooperation in general. One of the most disability-sensitive countries, Finland, allocates only 5% of its official development aid to disability (STAKES, 2003) which amounted to 32 million Euros between 1991 and 2002. This number is too small considering that 10% of the world population is estimated as disabled and they lack major preconditions to participate in any development cooperation activities. However, Finland is one of

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<sup>4</sup> Attention has to be paid for the fact that being disabled persons does not mean that they are poor. For instance, I met several disabled people in Central Asian countries who are working at politically influential positions. Uganda and South Africa have some Members of Parliament who are disabled. Thus poverty and disability tend to influence each other but do not determine that everyone is involved in the vicious circle.

the few Northern countries that allocate relatively a big ratio of money out of its budget to disability projects (Tuomioja, 2005). The Nordic countries had a conference, “Disability in Nordic Development Cooperation,” in November 2000 to mainstream the disability aspect into development. That is, disability is not included in the mainstream policies yet. The Nordic countries proposed to increase their financial contribution to the disability field in development by earmarking 1% of total development funds for disability-specific projects and 1% of any project budget for inclusive measures in mainstream programmes in bilateral as well as multilateral contributions (Nordic-, 2001). In other words, disability is totally out of the mainstream and does not even reach 2% of the total development funds yet. Although NGOs increase the total amount allocated to disability field, it is clear that disability has not become a cross-cutting issue as gender and environment in development cooperation. For instance, non-Disability NGOs do not involve disabled people to the decision making practices because they think disabled people are “irrelevant” to their projects, even though 10% of the population are disabled (Katsui and Wamai, 2003). In other words, even if development cooperation activities are meant for poor people, they often ignore disabled population. Good example is microfinance activities that invest small capital to poor people mainly to establish their own income-generating activities. Disabled people are often not included into this scheme because of the prejudice that disabled people are not competent to work (Katsui, forthcoming). At international level, only few indicators to monitor the progress of Millennium Development Goals include disabled people as stakeholders (Raijmakers, 2005). This scarce attention to disability field coincides with the aforementioned statistics that only 2% of disabled people in the South receive some kind of support (United Nations, 2000; San, 1999). In other words, development cooperation interventions are further disabling disabled population in the South by continuing to ignore them.

Under the circumstance where international and national supports for equal opportunity are scarce, more and more Disability NGOs are encouraged to head for the South to tackle the poverty of disabled people in the South. In the Finnish case, for instance, the maximum project cost covered by the government is usually 80% whereas Disability projects could get as high as 90% (MFA, 2003). The ratio of support from the Ministry is increasing to 85% and 92.5% respectively in 2006 (Seipäjärvi, 2005). Since 1990s after this disability sensitive budgetary policy was adopted, the number of projects in the disability field increased. In 2005, 17% of all Finnish NGO project applications were targeted to disability-specific themes (Tuomioja, 2005). However, when the content of the development cooperation in the disability field is scrutinised, it further proves the limited practices of the human rights approach. The study of STAKES (2003) found that most of the projects were based on the “dominant social welfare approach” rather than human rights approach. That is, human rights ideology has led to international intervention to improve the quality of life of disabled people in the South rather than hitherto charity giving. However, various challenges hinder the actual implementation of the human rights approach into practice, which is clarified in the next chapter.

## **Challenges of Human Rights Approach in Development Cooperation Practices**

Human rights approach is North-oriented<sup>5</sup>, while implementation takes place in the South where the notion of their human rights are often different from the individualistic North-oriented human rights (Hellsten, 2004). Naturally this approach faces various challenges. If not scrutinised, human rights approach as such can hide unintended impact of development cooperation especially to disabled people in the South, who are regarded as one of the most marginalised groups of people. This

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<sup>5</sup> Human rights philosophy itself is not North-oriented. Many African and other Southern countries have similar conceptions in their cultures (Hellsten, 2004:63).

chapter, therefore, explicates the practical challenges in development cooperation practices in the South.

I shall discuss the challenges of development cooperation practices with human rights approach at mainly three different levels among others: development cooperation system at international level, intolerance of the Southern government at national level and gap with reality of disabled people in the South at local level. Development cooperation includes both governmental and non-governmental interventions. All these different levels interact and create challenges against the implementation in practice.

The development cooperation as a social system has peculiar donor-recipient culture in favour of the donor (Tvedt, 1998; Hoksbergen, 2005). This asymmetrical power relationship is epitomised into accountability practices. Accountability is a social construction which is conducted to justify and legitimise organisational activities, make evidence of current and future actions and deconstruct and/or reconstruct for organisational stability (Yakel, 2001). Accountability is multiple both upwards and downwards (Edwards and Hulme, 1998) or mutual when stakeholders have no hierarchical relationship (Yakel, 2001). In development cooperation system with hierarchy among actors, recipients are required upwards accountability to donors, while downwards accountability is rarely demanded (Townsend and Townsend, 2004; Johnson, 2001; Edwards and Hulme, 1998; INTRAC, 1998). Corruption management and good governance theories accelerated this phenomenon to highlight the importance of accountability (Seyf, 2001; Mawdsley et al., 2005). In this system, recipients are expected to create a report with positive impacts to account for the intervention. The loaded tasks around accountability increased administrative paper works and consequently decreased human resources for implementing activities. As a result, many Southern NGOs started to become dependent on Northern ideology, resources and decisions with or without their intension. Poor resource of Southern NGOs, lack of legal environment and/or urgent needs of the members also urge many other Southern NGOs to become dependent.

Moreover, impact measurement of human rights approach takes time before measurable changes would take place and thus difficult to account for upwards. When advocacy and awareness raising activities of human rights are implemented, visible changes are hard to quantify. Changes are rather subjective than objective in such interventions. For instance, when people have less prejudice against disabled people, quantifying different levels of “prejudice” is a difficult task. Furthermore, disabled people in the South lack major preconditions. Thus effectiveness of any single project is difficult to be measured in general. Therefore, development cooperation with human rights approach for disabled people in the South makes the impact assessment difficult. Furthermore, project cycle that is too frequently the time frame of development cooperation focuses on short-term impact rather than long-term impact. Disabled people lack various preconditions, which necessitates changes at all different levels due to the existing discrimination against them. Let me introduce one illuminating example from Kazakhstan. With the project grant they won, one DPO staffs organised a computer literacy course to give equal opportunity also to disabled people. On the day of the course, only few showed up to the site. I interviewed several disabled people who live close-by for their reasons why they did not participate in the course. They did not have accessibility to the classroom, wheelchairs, literacy, interests, family support and/or the information about the course. Time frame had to be much longer, while resources had to be much more due to the disability-specific conditions. However, disability has not been mainstreamed as a cross-cutting issue in development discourse, which makes the understanding difficult. In other words, disability in development is marginalised within the social system of development cooperation. As a result of this system that demands quick impact without disability sensitive attention, development

cooperation activities are charity-oriented in practice because their impacts are easier to be measured.

When disability-specific dimensions are not understood, development cooperation activities in the disability field become too difficult to be implemented. On the one hand, Northern disability activists have to secure more resources than any lay development worker to be able to visit a country in the South. For instance, many of them need to bring their personal assistant(s) or sign language interpreter(s), which increases the cost right away. Accommodation in the South has to be accessible and hygienic especially for people using respirators or electric wheelchairs, which leaves only few international chain hotels that are the most expensive. In order to show the role model, they cannot be replaced by non-disabled colleagues. On the other hand, Southern participants also require various resources to be able to participate in a development cooperation activity. For instance, they need accessible premises, the provision of equipment, assistance, transportation and/or mentality change of both disabled people themselves and their family members (Katsui, 2005). “Human capability” concept is relevant (Sen, 1989, 2004). Sen (1989) argues that poor people are incapable to function due to the deprivation of basic needs. However, even prior to that, they need to be identified because many of them tend to be isolated and/or hidden. That is, accessibility to disabled people is a challenge. In this way, much more resources are required for implementing development cooperation activities for/with disabled people in the South. Development cooperation system, therefore, sets various challenges due to lack of sensitivity to disability and causes unintended negative effect to human rights approach to disabled people in the South.

In addition, many Southern governments are not necessarily tolerant to human rights ideology. Human Rights NGO, Freedom House, annually ranks “the world’s most repressive societies”. In 2005 report, the worst records were found in Burma, Cuba, Libya, North Korea, Saudi Arabia, Sudan, Syria, and Turkmenistan. Two territories also experience equivalent violation of human rights: Chechnya and Tibet. Next to those most repressive societies were Belarus, China, Equatorial Guinea, Eritrea, Haiti, Laos, Somalia, Uzbekistan, Vietnam, and Zimbabwe (Freedom House, 2005:vii). That is, many countries have challenges of human rights approach already due to such regimes on top of the lack of understanding to disability in development cooperation. My PhD thesis (Katsui, 2005) explored the reality of disability in development in Central Asia, which included Turkmenistan and Uzbekistan that were ranked badly. I shall introduce some examples from these countries that highlight the challenges of human rights approach in countries. The governments discriminate against authentic NGOs and restrict their activities with harassment. Government-oriented NGOs (GONGOs) have much less trouble to register, while authentic NGOs are very frequently denied (Polat, 1999). For instance, in Turkmenistan, “not a single independent citizen’s group was able to obtain registration” (USAID, 2001:153). As unregistered associational activities are illegal and subject to arrest, registration is compulsory. In other words, the governments do not encourage NGO activities with a free hand. Especially human rights activities are rare due to the tight control of the governments to discourage these kinds of activities that try to challenge the current policy and practices. Registration became very difficult for Human Rights NGOs in general. The tax authorities also send nasty inspection to harass such NGOs. Especially in Turkmenistan, the number of active NGOs has decreased from 200 in 2000 to 156 in 2001 (USAID, 2001:153) and further to 138 in 2003 (Freedom House, 2003). Research participants in Turkmenistan were virtually so afraid of expressing any criticism against the current regime that they hesitated to talk in the interviews to the tape recorder. It was a typical Turkmen statement to answer any question, “Everything is fine thanks to our President.” Self-censorship is, therefore, a very common tactic to defend their activities (Turkmen-, 2005). Turkmen Initiative for Human Rights vigorously addresses these human rights violation from Austria where its staffs are in exile.

When governments are intolerant, human rights philosophy cannot be as powerful as in the North. In other words, governments ignore disabled population due to their “legitimate reason” of lack of finance when human rights are not prioritised. These countries are somewhat extreme cases but have implications in any countries that violate human rights.

Lastly, the gap between the human rights philosophy and the reality of disabled people in the South also becomes challenges. As mentioned earlier, disabled people lack many preconditions due to severe discrimination against them. London (2002) claims that human rights approach marginalises already marginalised groups and focuses on internationally recognised matters rather than on locally essential matters. First argument of marginalisation is relevant to disabled population. London argues that vocal groups of people are prioritised. In that case, disabled people are disadvantaged due to the deficiency of preconditions because they have fewer opportunities to be visible when they have difficulty in going out from home, for instance. The second argument is the dilemma that NGOs globally face (Hakkarainen et al., 2003). In case of the disabled people in the South, material needs are big as well as many other needs. Thus when human rights are introduced, there remains frustration for the ideology not making material changes. In this respect, development cooperation with human rights approach has various challenges to be implemented properly into practices in the South despite its political significance.

### **Challenges of the Southern Disabled People’s Organisations in the South**

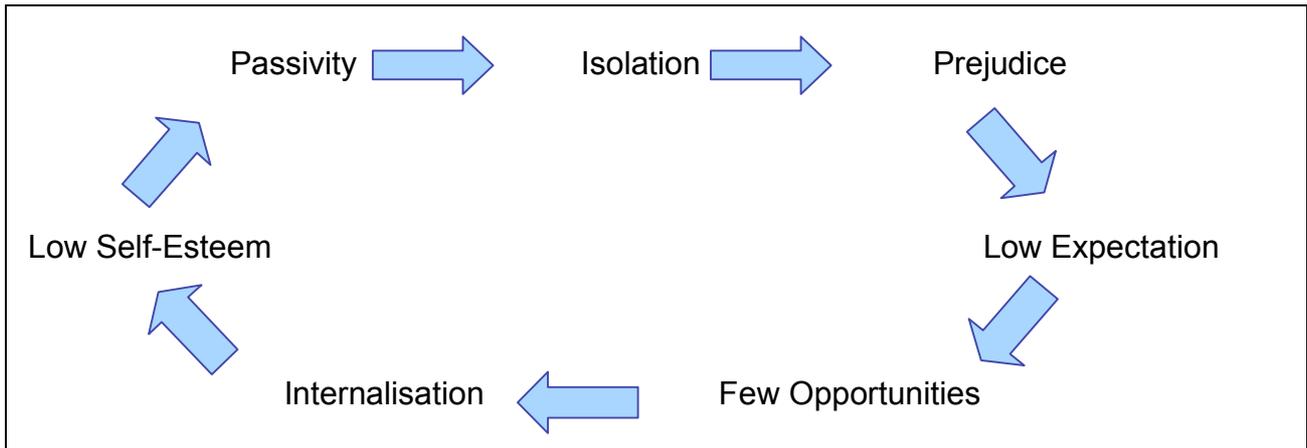
Despite the challenging realities, Southern actors are vigorously making efforts to make positive changes. For instance, Degener and Quinn (2002) claims that the Philippines is one of the countries that have the most progressive and comprehensive anti-discrimination laws together with Australia, Canada, Hong Kong, United Kingdom and United States of America. Southern actors are not only passive objects of development cooperation or any other external interventions. They are also actively involved in creating national and international disability movement to improve the QOL of disabled people. Particularly DPOs are the main actors leading the movement in each country. This chapter focuses on the challenges in the framework of DPO activities in the South. This part summarises the findings from an evaluation study<sup>6</sup> of one Finnish DPO, Abilis Foundation (Katsui, forthcoming) and from my PhD study (Katsui, 2005). Despite the different contexts in different countries, Southern DPOs had the following common challenges: 1) lack of preconditions for beneficiaries, 2) variety of “ownership” and 3) lack of various resources.

Both chairpersons and beneficiaries strongly feel that the beneficiaries lack major preconditions to be able to participate in DPO activities. Due to the low self-esteem caused by discrimination, disabled people tend to isolate themselves. This isolation causes mental pain, which often leads to self-blaming and desperation. Overcoming such psychological barrier is too difficult for many. Thus they start to accept disability and give up. The most common way to deal with the mental pain is to remain passive and stay at home. They become more and more passive in the process. They start to believe that difficulties are due to their impairments by internalising the view of discriminating society. In this way, on the one hand, the problem is individualised. Non-disabled people, on the other hand, remain ignorant of the whole issue of disability because of the isolation. This reinforces the prejudice. Consequently, this isolation normalises discrimination.

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<sup>6</sup> The study involved 23 DPOs in Bangladesh, Sri Lanka, Uganda and Zambia. 137 interviews were conducted in summer-autumn 2005 that included 25 interviews to chairpersons/ coordinators and 102 to beneficiaries. Beneficiaries were carefully selected not to be biased to one group of people with similar impression of the projects but to include as many varieties of people as possible with the given resources.

## Vicious Circle



This massive mechanism against disabled people reinforces discriminative society in all studied countries despite their country-specific conditions. Therefore, disabled people too often lack necessary preconditions to actively participate in DPO activities and remain passive. This passivity of beneficiaries follows the second challenge of “ownership”.

Ownership concept cannot be taken for granted but has to be scrutinised in terms of 1) who is involved, 2) how and 3) on whose terms. The gaps between chairpersons and project beneficiaries are big in general (Katsui, 2005). That is, voices of the project beneficiaries are frequently not listened to under current system unless special attention is paid throughout the project period. Furthermore, disabled people are different from each other even among the beneficiaries. Thus closer look at the reality from the viewpoint of different beneficiaries become of importance to understand the different layers of reality. The interviews revealed that beneficiaries feel ownership to the end result of the DPO project they were involved in. In other words, what happened to their lives as a result of a project is central. Especially material changes were important for the beneficiaries. However, when it comes to project process or organisational management, they do not feel ownership. DPOs and their projects are perceived as places where they get support but not as places where they play a role in collective efforts for a common goal. Project and organisational management are understood as chairpersons’ works. Therefore, chairpersons who are usually project coordinators hold strategic decision making power over their projects starting from planning, implementation and evaluation. That is, the ownership at this stage is on chairpersons’ terms. This phenomenon was valid regardless of the type of DPOs. Therefore, “disabled people” have ownership to their DPO activities. However, only handful of the “disabled people” actually owns the whole process, while others remain as beneficiaries of the end result. This common challenge requires various resources, which is the third challenge.

When lacking preconditions and human resources of final beneficiaries, Southern DPOs need various resources to be able to involve them. However, lack of resources is a common experience among Southern DPOs. Most of the Southern DPOs in the two studies were dependent on their Northern donors including Northern DPOs. Many DPO chairpersons state that it is impossible to implement their activities without the Northern support. However, when Southern DPOs are dependent on Northern donors, their ownership and decision making power is jeopardised. Although Southern actors do their best with the limited resources, it is a common knowledge for both the chairpersons and the beneficiaries to believe that making changes take for a long time.

Southern DPOs face these internal, organisational challenges as well as external ones as mentioned in the previous chapter. These challenges of Southern DPOs are similar to those of Northern ones to

a different extent. Under this circumstance, human rights of disabled people in the South are too often infringed in many ways.

## **Case Study: Finnish NGO Intervention in Central Asia**

Despite this generally challenging circumstance, one Finnish NGO implemented development cooperation project with human rights approach with disabled people in Central Asian countries. The name of the NGO is Kynnys ry in Finnish (Threshold Association in English). This is disabled people's organisation (DPO). Currently, activities include legal services, consultation services by peer, employment promotion activities and the arts. 1500 disabled and non-disabled members belong to Kynnys at the moment. Kynnys implemented a development cooperation project in five Central Asian countries between 2000 and 2003. Finnish disabled activists with different impairments were the trainers in the series of seminars they organised with Central Asian DPOs. The seminars aimed at knowledge transfer of human rights approach of disability. The target group was "current and future leaders of the disability movement," who were actually mostly chairpersons of Central Asian DPOs and active members of DPOs chosen by the chairpersons. Kynnys aimed at empowerment of both individuals and DPOs in Central Asia and furthermore creating a network among the countries. At the second stage, representatives of Central Asians visited Finland to exchange experiences with Finnish disabled activists and among them. Then finally, Central Asian DPOs organised a seminar in Kazakhstan with the funding they have applied and gained from another Finnish DPO, Abilis Foundation<sup>7</sup>. The Finnish actor considers this seminar as one of the visible fruits of their project because the aimed ownership was created and the responsibility was transferred successfully to the Central Asian actors, while the Finnish actor withdrew totally. This "success" is both true and false when human rights approach of this project is elaborated further.

The project stakeholders, particularly the Central Asian project participants, were very clever in localising and materialising the human rights philosophy in a suitable way for their contexts. As mentioned briefly before, Central Asian countries are not the most tolerant countries to human rights. Thus human rights philosophy can be materialised, while the word "human rights" cannot be used not to induce governments' negative overreaction. In these countries, government officials often participate in the NGO seminars in order to censor the content instead of forging partnership between civil society and the governments for the common goal. The project seminars were not the exception. Central Asian participants were careful not to explicitly oppose the regimes but to superficially go along with the government policy. Especially when the Central Asian project participants delivered the gained knowledge to their members of the DPOs, they deliberately did not use the words "human rights" but conveyed the message of the philosophy based on the daily needs of the members. For instance, one Kazakh project participant, Dana<sup>8</sup>, gained project grant from Abilis Foundation and organised a seminar to disseminate the knowledge gained from the project. It was a common practice among Central Asian DPOs to ignore the "passive members"<sup>9</sup>, while Dana challenged the barriers making them look passive. She invited particularly those who are imprisoned at home for a long time. She carefully planned the seminar so that all the preconditions are cleared for the participants to attend the seminar. This sensitivity of local living conditions is too

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<sup>7</sup> Abilis Foundation is a Finnish DPO whose activity is to give small grants to projects organised by disabled people and their organisations in the South. For more information, please visit [www.abilis.fi](http://www.abilis.fi)

<sup>8</sup> Dana is a given name by myself. The real name is not disclosed for securing her privacy.

<sup>9</sup> According to Central Asian DPO chairpersons, "passive members" are those who do not participate in DPO activities though they are informed about them. They cannot show up because they lack accessibility at home, technical devices, accessibility of the public transportation, or money for it, to name a few. This lack of preconditions makes many disabled people "passive" in addition to internalisation of the negative image of self through daily conversation with family and close people.

difficult for any outsider to fully understand. Thus Finnish actor left the responsibility deliberately to the Central Asian people so that the experts of their own cultures can implement the human rights philosophy in their practices. Dana showed a successful localisation and materialisation of the philosophy by not contradicting with the government in this way. While many development cooperation seminars benefit only handful of those who actually participated them, this Finnish intervention had an impact to disabled members who are not invited to such international happenings through Dana's project. Those disabled people who attended the seminar organised by Dana expressed that the human rights philosophy empowered them mentally at individual level, which even led to collective ownership to disability issues. That is, when the "passive" disabled people are given the opportunity and when their preconditions are cleared, they are as active as any non-disabled persons. They just have too few opportunities to build and prove their capacity.

Nevertheless, this project is not an exception. Due to the challenges in development cooperation in general, this project also had difficulties in implementing the project with human rights approach as was enlisted above. This part focuses on three major difficulties: 1) asymmetrical power relationship among different stakeholders, 2) lack of resources for implementation and 3) ignorance of the most marginalised groups of disabled people.

Firstly, asymmetrical power relationship among different stakeholders made the project complicated. Southern project participants are required for upwards accountability with positive remarks due to the Northern situation in which Northern actor has to account for their own donors. However, the impact of knowledge transfer is a difficult one to objectively measure. Thus Finnish actors relied on the statements made by the Central Asian chairpersons. Due both to the cultural difference and to the asymmetrical power relationship, Central Asian chairpersons expressed positive impact. Nevertheless, when I interviewed them in personal environment, their impression of the project was quite a different one. Some regarded the human rights philosophy as a "luxury only available in the North." In addition, the internal gap between chairpersons and members is also problematic. Members, who are at the bottom of the structure, did not gain much because information did not reach them. Northern actor decided when to terminate the activities: when the project period is over, the activities were terminated. This strategic decision making power in the North makes the following activities difficult for the Southern actors.

Secondly, the above power structure becomes problematic particularly when implementation has to take place because that is the hardest part which requires most resources. For instance, information delivery to the members was expected by the North as a result of the project seminars. However, each DPO does not have enough resources to reach even members, let alone non-members who are the majority of disabled population. Many disabled people did not have communication devices, which left the only choice to visit them one by one when information has to be delivered. However, DPOs did not have equivalent resources to be able to disseminate the knowledge.

Therefore and thirdly, the most marginalised groups of disabled people are easily ignored. That is, the most excluded people are not exposed to human rights philosophy, let alone actual positive changes in their lives. Human rights are remote ideology for them. Current development cooperation system is too ignorant to disability issues that it ends up in enlarging the gaps between the rich and poor further even when human rights approach is tried to be applied. Human rights approach requires long-term commitment at all different levels, while small scale projects and programmes cannot make big changes. More resources have to be mobilised so that the Millennium Development Goals are applied not only to the affluent part of the population but also to disabled people in the South. Why Northern resources are limited even though they have the development

policy with human rights approach? The next chapter deals with the challenges of public awareness-raising in the North that partly explains the limited action in practice.

## **Challenges of Public Awareness-Raising in the North**

United Nations set the objective to allocate 0.7% of GNI to development cooperation. Achievement of this objective has been one way to measure the North-South solidarity, although quality of cooperation obviously also matters. Only several countries have achieved this goal at present<sup>10</sup>. It is an interesting coincidence that those countries invest most in development education. Development education includes campaigning, education, awareness raising, advocacy and training to foster full participation of all citizens in world-wide poverty eradication and fight against exclusion (Lappalainen, 2005). United Nations Development Programme recommends 3% of official development aid (ODA) to be allocated to development education and public awareness-raising efforts. Nevertheless, most of the Northern countries are far behind this number. As a result, “88% of EU citizens still ignore the very existence of the MDGs” (Belgium-, 2005:5). That is, public consciousness to the global responsibility as global citizens is lacking. Therefore, public awareness-raising has become important means and goal to mobilise necessary resources to achieve the Millennium Development Goals.

For instance in the Helsinki Process co-organised by Finland and Tanzania, public awareness was raised as an important strategy as well as mobilisation of political will to “move from recommendations to implementation” (Tuomioja and Shareef, 2005). Public awareness and pressure to their politics eventually lead to the mobilisation of political will. Thus public awareness is a prerequisite. In Finland, a new curriculum of involving development education recently started. It offers values of global citizenship, human rights, multiculturalism and sustainability (Bourn, 2005). Bourn (ibid.) introduces this Finnish effort as one of the most successful cases that promotes development and global education in the mainstream education. In other Northern countries, such education is implemented in a short-term basis with limited funding outside of mainstream education system. He states that this partnership between Ministry for Foreign Affairs and the National Board of Education is a good practice among other Northern countries. However, when we take a closer look at the financial contribution of Finland to such education, we can witness that the percentage as of ODA has decreased from 0.69% in 2002 to 0.54% in 2004 (North-, 2004:29). One survey proves that only 14% of Finnish population knows the existence of MDGs, while as small as 5% knows more than one goal (Ulkoministeriön-, 2005). When the “successful” country remains this level, it is without saying that other countries pay little attention to public awareness-raising in terms of development cooperation, let alone human rights of disabled people in the South. Finnish Foreign Ministry started a campaign<sup>11</sup> in autumn 2005 to raise awareness of the MDGs in all elementary schools in Finland. As MDGs do not mention disability even once, disability in development is going to be marginalised further even if MDGs are promoted. As a result of the Northern ignorance and little attention to disability in the South, we reinforce the status quo in which disability is marginalised even in development cooperation works.

## **Challenges of Research Works in the South**

On top of the lack of public awareness, lack of research works also explains the reasons why development cooperation with human rights approach has not been promoted in reality. Research works are important to raise this theme and to mainstream disability as a human rights issue into

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<sup>10</sup> They are Denmark, Norway, Sweden, the Netherlands and Luxembourg.

<sup>11</sup> The homepage of the campaign can be found on <http://www.vuosituhattavoitteet.fi>

development discourse. In this part, my research experiences are cross-examined with another PhD study that was conducted also in the South, Zambia (Koistinen, forthcoming). We both used participatory research method<sup>12</sup> that is based on human rights philosophy. The challenges for research works to study development cooperation with human rights approach and to conduct the study itself with the approach are summarised on the basis of our findings in our article (Katsui and Koistinen, forthcoming). We found three main challenges: challenges in terms of 1) gaps between North and South, 2) variety of disabled people and 3) Northern academic culture.

First of all, disabled people in the South are highly inaccessible due to various barriers between the researcher and the researched. On the one hand, the researchers have to start with studying local culture and system. Language difference particularly of many ethnic minorities is one of the barriers. We both lived in their context to get closer to the realities and experiences of our researched people. The researchers, however, cannot totally fill the gaps between the different cultures over the PhD study period. On the other hand, local registration system often ignores disabled population. Even disabled people's organisations do not have good information where disabled people live when families try to hide them due to their feeling of shame. The communication tools such as telephone are also lacking in many households, which affects the accessibility on top of the physical gap between North and South. Particularly we had difficulty in accessing to disabled people in rural areas. Secondly, the knowledge gap between the researchers and the researched also complicates the research process. As many of the researched people had been isolated and illiterate, information gap was huge. Therefore and thirdly, the priority gap was also obvious. The disabled people welcomed the researchers and expressed their positive feelings for the face-to-face encounters. However, they were not interested in participating in the research process such as data analysis. As many had internalised negative image about themselves, many disabled people were passive in starting any new things. We both experienced many more similar experiences of gaps throughout our research works.

The second set of challenges stems from the variety of disabled people. The research methodology tries to secure equality among the researched people on the basis of human rights philosophy. As nation-wide statistics on disabled population is limited, we had to start from identifying possible varieties of disabled people to be included in the research works. 100 different ethnic minorities co-exist in Uzbekistan alone, which was a challenging context. Due to those barriers, representation was not fulfilled. The research processes and research findings aimed to empower disabled people in both studies. However, we do not know any unintended negative consequence of the studies. Furthermore, the research findings reached only to limited number of people. I created a popular version of my PhD thesis in Russian and published 1500 copies of them. That means, 300 copies were distributed to the five studied countries. Nevertheless, 380,000 disabled people are in Kazakhstan only. Research efforts to empower the researched people are thus unfortunately very limited. The third set of challenges explains this consequence further.

The third set of challenges is due to the Northern academic culture. Illustrating examples are 1) funding, 2) complexity of research process and 3) immeasurable research impact. First of all, funding plays crucial role in a research in the South because research works cost more money due to the cost involved to visits far away countries. Successful funding applications, however, require clear planning and identification of questions among others before any research is implemented. The participatory research methodology aims to plan and implement the research process together

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<sup>12</sup> In Disability Studies, it is called, "emancipatory disability research" (Oliver, 1997: Barnes, 2001: Oliver, 2002: Walmsley, 2001 etc.). In this method, researchers who produce knowledge make special efforts in making the relationship with the researched as equal as possible throughout the research process. The research process and findings are expected to empower disabled people and to contribute to equality.

with the researched people. This opportunity is already jeopardised prior to the research works due to this funding culture. We both visited the Southern countries with our own money to fulfil our aims based on the human rights philosophy. Human rights-based research is extremely time-, money- and energy-consuming in the South. Secondly, Northern academic culture has developed complicated concepts and jargons that are not understandable for non-academics. When many of our research participants were illiterate, this required lots of flexible arrangements. Thirdly, impact of the research works as well as that of development cooperation is difficult in disability in development due to the major lack of preconditions. Visible objective changes will take place after changes at many different levels. That comes back to the funding problem once again. When both academic and practical impact of the research works is not objectively measured, funders are not attracted to finance such studies.

The deficiency of research work, therefore, explains the scarcity of information on disability as a human rights issue in development. Therefore, understanding of the public and decision makers to mainstream disability in development becomes difficult, let alone human rights approach to disability in the South. Therefore, lack of studies in this area reinforces the marginalisation of disability in development particularly in the North.

### **Concluding Remarks: How We Can Support the Southern Peers?**

Human rights approach has been politically strong argument in the North, which affected the paradigm change to understand globalisation. The approach powerfully asserts the ownership of marginalised group of people and partnership among all actors to make a positive change towards non-discriminative global society. Development cooperation has become an important part of globalisation because North has the transnational obligation to the human rights in the South. Ingstad (2001:790) calls it “hope” that globalisation increased “global contact between DPOs, which increases the awareness of the rights of the disabled and the need for integration and normalization.” Nevertheless, when it comes to the impact of the approach on disabled people in the South, the effect is far too limited. First of all, disability aspect has been missing in the mainstream development cooperation, let alone human rights approach of disability. This system marginalises disability in development. Furthermore, human rights approach is challenging in development cooperation practices due to the development cooperation system at international level, intolerance of the governments at national level and gap between the philosophy and the reality of disabled people in the South at local level. In addition, organisational challenges within Southern DPOs also contribute to marginalise disability in development. Therefore, even though some Northern and Southern DPOs implement their development cooperation activities with the human rights approach, the impact has been limited. One of the reasons why development cooperation has not been paid enough attention to is major lack of development education in the North. Public consciousness has not been enough towards solidarity between North and South. Another reason is lack of research works. In this way, human rights of disabled people in the South have not been mainstreamed but further marginalised at practice level. Human rights approach itself is not legally enforceable even though the philosophy claims so. In this respect, the approach is more a voluntary manifesto which can be useful in raising public awareness but limited in actual action around the world and particularly in the South due to the prevailing poverty. Resources are too limited in every sense for the actual implementations.

How we can best support the Southern efforts is a question without one correct answer. However, it has become clear that marginalisation of disabled people in the South does never stop by itself without intervention. At present, we are increasing the gap by doing very little or nothing about this reality and further deteriorating the relative status of disabled people in the South. Consciousness

and solidarity to this issue is more than necessary today. In this sense, human rights approach is a means and goal at the same time so that rights of disabled people in the South are secured. It is high time to “**Think globally and act globally**” as well as hitherto slogan, “Think globally and act locally.”

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