Towards Equality

Creation of the Disability Movement in Central Asia

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By
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on Thursday, February 17th, 2005 at 12 o'clock.

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Summary

This study focuses on a political approach to civic activism in the field of disability, which is a cross-cutting issue between NGO (non-governmental organisation) discourse in Development Studies and DPO (disabled people's organisation) discourse in Disability Studies. Both academic disciplines theoretically started to focus on this political aspect as a driving force for sustainable and positive structural change by reflecting the hitherto failure of mere service provision that tries to fill the gaps in the deficiency of the structure. The political approach in this study refers to a rights-oriented approach that challenges the existing unequal power structure so that the ultimate goal of equality is fulfilled. This approach is elaborated through a project of the Finnish DPO, Kynnys ry, in Central Asian countries. In order to understand this organisational reality, its background context, namely the daily experiences of disabled people in Central Asia, is also investigated. The countries included in this study are the Former Soviet Union countries: Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan and Uzbekistan.

The basic qualitative methodology with in-depth, personal interviews and observation was applied. The study involved a variety of disabled people such as DPO chairpersons, staffs, members, non-members, beggars, and mothers of disabled children from both urban and rural settings. In total, about 260 interviews were carried out during the conducted fieldworks between 2000 and 2003. The interviews and research diary for the observation amount to 2300 pages of text, which was the primary data. The secondary data was from literature reviews, other relevant documents and informal conversation. Data collection and analysis were carried out with the utmost care for the ethical issues. The data analysis used a similar method as qualitative content analysis with the aid of the Atlas data analysis computer programme. The perspective was strictly the ones of disabled people themselves by applying disability theories: social and political models of disability. The final goal was that this thesis, including its process, both academically and practically, should contribute to the disability movement and their equality.

The main findings are three-fold: a vulnerability creation mechanism for disabled people, the heterogeneity of disabled people and the implications for equality. First of all, the study clarified the main factors in the vulnerability creation mechanism that makes and reinforces the deviant role of disabled people in Central Asia. This clarification proves that disability is a human construction not only in Western countries but also in ex-socialist states. In this sense, the West-oriented social model of disability makes sense in these countries to some extent. Seven main factors are the following: 1) Soviet legacy, 2) current government policy and practice, 3) profound prejudice, 4) deficiency of means to escape from the mechanism, 5) isolation, 6) existing DPO activities and 7) international intervention. Due to the underpinning philosophy of the Soviet regime, physical self-sufficiency and workability were prioritised over rights. As a result, disabled people were labelled as "invalid" and imposed into the mechanism to be isolated

from the rest of the society. The segregation policy and practice was inherited by the current governments especially in their medical and educational practices. This history and present have created a profound prejudice of society against disabled people, which forces disabled people to feel different and abnormal. Disabled people experience discrimination especially at every turning point in life such as education, employment and family life which could be a means for empowerment. Consequently, disabled people tend to be either institutionalised or confined to home. In the process of this isolation, disabled people individualise their daily challenges as a natural consequence stemming from their impairment and normalise this social oppression by internalising the negative image based on the prevailed medical model of disability. In this way, disability has hardly caught the attention of society as a social problem when the voices of the disabled population are systematically ignored.

When it comes to the organisational reality, the existing intervention of Central Asian DPOs is limited mostly to charity approach due partly to the political constraint and due also to the expressed material needs of disabled people who have internalised the individual tragedy and medical model of disability. DPOs in Central Asia are isolated from different actors and also among them, which prevents them from making bigger voices heard. In addition, DPOs tend to exclude more severely disabled people who need support the most. As a result, organisational activities reinforce the deviant role of disabled people. As for international intervention, it tends to fit into the limited framework that each government defines as the area of activities allowed for NGOs to play, which is typically a charity-oriented service provision. That is, activities in the political approach are not a common approach for the international community in Central Asia. Consequently, the essential structural change does not take place with current international intervention and reinforce the status quo. These different layers of reality make up the massive mechanism to create and reinforce the vulnerability of disabled people in society.

The second finding is the heterogeneity of disabled people which became clear through the interviews. The life of each individual disabled person is unique from each other despite the existence of the social mechanism. This heterogeneity can be analysed from two different aspects: environment and personal characteristics. The environment of each disabled person is different in terms of the attitude of their family, geographical location, the activities of the DPOs they belong to, government policy and practices and so forth, which all affect disabled people. At the same time, individual characteristics also make their lives different even if they live in a similar environment. Disabled people are not only disabled or impaired but also women, children, mothers, husbands, the middle-aged, Uzbek or Kazakh, or active in nature etc. Thus, disability should not be separated from the rest of the changing and/or permanent characteristics that make up their lives. Disabled people are first of all human beings who have got many different characteristics and positive aspects in life in addition to impairment and disability at a different time, place or occasion in their lives. That is, the existing mechanism against disabled people

does not necessarily lead all disabled people to feel abnormal all the time. Having acknowledged the multiplicity, fighting against disability needs multiple approaches firstly to deal with the multiple layers of the mechanism, secondly to deal also with other discrimination against sex, age, ethnic origin etc. and thirdly to meet the needs of individuals. The separation of disability and impairment from other aspects of lives cannot solve their problems.

Thirdly, this study found some implications toward equality. First of all, a political approach can play a role in Central Asia in a localised manner, even though it was feared to be difficult due to the authoritarian regimes. The time-, money- and energy-consuming efforts of a severely disabled Kazakh woman proved its possibility. Self-awareness of rights and ownership among the constituency is the key. This additional political approach should diversify the DPO activities aiming at solutions for the multiple layers of discrimination. When applying the political approach, the ideology, ownership and direct money transfer of the case study Finnish DPO are suggestive of implications towards the future Western intervention. Along with the implementation of a political model, material support is also necessary at the same time. Last but not least, it is important for all actors in society to realise that even a small change can make a difference, as the accumulation of small things at different levels by different actors makes up a massive mechanism against disabled people. Especially, the active role of disabled people themselves to make a difference with the political approach was articulated and highlighted.

The findings and the recommendations are based on the interviews conducted with Central Asian disabled people. Throughout this study, their perspectives were central. Each research participant was isolated from each other and had extremely limited influence on society under the current circumstance, let alone on the international community. However, when opportunities are provided, disabled people can actively make a difference. This study tried to bring out their experiences and possibilities for readers and in this way make a humble contribution towards equality.

Tiivistelmä

Tutkimus keskittyy vammaisten kansalaistoiminnan analysoimiseen poliittisesta näkökulmasta (political model of disability). Vammaisuuden poliittisella näkökulmalla tarkoitetaan oikeuksiin perustuvaa ja oikeuksia ajavaa lähestymistapaa, joka haastaa olemassa olevan epäoikeudenmukaisen valtarakenteen ja pyrkii lopullisena päämääränään oikeudenmukaisuuteen ja tasa-arvoisuuteen. Näkökulmaa on tutkittu analysoimalla suomalaisen vammaisjärjestön yhteistyöprojektia Keski-Aasiassa (Kazakstan, Kirgisia, Tadzhikistan, Turkmenistan ja Uzbekistan). Kansalaistoiminnan ymmärtämiseksi on tutkittu vammaisten arkea. Tarkoituksena on ollut selvittää vammaisten haavoittuvuutta ylläpitäviä mekanismeja, suomalaisen vammaisjärjestön kehitysinterventioon liittyviä monimutkaisia tekijöitä ks poliittisen näkökulman toteuttamismahdollisuuksia Keski-Aasiassa. Yhtenä tavoitteena on ollut, että tutkimus sekä akateemisena opinnäytteenä että käytännössä edistää vammaisten toimintaa oikeudenmukaisuuden ja tasa- arvoisuuden toteuttamiseksi.

Tutkimuksessa on käytetty kvalitatiivisia menetelmiä, (syvä)haastetteluja ja havainnointia. Keskeistä on ollut vammaisten oma näkökulma. Kerätyn aineiston analyysissä on käytetty hyväksi sekä yhteiskunnallista (social model of disability) että poliittista näkökulmaa vammaisuudesta.

Tutkimuksen tulokset voi kiteyttää kolmeen keskeiseen. Ensinnä tutkimus valaisee niitä mekanismeja, jotka vahvistavat vammaisten poikkeavaa roolia myös Keski-Aasiassa. Tutkimus osoittaa, että vammaisuus on myös Aasian entisissä sosialisissa maissa sosiaalisesti konstruoitua. Näin ollen läntinen yhteiskunnallinen näkökulma vammaisuuteen on vallalla myös Keski-Aasiassa.

Toiseksi, huolimatta haavoittuvuutta ylläpitävistä yhteiskunnallisista mekanismeista vammaiset ovat hyvin heterogeeninen ryhmä. Kamppailu vammaisuuden määrityksistä tarvitsee monta erilaista lähestymistapaa yhteiskunnallisten mekanismien monimutkaisuuden, sukupuoleen, ikään, etniseen alkuperään yms. perustuvan syrjinnän sekä vammaisten erilaisten yksilöllisten tarpeiden vuoksi.

Kolmanneksi tutkimuksessa tarkasteltiin tasa-arvoisuuden mahdollisuuksia. Tutkimus osoitti, että poliittinen näkökulma on mahdollinen paikallisena strategiana Keski-Aasiassa. On ensiarvoisen tärkeää, että yhteiskunnan kaikki toimijat ymmärtävät, että pienikin liikahdus voi aikaansaada suuren muutoksen. Tutkimuksessa muutos näkyi vammaisten aktiivisena roolina sen jälkeen, kun he poliittisen näkökulman kautta tulivat tietoisiksi oikeuksistaan.

Acknowledgement

I have participated in many academic conferences and seminars during the last five years. I got inspiration especially from the Nordic Network on Disability Research (NNDR) and the International Society for Third Sector Research (ISTR).

During my study, two very important disability activists passed away. I pray for the repose of Elisa and Jaak's souls.

I would like to thank the support from my friends. Staying in Finland far away from my home country has not always been easy. Eija, Hiro, Salla, Masako, Shin, Futaba, Ninghui, Hanna, Joni, and Satu, you have been so important for me. Ayako, Natsuki, Naoko, Tomoyo and Marie, I have had many nice meetings with you whenever I was back in Tokyo. I sincerely hope to be good friends with you all in the future, too.

Last but not least, I would like to thank my family for the unconditional love and support. My parents and my brother have been supportive to all the decisions I made. Thank you. I got married with Jerri this year. I am also very happy here with the new family, Loikkaset. Marga, Mara, Joel and AP have been already part of me. Jerri, you wrote down "Lucky me!" on the bottom of your shoes when we got married. Many of our wedding guests witnessed that when we kneeled down at the altar of the church. I know that I am the lucky one! You have been always with me. Without you, I would have been frozen here in Finland before today. You always warm me up. I love you!!!!

Hisayo Katsui
Helsinki, December 2004

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Chapter 1. Background to the Study

This study tries to investigate possible ways to alleviate the poverty and inequality of vulnerable people, especially of disabled people, by elaborating the organisational activities of disabled people in developing countries. This introductory chapter clarifies why this focus is important and relevant to study now. Firstly, the overall picture of the effect of globalisation on disabled people is described in connection with poverty. Subsequently, the hitherto literature review on NGO discourse on Development Studies and that on Disability Discourse is elaborated separately to introduce the reasons why I focus on the activities of a political approach. Finally, I summarise the chapter by highlighting the importance and complexity of the activities.

1.1. Globalisation, Poverty and Disabled People

> *Although poverty has been dramatically reduced in many parts of the world, a quarter of the world's people remain in severe poverty. In a global economy of 25 trillion USD, this is a scandal – reflecting shameful inequalities and the inexcusable failure of national and international policy (UNDP, 1997:2).*

The globalised economy has rapidly enlarged the gap between the rich and poor around the world. Consumerism is one of the key concepts to grasp globalisation, as all the countries under the General Agreement on Tariffs and Trade (GATT) are involved in the global market (Cahill, 1998). Global consumption has been increasing by 3% a year. As a result, the world consumption expenditure of both the private and public sectors doubled in 25 years (UNDP, 1998). The recent progress of information technology accelerated this phenomenon. This prosperity among developed countries/ Western countries[1], however, has not reached two thirds of the world (United Nations, 2000). The consumption growth is rapid among the rich, but **significant numbers of people in need have been left out around the world**. While the rich consume more and more, many others have been marginalised due to the low income, which led to exclusion, rather than inclusion. Between 1980 and 1995, the average GDP per capita annual growth rate increased 1.7% among Western countries, whereas it was -0.4% among the least developing countries (UNDP, 1998:185). This pattern applies to the relationship between people in urban areas and those in rural areas within a country. Moreover, the gap is even bigger in rural areas than in urban. Consequently, the highest 20% income earners enjoy 43.9% of the country's income in China, for instance (Tang, 1999:100). Despite this, the main strategy is development through wealth-creation that is underpinned by the belief, "improvements in social welfare would automatically accompany economic and social changes" (ibid.96). The world biggest mobile phone company, NOKIA, spent 1.17 billion Euro in 2002 on its advertisement and promotion activities, while the Finnish Ministry for Foreign Affairs (MFA) allocated 434.37 million Euro on Official Development Aid (ODA) (MFA, 2003-a; Rossi, 2003). In the same vein, another example shows that Chinese advertisement expenditure grew by more than 40% yearly between 1981 and 1992, which was far faster than the growth of GDP and reached the 8th biggest country in advertising expenditure as a share of GDP in 1996 (UNDP, 1998:64). On the other hand, the expenditure on education per pupil is the second least in the world in 1995 (UNESCO, 1995).

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[1] Western countries refer to developed countries defined by the United Nations. "West" is more frequently used in this study firstly because the research participants from Central Asian countries use this term instead of "developed countries" and secondly because no country is developed yet in disability discourse.

This global economy overwhelmingly subordinates other welfare and development policies (Beresford and Holden, 2000).

On top of the enlarging income gap, globalisation has damaged the quality of life (QOL)[2] of poorer people more severely than the richer ones. Three big challenges, 1) degradation of the environment, 2) change in the traditional culture and 3) the increasing population, hit the most marginalised group of people. Firstly, the environmental damage hits those living in poverty the hardest, even though the rich generate more waste and put more stress on nature. Air pollution, for example, caused more than 175,000 premature deaths in 1995 and nearly 2 million cases of chronic bronchitis, the majority of which were poor people (UNDP, 1998:70). Obviously, rich people live in better conditions than the poor, which prevents the disease. Also they have much more income to pay for medical care, which is not accessible to poorer people. The gap becomes bigger in countries where the governmental funding is allocated to economic development but little for health or education for all. In this sense, poorer people suffer more immediately and directly from the environmental damage. In spite of the big damage in the economic sense as well as the health problems, the resource allocated to the environmental problems is too scarce, compared to the investment in economics (Tang, 1999).

Secondly, the market economy brought sweeping change in the traditional culture in each country, which exacerbates the situation of poorer people as well. Asian people, for example, are encouraged to care for elderly people and disabled people because of respect for age and the strong family bond (Zhu, 1997; Whyte and Ingstad, 1995; Parsloe, 1990.). They have strong collectiveness in rural communities to take care of the elderly. However, one survey shows that the introduction of the Western individualistic culture has changed the traditional attitudes and values. The examples include the rise of materialism, the fading of ancestor worship and the rejection of moderation and harmony (Zhu, 1997). The loosened collectiveness contributes to isolate and impoverish the poor people.

Lastly, the increasing population is a fundamental threat to the world, because of an "ugly problem" of the ratio of population to resources (Rigdon, 1996:556). Despite the growing economics, modernisation and decreasing ratio of people in poverty, many countries still suffer from a high absolute poverty rate. That is, **polarisation is taking place**. For instance, while South Asia enjoys a 50 million decrease of people in extreme poverty between 1990 and 2001, Sub-Saharan Africa increased the ratio to 46% in 2001. On the other hand, people living on less than two dollars a day in Eastern Europe and Central Asia rose from eight million in 1981 to more than 100 million in 1999 (Kowsmann, 2004). Today, it is estimated that 1.3 billion people live under the poverty line of 1 USD per day. All these elements of the environment, cultural change and increasing population have been enlarging the disparity between the rich and poor, and eventually making the poor people even poorer.

In addition, "new global pressures" such as conflicts in 30 countries and the threat of HIV/AIDS accelerate the impoverishing mechanism for the poorer people. (UNDP, 1997:3). Zimbabwe, for example, faces 26% of HIV/AIDS positive people among its population between 15-49 years of age (UNDP, 2000:192). On top of that, the public sector in each country is biased to the rich and

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[2] Quality of life in my study is not defined or affiliated to any theoretical definitions because the definition depends on each person. In that sense, the term is used in a more practical sense.

has not properly reallocated the wealth to the poor. In Ghana, the richest people received the public spending on health two and a half times more than the poorest in 1994. In Nepal, the richest have enjoyed almost four times more public spending on education compared with the poorest in 1996 (ibid.78). Richer people are benefiting more in this mechanism, while poorer people suffer more severely from deprivation. An increasing number of poor and vulnerable people, therefore, have been systematically created in a certain depriving structure around the world, both in developed and developing countries. In this regard, poverty is now redefined as multidimensional denial and deprivation of "opportunities and choices most basic to human development" (UNDP, 1997:5). This multidimensional nature of poverty is going to be important in the following empirical findings.

This universal **poverty problem is quite relevant to each disabled person**, because one in five of the world's disabled people are disabled through malnutrition (Oliver, 1996).

Chart 1. Causes of Impairment

Causes of Impairment

13 % 20 %
20 %
16 %
20 % 11 %

☐ Malnutrition

☐ Accident/Trauma/War

☐ Infectious Diseases

☐ Non-Infectious Diseases

☐ Congenital Diseases

☐ Other (including ageing)
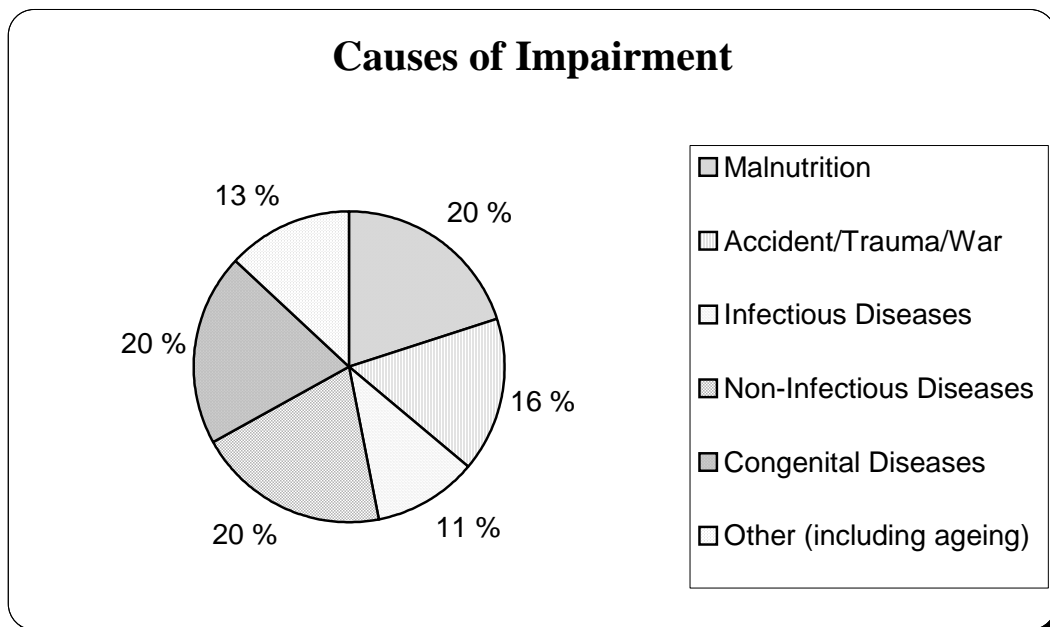
Source: UNESCO. (1995) Cited in (DFID, 2000:3) Graphed by the author.

Moreover, disability is a very relevant issue in the poverty discourse because disability and poverty have a mutual relationship of cause and effect. In other words, disability leads to poverty, and vice versa, which creates a vicious circle to worsen the quality of life of those trapped in the vicious circle. The following two charts vividly illustrate the interconnection between impairment and poverty:

Chart 2. Impairment Causes Poverty
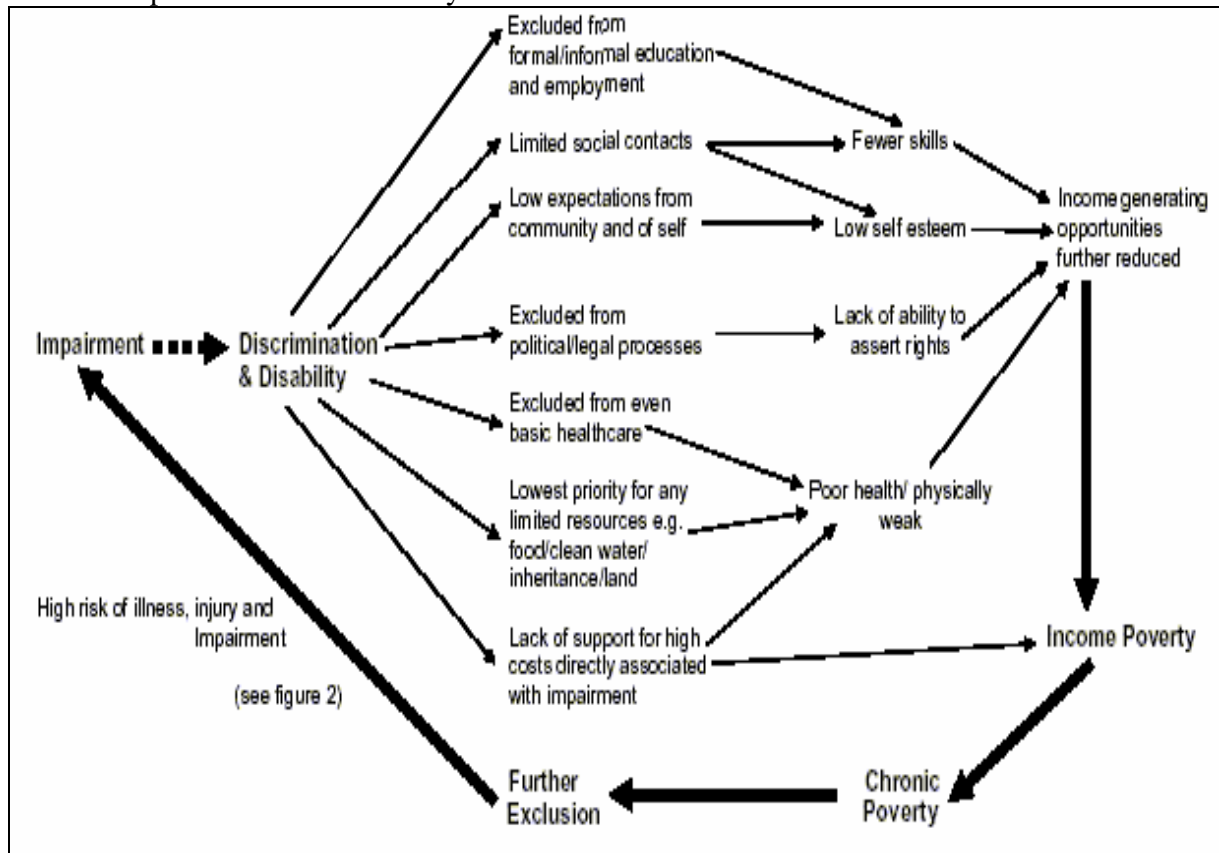
Source: (Yeo, 2003:572)
"figure 2" of this Chart means Chart 3 of this thesis.

Chart 3. Poverty Causes Impairment
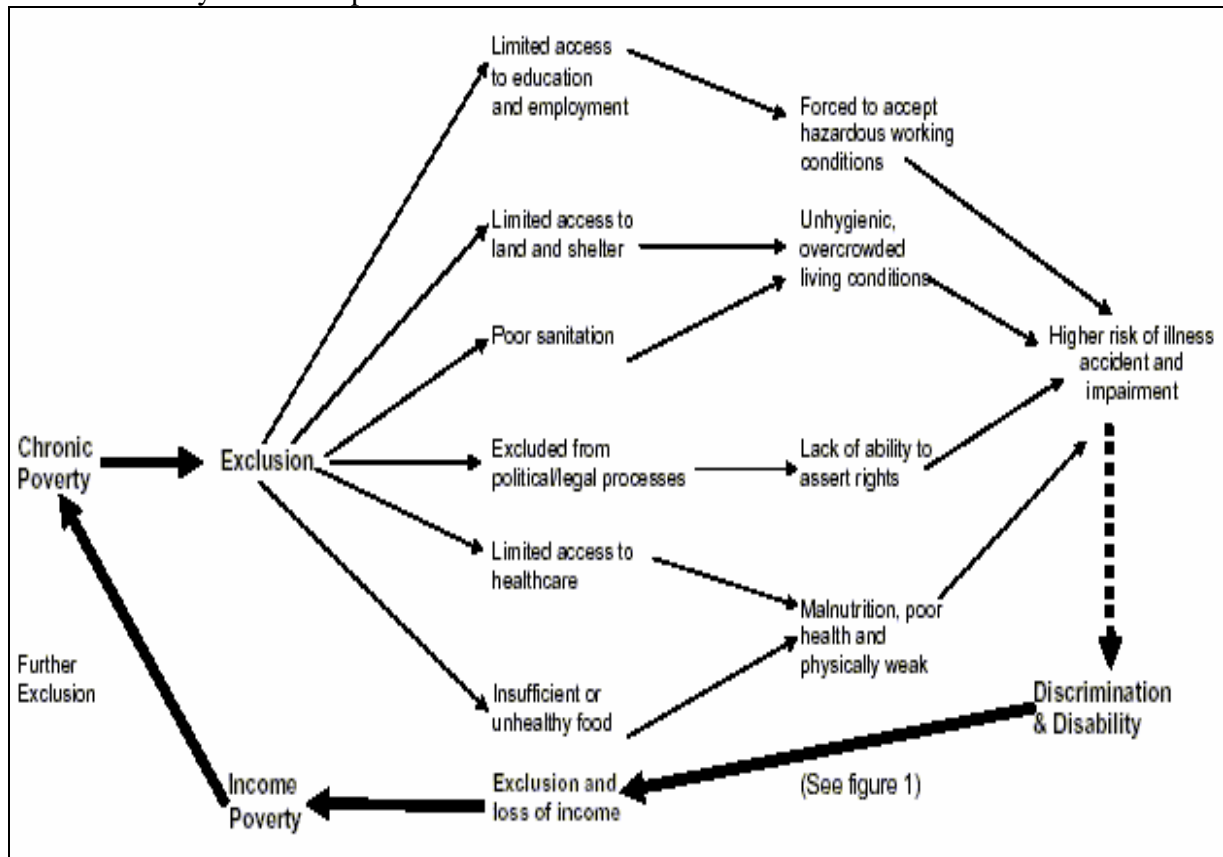
Source: (Yeo, 2003:573)
"figure 1" of this Chart means Chart 2 of this thesis.

Chart 2 explains the mechanism how an impaired person tends to become poor in many senses. 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. Chart 3, on the other hand, explains how a poor person tends to become impaired. Due to the exclusion from different levels of the system, the 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. These two charts complementarily prove the deep connection between poverty and disability and also the difficulty of those to get out of the degrading system if no intervention is made.

Nevertheless, "The removal of a disabling physical and social structure is unlikely to be prioritised within the imperatives of a globalised economy." (Holden and Beresford, 2002:194). For instance, the Structural Adjustment Programme (SAP) in Zimbabwe seriously affected disabled people. The introduction of SAP restructured the workforce and left many people unemployed. As a result, disabled children were the first to be deprived of their education under the deteriorated financial circumstances in households (Kabzems and Chimedza, 2002). That is, those who are left out of economic policies are more likely to be excluded from the mainstream and become disabled. Kabzems and Chimedza (2002:156) conclude their article as follows:

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Political unrest, environmental disasters, declining economic performance, the introduction of structural adjustment programmes, weakened infrastructure, changing population demographics including the effects of HIV/AIDS and economic globalisation have all impacted negatively on the welfare of persons with disabilities.

In other words, disabled people are vulnerable under the current environment, which reinforces their position in society. Disabled people are not necessarily all poor. However, they are vulnerable under the current structure unless enough attention is paid to their issues. This is one of the global problems. At present, **the number of disabled people around the world is estimated at 600 million**, 80% of whom live in developing countries (WHO, 2003-a; UN/Division, 1999). UN statistics prove that 82% of the world's disabled people live under the poverty line (DPI, 2001). Healthlink Worldwide (2004) claims that the impairment of 500 million people is estimated as able to be prevented or treated. This argument can be uncertain considering the above-mentioned causes of impairment in Chart 1. However, it is true that in spite of the significant number, disabled people have been literally excluded from the poverty alleviation programmes, as only 2% of all disabled people in developing countries receive some kind of support (United Nations, 2000; San, 1999). That is, **disability and poverty is connected through their vulnerability**. When it comes to Western countries, the word "disability" still connotes social inferiority or stigma. Under the mechanism of vicious circle, "disabled people are the most marginalized group, multiply handicapped by social, economic, physical and political conditions" (San, 1999:147). Disability is a universal problem and has become even more globalised through industrialisation and the market economy.

Intervention towards policies and practices for disabled people both in developed and developing countries is increasingly necessary because the market force does not result in security, equity and equality but jeopardises the reality (Coetzee and Wiman, 1999). On top of that, the exploding and ageing population and HIV/AIDS follow prevalence of disabled people, which makes the situation even more urgent. Nevertheless, "too many governments are uninterested in disabled people" (United Nations, 2000). It has been pointed out by a Finnish research institute, STAKES (2003:67), that **Millennium Development Goals do not focus or even mention disability**, which exemplifies the fact that disabled people are excluded "even at the highest level of international policy frameworks." That is, one of the main problems for disabled people is exclusion from the mainstream. To cope with the deficiency of public social services and the existing structure making disabled people vulnerable, a significant number of NGOs and International NGOs have been working for them both in developed and developing countries. **NGOs have been increasingly playing a big role in the lives of disabled people**. Therefore, this study focuses on the role of NGOs in the quality of life of disabled people.

1.2. Definition of NGOs in This Study

NGOs belong to part of the civil society concept which refers to various kinds of voluntary associations or behaviour working for the public good in social space outside of the state and private sector. Civil Society, therefore, encompasses both formal and informal activities. This study focuses on NGOs rather than civil society because in the research target countries in Central Asia, civil society is conceptualised as formally organised NGOs due to the government and donor frameworks, which will be mentioned further in Chapter 4.1. Despite the increasingly

and widely recognised existence of NGOs, there is no universal agreement on the concept and definition (Fowler, 2001), although attempts have been made (for example see Martens, 2002). Mälkkilä and Hossain (1998) argue that the positive image "is based purely on general assumptions, expectations, feelings and beliefs" (1998:30). They continue that the prevailing image is too broad and too general as if all the NGOs have the same characteristics. The variety of NGOs, however, should not be solved by a too simplistic generalisation to compensate for the hard task of fitting all sorts of NGOs into one concept or category. Rather, the **variety among NGOs** should be recognised because the activities of NGOs are significantly different from each other in terms of target population, donors, composition of staff members and so forth (Hakkarainen *et al.*, 2003).

Moreover NGOs could develop and change over time, as Korten (1990) demonstrated in his theory:

> ***First generation***: *Relief and Welfare –NGO is a Doer for some immediate shortage targeted to individuals and family*
> ***Second Generation***: *Community Development –NGO is a mobiliser for community project*
> ***Third Generation***: *Sustainable Systems Development –NGO is a catalyst for regional or national wide policies and institutions*
> ***Fourth Generation***: *People's Movement –NGO is an activist or educator for national or global issues*

(Summarised by the author)

This four generation model is analytical in theory. However, it is still not enough to cover the multiplicity of NGOs in practice and thus somewhat confusing. For instance, NGOs do not necessarily "develop" according to this model and some NGOs can conduct cross-generational activities at the same time. Moreover, fourth generation can be interpreted that Western development cooperation is not necessary at all at this stage, which can be misleading. Furthermore, when donors coerce the establishment of NGOs instead of establishing them on the basis of genuine local initiative, this generation theory totally fails as is clear in the study of Furguson and Gupta (2002) and Tvedt (1998). The critical theorists question the origin and space of NGOs rather than accept NGOs without elaboration or politicisation. This critical view allows us to understand the multiple, contextual meanings of NGOs. Therefore, this study uses his theory just as an analytical tool due to the multiplicity of NGOs and that of the surroundings.

This research is conducted on the basis of the recognition of the variety of **NGOs** in their nature and follows the definition of the United Nations:

> *A non-governmental organisation (NGO) is any non-profit, voluntary citizens' group which is organized on a local, national or international level. Task-oriented and driven by people with a common interest, NGOs perform a variety of services and humanitarian functions, bring citizens' concerns to Governments, monitor policies and encourage political participation at the community level. They provide analysis and expertise, serve as early warning mechanisms and help monitor and implement international agreements. Some are organized around specific issues, such as human rights, the environment or health (United Nations, 2003).*

The research investigates more deeply **Disability NGOs** which are acting for the improvement of the QOL of disabled people as their primary target on a non-governmental and non-profitable basis. Disability NGOs include both NGOs of disabled people and those for disabled people. More precisely, the research focuses on the **Disabled People's Organisation (DPO)** that is run by disabled people themselves for the improvement of their lives. This is because DPOs are considered to be the important driving force for creating a disability movement in the disability discourse, as has been articulated above in the fourth generation (Korten, 1990). The activities around the fourth generation are gaining significance as a big role of civic activism. In this sense, concentrating on the disability movement from the rights-oriented viewpoint is both academically and practically important for the future of civic activism. This study concentrates on the intervention of Western NGOs implementing their projects in developing countries with local NGOs. The case study is on Finnish DPO intervention in five Central Asian countries. This inclusion of Central Asia is of a great significance because Disability Studies geographically focus mostly on Western countries, namely the United States and Great Britain, although this issue is global (Blaser, 2003:604). In this respect, this study is unique and significant. The following sub-chapter explains the importance of this focus on NGO activities in general, which is then going to be followed by two sub-chapters that explain more in detail the significance of this study from two discourses: NGO discourse in Development Studies and that in Disability Studies.

1.3. History of NGOs
~ From Periphery to One of the Central Actors ~

The state / market failure theory explains that NGOs have been mainstreamed in development discourse on the one hand (Hossain, 2000; Hulme, 1994, etc.). The historical context such as the collapse of the communist bloc supports the argument of state drawbacks, while the enlarging gap between the rich and poor, the market failure. On the other hand, the donor community of the West constructed an international social system of development cooperation which introduced isomorphism in NGO management in developing countries speaking the same language as the donors (Tvedt, 1998). The sharp increase of donor money channelled into NGO activities in 1980s coincides with the global increase of the NGO number, scope and significance. More than 50% of the Finnish NGOs in the field of development were established during the last two decades (Katsui and Wamai, 2003:7) and almost 20% of today's international NGOs were founded after 1990 (UNDP, 2002-a:102). Despite the decrease in ODA especially after the end of the cold war, the increase in funding through NGO activities was more than sevenfold in the past three decades (ibid.). In 2002, 10-15% of Finnish ODA is channelled to 170 Finnish NGOs at €38.7 million. These NGOs conduct 430 projects in 70 countries (MFA, 2003-b). Today NGOs are expected to play a big role in greater pluralism, democracy and participation as one of the central actors in development (Nederveeh Pieterse, 2001; Fowler, 2000).

NGOs have drawn much attention owing to the conceptualised opposite characteristics of state and market: more effective, non-bureaucratic, flexible, innovative, non-corrupted, non-politicised, participatory and reflective of the needs of the poor (Mälkkilä and Hossain, 1998:32) and non-profitable. This idealised image matched the development discourse that had sought for new and more effective paradigms of development. With the expected favourable characteristics, NGOs have been increasingly involved in development around the world. The UN, for example,

set the International Year of Volunteers in 2001 to promote the voluntary activities that are "the basis of much of the activity of NGOs" and other sectors (UN Supporters, 2000:1). In this way, some of the NGOs have been mainstreamed in the discourse on development cooperation, which created "NGOism." This phenomenon facilitates governments to give responsibility to NGOs too easily without assessing their efficiency (Vandeloo, 1997; Gligo, 1995). Some NGOs have become part of the structure of either states or markets rather than remaining separately and independently as "the third sector."

This worldwide tendency to employ an increasing number of NGOs in development cooperation is not exceptional in the realm of social policy towards disabled people in developing countries. Fowler (1995) states that this process of the globalisation of social welfare is accelerated by the providing channel through NGOs. More and more Disability NGOs are encouraged to head for developing countries for this purpose under the expectations about their activities. In the Finnish case, for instance, the maximum project cost covered by the government is usually 80% whereas Disability NGOs could get as high as 90% (MFA, 2003-b). At even a more international level, UN ESCAP mentions in its "Standard Rules on the Equalization of Opportunities (Standard Rules)" that a "state should encourage and support the exchange of knowledge and experience among non-governmental organisations concerned with disability issues." Deacon (1997) argues that NGOs are important because policies are not enough to fill the gaps in practice. Although many policies and rules are enacted every year, "in the reality very few things have happened. There are lot of good wishes and lip service but practical actions on the part of the UN are virtually non-existent" (Könkkölä, 2000:16). In other words, 600 million disabled people around the world are segregated and deprived of virtually all their rights (Despouy, 1993). As a result, international organisations and national organisations increasingly promote the activities of NGOs as provider of social welfare services (Hertzberg, 2000; Deacon, 1997; Wiman, 1996). Deacon (1997:157) mentions that "(t)he study of non-governmental organisations is of fundamental importance in any study of globalism and social policy." The increasing number of Disability NGOs indicates the big impact on the lives of disabled people through intervention. However, the impact of Disability NGOs has been hardly paid enough attention to, let alone the impact of DPOs. DPOs occupy a very small part of the whole civic activism and thus the attention has been extremely limited, despite its big role to disabled people. Therefore, to investigate the complex reality of the intervention and to clarify their impact on QOL of targeted disabled people are the biggest significances of this research. The specific role of DPOs is to be discussed more in Chapter 1.5.2. in the following.

1.4. NGO Discourse on Development Studies

About one and a half decades ago, Hellinger (1987) expressed his fear that greater NGO interaction with and funding from official aid would negatively affect their civic values and origins and homogenise their practices. Today, evidences prove that this fear came true (Fowler, 2000; Tvedt, 1998). My previously conducted research revealed that NGOs can actually degrade the quality of life of the target group in spite of their intention to empower them (Katsui, 1999). The imbalance of power between NGOs and recipients can unintentionally cause further degradation of the recipients' position. This analogy has been witnessed in the whole

development cooperation system between implementing agencies and targeted beneficiaries[3] such as Finnish government and local beneficiaries in its bilateral development cooperation (Moore *et al.*, 1996). A journal, Development in Practice Volume 10 Number 3&4 opens its discussion with an article of van Rooy (2000:300) mentioning **NGOs are in crisis**. Among many deficient aspects, many articles discuss on lack of political aspect in NGO activities. NGOs have been losing political power or have not participated in political aspect of development (Joseph, 2000; Tandon, 2000). Murphy (2000) argues that NGOs are charity-oriented in reality, which should be changed to more ideological-oriented approach that follows citizen's movement. NGOs globally face the tension or dilemma between continuing demand of service delivery from the local people and the future-oriented ideological pressure towards shift into policy-oriented activities (Hakkarainen *et al.*, 2003). One explanation for the deficiency is the deliberate choices of donor agencies not to allocate funds for such activities. For instance, van Rooy (2000) states advocacy work has not attracted donors. Hakkarainen *et al.* (2003) points out that **on top of state, market and civil society spheres, donors make the fourth arena in the picture of development**. Another explanation is the hard reality of day-to-day NGO activities. Anderson (2000) cites from Clark (1991:147) that "advocacy may be seen as important but it is not urgent. Consequently it is easily squeezed out by the day-to-day dilemmas and crises arising from the project activities, from donor pressures and from media enquiries." This **project cycle framework** does not allow so much room for activities outside of the projects (Katsui and Wamai, 2003).

In spite of the difficulties in practice, this **political aspect** started to be focused for NGOs to find the way out from the "crisis." Joseph (2000) explains that political aspect is fundamental for development. He challenges that adding social dimension is not enough because it does not challenge the existing framework of neo-liberalism. He points out that the problem is that NGOs failed to identify where to start in order to develop a critical, holistic and practical-based analysis. In other words, NGOs have been trying to fill the gap between the policies and practices by providing service delivery instead of challenging the fundamental problem. He continues that ethical principles, cultural values and concern for the QOL should be the starting point rather than "optional extras." Human development is the development of society. This coincides with the idea of Wiman (1999:226):

> *Economic development is not a goal in itself. It is only an important but not sufficient prerequisite for social development. And only social development is development from the people's point of view. **People must be put at the centre of development**.*

Without involving the social and political practices of the people themselves, laws are no more than lip service or rhetoric. Therefore, the content of the democracy should not be solved only by law, but should be the practice of the people (Joseph, 2000). Development starts from the stage when the power is in the hands of the people themselves, who eventually affect policy-making on their own account. Joseph (ibid.) describes the consensus building process of the people themselves as "public space". In other words, people should be at the centre of the discourse with their own choice among other choices. This is the way in which people could challenge the status quo and gradually change society of their own in the way they want. In this sense, NGOs are

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[3] Beneficiaries are those who benefit from an intervention. On the other hand, stakeholders are "an individual, group or organisation" that "gain or lose from involvement in a development project." As stakeholders own some stake, they have responsibility and rights which are different from mere beneficiaries (Moore *et al.*, 1996).

politically important actors to change society with a bottom-up strategy. In summary of the hitherto literature, **NGOs are now expected to act more as a social mobiliser with a policy-oriented approach rather than hitherto service provider**. This study, therefore, tries to find out the reality of NGOs in the fourth generation which are under severe criticism and great expectations.

1.5. NGO Discourse on Disability Studies

NGO discourse on Disability Studies also points out the importance of political intervention. Firstly, the history of "mainstream" disability policy in relation to disability movement is introduced to understand the hitherto discourse. Secondly, the discourse on NGOs in this specific study is summarised.

1.5.1. History of "Mainstream" Disability Policy and Disability Movement

The UN has adopted various international conventions and rules that are to promote the equal rights and opportunities of disabled people during these five decades starting from The Universal Declaration of Human Rights in 1948 (Communiqué, 2000).

1948	The Universal Declaration of Human Rights
1966	International Covenant on Civil and Political Rights
1966	International Covenant on Economic, Social and Cultural Rights
1971	Declaration on the Rights of Mentally Retarded Persons
1975	Declaration on the Rights of Disabled Persons
1979	Convention on the Elimination of All Forms of Discrimination against Women
1982	World Programme of Action Concerning Disabled People
1989	Convention on the Rights of the Child
1993	UN Standard Rules on Equalization of Opportunities for Persons with Disabilities (Standard Rules)
1993	Vienna Declaration and Programme for Action
1994	Salamanca Statement and Framework for Action on Social Needs Education
2000	The Commission on Human Rights

Source: (Communiqué, 2000; Michailakis, 1997 and some addition by the author)

This Declaration states the principle ideology of the UN in its Article 1: All human beings are born free and equal in dignity and rights. Furthermore, Article 2 continues:

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty (United Nations, 1948).

In this Declaration, disabled people are not explicitly mentioned in any Article except for Article 25:

*Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, **disability**, widowhood, old age or other lack of livelihood in circumstances beyond his control (emphasis added).*

Nevertheless, the words such as "all human beings" and "everyone" could be interpreted to include disabled people as "other status". That is, at this point, disability was not highly recognised as significant minority yet. The International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights also did not have any articulated statement on disabled people except for the expected connotation in "everyone."

Disability came into the mainstream with the Declaration on the Rights of Disabled Persons in 1975 and with the UN International Year of Disabled Persons in 1981. In the following year, the World Programme of Action Concerning Disabled People was published. This Programme set "the guidelines for a world strategy to promote the adoption of effective measures for the prevention of disability, rehabilitation and the achievement of 'equality' and 'full participation' of disabled persons in social life and development" (Despouy, 1993:2). The World Health Organisation (WHO) made a distinction between impairment, disability and handicap, which was included in the World Programme of Action:

> ***Impairment:** Any loss or abnormality of psychological, physiological, or anatomical structure of function.*
> ***Disability:** Any restriction or lack (resulting from an impairment) [sic] of ability to perform an activity in the manner or within the range considered normal for a human being.*
> ***Handicap**: A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal, depending on age, sex, social and cultural factors, for that individual.*

(Despouy, 1993: 11)

In this way, handicap is considered to arise as a direct consequence of individual impairment in this model (Oliver, 1990). Therefore, this classification leads to medical and administrative solutions of cure or rehabilitation of disabled people from the viewpoint of scientific authenticity. This International Classification of Impairment, Disability and Handicap (ICIDH) had been the predominant definition of these terminologies until very recently. ICIDH has been named **medical model of disability** in Disability Studies due to its medically-oriented understanding of disability.

In spite of the mainstreaming of disability in international policies, disabled people have not been satisfied with this international trend. **Disabled people started to organise themselves in 1960s and 1970s** as Könkkölä and Sjövall (1993:7) describe the phenomenon: "People with disabilities 'woke up' in different parts of the world simultaneously." This coincides with the time when other social movements were created to pay attention to differences and vulnerable minority groups. The disability movement was one of such social movements to seek for equal rights with others.

Some disabled activists started to argue that they need much more than the medical 'facts' in order to understand disability as a collective experience in society which goes beyond the existence or experience of individual disabled people. Accordingly, disabled people started to assert their own needs by establishing organisations *of* disabled people which enables the collective voice to be heard. The tension between non-disabled people and disabled people became decisive in the International Year of Disabled People in 1981. A number of non-disabled people had an agenda of their interests such as residential care, which was clearly different from the expectation of disabled people. Therefore, some disabled people started to focus on their own and real problems apart from the mainstream events, while non-disabled people were wasting time on "irrelevant" issues (Hasler, 1993). Disabled people stress that their experiences must be expressed in their words and integrated in the consciousness of mainstream society (Brisenden, 1998; Morris, 1991). In this way, the disability movement was concerned to alter this medical conception and to empower disabled people. In its process, **social model of disability** was formed which challenges the very assumption of "normality" and re-defines disability as social oppression (French, 1994). The comparison of ICIDH and the following definition clarifies the difference between these two models. The Physically Impaired against Segregation and Disabled People's International defined:

> *Impairment: the lack of part or all of a limb, or having a defective limb, organ or mechanism of the body.*
> *Disability: the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers*

(Finkelstein and French, 1993:28)

In other words, the problems are not within the individual disabled person but within society (Oliver, 1990). Since the creation of this social model, disability activists chose to use "disability" and "disabled people" rather than "handicap" or "people with impairments" in order to politicise the word and to highlight the social aspect (Blaser, 2003).[4]

This social model is partly explained by the work ethic of capitalism or industrialism in the late nineteenth and early twentieth century (Chappell, 1998). In the feudal, peasant societies, disabled people were important members of families who conducted some part of work within the families. The introduction of the industrial work ethic was the turning point that changed the position and the role of disabled people in the material framework of society. People as labour power started to work outside of the family space for getting money instead of crops. The change of life style, which encompassed reliance on wages, resulted in the creation of the concept of burden towards disabled people without work. Subsequently, professionalism was conceptualised that created more hierarchy in society. In addition to the practical separation and economic discrimination, middle-class ideology or bourgeois hegemony came into force under industrialisation where the idea of "average" and "norm" were the central issue. The dominant, eugenic perspective differentiated standard and non-standard, norm and non-norm, which, in

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[4] "**Deaf**" with the capital D instead of "deaf" is another such deliberate choice of activists. Deaf people's movement defines Deaf people as a linguistic minority who use sign language instead of verbal communication. In this respect, Deaf people are a cultural minority. "Deaf" is a politicised word different from "disabled people" in order to distinguish the Deaf movement of a cultural model from the disability movement of a social model. This rejection of disability identity is important in the concept of Deaf (Skelton and Valentine, 2003).

effect, created the concept of a disabled body (Davis, 1997). Since this turning point, the persistent eugenic idea has labelled disabled people as powerless who are different from the norm (Keith, 1995). As a result, oppression is manifested both through material and ideological dimensions in the process of modernisation, which justify the assertion that the biological difference is a consequence of social practice (Abberley, 1987). This **historical mechanism** is claimed to have made disabled people vulnerable.

After a long history of exclusion, disabled people have been included in the series of international policies especially during the last two decades although these mainstream policies are mostly on the basis of the medical model of disability. That is, disabled people are considered to be "special" in these contexts. Another layer of history shows that disabled people themselves started to work for their own needs, one of which was the establishment of the social model of disability in order to change the discriminating society. These two layers were totally separated until recently.

1.5.2. Importance of Disabled People's Organisations in Disability Movement

The common principle among the series of international policies established during the last decade is that "adults and children with disabilities are entitled to rehabilitation and entitled to participate in the life of the community on equal terms with people who do not have disabilities" (SIDA, 2000:6). That is, these international policies have succeeded in including disability aspects in their mainstream policies after more than two decades of international campaigning.

However, one global survey[5] by the UN Commission for Social Development underpinned that the international policies are not enough. A follow-up questionnaire of the Standard Rules was sent out to 185 UN member states and to 600 national NGOs within the disability field, of which 83 states and 163 NGOs answered from all over the world. Despite the low response rate, the survey clarified little change in practice. The majority (63.5%) of NGOs reported that the governments have enacted no new legislation since the adoption of the Standard Rules. The results reveal that emphasis in national policy is still much on rehabilitation, which thus indicates that the national policy is still a medical model of disability. Moreover, law does not guarantee the practical needs of disabled people such as "independent living and participation in decisions affecting themselves" in the majority of countries (more than 60%). Accessibility to buildings, media, and information is also very low (between 27 and 40 %).

When it comes to the development issue, the Nordic countries had a conference, "Conference on 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 Conference on Disability and Development, 2001). To sum this up, **disability is totally out of the mainstream and does not even reach 2% of the total development funds yet**. Naturally, the practical needs of disabled people around the world are very often far to be fulfilled even after states adopted the Standard Rules. "**The law is necessary**

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[5] More about the survey in http://www.independentliving.org/STANDARDRULES/UN_Answers/intro.html

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but not a sufficient precondition for achieving the sort of social change which will lead to people with disabilities being treated as equals" (Michailakis, 1997).

In regard to NGO discourse in Disability Studies, the overall political discussion of NGOs in development coincides with the disability movement. "Disability has long been defined on the basis of medical factors and only more recently on the basis of social conditions" (ibid.). The newly defined ICIDH (ICF), the Standard Rules and many other international policies started to emphasize the **environmental factors of disabilities**. This is one of the recent achievements of disabled people themselves. The inclusion of the contextual factors indicates that "(g)reat importance is attached to persons with disabilities and their organisations themselves actively participating in social planning and in political decisions" (SIDA, 2000:6). The UN Standard Rules on Equalization of Opportunities for Persons with Disabilities of 1993 also states in its Rule 18 that the work in every country concerning the implementation of the Standard Rules should be carried out in co-operation between national authorities and DPOs. This is because DPOs have an ability "to provide decision-makers with insights and knowledge of the problems, needs and requirements of people with disabilities" on the basis of their experiences of and expertise in living with disabilities (Michailakis, 1997). Michailakis continues that "(w)ithout the co-operation with DPOs it is very likely that policy makers will misinterpret the directives/guidelines." That is, disability policies highly recommend a "bottom-up" model, "participation," "putting people in the centre" and "pluralistic" development as any other current policies for social and/or human development.

Finnish disability activists established the third concept of disability, the **political model of disability**, so as to achieve the ultimate goal of equality. They argue that the medical model aims at the prevention of impairment for patients, while the social model tries to rehabilitate clients by taking away the disabling environment. The first two models are coincidentally quite identical to the English models. The political model, however, considers disabled people as citizens. In other words, at this stage, disabled people do not wait as an object but become a subject. "It is necessary and vital that people speak for themselves. Disabled people must be the movement's decision-makers as well as the executors of the decisions" (Könkkölä and Sjövall, 1993:8). These Finnish activists put "action" forward on the basis of the ideologies of social model as the next step. Instead of "putting people in the centre of discourse," people themselves are first self-aware of the role of themselves and their arguments in the discourse. Therefore, they are not passively put by somebody else into the discourse, but actively place themselves in the dialogue. In this way, their two main objectives are to be fulfilled: "firstly to make the world better for disabled persons and secondly to strengthen disabled people for the realisation of the first objective" (ibid.). This study defines "the political model" as follows:

> *The political model* understands disability as a lack of rights. This rights-oriented view articulates that superficially personal problems stem actually from the surrounding structure that disregards the rights. That is, the problems are to be solved socially and collectively in the form of structural change rather than solved individually as individual issues. The strategy to fight against the vulnerability would be two-fold: the empowerment of individuals through self-awareness activities and empowerment as a group through collective action to fight against the structure. In this respect, the concerned people are the very actors to mobilise their collective power and voices to be heard so that the degrading structure, such as law and policy, would be changed according to their needs. At the same time, individual tacit behaviour against the structure also consists of this process. The political approach, therefore, both individually and collectively challenges the existing unequal power relationship so that the ultimate goal of equality is fulfilled. The political approach seeks for sustainable change that affects the quality of life rather than temporal change.

The differences in the three models can be summarised in the following table:

Table1. Three Models of Disability

Models	Medical Model	Social Model	Political Model
Paradigm	Positivist	Interpretive	Emancipatory
Problem	Individual	Social	Political
Disabled Persons as	Patients	Client	Citizens
Focus	Impairment	Disability	All personal experiences
Vis-à-vis Mainstream	Exclusion	Inclusion	Participation
Position	Object	Subject	Subject in action
Solution	Medical care	Accessibility	Human rights
Sphere	Health	Society	Human beings

The medical model and the other two models are significantly different due to the difference in their perspectives: disabled people are the object in the medical model, while the subject in the other two models. When it comes to the latter two models, they are a **continuation** rather than totally different models as such because the contemporary social model started to be understood more with the human rights approach. Further discussion on the evolvement of the social model is in Chapter 3.4. There is no clear-cut border between these models. The political model has stronger emphasis on the subjectivity of disabled people in their action compared with the traditional social model that vigorously accuses society as the primary reasons. The political model considers **self as an important driving force**.

This self-awareness is essential because disabled people very often internalise the negative image of non-disabled people around them and eventually share a very similar negative image about themselves (Katsui, 2002; Katsui, 1999). In my previous studies, I found a mechanism for creating the dependency of disabled people in their daily human relationship (Katsui, 1999). One participant of the study described her life as follows:

Disabled people get used to things happening. Somebody helps and determines where they go, what to do and where to do it, all the rest of it. (...) They won't get used to being left completely free like that.

Paul Hunt (1966) who was one of the very first disability activists claimed a very similar circumstance of disabled people four decades ago:

I have seen disabled people hurt, treated as less than people, told what to do and how to behave by those whose only claim to do this came from prejudice and their power over them.

In short, the low expectation of able-bodied people means little opportunities on a disabled person's own choice, which follows a limited experience and ends up with a vicious circle of dependency. Consequently, disabled people become powerless and vulnerable and come to believe that the oppression stems from their own impairment. Therefore, as has been argued, the attitudinal barrier against disabled people is very relevant to the way how disabled people think about themselves and how they act accordingly. In this regard, self-awareness needs to come before coerced inclusion into mainstreams in order to avoid the "false representation" of a disabled person who has internalised the medical model of disability.

Wiman (1996:126) introduced three essential barriers to be removed for full participation of disabled people in developing countries: 1) lack of rehabilitation and equipment, 2) physical barriers and 3) attitudinal barriers. He argues that the **partial solution is not considered as inclusion but as exclusion** (Westland and Wiman, 2002). The following is a simplified depiction in a picture:

Picture 1. Overcoming Obstacles Requires an Integrated Approach
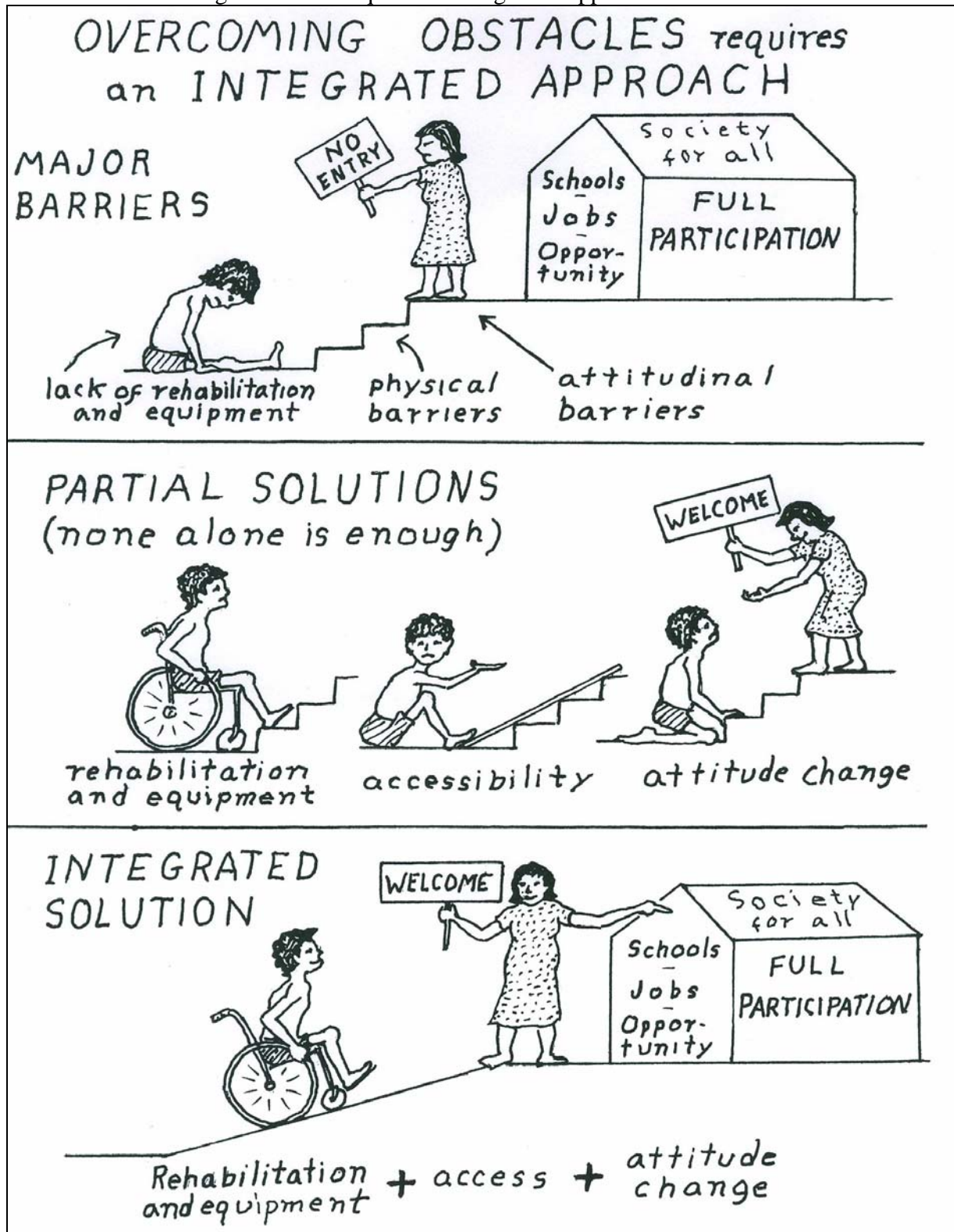
Two important themes emerge from this picture. Firstly, **lack of rehabilitation is an important barrier to be removed** although this is a medical and individual solution which tries to "normalise" disabled people with the help of equipment and technology. As today's Disability Studies argue, medical or individual concern should not be completely replaced with the social model of disability which argues society should change but not disabled people. Feminist activists who themselves are disabled people started to pose questions about the total ignorance of this individual point of view because individual impairment also consists of personal experiences and daily inconveniences (Morris, 1991). Chappell (1998) also pointed out that the social model excludes people with "learning difficulties." These individual feelings and experiences compose an essential part of disabled people's lives. This goes along with the slogan of gender studies: "personal is political." Even after the social discrimination is totally taken away, individual daily experiences remain: pre-menstrual tension or exhaustion from pregnancy for a woman or inconvenience, physical pain and mental pain for a disabled person. More precisely, the negative experiences of disabled people could be constant and on a daily basis.

Moreover, in reality, it is hard to fulfil the needs of everybody only by changing society. For instance, the needs of a blind person who would like to have a gap to distinguish a pavement and a roadway and those of wheelchair users who would not like to have any sort of gap for their mobility have to be compromised with a small gap which is manageable for both parties. Therefore, individual aspects are to be included, though the social model should be the central model which has liberated many disabled people from the hitherto binding blame to themselves regarding impairment as personal tragedy. Today, the social model has enlarged their scope and accommodates more comprehensively the lives of disabled people in the discourse because "we are not just disabled people, we are also people with impairments, and to pretend otherwise is to ignore a major part of our biographies" (Shakespeare and Watson, 2002). The dichotomy between impairment and society is not sustainable in the sense that "everything is always already social" (ibid.). That is, experiences of impairment which were considered to be individual are also a social issue.

Secondly, the political model of disability challenges this picture. What is missing from this picture is how the disabled person came to the point to claim her/his rights to enjoy the full participation. Due to the above-mentioned internalisation, disabled people very often do not expect the same rights as non-disabled people because the discriminating society makes them think so. Therefore, the first barrier is the **psychological change** of disabled people themselves by increasing self-esteem and by becoming aware of the equality principle thoroughly. This is exactly what the Finnish activists pointed out in their publication. As most of non-disabled people are ignorant of disability and rather degrade the lives of disabled people by a negative image, disabled people themselves are the important actor to be able to play a role in training about equality and increasing self-esteem of those who are not aware of them yet. Disabled people are the only people who know about disability from their own experience. In this regard, DPOs are very important in the disability movement to make society equal to disabled people especially in the initial stage of the movement. The importance of DPOs has been strongly argued during the past two decades in Disability Studies. In this regard, this research uses social and political models of disability as theoretical tools for understanding the vulnerability and focuses on the activities of DPOs.

However, the above-mentioned global survey clarified that 60% of participating NGOs reported that there are no legal provisions mandating the representatives of disabled people to participate in policy-making. That is, inclusion of DPOs in the policy-making process still remains at a minor level. In other words, the voices of disabled people are not heard enough nor reflected in national policies. Moreover, DPOs are very often confused with organisations *for* disabled people despite the differences between them. In spite of the fact that some organisations *for* disabled people unintentionally create dependency and degrade the QOL of disabled people, these organisations have been put into the mainstream service provision, for instance, in England (Katsui, 1999). The criticism of these organisations became bigger, as "NGO" activities have been highly appreciated without careful evaluation of their **negative impact on the QOL of disabled people** from the perspective of disabled people. Many NGOs still concentrate on service provision. 80% of the allocation of Finnish ODA to NGO activity, for example, is social services (Hossain and Myllylä, 1998:18). Most of development projects for disabled people still focus on the medical model of disability. Therefore, disabled people are most often recipients of services and not involved in the decision-making process (Katsui and Wamai, 2003).

When these arguments are considered within the framework of the above-mentioned **three models of disability**, the following points are clarified. The **medical model** of disability blames discrimination due to the impairment of individuals and thus was criticised heavily for ignoring the social oppression. On the other hand, the medical approach is necessary as an essential part of the social rehabilitation process. Without the necessary medical treatment, equipment, rehabilitation and medication, the lives of disabled people can be seriously degraded. When it comes to the **social model**, it contributed to liberate self-blaming of disabled people because the focus became social oppression. It was criticised, however, for undermining individual personal experiences. The removal of mere social barriers cannot solve the problems that disabled people face because individuals have different conditions in terms of gender, ethnicity, impairment, personal characteristics, living conditions and so forth. The third model, the **political model**, is thus based on the lessons learned from the previous two models based on the similar ideology as the social model. This model is based on human rights ideology that encompasses all personal experiences rather than separating impairment, disability or any other characteristics of individuals away from persons. This model even more strongly politicises the issue compared with what the traditional social model did. It tries to claim especially the importance of political rights and social movement. Disabled people are the subjects to make the changes. The shortcoming of this model could be that the necessity of basic human needs and material needs such as food and clothes is undermined by concentrating more on the political aspect though the needs are included in the discourse. These are some of the major positive and negative aspects of each model of disability in theory.

WHO has conceptualised Community-based Rehabilitation (CBR) that has attracted donors' attention greatly. WHO (2003-b) explains CBR as follows:

> *__Rehabilitation__ is a process that assists people with disabilities to develop or strengthen their physical, mental and social skills to meet their individual/collective specific skills. Rehabilitation traditionally involves provision of therapy (physical, occupational and speech) in various settings like special institutions, hospitals, out-patient clinics or community homes. __Community-based rehabilitation__ is characterised by the active role of people with disabilities, their families and the community in the rehabilitation process. Knowledge and skills for the basic training of disabled people are transferred to disabled adults themselves, to their families and to the community members. Personnel skilled in rehabilitation technology train and support community workers, and provide skilled intervention as necessary.*

The concept of CBR has been understood and supported in different ways in different countries by different development agencies. That is why the concept is controversial due to the different understandings. It was studied and analysed by STAKES (2003) that CBR has changed its focus more on environmental factors instead of rehabilitation. As family, neighbours and the community have a more significant role in meeting the needs of disabled members especially in Asian countries, some study stresses the strength of this sort of family-oriented approach as an alternative to Western individualistic models (Miles *et al.*, 1996). The study proves the essential role of the family and closest people in the lives of disabled people, which led to the conclusion to stress them more rather than professionals. CBR started to be understood as right-based and community-based strategy (Hartley, 2002).

Nevertheless, some disabled activist such as Shoji Nakanishi expressed severe criticism of the underpinning idea of CBR as a medically-oriented one in the World Assembly of Disabled People's International (DPI) held in Sapporo in 2002. Service delivery in development assistance too often falls into either medically-oriented activities or charity-oriented ones. "Multinational corporate donors like the charitable model as it shows them 'giving' to the less fortunate in the community –the perceived strong assisting those perceived as weak" (Kabzems and Chimedza, 2002:151). Service delivery is inevitable and essential for the daily lives of disabled people who live in too unequal and discriminating societies. However, the weak point of the mere service delivery is that it does not challenge the fundamental structure of the discriminating society. More precisely, mere service delivery just fills the gaps of services and does not challenge the discriminating reality in which disabled people have little power over their own lives. Without real participation and representation, the discriminating reality never changes by itself, because disabled people are always a minority in each society and thus their voices tend to be ignored. Nevertheless the reality reinforces the visibility of organisations *for* disabled people rather than DPOs. **DPOs have had "minimal involvement in the discussion or development of policy**" (Beresford and Holden, 2000:982). Therefore, this study focuses on the activities of disabled people themselves and those of DPOs which aim at achieving their genuine needs and goals both at individual and collective levels rather than on the globalisation of disability through service-oriented activities.

1.6. Voices of Hitherto Voiceless People, NGOs and Political Theory
Oliver (2002) summarises that academic theories changed over time from a positivist paradigm to an interpretive paradigm, and further into an emancipatory one. 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". At this stage, the vulnerable group of people is excluded from the mainstream. 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 group of people is included in the contextual framework of the mainstream where rich and non-disabled people need to reduce inequality by changing the mainstream. This dichotomised picture of rich-poor and disabled-non-disabled eventually becomes less important in the emancipatory paradigm when NGOs and DPOs are in the third and fourth generation because they have the power, in theory, to improve or change the policy. The social movement theory explains the role of such a formal or informal organisation for changing individual discontent into collective action. The meaning of social movement is constructed through the activities of organisations in this theory (Wiktorowicz, 2004).

In practice, however, the voiceless people have difficulty in physically being in touch with each other, which will be mentioned in the following Chapter 3. This is, thus, a theoretical argument. At this stage of social movement creation, integrated, holistic and multi-dimensional solution is necessary as poverty, vulnerability and disability are complex phenomena. In other words, holistic empowerment and thus the inclusion of the political approach is relevant. In this way, global issues are to be solved locally. This is the scenario in which the voices of the voiceless people such as poor and disabled people are to be heard and taken into account in mainstream policies and practices. This core principle applies also to various other disadvantaged groups of people concerning women, ethnic minorities and elderly people.

Lewandowski (2003:115) argues, "in the past several years, the social theory of globalisation has begun to present themselves as political theories of democracy." However, he continues that globalisation lacks the political power as NGOs can only play an important role in raising 'global consciousness' whereas the institutional power to make decision remains in the sovereign parliament and senates (ibid. 125). This is the reason why NGOs in development discourse and DPOs in disability are, at least in theory, seeking for the change into the third and fourth generation of NGOs as Korten describes so as to challenge the power structure. Otherwise, the structure and mechanism to create marginalised groups of people would never change by itself. **Participation alone is, therefore, not enough** for the methodology of NGO activities, though it is indispensable for their legitimacy. The **political approach by involving the structure** is the way how NGOs could change the discriminative reality. Sustainable development is otherwise not achieved because NGOs of the first and second generation would face the structural problem. Therefore, the political approach is getting increasingly more important in theory.

However, being political equals to **power change** in the structure which goes against the existing mechanism that reinforces the reality. When a disadvantaged group of people gain more power, the relative advantage would naturally decrease for the other party which has enjoyed the hitherto power structure. Therefore, this change could be a threat and jeopardise greatly the other party, which could lead to their resistance with and/or without their intention. Therefore, the **political approach is less welcome in many cases, whereas filling the gaps between policy and practice by service provisions is welcomed due to the much less political or totally apolitical nature of the activities.** The voices of politically voiceless people are difficult to be heard due to this mechanism. This complexity of the political approach is investigated in this research. In this regard, research into an NGO of the political approach has great implications for the future of

civic society discourse for the real empowerment of disadvantaged and vulnerable groups of people.

Chapter 2. Methodology

2.1. Objectives, Key Research Questions and Significance

The purpose is to investigate the complex reality of Western NGO intervention in the disability field in a Central Asian local context. Especially, activities with a political approach are the central focus. Thus, clarification of the impact of the NGO intervention on the QOL of targeted disabled people is one of the most important goals in this research. The overall objective or final goal is that this thesis including its process contributes to the disability movement and their equality.

Key Questions for this research are:

- What are the main factors of the mechanism making disabled people vulnerable in Central Asia? How disabled people could be empowered?
- What is the reality of Finnish NGO intervention in Central Asia from the perspective of disabled people themselves?
- Could disabled people in Central Asia consider the political approach as their future possibility?

In this research, important key words depend on the conceptualisation of local participants. For instance, understanding of the local participants of **disabled people** is used in this research, as **disability is defined very differently from country to country**. For instance, the UN estimates that 10% of the world population consists of disabled people. 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. 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 positive persons, 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). In this regard, "disability" needs to take into account the local conceptualisation so as to best fit the local reality. Chapter 3.2 will clarify the official meaning of disability and the experiences of disabled people around the definition in Central Asia.

The first significance of the research is that **hidden voices of individual disabled persons are to be heard**. Ignorance of the voices of disabled people reinforced the medically-oriented solution for their lives. Therefore, this research tries to help disabled people by **translating personal troubles into public issues** as Mills (1959) mentions as the Social Scientists' political role. In this sense, this is the most essential significance of the research. This follows secondary values: this revelation of their reality-oriented needs leads to the **provision of practical advice on North-South Development Cooperation in the field of disability to relevant actors.** Without understanding the lives and their environmental contexts, practical advice cannot be given. This research tries to provide essential knowledge for their goal of equality by especially focusing on **the competence of the political model** in practice which goes beyond the hitherto charity, individual or medical approach. Not only the impact at an individual level but also the collective

one is aimed to be studied which includes the **impact of the NGO intervention on the creation of social policy in the targeted country**, as one of the common aims, "sustainability of projects" will eventually affect governmental policies (Wiman, 1996). Moreover, not only the knowledge creation, but also the actual empowerment of participating disabled people is also of significance. With the clarification of the complex reality and with the methodology that involves the targeted disabled people due to its participatory nature, this research tries to **contribute to the equality of disabled people in practice**. At the same time, the created knowledge is of **great relevance to any other discourse of disadvantaged groups** such as women, ethnic minorities and elderly people.

The **expected readers** are those who have interests in equality not only for disabled people but also for any vulnerable group of people. They are expected to learn from the voices of the research participants, which have been hidden. At the same time, it should be also stressed that those who are not interested in the equality issue are also the targeted readers because they maintain significant power to make the change as a disadvantaged group of people are usually the minority, excluded and have less power in relative sense. This doctoral thesis hopefully could play a role as a bridge between these different groups of people and provide useful knowledge for those who are also working as a bridge.

2.2. Participants in This Study

All the primary research participants are disabled people themselves or parents of disabled children. The first group of participants were the ones who attended the series of seminar events held within the framework of the project organised by a Finnish DPO, Kynnys. The second group of participants were those whom I got to know in my fieldworks with a snowball effect. I visited these people either in their homes or in their organisations, which gave me great learning experiences both from interviews and from observation.

Kynnys (Threshold Association in English) was chosen as a primary Finnish DPO due to the criteria set for attaining the objective. When I was looking for a certain type of DPO which has a development cooperation project in developing countries, eleven Finnish Disability NGOs were possible candidates. The criteria were a DPO which implements 1) **cross-disability activities** challenging social discrimination from the political model, 2) activities **controlled and implemented by disabled people themselves**, and 3) **interactive activities** to learn from each other. Therefore, it excluded impairment-specific aid, those of the medical model approach, organisations *for* disabled people, Disability NGOs with donation activities and those organisations in which the underpinning presumption is that "North teaches South." Rather the DPO with a social and political model of disability was central. I consulted a few specialists in this area such as the secretary general of the National Council on Disability in Finland and the project coordinator of Finnish Disabled People's International Development Association (FIDIDA). With their help, I eventually found out that Kynnys was the only DPO which met the desired criteria.

Finland is an interesting country in terms of development cooperation policy and practice in the disability field. The disability activism has been making an impact on policy and practice. For instance, it was clarified in the research of STAKES (2003) that **5% of all the development-related funding goes to disability specific projects** which amounted to 32 million Euros

between 1991-2002. This number is too small considering that 10% of the world population is estimated as disabled. However, Finland is the only country that I know which allocates such a big ratio of money out of its budget to disability projects among developed countries. For instance, Sweden, another disability sensitive country, has allocated only 1-2% of the budget according to the representative participating in a World Bank Conference held in Helsinki in 2003.

This superficially good number, however, does not mean that the disability issue is mainstreamed in Finnish development policy and practice firstly because 70% of the money is through Finnish NGOs and official bilateral or multilateral aid is quite limited in this area. Furthermore, the 6 biggest Finnish disability NGOs occupy 80% of the total funding for disability as was clear from the study of STAKES (2003). Five out of the six are impairment specific NGOs. Only FIDIDA is a cross-disability organisation. The same study found that **most of the projects were based on the "dominant social welfare approach."** Thus, the sector wide approach tackling collective and social discrimination from a political and social model of disability is fairly limited.

When it comes to the general picture of Finnish NGO activities in development, one study reveals that those NGOs whose projects are not disability specific do not involve disabled persons in decision-making processes "because they are irrelevant in our project" (Katsui and Wamai, 2003). Thus, the overall picture of Finnish development in relation to disability aspect can be summarised as follows: 1) Finland allocates a relatively generous ratio of money to disability specific projects thanks to the vigorous disability activism, 2) only disability specific projects involve disabled people in decision-making, and 3) disability specific projects are mostly impairment-specific. The paradigm change has been taking place since the social model became mainstream in disability discourse at least at the policy level. However, **practice shows that disability is not tackled enough**. Therefore, the project of Kynnys trying to tackle the social issues with a cross-disability approach and a political model is an interesting case.

In addition to the interesting project, **the strength of Kynnys is in its history of the movement at the national level**. The disabled students of Helsinki University established this organisation in 1973 due to the severe discrimination problems in their daily lives. These students claimed an ideology of independent living with a political stance. Unlike other activities for disabled people that are run by non-disabled people on a charity basis, disabled people themselves have run Kynnys because they have the policy that genuine improvement can be made only through their own action. Their disability movement and active campaign towards equality succeeded in sending a severely disabled activist, Kalle Könkkölä, into the Finnish Parliament as a member of parliament in 1983. Kynnys has organised many demonstration and campaign activities to appeal to their needs, which have gradually improved the social services and living conditions of disabled people in Finland. That is, Kynnys has good expertise in the disability movement in its own country.

Kynnys has also been involved in international cooperation activities with other DPOs since 1981. Kynnys started its first project in developing countries since 1984. Another interesting turning point is when Finnish disability activists from different impairment specific NGOs put their efforts together and established **FIDIDA** in 1989 for cooperating in development cooperation projects. This was a great step forward for the collective movement to progress in activities in developing countries. In autumn 2004, along with the trend of the decentralisation of

the institutionalised decision-making power of the Finnish MFA, FIDIDA was chosen as a temporal external examiner on projects in the disability sector. The role of FIDIDA has been increasing over time, which is an epoch-making attempt for an improvement in Northern development. However, cooperation efforts among Finnish DPOs in development are limited. For instance, the study of STAKES (2003) points out that FIDIDA is almost the only cooperation space.

Another very interesting effort stemming also from Kynnys members is the establishment of the **Abilis Foundation** in 1998. This Foundation funds only those projects of DPOs in developing countries. This NGO along with KIOS and Siemenpuu is very unique among the development aid activities of the Finnish Ministry for Foreign Affairs.

Active members of Kynnys have played a big role in the establishment of these NGOs for the improvement of the lives of disabled people, not only in Finland but also in developing countries. Currently, activities were expanded greatly and 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. In conclusion, Kynnys has always been active in the empowerment of disabled people by challenging the fundamental, discriminating structure of society. Kynnys has created some public space for the voiceless disabled people to raise their voices both in Finland and in developing countries, which is the strength of Kynnys.

In this way, I have chosen the Central Asian project of Kynnys for my primary project that organised a series of seminars and training for the future and current leaders of the disability movement in Central Asia. The primary research participants include seven Finnish disability activists and around seventy seminar participants from DPOs in Central Asian countries. However, the **seminar participants were already the chosen ones and thus biased** because they are rather active and outstanding among general disabled people in each country, although most of them had gone through difficult changes and gained visibility by themselves. Moreover, the seminar language was Russian which restricted the participants only to relatively educated people. Furthermore, the seminar participants were mostly physically impaired people due to the historical fact that blind and deaf people were ideologically allowed to exist in society, while physically disabled people were not. Thus physically disabled people's organisations tend to distinguish themselves from blind and deaf people who already had their space in society. People with learning difficulties or mentally disabled people were not included in the seminars. In this sense, interviews only with those seminar participants could lead to bias. Those who had been included in the seminar happenings were not enough to grasp the impact on the lives of general disabled people.

Therefore, in the last fieldwork held in autumn 2003 in Kazakhstan and Uzbekistan, non-seminar participants were interviewed to fill some of the gaps so as to listen to the important **majority of general disabled people**. These **two countries for the last fieldwork** were carefully chosen out of five due to different research-related factors and practical matters. Even though they all belonged to the Soviet Union and had a fairly similar policy and practices in the disability field before independence, they show differences already in current reality. I did not want to generalise on this vast area of Central Asia as if they are all the same. In a seminar organised by the Finnish Helsinki Committee in 2004, human rights activists, Adolat Najimova from Uzbekistan and Vitaly Ponomarev from Turkmenistan, strongly suggested Western journalists and academics not

to generalise the five countries. I wanted to be careful and choose two different countries in terms of their tolerance towards NGO activities. From literature reviews and previous interviews of representatives of the five countries between 2000 and 2003, I found that Kazakhstan and Kyrgyzstan are more open to civic activism than the other three. Kazakhstan rather than Kyrgyzstan was chosen because the last seminar was held in Kazakhstan and it was practically more convenient to continue the fieldwork during the same trip. Among the other countries, Turkmenistan was avoided because people fear too much to give their honest opinion, let alone tape record such statements. Speaking about disability is too political an issue for them to speak to me. Uzbekistan was the next most undemocratic country after Turkmenistan and thus was chosen.

More than 50 general disabled people were personally interviewed with special attention to involve people with different impairment, both male and female, both members and non-members of DPOs, beggars, both urban and rural people, people with different ages and mothers of disabled children. I tried to have varieties among the research participants after studying about them for several years. However, disabled people themselves are hidden in Central Asia, which makes it hard to find out who are the representatives. Thus this study is not aimed at covering the representatives of the disabled population but tried its best to cover different groups of them. I asked chairpersons of DPOs to classify their members and accordingly involved both "rather active" and "passive" groups of members. The definitions of these groups are mentioned in detail in Chapter 4. Members were easy to make contact with because their contact information is available in any DPO. On the other hand, those who do not affiliate with any DPO had difficulty finding out. Even leaders of big DPOs have no idea where they are. Therefore, I mobilised all possible means to seek them out. I asked neighbours and friends to let me know if they know any disabled people in their neighbourhood. I also visited bazaars both in Kazakhstan and in Uzbekistan where disabled people beg for money for their daily living. Hardly any disabled people were on the streets but whenever I encountered some disabled people, they were spoken to. Disabled people in the suburb area of Almaty and rural area in Uzbekistan also participated in the interviews. In this way, about an equal number of members and non-members with rather good gender balance were included in this work. More females were interviewed. This is due to the fact that about two-thirds of the seminar participants were males. Thus, I intentionally tried to keep the gender balance by asking more females to participate in this research during my last fieldwork period. When parents of disabled children participated in my research, they were mostly mothers, which also contributed to increase the number of female research participants. However, attention was paid as much as possible to listen to the disabled children though close family members tended to dominate the conversation with me.

In addition to the seminar participants, more than 20 **DPO chairpersons** were additionally interviewed. I paid attention to include those with different target groups, both GONGOs and independent DPOs, well-established and newly-established, and urban and rural ones. I interviewed also several staffs working in DPOs. Their interviews filled the deficiency of voices of deaf people, blind people, people with learning difficulties, war veterans and disabled children. In order to get information on these DPOs, I reviewed internet homepages, visited international NGOs and donors and interviewed some specialists such as professors and lecturers in both countries. I also visited a number of relevant places for the lives of disabled people such as boarding schools and rehabilitation hospitals which enriched the perspectives from the observation and interviews to the people surrounding disabled people. At the same time, 10

government officials were also interviewed to listen to their views on the lives of disabled people because interviews with the seminar participants at the beginning of the study already revealed a big gap between the views of the officials and disabled people themselves. Nevertheless, officials occupy a minor part of the study because the main light is shed on disabled people themselves as has been repeatedly mentioned.

2.3. Methodology
~Qualitative Methodology and Emancipatory Approach~

The **social and political models of disability** have been the theoretical tools for this study. That is, the perspective is not from the predominant medical model but from the viewpoint of disabled people. This emic view firstly reveals their hidden experiences and feelings in their daily lives including the ones associated with DPO activities, makes sense of them in their terms, and eventually theorises the collective civic activities towards the disability movement and equality. I decided to start by listening to their background conditions and context so that I could locate their issues in their context. Without this **context analysis** process, I would not have found the rooted mechanism that made them disabled. The study of STAKES (2003:50) criticises the deficiency of this perspective for a development examination in Finnish development cooperation in disability issues.

The **qualitative research methodology, namely interviews and observation**, tried to create a process to include disabled participants so that they could benefit from this study because the academic community also carries the responsibility not to reinforce the discriminative reality. Disability Studies especially highlight the creation of useful data with an **emancipatory approach** for changing the policy and practice to meet the needs of disabled people (Barnes, 2003). Therefore, throughout this research work, I have tried my best so that this study contributes to let the research participants feel the power of control and also the equality at their collective level. Westland and Wiman's statement was my motto in this study:

> *To be included is a fundamental human right that cannot be compromised. A ´partial solution´ to inclusion means exclusion (Westland and Wiman, 2002).*

For this aim, the **qualitative methodology** was more suitable though quantitative methodologies also contribute to equality in many other ways. As this study was interested in the research participants' view rather than my own concerns, qualitative research methodology was more suitable. More precisely, these ownership issues were taken care of in the following ways. First of all, careful attention was paid already when I called for participation in this research. At the beginning of each seminar, I explained the nature of this research work and the rights the research participants had regarding the information sheet (see Appendix 1) in Russian for Central Asian people and in English for Finnish people. Then two informed consent forms (see Appendix 2) were delivered to each person, which articulated the nature of the research, access information to the researcher, their confidentiality for protecting the privacy and their rights to deny any specific questions freely and to withdraw at any time without any negative consequence. For blind participants, the informed consent form was replaced by a tape-recorded form. They decided if they would participate in this research or not by themselves. Once they decided to participate, then they filled in the form and brought it over to me. One form was kept for each participant and the other form for me. I placed a small seal on the nameplate so as to be able to distinguish those

who had shown their willingness to join the research process and those who had not. In this sense, the participation in this research was totally up to each person. For those who became the research participants in the last fieldwork, I asked about their willingness over the phone when making an appointment. When we met, then the same procedure took place for making sure that they were willing to do this at their own will.

In **interviews**, I tried to avoid exploitation of the participants only as a research tool. The research participants have also participated in the research process under minimised power relationship between the researcher and the participants. The participants controlled the conversation especially during the interviews, which could emancipate them in effect (Stalker, 1998; Swain *et al.*, 1998; Bewley and Glendinning, 1994). The interviews were almost totally unstructured and quite open as to the willingness of the participant what to talk about and how long to talk. Certain questions that I asked were if they belonged to any DPOs and what the urgent issues in their lives were. Other than these, the participants expanded their issues freely. From the conversation-like interviews, I tried to understand their answers to my set three key questions. They figured out the vulnerability creation mechanism, reality of Western intervention with a political approach and the possibility of the political approach in Central Asia. Especially, the second key question was to be answered through an analysis of both the Finnish and Central Asian research participants and all the key questions through that of Central Asians.

Of **Finnish research participants**, I asked their feelings and experiences around this project and those related to their daily lives. Of **Central Asian research participants**, I had a different strategy so that the different groups of individuals would feel comfortable. For instance, I noticed that general disabled people were not willing to talk without being asked any questions, while chairpersons had a lot of things to talk about without me facilitating the conversation. Thus, I asked some general questions in my aid memoir to general disabled people at their request. The aid memoir, for instance, included "How do you usually spend your day?" or "Could you tell me about your experiences at school?" During the interviews, I expressed that all information about their lives and feelings are very important and helpful for my study. I regarded silence also as an important method to leave enough space for the participants to talk and to listen to them. When I interviewed the same person many times, then I had certain tailor-made questions for clarification or for further understanding. Especially for the seminar participants who also became research participants, I had several chances to meet them over time. Thus this way of interview methodology was applied.

I had only two to four interviews per day so that each interview can take **long enough time**. When **finishing each interview**, I had two things. Firstly I asked from the research participant what s/he expects from my study. This is to reflect their needs in my study. Secondly, I left space for the research participants to ask any questions of me. Most of the questions were either about social policy and practice regarding disabled people in Finland or in Japan or about me.

A shorter conversation lasted only 10 minutes, whereas long interviews took over 4 hours. This **period of time** is not the length of the interview as such, firstly because it took a longer time when two interpreters were needed. For instance, when talking with a deaf person, two interpreters were necessary, first a sign language interpreter and then a Russian-English interpreter. Secondly when talking with a person with a speech-related impairment, the

conversation took a longer time. Some participants did not need any interpreter, which also made a difference. Thus, the length of the interview is not as relevant as in other interviews.

More important aspect is that the interview mostly took place in a **personal environment** where they could freely express their honest opinion without being overheard. In seminar settings, I tried to create a personal environment by either inviting the participants to my room or by visiting their rooms. In Uzbekistan and Turkmenistan, the atmosphere was tense for expressing negative feelings and experiences. Thus I paid special attention to secure such space so that only I and my interpreter were in the same space. Some conversations were also made over a cup of tea during the seminar breaks, which were not such a personal environment. However, I then did not ask too personal questions by taking into consideration this privacy issue. During the fieldwork in 2003, the personal environment was secured for most of the interviews so as to hear honest feelings and experiences about their lives. However, in some cases, I had a difficult time securing this space because I mostly visited houses of disabled people where family members also live. Some family members, especially the mothers of disabled children, wanted to answer the questions instead of their children. Otherwise, I could offer quite a personal environment for the research participants.

I had **personal interpreters** for interviews with most of the Central Asian research participants. All the interpreters were females so as to facilitate the interviews with female participants because gender discrimination is severe. I tried my best to find persons who got along with people because that is indispensable for my study to be able to communicate with my research participants. Each assistant went through a brief training to make sure: 1) word-to-word interpretation, 2) not expressing her own opinion in the interviews and 3) keeping confidentiality. The training was important to assure validity for the interpreted information as it is "second-hand" (Devereux and Hoddinott, 1993). I did not have any interpreter for interviewing Finnish participants as they were held mostly in Finnish in Finland before and after the seminar events. The interpreters were of my age and professional in Russian-English interpretation. Russian was important due to the Russification during the Soviet time. Those who had compulsory education during the Soviet time were fluent in Russian. However, for those who were uneducated and who lived in a rural area, Russian was not their mother tongue. When the research participants wished to speak in their own language or could not speak Russian, my interpreters spoke local languages such as Uzbek and Kazakh. In Karakalpakistan, however, my interpreter could not speak the local language and I asked one local person to help our conversation. I tried to maximise the possibilities for the research participants to be able to express freely in their familiar languages. However, in some cases, I have to admit that there was a limitation. Yet it was important that I had all the conversation-like interviews with the research participants instead of some research assistant conducting them on my behalf.

Interviews were tape-recorded with the acceptance of each participant. After the interviews, I gave the research participants some **small presents** such as useful stationery, symbolic gifts from Finland and Japan, photocopied pictures of disabled athletes, artists and performers, or information on international organisations in the field of disability when asked. Stationeries were especially meant for disabled children, pictures for general disabled people and information on organisations for chairpersons. Prior to the research work, I was advised to prepare some small money for each interview by a researcher in Central Asian studies. However, I decided not to give any money in thanking them for their contribution because I did not want to reinforce the passivity in them by visiting them and leaving some money. I rather tried to encourage their

activeness through my selection of presents. Exceptions were made for beggars. As I had to interrupt their "working hours" with my interviews, I decided to donate some money at the end of the interviews though none of them asked me for money, except for one.

In addition to these deep, personal interviews, **observation** was another essential way to collect experiences especially in terms of behaviour. I kept a research diary for documenting observed happenings, findings and codes given for each name of participant in order to distinguish the voices on the tapes. In seminars, special attention was paid to who controlled the seminar conversation. I paid attention to how female participants and younger participants behaved in comparison with males and elderly ones. That is, I observed hierarchy among the actors by focusing on who sat with whom and who surrounded the powerful figures in order to understand the local power structure within the seminars. In Uzbekistan and Turkmenistan, I also focused on signs to control the conversation by some powerful figures. Another important observation was made on some changes over time in the series of seminar activities. These subtle and obvious signs were written down in the diary. When visiting the houses of disabled people or offices of DPOs, I observed their willingness to talk with me, feelings about each theme what they talked, about the condition of the places, how the disabled people were treated by their family members and neighbours and naturally the disabled people themselves. The general behaviour of society towards disabled people was also observed through walking down the street with a few disabled people. I also observed people in bazaars giving money to disabled beggars. My personal interpreters also helped me to interpret different expressions for valid observation in a local context. The collected information was later on added to suitable places in **transcriptions** as supplementary data. Transcriptions were made mostly on the same day of the interviews and exclusively made only by myself so as to keep confidentiality. The transcriptions describe the feelings and the way how statements were expressed in addition to the word-to-word statements themselves. Feelings and body language were written in brackets. For instance, when the person was excited and talked about some issue in a louder voice than usual, then I wrote "(talking loudly and looking excited.)" In total, 260 interviews were made. The transcription of the interviews and observation notes made up to around 2300 pages.

In the following text, many **excerpts of the research participants** are introduced to describe, explain and analyse the reality. Their statements are powerful and important because their reality was expressed in those specific words. As I wanted to introduce their subtle nuances, I tried my best to preserve the statements without rephrasing them. When parts of the statements are omitted in the following citation, it was expressed as "(…)" in this study. All my statements in the conversation are after "R" meaning researcher and research participants are abbreviated as "P." Excerpts of the research participants are introduced by featuring the country where they live, urban-rural differences, male-female differences and position in the DPO they belong to. When they do not belong to any DPO, then they are described as "non-member." For instance, a staff of a DPO in an Uzbek urban area is "Staff B in an Uzbek urban area." Therefore, "Uzbek" does not equal ethnicity but the country where this person lives. It applies the same for the seminar participants who were described as "Uzbek Participant A" if one is from Uzbekistan.

Secondary data such as literature, relevant documents produced by DPOs and non-taped communication also supplementary support for the arguments and description of the reality. When it comes to the **data processing and data analysis**, The Atlas software program was used. With the help of this software, I could encode all texts thematically and find the necessary texts

easily. Almost 2500 codes were made for covering all the themes of the interviews held during the last five years. This rather large number of codes is to avoid de-contextualisation of the text (see for instance Bryman, 2001). I have used similar techniques as **qualitative content analysis**. In the process of coding, groupings were made according to who speaks in terms of his/her nationality and what is the specific theme or concept under a big category. When a plural number of hits was found for one code from more than two different Central Asian countries, I created another code for "ca (Central Asia)" for the similarity. Finally, the data was categorised under large themes such as disability, disabled people's organisation, future hope, Kynnys project, history, independence, international contact, NGO, current trend in society, and my research. Concepts and themes under disability, for instance, were definition, education, employment, family, loneliness, passiveness and so forth. As a result, I made "dis/ca/family help the disabled member" for coding statements related to creation of disability in terms of family dependency theme which is shared by more than two Central Asian countries. This code has 148 hits, for example. According to the intensity of their interests mentioned, I structured this **writing** by maximising the coverage of their expressed experiences. I tried my best to include even a theme stated by one person. However, I admit that I tended to include more of the highly expressed experiences if I dared to compare them.

In order to make the research process **participatory**, when a draft paper of each event was ready, I introduced it to Finnish participants so that they could check the citations that I made if their subtle nuance had been captured correctly. At this point, Finnish participants had the chance to participate in the data processing activities. When it comes to Central Asian participants, however, this process had mostly failed to take place until the last fieldwork due to: 1) language difficulties, 2) deficiency of communication technology and 3) geographical remoteness. In this sense, Central Asian participants were much more excluded from the research process compared with the Finnish peers. This point was partially solved in the last fieldwork which gave opportunities for the Central Asian seminar participants to check their previous statements. Furthermore, I asked one disability activist from Kazakhstan to read through my text to make a comment on my understanding and interpretation so that the local person could have a chance to correct false arguments. I personally wanted to ask more local representatives to read and comment on my draft but could not do it, due to a lack of the above three reasons.

Finally, the **accessibility of the final PhD thesis** is another crucial challenge for inclusion. The thesis is aimed at being accessible to as many people as possible. More precisely, the thesis is placed on a homepage to enlarge the potential number of readers and converted into a readable form for blind readers by using a computer programme. This research is preparing a popular version[6] for wider readers in different languages so that the findings and messages are more easily understood and conveyed firstly to the research participants and to a wider audience. Printed materials are to be sent to the Central Asian countries except for Turkmenistan where the censorship of foreign books is so strict that it is highly predictable that the information will not reach the expected audience. Thus for Turkmen audience, I will send the material by mail to a human rights activist who promised to send them on. This person currently lives in exile in a foreign country and thus his position is not harassed by supporting me. I try my best to deliver the information and secure accessibility. This is important firstly because the knowledge is

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[6] In December 2004, Finnish Ministry for Foreign Affairs admitted Kynnys to allocate money for the publication work of the popular version including translation work from English into Russian.

mostly coming from disabled people themselves and so should not be hidden from them, and secondly because any useful knowledge for their goal of equality should be freely shared to achieve it.

2.4. Ethical Issues

The data collection in the form of interviews and observation usually generates serious ethical issues to pay attention to throughout the research process before, during and after the interviews and observation are carried out. In addition to the above-mentioned information sheet and informed consent form, the following points were paid special attention to. Names, ages, genders of the participants and/or places of the interviews have been hidden in any **written material** when the exposure of the information would hamper the lives of the participants[7]. When I judged that one consistent calling name would cause identification of the interviewee, then I have intentionally created another name for the same person. They have deeply trusted me and my work, on the basis of which they have given their honest opinions. Therefore, privacy is to be kept confidential. All the gathered information has been kept under strict control and access only by myself.

As I become part of the research process due to the feature of qualitative research, there are some difficulties especially when **"disengaging" from the field setting** because of the attachment. When it comes to disabled people, they are one of the most vulnerable groups of people who are expected to depend on the constructed relationship with the researcher (Taylor, 1991). In order to avoid the negative feeling of the participants, such as "being exploited" or "being let down" and also to satisfy my personal wish, I have kept and will keep in touch, to my best extent, with the participants when they wish. Kleinman (1991:194) summarises this part in the following:

> *Does it seem burdensome that, in addition to spending time and effort in the field, field researchers also must deal with their fears and other unpleasant feelings? Because we are the instruments of research, it can be no other way. And this unfair burden may have a brighter side, for it allows us to gain deeper knowledge about others and ourselves.*

That is, **researchers have various responsibilities** in compensation for the acquisition of knowledge. In order to take the responsibilities and fulfil my personal wishes, I will be engaged in disability-related activities. Taylor (1991:247) explains that "sometimes leaving the field means staying in the field and struggling with the human issues raised by the fieldwork." I sincerely hope to be engaged in the follow-up activities even after this study.

I heard that some research participants became active after meeting me. For instance, one female got to know about the existence of a DPO through conversation with me and made contact with it after meeting me. However, I have not conducted a follow-up review if I really did not make any unintentional and unexpected upsets for the research participants that could take place in any social research (Boothroyd and Best, 2003). I cannot deny the possibility that I have left any negative feelings with the research participants, despite my attention to this ethical issue to my best extent.

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[7] Kalle Könkkölä, a Finnish research participant, is an exception. He claimed that he would like to take responsibility for his own words and so would like to have his name revealed in this study. His name is always mentioned because he is a well-known disability activist and politician in Finland and worldwide.

2.5. Role of the Researcher and Validity of the Study

I, as a researcher, had a big impact on this research work, which is the room for validity discussion of this research. I am Japanese, young, female, a non-disabled researcher and live in the West carrying certain ideas biased to the principles of Disability Studies, all of which must have affected the study in some way or another. This sub-chapter introduces my major characteristics so that the readers can judge and evaluate the facts when reading the following text.

My background is as follows. I started to be involved in the disability movement 15 years ago when I visited a Japanese institution for severely disabled people for the first time. I visited there to work as a volunteer. Till then, I did not know that such severely disabled people existed in this world and was virtually shocked to learn the fact. Then I started to think of the reasons why I was so shocked. I came to the conclusion that it was because they were isolated so far away in the mountain area and so I had not had a chance to meet them in my daily life for 14-15 years. I thought this government policy was very wrong and started to be involved in activities in the disability sector. As I took my Master's Degree in Disability Studies in 1999 when the social model of disability was enjoying dominance in disability theories, I was forced to realize that as I am not disabled myself, it can be a negative factor in this movement. I felt that many radical disability activists then did not welcome **non-disabled** people for fear of repeating the history of their control. The ownership and control of disabled people was stressed, while the argument to involve non-disabled people in this study was barely mentioned. Barnes (1992) was the only one that I knew then. Nevertheless, I wanted to contribute to this movement. At the same time, I felt that exclusion of non-disabled people would end up in the isolation of disabled people. At the beginning stage of the disability movement and when it concerns peer support, being disabled is the necessary factor without question. However, I realized that being non-disabled is not a totally negative factor because the majority of non-disabled people should be included at some stage in this movement to actually change the discriminating world. I then thought of being a researcher supporting the arguments of disability activists with scientific research because activists tend to assert themselves without such objective support but with subjective experience. Subjective experience is powerful and political, while they sometimes miss the nuances of the scientific aspect. I was asked many times in Central Asia to tell the reason why I am interested in disability issues and explained the above background. The research participants then understood my thoughts. It took time before I gained the trust of some people. Especially, those at a high level tended to speak rhetorically and did not tell the reality as if everything was fine in their countries. When it comes to the seminar participants, it seems to me that the trust was established gradually over the years. I noticed that especially Uzbek people were more careful to tell own opinions compared with Kazakhs before knowing well enough me or before securing confidentiality. So I took more time to explain the nature of my study to Uzbek people before the interview started, while Kazakhs were more open and trusted me without much explanation. I got an impression that people welcomed me from my experience so far. However, I wonder how it would have gone if I were a disabled person.

I, as a **Japanese and non-Finn,** was a good example for visually showing independence from the Finnish participants for studying this Finnish intervention. When dinners were organised within the framework of the project, I always sat down among Central Asian people, whereas the Finns were escorted to sit at the "best table" without Central Asian people. Especially, many Central

Asian research participants felt closer to me as the same Asian from my appearance because I was often told that I looked like a local person. I helped the project as a general assistant or a personal assistant in addition to the role of a researcher. As the number of assistants was always scarce, I voluntarily worked as a general helper for everybody. This is because as a Japanese person, I always feel myself as a member of the group rather than thinking of myself as an individual, though this dichotomy between individualism and collectivism is considered to be a typical divide between donor countries and recipient countries (Hofstede, 1991). I tend to think of the best possible consequence as a group in which I am involved. Both Finnish participants and Central Asian participants thanked me a lot for my spontaneous help. However, the Japaneseness made some participants feel that I am the window to the rich countries such as Japan and Finland. Having learned to know this during my first visit, I prepared a list of international organisations and foundations and their contact information so that I could give the paper out whenever I am asked to introduce some relevant organisations especially for the chairpersons. I also sent further contact information and other information later if answers to the questions asked were not included in my prepared list. Most of the questions were about donors. Thus the Abilis Foundation and Japanese Embassies in respective countries were introduced in such cases. In addition to such a request, I as a researcher also tried to contribute to the work of practitioners and academics in the disability sector. My articles were published in both countries: one asked by an Uzbek government official and the other by a Kazakh disability activist.

I lived in a family of disabled persons in Uzbekistan and a family who had a disabled member in Kazakhstan. I stayed in each family for one month. In Karakalpakistan, I rented an apartment. This choice of accommodation allowed me to closely experience their lives and also gave the impression to others that I was trying to understand it. Both of my host families lived in the outskirts of the cities, which gave a positive impression because my living standard then was close to many of them or worse. However I cannot deny the possibility that some participants deliberately told some negative experiences of me due to their expectation to my connections though I tried my best to explain that I am a researcher and not a donor.

I am a **young female** which had ambivalent effects. On the one hand, it seemed that it was easy for the research participants to teach me their lives because I am inferior to many of them in the local culture as I am younger and I am female. On the other hand, the fact that I was not married at my age (28 years old in 2003) and do research work instead was a worrying fact for some locals, especially males in the rural areas, because woman of my age should have a few children rather than pursue research work. In order to avoid the conversation to be dominated by this theme, I learned to answer towards the end that I have a husband, which was true in the sense that I was cohabiting with my current husband already then.

The fact that I am **not a local person** naturally meant that I lacked local knowledge. However, I have learned it through the interviews, literature review and my interpreters who supported me with local interpretations. After transcribing the interviews of the day, I always made sure of some unclear interpretation from my assistants to increase the validity. For this reason, I typed up the interview texts on the same day though it was physically very challenging work. As an outsider, I tried not to distort the interview excerpts in order to introduce the local knowledge as it is. Therefore, I chose the writing style to include many excerpts in the following text to respect the way how they were expressed. At the same time, the fact that I am a foreigner was a rather good factor as it was easier for the research participants to believe that I was an independent

researcher not belonging to any side in the local power politics. In Central Asian connection culture, having connection to one could both enlarge and restrict possibilities. It enlarges possibilities for getting to know the connected people, while restricting possibilities for knowing his/her oppositions. Moreover, a local researcher[8] whom I met at a conference told me that it was difficult for him to study about civil society in his country because he could not express freely about the current regimes. For instance, if he used the word, "authoritarian" to describe his government, he will lose his job. He also said he could not meet many NGOs because they were suspicious about a "local researcher" asking about their organisation. On the contrary, foreign researchers are free to express anything about these countries when having places to express. In this sense, being a foreigner enlarged the opportunities to get in touch with different groups of people, which was very important for this study. Moreover, it is important that I can bring back the collected information back to Central Asia through the publication of this thesis in a popular version. The information will be important for the local people because they cannot publish their reality as it is.

All of these motivations and my characteristics played a certain role in this study both positively and negatively. The result was positive for this study when the research participants trusted me as I am and expressed their honest opinions, while negative when some characteristics in me attracted more attention than the research objectives themselves. I tried my best to maximise the positive result out of my characteristics in this study which hopefully increased the validity. It is, however, up to the reader to decide the validity.

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[8] I withhold his name to protect his privacy.

Chapter 3. Normalisation of Discrimination

~Analysis of Central Asian Reality from the Social Model of Disability~

The lives of disabled people in Central Asia are explored in this chapter so as to understand the hidden but systematic mechanism that makes them vulnerable. This is important because the vulnerability tends to be a common feature of disabled people in ex-communist countries, which means that clarification of the mechanism will be of use in many different countries to fight against it. The structure of this chapter is firstly to figure out the influence of the Former Soviet Union (FSU) on the creation of the concept around disability, "invalid". This explanation is followed by a description of the current governmental policy and practice that inherited the FSU invention. These historical aspects enable us to understand the systematic and institutional impact on the lives of disabled people. Coerced passivity is one of the most visible forms of the vulnerability. This passivity is analysed in the framework of different aspects in their lives in order to deepen the understanding on different layers of the mechanism throughout their lives. On the basis of the findings and description of their lives, this chapter concludes by proving that the West-oriented social model of disability is, to some extent, applicable in a Central Asian context to explain their disability, which helps us to understand their reality in more theoretical terms.

3.1. Contemporary Central Asia

Prior to the analysis of the reality of disabled people, this sub-chapter briefly describes the current situation of Central Asia especially the dynamics after independence as background information to locate the following texts. The focus starts with macro change. Subsequently micro changes in the lives of people are briefly introduced.

From Former Soviet Union to Independent States

Until independence, all the Central Asian countries had been under the totalitarian system under the control of Moscow. Virtually all aspects of life were subjugated to Soviet ideology. Their economies were also planned by and for Moscow (Carley, 1995). Therefore, it was natural that those countries lacked the management capacity in all aspects when they became unexpectedly independent. With the loss of central control, all Central Asian countries slumped into **negative economic growth** up until 1995. Hyperinflation occurred in all the countries. The turmoil in Russia has worsened the situation (Falkingham, 2002). All the countries reinforced the Soviet Union structure without struggle except for Tajikistan where civil war broke out and continued till 1997 and ethnic tensions in Uzbekistan at the beginning of independence. The following Figure 1 clearly shows the difficulty that these countries faced after independence.

Figure 1. Cumulative Change in real GDP in Central Asia 1989-2000 (1989 = 100)

Note: The figures for 1999 are estimates and the figures for 2000 are projections
Sources: 1990 and 1991 (European Bank for Reconstruction and Development 1997);
other years (European Bank for Reconstruction and Development 2000)
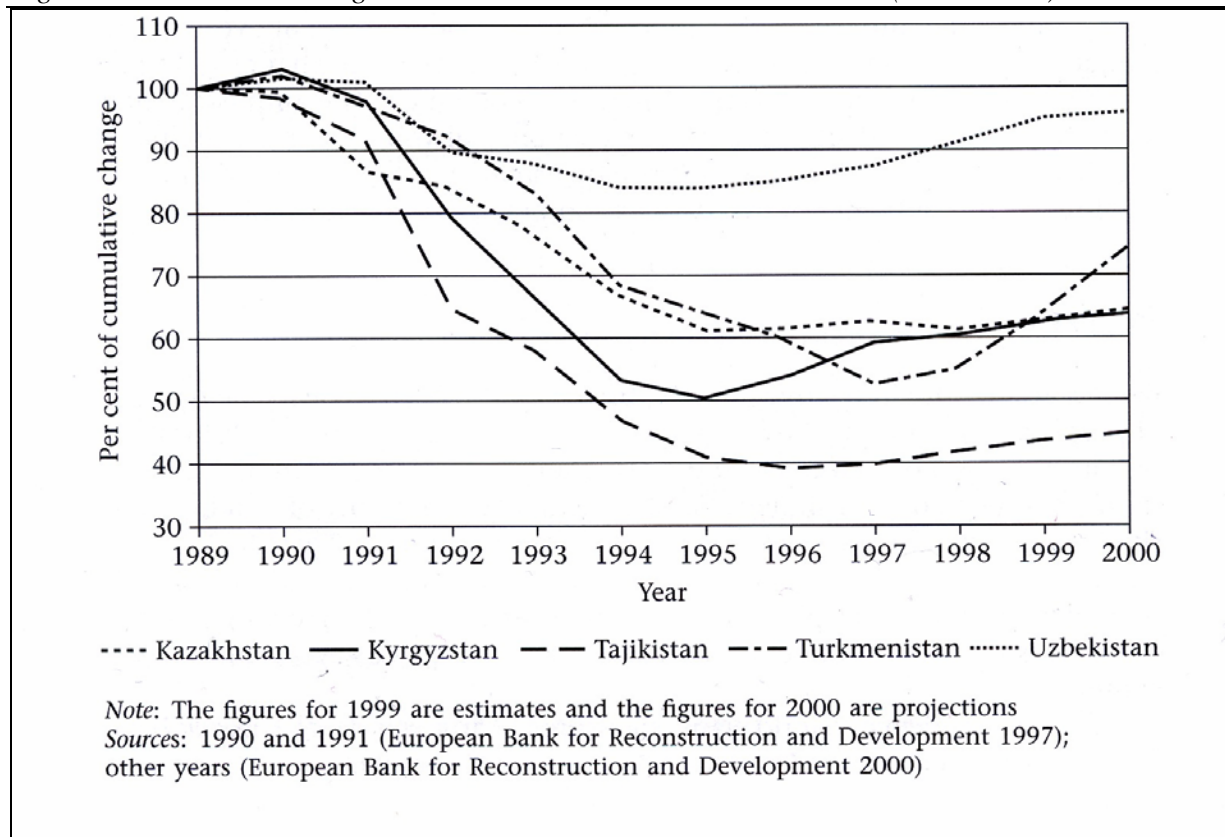
Source: (Falkingham, 2002)

This macro economic change made many people unemployed as each government could not maintain the production lines which were not meant for a competitive market economy but for inter-Soviet Union trade under leadership from Moscow. People lost their property in cash due to the inflation at the same time (United Nations, 2001). The Soviet Union guaranteed full, life-time employment, food, house, free education and health care with a favourable pension system for women with maternity leave. **All these egalitarian systems were jeopardised with the economic crisis**. Virtually all social support systems disappeared with the unexpected transition (Narayan. *et al.*, 1999). The prevailing bribery in the previous regime pressured poor people from getting employment, health care and social services because they were expected to give enough bribes to acquire those necessities but could not afford to do that. Many emigrated from these countries due to the deteriorating living conditions (United Nations, 2001). Under these circumstances, many people did not have money even for their medical services. One survey in 1996 showed that 25% of the people in Kyrgyzstan (20% urban and 29% rural) could not use the medical services because they were too expensive. When it comes to Tajikistan, 33% did not use medical assistance for the same reason in 1999 (Falkingham, 2002:51). On the other hand, a few elites started to take advantage of the privatisation and accumulate wealth through globalisation (Yalcin, 2002). In this way, **the gap between elites and the "dispossessed" was enlarged** and caused polarisation in society (Nazpary, 2002).

Poverty in Central Asia

Table 2. General Statistics of Central Asian Countries in Comparison with Estonia and Kenya

Country	Population (millions)	Urban population (as % of total)	HDI Rank*	Life expectancy at birth	GDP per capita (PPP US$)	Seats in parliament held by women (as % of total)	Public expenditure on health (as % of GDP)
Kazakhstan	16.2	55.8	79	64.1	5,871	11	2.7
Kyrgyzstan	4.9	34.4	102	67.8	2,711	6	2.2
Tajikistan	6.1	27.6	112	67.6	1,152	12	5.2
Turkmenistan	4.7	44.8	87	66.2	3,956	26	4.1
Uzbekistan	24.9	36.7	95	69	2,441	7	3.4
Estonia	1.4	69.4	42	70	10,066	17	5.1
Kenya	30.7	33.4	134	50.8	1,022	3	2.4

Source: (UNDP, 2002-b) Tabled by the Author
* HDI stands for Human Development Index which includes life expectancy at birth, adult literacy rate, combined enrolment ratio and adjusted per capita income in PPP US$. When the rank is closer to 1, human development is more developed.

Although the present social indicators in Table 2 show relatively good numbers compared with the least developed countries, the situation is getting worse. The withdrawal of already scarce service hit a significant proportion of the population. **The increase in poverty is much more rapid in Central Asia** in comparison with other regions as the following Figure 2 shows:

Figure 2. Proportion of Poor People in Transition Regions
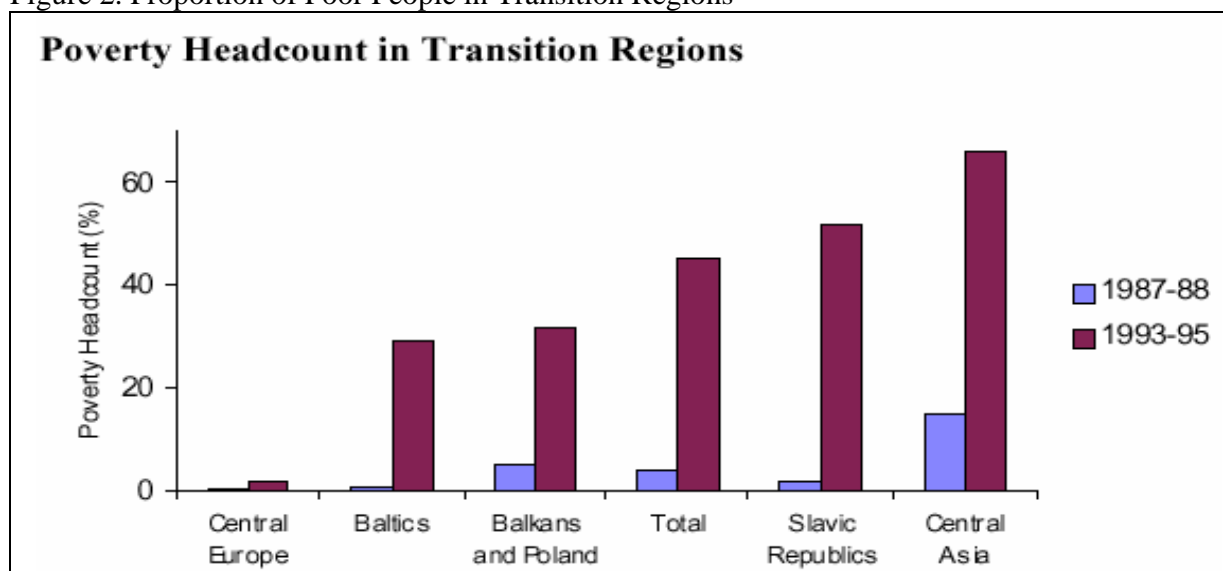
Source: (Narayan *et al*., 1999)
"Poverty Headcount" means proportion of poor people in the above research.

In the Soviet regime, poverty was considered the result of laziness or association with criminality. That is, poverty meant "lack of social and moral worth" (ibid. 54). Due to the stigma attached to poverty, people have severe problem to survive when they are ashamed to ask for the necessary help especially from outside their network such as family and close friends. This strata of the population is, thus, extremely vulnerable. As a result, very poor families commonly institutionalise their children so that they can secure food, even though the living conditions of such institutions are very poor. In Uzbekistan, the tendency is especially stronger for Slavic families compared with Uzbek families who consider it as shameful if they cannot take care of family members (Wazaki, 2003). Especially **people in rural areas are vulnerable** to this change because collective farms were closed down on top of the fact that their financial capacity had been lower during the Soviet era despite the then egalitarian policy (Yalcin, 2002). As a result, "Approximately 35% of people are more likely to be poor and 58% to be extremely poor in rural areas and this is where 63% of the total population of Uzbekistan lives" (United Nations Office in Uzbekistan, 2003:17). Many families emigrate from rural, poorer areas to urban cities to seek employment but end up in hard physical labour at a low salary, as all the better jobs are occupied by urban people. These "new poor" involve their children in labour activities to help the household (Ilkhamov, 2001). Consequently, income generating activities are prioritised over education for children in poor families. Although official statistics show more than 90% for the primary school enrolment ratio (UNDP, 2003-a), actually only 73% of students attend school in practice in Uzbekistan (United Nations Office in Uzbekistan, 2003:21). Even though primary education should be guaranteed to be free for all nations in Central Asia, families of the poorer strata of the population cannot afford to pay for textbooks, for instance. In this way, poor people lack education, are disempowered, and marginalised in society. The general population is thus vulnerable as a result of all these changes. In this regard, Nazpary (2002:182) questions, "Whose transition?" and continues, "**What the dispossessed call chaos is celebrated by the elite and the West as a transition to capitalism** which is exalted as the natural order of life." He (ibid. 183) points out the common features of post-Soviet states as follows:

- Economic, and to a great extent political, subjugation to the West, particularly the US, through the macro-economic reforms and debt regulation mechanisms, implemented by the Bretton Woods institutions.
- Social polarisation characterised by the accumulation of wealth on the one hand and poverty on the other.
- Disintegration of the social fabric of daily life while violence, ethnic tension and mass exodus have become defining features of society.
- Privatisation of state property, deindustrialisation, cutting wages, destruction of agriculture, dislocation of educational infrastructures and health-care.
- Dollarisation of prices.
- Formation of a criminal economy, a shadow state and the flight of capital, mainly through money laundering.
- A dual economy: export-oriented economy on the one hand, and the stagnant parts of agriculture and industry, which are not profitable for multinationals, on the other.

Poverty around Disabled People

In the post-Soviet states, the macro changes hit the poorer strata of the population very badly. My research participants expressed the following general changes in their daily lives. Communication

and travel fees which once were free or cheap became very expensive, let alone fax and e-mail. **Only elites enjoy the information flow from the world**, while the majority of others lack access to it. The internet access is very restricted and only approximately 0.2% of the population had the access in Kazakhstan in 2001 (Adamson, 2002; Johnson, 2001). Domestic mass media, on the other hand, still defended themselves with the strategy of self-censorship being afraid of harassment. **Self-censorship is a typical way to react to a lack of political space**, which is also witnessed in different countries (Hakkarainen *et al.*, 2003). There is no independent newspaper in Uzbekistan. Freedom of speech is not guaranteed even in relatively democratic Kyrgyzstan. All are still under the tight control of the regimes. Much of the available information is still manipulated. Therefore, many people are aware of the fact that public statistics are not trustworthy. Despite the deficiency of information, however, the poorer population can now see the commodities in stores that the elite can afford to buy, which increases the appetite for consumerism on the one hand and **nostalgia for the Soviet Union** on the other, when the egalitarian system and welfare state protected them relatively in an equal manner.

Chaos and tension leads the visibility of the Mafia and **ethnic conflicts** in each country where 100 ethnic groups live only in Uzbekistan. Especially, the ethnic minority emigrates from the countries due to the unfavourable policy that benefits only the dominant ethnic groups. For instance, the promotion of a national language of only Uzbek and Kazakh pressures Russian speakers away from the important public jobs and as a result from Uzbekistan and Kazakhstan respectively. As the Slavic population was privileged in the Soviet era as an "immigrated population" among "indigenous" ones, the upheaval led to great panic among them (Yalcin, 2002).

Wide-spread **unemployment** brought alcohol addiction and domestic violence for males and the introduction of a stigmatised sex industry for females even at a very young age:

> *You see in the bazaar mothers selling their daughters for USD 300. Do you agree with this situation? (...) Where is our tradition about the strong bond of family? (Tajik Participant E).*

The **gender gap and urban-rural gap have been increasing very rapidly** due to this "transitional" period. Under these circumstances, those who had support in the Soviet system are particularly vulnerable after the sudden independence.

Summary

The major macro economic crisis after the independence hit the already marginalised population the most and caused polarisation in society. Especially, the poverty around the lives of disabled people is severer. Some literature stresses more the effort of each country to maintain a welfare system (Yalcin, 2002). This same literature continues to claim that the governments ensured access to health care and education in such a difficult time. However, it is not true for the lives of disabled people. It will be clarified further in the following that disabled people in the Former Soviet Union countries have suffered even more seriously from this significantly worsened standard of living even among the dispossessed strata of the population.

3.2. Concept of Disability

In order to deepen the understanding of the lives of disabled people, this sub-chapter explores the normalised concept about disabled people: "invalids." Concept analysis is important at this point because the very concept follows the practical difficulties in the lives of disabled people at present. This part firstly tries to understand the historical aspect that created the concept and secondly the contemporary governmental policy and practice that reinforces the history.

3.2.1. Soviet Union and the "Invalid"

Hidden Population

The current reality of disabled people is deeply rooted in the policy and practices of the Soviet regime, as they were based on the statement, **"The USSR has no disabled people."** This does not mean literally that there was no single disabled person in the Former Soviet Union. It means that disabled people did not have space in the then ideology and thus did not have space in society either. I witnessed a few exceptions among the research participants who achieved high social status by obtaining their PhD in prestigious universities. However, those cases remain at a minor level. Many other research participants mentioned the **legacy of the Soviet Union** where "disabled people were not accepted anywhere (Uzbek Participant R)" until only a decade ago:

> *This is due to the legacy of the Soviet Union because the USSR didn't respect law nor the rights of people. People were not in the centre then. For instance, the international year of disabled people of the UN was not informed but was hidden in the Soviet Union. Instead we were told, "There are no disabled people." "There is no problem." (Uzbek Participant E)*

People were "objects" in the USSR in which people were supposed to share the same ideas as the regime. Non-disabled people were coerced to believe that there is no disabled person. Non-disabled people learned to believe this because **disabled people were mostly either institutionalised or imprisoned at home** so that society did not encounter them, even though disabled people had existed throughout history.

Among the disabled population, some groups of disabled people were considered to be more "valuable" than other groups in the sense that the former could contribute to their economy. Due to Soviet ideology, all citizens were supposed to be involved in work when private interest and the public good were synonymous (Pottenger, 2004). The Soviet Union started to give their enterprises to the former groups of disabled people since 1930s (Werner, 1995). The former group consisted of blind and deaf people, while physically disabled people, people with learning difficulties and mentally disabled people were the latter group. This **tendency to favour more blind and deaf people** was witnessed also in Western countries in the eighteenth century (Metts, 2000). Werner (1995) claims that close to 85% of disabled people in the Soviet Union were employed by 1955. These production lines were managed typically by deaf people's organisation and blind people's organisations. These were the few organisations that were allowed to exist during the Soviet era. The former group of disabled people enjoyed then a "normal" life of employment in state enterprises which were located in physically isolated places away from the non-disabled population. On the other hand, the latter group were given medical identification cards with a phrase, "Cannot be employed." Uzbek Participant C remembers that this card was

valid until independence in 1991. They are mostly the people who were institutionalised and imprisoned at home. Physically disabled people and others were not allowed to organise any corresponding organisations either. In the process of the history of the Soviet Union, **the concept of "invalid"** was introduced to describe those disabled people who were not considered employable and thus not worthy. In this way, both the former and latter groups, thus the whole disabled population were physically isolated from the rest of the population to maintain the ideology.

After the World Wars, war veterans were called war invalids and were respected. During that time, invalid still had positive connotation. However, sometime after that, invalid started to mean physical difference or "abnormality" and an inability to work when the norm was based on the ideology that "a real Soviet man must be healthier, more beautiful and stronger than a man from capitalist countries!" (Kazakh Participant D). That is, **physical "normality" and workability was very important in the Soviet time**, which led to the counter concept of an invalid. These people were given much more negative words in the Russian language. "We have Russian words that show disabled people as ugly, dirty, beggars such as 'kaleka (=cripple)'" (Kazakh Participant D). In comparison with these totally negative words, invalid sounds "more neutral," she says.

Welfare Policy for the "Invalids"

These "invalids" were not totally forgotten in Soviet policy and practice, even though they were segregated. They were protected by the welfare state policy and practice. For instance, the Soviet Constitution adopted in 1977 has an article entitled "Welfare." It says:

> *(1) Citizens of the USSR have the right to maintenance in old age, in sickness, and in the event of complete or partial disability or loss of the breadwinner.*
> *(2) The right is guaranteed by the social insurance of workers and other employees and collective farmers; by allowances for temporary disability; by the provision by the state or by collective farms of retirement pensions, disability pensions, and pensions for loss of the breadwinner; by providing employment for the partially disabled; by care for the elderly and the disabled; and by other forms of social security.*

Disabled people were given pensions in addition to different kinds of privileges for houses, utilities, medical treatment, communication fees, transportation costs and so forth according to a given category of impairment. With such benefits, disabled people could exist, though without dignity. Disabled people were categorised into three groups according to the severity of their impairment mostly judged by their workability and physical self-sufficiency, namely walkability[9]. That is, medical evaluation directly affected if they should work or not. In other words, the medical model of disability conceptualised in the West was also applicable in Soviet times. Even though the line between disabled and non-disabled people was not clear because of the continuum of the word, "disability," (Keary, 1998) the **Soviet Union managed to separate disabled people out from the mainstream with this category system.** Disabled people did not have to worry about their lives because they were given what they were entitled to, though "normal life" with engagement to employment was not offered to them:

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[9] Walkability is the word that I have coined to refer to the ability to walk in a self-sufficient manner without support of any other person. Walkability and workability have been the key criteria for the category system.

Our [medical] treatment was free of charge. You could live even on the smallest salary. Any person who had an average salary could afford to go somewhere for a holiday to rest. There was guaranteed treatment. Their privileges were written clearly into our constitution and laws. We got education (Female member C in an Uzbek urban area).

Thus both those who were considered to be eligible to work and those who were judged not to be able to work enjoyed different kinds of privileges entitled for disabled people. This welfare system and employment policy determined the lives of disabled people because they did not have any choice but had to remain hidden from society in institutions or in hospitals.

The practices of the **institutionalisation and hospitalisation of disabled people are not considered merely negative** according to the research participants. For instance, disabled people of a similar diagnosis got to know each other in such places and learned practical coping strategies from the others. Thus not only materialistic and medical support but also the side effect of socialisation among disabled people came along with the policy for those who needed medical rehabilitation:

We were all acquaintances and we got to know each other through the hospital where we went for rehabilitation training. Not all of us were in the hospital but we introduced each other by our acquaintances. Now these hospitals were closed down. And this kind of connection is not in use anymore. We don't get rehabilitation training anymore. We don't have any new members [to this DPO] (Female Member B in a Kazakh urban area).

Currently many such medical hospitals have been closed down, which will be mentioned further in the following sub-chapters. Disabled people stayed in such rehabilitation hospitals for a few months and got to know each other very well. Newly impaired people got advice from experienced ones in this hospital which played the role of peer support. Sanatoriums were all over Soviet territory and disabled people could visit those for free.

In this way, **according to the diagnosis of their impairments, life style for them was determined by the government**. This system made disabled people passively wait for things to happen. In this way, passivity was systematically coerced. Therefore, this concept of "invalid" has a psychological effect for disabled people. At the same time, the concept has practical inconvenience for disabled people because of the "non-existence" of disabled people during the time of the Soviet Union. The non-existence caused major ignorance of society towards disabled people and their issues: prejudice. Furthermore, the ignorance means no attention to the physical needs of disabled people for securing accessibility in a physical environment:

We were the Soviet Union. For example, then the state was giving more money but not opportunities for disabled people. In exchange, it didn't want them to come to seek for a job. So they stayed at home and did nothing. That is why many buildings didn't, or do not have such facilities for disabled people (Male non-member A in an Uzbek urban area).

After the Soviet Union, all the problems of disability which had been hidden appeared on the surface. We realized that there were many disabled people. It turned out that we did not have any accessible infrastructure for disabled people. We then faced the problems. If

our government did something about the problems during that time, we wouldn't have faced these at present (Uzbek Participant C).

When society is designed to be accessible for disabled people from the beginning, the difference in the construction cost is marginal. However, a senior economist of the World Bank claims that reconstruction of existing inaccessible buildings into accessible ones requires much more resources (Braithwaite, 2004). This is one of the significances for urgently starting to implement disability policies in practice.

Summary
This fact that Central Asia used to be the Soviet Union is unfortunate history especially for disabled people because they did not have equal opportunities and rights. Soviet Union labelled disabled people as "invalid" who are not eligible to work when workability was essential for their ideology. Disability is an ambiguous concept. Nevertheless, the Soviet Union regime succeeded in differentiating disabled people from the rest of the society by using the medically oriented category system. Disabled people were mostly taken care of outside the mainstream society and thus forgotten in society. As a result, huge prejudice and physical inaccessibility still remain as major Soviet legacy in the lives of disabled people even after independence. The current regimes reinforced this concept of "invalid" and moreover withdrew many of the welfare services that were once the entitlement of disabled people. Current governmental policy and practice is the next theme to understand the important part of the mechanism why and how Central Asian disabled people are made vulnerable at the moment.

3.2.2. Government Policy and Practice Reproduce the Abnormality

As was mentioned in the previous sub-chapter, the Former Soviet Union has left mostly a negative impact on both the psychological and physical environment of disabled people. This sub-chapter moves on to understand the policy and practice of the current regimes over the lives of disabled people. Due to the fact that the current regimes inherited many policies and practices from the Soviet ones and try to control many aspects of the nations, the impact of current regimes over the lives of disabled people is still extremely big. The previous and this sub-chapter describe one of the major background conditions for their lives. This part especially focuses on their lives from two different viewpoints: that of government officials and that of the disabled people themselves. Interviews of these two different parties reveal significant difference in the description of their lives: government officials call them "prestigious" while disabled people feel desperate. This dialogue clarifies that the government officials' view is quite medically-oriented, while disabled people suffer from different challenges after independence such as the major withdrawal of social services and practical difficulties around governmental institutions. Through the dialogue, this part articulates that the ignorance of disabled people of their own rights has been systematically created and reinforced deliberately by the government policy and practices.

Inherited Medical Model
Independence was generally welcomed in the sense that disabled people could exist in society in theory:

> *R: Do you see lots of differences before independence when it was part of the USSR and now after independence?*

P: It's better now than in the Soviet time. In the Soviet time, disabled people were isolated in hospitals and no one needed them.
R: And now?
P: Now it's better than in the Soviet Union.
R: What kinds of things are better? If possible, could you tell me more about it with examples?
P: In the Soviet time, the issue was hidden and the state mentioned nothing about them and nobody knew about it. But now you can freely talk about this and many people can learn about this issue.
(P: Male staff A in a Kazakh urban area)

In principle "many people can learn about this issue," though in practice a positive image of disabled people is hardly reached under the current situation. **All independent governments in Central Asia inherited the concept of disability with a negative connotation** based on the traditionally predominant medical viewpoint in which "no one needed them." This inheritance is well epitomised in the still functioning **category system** that is identical to the Soviet one. Interviewed government officials were proud to explain their system. Disabled people get a category on the basis of medical diagnosis and workability which also determines the amount of monthly pension. Uzbek government official B explains the differences of the three categories:

There are three categories. The lightest one is the 3rd category. Those disabled people who cannot partially work. The government pays pensions. And they are working to be economically independent.

The 2nd category are those people who have functional disorders. They cannot work. But they don't need care or assistance. But there are some people who can work under some special conditions. For example, blind people, they can work in a special condition.

The 1st category are those people who need the assistance and supervision of others. These are the socially poorest people. According to the categories, social protection is built. Those people who don't have any relatives to take care of them belong to here, too. All documents concerning the definition of categories are under the control of the Ministry of Health and then the Category Department. And then experts define the category of disability and give a special form of document. (...)

During this period [when a category is given], these disabled people are under the control of local hospitals in every district. They are taken care of by doctors from the Category Department. They provide rehabilitation, different kinds of rehabilitation. (...) And the people improve their health and start to work again.

The category determines the passive role of disabled people as those who need "supervision" or who "are under the control of" doctors. Regardless of individual differences, disabled people are categorised roughly into these three groups. In this sense, disabled people are regarded as an object in this medical system. Even nuance of disabled people's ownership is non-existent in the above excerpt. Instead of talking about disabled people, government officials talk about doctors. Kazakh government official B proudly stated that the doctors working in the Category Department are the best ones in the city. As the doctors are specialists, each disabled person gets

the proper category. The **strong belief in the work of the medical professionals and specialists** accelerates the reproduction of the disability concept as medically-oriented one (Barnes, 1991):

> *There are some cases when people are not satisfied with our category. They can go to the Social Protection and Employment Department [to apply for the necessary change]. But there are only few cases when they have to change because we are specialists (Kazakh government official B).*

Medical specialists are hierarchically much more powerful in this system than disabled people to determine about their lives. Government officials continue, that in addition to the pension and all kinds of rehabilitation work including social and vocational rehabilitation, they get the necessary equipment such as wheelchairs and prostheses for free without queuing (Kazakh government official A, B, C and Uzbek government official B, C, D and Karakalpak government official A and B):

> *Medical rehabilitation is under the control of health. Taking into consideration that medical rehabilitation could be for a long time, this is a treatment of medical care, medicines, Sanatorium care and treatment, according to the doctors in the local policlinic, and these are taken care of. In our rehabilitation centre, patients can come with a doctor's prescription. Doctors commission our category department.*
>
> *Social rehabilitation and professional [vocational] rehabilitation are taking place with medical rehabilitation. Social rehabilitation includes any need for prosthesis. Paralysed people can work with special equipment. Social rehabilitation teaches them to take care by themselves how to eat, to get information through TV and radio, to teach people how to clean the prosthesis, how to equip your apartment meant for disabled people, how to put on clothes and wash your teeth and so on.*
>
> *There is also professional [vocational] rehabilitation. According to the previous profession of the disabled people, there is a special definition to make if this person is workable or not. If there is any problem to get work after getting the disability, he should be trained again. Or we provide some vocational training to get another work. And he works. Depending on how and when he can work are all taken care of in this professional rehabilitation. We conduct a questionnaire to see if he can do the work, if he is satisfied with the work and so on. On the basis of this, disabled people can get a recommendation letter from the Labour Department (Uzbek government official D).*

Workability is an important criterion to judge if one's impairment is cured or not after going through different rehabilitation. Various kinds of rehabilitation are planned according to the law so that the person can eventually work again, despite the fact that impairment is a chronic condition. Chronic impairment is thus mixed up with illness or temporary injury that are to be cured and rehabilitated. This misunderstanding reinforces the **abnormality concept** although the impaired body is the normality for disabled people. Impairment is "abnormal" firstly because it is different from a "normal" healthy condition and secondly because it is not cured. The "abnormality" is directly to do with the inability to work, without considering the reasons which actually make disabled people unable to work. For instance, physical barriers are one of the major reasons that hamper the mobility of disabled people, which is not taken into account in this

category system. Rather all social limitations are unconsciously understood as direct consequence of their impairment due to the medical model way of thinking. In this way, the impact of government policy and practice over the lives of disabled people is typically large in ex-Communist countries, in comparison with Western countries which started to realise the role of society as a whole for creating the discrimination. Workability and walkability are the key criteria for the "normality."

"Prestigious Life"

Regarding the necessary equipment, Uzbekistan even has a production line for wheelchairs under the government structure (Uzbek government official D) (which was closed down by the time I visited it in autumn 2003). Kazakh government allocated 9 million Tenge (=around 57,000 Euro) to purchase wheelchairs in 2003 (Kazakh government official A). Other privileges include free medical treatment, discount in tax payment, compensation for utilities and aid devices according to their category (Uzbek government official D). With various kinds of governmental support, "most of the [disabled] people get a higher education" (Karakalpak government official B). Uzbek government official D explains the mechanism for disabled people to get employment:

> *These people are also training for different professions according to their disorders. We have special colleges with pathologies where they can get training to get a future occupation and they get a grant for studying in those colleges during their studies. After finishing their school, they are employed.*

The whole system is directed to the final goal of employment. When it comes to those who acquired impairment later in their lives, psychological rehabilitation is provided (Uzbek government official D):

> *For example, people after a car accident, there is no prosthesis. He must get used to it because it happened so quickly. He must learn to get used to it. For example, he is shown examples of those in the same situation. They can see that those similar conditioned people can paint and create sculptures without their hands, for instance. On the basis of these examples, they are getting ready for reality.*

That is, peer support is organised for them. The interviewed government officials describe the good care of disabled people with various privileges. Due to the given privileges, Uzbek government official C describes their lives as "prestigious":

> ***Disabled people are very prestigious with lots of privileges.*** *People get pensions with different privileges instead of working and getting salaries. If one disabled person commits some crime, he gets privileges even in the court process. The government tries to help disabled people. We have so many political problems, but the government tries to help disabled people.*

When employment is the final goal, being out of work is "prestigious." In order to explain how well the governments are taking care of the disabled population, this government official gave the example of privilege in a court case (though Uzbek Participant C explained to me that disabled people are amnestied because prisons are physically inaccessible.) Kazakh government official A assures that the governmental services are applied to every republic level and thus urban and rural

areas have little differences, although she admits the possible difference in some levels of the services. Kazakh government official B admits that disabled people used to be hidden but not anymore:

> *Previously they were neglected and forgotten. Now people are very responsible. The mayor himself tries to see the problems of ramps and other problems.*

Kazakh government official B says they actively use the media to introduce the state of disabled people. She implies that society is thus aware of this issue. Kazakh government official A introduces the future plan to establish a rehabilitation centre for disabled people in 2005 using 40 million Tenge (= around 255,000 Euro). **According to the interviewed government officials, it seems that disabled people in Central Asia are well taken care of** under the medical model and the Soviet legacy of the workability model of disability. Government officials assure a bright future for their disabled population under the total care of the governments.

Dialogue between Government Officials and Disabled People

Unlike the rhetorical description of the government officials, disabled people themselves expressed the stark reality from their viewpoint in the interviews:

> *R: It (your story) is very different from what the Ministry of Social Protection told me.*
> *P: I can tell you more truth because it's about our life. Those people [government officials] have everything. I have been suffering for seven years, I am almost alone. I cannot afford more than a potato and bread and I forgot what meat is like. I have anaemia and so have lost most of my teeth. (She took off her artificial teeth and showed me her condition.)*
> *(P: Uzbek Participant D)*

Disabled research participants heavily criticise the rhetorical speech of the government officials. They describe their reality in a very different way. In both Kazakhstan and Uzbekistan, categories are given only after 16 years old. Before that, they are entitled to one category, "disabled children." This directly leads to a practical problem because allowance is the same amount regardless of their severity of impairment especially during childhood.

The category system also causes **practical problems** for disabled people. First of all, the governments try not to give categories to save money after the financial crisis:

> *Nowadays it's very hard to find hearing impaired people because **it's very difficult for them to get the disability categories**. Our state always wants to save money even by sacrificing the health of its citizens. The Medical and Social Expertise Department is very strict. (Chairperson B in a Kazakh urban area).*

The government officials did not raise this reality at all in the interviews. Moreover, the above government official stated that those who are not satisfied with the decision taken can appeal and complain to get the proper category. However, in reality, people are afraid of the negative consequences and cannot fight with authority. Under such fear, **self-censorship is the coping strategy against their governments** even in relatively more democratic countries such as Kyrgyzstan and Kazakhstan:

I am supposed to be in the second category. But the experts do not grant it because the second category is paid more. So I am in the third category. We have those people who cannot move, who are supposed to receive the first category but they [the government] want to save money so they give those people only the second category. I'm supposed to receive the second category. I have diseases from head to toe. But I got the third category. But I keep quiet because if I complain, I'm afraid that they don't even give me the third category (Chairperson C in a Kazakh urban area).

Even this chairperson cannot make a complaint even when having more connection with politics than general disabled people. Thus it is unrealistic for a general disabled person to think to fight against the authority, which is understood as a fight against the whole system where the president is at the top. Even some hospital doctor who is a government official criticises the Category Department because the department does not accept the recommended diagnosis given by the hospital but changes it "easily with their power" to another one (Uzbek government official C). Giving a category directly means that the government spends money in the form of an allowance, which gives an incentive to the government not to give out the proper categories but a lower one or none. As a result of this government "manipulation," the number of disabled people is much less compared, for example, with Russia:

We have 2.5 times lower statistics of the number of disabled people than in Moscow due to the fact that people cannot register themselves as disabled here (Zagyrtdinova Feruza Borisovna in personal communication).

At the same time, **the absolute number is decreasing** in Kazakhstan:

On a conservative basis, we have 380,000 disabled people in Kazakhstan. Earlier, we said, 480,000 disabled people. Where are the 100,000? Maybe there is a financial problem and so [the government] cancelled the category grouping of disability (Kazakh Participant B).

This reality shows the **profound vulnerability of the disabled population in "transition"** who rely on allowances and cannot get them easily. Furthermore, the amount of pension is decided according to the number of years engaged in employment, while disabled people especially those in the first categories "cannot work." That means, disabled people get the minimum pension due to this structural contradiction (Wazaki, 2003). In other words, priority is not on disabled people in the structure.

Both Kazakh and Uzbek government officials admit that the problem is a lack of money to implement all the possible services written in the law:

We are trying to do our best. It depends on our economic situation. If we have a stable economy, according to the president, pensioners and disabled people should get help. (...) The economy is the first thing. The social question is not the main question. If you have USD 100 in your pocket, you can buy with your money lots of things in the bazaar. But you cannot afford yourself a Limousine with the money you have. This is the reality. You should take this into consideration (Uzbek government official D).

A recession in macro economics is often considered as an "irresistible" force to cut down welfare services also in developed countries (see ex. of Finland in Vehkakoski, 2004). **Government officials think additional services for the disabled people are a luxury rather than a right.** The basic needs are, thus, considered as not necessary, which is wrong. The governments prioritise their financial condition over the rights of disabled people in this practice related to the category system. However, the government has absolute power. Thus disabled people are afraid to raise their voices against the injustice due to fear of their governments. They keep silent even though not only their pensions but all sorts of benefits were cancelled or reduced after the financial crisis in Central Asia. For instance, "Fewer and fewer [disabled] people get higher education" (Kazakh Participant C):

> *It changed. Now we have to do everything ourselves. Previously, we relied for everything on the state. In Soviet times, we had education and everything. But now we have to arrange them ourselves (Male non-member A in a Kazakh rural area).*

> *I remember that I had privileges before. The necessary medicines were free of charge. It was easier. Then privileges were cancelled. And when the privileges were cancelled, **many patients with asthma died because they couldn't afford to buy the medicine on their own.** There were so many deaths. I cannot explain. Many people died. It was 5-6 years ago (Female member C in an Uzbek urban area).*

The reality after the independence is devastating for disabled people due to the vulnerability when they need certain services to survive and those are cut off. Various benefits were cut off by now all over Central Asia. All that is left for them is mostly only an allowance depending on different categories. However, almost all research participants claim that this is too small to live on:

> *R: How much is the rent of the apartment and the pension?*
> *P: This is my example. My pension is 10,000 Som (=10 Euro) and the rent is 14-16,000 Som per month, which includes utilities.*
> *R: Ok, I see. Then it's really not enough. You really have to work. For the person in a wheelchair or those persons in the 1st category, is the pension enough for them?*
> *P: No. If we can walk, then good. But they have to take a taxi.*
> *(P: Uzbek Participant A)*

On top of the rent, disabled people need to pay for food, clothes, medication, transportation and so forth. Under the current situation, more severely disabled people suffer more because the allowance is the same and they need more resources due both to disability and impairment. That is, the **capability approach in development** (Sen, 2004; Sen, 1999) is valid because disabled people need much more resources to survive than non-disabled peers and thus income poverty affects disabled people more badly than non-disabled peers. Uzbek Participant C says ten times of the amount of pension is necessary for the living, which is around 100 Euro. When non-disabled people expressed that they need 50-80 Euro for their living (Wazaki, 2003), 100 would be an honest and realistic estimate for a disabled person because s/he needs more money for handling both disability and impairment on top of the daily expenses. War veterans have a slightly better pension and some compensation money for utilities, though they also face similar

problems of much reduced privileges. The **newly introduced market economy employs few disabled people** who are labelled as non-competitive and "invalid" due to the discriminating environment. At the same time, people inherited the tradition to stay passive and rely on the government. Therefore, quite a few disabled people have to beg money to make their ends meet after the dramatic change in their lives. That is, disabled people are extremely vulnerable especially after independence.

<u>**Practical Difficulties**</u>

The practical difficulty is not only about the decrease in welfare services. Different practical difficulties are within the category system itself. Firstly, **the category has to be renewed quite frequently.** The category is valid for a limited time such as for six months, one year, and two years. That means, the people concerned have to renew their categories when the previous one expires. This is because the category system is meant for the whole population, not only for disabled people. When one's health has deteriorated by temporary conditions such as breaking bones and illness, this category is also applied for these people. For those people who suffer from temporary illness and injury, recovery is expected after some treatment and rehabilitation. This cycle is applied for the chronic condition of impairment, which is the reason why they also have to go through the same procedure of renewal as others. Kazakh government official B explains this renewing rule:

> *R: In case of a chronic condition of disability or chronic disease, do they have a longer period of category or do they have to renew every six months, one year or two years?*
> *P: Those people who are retired, 63 years for men and 58 for women, they get a category without any period. For example, those who have been under observation for a long time, and didn't change their situation. For example, those who are under our examination for four years under the 1st category and six years under the 2nd category with the same condition can get the category without any period. If they don't have any significant change, we give a category without any period. If he has a slight change, then he has to renew his category.*
> *(P: Kazakh government official B)*

What the government official assures us is once again different from the reality explained by disabled people. Disabled research participants claim that they usually have to go through this renewing process although they have a chronic condition of impairment:

> *I know one lady with breast cancer, whose breast was cut away. Then she has another cancer spread from the breast. Every year, still she has to go through the procedure to confirm her category. Every year, she must show her breast to prove that she does not have them. She said, "It's written in the document that I don't have a breast. Why do I have to show them every year?" She is now under treatment and hospitalised. But she anyways needs to go through the same procedure to confirm that she needs the same category of disability for the following year, too. She is very upset about this (Female non-member A in an Uzbek urban area).*

This category situation is the same for disabled children. This **"equal treatment for all" policy rather than "equal opportunities for all" policy** is reinforced by the category system. Every time when they go through this procedure, they reassure the label of abnormality.

With these unpleasant experiences, some disabled people try to go around the repetition:

> *Last year, her sister gave her enough money to get the disability status easier. That is, the money was used for bribery. Now everyone should pay for getting the category for a longer time because everyone is fed up with going through the same procedure every year always from the beginning. It's very difficult and needs lots of money (Female non-member A in an Uzbek urban area).*

Bribery is one of the coping strategies for those disabled people who are aware of their proper category, who want to have them and who have enough money to pay:

> *The complicated situation to get a disability category means non-disabled people can get categories to get their pensions. This phenomenon is the very struggle that we have here, **corruption**. I and my colleague are both disabled. She has a lever malfunction and her pension is about 15,000, while I am disabled person from birth and I am treated well and my pension is 3000. My friend has the 2nd category and I have the 3rd category. (...) But as she has her husband who has a good job and both of her children are working as medical doctors, she can get the higher category of the 2nd category unlike me. I ask, "Why do you need the pension when you are not poor?" She says, "If some money is available, why not use the opportunity? There is no way not to use it." I know that there are many corruptions like this. In reality, real disabled people don't have the money to pay for bribery to get the category or a higher category. Those people who have money can get illegally these categories and pensions. Now we can say that this is the struggle of corruption. This is against disabled people (Female non-member A in an Uzbek urban area).*

That is, disabled people are financially vulnerable, firstly due to impairment and disability that require additional money and secondly due to this corruption. Only few disabled people exceptionally acknowledge their rights and also know who is entitled to get categories by reading law because the information is not available. In order to get the wished category, some choose to act instead of giving bribery:

> *R: Is it difficult to change the categories?*
> *P: Yes, very difficult. As I am [well-educated], I knew how to prepare the necessary documents and how to behave to the commission of the Category Department. [My husband] was laughing at me because if the staff of the Category Department would see me at home or at work, they wouldn't give me any category. I had to pretend to the commission that my disability is much severer than it actually is. For example, I told them that it's difficult to walk and I have to have the support of the wall to walk. I have to complain about life to get this category (Uzbek Participant W).*

Those who know this cunning technique are few. Most of the disabled people are given some category and have to follow the made decision.

The third strategy is to use connections. One of my neighbours in Uzbekistan has a cousin working in the Category Department. With this connection, the father of this neighbour got a

good category and pension. This cousin told her, "People can get only the 3rd category if you don't have good connections or money to pay for bribery." The neighbour told me, "The richest doctors are working in the Category Department because they get bribery for giving categories." The majority of disabled people, however, do not have money, knowledge of law nor connections and thus are left without a proper category. Thus vulnerable disabled people are made even more vulnerable through this category system.

Medical institutions are not only harassing the entitlement to have a proper category, but also cause other practical problems in the daily lives of disabled people. **Medical doctors are often very ignorant of impairment** and cannot give proper advice or treatment. Some doctors are even scared of seeing disabled people (Uzbek Participant W). Some "doctors give only a vitamin injection. Not physiotherapy, not occupational therapy" (Chairperson A in an Uzbek rural area) and other doctors just say, "It's useless to treat anymore" (Female member C in an Uzbek rural area).

Government officials rhetorically spoke about their free medical treatment. However, in practice, **medical treatment is not free**. Patients need to pay some money to the doctors:

> *When you come to a clinic or hospital, we have no medicine, we have nothing. If you pay money illegally to doctors, then he has everything and says, "OK, I do it" (Uzbek Participant M).*

This means disabled people cannot get medical treatment because they cannot afford to pay any money out of such small pension:

> *In Dushanbe, there is one rehabilitation centre. This is a centre to define what category of disability people have. And to some extent you can get rehabilitation. There is a health station, some small rehabilitation points. But for some reason, they are not reachable by disabled people. Firstly, they are far away from the homes of disabled people. Wheelchairs cannot get there because buses are not accessible for them. Unfortunately, these services are too expensive. Because the pension is so small, those services are not reachable by disabled people (Tajik Participant B).*

Government officials are right in the sense that medical institutions exist for disabled people. The reality, however, is that they are not making any difference for disabled people because **the services are not available** when disabled people do not have enough prerequisites for getting the services such as accessibility and extra money for treatment. Government officials are satisfied with the services without taking into account the reality. The **perspective of disabled people is totally missing.** In addition, Kazakh Participant F points out that there are too few hospitals and too many patients. Moreover, skilful professionals and specialists have emigrated (Chairperson B in an Uzbek urban area). At the same time, equipment is scarce. Therefore, the condition of the medical institutions is not ready to pay attention to the needs of disabled people. Especially preventive works and rehabilitation work for small children and rehabilitation in general are very limited, not to mention social rehabilitation. In this way, the health condition of disabled people easily deteriorates with the lack of enough medical treatment. This increases the vulnerability even more. That is, governmental medical policy and practice is clearly part of the vulnerability creation mechanism.

Systematically Produced Ignorance

On the one hand, disabled people are not aware of their own rights written in the law, and on the other hand, the laws are not implemented. Without knowing the law well, some disabled people even lose the acquired category:

> *The Category Department always gives a category only for one year. She got the treatment twice a year, and she came to the Department again. They asked, "Has the symptom got any better?" And she honestly answered, "Yes" as she was feeling better. And they told her, "In that case, the category will be changed from 2nd to 3rd." And she agreed but she had no idea what it meant in her real life. In reality, it's very difficult for her to get the 2nd category back. They always try to make the category lower and it is really a big problem for disabled people (Uzbek Participant W).*

It is easy for the medical specialists to control disabled people because they are ignorant. **Disabled people cannot feel ownership of their own lives** because they are ignorant as sufficient information and informed consent are missing. The lack of knowledge of their rights also means that they cannot lobby for the violation of the law of their own governments:

> *Our officials also break the law. In the law, all is mentioned, barrier-free environment, getting information, education and medical services, but none of them is working. But when we don't know the law well enough ourselves, we cannot complain to the officials about the law (Tajik Participant A).*

Disabled people usually know little about their own rights because of various reasons. First of all, once again the **history of the Soviet Union** was mentioned as one of the reasons for the lack of information:

> *Previously, we didn't know about the problems of disabled people during the Soviet time. When I encountered this problem, I couldn't find any information anywhere. I couldn't find answers to my questions anywhere. And I began to work in this field myself and I began to be involved in the Third Sector. I couldn't find any publication related to deafness (Chairperson B in a Kazakh urban area).*

People were made passive then. Furthermore, they did not have any rights whatsoever. This history was valid until only a decade ago. Therefore, people, including disabled people themselves, are not ready to think that disabled people also have equal rights. Only a very limited number of people started to seek for information actively as this chairperson, while many others passively waited for things to happen.

Another explanation is the fact that **disabled people and their families are isolated** from the rest of society, which also prevents them from reaching the necessary information. **Information delivery** is one of the big problems. Due to the need for additional support for going out under current circumstances, it's simply difficult for disabled people to go out. Information, therefore, does not spread easily. Furthermore, frequent amendments in the law after independence make the situation harder:

Many of them don't know about the existing privileges. Every year, there are some amendments in the laws and many people don't follow these news especially in the villages (Chairperson D in an Uzbek urban area).

In this way, most of the disabled people cannot enjoy decreasing but anyways existing privileges only because they are not aware of them. In Uzbekistan, disabled people are entitled to have free medical treatment once a year. However, those who are not aware of this right are away from any medical care for even 10 years (Male staff A in an Uzbek rural area). Their rights are so badly ignored:

R: How you know so much about the privileges? Does anybody tell you about it?
P: I heard it from my friend and she got to know about it from her friend. I learned about it later in my life. These privileges began in 1991, and I learned about it only in the last 5 years.
R: Oh, so the first 6 years, you didn't get any privileges?
P: No. I paid in the same way as others.
R: So you have to know about it to get the privileges.
P: Yes, yes. No one told me.
(P: Female member A in an Uzbek urban area)

Knowing other disabled people is an advantage for getting such relevant information for some. However, as was mentioned earlier, many of the places where disabled people met each other such as rehabilitation centres and institutions were closed down after independence because of the "irresistible financial crisis." Therefore, disabled people are even more isolated from each other.

While several Kazakh disability activists published about disability during the last several years in Kazakhstan, I had difficulty in finding any written information on disability in Uzbekistan. Uzbek Participant W reveals that **information is hidden** so that disabled people would not start demanding privileges:

R: I am trying to find literature or information on disabled people's lives, but I cannot find them. Do you know where can I find them?
P: I can tell you my story. When I was working in the Republic DPO, the statement of the DPO was hidden in a big safety box and was locked very tightly. We have a law called, "Obligations and responsibilities" which mentions the rights of disabled people and some privileges. And then it was explained, if disabled people know about this law, they will demand them. And neither the DPO nor the government can satisfy the demands of disabled people, if they once demand them.
(P: Uzbek Participant W)

She continues, "You cannot find the document even in the disabled people's organisation!" DPOs are one of the few sources of information for disabled people. However, especially GONGOs follow the governments' example and hide the information of disabled people. In this sense, many GONGOs are part of the discriminating structure. As a result of many barriers, government policy is out of reach from disabled people. Only those who are lucky enough to have learned their rights can enjoy them at the moment both in Kazakhstan and in Uzbekistan. Some

interviewees, especially those from rural areas, state that they have a good life without knowing other choices. **This system of information delivery makes already passive people remain ignorant.** Ignorance of disabled people is systematically produced so that governments do not need to devote too many resources on them.

Under these circumstances, disabled people know **lawlessness** from their own experience:

> *Our constitution is right. All people have rights to education and rights to health insurance, but only in the constitution. They do not have wheelchairs for moving. That's why they mostly stay at home. There is no ramp. Our law is violated because we have no rights to education and no rights to medical insurance (Uzbek Participant C).*

Some chairpersons of DPOs try to convince government officials about their reality. However, they fail because there is a big gap between disabled people and government officials:

> *When we go to our government, we don't understand. They cannot understand us. We cannot understand each other, because they are not disabled (Uzbek Participant C).*

Government officials are ignorant about the reality of disabled people. Disabled people, therefore, cannot influence the government by direct means. When it comes to an election, disabled people do not have **right to vote** either in many places and cannot influence:

> *There are those people who are disabled and they cannot go to these places to vote. That's why the election committee will go to their homes with a special basket so that they can also vote. This was only in our district. Other districts didn't have this system and so disabled people couldn't claim their rights. And democracy is first of all the freedom of choice. And voting for those people will tackle problems for you. You can vote the best candidate for you (Chairperson I in a Kazakh urban area).*

In his report on mentally disabled people and people with learning difficulties in Central and Eastern Europe, Goldston (2004) points out the deprivation of various rights, which includes the inability to participate in public decision making through voting in these countries. In Central Asia, due to the inaccessibility and huge prejudice that physical impairment means mental disability, many physically disabled people cannot participate in voting either. This lawlessness and distrust of government officials, especially local authorities, are commonly perceived problems that the disadvantaged group of people experience in general (Gleason, 2001). However, the pressure of self-censorship does not allow disabled people and their families to speak up about their problems to the governments:

> *Parents are afraid to complain to the government about the poor conditions of the institutions. They are somehow under pressure that something bad happens if they complain. (Tajik Participant E)*

In this multi-layered systematic hindrance, the issues related to the lives of disabled people have still been hidden in society because individual **disabled people do not have any means to influence the decision makers** under the current circumstances in Central Asia.

Summary

In summary, the Central Asian governments have taken over the Soviet practices towards the lives of disabled people as if they are all curable and workable in the near future. In this regard, the medical model of disability makes great sense in Central Asian governmental policy and practices because the governments conceptualise disability as an individual abnormality rather than the discriminating social environment. The difference from the Western model is the much bigger role that the governments play in the lives of disabled people in Central Asia. As current regimes took over the authoritarian and controlling role of the government from the Soviet regime, the government practices have a big impact on the lives of disabled people. Especially as the governments reproduce the abnormality concept in disability, disabled people, especially those who have been left out of the disability mainstream of blind and deaf people, suffer greatly from the lack of equal opportunities and rights. Disabled people are still mostly excluded from society without proper education and employment, which was accelerated by the introduction of the market economy which imposes competition on "invalid" and non-competitive disabled people due to the environment. Furthermore, disabled people do not have any means to appeal against this injustice to the government in addition to the fact that they are systematically made ignorant of their rights. As a result, disabled people are still hidden and forgotten in Central Asian societies. The next sub-chapter explains the social mechanism under this government policy and practice that force disabled people to become passive to cope with the reality.

3.3. Mechanism for Creating Passivity as a Coping Strategy

What actually happens in the lives of disabled people as a result of the above-mentioned background conditions in Central Asia is the next theme. Many different aspects of daily experiences make up the mechanism that is against disabled people to be mainstreamed. Clarifying such aspects is important in the sense that disabled people can tackle them in their daily lives later on when they are aware of the factors instead of taking it for granted as an individual issue. Firstly, the prejudice of both society and the closest people profoundly affect the way of thinking of disabled people. In daily communication with the surrounding people, an inferiority complex and low self-esteem are created. This psychological aspect is one of the main difficulties to overcome because they are created through the relationship with the closest people who are influenced by the governmental policy and practice. Secondly, different turning points in the lives are to be investigated. They are education, employment and family life. They are the most frequently mentioned turning points that reassure their deviant position in society. These turning points make mainstreaming of disabled people more and more difficult, as time goes on in their lives. Finally, isolation is too frequently the result of such a mechanism as people are systematically forced to become passive in their lives. Different changing and evolving aspects affect their lives, which means that disability is not the only decisive aspect determining one's life. However, the social mechanism surely exists which tends to pressure disabled people to become isolated and thus vulnerable. As they are made isolated, they naturally do not think of their issues as social issues but individual ones. In this way, discrimination is eventually individualised and normalised in their lives. This whole mechanism prohibits disability issues from being acknowledged in society as if there was no such issue at all. This sub-chapter, therefore, tries to prove the main factors of the mechanism at different stages of their lives. Another important point to pay special attention to is that the disabled research participants describe their lives in their own words.

3.3.1. Prejudice of Society and Family

Prejudice is one of the main reasons for the mental pain of disabled people and one of the most difficult problems to overcome (Morris, 1991). This part focuses on the issues around prejudice in their lives. The investigation of this theme would lead to some possibility in the future to overcome this one of the most difficult problems. In that sense, this theme is important. The discussion starts with how the prejudice has been so profoundly created by now. Experiences of the disabled research participants prove that the prejudice is deeply rooted in society: prejudice in the public sphere. The closest family and friends of disabled people also have such a prejudice against them in such discriminating society: prejudice in the private sphere. In this way, many different layers of prejudice exist both in public and private spheres in society. As a result of the profound prejudice, the first consequence is that disabled people are hidden and not recognised as victims of social oppression because they are physically isolated. The second result is that disabled people lose power over their own lives as they internalise the negative image of themselves through the dependency creation mechanism in the relationship with the closest people. Eventually, disabled people are reinforced to remain vulnerable. In this regard, prejudice both in public and private spheres is one of the biggest and the most acute problems to tackle.

Prejudice in the Public Sphere

The Soviet segregation policy and current governmental policy have contributed to create the large ignorance of society towards disabled people and their issues because disabled people have been excluded and thus society is not familiar with disabled people. The Soviet legacy leads to the reality that still 1.3 million children, disabled people and elderly people live in 7,400 institutions in Central and Eastern Europe and in the Former Soviet Union countries (Tobis, 2000:v). On the other hand, some institutions and rehabilitation centres were closed down due to the "irresistible financial crisis," which unexpectedly brought many disabled people physically back to society. Society did not have previous experience of the community-based social services of disabled people. As a result, prejudice has now come to the surface as a big problem for disabled people in society. **Endless examples** were mentioned in interviews about their prejudice experiences:

> *When you are out in the wheelchair, you are like a monkey in a cage, so you are fed up with that. So you can only be either in your flat or outside. You cannot go to any kind of building, hospital or something. And there are children staring at, people pointing with their fingers, so you are fed up with it. (Turkmen Participant C)*

> *When I use public transport, I use it very rarely, but when I use it, even if I am not disabled as badly as in a wheelchair, I feel the attention to myself all the time. When you are on the streets in these republics, you don't see disabled people. That's not because there are no disabled persons in our countries, but because of the attitudes of people. People are very intolerant and rude, like "Why are you here? You should be sitting at home." (Kyrgyz participant D)*

> *I was living on the 4th floor, when I sustained my injury. And we moved into the first floor after the injury. My neighbours from the old house know that I am not mentally disabled and they treat me like before as if I don't have any impairment. But neighbours in the new apartment treat me as a mentally disabled person because I am in a wheelchair. A*

wheelchair does not necessarily mean that I am mentally disabled! (Female Member B in a Kazakh urban area).

A direct encounter with people in society is a difficult experience for disabled people (Goffman, 1963), especially for those who are severely disabled people because society has normalised the idea that there are no disabled persons in society. In other words, society does not expect disabled people to exist. Disabled people are "invalid" and are treated accordingly as if "We are people of the second class" (Tajik Participant A). **Stigma** is attached to disabled people (Goffman, 1963). A non-disabled chairperson working for an NGO for disabled people explains the feeling when he started to work for disabled people for the first time:

> *I tell you one story. When I was a newcomer, I couldn't see disabled people's eyes. I felt guilty because I am healthy and they were disabled. If you can forget such a feeling, you can work and try to help them. It's very hard for some people to see disabled people without legs and arms. That's why they cannot work with disabled people. You can see a disabled person only once a month, not everyday (Chairperson C of Disability NGO in an Uzbek urban area).*

Non-disabled people do not know how to deal with disabled people due to the lack of previous experiences and thus prejudice. This **ignorance is mutual between disabled people and non-disabled people** (Goffman, 1963). One club organiser for disabled people and non-disabled people conducted a survey and found out that non-disabled people are afraid of disabled people and vice versa:

> *I made a social survey if they [non-disabled people] are willing to communicate with disabled people and why they didn't communicate with disabled people. They said they would be willing to communicate with them, but if they see disabled people on the street, they cannot come and talk to them to get acquainted with them because they are afraid to hurt them. Then I called to disabled people asking them why they are not communicating with healthy people. They again said they are afraid of talking with them because they are afraid of annoying healthy people. Then it turned out that disabled people are afraid of healthy people and healthy people are afraid of disabled people (Female non-member B in a Kazakh rural area).*

The mutual ignorance is a big barrier. The interaction between disabled people and non-disabled people is scarce, which reinforces the prejudice of society on the one hand. On the other hand, the fear of disabled people to encounter society limits the interaction. Without knowing the ability of disabled people, society tends to pity them and faces them with a **paternalistic attitude**:

> *When talking with healthy people and when they have a different opinion, they begin to force on us their opinion (Female member D in a Kazakh urban area).*

Disabled people, therefore, are deviant in the social structure. Kazakh Participant D often gets money without begging just by moving on the street in her wheelchair because people pity her. One common coping strategy for disabled people to deal with this huge prejudice is to disregard them. However, not many can handle this situation in this way because of their painful and continuous experiences. Many rather tend to limit their opportunities because they do not want to

face the prejudice. That is, **they try to avoid the interaction with society by staying at home in self-defence**. Some bravely do try to be mainstreamed by encountering society. Yet, even those who temporarily manage to succeed in integrating themselves with mainstream society cannot avoid facing the **continuous prejudice**:

> *Another disabled person, [name of the person]. He is also very clever. He is also a qualified computer programmer. He can make programs. He was recommended to work in a foreign company. But then the director of the company came to him and said, "Your existence spoils the image of the company when our clients see you. My clients will stop coming here." He wanted to work very much. The company used his skills and experience but he had to work at home due to the words of the director (Female non-member A in an Uzbek urban area).*

These **prejudice experiences force disabled people to reassure their labelled abnormality** even when they are mainstreamed at some point in their lives. This is one step to the internalisation of the negative image of self.

The mass media was accused of this prejudice for broadcasting little about disability issues to society, unlike the supportive argument of the government officials towards the media:

> *R: About the mentality of people that you cannot change, why do people have such a mentality towards disabled people?*
> *P: This is due to the lack of information from the mass media. There should be more information. There should be articles in the newspapers about them. The mass media need to propagate the lives of disabled people. Not like an advertisement. I'm not a professional in the mass media, but there should be some work in the mass media about this.*
> *(P: Uzbek Participant P)*

That is, an **indirect encounter with disabled people through the mass media is also limited** to society. As both direct and indirect encounter with disabled people is extremely limited, society still carries the same prejudice against disabled people since Soviet times. This conversely means that current society is not yet ready to accept disabled people as active members of society:

> *There is an attitude of society of healthy people towards disabled people. "What else do you need? You have a pension. It is not sufficient but you have a nice apartment and it's warm and in very good condition. You sit at home. You don't have to work. You can sit. You can watch TV. What else do you need?" The attitude of society is not ready to accept disabled people as active members of society (Female Member B in a Kazakh urban area).*

This is similar to the statement of the government officials in Chapter 3.2.2 calling disabled people "prestigious." Disabled people are not allowed to make their own decisions in this context but are expected to remain happy and passive under the "prestigious" conditions. This **prejudice ignores the possible abilities of disabled people outside their homes.**

Possibilities to Deconstruct the Prejudice

Prejudice is a socially-created attitude and thus changeable though it is "extremely resistant to change" (Dolisso, 2000:16). Dolisso continues that a change occurs in three primary ways. The first way is to encounter the object directly. Secondly, effective communication also plays an important role to change the attitude. Finally and thirdly, "forced compliance" can also help in changing the attitude. When one has inconsistency between his/her attitude and action/behaviour, then s/he is more likely to change the attitude to adjust for the same direction as the action that one is motivated to follow. Festinger (1957) calls this third way a cognitive dissonance theory. When these theories are put into the context of Central Asia, the following result most likely takes place. Firstly, encountering disabled people is very limited in the daily lives of non-disabled people due both to the physical and psychological barriers for disabled people to go out from home. Almost the only encounter for society is that with disabled beggars. Begging activities were prohibited during FSU, which became permitted after independence. The number of beggars has been increasing drastically from 1702 people in 2002 to 2034 in 2003 in Uzbekistan (Wazaki, 2003). The same study on Uzbek beggars shows that 12% of the studied beggars were blind and 13% physically disabled people. Subsequently, a non-disabled person would more likely to have some negative attitude towards those beggars because self-evidently the beggars cannot fit into the current system. Therefore, the first way to change the attitude is yet extremely difficult in Central Asia. When it comes to the second way of effective communication, it is even more limited. Only few are aware of the rights of disabled people and have a capacity for the effective communication to take place. Therefore, the second way does not take place often either. Finally, their negative attitude and their negative action are quite consistent in these countries that people do not feel "forced compliance" for changing the attitude to anything better. As a result, **the prejudice remains if no intervention occurs**.

Positive Attitude Is Only a Minor Experience

Some exceptions were mentioned in interviews. Positive comments about their society were mentioned by those who were integrated into society such as those who went to mainstream schools and universities instead of special boarding schools for disabled students (Uzbek Participant W, Female member F in an Uzbek urban area, Female member B in an Uzbek rural area). They did not experience much prejudice in the integrated environment. War veterans are also treated with honour and not with prejudice though they are also disabled people:

> *R: Do you think the attitude towards ordinary disabled people is different in comparison to veterans?*
> *P: Maybe many people show more pity for ordinary disabled people than for veterans. For example, if a person is disabled from birth, then we of course feel sorry for him. But as for me, Afghan veterans and ordinary disabled people are two different groups of disabled people. It's another thing because an Afghan veteran became disabled due to fighting for the motherland. It was the order of our government.*
> *(P: Chairperson D in an Uzbek urban area)*

This social distinction between the war veterans and disabled people indicates that disability can be socially deconstructed. Disabled people can be mainstreamed when society treats them differently. However, the number of mainstreamed disabled people is too few. As has become clear, prejudice against disabled people in the public sphere is severe. At present, this socially constructed disability has too little mechanism to be deconstructed because even the closest

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people such as family members of disabled people also carry this profound prejudice. Prejudice in the private sphere is the next theme.

Prejudice in the Private Sphere

The family's attitude is directly influenced by the prejudice of society as they live in a discriminating society. Therefore, the history of the Former Soviet Union and the current governmental policy and practice significantly influence the lives of disabled people also through the relationship with family members. Some families are very supportive, while many others unintentionally contribute to degrade the lives of their disabled members. **When a disabled baby is born, the unfortunate story quite frequently begins already.** Some parents such as the parents of Uzbek Participants A, B and C abandoned the infants and left them to some institution:

> *R: What happens when a disabled child is born?*
> *P: It depends on the family. Usually, parents don't fight for the coming life, but give the baby to a boarding school institution and they try to have another baby who is healthy. **The idea is to get rid of the disabled babies**.*
> *R: Does it mean all the children in the institutions are abandoned?*
> *P: Most of them are. The government takes care of them. Both parents are alive, but very brutal. When they leave the baby to institutions, they give up their responsibility. You don't have to take care of the baby anymore. The institution will do that. Some parents visit the babies, but mostly do not. Maybe once a month, some parents visit the babies. Mostly as the years and years pass, parents don't visit them.*
> *(P: Tajik Participant E)*

Orphanages are occupied by a number of abandoned disabled children (Sabonis-Helf, 2004). This fact proves the prejudice of families.

While many Western countries have been deinstitutionalising disabled children and people, Central Asia still continues this practice. While the West started to acknowledge the rights of disabled people, Central Asian countries continued to segregate disabled people from the rest of society. This is an eloquent example of the prejudice of their family against disabled people in Central Asia.

Many reasons are mentioned for abandoning disabled children, such as low expectation for disabled children, poverty and traditions. First of all, **low expectation** is deeply rooted in quite a few families as society and the parents are ignorant of the disability issues:

> *There are also families who would think that a baby born disabled would not be a person who could independently live and enjoy the life. With such a family, disabled people are prohibited from the freedom of speech and the right to be happy. They lack all the joy of life, and they have only the right for food and they are thought to be helpless persons. They are considered as far from non-disabled peers only because they have some impairment. (Tajik Participant F)*

Until the baby is born, the family consists of the discriminating society. Therefore, low expectation is natural for them. With the low expectation for disabled children, many families abandon their disabled children. The prejudice leads to this action. Especially Slavic families tend

to institutionalise their disabled members in comparison with Uzbek families in Uzbekistan (Wazaki, 2003). Some other families decide not to institutionalise the disabled babies. Although families keep disabled members at home, parents tend to expect very little from disabled children and give away many opportunities that the same age peers without impairment would enjoy. Several mothers of disabled children told me in front of their disabled children, "There is only hope left for the daughters (her son is disabled)" (Mother A of disabled child in an Uzbek rural area) or "It's pity to see him all day like this" (Mother B of disabled child in an Uzbek rural area). They did not treat their disabled children as full human beings but treated them as if the children did not have any dignity. If family members differentiate disabled children from non-disabled siblings, the most natural consequence is that the **disabled children learn their role as deviant from such daily conversation** and the attitude of the family members. This low expectation exemplifies the profoundness of the prejudice against disabled babies and children.

Another frequently mentioned reason is **poverty**. Some families abandon their children because the birth of a disabled baby means that one of the parents has to stay at home, which is most probably the mothers:

> *One always has to stay at home to take care of the disabled child and the financial situation of the family is very bad (Female member C in an Uzbek rural area.)*

Many fathers abandon even their wives when a disabled child is born:

> *The situation of the disabled children's family is catastrophic. When a disabled baby is born in a family, the father leaves and the mother stays at home to take care of the disabled persons. There is no treatment mechanism. The mother has to quit her work. There is no other income except for a 3500 Som (=3,5 Euro) pension. (Citation of an Uzbek person in Hahle, 2003)*

In this way, some families send their children to boarding school institutions because they have to work to earn their living for other family members:

> *On the one hand, it's very painful to have a disabled child in the family. But on the other hand, you can overcome it if you are working with their children. But some parents are not strong enough, not devoted enough to make efforts to work for the upbringing of their children. I know that we live in a very hard economic situation. And sometimes parents have to earn money (Chairperson A in a Kazakh urban area).*

This poverty leads to a different result for some other families when they are encouraged to get even a small pension to support the income of the families. When children are sent to boarding schools in Karakalpakistan, the pension has to be taken away from the parents and transferred to the boarding schools where the children study. One survey revealed that 72% of the studied parents were not ready to send their children to boarding schools, of which 22% answered the reason being due to the fact that they have to transfer the pension to the schools (Uthepbergenova, 2002). Families also get education compensation money of 3711 Tenge (=24 Euro) for teaching their children at home in Kazakhstan (Dumbayev, 2003). This poverty also explains the reason why disabled children suffer from much less opportunities. Different reasons make disabled children stay at home:

Not all families with disabled children send them to governmental institutions. They choose not to send them because of different reasons. Some cannot imagine how it's possible for some to give your own helpless child into strangers' hands. Others do not know about the existence of such institutions. The third reason is that they are afraid that they don't get a pension for the child because it's not paid when the child is in an institution (Uthepbergenova, 2002).

In any decision, **disabled children do not have the ownership to decide what they want**. They are considered "helpless" and the surrounding people decide the most suitable solution regardless of the wish of the children.

When disabled children stay at home, then **tradition** hinders them. Traditionally, families are to take care of any family matters. An Uzbek *mahalla* (neighbourhood committee) officer says disabled people rarely come and ask for any help from *mahalla* "firstly because there are only few disabled people in this district and secondly because disabled people usually live with family or relatives and so live a good life." One mother also mentioned that they do not belong to any DPO because "First of all, I have to do everything for him while I'm alive" (Mother of Male non-member B in an Uzbek urban area). Social consensus that the family should take care of disabled members is still the mainstream way of thinking all over Central Asia:

Shame is one of the ways of public blaming. That is why families try to solve their problems inside the families (Uzbek Participant O).

Zagyrtdinova Feruza Borisovna, an Uzbek disabled female lecturer in the Second Tashkent State Medical Institute, clarified the deeply rooted tradition of this family care from the Koran:

The Koran says, "Orphans and disabled people must not go out from the family. If there is no family, he shouldn't go out from relative connections."

In this way, many disabled members stay at home, if not institutionalised. However, they do not get the proper dignity that they deserve because parents are ashamed of their disabled children due to the penetrated social prejudice:

There are illiterate children where we are supposed to get free education. Many parents are guilty of this phenomenon. The mentality of [the rural area]. If you have disabled children, then parents hide them and force them to stay at home. It's the mentality. They cannot understand that they are also human beings (Uzbek Participant V).

This tendency of **stigma and shame** is more frequently mentioned in Uzbekistan than in Kazakhstan and more **in the rural areas** than in the urban areas. Especially in rural areas in Uzbekistan, these disabled infants are hidden at home and they are not recorded in the statistics at all (Uzbek Participant W). That is, disabled members do not count as part of the population.

Another family tradition of the order of marriage also deprives disabled people of love from their parents:

In this culture, before the oldest daughter gets married, nobody could get married. And parents are upset when the oldest one is disabled and three more daughters are waiting for marriage. This is hard for the oldest disabled people (Discussion among Tajik men in the seminar in 2002).

Respect for elder persons is still a visible cultural practice in Central Asia. The positive aspect in this statement is the fact that disabled people are not totally ignored. However, when this is applied to the context of disability, it becomes pressure. Due to prejudice, the first born disabled females have difficulty in getting married, while the family pressures her to marry for the sake of the younger siblings. She is in a dilemma between society and the family. This **cultural norm** reinforces the tendency for the disabled members to become vulnerable at home on the one hand, and justifies the institutionalisation on the other. This gives a great incentive for the family to give away disabled girls. In this way, disabled people tend to be deprived of opportunities within each family in society.

Impact of Prejudice against Disabled People
Any issue related to disabled people is still hidden within institutions or in each family. Therefore, disability does not become a social issue. This treatment of family members leads to both practical problems and deep psychological pain for disabled people. When disabled members stay at home, they "**depend on the family completely**":

R: How much support do you need from your family?
P: Almost everything. Almost all my life depends on them.
(P: Female Member A in a Kazakh urban area)

We completely depend on the family because we don't believe in the government, so we depend on the family. We depend on neighbours, too. They are very close to us. I never starve. I can always get a piece of something from the neighbours. It's not like "to live" but "to exist". This is my opinion but all Tajik people cannot live with dignity but just to exist. If you live, you enjoy your life, but here you have to worry about how to get food everyday in order not to die (Tajik Participant I from a rural area).

All sorts of practical supports are offered by closest people to such as family members, relatives, neighbours and friends when the government support is not reachable. From food shopping to toilet support, disabled people depend for many things on their closest people around them. Even finding work depends on the family members. Only when the family has good connections, then the disabled person gets a "decent job" (Chairperson B in a Kazakh urban area). The above citation from Tajik Participant I epitomises the difficulties in this dependency on the closest people that they "exist" without dignity.

One deteriorating factor around dependency is the **practical difficulty** to cover all the needs of disabled members. What is a simple thing for a non-disabled person is not simple for a disabled peer due to the discriminating society. For instance, going out from home is very demanding work without accessibility at home, equipment, accessible transportation, and enough money to be able to pay for a taxi. One female person could not visit a dentist for 10 years and suffers from the pain because nobody could take of her there (Female member C in a Kazakh urban area). Furthermore, disabled people often need additional expenses for medicines, medical treatment

and technical devices, which make them and their families financially vulnerable on top of the existing poverty. **Families with disabled members have to work very hard** to meet the needs of the disabled members:

> *She [my daughter] needs to work because she has no other choice. She has to pay for me. My pension is only enough for my medicines and she has to pay all the rest like the apartment rent, utilities etc. She has three jobs. She is 28 years old. She has no personal life. She has no time for that. (Female member C in an Uzbek urban area).*

Due to the lack of rehabilitation work and due to the expensive medical treatment, many cannot afford such medical treatment regularly. As a result, medical care becomes also the responsibility and another "burden" on family members or disabled people themselves. However, they are isolated from each other and do not have knowledge of proper medical care:

> *I diagnosed many children when they were small babies. They were not bad when I diagnosed, but without proper rehabilitation, their symptom usually became worse after some time. Children don't have any second prevention work, in other words. Those children who were able to speak failed to do it because they didn't have proper treatment and rehabilitation. Many children came with paralysed arms and legs due to a lack of rehabilitation. Parents didn't know what to do with the children. We decided to organise some activities in our regions (Chairperson A in an Uzbek rural area).*

> *The treatment is very expensive. I cannot be in any hospital because I cannot pay for it. I'm always at home and treat myself here (Female member B in an Uzbek urban area).*

That is, families are ignorant about the whole issue of disabilities, while the discriminating society is not ready to offer proper support for their conditions. In this way, the health condition of disabled members of the family easily deteriorates. These additional conditions that families have to provide are so many under the current reality. The care of the family can determine the improvement or deterioration of the living conditions of disabled members. At present, families tend not to be able to provide all that is necessary, which easily deteriorates the health condition, for instance, that makes the care even more difficult as a result. This makes dependency practically even more difficult for both the disabled members and the families.

Dependency is problematic also in terms of the **psychological aspect** of disabled people. The relationship with the family often causes deprivation of their power through psychological difficulties. Due to dependency in difficult financial and physical conditions, disabled people often feel that they are a "burden" and "worthless" to their family:

> *I'm dependent on my parents and it's very embarrassing at my age because my pension is enough only for the utility (Female Member A in a Kazakh urban area).*

It is a painful experience for disabled members to see their families suffering from further poverty because of them. The disabled people feel negative about their existence from the relationship with the closest people. They get **low self-esteem** as a result.

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On the other hand, they are very grateful for what the families and closest people are doing for them in this unfavourably constructed world (Tajik Participant R, Female member B in a Kazakh urban area, Female member D in an Uzbek urban area etc.). They have to be grateful for their help because they know that "they do this on a voluntary basis" and so "I am grateful to them but they cannot help me every time (Female member C in a Kazakh urban area)". This **feeling of gratitude makes disabled people vulnerable** because they continuously feel that they owe something, which creates a hierarchy in which disabled people are inferior.

> *R: Somebody comes to help you out, then?*
> *P: I ask my relatives and acquaintances, but cannot ask them for free because petrol is very expensive and it's hard for them, too. If he or she will help me for free, for the second time I feel very uneasy to ask him again.*
> *(P: Female member D in a Kazakh rural area)*

In this way, even though a disabled person has his own will, too many things rely on those closest people and their **decision-making power is gradually but systematically deprived away from them through mental pain**. This is witnessed in a Western context in the relationship between volunteers and disabled people (Katsui, 1999).

Another psychological factor is the **internalisation of the negative image** that family and the closest people carry. "The stigmatized individual is also asked to see himself from the point of view of a second grouping: the normals and the wider society that they constitute" (Goffman, 1963:115):

> *Mentality is not only your point of view. Your point of view is according to the point of view of society and its environment. So it does not depend just on you. So your parents teach you and your friends to say something and you form your point of view with the help of them. So it depends what people are surrounded by. These things are interrelated (Male non-member A in an Uzbek urban area).*

As a result, disabled people learn to have an "**inferiority complex**" when their closest people feel negative about them (Uzbek Participant A). This deeply-rooted prejudice has been internalised into the way of thinking of disabled people. Thus disabled people often carry the same negative image stemming from the medical model of disability in the discriminating society. Consequently, disabled people end up having low self-esteem. In this way, the daily lives at home with their family cause different problems concerning dependency.

As a result of these practical difficulties and psychological pains, dependency takes away the decision-making power of disabled people. Disabled people cannot decide by themselves because they depend for many things on the closest people. I asked, "How often do you go out?" One disabled male answered, "Depends. When my friend is free, I go out" (Male member A in a Kazakh urban area). They **cannot make decisions independently due to dependency**. This dependency eventually leads to the creation of **passiveness** as their coping strategy. Here is the mechanism. As disabled people depend so much on their family and closest people, it causes problems when family members get tired of taking care of them. Some feel **psychological violence** when a family member ignores them, while others experience physical violence as well (members of Kazakh Participant D). Disabled people have great difficulty to avoid the violence

and so have to accept it instead. More than that, the family members who take care of the disabled people at home make them not only physically dependent but mentally dependent due to **overprotection and low expectation**:

> *In our country, even if your son is 40 years old, she [the mother] does everything. She gives advice even if he doesn't want it. She forces her opinion. "You must not do this." "You must do this." That's why there are many young people who are dependent and don't work because they got used to other people deciding the well being of the person from childhood. He does not have any idea what he would do. (Uzbek Participant F)*

> *There is one more problem that parents don't bring up their disabled children properly. They treat them as sick persons, so children sometimes are too overprotected and cannot live in society. They cannot help themselves. I think this is a world-wide phenomenon but it's more acute in Kazakhstan (Chairperson A in a Kazakh urban area).*

> *Now we face those teenagers with disabilities who cannot do anything. First of all, we work with the parents explaining to them that if the parents die, what the children are going to do? (Chairperson B in an Uzbek urban area)*

In this way, the guardianship makes disabled people in Central Asia passive. That is, the decision-making power is taken away. This guardianship is observed also in the West (Pascall and Hendey, 2004) and in Central and Eastern European countries (Lewis, 2002). Therefore, finally when disabled people lose parents, disabled people are left "all alone" without proper skills to survive in this world (Tajik Participant S, Male member A in an Uzbek rural area). Their lives are determined due to this environment where **dependency is the only way to "exist" rather than to "live."**

Positive Change Demands a Lot from Families

There are examples of understanding family members who try to make positive changes, though such active parents are not many. In the West, too, "exceptional parents" are the driving force to overcome environmental problems of young disabled people such as the challenges of housing needs, a discriminatory labour market, the need for personal assistance and transport (Pascall and Hendey, 2004). In the West, these parents are typically those with a high education with prior experience of disabled people and with bigger economic resources to mobilise. Therefore, the social stratification is reflected in the lives of disabled children if they could enjoy independence in the future or not. On the other hand, in Central Asia, parents are typically passive due to the legacy of the Former Soviet Union. Furthermore, the social prejudice against disabled people is huge. Therefore, **"exceptional parents" are a minority**. Moreover, an understanding family practically means that they have to fight against the discriminating society. Some parents were very determined to give education, medical treatment or some other necessary opportunities to their children. Then, "[t]hey live for the sake of me" (Female member D in a Kazakh rural area). Therefore giving up and "**not thinking about the future of a disabled member is convenient for the parents**" (Chairperson A in a Kazakh urban area). Depending on the persons around disabled people, some get lots of care and others don't have any (Uthepbergenova, 2002). That is, "exceptional parents" are also the driving force for disabled youngsters to overcome their challenges. In this regard, the family plays an essential role in Central Asia as well as in the West.

At present, however, they tend to play a negative role to deteriorate the lives of disabled people, with or without their intention.

Summary
In conclusion, the segregation history of the Former Soviet Union is reinforced in the current regimes in Central Asia. This governmental attitude is reflected well in society in the form of prejudice and hits disabled people also in the relationship with the closest people. In this way, the everyday life of disabled people is surrounded by multiple layers of prejudice both in the public and private spheres, which effectively make disabled people internalise the abnormality concept. That is, **the governmental policy and practice follow eventually the practical difficulties and psychological pain of disabled people in their daily life experiences**. In its process, disabled people are made dependent and powerless. They are reproduced as passive and ignorant. The next sub-chapter highlights the turning points in their lives when they reinforce their abnormality and deviant role in society.

3.3.2. Turning Points in Lives ~Education, Employment and Family Life~

At certain turning points in their lives, disabled people strongly reassure their deviant role in society. These are education, employment and family life. They were the most frequently mentioned spheres of discrimination. These overlap with the spheres of the Western disability movement towards the independent living of disabled people (Blaser, 2003; Goffman, 1963). These turning points could be the very opportunities for non-disabled people to overcome vulnerability if any and to increase their status in society, which should be the case also for disabled peers. However, this part reveals that it seldom happens so for disabled people. In this sense, these turning points are one of the decisive differences from non-disabled peers. Investigation of these turning points clarifies that the vulnerability is a social creation that stems from the previously mentioned and deeply rooted prejudice. Disabled people lack chances to get out from the mechanism, which is the main point of this sub-chapter.

Education
As for the education of disabled people, governments in Central Asia inherited the **segregation policy** of the Former Soviet Union. This is the first turning point in the lives of many disabled people that makes them feel different from their non-disabled peers. The **quality and quantity of education decreased all over Central Asia** after independence, which hit disabled children badly on top of the already discriminating educational system:

> *With the decline of the Soviet Union, over those years when our country has been developing, the quality of institutions for disabled children is decreasing because the best teachers left the institutions. And there isn't so much funding. Children don't have textbooks and devices. Special libraries are worsened. For example, a library for blind people with Braille materials. That's why the quality of education declined drastically also at home. But the requirement for the entrance exam has increased. It has increased due to commercial education. But many disabled children are from poor families. That's why over the last 10 years, so few [disabled] people have had higher education (Kazakh Participant C).*

*With decline of the USSR, the situation was worsened because some cities cannot stand this kind of **financial burden**. Even in Almaty, two types of boarding schools were closed down in 1990, at the beginning of the Perestroika period (Kazakh boarding school teacher).*

Segregation policy is now changing into exclusion from education as a whole. Governmental committees examine six-year-old-children, identify diagnosis and make a decision if a child should go to a mainstream school, special boarding school or stay at home. "Initial diagnosis" is given earlier than this but in terms of education, this committee makes the decision. Thus "there is no choice" for the parents what to do with their children (Chairperson B in a Kazakh urban area). Once again the decision making of the governments play a big role in this field of education as well as the above-mentioned medical services. Disabled children very rarely go to mainstream schools because the committee does not allow them, regardless of their wishes. Disabled children need to have a special permission document from the committee to enter into mainstream schools. That is, the medical model of segregation policy is also applied in educational policy and practice. Tajik Participant F introduces the view of government officials:

When you visit officials, they say, "Disabled children are not worthy to study with non-disabled peers. They need to go to special schools" (Tajik Participant F).

Government officials are not exceptional for the penetrated prejudice. Governments in Central Asia stipulate universal free education up until secondary education in their Constitutions. However, many research participants claim that the law is violated because it is not applicable to disabled children. Many disabled children cannot study not only in mainstream schools but also in special boarding schools. Uzbek Participant O points out this fact from her own statistics on disabled children in the district of her DPO activities:

Now we gathered information on education. Only 13-14 (disabled) children out of 385 (disabled) children in our region are studying (Uzbek Participant O).

At the moment, **"[a]lmost all disabled children are illiterate in our country"** (Female non-member A in an Uzbek urban area). Those children who do not get education are not included in the public statistics, which an Uzbek boarding school teacher thinks wrong. This statement vigorously supports the existence of the big gap between the reality and the public statistics which shows a high percentage of the elementally school attendance rate. However, the government does not change its practice. Thus the governmental education policy and practice hides the whole issue of education for disabled children in many senses.

Various barriers prohibit disabled children even to go to special boarding schools. When I visited one boarding school meant for physically disabled children[10], no child in a wheelchair was studying there. Teachers explained this is due to the lack of the facility. That is, "Physical independence is the key criteria for the entitlement to education in this country" (Male member B in an Uzbek urban area). **All those who are not physically self-sufficient are not able to study even in special boarding schools.** This physical self-sufficiency is one of the most important criteria to enjoy a "normal" life in Central Asia, which will be mentioned further in the following.

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[10] Pupils are categorised according to their diagnosis and placed in special schools that are specialised in the diagnosis.

Another reason to explain the low number of enrolled disabled children in boarding school institutions is the fact that **boarding schools are mostly located in big cities** and the number is limited. Therefore, children have to be sent far away from home:

> *While you cannot move by yourselves, you cannot get into a kindergarten. It applies the same for schools, too. So if you cannot move, then children stay at home. I thinks it's a better idea for children to stay at home and study rather than sending them to far-away-institutions because I worry about the child if he is far away (Mother G in an Uzbek rural area).*

The available choices are so few for disabled children: staying at home or being sent to boarding school institutions. **Leaving the family behind is a tragedy** from the point of view of the children:

> *There are too many children studying there, and many are from rural areas. They visit home only for holidays, and so they are like guests at home. Those who are from Tashkent can visit homes on holidays. So for them, it is better. Those parents who have opportunities visit the school, but the children whose parents don't have opportunities to visit them, they go home only for 3 months [a year]. To say honestly, if a child is in a boarding school, it's tragedy that you live away from the families (Female member D in an Uzbek urban area).*

Boarding school education, therefore, takes away the rights of many disabled children to live with their families. For families in rural areas, this is too difficult. As a result, the children stay at home without proper education. In either case, the rights of disabled children are not carefully taken into account.

Furthermore, **financial poverty** after the drastic change in the economy also explains why disabled children are not even in special boarding schools:

> *There are four terms in one year and after each term, they go back to their family but at their own expense. Therefore, the transportation cost is too much for some families. Poor families let children stay at home without education. Before [During the Former Soviet time], there was a privilege of 50% discount for transportation but there is none now. But they have to be accompanied by the parents, and so the transportation fee is a big problem for children's education. Thus before, there were 300 students but many children from regional areas don't come to school anymore due to that. Privileges were cancelled after the privatisation of the railway company around ten years ago (Boarding school teacher in Uzbekistan).*

Many families with disabled children in rural areas cannot afford to send their children to schools, as they are already financially vulnerable by paying additional costs such as medical treatment and medicines. One teacher in a Kazakh boarding school explains that parents donate money for purchasing materials so that children can sell their handicraft products. Parents also need to buy stationery and textbooks. Education is supposed to be free but not in practice. Disabled children in these countries are not allowed to enter into the mainstream schools nearby

their houses due to the medical diagnosis. Furthermore, they cannot go to boarding schools far away from home either.

For those disabled children staying at home, some teachers teach them at home in principle according to the law. However, the quality of the education at home is much worse than that in schools:

> *P: The teacher came here for three years but she stopped visiting us.*
> *R: Why?*
> *P: Because the Social Protection Department pays so little money to her and she does not bother to come and visit us because she has enough work to do in the school she belongs to. They were tired to come here for one and a half hours. (...) She became very tired after her teaching in her school. She made him (my disabled grandson) write something and fell a sleep. No one comes now because they are tired in their work.*
> *(P: Grandmother of male member B in an Uzbek urban area)*

Once again, the convenience of surrounding people determines the important aspect of disabled children. **Disabled children do not have ownership in education either**. Many mothers of interviewees revealed that teachers visit the children for very short time such as 2-3 times a week for 30 minutes (Mother B in an Uzbek rural area) or even several minutes at a time (Mother A in an Uzbek rural area). Other teachers stopped coming and disabled adults are "completely illiterate." For instance, Male member B in an Uzbek rural area got his education only up to the first grade. The UN Office for the Coordination of Humanitarian Affairs (2004) reports that teachers have low salaries with much reduced benefits. As a result, teachers mostly have to work in some other places to be able to make ends meet. This generally difficult working condition for teachers does not motivate them to additionally teach disabled children at home. Uzbek Participant M studied at home for a while and entered a special boarding school. She tells how bad the education at home was from the comparison between them:

> *I had the same experience because I studied at home till 7th grade. I was educated very badly then. Then we wrote a petition to a magazine. The magazine published the letter, "This girl needs help to be able to study properly. She needs a special document to be able to study in the boarding school." I got the document and entered the boarding school. And this was the worst time in my life. From 4th till 7th grade, I needed to study once again. I started from the 4th grade in Tashkent. I almost didn't know any Russian words (Uzbek Participant M).*

Education in boarding schools is better than studying at home. However, it is far from mainstream school education because "Education here is lower due to their diseases" (Uzbek boarding school teacher). Their studying hours and curriculum are set at a lower level in comparison with the mainstream schools due to the low expectation towards the pupils. In special boarding schools, students do not learn several "complicated subjects such as physics, chemistry and biology" (Uthepbergenova, 2002).

When it comes to education for deaf students in both Kazakhstan and Uzbekistan, they are also not satisfactory because teachers cannot speak sign language and force students to speak verbally instead:

Mostly these children go to kindergarten and are taught how to distinguish sounds and how to improve speech. The school tries to avoid sign language. These children cannot understand what they are asked and leave the schools without understanding what to do and being furious and annoyed (Chairperson B in a Kazakh urban area).

The medical model insists on "rehabilitating" deaf pupils to speak, instead of giving them an opportunity to speak in sign language. The education system moves with the medical model, which causes various practical difficulties for disabled students. Moreover, living conditions in schools are also not good. Tajik Participant E says, "Those children always have to fight for a piece of bread." When I asked for information about boarding schools from Kazakh government officials, they tried to hide the information by saying, "Both the special boarding schools and institutions are under construction and so you cannot visit them." However, Kazakh Participant D immediately pointed out on the same day that they were not under construction. This experience suggests to me that these schools are the weak points in their governmental practices that **the government officials want to hide from outsiders**.

As for the **attitude of society**, prejudice is huge against such boarding schools. Another experience of mine supports this fact. When trying to catch a taxi, I faced the difficulty in finding a taxi to take me to the school. Many drivers did not just go into the area "because that area is for disabled people." Some drivers burst out laughing and said, "Are you sure you want to go there?" This was an explicit example how society deals with disabled people. Teachers of the schools also reflect this prejudice when they talked to me about prenatal abortion:

The government should promote abortion for those disabled children because it's so difficult for the family and the children to be born disabled. This is a governmental problem and so we cannot solve the problem (Boarding school teacher in Uzbekistan).

This **eugenic thought** came directly from the Central Asian medical model that labels disabled people as invalid, abnormal and/or worthless. This deeply penetrated medical model in the attitude of the teachers causes **psychological problems** for the students. Uzbek Participant A recalls her school days in a special boarding school and says, "We noticed that our teachers began to think on our behalf and we became passive". She continues,

There is a certain barrier after finishing school in such an environment. We cannot usually decide what to do after graduation. And now I know that our graduates still face the same problem (Uzbek Participant A).

Passivity is created among disabled children in the relationship with the boarding school teachers because once again disabled children are not treated as full human beings. They are deprived of their decision-making power during the school period. The independence of the countries did not automatically change this practice in schools.

Uzbek Participant K mentions the **mechanism for disabled children who eventually become beggars**:

Sometimes a normal [non-disabled] woman gives birth and the baby is disabled. Then she refuses it and leaves the baby to the hospital. These babies stay in the hospital for a while and move into a special institution, awful. Most of the children live in a special institution, and become homeless and beggars because they don't put up with facilities. No money. They are treated very brutally. It's better for them to be on the street and poor but they are more independent than in special institutions. In these institutions, you are always fully dependent on other people, and nothing is good. They are beaten, discriminated against because it's not home (Uzbek Participant K).

Without self-management skills, children in institutions have no power "to show themselves what they can do." Therefore, after children turn 18 years old when they have to leave the schools, they hardly have any skill to live independently and with dignity. For instance, a study claims that 60% of the graduates of blind people's schools cannot find jobs and consequently become beggars in Uzbekistan (Wazaki, 2003).

Especially spending time with non-disabled people is totally new and overwhelmingly difficult after living only with disabled peers in such special boarding schools:

You know, it's like an inferior complex. We had one world, boarding school, and there are only disabled people around you. When I was faced with healthy people, we didn't understand each other (Female member F in an Uzbek urban area).

While studying in boarding school, disabled children are isolated from healthy children. When they graduate from boarding schools, it's just problems for disabled children to adjust to the healthy society and to be employed. They have a lot of stress. They feel like second class people. And on the other hand, other people treat you as abnormal persons. And the second problem of isolating disabled children from the rest of their peers is that the other children will think that these disabled children should be isolated (Kazakh Participant C).

Primary education is a big turning point for disabled children in Central Asian countries in the sense that society normalises prejudice and segregation policy in its process. Furthermore, throughout the education period, disabled children gradually lose the decision-making power both at home and in boarding school institutions. Education is a place for disabled children to learn their "abnormality" once again.

As for higher education, disabled people need special permission from hospitals to enter into mainstream universities. Even if a disabled person gets good enough scores in entrance examinations, s/he could be rejected:

My son passed the entrance exam of a very prestigious college in Almaty. He passed 5 exams. And he got 2 points more than other students. The director denied his entrance to the university because he was a disabled person. And of course I couldn't put up with it (Chairperson D in a Kazakh urban area).

Discrimination is normalised because society does not consider disabled people as part of society. The problem clearly lies with society. Disabled people can go to higher education very rarely in

all Central Asian countries due to different barriers hampering them, especially the low educational level in the special boarding schools and the profound prejudice. However, this excerpt shows how difficult it is for a disabled person to be mainstreamed even if s/he qualifies. The educational system in Central Asia makes disabled children feel different, abnormal and prepares them to be separated from their non-disabled peers for the rest of their lives. Furthermore, the introduction of a market economy and competition worsened the situation by following the steps of the West (Rouse and Florian, 1997). At the same time, segregating disabled people in different educational institutions or at home limits opportunities for non-disabled peers to get to know disabled peers. This contributes to reinforce the prejudice among non-disabled peers also in the West (Doddington *et al.*, 1994:212-215). Western "special needs schools" also make disabled children internalise the sense of inferiority and constructs low self-esteem (Barton, 1988). The negative attitude of society is reflected in the space of education, which eventually affects the psychology of disabled people in a negative way. In this sense, education is one of the biggest turning points in the lives of many disabled people to reassure their deviant role in society. This turning point is deeply linked to the second turning point: employment.

Employment

After graduating from such boarding school institutions, "**We have few choices because we are disabled**" (Female member A in an Uzbek urban area). At this point, many disabled people have already internalised the socially constructed abnormality as normal. Many cannot find employment and so have to depend on their parents. This is another major turning point in their lives when they feel that they are different and inferior to others:

> *Another problem is the low educational level and unemployment. Sometimes it happens that the government officials don't realize our needs. They argue that disabled children can be isolated and it's better for them. Many graduates of special schools should be dependent on their parents because they cannot pursue further education or they cannot find work. So they depend on their parents (Tajik Participant W).*

A society which segregated disabled peers during the educational period is naturally not ready to welcome them to be integrated because the profound prejudice hinders it. When disabled people are employed, they can pay tax to the government rather than receive a pension. Judith Heumann, the advisor on disability and development at the World Bank, claims that this economic benefit has been widely unrecognised around the world (Heumann, 2004). As a result, after graduating from segregated boarding school institutions or studying at home, if there is any provided education at all, disabled youngsters continue to be segregated by staying at home.

On the other hand, **deaf and blind students tend to get jobs in workshops** belonging to DPOs and state enterprises. This tradition of the Former Soviet Union still continues to some extent though the number of enterprises has decreased, as independent governments cut down support for these enterprises:

> *There is a tendency: children enter school after graduating from the kindergarten for deaf children and after the boarding school, they are employed in different production units of DPOs. They receive a room in a dormitory belonging to the units. They produce haberdashery goods, robes and other things (Uthepbergenova, 2002:21).*

The number of officially registered deaf people, people with speech and hearing impairments is 20587 as of 1st of January 2001. Out of which 13330 people above 16 years of age are the members of this organisation. 10510 are employed: 4501 in state enterprises, 4219 in agricultural work, and 880 in our organisation. (Chairperson I in an Uzbek urban area).

Statistics rely on the number of people who have been given categories, which was proved to be difficult to obtain. In that sense, the numbers are only indicative as there might be more deaf people who could not get the medical category for some reason. The tendency to be employed in state enterprises, however, was mentioned by many. That is, deaf and blind people are segregated throughout education and employment from the rest of society. The employees even live in a dormitory type of accommodation, which physically separates them from society. This is one of the practices reinforced since Soviet times.

The reality of employment in Central Asia is hard in a different way for physically disabled people due to the lack of state enterprises and physical accessibility. Some continue on to special colleges for disabled students and learn vocational skills. However, the skill cannot be used in many practices due to the physical barriers:

P: I finished the special needs school, and then went into a special college.
R: Ah, there you learned the skill of sewing.
P: Yes. Yes. I studied there for three years.
R: After that, could you get a job?
P: No. It's very difficult for me to use public transport.
(P: Female member A in an Uzbek urban area)

Once again, the **criterion to survive in society is physical self-sufficiency** especially walkability in order to secure employment.

Those who managed to get a job are grateful for the education in the special boarding schools:

We got very good knowledge and education there. It helped us very much when we are employed (Uzbek Participant A).

This statement undermines the reality in which many disabled people cannot get good enough education at home. Thus graduates of boarding schools are grateful for the relatively good education compared with no education at all. Employment is difficult for many, especially when their families do not have good personal connections both in Kazakhstan and in Uzbekistan. Furthermore, the allowance depending on different categories is paid regardless of the fact whether the disabled person is employed or not. Thus, the Uzbek government is reluctant to pay both a pension and a salary to disabled people and try not to employ disabled people (Uzbek Participant W).

Furthermore, **employment or higher education as such does not directly mean that the disabled person is integrated into society** because the prejudice is everywhere and s/he has to fight against it continuously:

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The biggest difficulty is communication with healthy people. I studied among healthy people in higher education. But they didn't want to communicate with me. I communicated only with my own brain (Female member D in an Uzbek urban area).

In this way, many disabled children both studying at home and in special boarding schools become passive, are afraid to face "healthy people" and as a result isolate themselves from society without employment. Only few of those who entered into mainstream schools and who managed to overcome the psychological difficulties are integrated in society. Many others are trapped in this government-oriented practice of segregation and cannot leave the vicious circle that keeps putting them down.

Family Life
The third turning point of **family life is a more serious issue for disabled women than for disabled men**. Despite the fact that many disabled women express their "hope" and "dream" to have a family (Uzbek Participant H, Tajik Participant O, Female member D in an Uzbek urban area, Female member A in an Uzbek urban area etc.), the problem of marriage faces disabled women to a greater extent than disabled men:

I have one problem, a health problem to have a family. It necessitates finance. My personal problem is to establish a family. I want my own family. I'm honest. I say everything directly. I want to bring up my own child. I really want my own baby. And I want such a man who is good enough for my baby (Female member D in an Uzbek urban area).

I hardly know any woman who got married to a non-disabled man. For some reason, disabled men get married to healthy women, but not the other way around. There is this tendency (Tajik Participant A).

Our aim is to communicate more and meet more frequently because many people cannot find the company for getting married. A male can solve the problem 50% but a female cannot solve 90% of marriage and employment and other problems. I faced a lot of problems. (Uzbek Participant A).

That is, **disabled women are even more severely discriminated against in different turning points in life** (Rousso, 2003). The doubt and prejudice against disabled women reaches a peak when the time comes to establish a family:

R: Why do disabled women think that they are so different from the rest of the population? P: It is the attitude of society because society is not used to seeing disabled people so much. When a disabled person is out of home, for example, society shows that the person is disabled. As for a disabled woman, she can feel herself as a woman when she gets attention from a man. Even relatives of disabled women show that they have a disability and they'd better sit with the computer. A disabled girl is raised as disabled and she cannot feel herself as a woman because it has been going on since her childhood. It's a traditional point of view that women should be mothers and wives. When you think about

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disabled women, society thinks, "Can she become a mother? Can she take care of her husband? Can she take care of the household chores?" That's why society doubts us.
(P: Dana[11])

The prejudice leads to **doubts in society without seeing positive examples**, while disabled women have internalised the deviant role by the time family life becomes relevant. She continues that due to this doubt of their ability to play the **traditional role of women as mothers and wives**, disabled women are not considered to play any role as women:

> *Even local authorities do not understand that we are women. They cannot accept it. They don't see women in us. They don't see persons in us. They think that we are low necessities. (...) Our society always thinks that disabled women can never have a normal child. Society thinks, "Why do disabled women want children? They don't have money to raise disabled children." The community does not know that disabled women can deliver healthy children. They think, "Disabled women deliver disabled children and live in poverty, then why do they want children at all? At home, she gets a pension. She watches TV looking out of the window. Why should they have children at all?" So **reproductive rights** are another problem.*

Governmental segregation policy, poverty and prejudice are all interrelated to create huge discrimination against disabled women. Society does not blame the fact that it cannot accommodate disabled women but instead doubts their capacity. The rights of disabled women are badly ignored. Uzbek Participant K reveals, "Disabled women are very often sterilised. Very often they cannot have children." This is one of the most eloquent examples to deny the ownership of disabled women over their lives. In Central Asia, playing the traditional role of women as wives and mothers is so important that those who cannot play that role are labelled as "abnormal." Disabled women are labelled as abnormal already from prejudice even before they are given an opportunity to establish family lives. I have experienced this from my own experience in Central Asian countries when some male interviewees were astonished by the fact that I was researching at my age of 28 instead of having a few children. I was then considered abnormal.

> *A woman must be happy to have her husband even in polygamy because in Uzbek tradition women staying single are abnormal (Minnesota Advocates, 2000:23).*

This negative image of society about disabled women is once again internalised and plays a role to psychologically damage disabled women. Uzbek Participant A clearly says, "If a woman does not have a child, she wouldn't be a woman."

In spite of this public pressure towards non-disabled women to play this certain role, not only society in general but also close people such as families and boarding school teachers pressure disabled women not to become pregnant due to their prejudice. Society tends to believe that

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[11] Dana is a given provisional name in this study for a severely disabled woman in Kazakhstan who makes an impact in creating the disability movement in Kazakhstan after participation in a Finnish project. Her activities are introduced more in detail in a later Chapter 4.3.

children of impaired women are also impaired. Parents of disabled girls forbid them from having an interest in boys:

> *I have been working in an organisation since the establishment. We had girls of 11-10 years old. When they are grown up, they got interested in boys. We gathered together and asked them, "What do you feel about boys?" and "How you are going to behave?" Then these girls told me that their families are against their pregnancy. CP (Cerebral Palsy) children move with difficulties. Their parents told them, "No boys and no children because your children are going to be like you" (Chairperson J of a Kazakh urban area).*

Kyrgyz Participant B also witnessed some unsupportive family attitude towards disabled girls:

> *There is an example. A CP girl, who became pregnant. And she told her relatives and was thrown out of home. She had to find a place to live while being pregnant. And the doctors proposed having an abortion, but she refused.*

Disabled women are regarded as sexless and thus not qualified for family life on the one hand. On the other hand, when they get pregnant, they are rejected rather than accepted. When they become pregnant, medical doctors often pressure disabled woman to make a decision for **abortion** (Uzbek Participant W, Beggar A, Kazakh Participant D etc.). Disabled women are then in the **dilemma** between an internalised negative image of self as a disabled person and her feeling as a woman. This **identity** issue becomes problematic as their wish and discrimination in practice are conflictive. Doctors are not helpful according to many interviewees. Instead of advising them with different choices, the doctors reflect the general prejudice and ignorance towards disabled women. For them, "healthy children" are important:

> *Doctors are against pregnancy because during the pregnancy and delivering period, mothers and children are at a risk. Moral support is not available. When you become pregnant, they go through medical research in a hospital. If booked, then mothers go through ultrasonic tests. If the foetus is not developing normally, then pregnancy is terminated. Hospitals place an obligation poster saying, "It is not important whether the baby is a girl or a boy. It is important that the baby is healthy" (Kyrgyz Participant B).*

Without enough information, disabled women are pressured from every direction not to have a child and to have an abortion. However, before they become pregnant, nobody teaches them about family planning because society thinks it is an irrelevant topic for them. For instance, boarding schools do not teach family planning skills to their impaired students:

> *I was very puzzled because boarding school didn't give us any information on the family. Now I don't feel easy about it (Uzbek Participant A).*

Therefore, when they get pregnant, disabled women usually have to think what is the best solution by themselves without support from anybody or enough information. Kazakh Participant D experienced this **isolation** when she got pregnant:

> *If somebody tells me if I get a disabled child or not, then I will think about pros and cons and will decide for myself.* **Nobody explained anything to me** *(Kazakh Participant D)*

She continued her very painful experience of abortion. That was a baby of her partner. However, nobody knew what would happen. All were rather pessimistic about her getting a baby as a disabled woman. None of the doctors has gone through the delivery of babies from disabled women when she visited a hospital. Therefore, doctors were not supportive of the pregnancy due to their ignorance. She had to think how to support the baby when the partner leaves her because that often happens to disabled women in reality. She **struggled all alone** and came to the conclusion that it is sensible for her to have an abortion. She cried so much at that time and still feels devastated about the experience. **All the decision making and physical and mental pain remain in disabled women** as they are not treated with dignity.

Decision making about their baby is not the only struggle for disabled women. Those who decided to have a baby immediately face **financial problems** whether the baby is impaired or not impaired:

> *If a woman can do it [deliver a baby without a husband], she does it. I wouldn't do this if I were alone. But he desired this child as well. [They decided not to use contraception.] I also wanted to do this. Many people have children even if they are not married if they can afford this, if they can give all the necessary things and not abandon the babies. Our allowance is 50 dollars per month. And this is a very small amount of money to raise a child on your own, if you want to educate him and to dress him (Female member D of a Kazakh rural area).*

Financial responsibility is one of the first criteria that increases doubts about the capacity of disabled women. Once again, disabled women are vulnerable to making their own decisions due to the living conditions. This is the first hurdle for having a baby. Moreover many husbands and partners very frequently leave the disabled mothers and children. Yalcin (2002:22) claims that generally divorce is "extremely rare" in Uzbekistan, which is not true for disabled women. As a result, **many disabled mothers have to take care of the children alone**:

> *R: Are there lots of disabled women raising their children alone?*
> *P: There are a lot of them.*
> *R: Without getting married?*
> *P: Some of them got married and divorced and some are without any husband.*
> *(P: Female member A in an Uzbek urban area)*

Therefore, a pregnant disabled woman struggles with her feelings that she wants the baby and with the fear that she has to raise the child on her own in the future. Family planning is thus a tough experience for disabled women because the responsibility is mostly on them whatever they decide. In this sense, they are all alone.

For those who got married and acquired impairment later on, **divorce** is the common scenario:

> *R: Are there lots of single mothers?*
> *P: The majority because it is an acquired disability. In such cases, husbands easily abandon their wives or become an alcoholic. It's better for the man to leave the family*

when he is an alcoholic because he demands his wife to give money for his drink or he beats and physically violates her. So in such cases, we suggest such a family to divorce. (P: Chairperson E in a Kazakh urban area)

Stigmatised disability can be justified as a good reason for divorce, which proves that disability is a human construction. People decide the value of a person automatically lower when she acquires impairment. When a woman gets impairment, her dignity tends to be ignored:

I have friends in [a place] and all they do is to make up a disability because their husbands don't take the wives when visiting guests. They have such a mentality that anyway she wouldn't come with me. "I would be embarrassed and ashamed to be with her." And sometimes it transcends all limitations because sometimes husband takes his lover home and sleeps with her in the house not considering the wife as a woman. And the wife would consider this as normal. She does not even try to get money. She does not think she could work (Kazakh Participant D).

As soon as a woman gets impairment, she **becomes an object** but not a human being with dignity. She then starts to internalise and normalise this as the closest people treat her in this discriminative way.

Along the same line, disabled women are too often **objects of violence**. Many women experience different forms of violence: some experience physical, some sexual, some verbal, and others psychological violence. This is sadly an international tendency for disabled women (Anderton, 2003):

When I was 19 years old, I got married to an [ethnicity] man. I believed that he loved me. But it was actually not true because he only wanted to have the residence permit as my husband wanted to flee his own country as a refugee. I got pregnant later on, but I was kicked in the stomach by my husband, which caused a miscarriage. The domestic violence was so bad that I decided to divorce him (Uzbek Participant H).

The third problem is violence against disabled women. When talked to a focus group, we found that over 50% of disabled women experienced violence both from the family and others. The violence is like a beating. You know, a disabled woman has tiny pension, and the other family members are drinking vodka. And they don't work. They spend the allowance of the disabled woman to buy alcohol. They beat her to get the money. This is not one case. This is regular practice. This happens often in many families. This is just because our women do not talk about it openly. They don't admit and feel shy to talk about it. (...) We found out that our women are raped often. Raping is another problem. Talking about it, we conducted a confidential questionnaire and there we identified that they were raped and not protected against it. They have never talked about it to anyone (Dana).

In this way, many disabled women are not protected from painful experiences in their family lives. As individual disabled women experience these hardships all alone, the issues are individualised although the experiences are common ones. Considering the context in which poverty prevailed after independence, disabled women are doubly vulnerable due both to poverty

and to the disability. Although the problems are in non-disabled people, disabled women are the ones to suffer. Furthermore, disabled women do not have the ownership over their solution. They have no means to tell the truth to others partly because they are made passive and mostly because they are isolated. Therefore, society does not get to know about this severe reality of disabled women as social issues although this takes place far too often. In this way, experiences in family life convince disabled people, especially disabled women, to feel abnormal and different from others. This is the third turning point in life.

Summary
The series of experiences around these three turning points in the lives of disabled people continuously reinforce their differences from non-disabled peers due to the different experiences. A variety of individual characteristics and changing valuables could lead to different consequences, which will be discussed more in detail in Chapter 3.4. However, mostly disabled people are forced to engage in the mechanism that continuously tries to put them under the abnormality label throughout their lives, especially through these three turning points. The reality around these three turning points clearly reveals the difficulty of disabled people to be mainstreamed despite the multiplicity among them. They lack the means to escape this reality. Consequently, what is waiting for them is isolation, which will be the next theme.

3.3.3. "I am all alone."
~Isolation Individualises and Normalises Discrimination~
As has been clear from the above Chapters 3.3.1 and 3.3.2, discrimination against disabled people is so severe that they remain vulnerable. In spite of the fact that too many disabled people suffer from social oppression on a daily basis, this issue has hardly attracted attention in society. The reason why this disability issue does not become a social issue but remains an individual matter is because of their isolation. Isolation is another layer of mechanism that reinforces the status quo. This dimension is important to study because this is too often the consequence of being a disabled person in Central Asia. At the same time, it is also important because this isolation explains the prejudice that was mentioned before. The word, isolation, accommodates so much mental pain underneath, which is clarified in the following.

Mental Pain
Disabled people tend to be isolated from the rest of the world as well as from other disabled peers. Therefore, they lack the mechanism to realise that this is a social issue because they live in a limited personal environment, internalised the medical model and believe that this life is difficult because of the impairment. That is, they are trapped in the medical model of thinking due to the environment which has been constructed around this model. For example, what disabled people want is **physical independence** because that clearly differentiates them from the rest of society. This is natural consequence of the internalisation of the dominant medical model, which also took place in the West (Morris, 1994):

> *If a person loses his physical power and ability, he automatically begins to lose his mind and soul (Uzbek Participant E).*

Walkability is the only way out at the moment for Central Asian disabled people to be integrated into society. Thus to be able to walk is a dream for many, such as female member A and C in an

Uzbek rural area. Financial independence through employment is another frequently mentioned dream. However, even the "work" of beggars requires physical self-sufficiency and good social support. Some of the beggars I interviewed did look physically non-self-sufficient. However, all of them have somebody who takes them to their "working places" and picks them up from there to home. Some implied to have a solid connection with the Mafia. From these interviews, it turned out that these people can move around by themselves or have some support from a close person to be able to commute. Severely disabled people are excluded even from begging.

When one is financially and physically dependent, the medical model is easily and deeply internalised in the mind of disabled people. Impairment is a chronic condition and thus disabled people cannot really obtain physical self-sufficiency under current conditions. In other words, disabled people feel they are abnormal and useless. They think they have to put up with the limited reality "because we are disabled." This **psychological barrier** prevents disabled people from working:

> *50% of disabled people have lost the meaning of their lives by themselves. There are some people who live at the expense of their children and their parents. I know one doctor who has the second category of disability. He can walk and visits me sometimes and complains to me about his life. And I told him, "What else do you need? You can walk and work. I can help you to find a job in a clinic or a hospital." But then he said, "I'm a disabled person. I cannot work" (Kazakh Participant F).*

> *There are many **problems of self-esteem**. I always have this thought, "Can I manage to be able to do this or not?" Maybe I need several years to be able to become more powerful and responsible. I achieve things that I am told to do, but not by myself starting new things. I have to study still. I need to study things. (...) I am just afraid to take the first step. I will need support so that I do not fall down in the street [metaphoric meaning]. (Tajik Participant J)*

Due to society which automatically labels disabled people abnormal, disabled people have little confidence in themselves. The doubts of society are reflected in the mind of disabled people about their own ability and possibility. Low self-esteem or inferiority, therefore, tends to be another consequence for many disabled people (Goffman, 1963). They have to struggle with a difficult psychological problem to come to terms with their impairment and disability that forces them to feel "different" from others:

> *On the one hand, people want to be part of society, but on the other hand, there are people who want to make ends meet. Disabled people have many more costs connected with their psychological stages because **injury is not only in the legs but also in the mind**. They need to buy medication and rehabilitation, so there is a greater need of money. And persons don't want to be differentiated from the rest of society, but there are so many more costs to cover. Disabled people are more sensitive to negative impacts than non-disabled people. For example, non-disabled people might think OK for a certain condition, but it is not OK for disabled people. Mostly disabled people feel fear of society. They try to be like other people, but **deep down in their hearts, they feel that they are not the same as the rest of society. And that is the feeling hanging over us** (Male member B in a Kazakh urban area).*

This psychological aspect is often undermined. There is hardly any program ready to protect disabled people from a series of mental pain, while society frequently reminds disabled people of their "abnormality." Many face this same psychological problem. They know, "I just understood that if I overcome this barrier, then I can live" (Female member F in an Uzbek urban area). Many, however, cannot stand this reality and become an alcoholic or a drug addict or commit suicide (Kyrgyz Participant A). This is the clear and sad example of **self-blame** stemming from the medical model:

> *There should be some key to people which would be very necessary when working with them. I would like to have such a key. For example, that girl whom I mentioned, she became very inward-looking saying, "I am a sick person. So I cannot go out and I cannot do anything." She isolated herself and committed suicide. (...) The death rate has increased over these three years. People die because they cannot overcome the psychological barrier and so they commit suicide (Chairperson H in a Kazakh urban area).*

Thus, one consequence of the isolation is desperation. This tells how profound the discrimination and the isolation are for disabled people.

Family members especially mothers of disabled children also feel desperate because of the reality. Some mothers struggle with alcoholic husbands, while others suffer from divorce due to the delivery of disabled children:

> *She does not want to live anymore. Her husband is an alcoholic and her child has CP. We helped her. She said that she had to live only for the child. This is a very common situation among the seminar participants (Chairperson B in an Uzbek urban area).*

> *For the last 11 years, our [DPO] has done great work in terms of supporting the most underprivileged group of the population. This includes disabled young people and mentally disabled young people. Most of them are brought up by single mothers (Chairperson A in a Kazakh urban area).*

> *R: Are there lots of husbands abandoning wives and their disabled children?*
> *P: 80% of males. If the child is ill, he cannot feed him. He can leave him. And these women have to live on 10,000 Som per month (=10 Euro) with the baby. This is the situation.*
> *(P: Chairperson B in an Uzbek urban area)*

Disabled people and their families suffer from the feeling that **they are all alone**.

<u>Acceptance</u>
Overcoming the psychological barrier and other barriers is too difficult for many disabled people and their families under the isolated environment. Thus, **disabled people start to accept disability and give up**:

> *R: What do you want to be after college?*

P: I want to be what I can be.
R: Don't you have any dream?
P: No.
(P: Male non-member B in an Uzbek urban area)

Acceptance of the reality as it is, therefore, becomes the natural consequence following profound isolation and discrimination.

Another psychological solution is to **believe in God**, which also helps disabled people to come to terms with their disability:

> *I made the conclusion myself. One can tell that one has such a condition. Why should one live with problems? If I don't like my work, but still I live. Then I began to ask myself. God created us to do something in this world. I made the conclusion that God created us because someone should be like us because by looking at us, healthy people could think that disabled people have very bad lives. This leads to the feeling of kindness. We help each other with our existence. They become kind because of us. And I never sit at home as a result. When people feel bad, they began to think what I am for. Remember my words. Anyway I make people feel kind (Female member D in an Uzbek urban area).*

They would like to have some significant meaning in their difficult lives to come to terms with. By believing that this was the good intention of God, some disabled people can accept their reality (Beggar H, Female member E in a Kazakh urban area etc.). They try to associate their lives with the discriminating society in this way. On the other hand, the corresponding behaviour takes place among non-disabled people. Non-disabled people feel "mercy" for disabled people and help them by believing "if you do good things, God will bless you and give it back to you twice over" (Director of the hotel where one of the seminars was held). In Islamic interpretation, beggars are understood to be the mediator with heaven for those who help the beggars (Wazaki, 2003). This self-profit of the givers rather than altruism frequently plays a role in the interaction between beggars and the givers. In this way, the roles of both actors match in the understanding of God's mercy, which gives complementary legitimacy for the action on both sides. This religious interpretation has the risk of reinforcing the inferiority of disabled people in relation to the superiority of the givers because disabled people accept the inferior reality in this specific relationship.

The third solution is to **remain passive and stay at home** instead of fighting with psychological and other problems. This is the most popular solution made by disabled people. Passivity helps disabled people to live a "good life" without knowing other possibilities:

> *Considering the passivity, is this our national feature? No, I don't think so. Maybe this image is profitable for our government. (...) I don't think passivity is the national feature. Maybe our government is interested in making the population passive. Passive can be treated in one day. Maybe we live well because we are passive now. For example, there is no heating system in Russia. They went on strike. But when that happens here, we just put more warm clothes on and wait till the heating system works. I still don't have a working heating system. I paid for the heater but why should I pay for the not working heating*

system? They just say, "It's your problem" (Zagyrtdinova Feruza Borisovna in personal communication).

As long as everything is due to the impairment and tragedy of individuals according to the prevailing medical model and workability model of disability, individual disabled people are the ones to deal with it. It is their fault that reality is against them with this model. In this way of understanding, disabled people can only passively stay at home and be isolated.

Isolation

Isolation becomes "normal life" for them. As they were trained to passively accept the way it was without any alternative ideas under the Soviet regime (Palubinskas, 2003), they naturally still feel that they have to live in the way they lived:

> *I had elderly parents and it was very difficult for them to take me out. Sitting at home made me feel that **I am destined to sit at home**. (...) I have never been outside for 10 years. I thought my way of living is quite rational. Relatives told me, "Be happy that you are alive. Be happy that you can talk." (Female member C in a Kazakh urban area).*

The natural consequence and solution, thus, for many disabled people in Central Asia is to stay at home when other choices are not available to them. Due to the multi-layered mechanism against them, there is hardly any space left for disabled people to suspect their possibilities. They are literally **imprisoned at home**:

> *I had an operation in 19**. Until then, especially when I was small, I had to stay in my room for 6 years without going out. I was talking with the walls at that time. I had a harsh history. (Uzbek Participant D).*

Only those who can go out at present can look back on history and think it was "harsh," while many others who still stay at home continue to think it is their destiny. What disabled people do at home is often just doing nothing:

> *My life is not interesting. I wake up in the morning and do some simple exercises. Our disease demands me to do this. I have some weight devices with me. I take a bath, cold and hot and cold and hot. Then I have breakfast. Then I watch TV. This is my daily life. Everyday is the same (Female member A in an Uzbek urban area).*

Staying at home for such a long time is psychologically very hard for disabled people. They feel themselves "very limited (Male member A in an Uzbek rural area)" or "You don't make any progress in life" (Male member A in a Kazakh urban area). After staying at home for a while, disabled people tend to **become even more passive**:

> *P: I cannot tell you exactly. I don't need anything. I became so passive.*
> *R: Since when you have become a bit passive?*
> *P: I noticed it has been two years since I started to be passive. I cannot say that I am really passive, but I put myself within these walls.*
> *(P: Female member A in an Uzbek urban area)*

While imprisoned at home, disabled people lack communication and "talk to the walls" (Uzbek Participant D) or "look at a mirror" (Female member E in an Uzbek urban area). In this way, they become "afraid to leave home and to be with people" (Female member F in an Uzbek urban area). Consequently, disabled people are **isolated from the rest of society** and lack information as well:

> *You know, a healthy person gets a psychological or physical injury and goes to a hospital after the injury and he does not know what to do being surrounded by four walls. A person has to fight against not only his injury, but he has to face solitude because there is no condition for disabled people in our country. (...) The most important thing for disabled people is communication with other people so that he or she could feel equal to others. And 80% of such people don't have the will or knowledge or intelligence to overcome these difficulties and lose all the meaning to their lives. (Kazakh Participant F).*

Without communication and things to occupy themselves, it is hard for them to avoid the psychological pain of feeling worthless. Though the feeling is the product of the environment, each disabled person is isolated and has few means to understand the surrounding social mechanism.

On the other hand, **non-disabled people remain ignorant about the whole issue of disability**. No one knows the situation of disabled people because they are imprisoned at home and hardly any disabled persons are on the streets. Family members and neighbours who help disabled people are also ignorant. Therefore, disabled people and their family do not have the means, knowledge or information not to be isolated. In this way, **disability issues are individualised and normalised** as long as disabled people remain isolated, passive and ignorant. As a result, nobody knows what disabled people want (Tajik Participant F). In this way, disabled people and their needs continue to be hidden from society. This **isolation, therefore, reinforces the prejudice**.

This passivity makes disabled people think that the government is responsible for solving this issue:

> *It all depends on the government. If the government is not interested in this issue, an ordinary person cannot do anything about it. (...) Our life in Uzbekistan depends on the government how it takes care of us (Uzbek Participant W).*

The majority of the interviewees answered that their governments should solve the problems when they are asked, "Who is responsible for solving your problems?" According to the study of Zagyrtdinova Feruza Borisovna on 250 disabled people in the capital city, Tashkent, the finding was the same. They depend on government decisions partly because they have been passive since Soviet times and partly because the government is too strong to make any influence on. Only some mentioned that they themselves are responsible for the solution. That is, disabled people do not take any action to escape this mechanism, while the government actually contributes to trap them into this mechanism with its policy and practices.

Vicious Circle

In this way, the following vicious circle exists and traps disabled people for their entire lives so that they could hardly ever escape from it:

Chart 4. Vicious Circle in the Lives of Disabled People
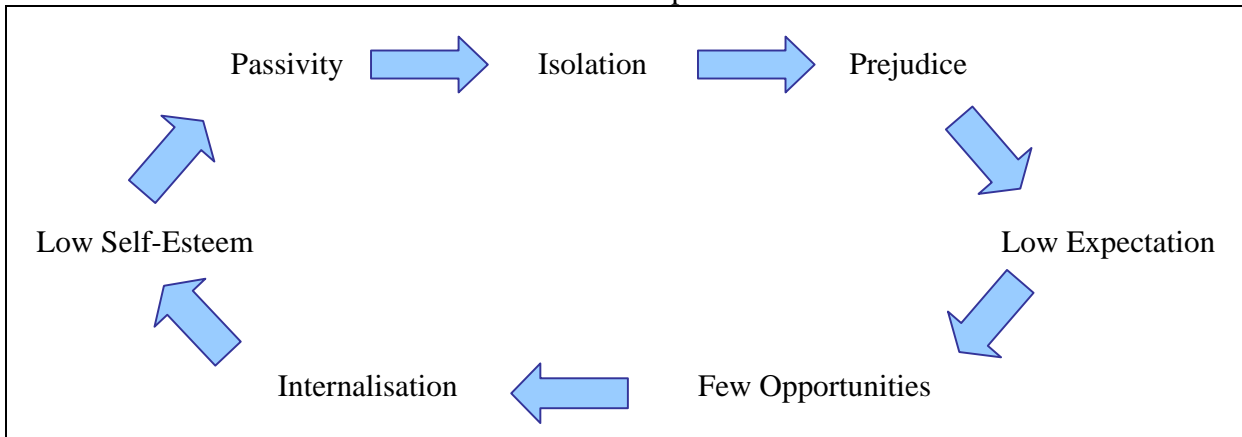
This sub-chapter 3.3 started the analysis from prejudice that follows low expectation and the powerless image of disabled people. The low expectation of the government is reflected in medical treatment, education and employment policy and practices that limit the choices and opportunities of disabled people. This government attitude is reflected also in society as a whole and even in a family member of a disabled person. In other words, multiple layers of social oppression in different forms force disabled people to reinforce their deviant position in society. This environment causes internalisation of the negative image that follows low self-esteem. This psychological damage along with other physical barriers eventually isolates disabled people from society. In this way, disabled people are hidden while the disability issue is individualised in the process. Disabled people come to believe that it is normal for them to be isolated because of the predominant medical model and workability model of disability. Furthermore, every possible opportunity to escape from this vicious circle such as education, employment and making a family is barred from disabled people. Without the proper means to escape this circle, disabled people tend to remain vulnerable as a result of this mechanism.

Few people who could manage to escape the trapped vicious circle feel themselves non-disabled. Their identity changes only when they are physically independent and also when they are financially self-sufficient with proper employment:

> *I never knew if I was healthy as I got [name of impairment] since I was ** [age]. But I work and succeed and don't consider my significance as disabled (Male non-member B in a Kazakh urban area).*

> *After entering and graduating from [name of a mainstream university], I have never felt myself disabled (Uzbek Participant W).*

The identity could be a woman, father, Kazakh and so forth depending on the different occasion, place and time. However, it is most likely that Central Asian disabled people feel themselves disabled due to the too frequent encounters of discrimination against them.

Summary
In short, the discriminative society stemming from government practices controls the psychological aspect as much as any other aspect of the lives of disabled people in Central Asia. Therefore, due to the many layers of mechanisms surrounding disabled people to become inferior and vulnerable, the fate of disabled people is most probably determined to be socially vulnerable:

> *I dare to say right now in Tajikistan, people with disabilities are regarded as second-class people. (Tajik Participant A)*

Imanaliev (2003:39) summarises the common challenges for disabled people all over Central Asia as follows:

- *Underdeveloped infrastructure, lack of access for disabled people to the existing infrastructure,*
- *Lack of education facilities for disabled children and young disabled people, unaffordable higher education,*
- *Lack of employment opportunities and shortcomings of the tax legislation to encourage the employment of disabled people,*
- *Lack of legislative foundations in all sectors of the economy and social opportunities that prevent disabled people from integrating into the community,*
- *Lack of equipment opportunities for disabled people (wheelchairs, crutches, prostheses, hearing aids, interpretation devices etc.),*
- *Lack of facilities to engage disabled people in cultural, social, sport and other community events,*
- *Organisations of disabled people in Central Asia are not numerous, not very well equipped, suffer from a lack of coordination with local authorities and mostly implement a somewhat begging policy,*
- *Most of the efforts of disabled people's organisations in Central Asia are supported and funded by international organisations.*

The above summary reveals the major lack of the perspective of disabled people in society. This massive mechanism against impaired people reinforces discriminative society in all Central Asian countries despite their country-specific conditions. The Central Asian tradition in addition to Soviet legacy and poverty interact and create the mechanisms to degrade the lives of disabled people and make them vulnerable. In Western countries, passivity and disability are not synonymous anymore as disabled people are empowered to some extent (Hughes, 2002). In Central Asia, however, disability still tends to connote passivity in reality because the isolation individualises and normalises discrimination. **Disabled people are alone in too many senses**.

3.4. West-oriented Social Model and Central Asia
This part summarises this Chapter 3 by concentrating its discussion on the social model of disability. The above findings reveal that the West-oriented social model of disability makes

sense in Central Asian contexts, to some extent, which is the main point of this part. Further analysis tries to focus on some context-specific aspects in Central Asia with the latest discussion in the West on this model. This part figures out the importance of attention to individual characteristics along with the collective social oppression experiences. Disabled people are human beings different and unique from each other who nevertheless have a great probability of being trapped in the mechanism to become vulnerable. Both collective and individual aspects are the focus of the disability issues.

Similarities between West and Central Asia

Erving Goffman and Robert Scott academically challenged the dominance of the medical model of disability in the late 1960s, particularly by focusing on the process of stigmatisation and the social construction of dependence (Barnes, 1996-a:44). Those theories marked the starting point of the transference from merely the passive attitude of disabled people to the more active disability movement against the collective experiences of social oppression beyond individual ones (Priestley, 1998). These disability activists started to conceptualise disability as the direct cause of capitalism after feudalism (Hunt, 2001). These early activists asserted that unemployment and benefits were then the social issues rather than individual ones. Subsequently, disability theories are affected more by an ideological approach and by the feminist's post-modernist approach. Identity, lifestyle and culture became central issues (Horsler, 2003). This social model of disability from the West originated from a kind of anti-capitalism is surprisingly relevant and applicable to the context of ex-Soviet countries. Firstly, the original focus in the Western disability movement is close to what Central Asian disability is locating its problems at present:

> *The term disability is a capitalist creation. Historically one can say that disability was used to define a category of people unable to work. Disability is about not having control over your life (Hunt, 2001).*

That is, the initial disability concept came from the recognition of the differences between having employment or being unemployed from the common experiences of disabled people within the context of the then new capitalism (Davis, 1997). However, as employment is the central issue also in communism, the disability concept established at the beginning around **work ethics** also makes great sense in ex-Communist countries where many disabled people, especially physically disabled people, were excluded from the work force only because they were labelled as "invalid." At present, the sphere changed in the Western social model from merely work-related issues into more ideological concerns such as identity and culture. Therefore, at present, the focus looks different in the Western disability movement and the Central Asian one. Nevertheless, due to the origin of this disability theory from problems around work issues, the social model itself could be applicable, to some extent, to the Central Asian context at present.

The importance of the social model lies in the change of perspective to see their vulnerability as a creation of society rather than individual problems. This **paradigm change** is applicable in the Central Asian context as has been clear from the above description of their reality and discussion around their lives. Secondly, governments use the measure of category to differentiate groups of people as invalid and abnormal on the basis of the authenticity of medical science. Medical professionals and specialists are powerful in labelling disabled people. The West had a very similar history in which professionals controlled the lives of disabled people (Hunt, 2001). In this

medical perspective, the social model of disability of the West makes great sense because the **category is a socially-created system**. Thirdly, the physical infrastructure was modernised during the Soviet period without paying attention to the needs of disabled people. Therefore, the **physical environment and material perspective** are also relevant in this context as well as in the West (Oliver, 1990). The material context is also socially constructed in Central Asia. Fourthly, the **prejudice** of non-disabled people is huge against disabled people due to their ignorance based on the Soviet policy. Therefore, this psychological aspect created in society also has a big impact on the lives of disabled people. These are all very similar aspects of the Western reality or latest history (Morris, 1991), which proves the great potential to be able to use the social model for eradicating these social creations in a Central Asian context.

Differences between West and Central Asia
On the other hand, Central Asian context-specific differences also exist in disability discourse. Firstly, the **governments play a bigger role** due to their authoritarian way of control over their societies. Their policy and practice is a decisive factor to determine the lives of disabled people especially in several turning points in their lives. This is to some extent observed in a Western context but not to the same degree. Another context specificity is **gender issues**. Once again, the West also faces gender discrimination. However, the intensity is bigger in a Central Asian context that it makes a great difference in disabled people's lives. In other words, gender issues are even more acute issues in Central Asia compared with the West. Thirdly, **work ethics** are important due to the legacy of Communism still at present, while in a Western context, the work itself is not the central issue anymore but one aspect around independent living ideology. Workability is an even more essential aspect in the lives of ex-Soviet population as this work-centred view still directly causes the abnormality concept in Central Asia. Thus it is once again more essential to the Central Asian context. Fourthly, **ethnic diversity** is much bigger in Central Asian countries than in the West due to history and geography. The different ethnic background, culture, religion and so forth have more daily significance. Lastly and importantly, Central Asian countries are categorised as **developing countries**, which significantly differ from the West. That is, the **Western social model of disability needs to be localised** and then applied to tackle the local context. In principle, however, the social model has a great potential to function in mobilising disabled people to collective action against their collective, discriminating experiences. This is the reason why the following Kynnys intervention in Chapter 4.2.2 can contribute to make a difference with their ideology transfer of the paradigm change, while Dana in Chapter 4.3 makes a bigger difference with a context-specific approach. This theme is discussed more in Chapter 4.4.

Heterogeneity
Another important point in this discussion is located in the other edge of the spectrum: the variety of individual characteristics. Collective experiences and tendency have been focused much in this Chapter 3 by figuring out the social mechanism, which is a crucial focus for creating the disability movement. However, if the individual aspect is forgotten, few would be interested in this movement. **"Personal is political" and vice versa is a cliché** that has been used widely in other minority movements. The disability movement cannot ignore this individual and personal aspect of lives, which actually consists of the main part of the lives of each disabled person. Attention should also be equally paid to the individual variety and multiplicity regardless of the fact that social oppression tends to be a collective experience.

These individual differences and changing values in their lives often play a big role to experience similar things differently. Central Asian disabled people, for instance, face various types of discrimination against different characteristics such as sex, age and ethnicity and/or face positive experiences related to the very different changing and permanent factors. All these factors make up their reality, which should not be forgotten. **Disabled people are first of all human beings who have got many different characteristics and positive aspects in life in addition to impairment and disability at a different time, place and occasion in their lives.** That is, the existing mechanism against disabled people does not necessarily lead all disabled people to feel abnormal all the time. The series of interviews to a variety of disabled people clearly proved this fact. The **lives of disabled people cannot be generalised in such a simplistic way** even though the mechanism surely exists and pressures them too frequently out of the mainstream. Multiplicity should not be underestimated because one single panacea cannot solve individual difficulties especially of minorities such as Deaf people (Skelton and Valentine, 2003), disabled people facing racism, sexism and heterosexism (Morris, 1991).

The initial stage of the disability movement in the West was criticised as elitist ideology by being accused of unconscious oppression against a minority among disabled people (Vernon, 1998:203). Western literatures, especially female writers, focus on this issue of different aspects of lives not only as disabled persons (Meekosha, 2004; Thomas, 1999; Morris, 1991; Thunem, 1966 etc.) Including multiplicity is an indispensable perspective in disability discourse not to repeat the same mistakes. This theme is important to mainstream disabled people and not to isolate their impairment and disability as the only essential issue in their lives.

This theme is also important to tackle all kinds of social oppression so as to aim at the ultimate goal of equality. **Equality is not exclusive to disability issues**. This study acknowledges the individual heterogeneity and yet still focuses on the oppressive social mechanism because it tries to eradicate such social barriers and discrimination against disabled people. For instance, the **gender approach in disability discourse** is one of the examples to prove the multiplicity in the lives of disabled people. Gender issues were the most intensively mentioned discrimination among the research participants aside from disability which are followed by geographical disadvantage in rural areas and age. The following excerpts make us realise the importance of the multiplicity. This is the conversation that took place over a lunch during one of the seminars:

> *Kyrgyz Participant G: Central Asian women are very shy because it is in the history that we are always suppressed by men.*
> *Kyrgyz Participant B: Women are important in the house, wash dishes, but there is so much violence against women.*
> *Tajik Participant K: I have no experience of violence, and so I cannot understand that anybody could keep silent after such violence.*
> *Kyrgyz Participant B: I had such experience.*
> *Tajik Participant K: That's why we have different concepts of the individual life of disability.*

Later on, Tajik Participant K talked about her life further in the personal interview:

> *Actually, I didn't live with such problems because I got the injury when I was mature. But those people who are disabled since their childhood, they experienced the violence. I am*

not a young girl, and so do not experience such violence. If I were a young girl, it would be a hot issue for me. I also didn't worry much about the gynaecologist and children. Mostly people who have had disabilities since their childhood are facing these problems. But for me, it was not relevant. A great difference.

Tajikistan went through a civil war up until 1997, which also caused different experiences for disabled people especially disabled women when crimes took place in their daily lives. Girls were prohibited by their parents to go to schools due to the high crime rate. Many disabled girls who had the chance to study stopped their education at a higher rate than boys due to the conflict and post-conflict situations. The lives of disabled women are so different in different countries and even different from each other within a country, as the lives of non-disabled people are.

The geographical location also makes differences in the lives of disabled people. When it comes to the lives of disabled people in rural areas, Aibek Dumbayev, the author of "Social Protection of the Disabled and People with Psychic Disorders," summarises the differences as follows:

> *We can divide disabled people into two groups according to where they live, rural area or city. The differences are in their health care and education. Disabled people living in rural areas have better nutrition and better food than those living in cities. It is related to the communal activities because they have agriculture. Besides the allowance that this person gets is not spent on public transportation or some other utilities or expenses. That's why their nutrition is better. But they are inferior to those living in cities in terms of accessibility to health care and education. According to the statistics, disabled people living in rural areas don't have good education and health care in comparison with those living in cities and that's why opportunities for rehabilitation are limited. That's why rural disabled people in terms of education and accessibility to health care are at a lower level than city disabled people. And my personal opinion is that disabled people living in rural areas lack information. This is the state of disabled people in rural areas in comparison with those living in cities.*

Due to the geographical conditions and physical distances, disabled people in rural areas cannot reach existing services that are mainly concentrated in the urban areas such as health care and education. Even government official admits the gap:

> *Our situation of [a city] is better than in rural areas because those people in rural areas even don't know their diagnosis and how to get treatment by themselves. But people in [the city] are usually familiar with their diagnosis and treatment. They have been treated previously and have some advantages (Kazakh government official B).*

Disabled people in rural areas live far away from each other and thus they are isolated. Female member F in a Kazakh urban area used to live in the countryside and recalls her life there. "There is no telephone line in our rural area. And we don't write letters either." Kazakh Participant D says, "When we visit rural areas, disabled people are really locked in their houses." In addition, the mentality to try to hide disabled members at home is much stronger in rural areas than in urban areas. Therefore, disabled people in rural areas tend to be isolated and shut out from the rest of society. Special boarding schools are few in rural areas and disabled children stay at home

without any education. Thus, many disabled people in rural areas are illiterate and can speak only the local language and not Russian. Without proper education, employment is impossible. Urban cities offer some work for disabled people, while rural areas can hardly offer any choice of employment:

> *I noticed that people with a higher education in [a city] can have employment and many of them even have computers at home. But it's not general practice in [a rural area] that disabled people are employed somewhere. No one pays attention to disabled people to be able to find employment. It's not the practice here that disabled people are hired for translation and computer work. But here in [the city], disabled people are working at home with their computer or as an accountant or other (Female non-member B in rural area).*

Employment is limited because most of the available work is agricultural and require physical abilities. Therefore, parents or children of disabled people produce an agricultural product for their daily living, which is a common practice in rural areas (Tajik Participant S). On top of these, the local authority has too little money to allocate to such a minority of the population and cannot afford to buy enough wheelchairs:

> *The most difficult problem is to get a wheelchair for disabled people. Many people are waiting for this. Both adults and children. The Ministry of Social Protection gets wheelchairs very seldom. And our DPO does not have any possibility to buy them ourselves (Uzbek Participant M).*

The policy and practice of the local authority influence a lot the activities of DPOs in rural areas as well as disabled people themselves:

> *R: Do you think the situation of disabled people is different from those in [a city] centre?*
> *P: Like the sky and the ground, such a big gap.*
> *R: What is so different? The allowance must be the same.*
> *P: The mayor of [the city] made this obligatory for some enterprises to support lonely disabled people. But our authority does not do anything about it and they overlook this problem.*
> *(P: Chairperson G of a Kazakh rural area)*

When the number of disabled people is scarce and their visibility is even worse than in urban areas, disabled people are paid little attention to in rural areas in both Kazakhstan and Uzbekistan. The geographical location makes a difference in their lives.

> *My Visit to the Aral Sea Area*
>
> *I visited the Aral Sea area on the Uzbek side where the rough development and irrigation during Soviet times caused an environmental disaster. The water supply is not stable and its quality is incredibly bad. The water tastes very salty and so all the food is salty. The land is covered by crystallised salt and white, while the other part is either desert or cotton fields. Many locals claim that this environment led to high ratio of disability in this area. 10-40% of salary is added to normal salary to compensate for the environmental consequence. 50% of tax is exempt for companies working in this area for the same reason. The family consists usually of 4-5 children and mothers stay at home. Women are in traditional one-piece-skirts and do household work. I was invited to a big lunch with the leader of the village because I was the second foreigner in its history who visited this village and was honoured. Some foods were eaten with the hands. The women of the family cooked and served food but never joined the table. I visited two disabled people in this village, both of whom are illiterate. Without the necessary equipment such as wheelchairs and without a paved road, it is too difficult for them to go out when they want to. Toilets are outside without running water, which looked difficult for them to maintain their hygiene. Their clothes looked unwashed. They stay at home all day lying down. They both wished for an increase in their pension. The network with neighbours, however, seemed to be strong and they always help these disabled people with food and other needs. These disabled people exist without dignity.*

When elaborating the applicability of the social model, this individuality and different contexts are always important aspects not to be ignored. Both the collective and individual aspects should be focused in any disability issues.

Summary

The social model of disability can facilitate our understanding on the disability issues in Central Asia to some extent due to the similarities between the West and Central Asia. Many aspects of the disability in Central Asia are proved to be human construction when the social model is applied as an analytical tool to elaborate their reality. However, the differences need to be taken into account as well as the similarities. Central Asia is different from the West in many senses. At the same time, the Central Asian countries are different from each other. Therefore, the social model has to be localised to accommodate the local context. Furthermore, environment or context is not the only criterion to understand the reality because individual disabled persons are also significantly different from one another. That is, both the collective and individual experiences are indispensable when elaborating the disability issues.

Chapter 4. Globalisation of the Disability Movement
~Possibility towards Equality from the Political Model of Disability~

The next theme is the organisational activities of disabled people. As disabled people are a minority everywhere around the world, collective organisational activities are the key for the voices to be heard and to change the reality towards equality. In this sense, this theme is globally very important for the lives of disabled people. The goal of this chapter is firstly to study the development of organisational activities in the disability sector in Central Asia. I elaborate the development by looking into the relationship with other actors and ownership issues which are both one of the important keys for civic activism to play its role. Subsequently, international intervention is focused in Chapter 4.2. This international aspect is interesting to follow the globalisation of the disability movement in Central Asia which had been isolated for a long time from this kind of social movement. Chapter 4.2 highlights a case study of a Finnish DPO, Kynnys, which has projects with a political approach. The possibility for paradigm change towards equality is discussed through this case study and the activities of Dana, a severely disabled woman in Kazakhstan. Her ways of activities that link with the international movement and implement its ideologies in a localised manner prove that disabled people are not totally passive and an object in their society, although society tries to influence them to be so. Her examples open a new phase of disabled people's activities as active subjects. Under the difficult environment with many constraints, Dana can still make a difference towards equality. Her activities imply the possibilities of paradigm change towards the disability movement and ultimately towards equality.

4.1. Development of NGOs in the Disability Sector ~Sign of Democracy?~

In these Central Asian "transitional" states, NGOs are a new phenomenon which became visible during the Perestroika period. The concept of civil society equates with the work of NGOs (Connery, 2000:9). They are used interchangeably. This is partly due to the strict framework that each government forces their civil society organisation to play in a non-governmental and apolitical manner and partly due to the imposed pressure from the international community to conduct development cooperation projects with local NGOs. These frameworks from the governments and the international community determine the concept and activities of current NGOs in Central Asia in many ways, which will be mentioned further throughout this Chapter 4. This sector, namely NGOs, "spread rapidly" in Russia and Central Europe (Hodgkinson and Painter, 2003) and Eastern Europe (Palubinskas, 2003). Due to the former Marxist-Leninist ideology in which private interest and public good were synonyms, civil society did not have both ideological and physical space before (Pottenger, 2004). NGOs are now expected to be or already acknowledged as a sign of democracy in these post-Communist regions in general. The number of NGOs in Central Asia has also been increasing, which was a 66% increase in 2000 in Uzbekistan, for instance (UN Office in Uzbekistan, 2003:39). The increase in number, however, does not necessarily equal the sign of democracy in Central Asia. This sub-chapter tries to understand if the increasing number of NGOs really means a development of democracy by focusing on two aspects: relationship building with other actors and ownership issues within the organisations. These two aspects prove that civic activism is not rooted in Central Asia especially in the disability sector due to the different constraints already mentioned above. This background organisational condition makes international intervention complicated, which will be mentioned later in Chapter 4.2.

4.1.1. Historical Development ~Increase in Magnitude~

This part describes the historical development of NGOs in Central Asia, especially the development of NGOs in the disability sector. The intention is to investigate the development beyond a superficial increase in magnitude. It is meaningful to take a closer look at this general development of NGOs because that is reflected well in the overall activities of NGOs in the disability sector.

Civic Activism in Central Asia at a Glance

Civic associational activities had not been common practice until the twentieth century in Central Asia. "All the empires formed there had an impact on people's lives, but none attempted to build a serious civil society" (Yalcin, 2002:295). Before Soviet rule, the way of living made a stronger identity consciousness among Central Asian people rather than the ethnic or national identity. People recognised themselves either as sedentary or nomads, both of which were highly authoritarian or feudal in the nature of their management. Kinship culture or the clan system and tribalism were very strong even before the Soviet era (Carley, 1995).

During the Soviet era, NGOs were existent in the 1920s and 1930s under a Decree on Volunteer Unions and Societies issued in 1930 (UNDP, 2002-a). However, Moscow started to control everything including grassroots activities. Thus the Soviet period is described as follows in relation to civic actions: "The Soviet system was one in which virtually no civil or public life was allowed to develop, nothing that was not under the control of the regime" (Carley, 1995:299). The strict restriction and bureaucratisation was not loosened until Perestroika between 1985 and 1991, when a number of groups began to be founded. An exception is the Uzbek and Tajik *mahalla*s, which are a traditional community-based group. They identify people in need and ensure a social safety net for them. For instance, they take care of repairing someone's home, weddings, funerals and family problems. (Freedom House, 2003; UNDP, 2003-b; Coudouel and Marnie, 1999). Their activities were not encouraged under the Soviet regime but they have existed throughout the Soviet period until now.

The development of various social activities including NGO activities affected Perestroika and the collapse of the Soviet Union in 1991. This period of history was the significant turning point for the development of civic associational activities in Central Asia. **NGOs have increased in magnitude** in all five Central Asian countries since then. Hunt (2001:7) claims that **two main types of civil society organisations** have been established: "transformed Soviet social organisations" and "new NGOs sponsored or funded by foreign agencies." The first category includes *mahalla* and other nationwide organisations which are mostly organised by the government such as organisations of disabled people and war veterans. *Mahalla* was acknowledged in the 1992 Uzbek Constitution and was placed more responsibility to carry out governmental activities in 1999. The Uzbek President, Islam Karimov, declared 2003 as "Year of the *Mahalla*" and has given greater emphasis on its activity for the government (Freedom House, 2003). In this way, *mahalla* also became quasi-governmental institutions after independence. However, the activities and decision-making process of *mahalla* is not transparent and thus power is centralised in the chairperson of each *mahalla* at a local level. Chairpersons and secretaries are nowadays paid by the government when the coverage of inhabitants is more than 500 households. The chairperson is elected but all the candidates have to be approved by the mayors who themselves are appointed by the President (Coudouel and Marnie, 1999). This kind

of financial support and privileges over associational activities of this category are feared to be a way of government control. Nevertheless, these **government-oriented NGOs (GONGOs) occupy a significant space** of their definition of a civil society sector. The second category of civil society is the Western type of NGOs mushrooming since the Perestroika period. They are sub-divided into two groups: international NGOs working in Central Asia and local NGOs overwhelmingly funded by international donors.

Before going into the details of these organisational activities, it is sensible to focus on the definition of NGOs in this region, because that actually leads us to understand the nature of these organisations. Along with Soviet history, difficulties remain in defining NGOs in a Central Asian context because Central Asian NGOs cannot be totally separated from the current regime, if the definition of the "government" is also as difficult. In other words, NGOs convey more of the meaning of non-commercial or non-profit than non-governmental in ex-USSR countries (Kaluzhskii, 2000). At the same time, Islamic conceptualisation of NGOs is relevant to investigate as the majority of the Central Asian people are Muslims. In Muslim analysis, the "government" is the state with power of command and control, and overlaps with the Western concept. NGOs conduct activities on non-governmental basis and create the sphere of citizen's liberty, whereas Western concepts focus more on voluntary participation (Kelsay, 2002). In this regard, the concept of NGOs in Central Asia is closer to the one discussed in the context of ex-USSR rather than that of Muslim, though the **diversity of the concept in each culture should be acknowledged**. The legal status of NGOs in each country also supports this argument. The Kazakh Constitution, for instance, declares in Article 5, "Public associations shall be equal before the law. Illegal interference of the state in the affairs of public associations and of public associations in the affairs of the state, imposing the functions of state institutions on public associations, and the financing of public associations by the state shall not be permitted" (Analysis-. 1998-1999). This means, the existence of NGOs is legally admitted on the condition that they do not interfere in governmental policy and practices but go along with them. New NGO Laws in Kyrgyzstan and in Uzbekistan in 1999, amendments to the Tax Code in Kazakhstan in 2003 and a new law in Tajikistan in 2004 show **positive changes, legal acceptance** and tolerance towards NGO activities in the respective country at least on legal papers. The series of legal changes started to admit the existence of NGOs on the condition that they are not to oppose the governments.

The exception is Turkmenistan which still gives too little space to NGO activities (ICNL, 2003). The Turkmen government goes against the tendency to make more space for civic activism (Ponomarev, 2004). This political precondition affects the activities of NGOs. All these countries have quite strong, authoritarian governments controlling many aspects of the countries. Yalcin (2002) justifies the temporary needs of an authoritarian regime to seek for stability in this transitional period. However, the overall evaluation of the level of democracy in these countries is critical. For instance, Freedom House categorises all Central Asian countries as "not free" countries in its annual report (Karlekar, 2003). "Not free" is defined as their residents are denied basic political and civil rights. Freedom House lists also what it calls "The Worst of the Worst." Turkmenistan was one of the five countries under this category together with Burma, Cuba, Iraq and North Korea. Ample examples of "political prisoners" have been constantly witnessed in various investigations (Amnesty International, 2003; IHF, 2001; IHF, 2000; Olcott, 2000). Therefore, even if the number of NGOs rapidly increases, it does not necessarily mean the prosperity of civic actions in Central Asia. **Most of the organisations strictly remain in the**

limited area that does not oppose the governments. Despite the good constitutions to secure the freedom of citizens, their reality remains far from rhetoric. The Uzbek constitution, for instance, says in Article 58, "The state shall safeguard the rights and lawful interests of public associations and provide them with equal legal possibilities for participating in public life." In Kazakhstan, Kyrgyzstan and Tajikistan, the registration process became easier and less bureaucratic. In Tajikistan, for instance, after the drastic cut in the registration fee in 2001, the number of NGOs doubled to 1300. Such superficial conditions are improving which is well reflected in the increase in the number of NGOs.

The problem is that the number itself is very different from one statistic to the next. It is now estimated to have grown to 3000 in Central Asia in one statistic (Handrahan, 2000:18), while another statistic claims that about 6000 NGOs are in Kazakhstan only (USAID, 2001). At present, one statistic shows that the numbers of NGOs in the respective countries are as follows:

Table 3. Number of Registered NGOs

Country	Number of Registered NGOs
Kazakhstan	3,500
Kyrgyzstan	3,000
Tajikistan	1,300
Turkmenistan	138
Uzbekistan	2,300

Source: (Freedom House, 2003) Graphed by the author.

In terms of magnitude, civic associational activities have grown very rapidly since Perestroika in Kazakhstan, Kyrgyzstan and Uzbekistan and since the end of the civil war in Tajikistan. The exception is Turkmenistan where a limited number of existing NGOs was forced to close down by governmental decisions and pressure.

Despite the seemingly big numbers, only "between 600 and 1000 NGOs or between 20 and 30 percent of those registered, are actually active" in Kyrgyzstan (Freedom House, 2003:338). Furthermore, the statistics include different origins of NGOs such as GONGOs and independent NGOs. GONGOs consist of an important part of civil society in both ex- and current socialist countries where governments play a big role (see ex. Ma, 2002 for China and Duong *et al.*, 2003 for Vietnam), whereas independent DPOs are more similar to Western NGOs. The line between GONGOs and independent NGOs are becoming vague, for instance, in Kazakhstan. However, in the sense that GONGOs are established by the government or politicians close to the government, some organisations do not reflect the needs of the grassroots and people at all. On the other hand, some independent NGOs are initiated for the sake of receiving grants from international societies, which are also far from genuine civic activism. **Both governments and international donors play a big role in the statistics.** The number as such, therefore, should not be the only indicator to measure the development of Central Asian civil society and democracy. The superficial development is not necessarily the real development towards democracy which is based on genuine civic activism voluntarily defining its own problems and solutions with a participatory approach.

Furthermore the superficial number itself does not disclose that the government discriminates against authentic NGOs and restricts their activities with harassment. 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. Without this registration, associational activities are difficult and hardly attract any attention of donors. Thus registration is very important for the security, legitimacy and survival of Central Asian NGOs. The Soviet legacy of the lack of legitimate legal culture once again explains this phenomenon as **constitutional rights are easily ignored**.

Another rhetorical trend is the involvement of civil society in the governmental decision-making process by organising a forum between two actors. In July 2003, a fourth roundtable discussion was held for "partnership" between state authorities and civil society in Kyrgyzstan. In October 2003, the first Civil Forum was organised in Kazakhstan on the initiative of President Nazarbayev. NGO representatives were invited from all over Kazakhstan to have a discussion with government officials and politicians. This is one step forward in terms of the relationship between states and the civil society sector in these countries. Superficially, therefore, the development of civil society in Central Asia is huge. The reality, however, is different from the seemingly positive changes over time. In practice, challenging movements and NGOs were not invited to the partnership forum in Kyrgyzstan (Aslanbekova, 2003) and in Kazakhstan where I witnessed this fact myself. In other words, the governments of Central Asian countries do not encourage NGO activities with a free hand. Especially right-oriented 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 right-oriented NGOs in general. The tax authorities also send nasty inspection to harass such NGOs, which has been witnessed in all these countries. 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 towards 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. That is, the **activities of NGOs are still under the direct and indirect control of each government** which is especially strong in Turkmenistan.

When it comes to the substantial content of activities, Hunt (2001) argues that the types of services of NGOs are welfare-focused and service-oriented so as to fill the gaps in the government system. Although the Kazakh government, for instance, stresses that "NGOs provide important services in healthcare, education, environmental protection, women's issues and introducing the political process to Kazakhstan's 15 million people" (Embassy of the Republic of Kazakhstan, 2003), **NGOs are often pressured to fit into the framework of service provision** due to the above-mentioned government control. In Kyrgyzstan, however, where the "NGO sector remains the most advanced in Central Asia," NGOs started to form coalitions to advocate and lobby for changes in public policy. The Kyrgyz government prefers non-political activities, though top policymakers understand the significance of NGOs (USAID, 2001:93). To conclude the analysis so far, the political regime has been causing lots of trouble and restrictions towards

the development of the NGO sector in Central Asia at the moment but maintains a crucial role in its future development at the same time.

As for the NGOs in the disability sector, the upheaval and development of the organisations and democracy does not necessarily have a direct correlation due to the restricted activities of the NGOs in general. The disability sector ("Disability" and "Handicapped children") in NGOs occupy only 7.4% of the whole activities of NGOs according to the presentation of the Kazakh government in its Civil Forum as the following Table 4 shows:

Table 4. Percentage of Different Sectors among Kazakh NGOs in Official Statistics

Sector	% as of total
Ecology	15
Children and youth	13.6
Gender	13.3
Social protection	13.1
Culture, education, science and art	12.5
Human rights	7.6
Medical	6.8
Society support initiative	4.7
Disability	4.4
Handicapped children	3.0
Others	6

Source: Kazakh government publication for the Civic Forum organised in Astana in October 2003.

The Institute for Development Cooperation (2004), an NGO, asserts that the percentage of disability-related civil society organisations is 1%. In this respect, it should be stressed that **NGOs in the disability sector is a minor phenomenon** among the whole civic associational activities. The latter half of this sub-chapter is devoted to elaborating more specifically on NGOs in the disability sector. Firstly, the historical development is traced back. Secondly, GONGOs and independent NGOs in the disability sector are separately investigated.

History of Disability NGOs
The history of organisations in the disability sector goes back more than 70 years when the Former Soviet Union created **blind and deaf people's organisations**. They had centralised the Soviet-like structure where top-down decision making was implemented in all sub-divisions in the local area. The Soviet regime fully supported these organisations to maintain their factories and workshops by purchasing their products. Deaf and blind members of the organisations enjoyed full employment in these production lines owned by the organisations. It was only in the Perestroika period that an organisation of disabled people was established. Thus, the organisation of disabled people has only around fifteen years' history unlike the blind and deaf people's organisations. GONGOs include also other organisations such as organisations of Afghan war veterans and Organisations of Chernobyl catastrophe victims. Those are government-oriented organisations. Some **GONGOs** were established by political figures and government officials. These organisations are "**more respected and more prestigious**" (Chairperson I of a Kazakh urban area). He continues:

When different organisations apply for a grant, the sponsors would like to fund those who are owned by [a politician]. This is about sponsors in this district. Maybe this is wrong, but at this stage, this is one of the ways to gather money.

Chairperson F of a Kazakh urban area analyses these GONGOs:

They don't differ so much and they are common in terms of management and structure. And the main activity of disabled people's organisations is to provide help for disabled people with the help of local business enterprises and state help. But their advantage is that they are well organised and they have many members. For example, when disabled people live in A district in Almaty, they belong to the A district DPO. And the membership of these organisations varies from 500,000 to several hundred thousand.

This organisation of disabled people also followed the same structure with sub-divisions in every district. The Uzbek disabled people's organisation, for example, has 129 city sub-divisions, and the Tajik one 57. Each sub-division applies for the necessary support from the corresponding local authority. For example, the city level sub-division applies to the city government authorities. That is, chairpersons at the national level are entitled to deal with the governmental level though with difficulties. These three organisations were the main organisations in the field of disability at the early stage of independence in each Central Asian country. The organisations of deaf people and those of blind people were the most affluent organisations in the disability sector as they owned many workshops and property. As for organisations of disabled people, the government has also helped since their establishment. The Kazakh government gave alcohol and tobacco enterprises to the organisation, while the Uzbek government lottery income:

There was the group of disabled people who appealed to the Cabinet of Ministers to ask for permission to register their own DPO. The government agreed and arranged a meeting with them. And they even gave some money at the beginning to develop the organisation. They provided some privileges in our production lines, gave us the source of money from the lottery (Uzbek Participant C).

The organisations of disabled people did not own as much property as the other two counterparts. These **"big three" organisations are deeply related or initiated by the government**. Thus they are categorised as GONGOs. For example, the chairpersons in the sub-divisions were appointed by government officials:

I am so much offended because in 1932 when the blind people's organisation was established, the authorities gave them the necessary equipment and money. When the authorities wanted to establish our organisation, they just gave me a folder and papers. They said, "Just establish this organisation." They don't think that we need money. (Kazakh Participant I).

Only in 1988, were they [disabled people's organisations] established again. Then I was head of [previous working place], and I was called by my authorities and told, "You are a very nice employee. You work very hard. You don't have any difficulties and problems. So you have to do something for other disabled people." So in 1990, I became the head of the association (Kazakh Participant G).

Despite the deep relationship with the government at its origin, disabled people's organisations started to make a big impact on society because nobody knew that physically impaired people could also work. With governmental support and privileges, they also started to own many enterprises that employed physically impaired people:

> *We showed everybody how disabled people can work in this way. This was the main turning point when people started to think that disabled people can also work. So **we changed the psychology that disabled people cannot work** (Tajik Participant A).*

> *When the DPO was established, there were 18 enterprises and they employed 3000 disabled people which amazed the government because they didn't know that disabled people could work and could be profitable in their work. The government then started to pay attention to the DPO (Uzbek Participant E).*

However, due to the **economic crisis** of each government after independence, governmental privileges both for individual disabled people and those for their organisations were reduced or cancelled. When the governments stopped the subsidy, natural consequence was the **closure of many of the factories and workshops** owned by these organisations. These organisations could not offer employment any longer without governmental support. Many other grants from the government to these organisations were also withdrawn. The centralised structure, therefore, lost much of its meaning. A Cabinet of Ministers started to state on the basis of the introduced free market economy, "Now everyone has to find his or her own way" (Chairperson F in an Uzbek urban area). This change hit disabled people's organisations badly because they were the youngest among "the big three" and the foundation for further activities was not established yet by then:

> *Until 1990, they [deaf and blind people's organisations] acquired their own factories, workshops and different properties. They had produced many documents by that time already to be able to use now. It was much easier for them to continue their activities with the acquired properties. They had their own foundation of activities when our country gained independence. Whether the foundation was good or not, that is another question. But anyway they had something, while we [disabled people's organisations] had nothing. We now have to rent this building because we don't have any property. And deaf and blind people's organisations have buildings, factories, concert halls and many other things like restaurants and cafés. They have production units from which they can get a profit. But we don't have any such thing to start with. That's why it's very difficult for us (Uzbek Participant P).*

In this way, the centralised structure with the pivotal power of employment started to fall apart.

GONGOs
Since independence, Kazakhstan and Uzbekistan have chosen different paths in terms of this central structure. The Uzbek republic DPO still asks for a financial report and activity report from the sub-divisions, while Kazakh DPO stopped such an obligation:

> *It seems that we are together. But we are separate in reality (Uzbek participant V).*

I don't get any money from the [republic] DPO. (...) We give a report to them if they need. We have meetings for our accounting. For the last three years, I haven't seen any support or help from the Republic DPO. I just cannot remember the last help they provided. There was one children's competition. But it was not with their help. They just informed us about the event. This competition was organised by one Korean organisation. And I myself found some money for the plane tickets for five children and their parents to fly to Tashkent (Uzbek Participant M).

Each sub-division started to lose the hitherto strong hierarchical relationship with the national level DPO within its structure because sub-divisions became financially independent. However, the Uzbek organisation has tried to maintain this structure. The chairperson of the republic DPO maintains the power to reach the government level, while all the other chairpersons of sub-divisions and those of independent DPOs need to apply to the chairperson of the republic DPO to reach the government:

R: I wonder why only this DPO can lobby the government.
P: Because this is the special Republic DPO. And our government cannot accept all the 120 regional and district branches. And so they told us to accumulate all the problems coming from the branches and then bring them over to the government so that the government could be with only one and not 100. Of course, it's not prohibited by the law to appeal by petition to the Parliament. Of course, they can do that. But we have such a practice that if we don't apply to the Parliament, they don't take us into consideration. This is not an infringement of human rights. That's why our central apparatus exists to solve problems with the government. (...) Until the Republic DPO comes, the problems will not be solved.
(P: Uzbek Participant C)

No other means is available for other chairpersons. In this way, the Uzbek government still uses this hierarchy to control the activities of government-oriented DPOs in Uzbekistan, while the Uzbek DPOs also maintain their structure by maintaining the hierarchical relationship with the government structure. In Kazakhstan, the hierarchical relationship within the structure is gradually fading away.

The influence from this structure, however, similarly remains as a way of connection with each corresponding government authority and hierarchical relationship among the sub-divisions. These **GONGOs are still very powerful because they are protected by the local authorities** in many ways. For instance, local authorities give out humanitarian aid, help in raising funds or give some premises for free:

About the city government, they help us to find sponsors. The city government asks different companies and people to arrange events, giving some space in the park, or gives dinners (Chairperson C of an Uzbek urban area).

I call him sometimes. He [local authority] usually is responsible for providing us with humanitarian aid. I ask from them to provide me with humanitarian aid. He is the person to whom I apply. (Uzbek Participant M).

This is the signature of the mayor. It's written here that on 3rd of December, they [any local companies] have to help us properly. I went there in the morning and on the next day the mayor promised to find us a café to organise this event. We need to ask for help from this public structure because without it, we can do nothing (Chairperson G of an Uzbek rural area).

The DPOs of the sub-divisions even coordinate their activities with the local authority to be supplementary to each other. The local authority, for instance, finds money or wheelchairs for disabled people, which are distributed through the local DPOs. However, the availability of such support depends on the local authority and some DPOs do not get any support for a long time. For instance, Chairperson J of an Uzbek rural area gets several wheelchairs every year from the local Social Protection Department belonging to the city government, while Chairperson K whose DPO is situated about 100 km away has not received any wheelchairs since 2000.

The deaf people's organisations cooperate with the public medical institutions to find out who are newly diagnosed as deaf. The organisations get the information and help these people to get a pension and other available services. In this way, each sub-division organises their activities with their own fund-raising effort supported by the local authorities and local businessmen both in Kazakhstan and Uzbekistan. Chairperson I of a Kazakh urban area says, "**Although we are an NGO, people in this district consider us as a department of the city government**." This statement well reflects the status of GONGOs as part of the local structure. This relationship with the local authority is similar all over Central Asia.

However, their relationship with the corresponding government structure causes some difficulty due to its proximity. They are **restricted in freedom of speech** due to the dependence on the governments:

> *We have our own newspaper, [its name]. This is a non-governmental newspaper. But anyway, we cannot publish what we want to say openly there. There is no democracy. We would like to discuss the problem of the prostheses that our disabled people cannot get. If we publish this kind of article, the Ministry of Social Protection will begin a war against us. That's why we publish neutral articles only, as we don't have our own money and depend almost entirely on the government. Independence is first of all about political structure. And independence should have its own money account, not to be dependent on others. Unfortunately, now we are almost bankrupt. That's why we cannot publish openly an article on what we want to say (Uzbek Participant C).*

In this way, GONGOs tend to be part of the government without reflecting the real needs of disabled people, despite the big space that they occupy in the disability sector. Due to the fear of the "war," GONGOs have difficulty in raising disability as a social issue and as a result **reinforce the status quo**. Self-censorship is considered to be a useful strategy to survive. The mass media is totally under the control of the government in Uzbekistan. Thus this is a direct reflection of the restrictive society of Uzbekistan in general. Kazakhstan has more freedom in the realm of the relationship with the mass media. However, Kazakh DPOs face the difficulty of changing the mentality of the media personnel to broadcast their view because the media is usually

paternalistic towards disabled people. This will be mentioned more in detail in the following theme of isolation.

When it comes to the characteristics of GONGOs, there are several typical features. First of all, GONGOs usually have a **membership system** in both Kazakhstan and Uzbekistan. It is a "small amount of money" according to chairpersons. The membership fee is between 1-5 US dollars per year. Nevertheless, members of these organisations are not satisfied with what they can get from these organisations:

> *I was a member of the Republic DPO. We paid our membership fee. But we didn't get any help or events. Then I stopped paying the fee and I need to work for my family (Male staff A in an Uzbek rural area).*

> *When I was a member of one DPO and another organisation, I paid 500 Tenge (=3 Euro) for membership. But I didn't see any of the work of the organisations. They didn't even call me once to give humanitarian aid or to give me some tickets to resorts. I wondered why should I pay if they don't do anything for me (Female non-member B of a Kazakh rural area).*

Some disabled people cannot even afford the "small" membership fee such as Female non-member C in an Uzbek rural area. Uzbek Participant M admits that her DPO cannot help disabled members as much as she wants to:

> *Maybe they need money and tickets for a Sanatorium. But as we don't have any finances for these activities and help, so we keep silent.*

What disabled members want is material support, while DPOs do not have money to provide such support. This **lack of resources** is another fairly common feature of DPOs across Central Asia. With the difficulty in terms of financial self-sufficiency, many GONGOs have decreased the quality and quantity of their support to their members.

Passivity is another common feature. Especially in Uzbekistan in comparison with Kazakhstan, new activities start only when DPOs are suggested to cooperate with some international donors. Some donor agencies took the initiative for cooperative work with Uzbek DPOs. For example, DPOs chaired by Chairperson F and I in an Uzbek urban area started new programmes when international actors visited them and started "development cooperation projects." That is, those Uzbek DPOs passively wait for things to happen until international actors initiate the projects. Ownership of the projects is not much on the local DPOs but mostly on international donor agencies or intervention from outside. My visits for the interviews were also welcomed as many Uzbek DPOs expected that I would make a change by connecting them to some international donors. Their passive attitude is visible in another experience of mine. Only two chairpersons out of 20 interviewed chairpersons made contact with the Japanese Embassy after I provided some information of a grant possibility at their request. In general, these DPOs are passive in making a change and wait for something to happen. Aibek Dumbayev, the author of "Social Protection of the Disabled and People with Psychic Disorders," says,

DPOs in Uzbekistan even in Tashkent are worse than in Kazakhstan because there are less grant programs and their management is very poor and their activities are in the field of very insignificant areas.

He regards this **passivity as a deficiency of management skills**. Another explanation for the passivity was due to the **passivity of the population in general** in Uzbekistan:

Now we have the lack of democracy. I don't know. It's very obvious. It can be seen in every field and also in the field of disability. The population as a whole is not active. We have 4-5 political parties and their programs are similar and none of them are in opposition. As our population is passive as a whole, how can we find politically and economically active disabled people among the population? If all the population is passive, how can we talk about active disabled people? Now we must hope only for the development of our own strength. And we just can wait for the support of the closest surroundings (Zagyrtdinova Feruza Borisovna in personal communication).

This "Soviet mentality to undo" (Handrahan, 2001:471) explains the generalised passivity in their society including DPO activities. The deeply rooted passivity cannot be changed automatically. Thus external intervention is expected to liberate the mentality to a more active one, which is her argument that itself stems from the passivity. Having been established by the governments, DPOs remain "insignificant" due to various constraints such as political restriction, financial deficiency and passivity. In spite of these background conditions and changes over time, GONGOs are still involved deeply in the governmental structure even though the financial support is decreasing. The historical connection between government officials and GONGOs remains still deeply in the way of their activities. Along the same vein, the passivity is still the coping strategy for the GONGOs to deal with the reality controlled by the government so as to survive. In this respect, GONGOs have been contributing to reproduce the Soviet-like environment around the disability sector. International intervention has little impact to change their coping strategy so far. GONGOs are visible actors due to their massive structure. However, in terms of the impact on equality, it tends to remain minimal despite their efforts.

Independent DPOs and GONGOs
GONGOs, however, are not the only actors in the disability sector. Due to the severe reality of disabled people as described above, a number of independent DPOs have been established since Perestroika to improve the quality of life of disabled people. In Kazakhstan, the biggest three DPOs/GONGOs occupies 60% out of 500, the total number of disability related NGOs (Dumbayev, 2003). This high number is due to the fact that each sub-division of these three organisations is registered as an individual NGO with the Ministry of Justice. That, conversely, means 40% of them, which equals 200 in number, are initiated by people themselves. In the interview, Aibek Dumbayev pointed out that the number of disability NGOs actually increased even more. Currently, "there are about 700 DPOs in Kazakhstan" and "about 350 are newly established NGOs." Considering the fact that associational activities of only blind and deaf people were legally admitted during the Former Soviet time, **the number of disability NGOs has increased drastically**. According to Counterpart Consortium, an American-funded NGO working in Central Asia, the active number of NGOs and active number of disability NGOs are as follows:

Table 5. Number and Percentage of Active Disability NGOs

Country	No. of Active NGOs	No. of Active Disability NGOs	Disability NGOs as % of total
Kazakhstan	699	75	10.7
Kyrgyzstan	1001	126	12.6
Tajikistan	595	48	8.1
Turkmenistan	138	9	6.5
Uzbekistan	465	74	15.9

Sources: www.cango.net/db Graphed by the author.

These percentages in the above table reveals that **disability is a relatively active sector** when the latest figure from the Kazakh government shows only 7.4% of all NGOs are in the disability sector (Kazakh Government, 2003). A director of an international NGO also mentioned, "It's self-evident that handicapped people need support. And so activities for them are more easily justified compared with other projects" (Director of an international NGO in Uzbekistan). It is also true from this table and the statistics given by Dumbayev that only 10% (75 out of 700) of Kazakh Disability NGOs are active, while others exist only by name and registration. I also experienced the dramatic **upheaval of Disability NGOs** in the fieldwork in Karakalpakistan in Uzbekistan. I was given the latest list of disability NGOs with six names, four of which had been closed down by then. The chairperson of another DPO in the same area stated, "It's natural that they closed down their organisations because they completed their projects funded by international donors" (Chairperson G in an Uzbek rural area). **International pressure to create NGOs for democracy and good governance plays a role in increasing NGOs in number**. That is, much of the sustainability depends on the availability of project grants from international donors at present. For example, the Kazakh government admits that **around 90% of the income of NGOs in Kazakhstan depends on international donors**. Therefore, the development of NGOs in the disability sector cannot depend merely on the increased number of officially registered organisations due to the massive number of GONGOs and also artificial pressure from the donor community.

Furthermore, attention should be paid to the fact that one NGO in number cannot be equal to another NGO in terms of their significance because each NGO is different in size, objectives, leadership, management, membership, resources and so forth. Thus the above table should be considered to be **only indicative that does not tell truth in detail beyond the numbers**. The significance of each NGO is hard to measure in this kind of statistics. Therefore, this study chose to interview these NGOs in the disability sector to understand more the role of the organisations in practice.

The independent and relatively small DPOs are more similar to the Western type of "**Organisations of disabled people**" that are voluntary, self-help groups working for the empowerment of the constituency as peer and for structural change. This distinction between organisations for disabled people and organisations of disabled people used to be an important criterion to determine the ownership issue of those organisations. In the West, first organisations were established by non-disabled people, expanded their activities with charity-oriented approach

and actually degraded the lives of disabled people (Katsui, 1999; Oliver, 1998; Shakespeare, 1994; Barnes, 1991; Morris, 1991). This separatist approach from non-disabled people was important especially at the beginning of the Western disability movement to create space for disabled people (Campbell, 1997). The distinction has been becoming vague between these organisations in the West, as the disability movement started to seek for an alliance after establishing itself. At the beginning of disability movement, such time was necessary but today the need to get out of isolation started to be recognised (Horsler, 2003; Hunt, 2001).

In Central Asia, the current **dichotomy is between GONGOs and these independent DPOs** because almost all organisations including GONGOs are run by chairpersons who are disabled people. In this sense, they are all "organisations of disabled people" according to the then Western dichotomy. Central Asian DPOs have a different history for the establishment initiative and relationship with the government:

> *Let's take a look at Uzbekistan. Why do NGOs have a different success while they are in the same country? It's a very Uzbek characteristic. Because some NGOs in Uzbekistan are helped by the government because they support the governmental point of view, while the others who stick to their own point of view and criticise the government are not helped (Kyrgyz Participant D).*

"Success" is first of all about gaining space in society. In Central Asia, where the absolutist approach was inherited (Pottenger, 2004), making space without government support is extremely difficult. Success in this sense depends on how close the DPOs are to government policy. Therefore, in comparison with GONGOs, these independent DPOs are disadvantaged in terms of their relationship with government officials because they are more favourable to GONGOs. This tendency is stronger in Uzbekistan than in Kazakhstan. The activities of the independent DPOs are relatively more corresponding to the different needs of disabled people though their area of activity and influence is very limited:

> *The republic DPO is the only official DPO which depends on the government but has a connection with the government. There are independent DPOs like [name of a chairperson's] one that I respect a lot as he does real work and helps disabled people. But their activities are independent of the government and have little influence. Influence is only on certain individuals who contacted him (Female non-member A of an Uzbek urban area).*

The coverage of activities provides, first of all, a significant difference in these two different DPOs in origin. Independent DPOs have activities in a certain area of a city with a much fewer number of members. They have both new ideas based on the needs and charity-oriented activities similar to the ones the GONGOs have.

<u>**Summary**</u>
Under this dynamic upheaval of NGOs in the disability sector, the number itself has been increasing dramatically. However, when taking a closer look at this phenomenon, GONGOs occupy a big part of the number with support from government officials. In addition, international pressure accelerates the increase in numbers without much genuine civic activism. Furthermore, the numbers cannot accommodate the reality especially in terms of their

significance in practice. On the other hand, independent NGOs are small in the number and significance of their activities even though some of them meet the needs of their members. Despite the differences, however, both groups tend to end up in a similar consequence: activities are not accessible to the final beneficiaries of disabled people. The next theme, isolation from different actors, explains part of this reality.

4.1.2. Isolation ~International Cooperation Is the Only Lifeline But…~

This part sheds light on the relationship of DPOs with other actors. Self-empowerment of disabled people is one important area of activities within the framework of the political model, while networking with other actors to advocate this issue beyond the circle of disabled people is another. This sub-chapter focuses on the latter. Networking with different actors is indispensable for developing the disability movement because disabled people are a minority in respective countries and have to involve different actors to create the movement. Relationships with other DPOs, government officials, local sponsors and the mass media are respectively elaborated. They are the main actors that have great potential to contribute to fulfil the goal of DPOs. This part reveals the isolation of DPOs from these actors due sometimes to the specificity of disability-related challenges and due at other times to the general local culture that is not familiar with DPO activities. This part explains the reasons why Central Asian DPOs tend to look for partners from abroad, which will be the background information for understanding the main theme in Chapter 4.2.

Relationship with Other DPOs

First of all, DPOs have a limitation in terms of cooperation among them due to the **severe competition**. This is a common phenomenon in many other developing countries (Hakkarainen *et al*., 2003) and even in Finland (Finnish Participant D). Both Kazakhstan and Uzbekistan share this problem of competition among DPOs. Fowler (2001) argues that conflict is part of civil reality. Conflicts mean encounters of different actors with diverse opinions. In that sense, it can be a sign of democracy. However, their situation is slightly different from democratic conflict: Kazakh DPOs have some framework of cooperation though not working due to rigid ideas which is to some extent similar to the Western conflict, while Uzbek DPOs are not cooperative due to a failure of the republic DPO in its centralised structure. This part describes firstly the situation of Kazakhstan, which is then followed by that of Uzbekistan so as to highlight the big differences between them. This is a good example of variety within Central Asian countries.

In Kazakhstan, 90% of DPOs are situated in big cities. Those DPOs in the cities started to coordinate themselves to tackle collective issues by establishing a coordination committee in the framework of the city council with city government officials and government officials from the Ministry of Social Protection and Labour of Population. The existence of this committee, however, is a **superficial relationship among DPOs** because "When meeting together among DPOs, they are friendly, but they don't get along outside" (Kazakh Participant D). In the personal interviews, almost all DPOs criticised some other DPOs for "not doing their job like us." Chairman F in a Kazakh urban area says,

> *DPOs are very mysterious in the sense that their leaders are very different. I wrote about it in the newspapers and also talked about it at press conferences. DPOs are the most controversial sector. The sector in which there are so many disagreements.*

Several **powerful key persons** make the situation complicated. Some are close to the government officials and others to the donor community, both of which are essential for the sustainability or survival of each DPO. As an increasing number of DPOs tries to find resources from the same available sources, they are all "rivals" in this competition:

> *When our organisation was established, other organisations were not happy about it because I am one of the rivals, a new rival (Kazakh Participant D).*

Chairperson I in a Kazakh urban area recalls that it was easier before:

> *When there were few NGOs, it was easier for us, but there are more NGOs and social associations.*

Right after the independence of the country, only a few DPOs were holding seminars. At present, however, each DPO deals with its own specific issues. Thus seminars are scattered around without inviting chairpersons working for different target groups of disabled people (Kazakh Participant F). Different needs according to diagnosis are stressed and accelerate the conflictive situation. At the same time, different ways of support for disabled people also cause antagonistic feelings. For instance, one DPO seeks for equal opportunity, while other DPOs give out humanitarian aid and make disabled people dependent and passive. These differences came to the surface as many more organisations were established. Therefore, only few who agree with the policy of each other cooperate at personal level among chairpersons. In other words, **organisational cooperation is far from a reality though the framework is ready**. Few chairpersons realize that this competitive and conflictive situation is a hindrance to their activities:

> *Nowadays everybody wants to be a ruler of his organisation. That prevents us solving problems together (Kazakh Participant E).*

Chairperson B in a Kazakh urban area foresees the future direction of cooperation:

> *At last, people understood that if they attract attention only to their organisation, there will be no use. It is very convenient for our officials when we argue against each other and don't agree on some topics. We understood the intention of the officials and began to work together in the coordination committee and we are working towards this direction.*

Finally this framework of coordination committees will be of use in the future when many more chairpersons start to think in the same way. Its tendency is observed. For example, drafting a law on Social Protection of Disabled People now attracts the attention of many DPOs to work together, which is expected to lead to more cooperative and collective work. **Different activities and diversity are necessary to correspond to different needs of individual disabled members. However, collective activities will also strengthen them as a group and is to be developed further in Kazakhstan.**

When it comes to **Uzbekistan**, competition is not a simple result of sharing the same source of money or diversity of activities. Competition is more the result of the **failure of the republic**

DPO which has the centralised power in this sector. As was mentioned above, the republic DPO still has a big power to deal with government officials because their sub-divisions are almost included in respective local structure. For instance, these sub-divisions often get premises from the local authority and organise holiday events with the local authority. While Kazakhstan also inherited this centralised structure but fell apart in financial terms to keep all the sub-divisions, Uzbekistan still maintains this structure but fell apart morally. While Kazakhstan started to lose the hierarchical relationship among sub-divisions, Uzbekistan tightened the hierarchy. In this way, the chairperson of the republic DPO **centralised big power and personalised** it. In other words, the Uzbek society in which the president is on top of everything was reflected in the structure of DPOs.

During the chairpersonship, ex-chairperson of the republic DPO decided to "get rid of the opposition" (his own words). Board members sitting together with the chairperson since the establishment of this DPO were kicked out one after another due to a difference of opinion with the chairperson. His policy became much closer to that of the government officials due to his own **closeness to the government**. Uzbek Participant O explains the situation with an example of the cancellation process of transportation privilege for disabled people:

> *When we demanded free public transportation, [the ex-chairperson] said, "No, we don't need such a thing. Each of us could pay for it." Now we don't have this privilege. And all disabled people no matter if the person is severely disabled or not need to pay for public transportation from a small pension.*
> *Her colleague: [the ex-chairperson] was very useful for our government. But disabled people couldn't get anything from him. This Republic DPO should protect the rights of disabled people. But he chose to protect the government, the opposite of what people wanted from him.*

On the one hand, the government made use of the representative democracy with the false representation of this ex-chairperson. On the other hand, the chairperson gained power through connection with the government. It was a win-win situation for them, while the majority of disabled people lost out in this system.

Finally, many disabled people could not put up with his policy anymore, though no one could actually oppose him due to his accumulated and personalised power. People in this sector were virtually scared of him:

> *We established a DPO because we kept a distance from the Republic DPO. We are trying to make an effort by ourselves. (...) We try not to cooperate with them because their **awful and foolish decisions were always adopted by one man**, by the [ex-] chairman. And everyone should vote according to his will because everyone was afraid of him (Uzbek Participant O).*

In addition to the self-censorship to deal with the government, self-censorship of the ex-chairperson was required in the DPO activities then. In this way, many small, independent DPOs were established due to the **antagonistic and hopeless feeling** against the then chairperson. These independent DPOs inherited the fear for their action because if they open their mouths, someone will attack them. Now that this chairperson is finally retired, the scepticism towards the

republic DPO still deeply remains among the independent DPOs, which restrains them from cooperation. **Chairpersons of small, independent DPOs are fed up with this centralised structure** where they can make little influence on society as they are not allowed to contact the government. Therefore, what they do is to work in a limited area and target group of people all alone:

> R: Could you explain to me why DPOs are not cooperative among themselves?
> P: Competition! I cannot understand myself. I cannot work with them. We need to support and need to help each other but they are just envious. That's why I don't want to cooperate with them. There is so many gossip and tricks. That's why I established my own organisation.
> (P: Uzbek Participant D)

> And now, even if we have several DPOs of [names of chairpersons], they exist only because of kindness and good leadership of them. DPOs should be united. But DPOs are working by themselves because they don't believe in the Republic DPO anymore and they don't cooperate even for producing documents and other things in common. (…) For the first time, they were cooperating with the Republic DPO. And then they became independent and didn't communicate at all (Uzbek Participant W).

This **historical context** is an influential factor to explain the current lack of cooperation among them. I felt this antagonistic feeling from my own experiences. When I phoned to make an appointment with chairpersons in Uzbekistan, some of them were so scared and said, "I don't want to see you because I don't know who you are." They were so afraid of the information to be delivered to other chairpersons. However, all chairpersons except for one accepted me when they learned to know that I am nothing to do with any local DPOs but an independent researcher from abroad. This one chairperson continued to refuse me due to the suspicion that I could be "a spy for some other organisations." It was expressed verbally on the phone. The **atmosphere was more than mere competition** over money, though such competition was also mentioned:

> Unfortunately, we are not cooperating. Every DPO is independent of each other solving their own problems. It's due to one reason: DPOs are all young and don't have stable finance. That's why DPOs apply for different grants and competition is very severe among us. We have created problems in finding the money, not to solve the problems. And there is big competition when getting money from the same source. We are trying to unite among DPOs and have seminars together. But in my opinion, without grants and a common project, we cannot cooperate together (Uzbek Participant C).

The international donors are thus making conflicts among DPOs, while they can also unite different DPOs with their "common projects." The **influence of donors is huge in the NGO sector** (Tvedt, 1998) also in Central Asia. At the moment, **cooperation is still an unknown concept for some**. For instance, one staff of a DPO confused this concept as working in the same field of disability even without any contact between organisations (Uzbek Participant P). Another mentioned "cooperation" is the annual meeting organised by the government for "the big three" DPOs: blind, deaf and disabled people's organisations. On the initiative of the government, these three DPOs are invited to the Cabinet of Ministers every year to have a formal meeting. Without an example of cooperation on their own initiative, some interviewees thought of this as

cooperation. With this formal meeting, the government can both defend itself against accusation for not listening to the voices of NGOs and also control their activities. As a result, mere personal friendship among chairpersons is some kind of conceptualised cooperation in the Uzbek DPO sector at present:

> ***"Cooperation" is personal relationship among leaders rather than cooperation in organisational activities*** *(Chairperson G in an Uzbek rural area).*

Under these circumstances, a common project and donor effort try to create a foundation for cooperation as Uzbek Participant C mentioned above. When a project is available under the requirement of coalition, they do make a coalition:

> *Anyway we can do this work. And now we have a big coalition of different NGOs that are interested in children's education. Now in our government, we have a program, "National action plan for education." This originated from a recommendation by the United Nations. The purpose of this program is to find out those children who really need education. (...) Now we are gathering the signatures of those who agree with this idea of education for all (Uzbek Participant O).*

This campaign attracted more than 28 NGOs and DPOs in the field of education for children by the time of the interview. With the financial help of an American NGO, they prepared a TV program to advocate this issue to society. However, the republic DPO was not interested in this coalition:

> *R: You mentioned about the coalition of NGOs, but is the Republic DPO included?*
> *P: We invited them, I invited [the new chairperson] to this coalition. But they have a very strange attitude. They explained to us that they were not responsible for the care of disabled children. It's very weird. It's very easy for everybody to understand that disabled adults begin from disabled children. But they are not interested. They have their own conflicts in their organisation which occupy their time. They have no time to do anything else than solve their own conflicts.*
> *(P: Uzbek Participant O)*

With the change of chairpersons, **internal conflict** still continues within the republic DPO. As the republic DPO is one of the only actors directly connected with the government, their cooperation has been long awaited. The new chairperson tries to activate the stagnant activities. However, before concentrating efforts on disabled people, they have to sort out their internal conflict. The new chairperson admits,

> *Since February (2003), **I was not busy with solving the problems of disabled people but busy with keeping the organisation alive**. (...)Order must be first of all made within the organisation, and then we could demand something from our government. Now we have a mess within the organisation.*

Now that the new chairperson tries to sweep all the hitherto customs of **corruption that** prevailed among chairpersons in the sub-divisions, some chairpersons blackmail and threaten the new chairperson and others try to become independent of the republic DPO so that the power

over their area remains in their hands. The Uzbek DPO structure is in a transitional period. The new chairperson says:

> *It's very dynamic now in Uzbekistan. This reminds me of the transition period from the Soviet Union, Perestroika. We are not going to let our DPO be destroyed like the Soviet Union. Now many people talk about the needs of regional branches to have their own charters. It will lead us to destruction, like the Soviet Republics asked from Moscow to be independent. Our regional DPOs also want to be independent.*

Many share **nostalgia for Soviet times** when the centralised system totally took care of the lives of disabled people. In the transitional time in Central Asia, people still have a **fear of the inexperienced and unknown way of management**. Changes, therefore, need time to get accustomed to the new idea. Disabled people are still sceptical about new ideas when their own lives have deteriorated badly since independence. This historical background and context is reflected in the above statement.

When it concerns Uzbek independent DPOs, they know very well about the internal politics of the republic DPO and do not expect much from it. They are isolated from each other and enjoy the independence which had been taken away for a long time from the previous chairperson. The effort of the donor is the only visible cooperation in the disability sector in Uzbekistan, except for single examples of the friendship relationship among chairpersons. **Information, therefore, is not circulated** among them as a natural consequence:

> *Information is closed. If you get some information, you don't give it to others. The same applies to grants. If you get some money, they limit the beneficiaries among certain people. Information on conferences is not open to even friends. This is a trend all over Uzbekistan, not only NGOs (Local staff A of an international NGO in an Uzbek urban area).*

Uzbek DPOs reflect the closed society itself.

With the conclusion of the relationship among DPOs, both Kazakh and Uzbek DPOs are isolated from each other within the sector. They rather enjoy the "independence" or isolation at the moment. **Movement requires sharing a common ideology and certain general goals among actors and a collective effort**. Fowler (2001) asserts that some "sufficient necessity" drives civic association and action. However, Central Asian DPOs work with a different ideology, different individual goals with little collective effort. Even though the individual efforts are significant in certain areas, **movement has not been visible at a national level yet**. This is also due to the fact that the registration process already defines or restricts the area of activities for each organisation, which does not then allow them to expand their activities so easily to the national level. The registration fee for national activities typically costs too much that general DPOs cannot afford to pay it. This aspect of the relationship with the government is scrutinised more in the following theme.

Relationship with Government
When it comes to the relationship with the government, it tends to make DPOs act in the limited apolitical arena. The **law already restricts DPOs** from engaging in any political activities. Even

though all organisations are required to go through the registration process, organisations with political activities tend not to be registered. During the first years of independence, **governments were sceptical** about the unknown activities of "non-governmental" organisations which were understood as anti-governmental. This mistrust and suspicion of the regime is similar in other developing countries such as Kenya, Vietnam and Namibia (Hakkarainen *et al.*, 2003). Chairperson A of DPO in an Uzbek rural area recalls that it took five years before finally they could register themselves. This **scepticism became alleviated after several years**:

> *Before this law [in 1999], there was another law passed in 1991, and it said little about NGOs' activities. That's why some of our government officials were not sure if the NGOs were doing the right things when they were registering the NGOs. So they asked for lots of information. And that's why when the NGOs apply, they find lots of "mistakes" and give the charter back and months and months pass. Now the situation is changing because of our President Karimov. In his speeches, he mentions about civil society development and NGOs. So this helps the official people not to be afraid to register NGOs. The information about civil society and non-commercial organisations came to society (Local staff B of an international NGO.)*

In these countries, **presidents are absolute**. Thus acknowledgement of the presidents enlarged the space for NGOs in general. However, still politically-oriented NGOs such as those aiming at human rights activities have a hard time registering themselves:

> *For instance, [name of the organisation] tried to register with the Centre for Legal Information but received a letter of rejection. One of the silly reasons was "protection of human rights are the activities of Uzbek lawyers and other people could not deal with this." It's ridiculous. Especially, registration of a human rights organisation has a very hard time still registering themselves to become a legal entity (Local staff A of an international NGO).*

The governments freely regulate the arena of NGO activities in this way. That is, the **goals and activities of NGOs have to go along with the governments**.

The **disability sector is one of the areas that Central Asian governments are tolerant** of as long as the organisations remain in charity activities rather than rights-oriented ones:

> *You can say that the NGOs themselves are not very active. Some of them are, but some of them are afraid of something, they are afraid of the government. This is again specifically of Uzbekistan. To speak loudly, we have to be careful. But they [government officials] are very open when dealing with children and disabled children. In comparison with the NGOs which work for human rights, it's an opposite situation. It's possible to build a relationship with the government. It will be successful (Local staff B of an international NGO).*

All the Central Asian **governments are quite tolerant of charity-type activities**, whereas those NGOs which concern politics are either not registered or pressured to close down. In Uzbekistan, people are afraid of any politically-oriented activities to implement and defend themselves by **self-censorship**. That is, they avoid establishing organisations with such a goal which is

restricted by the government. In Turkmenistan, only sports-related organisations for disabled people were allowed to exist and all the others in the disability sector were pressured to close down (Turkmen Participant C). Turkmenistan is an extreme case in Central Asia. However, all other Central Asian countries have this element of pressure from the government to a lesser extent. Therefore, **only few DPOs tackle human rights issues** because fighting for a better living for disabled people is not easy with the political constraints in all Central Asian countries.

This political pressure can be observed at different stages of the organisational reality. To start with, the **registration fee** is too expensive for many disabled people to be able to afford. A legal expert, Vsevolod Ovcharenko of the International Centre for Not-for-Profit Law, says the registration fee is USD 130 but eventually the registration process costs between 160-170 US dollars including all the necessary costs on top of the fee. He continues, "You know, disabled people are extremely poor and cannot afford this registration cost." When the pension for the first category is around 50 US dollars, for the second 30 and for the third 25, the required amount of money is far too much for almost all disabled people. Kazakh Participant D recalls the hardship:

> *When we were establishing the organisation, all the money problems were a burden. I had to pay for registration myself from my pocket money.*

Typically **chairpersons pay the fee from their own pockets**. Female non-member B in a Kazakh rural area still cannot register her organisation due simply to a lack of money. Another governmental indirect pressure by law on registration is territorial division. Registration needs to be made according to the territory of activities if they are local, regional or national. However, registering any national status costs more than USD 1000 (Ovcharenko, 2004). Therefore, politically-oriented organisations especially those aiming at working at national level are hardly registered due to the government attitude and also the self-censorship of people themselves. In Kazakhstan, activities are expected to be apolitical as the law prohibits civil society organisations from being involved in politics, while the government is also prohibited from being involved in civil society organisations. This is often a good reason for government officials not to help NGOs, especially non-GONGOs. Therefore, NGOs have started to gain the space to exist but their activities are restricted both directly and indirectly by the regimes. **Central Asian practice in civil society is different from that in Western countries**.

Another political constraint is the **ignorance of government officials about disability issues.** Disabled people are non-existent in Central Asian governmental structure, which many think is the reason why government officials are so ignorant. I participated in an informal meeting among young disabled people in Tashkent. The following conversation took place:

> *Female member E: We have to find a way to go to our Parliament.*
> *Female member J: We need our man in Parliament.*
> *Uzbek participant A: If a disabled person is the chairman of Parliament, does he solve our problems?*
> *Female member J: We have to choose our leaders by ourselves.*
> *Male member A: It's not necessary to be a chairman. We need several DPOs that apply to the government and Parliament to have a representative there.*
> *Female member D: We are DPOs. We also need to apply.*
> *R: Does it mean that at the moment, there is no mechanism to solve your problems?*

All: No.
Female member E: Only our activities and enthusiasm.

This **political representation** theme is an important focus because without representation, the voices of disabled people are hardly heard because political activities are prohibited by the DPOs. Chairpersons of the DPOs have tried to involve government officials in their activities but have so far failed to do so. Uzbek Participant O "invite[s] them many times to join us but they don't show up often." Kazakh Participant I has also been trying:

> *I have been trying to make an appointment with him [mayor] for one and a half years. But he is like an invisible person. He is always somewhere else. He pushes me to his deputy. I complain about medication and other things.*

Government officials are uninterested in the activities of DPOs and make decisions without involving DPOs, although the issues directly concern them. In Uzbekistan, the Republic DPO is to give permission for the relevant draft law on disability issues. However, "suggestions are not always included" and the final decision-making power is kept with the government (Uzbek Participant P). In other words, institutional power is not decentralised. **Ownership is not in the hands of disabled people**.

Furthermore, governments are not serious about the rights of disabled people. For instance, the Uzbek government enacted a disability-related construction law which includes norms and standards to create accessible physical conditions for disabled people. This law is applied to any newly constructed building. However, the implementation of this law is not monitored and thus not binding. That is, the **law is weak and too often violated**. When it comes to Kazakhstan, Female non-member B from a Kazakh rural area also points out the power of the government:

> *As far as I know, I haven't seen the NGOs' accomplishments in the field of working with the government. I haven't seen any result in that field. And I don't think that the government can see that some organisations can influence decision making on the change in the law. The final decision is in the hands of the government. I think so.*

The **decision-making power belongs only to the government** and not to NGOs. Another example is what I witnessed in the Civil Forum event in Almaty, Kazakhstan. On the President's initiative, the Kazakh NGOs were invited first to a regional civil forum and then some regional representatives were invited to the national forum for exchanging ideas with government officials and politicians. Whereas the regional forum was organised in Almaty, the city government officials had already decided which organisations could participate in the final forum at the national level without consulting the civil society organisations. The city government officials took undemocratic decisions in front of all the NGOs:

> *I hope this inner relationship will be improved soon. Even last time when we had a conference [regional civic forum event] in the city government, everything went according to the list of city officials, hints of city officials and they made decisions according to the wishes of the city officials. And voting was conducted without us because we didn't have any criteria for voting. And those who were elected to participate in the civic forum in October [2003] were not familiar to us. For example, I have been working*

in the third sector for 10 years and we know those who are worth going there and those who are not worth going there (Chairperson B of a Kazakh urban area).

In this relationship with the government, the voices of NGOs are not properly taken into account. Superficially, NGOs seem to have their own space in the example of such a civic forum. However, the **governments actually maintain the power of control in strategic decision-making occasions**. That is, some NGOs are included with the decisions made by the government, but they do not represent the NGOs. This **false representation**, therefore, is utilised by the government to superficially show the "dialogue" with NGOs and their "participation" in important decision making. This forum provided a chance of information delivery which is an important step forward for democracy, at least at the superficial level. However, it is not enough for fulfilling the participation elements in the sense that **NGOs are still objects and not subjects**. Physical participation does not equal real participation. Less powerful actors need to be empowered to become partners under the decentralisation process and participate in each decision-making process. The relationship needs to be reciprocal, in other words (Chambers *et al.*, 2001). At the moment, chairpersons both from Kazakhstan and Uzbekistan are desperate in this relationship building with the government because they cannot find any available means to make an impact on rhetorical policies and laws:

> *They [government officials] just tell me about laws and legislation that they are supposed to be in charge of the implementation but they don't. And **I don't know how I could make an impact on the implementation process. This is a problem because there is no way. I need to find a way out for this difficult question** (Uzbek Participant M).*

The relationship with the government is largely not developed because governments have not decentralised the institutional decision-making power and thus DPOs remain largely objects for the government. Central Asian governments have maintained a top-down management in their politics so far, which reserves rather limited space for NGOs.

Relationship with the Mass Media
As for the relationship with the mass media, it is also limited though this could be **the most developed relationship among domestic actors, especially in Kazakhstan.** Chairpersons of DPOs mobilise all sorts of network relationships and connections with the media so as to broadcast their activities both in Kazakhstan and Uzbekistan. This is one of the limited ways to attract attention of society to disability issues. **In Uzbekistan, the mass media is under the total control of the government** because they are run by the government. No independent media exists at the moment. Therefore, they broadcast events of DPO activities supported by the local authority to prove the "good welfare practice for invalids." At the same time, DPOs also would like to broadcast their activities. Thus the media is a common interest between the government and the DPOs in Uzbekistan:

> *We don't have a free mass media. Their salaries are paid by our government and the content is censored. Of course, the government would like to show something good. It looks that our DPO is doing something good for the government and we are citizens of our government. We are not asking people to go on strike but teach them some useful skills. (...) This is the advertisement of the DPO (Uzbek Participant V).*

As repeatedly stressed, the importance lies in the consistency with the government in Uzbekistan. The Kazakh media also tends to broadcast and "highlight jolly events such as holiday events" (Male staff A from a Kazakh urban area). The majority of chairpersons are happy with getting publicity through the media, whereas a few chairpersons are concerned about the way they broadcast disability issues. Kazakh Participant D is one of those who are annoyed with the **attitude of the media towards disabled people**:

> *P: Articles have the tone of **guardianship**. Journalists describe us as a separate society. "Look at them. They are like this and that." They don't write about us as part of them working together.*
> *R: Can't you influence the content of the articles that were published?*
> *P: I knew well about the process of the article. Journalist gives me the draft. Even before the interview, I warned them not to write such an article that causes only sympathy in people. Though they knew it, when they wrote the article, there was some kind of sympathy in it. The only thing I could do was to change the obviously sympathetic parts of the drafts. But the most important thing is that I could not change the mentality of these journalists.*
> *(P: Kazakh Participant D)*

Without exception, **journalists are also part of the discriminating society**. The mentality of journalists has never been challenged and thus continues to be paternalistic. Chairperson I of a Kazakh urban area is also concerned about the ignorance of the journalists:

> *When we had a seminar, on the 3rd of 4th day of the seminar, a reporter from [name of a TV channel] came to the seminar. And the journalist was so surprised at the guide dog of [a Finnish participant] because the dog didn't go directly to the stairs but went aside and chose ramps for himself. And journalists didn't know that a guide dog is a kind of rehabilitation for a blind person. Taking into consideration that journalists are like this, disabled people are almost illiterate about different international facts.*

The education of the journalists themselves is an acute need for establishing a better relationship with the mass media. As disabled people lack information about their lives, the mass media is expected to deliver relevant information but has failed so far due to their ignorance of disability issues. Consequently, disabled people remain ignorant.

Regardless of this difficult relationship, a **more active way of using the media has been developing in Kazakhstan**, not much in Uzbekistan due to the stricter political constraints. Chairpersons of different DPOs cooperate together to create a series of TV programs in Kazakhstan (see Appendix 3):

> *[One staff of a DPO] is now on TV because the TV channel [name] is going to shoot a series of programs, 10 minutes each and this is on disability issues. They will be in logical order, like disabled women and employment and so on and so on. And it is funded by the USIC (US Information Centre). She is an anchor person in this program. [Another staff] is a consultant. Depending on the topic of the series, there will be experts from different disability fields for shooting this program, for example, [names of different DPOs] and so on (Male staff B of a Kazakh urban area).*

That is, chairpersons are the active subjects broadcasting the message. This is a significant change in the mass media history because disabled people were always objects until then. **Donor intervention** was mentioned for supporting such an initiative.

Another way to use the media in a more subjective way is developed when they want to involve politicians in their activities:

> *Sometimes we invite officials, for example, the mayor. If the person does not appear, then we claim the fact to the mass media. And next time he appears because he does not want the mass media to accuse him (Kazakh Participant B).*

Therefore, even though the impact of DPO activities is limited due to various background conditions, the relationship with the media is considered to be progressive in Kazakhstan:

> *Now NGOs don't play such a great role in our country, only in the work of the mass media (Chairperson C of a Kazakh urban area).*

Both NGOs and the mass media are under a kind of governmental supervision and have similar conditions to work. In this reality, both sectors aim at enlarging their space sometimes with cooperation between the sectors.

When it comes to the experiences of general disabled people, however, the impact of the mass media is still limited though chairpersons expect a bigger impact:

> **We don't have a newspaper, TV, we don't have. That's why we have the gap between chairpersons and ordinary [disabled] people** *(Female member A of a Kazakh urban area).*

The mass media is not playing as much a role in the lives of members as in those of the chairpersons of DPOs. This gap between chairpersons and members is clarified more in the following. Nevertheless, some other general disabled people mentioned more frequent coverage of disability-related activities in the media in Kazakhstan lately (Male non-member A in a Kazakh rural area and Female member E in a Kazakh urban area). Kazakh DPOs often gain new members through media coverage. The places such as rehabilitation centres for socialising with other disabled people have been closed down by now. Under this reality, the media plays an increasingly big role in connecting disabled people and let them know about the existence of DPOs. The mass media has become an increasingly important actor for the DPOs to cooperate with in Kazakhstan and to a limited extent in Uzbekistan. Through the mass media, society started to learn of the existence of disabled people and that of their organisational activities. However, the understanding of society is not sufficient yet.

Relationship with Local Sponsors[12]

The relationship with local sponsors is an explicit example of the insufficient understanding of society. The lack of finance is one of the most frequently mentioned problems of DPOs in all five Central Asian countries. This is because **society has not learned well the role and significance of NGOs**. The understanding towards NGOs has still not prevailed, which is the first barrier for NGOs because without understanding, financial support does not take place. Especially after the deterioration of the macro economy, the incentive of society decreased to donate money for associational activities even for themselves, let alone for others. Furthermore, "There is no such institutionalised government support" (Kazakh Participant D) such as tax exemption for donations. This **lack of a legal condition**, which is a common problem in many developing countries (Hakkarainen *et al.*, 2003), also makes the situation more difficult for Kazakh and Uzbek DPOs to financially survive. I summarise the findings of Horton and Kazakina (1999) and my interviews in the following. Tax legislation in all the Central Asian countries except for Kazakhstan does not improve the willingness to give donations. Central Asian countries except for Kazakhstan do not distinguish clearly between profitable and non-profitable activities. In other words, NGOs do not have fundamental tax benefits and advantages for their activities. Tax benefits are granted on an ad hoc basis. Profit tax is exempted in general although the rates are adjusted with many exceptions. For instance, the rate is 35% in Uzbekistan. Central Asian countries in general accept "far less" tax deduction compared with Western countries. Value-added tax is also legally exempted. However, NGOs have a great problem with this exemption because they have to apply for the VAT refund. The process of which is **bureaucratic and complicated**. Property tax is to be paid only if an NGO conduct some business activities. The rate is 4 % of the value of the property in Uzbekistan. In Uzbekistan, the government considers grants from international donors as profit when that is used for paying the salary of staff:

> *As a DPO, we have been working since 1991. Our disabled women's organisation has been active since 2001. With our seminar and our work, we raised as much as 30,000 dollars and invested this money in this country, more than 30,000 all together by now. We provide our people with humanitarian aid, material and financial aid, which is equivalent to 2000 dollars each year. And we should pay all taxes for these activities. The government cannot take tax from the grant itself but those people who are involved in the project supported by the grant have to pay taxes, for example, from salary. **Every project is charity. But at present, our government demands that we pay taxes for our activities** (Uzbek participant O).*

Only GONGOs are exempt from taxes (USAID, 2001). On the contrary, Kazakhstan introduced a new, progressive tax code in which NGOs are free from paying taxes on interest earnings and other forms of "passive" income. Furthermore, NGOs are required to pay only one-tenth of land and property tax that counterpart commercial organisations pay. Especially tax exemption is broadly applied to social service NGOs unlike the preference of Uzbekistan to GONGOs. **The implementation, however, is far from the rhetoric** once again and leaves much room for improvement. NGOs need to be aware of their rights to be implemented.

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[12] The word "sponsor" was used to refer to the private sector by Central Asian research participants. It equals local enterprises and individuals who donate material and financial support to the activities of DPOs.

As for donations, Uzbek tax legislation allows tax benefits only for legal entities; in Kyrgyzstan only for individuals; in Kazakhstan both for legal entities and individuals. However, the total amount of donations should not exceed 1% of taxable income in Uzbekistan and 2% in the other countries. These tax legislations are not encouraging local businessmen to donate to NGO activities (Horton and Kazakina, 1999). Cooper (1999:224) argues:

> *There are no incentives (and in some cases there are disincentives) in place to encourage donations and philanthropy in general. Without the economic conditions or incentives for adequate financial support for the NGO community, what are the options available to NGOs? The choices are the international donors and development agencies as well as the governments in the countries in which they exist.*

Turkmenistan is maybe the most restrictive in terms of tax. Turkmen Participant C revealed contemporary tax policy where all possible tax exemption for the organisational activities was cancelled "about a few years ago." DPO activities are targeted at a disadvantaged group of people, which means many of them are not able to pay for the services they get. Therefore "**We can exist only on the sponsors' money**" is a shared experience among DPOs.

This financial problem became more acute when the **privileges of DPOs were cancelled towards the end of the 1990s** both in Kazakhstan and in Uzbekistan:

> *Up to 1997, DPOs were passive in terms of applying for grants because in 1997, the privileges of DPOs were cancelled. Then business was not so profitable because disabled people's work was not so competitive. Since that time, tentatively 1998-1999, DPOs started to apply for grants. They mostly applied for serving their disabled people. That means they provide health care services, education and training. And they organise seminars to discuss issues on a local level. (Aibek Dumbayev in personal communication).*

Since then, visiting local potential sponsors for their activities became routine work for DPOs because the bottom line of DPOs is that they need money for their activities for their members who suffer from the "transition." However, the positive reaction is difficult to get under this unfavourable condition for any sponsor. Chairperson D from a Kazakh urban area got only one positive answer out of 300 letters she wrote to different enterprises. Even if sponsors decide to donate some money, they do not give much and do not engage themselves for a long-term relationship with DPOs:

> *Most sponsors are doing one-time-sponsorship only for their PR (public relation) program. There is no such sponsor who supports us on a permanent basis (Chairperson B of a Kazakh urban area).*

> *If I apply by letter, they can help us only once. We don't have a concrete sponsor in the long term. We need to visit different companies and organisations. Many of them promised to give help, but they didn't keep their promises (Male staff A in an Uzbek rural area).*

That means **DPOs need to use their limited human resources continuously for fund-raising activities**. This situation is the same for GONGOs. Even though GONGOs are supported to some

extent by the local authority, they cannot get enough funding for their activities. Activities mostly depend on the result of fund-raising:

> *If I get any amount of money from the companies, then I can organise the event for the Disabled People's Day in December, dinner for disabled people to meet each other and talk to each other. (Uzbek Participant M).*

Especially because **members want material and financial support** from DPOs, the amount of money in the bank account is the decisive factor for what they could do for their activities. In this respect, **financial constraint is a big challenge to meet the needs of the members**. Male staff B from a Kazakh urban area analyses the negative image from this activity:

> *But you know that business structures see us [our DPO] as beggars for money.*

This "**begging policy**" is the way to survive in contemporary Central Asia, which reinforces the **image of passivity** because that is one of the few contacts that society makes with disabled people. Consequently, society superficially understands and reassures the deviant role of disabled people and their organisations without noticing the reinforcing mechanism behind the superficial fact.

The members of DPOs realise the lack of financial resources from the decreasing services in quality and quantity:

> *Everyone has a problem now. Our DPO cannot help me either because they don't have money. They gave me some money. Now I applied for some more money for the second time, but they cannot give any money (Female member B of an Uzbek urban area).*

> *They [DPOs] organise different events. The number of events is less and less every year. They don't have enough finances. (Female member A of an Uzbek urban area).*

From their own experiences of financial poverty, members accept the lessening activities of DPOs as a natural and "irresistible" consequence. On the other hand, local staff B of an international NGO in Uzbekistan thinks that money is not the essential problem but the **organisational capacity** is:

> *One project with USAID was kind of an evaluation of NGOs. And all of them [NGOs] mentioned that the main problem was finance. But then we were talking about this problem deeper and deeper, then it comes down to the problems of management. I mean, in good management, this problem is not so much. Because they sometimes say, "Give us money, we do everything." And we have many examples, when they get money, they cannot manage this money. And the organisations die. The opposite example, a very good NGO with very good management, they can do many things with a small amount of money because money is like a thing which you have today and tomorrow you don't know.*

However, the need for additional resources for the daily activities of DPOs in comparison with other NGOs meant for non-disabled people should not be underestimated. **Securing the prerequisites for activities** such as accessibility, equipment and assistance all lead to the need

for more money in addition to the cost of the activities itself. Considering the fact that disabled people themselves are deprived of such prerequisites, this question should not be overlooked. The ignorance of society towards the lives of disabled people, therefore, is also reflected in the fundraising activities of the local sponsors. The temporal relation only in terms of money and material help has not constructed any positive and sustainable relationship to tackle disability issues with the local sponsors. On the contrary, this kind of relationship directly limits the activities of DPOs.

Relationship with International Donors

As a result of all these factors, most DPOs in Central Asia try to find a way and depend on financial support from international donors:

> *It's very difficult to struggle for human rights, if the situation is like this. Because I feel, if I do and tell the situation of blind children, the government officials are not feeling responsible for what they are supposed to do. We have to struggle but it's very difficult here. You can start something but you get tired of fighting. And you start feeling, "Let things be like this." I want to help the situation of institutions but parents are afraid of the government. So I cannot get the cooperation from the parents either to make greater power. So **I feel very alone here**. I report to international organisations so that later on this question is raised. I try to find cooperation more from outside like international agencies rather than inside the country. I find sponsors from the international organisations and I feel very grateful to them (Tajik Participant E).*

This statement summarises very well the reality of organisational activities in the disability sector. Without supportive local actors, the chairpersons of DPOs often feel lonely only with a grant-based, temporal relationship with a donor community. Due to the importance of geo-politics after the September 11th terrorist attack, especially the United States has been increasing its interests in Central Asia[13]. However, not all DPOs can get support from international organisations. Only a limited number of DPOs repeatedly succeeds in gaining support, while many others are "**all alone**." This **isolation of DPOs** means that their impact is very limited in their society because they are not connected to different actors to make the voices louder. Without a sustainable connection with other actors, DPOs remain as a minority and cannot make a difference. The reality, however, reveals that DPOs are isolated even among them. Under these circumstances, **the support of international donors is the lifeline for many of the DPOs to survive**. However, the relationship with international actors has not been improving the quality of life of disabled people due firstly to the isolation of DPOs from different domestic actors. Furthermore, the organisational structure and activities also lead to negative consequences. This reality is elaborated in detail in the following part around the theme of ownership. The third reason is in the international intervention itself, which will be the theme of Chapter 4.2.

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[13] The American policy in Central Asia was heavily criticised in the seminar, "States without Alternatives? Seminar on Human Rights in Uzbekistan and Turkmenistan." Adolat Najimova (2004) from the Uzbek Service Director of Radio Free Europe claimed that American military bases were prioritised over human rights problems because American rushed into the agreement on the bases without negotiating the issues of political prisoners, for instance. In this way, the US deliberately undermines the importance of human rights, she says.

Summary

Central Asian DPOs face challenges both within their sector and with other actors. The DPOs are extremely isolated from different local actors who could make the impact on their activities. The DPOs typically use a begging policy to maintain some sort of contacts with other actors, which degrades further the image of disabled people. In this relationship with other actors, DPOs are hierarchically set at lower level. Furthermore DPOs are isolated from each other among them. The difference between the Kazakh and Uzbek realities was pointed out. The DPOs are extremely isolated under current circumstances. This local reality rushes DPOs to establish a good relationship with international development agencies including Western NGOs who seek for "partnership" with them. Thus the impact of international intervention is rather big among others.

4.1.3. Ownership ~Whose NGOs?~

DPOs themselves are isolated from the surrounding actors as clarified from the above. However, DPOs still have a possibility to gain visibility in society when their constituency of disabled members supports their activities. This ownership theme is important because it is a prerequisite for implementing the political approach. It has become increasingly important for assuring the participatory development cooperation that is considered to lead to effective and efficient cooperation (Moore *et al.*, 1996). Ownership means that the concerned people are the subjects and thus a positive word. However, it also connotes different negative aspects in a Central Asian context, which is mentioned in detail in this part. This sub-chapter deals with the ownership issue by asking, "Whose NGOs?" At the same time, it deepens understanding on what is the background condition that limits the ownership only to certain people and what makes this ownership work in any negative way. The analysis starts from the coverage of DPOs that is limited mainly because disabled people are passive according to the interviewed chairpersons. Furthermore, the gap between chairpersons and members is enlarged through the organisational activities. Various other disability-specific reasons and the general local context also create conditions to reinforce reality. As a result, ownership is not shared among the very members and they remain passive objects. This organisational life, therefore, is another layer of the reality that prevents the improvement of the lives of disabled people towards equality. The main point is that most of the existing DPOs are also playing the role to reinforce the status quo together with other social actors because of the lack of ownership among members.

Number of DPO Members and Their Expectation of DPOs

Interviews reveal the statistics of the disabled population and the number of their members as follows:

Table 6. Number of Disabled People and that of DPOs in Central Asia

Country	Official Number of Disabled People	Percentage as of total population (%)	Number of Members belonging to National DPO
Kazakhstan	380,000	2.3	60,000
Kyrgyzstan	98,000	2.0	30,000
Tajikistan	115,000	1.9	82,000
Turkmenistan	N.A.	N.A.	3,500-4,000
Uzbekistan	750,000	3.0	110,000

Source: From what follows and graphed by the author.
(Hahle, 2003) and interviews of different disabled people between spring 2002 - autumn 2003.

As this table reveals, the number of disabled people is much lower than 10% of the population which is the United Nations' general estimate. As mentioned above, the number seems to be lower due partly to the unwillingness of the government to recognise disabled people. Furthermore, the number of people belonging to the National DPO is also very small: around one out of six-seven disabled persons in Kazakhstan and Uzbekistan. There are blind people's organisations and deaf people's organisations which also have a national structure. In addition, many other smaller independent organisations exist with several dozens or hundreds of members.

Disability NGOs especially independent DPOs are mostly situated in the big cities. However, **even in big cities, Disability NGOs are not widely known**. For instance, in Almaty, the biggest city in Kazakhstan, only 11% of the disabled population belong to some DPO:

> *I just know statistically that out of 45,000 (disabled people), only 5000 are registered and so 40,000 are not registered anywhere (in Almaty City) (Kazakh Participant A).*

The situation is similar all over Central Asia. Having taken these numbers into account, the above statistics lead to a preliminary conclusion that **disabled people who do not have an affiliation to any DPOs are in the majority**.

When asked why many disabled people do not belong to any DPOs, **the most common reason was because they did not know of the existence and activities of the nearest DPOs** as most of the disabled people are made to be passive, isolated and stay at home:

> *I don't know about their activities at all. I stay at home all day and do the household work. I don't know much about anything (Mother B of non-member child in an Uzbek rural area).*

Most of the interviewed general members of the DPOs got to know of the existence of the organisations through friends and relatives or through accidentally meeting some staff on the street, while many interviewed non-members did not know even of the existence of such organisations and/or their activities. A female member who used to be the staff of one DPO supports this fact:

P: Each year less and less [people participate in holiday event]. They die, those who are pensioners. They die because of their age and diseases.
R: New members are not coming so much then?
P: No. But when I see somebody on the street, I give the phone numbers of the organisation. Even on the street, I try to invite them here.
R: That means that lots of young people don't belong to the organisation.
P: No. There are even lots of people who don't know about the organisation. We try to invite them.
(P: Female member E in a Kazakh urban area)

Therefore, the **lack of information prohibits disabled people from getting to know DPOs** to start with. The second explanation is the low expectation of disabled people towards any help after experiencing little help. Female member C in an Uzbek urban area explains the reasons as "**We know that no one can help us**." Their difficult and severe reality makes them think in a passive and pessimistic way not to expect much from others.

At the same time, it is also true that **DPOs cannot offer much**. One non-member who used to be a member of some DPO decided not to belong to them any more because "they don't offer anything and it's useless to pay a membership fee" (Female non-member B in a Kazakh rural area). When they know about the DPOs and feel really desperate, then they apply for help from DPOs. Otherwise, **they rather rely on family members** as society takes it for granted that the family is responsible for the disabled members. For instance, a *Mahalla* officer says, "Disabled people usually live with the family or relatives and so live a good life." When it comes to the opinion of chairpersons of DPOs about this issue, Uzbek Participant M as a chairperson of a DPO points out that the deficiency of organisational capacity is the reason:

R: Do you know why some people don't belong to this organisation and some belong to?
P: I know. Because they know that they cannot get the necessary help from here, even no help for the whole year. It's very difficult to involve them in our activities because they don't have any interest in us. (...) If we have the possibilities, then of course we help them. They ask for money, medical treatment, renovation of their apartments because their pension is too small for them to do that. They ask for medicines. It's impossible for us to provide help for 66,000 people.
(P: Uzbek Participant M)

Institutional support from DPOs is impossible. That is the area of governmental intervention in Western countries. DPOs cannot invite the majority of disabled people because the most common reason to belong to a DPO for the members is to get material help. They experience disability in individual and isolated situations and thus solving an individual material deficiency is what they are interested in. **Humanitarian aid, therefore, is the most expected area of activities among general members**:

Not a small help but a big, huge help is needed. Whatever material support is welcomed (Male member B in a Kazakh urban area).

All interviewed chairpersons admit that material help is the most applied needs of disabled people and their members:

> *Parents come here and say, "I came here. I don't have any more money to go back."* *Some children come to our workshop and they are starving. What can we do? We ask the* *kitchen to feed the children. This is our situation. I tell you the truth. This is our reality* *now. (...) From the early morning till evening, they ask, "How can you help us?"* *(Chairperson B in an Uzbek urban area).*

A few DPOs have a legal consultation service. However, only one call during the whole last year was related to a legal matter in one DPO, while all the others were to ask material support:

> *We always emphasise that we provide legal advice and consultation to disabled people.* *But when they know that we provide legal services free of charge and can provide* *services in court, they are not interested in this anymore because they would better get* *some money or a sack of potatoes. We have been preparing a report and wanted to trace* *trends about what cases mostly disabled people apply to us for in terms of legal* *consultation. The first one is that they apply for financial problems. And only one person* *applied for help to file a suit in court because he thinks he was discriminated against due* *to his impairment (Chairperson F in a Kazakh urban area).*

Disabled people are mostly not aware of their rights (see Chapter 3.3.) and so naturally do not ask for it to be fulfilled. They do not consider DPOs as places to solve collective issues or to challenge the discriminating structure. Instead, their major concern is to make ends meet in their individual lives. That is, DPOs are playing the role of gatekeepers for humanitarian aid.

Gaps between Chairpersons and Members

As DPO chairpersons have started to link their ideology to the international disability movement and want to mobilise their constituency for making a movement for the collective goal of equality, they face this gap with their members:

> *I want them to be independent with a goal and to be necessary people, not to be just a lazy* *person just begging and cannot work. And I want them to realize that nothing should be* *done without their participation. No problem can be solved without their participation. To* *do this, they have to know this and fight for their rights and draw attention to their* *problems. (...) Mostly they just complain about their situation. (Chairperson A in a* *Kazakh urban area).*

> *I'm offended by disabled people. They are not nice people.* ***They don't help. They only*** ***want to take something from you saying, "Give, give, give!"*** *(...) There are 4500* *disabled people in this area, but only 752 registered. But those who help us are only 5 or* *6 people. We try to help those who need our help the most. They [these 5-6 members] are* *not active members. They sometimes help us. For example, when we receive humanitarian* *aid, then we ask them to call other people because we cannot call everybody. (...) And in* *1995, we introduced a membership fee of 100 Tenge (=60 cents). But when they need* *help, they just come and ask without any membership fee. That's why I am so much* *offended. (...) Some disabled people, I really hate (Kazakh Participant I).*

The chairpersons are frustrated with the fact that **their members do not share the same collective goal** as them. This gap is acknowledged widely by both chairpersons and members. The chairpersons often face the situation that few show up for their activities because members are "passive":

> *People are a product of the environment. We have different mentalities. Few of the parents have any active mentality. There are a few of those who changed their mentality. Most of them have the mentality of the Soviet Union. (...) We had a summer project together with [an NGO], an American organisation, on education and information support. We wanted to send our kids to learn to use internet. We found only 2 kids and 2 grown-ups who wanted this [training] and one of the grown-ups was my son. There are very few kids who want to learn and study because they are so accustomed to gain sympathy from their parents (Chairperson D of a Kazakh urban area).*

DPOs try to implement new ideas by collaborating with international actors. Nevertheless, members are not interested in these long-term goals of independence and empowerment when they are concerned about material needs in their daily lives.

The need to change the passive mentality of members was mentioned frequently by chairpersons. However, because "we cannot force them in anything" and "they have to improve it by themselves" (Chairperson C of an Uzbek urban area), the task is left to the responsibility of each member. Some chairpersons hope that members will change by seeing the example of the chairpersons:

> *R: How are you going to change their mentality to have a similar ideology as you have?*
> *P: There is no written rule. Of course, it is very complicated to answer this question. Sometimes, I have some unexpected decisions popping up in my head. But mostly we try to show them our own examples, by holding some events trying to show them that they can solve them by themselves, and they just should not follow the Soviet mentality.*
> *(P: Kazakh Participant B)*

The problem of the Soviet mentality is widely acknowledged. Yet, a specific program to change the mentality of members was rarely mentioned except for a few seminar activities. This is also one of the reasons why the mentality has not changed. **Without specific intervention meant for the mentality change of the members, it is unlikely that disabled members spontaneously change the mentality being surrounded by the mechanism**.

This mentality difference clearly divides them into two groups: chairpersons who feel ownership to DPOs tackling collective issues and individual members who connect DPOs only as a means to solve individual issues (see Wiktorowicz, 2004). This gap already existed when DPOs were established because, first of all, **chairpersons are usually educated, relatively rich and even "better than healthy people" who are successful**. This is a common feature for leaders of NGOs in developing countries (Hakkarainen *et al.*, 2003). The chairpersons of GONGOs in Central Asia are deeply linked to the government, which thus accelerates this phenomenon:

The Soviet government established three DPOs, deaf, blind and the republic one. (...) They were very powerful organisations with their own enterprises where disabled people manufactured shoes and so on. And leaders of these organisations were elected on the decision of the communist parties and they were former Ministers. They were from such levels. These organisations were funded very well. Disabled people would receive cars with manual control during the Soviet time. And they were queuing for them. The keys of these cars were given from the regional department of the communist party (Chairperson F of a Kazakh urban area).

That is, the management of GONGOs was originally deeply related to the Communist Party politics. This already partly explains the gap.

When it comes to the chairperson from independent DPOs, they are also relatively well-off. They have to clear the registration hurdle with their own pocket money, which tells either of their own financial status or then a good relationship with powerful people on top of their strong enthusiasm to tackle this issue. These chairpersons usually establish organisations from their own experiences as disabled persons or as parents of disabled children. Therefore, the starting point is close to the general disabled people. However, the **chairpersons change through organisational activities**. Kazakh Participant D noticed that she started to be separated from the members:

I'm afraid to be separated from ordinary members in the future because I have witnessed that there are many leaders ruling their organisations for a long time. They forget about the needs of the members. I don't want to be like them. Now I am working for my members as friends. (...) It became obvious to me when once I wanted to organise an event for our [members]. I told them, "It's going to take place in one place and I settled all the buses and other matters." And they said, "Did you forget that we should prepare ourselves? It's easy for YOU." Then I thought, I began to separate myself from them (Kazakh Participant D).

Chairpersons are empowered all the time as they are exposed to lots of information and learn different skills and new contacts through their organisational activities. On the other hand, the lives of their members remain the same. Uzbek Participant C explains that the reason is a **lack of information to members and consequently lack of control of the members over the activities of DPOs**:

I have been trying to explain to members that our DPO is not A's organisation nor B's organisation. I tell them, "This is a disabled people's organisation for disabled people." And disabled people must be able to influence the activities of the DPO and there should be accessible information for them. But unfortunately, we don't have the information right now. (...) One of the reasons of the hitherto corruption was the lack of information. And the lack of control among members.

For instance, none of the interviewed general disabled members knew about what kinds of seminars and training chairpersons had been participating in. Even deputies of chairpersons and staffs of DPOs do not know such information:

R: Do you know about the seminars very well that leaders participate in?
P: No, I don't know much about such matters. My responsibility is to work here. For example, I repair broken wheelchairs.
(P: Male staff A of a Kazakh urban area)

Information delivery is to be ensured in the beginning stage of real participation (Chamber *et al.*, 2001) and thus is important. The lack of financial resources and the lack of interest of the members in information explains this reality. First of all, information delivery is costly especially when members cannot easily come and visit DPOs without accessible premises, transportation, assistance and so forth. Information delivery, therefore, requires some person to visit members one by one when the members do not have a telephone line. Thus **information delivery is virtually a money-, energy- and time-consuming activity** which is difficult to be implemented with limited resources. Secondly, members are not interested in information as much as in material support. Chairpersons started to realise the importance of information, while members are not interested in information as much as chairpersons:

> *About legislation, when we tried to organise a seminar about legislation, I called to our [members]. They said, "**What law do we need? We need money for medication**" (Kazakh Participant H).*

> *When I returned from [a Western country], I asked [deputy] to organise a press conference. It would cost 700 dollars for a 15 minutes press conference. And then we thought that if we organise this, ordinary members wouldn't understand this effort (Kazakh Participant D).*

Some chairpersons are just "lazy" or do not have time to engage in this activity, and others even do not think of information delivery as an important activity to prioritise because such needs are not expressed by their members. **Information does not reach members even though DPOs are usually the only source of information for disabled people** (Female member A in a Kazakh urban area). Chairpersons try to allocate the limited resources to meet the needs of the members. Thus the resources do not go to information delivery activities. In this way, members are left behind without enough conditions for their self-determination, while chairpersons are empowered all the time with different information. This **organisational structure keeps widening the gap between chairpersons and members**.

Success Depends on Chairpersons

The too centralised responsibility of the chairpersons also enlarges the gap because chairpersons need to make so much an effort for things to happen in this discriminating and difficult environment with different constraints. **They have to use all the energy for running the activities.** Activities usually depend much on chairpersons. The above-mentioned fund-raising activity is one of them. Another example is humanitarian aid activity. Humanitarian aid often goes to DPOs run by such chairpersons who are "quick and cunning":

> *Humanitarian aid is important in itself, but it's also necessary to check if it is allocated to those who really need it. Quite often humanitarian aid is allocated to those who don't need it so much. Humanitarian aid is allocated to those organisations that don't have any data base to whom to allocate. Sometimes organisations who have not so many people*

receive humanitarian aid because of the leader who is very quick and who can receive them. (…) And leaders of a humanitarian aid organisation sometimes deceive the organisation which gives humanitarian aid. That's why some organisations get humanitarian aid 100 times, and some get nothing (Kazakh Participant C).

"Success in activities" depends on the personal relationship of the chairperson when "Our city officials and state does not want any additional issues in a disability field" (Chairperson B in a Kazakh urban area). She continues:

When the state denies our proposal, we try to find personal contacts and money through personal contacts and we solve these problems.

This is the mentality of Central Asia to mobilise the **personal connection** in any business:

This is the mentality of Central Asia. Personal connection is very important. And many programs especially lobbying depends on leaders. When you only apply to the local authority and to society, it does not produce any results. If we have some acquaintances and you work with those people, then that enables our programs to progress. That's why [name of a chairperson] and I have quite a good relationship with the authorities. With some of them, we studied together at the University in [a city]. That's why we don't have any difficulties when we want to apply to them. (Kazakh Participant C).

Even in training organised by an international NGO for the Central Asian NGOs, this aspect of the personal connection was highlighted:

When we had training in [an American NGO], we were told that it is acceptable to reach your goal at whatever cost. For example, some leaders of an organisation accomplished something due to their personal contacts with powerful people or acquaintances in the President's family. And they also said that not only directly should we demand something for developing civil society but also in indirect ways (Kazakh Participant D).

Therefore, on top of all the activities and necessary works, chairpersons are also busy with maintaining their old connections and making new connections for their activities to be implemented:

*We accumulate experiences because, as I told you, firstly we were humiliated. The local authority didn't listen to us. Businessmen didn't listen to us. We saw so much misunderstanding. We had much to learn. For example, how to apply for different grants and how to make contact with the local authority, how to avoid conflict with them, how to try some ways to get along with local officials. For example, you saw this woman coming from our local authority. If it had happened several years ago, everybody would have fainted, because it was not a normal thing for us. But you know she came from the local authority building to our building. This is the result of our work because **criticism is easy and simple but trying to find the way to get along is much harder** (Chairperson A in a Kazakh urban area).*

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Personal connection with the powerful people is becoming one of the important means to run the activities.

Corruption: Consequence of Personalised Ownership of Chairpersons

When it comes to the grant application, this connection leads to even corruption. Kazakh Participant D recalls that she was naïve when she started the organisational activities. She did not know that there are "dirty things under the table for getting the money":

> *P: I tell you frankly. I treated [a person] so much for the first year. For the whole night, we drank. That was the time when I started the activities. And I was told that he is the key person and our activities depended so much on him. Because I know that other DPOs in this field belong to some other organisations. And if I come there, they don't understand me. (...) According to [the key person]'s word, he was successful in fundraising. 10 years ago when there were not so many DPOs, donors gave a grant to him. Due to this, he established good contact with them and when many DPOs began to be established, he started to represent them as a member of an expert commission.*
> *R: What is the expert commission?*
> *P: For example, when a grant is announced by a sponsor, the foundation has an expert commission to check if the applied projects are good enough for the grant or not. And [the key person] is in such commissions.*
> *R: Oh.*
> *P: That's why.*
> *R: So he has the direct power to decide which organisation is to get the grant.*
> *P: Yes, yes. If some organisation is established, he is the one to consult because he knows which project will attract the attention of donors from his long experiences.*
> *R: So you have to go through him!*
> *P: Yes. (...) [a chairperson] and some other organisation told me how a project is going to be promoted and what the procedure is like. [the chairperson] wrote a project himself and his project was successful. But I knew later on how much effort actually he made because he bought beer, sauna and girls for [the key person]. It's a general practice and when I experienced this, I was shocked.*
> *(P: Kazakh Participant H)*

Corruption, therefore, is part of the daily organisational activities for DPOs as well as any other organisation both in Kazakhstan and Uzbekistan to make things happen in the tightly controlled society. This personalised ownership of chairpersons leads to such negative consequences. Some chairpersons and staffs of DPOs start to personalise even the gained money and humanitarian aid:

> *Some chairpersons of NGOs live a very good life. They are educated. And they know the ways to get grants from different organisations. Your (Japanese) Embassy helps them so much. (...) You (Japan) spend lots of money. This money pays the trip for the chairmen to go abroad. It takes too much time. Maybe they bought 2 or 3 old computers to show Japanese representatives that they spent your money. The rest of the money goes to themselves, to the chairmen. There are many cooperation projects [with foreign donors]. I'd better not to tell you (Female member C in an Uzbek urban area).*

When we got the computer as a humanitarian aid from somewhere, it was given under the name of this DPO but it stayed in his [the chairperson's] apartment (Uzbek Participant M).

Secretaries and staffs of chairpersons have to close their eyes to such practices:

The secretary has to close his eyes, and so did I. There was no need to see. I made some mistakes (Female member C in an Uzbek urban area).

As corruption is one of the survival strategies, it is more important than pursuing justice. Corruption, therefore, is justified. In this way, corruption is institutionalised in quite a few DPOs. Some staffs could not stand such practices and quit DPOs (Female non-member B of a Kazakh rural area). As has been getting clear, chairpersons have lots of struggles in their daily activities for their survival which takes energy and attention away from their members. At the same time, **the ownership owned only by the chairpersons** creates the condition of corruption that keeps the chairpersons even busier to run their organisations.

In this whole process of organisational activities, the role of chairpersons is conceptualised among members as persons who take care of everything. Central Asia inherited the "Soviet mentality to undo" (Handrahan, 2001:471). This already passive mentality and logics in their local culture with hierarchy helps members to think in the following way:

Of course, other members helped her. But she is the leader and centre of everything. But you know her. And you can also say this (Female member C in a Kazakh urban area).

Maybe it [organisational activity] depends on the work of the chairperson. (Female member D in a Kazakh rural area).

At the same time, chairpersons also realize their own role as "**everything depends on the leaders**" (Chairperson D in a Kazakh urban area). Decision-making and the implementation of activities, therefore, is heavily on the shoulders of the chairpersons as they are the only ones with skills, knowledge, connections and other important criteria for managing the organisational activities when members would not dare to share the responsibility due to their made passivity. Members cannot affect much the activities of their DPOs without information and means, while they are also not willing to be engaged in any burdensome activities of the organisation. In other words, members are unwilling to have ownership for the collective issues because they have not had a chance to realise that this is a collective issue. In this way, these organisational activities create the mechanism to enlarge the gap between chairpersons and the general disabled people. The **lack of internal democracy** frequently takes place in the process of NGO management in different countries (Hakkarainen *et al*., 2003). It is easy for Central Asian DPOs to end up with this consequence due to the specificity of both the disability-related context and the Central Asian context.

Charity Activities

With this gap between chairpersons and members, charity activities are prioritised because inactive members are not willing to take part in other activities that chairpersons organise:

The participation of parents is the big and main problem because they have some old conception. For example, about health care. In the Soviet Union, we had free medical care. Now disabled people are denied any privileges and they have difficulty in putting up with that. Now we, parents, live in the situation where children don't have any privileges, even without transportation. So everybody is equal. But for parents it seems it's difficult to understand. They consider this as a difficulty. Whenever they go to some organisation, they demand that this organisation should help them. I was very naïve when I began this work. And I also encouraged parents to come or volunteer. But I didn't succeed because no one would come. Only some came. They couldn't work more than two days because they saw that it's hard work. To overcome this, we need some time because we have to change their mentality. I don't say that all the parents are like this, but most of the parents are like this. They like gifts and meetings so they come for special events and are invited to some holidays. So not only the children but the parents are also invited (Chairperson D in a Kazakh urban area).

*They want to get something like money and humanitarian aid. **When they are offered something, they are happy to take them**. (Female non-member B in a Kazakh rural area).*

Consequently, holiday events and humanitarian aid are the most frequently mentioned activities of DPOs according to the general disabled people. This popular event activity has many problematic aspects when investigating it from the rights perspective. Firstly, this activity excludes disadvantaged groups of disabled people. Secondly, this activity is an explicit example of a charity model activity that reinforces dependency and passivity of disabled members. The description of these events is followed by these two major problems.

One or several events are organised per year on holidays such as Central Asian New Year, Women's Day, the International Day of Disabled People and so forth. The frequency depends on the success of the fundraising activities of the chairpersons:

This is a poor organisation and organised only one event last year (Female member D in a Kazakh rural area).

On every holiday which is celebrated in Kazakhstan, we gather in a café or restaurant. Sometimes people from all districts gather and sometimes only one district. (...) Firstly I went to [one] district's DPO. I don't want to criticise anybody. But there was a leader who was an old woman. And she didn't want to do anything extra except for the humanitarian aid. And when she got some aid, she gave us food and something else. When I was in a prosthesis institute, I met some guy who told me about [another] district DPO. And they told me that it is at the city level. They wouldn't promise anything much, but they promised me moral help and a sports event among the activities of this organisation. And also material support and a present. I wish there would be more material support. But anyway it is good (Male member B of a Kazakh urban area).

Success of the chairpersons is measured by the frequency of charity activities because it tells how much they succeeded in raising funds. The members usually get a phone call from the chairpersons for the forthcoming events, as the local phone call is only the fixed monthly fee.

Chairpersons have a list of their members and pick a group of people to be invited to each event. Only a small number of members is invited at a time:

> *P: There are some events like eating in a restaurant and a children's camp. I think that was with the support of the mayor.*
> *R: How often do you have such events?*
> *P: Often not all people are invited. For example, I'm invited to a New Year event, and then after a while to Women's Day.*
> *R: So how many times a year are you invited?*
> *P: Once or twice.*
> *(P: Female member A in a Kazakh urban area)*

These party events are considered important for disabled people to "go out into the fresh air (Chairperson A of a Kazakh urban area)" and "discuss problems amongst them" (Chairperson I of an Uzbek urban area). Many disabled members also expressed that they enjoy these events.

The following is a description of an event that I was invited to. Around 100 disabled persons were invited to this event in a café sponsored by a businessman. This was an inter-district event of GONGOs. Representatives of all districts were present. Each district could invite the same number of disabled persons to this event. It started from 2:30 p.m. and lasted for four hours. During the event, people were served with a full course lunch and alcohol, a small present such as toothpaste, and enjoyed dancing and the performances of orphans. One female participant told me, "I got to know about this event 1-2 days ago. It's difficult but OK to arrange the schedule at this short notice." The notice was given to me also one day before. I went around to different tables and asked about the criteria who were able to come here. One female participant said, "Those who can walk are invited." Another male participant said, "Active members and those people at the management level of DPOs are invited here." One other female said, "We are always the same members from our district and so I know all of them. We visit each other's place by now and are very good friends. But this is the only chance for us to meet with disabled members from other districts." These were all true because all familiar faces of chairpersons were present together with their vice-chairpersons. Furthermore, only one disabled person was in his wheelchair who is one of the chairpersons. None of the invited members were in wheelchairs. All were physically self-sufficient and could dance. This **walkability was necessary** as the toilet was located in another building which had ten stairs in front. I also noticed a big problem of transportation because this café was far away from many districts. None of my research participants in wheelchairs were able to attend the event because "paying a taxi to get there is too expensive." In this way, I witnessed that **only a limited group of disabled people could enjoy the activities of DPOs**. More precisely, the events exclude disadvantaged groups of disabled people.

The event activities are not the only activity that limits the targeted participants. This transportation problem and inaccessibility of premises for severely disabled people are common problems for any DPO activities. The lack of transportation means is one of the most frequently mentioned challenges for DPOs:

> ***The main problem is transportation. Transportation!*** *Children don't have any opportunity to come and we don't have any means to carry them to visit us. And of course*

such children cannot leave their places because they need at least two persons to get on the bus. And the child can be so paralysed that they cannot really move themselves. We applied to different foundations for getting transportation. Even if we had children who live nearby, they cannot anyway come to our place because there are no special ramps on the streets (Chairperson D in a Kazakh urban area).

There is no money for a taxi. Many children want to study here and to learn some skills but they don't have money for their transport to come here. We don't have the transportation (Uzbek Participant D).

Activities cannot be implemented as much as chairpersons want due to the limitation of transportation means both for disabled members and for DPOs. Research participants claim that d**ifferent international foundations and donors usually have rules that they do not cover the cost of transportation.** Thus they can never secure transportation means. It is an especially serious problem for people in rural areas:

Here is the centre. It's very difficult for disabled people who live in the villages in a farm to come here. If we have the possibilities, we could come over to their houses to give a present and give money, but we don't have the possibilities. If we have the possibility, we can, and now we cannot. If we don't have the possibility, we cannot help them. (...) They cannot come here so we have to go there by ourselves to give some presents. We don't have any transportation means ourselves so we hitchhike. It's very difficult without transportation. If one can move around, there is no problem. One can go to the holiday events and then can come back without a problem. Not only one lives here but there are too many of them in this district. It's impossible for us to visit each one of them (Chairperson J in an Uzbek rural area).

Most of the interviewed chairpersons and disabled people mentioned this is a huge problem for them. Nevertheless, one chairperson invited many severely disabled children to one event. She admits that "this is a very expensive pleasure" (Chairperson B of a Kazakh urban area). **With the limited resources, chairpersons tend to invite those who are physically self-sufficient**:

When DPOs organise an event, they don't invite people in wheelchairs because it's problematic for them. It is easier for them not to invite us because they are going to have trouble with accessibility, how to get us to buses, how to take us, who is going to assist us leaving the house. We didn't have so many opportunities to communicate with other people because we were not invited to any events (Female member B of a Kazakh urban area).

In this way, severely disabled people without transportation are systematically excluded from DPO activities.

However, **chairpersons get an impression that members are "passive" when the invited disabled people cannot come to the events.** When I was told that there are few active and a majority of passive members in DPOs, I asked the chairpersons to introduce both groups of people according to their categorisation. Then it turned out that chairpersons picked up severely disabled people as those who are passive because they do not participate in the activities. That is,

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chairpersons consider severely disabled people as "passive" rather than those who are deprived of opportunities to become active. **Even those chairpersons have not realised the vulnerability creation mechanism**, which is a very serious problem. The reality for such severely disabled people is that they cannot participate without any assistance, accessibility, transportation and good health condition which are prerequisites for participation:

> *If, for example, there is an event once a year, it's a problem for me. I cannot go downstairs because I live in an apartment on the high floor. (...) Not organisation. My friend helps me. If, for example, an organisation arranges something in a restaurant, [chairperson] calls me and tells me about it. And when my friend is free, I can go there. But if he is not free, I cannot go there (Male member A of a Kazakh urban area).*

> *Last year, I participated often, but this year I have participated much less because I have problems with my prosthesis. I sometimes have swollen legs and bad blood circulation, and cannot always participate (Male member B of a Kazakh urban area).*

These acute conditions for severely disabled people are not taken into account when events are organised by most of the interviewed DPOs. The DPO introduced in Chapter 4.3 is one of the few exceptions that take this mechanism into account seriously. Severely disabled people do not mean to be inactive but simply cannot participate in activities without the proper preconditions. Once again, the environment makes them "passive."

Despite the limited number of people who can come to such an event, one female participant said, "I used to feel myself very disabled. But now, I don't feel it after participating in a sports event and I feel more active about my life." For some disabled people, these events are important for meeting peers to gain moral support:

> *P: We haven't much opportunity to meet each other and they [DPOs] try to give us an opportunity to speak to each other, just parties. Mainly parties.*
> *R: Like social events.*
> *P: According to the holidays.*
> *R: Does it actually help you if you participate in them?*
> *P: Yes. It is great when a person tries to rehabilitate himself. It's more difficult for those who became disabled, not from birth. When you were healthy, you can compare between situations when you were healthy and when you got your disability. It is very difficult to begin a new life. This organisation helps in this situation.*
> *(P: Female member E in a Kazakh urban area)*

As places for meeting other disabled people became less and less, this kind of event is considered to replace the withdrawal of social services and space that were provided during the Former Soviet time. **These events play a role of social space** for a limited number of disabled people who are physically self-sufficient and who managed to belong to some DPOs.

On the other hand, not all disabled people are grateful for these event activities. Some think events do not actually help the situation, while others think **events are used for governmental propaganda** to show other nations that disabled people are well taken care of:

R: Do you enjoy these events?
P: To be honest, I didn't enjoy them because they were not organised well.
R: What happens on those days?
*P: They give us some tickets to have a dinner and some tickets for entertainment. **They didn't provide any real help**.*
(P: Female member A in an Uzbek urban area)

Have you seen our holidays? It costs a lot of money. We can live without those holiday events. It's better to give money to old people and disabled people instead of those holiday events. If they can give 10,000 Som (=10 Euro) more [pension], they are much more happy. This holiday costs about 1 billion Som. We have this tradition to show others how well off we are, and on the other hand let people die. It's easier for the government when people are dying and the government pays less (Female member C in an Uzbek urban area).

These temporal events are not considered to solve any of their problems in a sustainable way. Moreover, these events are criticised because **they reinforce the passive mentality of disabled people**:

Only after seeing material changes, then they will be glad. There are some people who are invited to some events and charity evenings. They say, "There is no sense to go there. Just give me money". But I think that these people consume, consume and consume, not give something or share with others (Female member B in a Kazakh urban area).

Disabled people expect something from organisations. When a chairperson invites them to some events, the people start to expect this organisation to do something for them again (Female non-member B in a Kazakh rural area).

The induced passivity is consequently reinforced by the DPO activities. One research participant is fed up with the negative effect of such events also due to the **paternalistic attitude of the sponsors** towards disabled people who see them as **objects of pity**:

At the beginning of the activity, I wanted to apply for sponsors because while working in the DPO, I got used to applying from different places. But then when I established this club, I thought it's embarrassing because members have allowances and some of them have work. We could afford to organise events at our own expense. I had the idea to collect 500 Tenge (=3 Euro). It's a cheap city not like Almaty where the prices have sky-rocketed. We go to a restaurant and collect money together. This 500 Tenge is enough for a musician, food, alcohol and beverages. At the beginning of the activities of the club, I told the members that I was not going to apply for money from the sponsors because once I had a very awkward situation. When there was one event, while we were eating, the sponsor came up and told us to enjoy our food. He was very glad to see us eating. He humiliated our dignity as if we were hungry, as if we didn't have anything to eat. And I felt so much embarrassed. Our members are well-to-do people. There are no poor people among us. We can afford everything ourselves. There should be nobody behind our back saying, "I helped them" (Female non-member B in a Kazakh rural area).

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The dignity of disabled people is totally neglected in such an event, she says. That is, events and charity type of other activities actually play a role in reinforcing the passivity of disabled people (Barnes, 1991). At the same time, those underprivileged groups of disabled people such as severely disabled people, people with learning difficulties and those from rural areas are excluded from these activities. That is, not only the discriminating society but even **DPO activities ignore the group of disabled people who need support the most**.

At the other end of the spectrum, however, general disabled people and members are not interested in other types of activities which would empower them. DPOs offer computer literacy training, educational opportunities, income generating activities, legal support and/or medical treatment and rehabilitation in addition to the above-mentioned events and humanitarian aid distribution. Through these activities, DPOs aim at moral support, a change in mentality and improve quality of life in real terms. DPOs not only try to meet the needs of holiday events but also try to create positive and sustainable changes in the lives of disabled people with new ideas. Nevertheless, due to the lack of accessibility and information delivery from the DPO side and the induced passivity from the members' side, disabled people cannot take advantage of the existing activities of the DPOs. This is the reality of organisational activities. That is, many DPOs rather consist of an important part of the vulnerability creation mechanism despite their good intentions. Due to these background conditions, **both most of the GONGOs and independent DPOs are part of the vulnerability creation mechanism** despite their differences.

Summary
The Western concept of DPOs is voluntary self-help groups working for empowerment of the constituency as peer (cf. peer support) and structural change towards equality. "Western democratic thought generally assumes that the representative structures provide an adequate channel for the political involvement of the intended beneficiaries of an action (Moore *et al.*, 1996:29)." However, the above interviews and observations prove that the assumption tends to be wrong in a Central Asian context because DPOs are owned by disabled chairpersons but a disabled constituency typically does not have the ownership. This is firstly because the issue is not acknowledged as a social issue and secondly because activities are based on the charity model and are organised mostly by the chairpersons alone. Moreover, the process of organisational management has been enlarging the gap between chairpersons and members against the intention of the chairpersons to improve the situation of disabled people. Many of these DPOs are just for fulfilling a deficiency in governmental support and thus included in the governmental structure that reinforces the reality.

In conclusion, contemporary DPOs in both Kazakhstan and Uzbekistan have an ownership problem. **"Disabled people" are too generalised** in the context of DPOs, which consequently ignore most of the more disadvantaged groups of disabled people from the discourse. Therefore, even though the number of DPOs has increased over time, it does not directly mean that democracy has been mediated through DPO activities. At present, DPOs are isolated, as disabled people are. Development of NGOs in the disability sector is in the very initial stage that the existing actors are, in theory, potential mobilisers of the disability movement (Wiktorowicz, 2004). Without any significant change, however, most of the DPOs remain as part of the discriminating mechanism against their will. Empowerment of the constituency is indispensable for the Central Asian DPOs to become an actor for democracy. The majority of excluded constituency has to be empowered to be able to see disability as socially constructed difficulties

and to liberate their low self-esteem. Disabled members have to become subjects and feel the ownership of their issues.

4.2. International Intervention ~Globalisation of Social Justice~

As has been indicated repeatedly in the previous chapters, international intervention plays a big role in the dynamic changes of Central Asian civil society. For instance, foreign aid is the biggest single source of hard currency in Kyrgyzstan (Handrahan, 2001:472), which tells the big role. Kyrgyzstan has attracted the most attention in terms of foreign aid due to its more democratic policy and practices, as the West "rewards" Kyrgyzstan and in this way encourages other Central Asian countries to follow its example. Nevertheless, this reality that foreign aid occupies a big part of the money flow is witnessed to different extents in this region since independence. This flow is the sign of both expectation and encouragement towards democratic state building. This sub-chapter focuses on the international dimension. Firstly, general trend of international intervention is briefly described. As Central Asia has been politically and geographically isolated from the rest of the world, the local knowledge of Westerners is limited. This lack of local knowledge leads to a paradoxical outcome. The second part introduces one Finnish case study. The Finnish DPO, Kynnys, tries to tackle this issue by employing the political model which started to be focused as an important model in theory both in disability discourse and development discourse. In this sense, investigation of their project is both academically and practically important because still most of Western DPO activities focus either on individual needs depending on specific diagnosis or on service provision. Globalised disability movement offers the possibility of paradigm change towards equality. The implementation of the political model of disability, however, was difficult for many Central Asian project participants to understand, while some started to prepare for their way of disability movement as is going to be presented in Chapter 4.3.

4.2.1. Paradoxical Outcome of the Hitherto Intervention

The brief history of international efforts in terms of development cooperation in Central Asia proves the actual difficulties for both Western and Central Asian actors to implement the political model in practice. The difficulties too easily convince Western actors not to touch the essential political constraints, which thus reinforce the reality without fundamental change. In this way, Western actors also play a role in reinforcing the existing mechanism against disabled people (see Hofstede, 1991). Firstly, the general trend of international intervention is analysed. Subsequently, the focus moves on to intervention in the disability sector. This sub-chapter introduces the Central Asian local context in relation to the international aspect so as to understand the background condition of the project of the Finnish DPO in the following.

General Trend of International Intervention in Central Asia

NGOs from Western countries started to engage with local organisations in development cooperation especially since 1994, as Central Asian NGOs began to establish themselves. "They [Western NGOs] equated the creation of local NGOs in the short term as a tool to engender the development of a viable civil society in the long term" (Luong and Weinthal, 1999:1272). Local NGOs are expected to facilitate the democratisation in these authoritarian regimes by depending on the experiences and support from international donors. Many scholars and practitioners admit the great role that the West plays in the area of organisational development and infrastructure (Mininni, 1998; Bekturganova, 1997), connecting isolated local NGOs (Luong and Weinthal,

1999; Galbraith, 1997), the financial contribution, information provision, and navigation of local NGOs (Luong and Weinthal, 1999; Bekturganova, 1997). However, there is big room for better cooperation:

> *Western foundations and NGOs don't always have a clear understanding of the situation in our country, so their activities often fall prey to two extremes: either they offer no advice whatsoever, or they attach too much importance to their own notion and models of how to solve the problem. An organisation that attempts to analyse the situation and master its specific characteristics is a rare exception (Kuratov, 2002:12).*

Western intervention has been unintentionally and ironically causing non-democratic outcomes in Central Asia. Firstly, this peculiar political precondition is difficult for the Westerners to understand:

> *It is a **political culture** that Westerners cannot hope to relate their own experiences to, as few, if any, overlap with those the Central Asians have endured. Those who desire to "help" them must take into account this almost wholly alien political culture, rather than viewing their current situation through the prism of Western experience. It will likely take a generation at least for meaningful and long-term change to be possible. (...) Whatever happens in Central Asia, the development of civil society in those new countries is going to be a slow and difficult process (Carley, 1995:315).*

The simplest consequence that stems from the ignorance of the local reality is the **proliferation of GONGOs** because donors demand to increase the number of NGOs without checking the profile and engage with GONGOs for their cooperation projects. Handrahan (2000:19) accuses the Western partners for their little consideration of the choice of local NGOs. She suggests that the West should take time to examine the NGO profile. The gap between GONGOs and other independent NGOs is getting vague. Nevertheless, the tendency of GONGOs is frequently towards consistency to government policies and practices. In this sense, engagement with GONGOs needs careful insight depending on the aims. On the other hand, GONGOs cover a bigger population and thus can lead to a bigger impact, which could be made use of in some cases.

Even if Western intervention managed to be engaged with independent NGOs, they still cause paradoxically a non-democratic result under the political conditions in Central Asia. Under the restrictive circumstances against political and social change, local NGOs prioritise more the fund-raising activities towards the Western development community. As the Western community is willing to allocate funds for NGOs in Central Asia, there is less incentive for the local NGOs to make more of an effort to be engaged with their government or with potential local constituencies in their community. That means **local NGOs pay more attention to international needs rather than local needs**, which subsequently leaves out the government and people from their activities by cooperating with the West alone and by manipulating with Western buzz words. The series of negative consequence have been witnessed in NGO activities in different countries (Hakkarainen *et al.*, 2003; Moore *et al.*, 1996). Cooper (1999) describes that local NGOs are "project-driven" without long-term sustainability.

NGOs in Kazakhstan are concentrated in the big cities due to the high concentration of donor communities there. Only 8% of the total number of Kazakh NGOs is situated in rural areas (UNDP, 2002-a:24). On top of this **geographical imbalance**, one of the most common Western interventions of seminars are considered to have a "very limited impact and are not visible to the general public" in Tajikistan (USAID, 2001:151). Consequently, Western influence is little for the governments (Polat, 1999). Cooper (1999) introduces the result of one survey where Kyrgyz urban people showed lower interest in the activities of NGOs compared with the rural population although Kyrgyz cities have been attracting the interest of international agencies the most in Central Asia. He continues to explain this phenomenon by arguing that the hitherto failure of international support has degraded the image of NGOs in the city areas. The public image of NGOs is "either fronts for 'opposition' forces or as grant-driven heavens for intellectual elites" in Kazakhstan (USAID, 2001:86), "implementing organisations for foreign agencies" in Tajikistan (ibid. 152) and "solely dependent upon international donors" in Turkmenistan (ibid. 156). As a result, **local NGOs are increasingly isolated from the local environment** rather than fostering the targeted democracy (Luong and Weinthal, 1999).

At the same time, **Western NGOs either intentionally or unintentionally avoided a political approach to activities** especially in order to compromise with the political situation that restricts such activities. The general lack of funds for advocacy and political activities from Western donors has been witnessed in different developing countries (Hakkarainen *et al.*, 2003). However, it is a more acute problem in politically restrictive countries such as Central Asian countries. This kind of Western intervention has been heavily criticised for degrading the local activism and forcing them to act only in a safe area which does not challenge institutional changes (Weinthal and Luong, 2002). For example, Kazakhs people once mobilised the Nevada-Semipalatinsk movement to fight against the nuclear test site and succeeded in 1991. This kind of public pressure has been undermined after Western intervention came into the picture of Central Asian civic activism. Moreover, West intervention could cause **negative competition** among local NGOs for external assistance such as funds, information and connections (Richter, 1999). Because of the restrictive environment, access to Western community determines the sustainability or success of a local NGO. Therefore, tension comes up among local NGOs rather than a better relationship among them. Under the above-mentioned circumstances, the Western models are hard to be applied to the reality in Central Asia.

Partridge (1999) points out that it takes a long time for the West to understand this region. Central Asian NGOs are changing and trying to adjust themselves in the best possible way to compromise in between different constraints in the specific local conditions and intervention from the West. More precisely, local law and the donor community define the activities of Central Asian NGOs. In this respect, NGOs are also at a "transitional" stage because both the local governments and donor communities are seeking for a suitable change under the new circumstances. In this regard, the Central Asian relationship with international donors and NGOs is not an exception to the major criticism against Western NGOs in development with the **camouflage of "partnership in development" which is in favour of the powerful** (Fowler, 2001).

International Intervention in the Disability Sector
When it comes to the disability sector, the disability movement in the West was globalised to let other disabled people in other countries realize the possible paradigm of change: society needs to

change rather than adjusting disabled people to the discriminating society. In the West, different technology and material invention started to offer the means for disabled people to be employed. However, Hunt (2001) asserts that this market economy has been globalised and intensified the discrimination around work ethics in different parts of the world. In this way, aware Western disabled activists started to be involved in the **globalised disability movement for globalised social justice**. They started to demand **representative democracy** also for disabled people in the so-called "developing countries," though **in terms of disability issues all countries are developing countries**. The literature exactly on international cooperation in the disability sector in Central Asia is rare. Other Eastern and Central European countries have experienced paradoxical outcomes. For instance, multiple donors donated a large amount of money for an institution for mentally disabled people in Romania (Goldston, 2004), while the Western disability movement stressed deinstitutionalisation already 1960s and 1970s. The **rights perspective is missing** in such intervention. Even when Western disabled activists are involved, it can still leave some difficulties of representation issue as they are not the representatives of the local disabled people, though they have the similarity of disability experiences in respective Western countries. The underlying theory of participatory democracy can be threatened if enough attention is not paid. Thus Western disabled people want to empower the local disabled people with the paradigm change from the medical model to the political model of disability. That means the Western actors have to withdraw from the main actor's position so that the ownership is taken over by the local disabled people so as not to repeat the history of control in the West. With this political constraint and specific difficulties of the disability sector, **international intervention in Central Asia is challenging**.

Summary
Central Asia has been experiencing a series of paradoxical outcomes of the Western intervention without exception. Existing literature acknowledges some positive aspects of the intervention. However, some interventions are criticised for their major lack of sensitivity to the local context. Other interventions are criticised for their reconciliation to the local political constraint. In this way, the interventions actually reinforce the structure. Literature on the Western intervention in the disability sector in Central Asia is rare. However, the experiences of other countries reveal negative consequences due to the charity approach of the Western intervention. The rights perspective has been missing. The next case study of a Finnish DPO reveals reality of an international intervention with a political approach that has been intentionally avoided by many other Western actors.

4.2.2. Case Study of a Finnish DPO

This case study of a Finnish DPO, Kynnys, clarifies the complex reality around implementation of the political approach in a Central Asian context. Different groups of people expressed different opinions about this project, which is the interesting part of this sub-chapter. These different opinions gradually figure out the difficulties and possibilities of the political approach to be implemented in the disability sector in these countries. The discussion starts with a brief description of this project to understand the nature. Then, different opinions are cited. Special attention should be paid to some slight change of opinions as the project goes on. In the first seminars, Central Asian people showed big hesitation towards this political model, which then is gradually digested in the following events in the project. Some project participants started to understand the whole idea of this project, while many others find it still difficult. A Kazakh

disabled woman, Dana, is one of the persons who understood the rights seriously, which is going to be the focus in the following Chapter 4.3.

Project Description

This Finnish DPO, Kynnys, implemented a development cooperation project in five Central Asian countries between 2000 and 2003. Finnish disabled people with different impairments were the trainers in the series of seminars they organised with Central Asian DPOs. The target group was "current and future leaders of the disability movement," who were actually mostly chairpersons of 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. Kynnys conducted this development cooperation project with the political model from the reflection of the failure of the hitherto charity and medical model of disability. That means the ultimate goal is structural change for equality. However, as the **"Finnish model" as such cannot be applied in any other country**, the way how to reach the goal is left as the responsibility of the Central Asian actors. "**They know about themselves the most**" is the principle behind it. This is the philosophy running through the disability movement as the Western disabled people experienced the control of non-disabled people over their lives in the history and assert ownership for their lives.

In the first one-week seminars, Kynnys introduced principles such as equality and rights and showed their role model as a former Member of Parliament in Finland, for instance. Another topic included some results of the vigorous Finnish disability movement such as independent living and the personal assistance system. The United Nations Standard Rules on the Equalisation and Opportunities for Persons with Disabilities (**Standard Rules**) was introduced. Many development cooperation projects base their activities on the Standard Rules regardless of their countries of origin, as the study of STAKES (2003) mentions. In this sense, it has significant importance as a solid foundation because each country can formulate their own design of policy and practice on the basis of the Standard Rules in a specific local context. The results of such national and international movements were not the only focus to be introduced. Also importantly the process to achieve those was described carefully, which revealed the hard reality of the fight for equality. The chosen themes allowed both Finnish and local participants to share similar problems to tackle, despite the differences of their background conditions and history.

In each local seminar in respective countries, 5-6 representatives were chosen to participate in the following seminar in Helsinki. The objectives of the seminar in Helsinki were two-fold: to experience lives of disabled people in Finland and to create network among Central Asian countries. The themes were similar to the local seminar but were organised in the form of discussions or comparison among different countries. This seminar also included some study trips to the technical device exhibition, different disability specific facilities and DPOs to actually see and experience the lives of disabled people in Finland.

After this project was completed, a Kazakh DPO organised a follow-up seminar in 2003 by inviting representatives from other Central Asian countries to Almaty City. This project was organised on the initiative of the Kazakh DPO together with other Central Asian DPOs through communication after the Helsinki seminar. In this sense, 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 is the Finnish version of the project description, which is different from the Central Asian version. The following consists of dialogues between different actors about the impact of this project.

Dialogue between Finnish and Central Asian Actors

Already at the beginning of the project in each country, some **negative consequences** took place. Firstly, when choosing participants for the local seminar, the local coordinators deliberately chose their friends and subordinates but few or none opponents or rivals. This action is based on the conflictive relationship among DPOs in respective countries as has been investigated in Chapter 4.1.2. Furthermore, another stage of choosing the Helsinki seminar participants caused conflict once again. These participants were supposed to be chosen on the basis of an election among the participants of the local seminar. However, the Finnish participants "manipulated the result" and chose a few out of the five regardless of the election results. This caused a big tension against the Finnish participants and consequently also against the local coordinators, though it was not expressed in the seminars but in personal interviews:

> *In the seminar, the election was shocking for everyone. We stopped respecting those Finnish representatives because of that election. We thought that those people who can talk about their problems so freely would be democratic, but the election was like that, just like any other undemocratic meeting. It was an example for us to know that even people from a democratic country cannot follow democratic rules. And this was the reason why we were separated from the [DPO which organised the seminar]. We became very far from each other since then. We understood that those people who were very active could not go (to Helsinki), and those who were very passive could go (Uzbek Participant O).*

Due to the "manipulation" of the election result, the Finnish participants and the local coordinators made many enemies who were supposed to fight for the rights together. As a result of these conflicts, the suggested cooperation became difficult.

When it comes to the content of the seminar, seven main Finnish participants in this project made a generally positive impression except for the impact on Turkmenistan where the authoritarian regime does not allow any space for genuine civic activism. The Finnish participants believed that Central Asian participants were ignorant in a democratic way of thinking, disability issues, cooperation with the international movement and their own rights in law. Therefore, the new information and strategy of political approach have opened up new opportunities for them both as individuals and also as organisations:

> *This seminar forced the participants to a new way of thinking or at least the beginning of a new way of thinking. For more than over three generations, they followed the Soviet model. And now they entered into the free market model where DPOs, disabled people and each person can influence society through their own organisations. I think they didn't have any idea about how to take care of disability issues and culture in a free market environment, namely in competitive society (Finnish Participant C).*

> *The level of education for disabled people is very low there. There are few active disabled people who understand international significance. During the project period, people*

started to wake up and to see that they can also do something by themselves (Finnish Participant A).

I am very glad to notice that our work here has been very fruitful. And of course most of it is because the Central Asian NGOs have learned so much about their equal opportunities and rights (Finnish Participant F).

The Finnish participants thought that the ideology transfer was sustainable (Finnish Participant C). The Finnish participants also felt that Central Asian participants became active through this project. The positive impression is related to the positive statements by Central Asian participants expressed during the series of seminars. In the seminars, the Central Asian participants praised the Finnish project by reading their mind:

As my colleague has already expressed, the seminar was perfect. All the important things were shown in the presentation. As my colleague said, we have to continue our work in the future. It was interesting to get to know the political implementation in Finland. When we met some representatives of disabled people in parliament, it was a very important part of the seminar (Turkmen Participant B).

Each of us knows what to do when we go back home. In that sense, this has been a big study and helpful for all of us (Uzbek Participant E).

In Finland, we have seen the future of our countries some time later. And we are admiring how disabled people in Finland live. (…) We have to try the same thing in our own countries (Kazakh Participant E).

This seminar has been very necessary seminar because I have got much information (Kyrgyz Participant E).

In personal interviews, however, many Central Asian participants expressed their honest opinions which were different from what were expressed during the seminar in front of the Finnish participants. The power relationship between the Central Asians and the Finns explains this phenomenon. **Any such unequal relationship in development cooperation ends up in very similar remarks of the recipients in favour of the donors** (Director of an international NGO in Uzbekistan). The whole social system of development affects the pattern of behaviour of the recipients (see Tvedt, 1998).

The new information, experiences and ideology from Finland were appreciated widely among the participants, except for some participants to whom the information was not new at all:

R: Did it [the project] change your life in any way?
P: To be honest, not much. Why? Because we were told that we must do this and that. By then, we had been already cooperating with [an international DPO] for two years.
(P: Uzbek Participant V)

This seminar encouraged me to reconsider things that had been familiar to me already. And I made an analysis and it has become more interesting for me, though I knew all

before the project. But if I am to add some criticism, some lectures were meant for beginners. They were set so low. I think they underestimated our level and didn't do the work properly (Kazakh Participant B).

Those who already went through similar training seminars organised by some other international DPOs were bored. This tendency was especially stronger in Kazakhstan where donors had many contacts due to the easier environment with a relatively more democratic stance of the government towards NGO activities.

Moreover, many expressed that the lectures were too long and useless because the information was general:

In my point of view, the use of time was not very rational because there was quite a lot of repetition. So I could say, in a sense, that half of the days were wasted (Kazakh Participant B).

Many lessons and many lectures were general. In many lessons, I was bored. Then I listened to a life story. But I wanted to listen to the first step and second step of solutions, first difficulty is this, and fight was that. I wanted to listen to more concrete things. (Kazakh Participant D).

Many participants wanted to know **more practice than theories**. Uzbek Participant C explains why studying only theories is not useful:

When theories are not implemented in practice, after a month or so, they will be forgotten. That's what happens. If there is no mechanism to put into practice, then theories could be proving themselves useless. Thus in this case, the seminar could be shown to be waste of time, if I don't do anything. So I will pay most attention to the mechanism of the implementation in practice.

Another explanation why more practical information was necessary was due to the economic situation in their countries:

Basically I put it very simply. They live how we live, and teachers [Finns] tell us how to live well, but we simply don't have the money for that (Turkmen Participant C).

Very many [Central Asian] people in the seminar said, "Why are they [Finns] teaching us? If we had the same money, we would be able to do this. So, it's useless to teach us" (Uzbek Participant C).

In this way, the Central Asian participants were frustrated by the fact that practical implementation advice that could be applicable to their local conditions was totally missing. Theories and ideologies were not welcomed by some who already knew them and by those who do not have any means to implement them in practice. Both Finnish participants and Central Asian participants share the idea that implementation is the most important part. The Finnish party intentionally left that responsibility totally to the Central Asian party, while Central Asian party felt helpless for not being able to implement much in practice under their local conditions.

The **sudden ownership transfer** for the implementation part was not welcomed because they cannot implement ideologies right away with their current isolation and lack of resources, for instance. On the other hand, the Finnish participants strongly asserted that the Finns cannot change the situation on their behalf. Kalle Könkkölä states,

> If you think about this kind of project, you start thinking what is the meaning of this? We meet some people but all the difficult things remain in their lives. We cannot do anything (personal interview on 2.2.2004).

> But we can't go to Central Asia and change Central Asia. There are things that people there have to do. And we don't know what they really want. But I'm sure that everybody wants to get out of bed. (They want) Irrespective of which culture you are living in. People want to get out of bed, absolutely. There are some universal structures. But then how they want them, that's different. They have to think about that. So we give them materials to find their own way (personal interview on 14.3.2001).

This is because **identification of the problems and their solutions by taking into consideration the local context is impossible for outsiders**. "They know about themselves the most" is the philosophy behind this. Therefore, Finnish participants rather trust in the future action of the Central Asian participants in terms of all the following implementation including the information delivery of the acquired knowledge. However, the activism that the Finnish party wanted to convey as an important message had difficulty getting through already immediately after the seminar:

> Frankly speaking, I don't expect any result from this seminar. Or I think that everything will stay just here, in this [seminar] hall, and that will be the end of everything (Uzbek Participant Q).

> In your country it's possible, but in our countries it's impossible so far unfortunately. You have more opportunities because you are in Europe and we are in the ex-USSR, in Asia. Asia is Asia (Uzbek Participant F).

This pessimism was particularly strong in interviews with Uzbek participants who have a very authoritarian regime controlling their lives. Where self-censorship is the defence mechanism, the political model of activities was considered too challenging to put into practice. Mobilisation of the constituency, gaining understanding of society, cooperating with other DPOs, fighting for their rights and meeting the needs of the constituency at the same time were all considered too difficult at present. Isolation of disabled people and DPOs explains this pessimism. The dialogue between the Finnish and Central Asian people reveals the essential part of the reality for Central Asian disabled people is different from what European disabled people have.

Impact on the Participants
As for the psychological aspect, positive changes were mentioned. The Finnish party thought especially a **positive psychological change** took place when the Central Asian participants saw Finnish disabled participants for the first time who actively involved themselves in many things including politics. The Finnish participants believe that they were the first role model that Central Asian people saw in front of them. They continued that being disabled themselves played a big

role as they shared many similarities in common with the Central Asian participants. This was the shared experience. The mentality change was mentioned by the Central Asian participants as the merits of the seminars. Different positive psychological changes took place especially in those who participated not only in the local seminars but also in the Helsinki and Almaty seminars, while not as much impact was observed for those who participated only in the first local seminar.

First of all, this was the very first seminar for some participants in their lives. Therefore, the experience of this project was already positive. The fact that they were invited to the seminars and treated well was a different experience from their daily lives (Uzbek Participant W). Increase in self-esteem was expressed in personal interviews:

> *We cannot develop ourselves if we don't have any option to choose from. Firstly, we have to change the way of thinking of the community. We have to remove the isolation of disabled people. And the seminar like this does promote the way of thinking and increasing self-respect to encourage self-consciousness (Kyrgyz Participant B).*

> *Now I understood that I'm the owner of my own life and only I can decide what to do and how to live my life. If you want, you can achieve any goal in your life (Tajik Participant J).*

Some acquired **ownership of their own life and some of collective experiences** of discrimination. The increase in self-esteem was also induced by the role model of the Finnish participants who were severely disabled:

> *For example, Kalle has such a severe disability. Nonetheless, he is working. He has difficulties not only in moving but also in speaking. But he showed to the rest of the world that there are disabled people. (He is) Our model and approach for disability (Kazakh Participant H).*

> *I saw Kalle in a demonstration 13 years ago, and I understood that we could influence people's lives with our own power (Tajik Participant B).*

The existence of Kalle was mentioned the most for the source of energy gained after the seminars. Central Asian participants started to **see opportunities behind examples from Finland.**

Another psychological change was the understanding towards the strategy to **fight for their rights.** This feeling was expressed strongly during the seminars in front of the Finnish participants:

> *The most important thing is to get ideas. I got ideas from Finland. What surprised me the most is that Kalle wouldn't go anywhere even if the mayor himself invites him when there is one stair in a building. At that time, I understood that we should have a principle and we have to fight for that principle. (...) For example in Kazakhstan, there are some organisations for disabled people. Some of them have existed for 20 years or more than 20 years. But their main activities are to distribute humanitarian aid to disabled people.*

And the most important thing is that you fight, and then you can change something (Kazakh Participant D).

For a few participants, this understanding was a great turning point in their lives, which will be mentioned in Chapter 4.3. However, the very examples and experiences from Finland are considered unattainable at the same time:

For me, what Finns are doing is, of course, a role model but also something unattainable (Tajik Participant F).

The immediate impact on the participants was scepticism towards the actual implementation. This scepticism was alleviated when they visited Finland and saw the Finnish reality with their own eyes. The visit to Finland and Kazakhstan allowed the participants to compare the reality in their own country with these countries and to consequently realise their relative position. It is still a **"fairy tale" and "heaven" but "reality" at the same time**:

I visited Finland. That was my first trip. I was just impressed by the huge number of disabled people outside in the supermarket, underground, and on the streets. My first impression was heaven as you [Finland] have so many disabled people. When I thought of it, you don't have so many disabled people but your disabled people have access to public places and can freely go to public places. Unfortunately, when we go out, we hardly see any disabled people outside. In our city, we see only male disabled people. Females particularly in wheelchairs are very few, maybe myself and my girlfriends, that's all (Kazakh Participant D).

From this possibility of comparison, both a positive and negative impact was experienced. A **positive comparison** was made when participants try to find out the reasons why Finland can do and why their countries cannot do:

R: I understood that you have been very active recently in making changes for blind people. But had you been active already before meeting the Finnish people?
P: No, I wasn't. I was born as a [name of an occupation], and I was just working in a [place of the work].
R: What has changed you like that?
P: I heard that in some other country (Finland), many things are organised. And on the other hand, in my own country, even the simplest thing is not organised. That's why the local seminar gave me energy to fight and to get other fighters around me so that together we can make lasting changes.
(P: Tajik Participant T)

I liked Finland so much. The attitude towards disabled people was very nice. I had nothing to say about the well organised seminar. I would like very much even 10% of the things in Finland to be implemented in Uzbekistan. When I visited drug stores, I noticed that they are equipped with ramps because there are not only healthy people visiting the stores. Old people, mothers with babies and many people come here and use the ramps. I heard most of the places are equipped with the ramps. I wondered if it's difficult for us to do this (Uzbek Participant W).

These people see possibilities in the differences between Finland and their own countries.

A **Negative comparison** was made when participants focus much on the superficial differences rather than the mechanism which created the differences. Especially this tendency was big among those who participated only in local seminars in each country:

> *The Finnish delegation came and shared the experiences with us like ramps and accessible metros. Good information. It was very interesting to see. (...) He [one Finnish participant] was telling about his work with his computer. I'm sorry. But the living conditions in Finland and our living conditions are like the sky and the ground. He showed us how to operate his computer. We disabled people cannot buy it, not because one is lazy. I cannot buy any computer myself either. The **most important problem is to survive and how to feed the family.** This is what we are talking about. They are talking about different transportation with different types of accessibility. But we are talking about how to take a bus because we don't have enough money to take any transport. We have slightly different problems. All these videotapes that they showed us were fairy tales. (...) For example, in Finland, if a disabled person would like to live independently, the municipality could give an apartment to this person. We cannot understand what more they want! It's very interesting, of course, but we need to go there to see for ourselves. We need 100 years more (Uzbek Participant V).*

> *I know that for example in the West, disabled people are not entitled to any special benefits. But I understand that maybe they don't need them there. We are applying for the benefits in my home country because we don't have the economic situation as they have there and we don't have any special facilities which would allow us to work. So **benefits can be seen as a government compensation for not being able to create the conditions for us.** So there is also the mentality difference. In the West, if a disabled person cannot get a job, the government didn't provide him this, this and this, so the government is guilty of this. So they could give a fine or something. But in my country, if you cannot get a job, you see it's your own fault because your legs are abnormal, for example. So the mentality of the people is important to change. But if there is democracy in the country and a market economy, if the country is doing economically well, the mentality of the people could change quite fast (Uzbek Participant C).*

The difference in overall local conditions such as problems, economic situation, political situation and mentality of society were pointed out by many. These current differences were paid more attention to than the Finnish process to have created the differences.

On the other hand, a **comparison with Kazakhstan was much easier** for the participants to come to terms with and to learn from. Participants could focus more on why Kazakhstan can do and why they cannot do in their own countries:

> *Deputy of mayor and [name of a Kazakh participant], they developed a cooperative project between the government and DPOs. (...) They have cooperation with their city government. It's a very important thing. The deputy mayor is cooperating. We must be*

more active to get more information by ourselves and to share our experiences and knowledge with young people (Uzbek Participant A).

I was very surprised at cooperation of the Kazakh DPO with political parties. [Name of a political party] is going to put up a candidate of a disabled person for election. But we don't have such opportunities here. We should learn the Kazakh examples (Uzbek Participant C).

Having shared very similar problems, freedom of speech, cooperation with other actors and different standard of living were what other countries wanted to learn from Kazakhstan. This was also an intention of Kynnys that other Central Asian countries could see the development in Kazakhstan. This intention worked well to change the mentality of suspicious participants. In this way, psychological change took place for quite a few participants on this project. This is considered very important because the **mentality change is the source to mobilise the movement** in the end. Therefore, the Finnish actors regard the political model without any service provision as one of the successful strategies for tackling the local constraints.

Fish or Fish Nets?
When it comes to the local participants and general disabled people, they have different opinions. First of all, the Kazakh seminar was not an initiative of the Kazakh DPO because the actual initiative and pressure came from Finland. The local coordinator of this seminar got "hints from the Abilis Foundation" and received quite a few contacts from the Finnish side to organise this seminar. The **ownership** issues came up again. The seminar was carried out by the Kazakh DPO. However, this seminar was to meet the needs of Kynnys in the sense that it hoped to witness cooperation among DPOs across Central Asia as a result of the previous project. For the Central Asian DPOs, **seminar activities are not the first priority when their constituency wants something else, namely material support.** Members of the participating DPOs thought that the series of seminars was not what they wanted. The predominant medical model, workability model and various other constraints reinforce the passivity of general disabled people in their daily lives. Consequently, they want material support from DPOs as a result. The **significance of the seminar is hard for general disabled people to understand** especially without seeing concrete results or even information about the seminars**.** Male member B in a Kazakh urban area says, "Seminars don't provide wheelchairs." Mother of non-member children B in an Uzbek rural area says,

Information does not help us. There is no use for us to belong to such an organisation [DPO]. Please do something. Telephoning to Tashkent costs 1000 Som (=1 Euro) and our pension is 10,000 Som. We cannot afford to pay for calling even to Tashkent. I can only sit here and wait till something happens.

Especially when the gap between the chairpersons and members is big and the information delivery method is non-existent, the impact of seminars is hardly observed by the members. With such a burning need for material support for daily living and without a shared perspective towards the collective issues, the general members cannot understand the significance of the seminars at all. This is a typical consequence of internalisation of the prevailing medical model and workability model of disability.

The answers to the question, "Which do you think is more important, seminars or humanitarian aid?" epitomise the reality. Almost all interviewed members and some chairpersons think humanitarian aid is a more acute need than seminars at the moment. They answered so quickly that they did not even ask the content of the "seminars". This tendency poses a question if the political model of disability could correspond well enough to basic human needs. Humanitarian aid helps general disabled people because they are passive and cannot tell what exactly they want for their lives:

> *P: They cannot say exactly what kind of help they want. They just accept the help that we give them.*
> *R: I see.*
> *P: They ask everything, money, clothes, everything. It's very difficult with clothes, also.*
> *(P: Uzbek Participant M)*

Humanitarian aid is, however, criticised as not being enough (Male member A of an Uzbek rural area), dependence on availability from donors (Female member B of an Uzbek urban area), and unequal and patchy distribution (Kazakh Participant F). Some chairpersons started to realise the **weakness of the humanitarian aid activities** from the acquired right perspective:

> *Their [DPOs'] activities are the delivery of humanitarian aid. It is constant delivery and dissemination of humanitarian aid but it does not create opportunities for disabled people (Chairperson F in a Kazakh urban area).*

Some DPOs started their activities with humanitarian aid but realized after a while that this sort of activity cannot actually solve problems despite the big effort that DPOs have to make to find the source of the aid:

> *We distributed humanitarian aid, because poverty is poverty and any humanitarian aid is a big plus. Over a year, we realized that was not enough because we were running matters that the government is responsible for. We were trying to seek for sponsors, trying to buy wheelchairs, and seeking for allowances. These are responsibilities of the government, not ours. We spent money. We distributed food and wheelchairs. But the problems were not solved (Kazakh Participant H).*

They cannot fill the gaps because they are too huge to fill for any single DPO. Moreover, that does not solve the structural problem where disabled people have to play the deviant role. Therefore, some chairpersons started to realize that people need to be empowered by giving a "fish net" and teach them how to fish rather than giving the "fish." This was a frequently mentioned proverb. Rather than having fish, they would like to get the fish net so that they could learn how to fish and get the fish themselves.[14]

Seminars started to attract the attention of Central Asian DPOs as more sustainable support for individual members and for DPOs:

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[14] However, "how to fish" is not enough when the environment for fishing is not accessible. Therefore, in addition to the skills how to fish, further accessibility should be secured.

I can tell you that humanitarian aid depends on what they are. There are some cases of clothes in different sizes and children cannot wear them. It's not bad to have humanitarian aid to have milk. But a seminar is more useful because you might be able to drink the milk but otherwise you stay at home. Seminars can solve the problems that you cannot move out of your homes. With humanitarian aid, you cannot go out from home and you cannot be educated. Humanitarian aid cannot change society. And humanitarian aid comes and goes. Not all humanitarian aid reaches us. As for a seminar, parents know about something new which is going to be helpful (Chairperson A of an Uzbek urban area).

The first year after the establishment, we were busy with arranging humanitarian aid. And when I participated in a seminar for the first time, a person called [name] told me that it's not an NGO if they are busy only with charity. He suggested that NGOs should discuss the actual problems of disabled people. And then I realized that my activities were the wrong way to do this, and I started to do different kinds of activities to solve the actual problems. That's why I can say that seminars can give different knowledge and are useful for the organisation. Seminars are very important for NGOs (Uzbek Participant D).

Participation in a seminar is not only about information delivery. It is a combination of information and some crucial solutions. Especially, chairpersons see the importance of seminars for their DPO management. Practical knowledge and different choices are delivered in seminars not only to chairpersons but also to general disabled people. For instance, changing the trapped mentality takes place through seminars:

R: How could you change the mentality of people who are too passive to believe in themselves?
P: Seminars enable people to become active. By taking part in the seminar, their mentality is changing and they find new ways in their lives.
(P: Uzbek Participant A)

However, many claim that seminars are not for general disabled people in practice:

A seminar is mostly communication for chairpersons. Disabled people need more financial help because disabled people mostly need help (Male staff A in a Kazakh urban area).

Information, thus, is not considered as a "help." Some criticise that "seminars are only for a few people" (Chairperson F of a Kazakh urban area) and "too few of them" are organised (Uzbek Participant P). The following people tend to be excluded from seminar activities:

a) Chairpersons who are not updated with seminar information (Uzbek Participant M),
b) chairpersons in rural areas because seminars are not held in rural areas but in urban areas (Chairperson J of an Uzbek rural area),
c) severely disabled people because of the physical barriers such as inaccessible seminar premises (Chairperson H of an Uzbek rural area and Uzbek Participant D), and lack of equipment such as wheelchairs (Female member C of a Kazakh urban area),

d) disabled women in a rural area because they need the "permission of their husbands" due to the traditional male dominant culture (Chairperson B of an Uzbek urban area),

e) and those who are not interested in seminars due to their busy daily lives (Kyrgyz Participant F).

In this way, only a very limited number of disabled people can actually participate in seminars.

Under the current reality, Uzbek Participant V thinks that also humanitarian aid is necessary along with seminars:

> *To be honest, **both are very important**. I think when people are giving something, that's not the solution and way out. People should do something by themselves with their own hands. It will be much better. (...) This is the same analogy as having fish or having a fish net.*

Due to the severe reality for disabled people after independence, fish is also needed. Thus **humanitarian aid is still focused much more than seminars.** As arranging humanitarian aid itself requires lots of work for chairpersons, seminars are rarely organised to take out disabled people to expose them to different opportunities.

Furthermore, **seminar organisation itself requires total support** for the participants such as finding accessible premises, the provision of equipment, assistance and transportation and mentality change of both disabled people themselves and their family members. As general disabled people are deprived of such preconditions for participating in seminars, humanitarian aid is a much easier activity for DPOs. Therefore, even though some chairpersons realize the importance of seminar activities, DPOs tend to end up in the repetition of the same humanitarian activities, unless the international donor community helps in financial terms or in co-organisation of the seminars. Due to this reality around humanitarian aid and seminar activities, the Finnish project was widely appreciated but the information has not been disseminated further to other local actors.

Information delivery in both Kazakhstan and Uzbekistan is a big challenge, though Finnish Participant C stresses, "It's the responsibility of the participants to take care of the information delivery." That is, Central Asian chairpersons leave the responsibility of mentality change to the members, while Finnish participants leave the responsibility of information delivery to the Central Asian chairpersons. In this way, actual implementation did not take place much because the crucial activities of information delivery that would have connected different actors including their own constituency had been missing. This reality explains the overall small impact of the project both on general disabled members and chairpersons. Due to this mechanism, seminar activities in Central Asian states need one more push of information delivery before actual impact is observed. Ownership transfer is not enough. Information delivery means in parallel with supplying material support for their daily living are both important in Central Asia.

Summary
In conclusion, little change was perceived in practice except for the psychological change from this Finnish project. This psychological change of the participants is the source of concrete change. In this sense, an important impact was made. However, the next step for concrete change

had quite a few barriers to overcome before it is finally implemented. One of the biggest barriers is the preference of the fish over a fish net among the disabled people in Central Asia. When the daily and acute concerns of them is to get the fish, the impact of the seminars on the final beneficiaries such as non-participants and the general disabled people was not witnessed except on people in the following Chapter 4.3. Deficiency of information delivery partly explains this. The next part introduces experiences of one Kazakh participant, Dana, who made an impact. Her experiences prove the heterogeneity of disabled people, their possibilities and implication to challenge all the difficult local conditions to make a change.

4.3. Dana, a Severely Disabled Woman, Makes a Difference
~Towards Disability Movement~

The activities of Dana, a severely disabled woman in Kazakhstan, are focused on in this part. Dana is a provisional name given for the woman who understood the importance of the rights perspective and political model from the participation in the Finnish project. She vigorously fights against all the barriers including disability specific challenges and local context specific constraints. Her psychological change from object to subject of her life became the source of energy to implement her ideas in practice. Her experiences and experiences of people around her show the possibilities and applicability of the political model in a localised manner to some extent. This is the successful initiative of the combination of indigenous and endogenous efforts, though this is a drop in the ocean. This example conversely reveals the difficulties of making a difference under the circumstances.

Establishing a DPO with a Gender Approach

All challenges are problems when the rights perspective is missing. However, when looking at the reality from the rights perspective, **seemingly an energy-, money- and time-consuming way can be the only way**. While many other project participants were overwhelmed by the too big challenges and tend to repeat the same activities from the charity approach, Dana decided to implement the acquired ideology in practice. She established a disabled women's organisation in 2001. This DPO has been growing in terms of numbers of members and diversifying its activities despite the above-mentioned difficult reality. Her organisation held a seminar for its severely disabled members mostly in wheelchairs to deliver the information gained from Finland in a localised way so that it met the needs of the local members. This sub-chapter is devoted to listening to her experiences and the experiences of disabled women especially those who participated in the seminar organised by Dana.

As has been mentioned in Chapter 3.3.2, the life experiences of disabled women tend to be full of social oppression. Severe gender discrimination was studied and reported (Minnesota Advocates, 2000). Disabled women face different discrimination as individual issues due to forced isolation in the repeatedly mentioned mechanism. Disabled women are more likely to be trapped in this mechanism. Even DPOs have not been of much help for disabled women because they are mostly run by disabled men:

> *Men solve problems on global issues, but women solve issues in more daily things like cooking and child raising (Kazakh Participant D).*

There are always men in the leaders' posts, and it makes us lose self-confidence (Uzbek Participant A).

In addition, an American survey result shows that majority of American development projects does not assure the participation of disabled women (MIUSA, 2003). As Central Asia is affected at most by American intervention in terms of quantity of development aid, this finding is worrying. In this way, **current DPO activities lack a gender approach**:

> ***Medical care, education and employment are the three big problems in daily lives.*** *What are the reasons for that? First of all, the lack of access, poor infrastructure. These are the causes of problems according to our research. When we started thinking why these issues had never been raised, we realized that gender approach was never applied in disability issues. As I said, we think, our community thinks that disabled people are sexless. Sometimes people say that disabled women's problems are the same as men's problem. For example, ramps. They say, "You want to be a leader, a little boss, and that's why you want to establish such a new organisation." Yes, I realize that stairs and barriers are the same for men and women. (…) In our country, there is **dual discrimination**. Firstly for sex as women, and secondly for being disabled. These are the core problems. We learned it from international seminars from the World Assembly which I attended thanks to the Abilis (Foundation). Dual discrimination is a very big problem in Kazakhstan (Dana).*

The concept of dual discrimination came into the disability discourse after the interaction with international actors. More **personal problems** are to be focused on rather than "global" ones. In this way, disabled women's organisations were established both in Kazakhstan and in Uzbekistan at around the same time. The Kazakh one was established by Dana and the Uzbek one by Uzbek Participant A:

> *R: I would like to ask you why you wanted to establish the women's organisation. Did you think the existing DPOs were not good enough for fulfilling your needs?*
> *P: The big DPOs have big problems, and our problems are very small and they cannot be solved by those big DPOs. (The problems are,) of course, the discrimination against women. Everybody thinks that the road is for men.*
> *(P: Uzbek Participant A)*

This is a new phase of development in making variety in disability discourse. The Uzbek disabled women's organisation was established from a big impact of an American project, while the Kazakh one from that of the Finnish project. The Finnish intervention was not the direct reason for the establishment of the Kazakh organisation but had an impact on how it is run. Dana recalls the time of establishment:

> *In our city, we see only male disabled people. (…) We've been thinking over and over again. Why in our country where we have had the disability movement for so many years in the city of Almaty, where we have as many as 22 DPOs, why don't we have a female DPO? Probably our mentality of oriental and historical features. Most of our DPO chairpersons are men. We are too shy by nature. By trying to abolish our shyness, we are articulating our rights and interests. However, in summer 2001 we got together with ten girls, sitting in a café. We shared ideas and experiences and best practices. And at*

*maximum, we are ten disabled women who can share our ideas. There are so many disabled girls who are newly disabled people. They feel shy to go out. They feel shy to articulate their problems. We are the leaders. We have to talk openly about our problems because no one could protect us. No one could take care of us. This was in summer 2001. (...) In autumn 2001, we travelled to Finland. We visited a women's working group in a Finnish DPO. One month later, we came back to Kazakhstan, and we officially registered a **women's DPO.***

The participation in the Finnish project was the final push to establish the DPO though the idea had grown over a long time. One of the main staffs of this DPO also recalls,

We have known each other since 1994, much before the establishment of the organisation. After Dana returned from the Helsinki seminar, we gathered together at this table and discussed at this very table and decided, "Let's establish our own origination!" Of course, the main share of the work was with Dana. She has been managing the work mainly. This is a historical table! (Female member B of a Kazakh urban area)

As they felt the burning needs of disabled women who are excluded both from the disability movement and the feminist movement, they decided to establish their own organisation:

There are four or five of us who are active assets and who work full-time. Disabled women are away from the two main movements: firstly from the feminist movement and secondly from the disability movement because we are working with men within disability organisations. And with feminists, we are not on equal level with others and we are underprivileged from others. So that's why we wanted to establish this organisation, not to oppose feminists, but to show our opportunities and viewpoints (Dana).

They have been friends since they met in a rehabilitation centre which has closed down by now. Many disabled people with similar impairment got to know each other in such medical institutions before they were closed down. This organisation, therefore, started among friends:

There is no such significant change [between these organisational activities and our activities as friends]. We are friends. We have known each other before. And when we meet and have private talks, we can tackle our private problems as well. Sometimes we talk about organisations as well. There is a warm environment in our organisation. Most of us have known each other before the establishment of the organisation. So we don't have any separation of the organisation like, "You should do this and that" (Female member B of a Kazakh urban area).

This **shared feeling of ownership** towards the organisation creates space not only for Dana but also for the others. They are themselves the ones who have multiple barriers to go out from home as severely disabled women. Therefore, from this viewpoint, they organise activities which benefited those women with a similar condition of imprisonment at home:

There are those who cannot leave their homes. We organise recreation for them, taking them to mountains for the fresh air. And also like every organisation for disabled people, we allocate humanitarian aid because disability and poverty are very close to each other.

We organise training for disabled people to show them their opportunities. Then we also organise activities for disabled people.

This specific target group is a unique challenge which did not exist before due to different constraints. They are the ones who are always the first group to be excluded from any activities.

Another interesting trial of this DPO is that they try to seek for the reality of the lives of disabled women in more objective ways as well as their own subjective perspective:

*We started to **research into disabled women** in Kazakhstan, and conducted a number of polls and questionnaires. And we identified a number of problems (Dana).*

In this way, the problems and reality of severely disabled women in Kazakhstan started to be articulated for the first time. They firstly tried to organise events and deliver humanitarian aid to the members as many other DPOs typically do:

I go to a sports event and to events which Dana invites me to. Sometimes we have holidays. 8th of March was Women's Day and sometimes a seminar. Then we go outside. Dana is a very nice person. She organises events. She tries to take us out of our homes. She gets some sponsors and gives us some presents (Female member D in a Kazakh rural area).

However, after a while, the organisation realised that the effort of delivering **humanitarian aid does not change the reality**:

We distributed humanitarian aid, because poverty is poverty and any humanitarian aid is a big plus. Over a year, we realized that was not enough because we were running matters that the government is responsible for. We were trying to seek for sponsors, trying to buy wheelchairs and seeking for allowances. These are the responsibilities of the government, not ours. We spent money, we distributed food and wheelchairs, but the problems were not solved (Kazakh Participant H) (Cited also in Chapter 4.2.2.).

They started to realise their own role through their trials and errors.

Seminar
This conclusion led to a new stage of activity: a **training seminar**. Although this DPO still continues event activities and humanitarian aid delivery due to the financial poverty among its members, it started to enlarge its activities more to the empowerment of their own constituency and advocacy to society. Dana got this idea from Finland:

R: Where did you get the idea to organise this kind of seminar?
P: The idea came from the seminar in Finland. I brought this idea from Finland. In Finland, I understood that no one is going to solve the problems, and no one could understand the problems as much as we do. For example, however much I explain to Kazakh Participant B, I cannot let him know all women's problems like medical and gynaecological problems.
(P: Dana)

In this way, her understanding of the paradigm change was put forward in the concrete action of the seminar activity for severely disabled women who have been excluded from society and even from the activities of the existing DPOs. The **paradigm change became the source of energy for the new activities.** This DPO successfully got a grant from the Abilis Foundation for a project involving training activities. They decided to select participants who have the most acute needs:

> *In the process of selecting participants, we decided to choose those who stay mostly at home, those who don't have an opportunity to move out of home because there are some women who work and participate in activities. For them, it's not such an acute problem. But for those who stay at home, it is. So we decided to invite those on the basis of the cross- disability principle (Dana).*

Sixteen disabled women were invited, two of whom were not able to come due to suddenly worsened health conditions on that day. The fact that they invited severely disabled women directly means a demanding arrangement due to the lack of accessibility in many senses. For instance, Female member C in a Kazakh urban area had never gone out from home for the last ten years and did not have any wheelchair. The DPO had to start from this level to deal with securing the accessibility of all invited persons:

> *R: Related to the seminar, how did you get to know about the seminar to start with?*
> *P: Firstly I called to our regional DPO and I was told that there is an association of disabled women. And I called to Dana. I had been invited to seminars before, but I couldn't participate because I didn't have a wheelchair. Then Dana told me about the seminar, and discussed everything with me. This is the merit of Dana.*
> *(P: Female member C in a Kazakh urban area)*

Existing DPO activities ignore severely disabled people as "passive," whereas Dana tries to involve them by challenging the existing barriers that make them "passive".

Prior to the seminar, Dana asked what are the difficulties in the life of each participant and started to arrange the seminar in the way that meets the needs and answers their questions. Dana encouraged participants to go out from home and gave moral support for that. Therefore, the participation in this seminar was a big experience for those who did not believe that they could go out from home and could even participate in such a seminar activity for the first time:

> *I didn't know that it was so easy for me to go out from my house because every stair is an obstacle and you never know who will help you next time. (...) First of all, I changed my way of living by going to the seminar by leaving my house because before this I thought I was destined to stay at home and we are a burden for other people. And of course this is the merit of Dana because she is the so-called brain centre and she helped us morally. It's very good of her and I am very thankful to her. This is her merit as a person and as a leader (Female member C in a Kazakh urban area).*

> *It was the first time for me to participate in a seminar. Previously, I only heard about seminars on TV. Even when I watched some part of TV programs about the seminar,*

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which gave me a great impulse and feeling. I also wanted to participate in such a seminar. Such people are working hard and I also wanted to work hard. When Dana invited me to the seminar, I was very positive about it, and said, "Of course I will come!" (Female member B of a Kazakh urban area)

Experience to go out and on top of that to participate in a seminar was thought to be unrealistic which became their reality. This experience showed a new set of **opportunities** for the participants. In addition to the moral support, transportation was arranged so that each participant could arrive at the seminar site. The seminar site was carefully chosen to secure accessibility. Assistants were also invited. At the same time, they also thought of giving dignity to each participant to get the idea that they are equal members of society:

When I tried to organise the event for disabled women, I was trying to invite special guests like singers and performers. I wanted to treat disabled women with special dishes. When I was trying to arrange this seminar, they asked, "Why do you want to invite such performers and singers, and why do you want to treat disabled women to such dishes?" But I think that I wanted to show everybody that disabled women should be treated as ordinary people. They also need entertaining like singers and dances. And they also need to be fed very well. I wanted to show the level at which disabled people can be treated, not a charity event, but a higher level of event (Dana).

This kind of well-treatment was new for the participants who usually have low self-esteem because they feel that they are "burdens" on other people. Each choice had good reasons behind it from the rights perspective. The content of the seminar was discussed and decided according to the burning needs of severely disabled women:

R: How did you decide what to talk about and who to give lectures?
P: Firstly, we defined the topics. Double discrimination against women and disability. The rights of disabled people and legislation, issues of medical services, violence against disabled women, access, education and employment, reproductive rights. So after defining the topics, we raised the question of lecturers. We decided to invite specialists from healthcare and the law. We tried to invite not the ones tackling the problems, but those who have experience in solving the problems of disabled people.
(P: Dana)

That is, this seminar was **peer support** rather than a lecture series of specialists. All the participants actively participated to support each other. The following excerpt proves the ownership of their collective and individual issues:

It was to be organised as a seminar from peer to peer. Disabled women talked to each other and explained to each other how they are going to support each other. There was just an open space to share ideas. (...) What was exciting about the seminar? Apart from the few presentations we had in the seminar, we had interactive presentations. We were not just sitting down for an hour and a half for those lectures, but we had vital discussions. We were actively involved in discussions about violence. Violence was very actively discussed. In Kazakhstan, we have sexual violence, verbal violence, and

psychological violence when the family does not talk to you. These are all different forms of violence. It was a very exciting seminar (Dana).

That is, the participants experienced ownership in this seminar because they raised the themes to discuss and collectively thought over the solution to the problems. This **interactive seminar** gave a great impulse to participants:

*People made a great impression on me as well because one should film about everybody because everybody was so interesting. Every woman was wonderful with a difficult fate and I admired them all. **Issues raised in the seminar were so relevant** (Female member C in a Kazakh urban area).*

Dana used both her own subjective experiences and the objective survey results, which led to the feeling of "relevance" and ownership of the issues both as personal and collective experiences. This seminar made the participants realise that the experiences are similar among them and this issue is actually social rather than individual. This relevant feeling was the crucial turning point for many participants to change their paradigm and emancipate their low self-esteem.

The self-esteem issue was tackled also as one of the important themes because huge needs were expressed in advance. The self-esteem program is explained as follows:

P: There was a psychologist who held a lecture on 10 steps to love yourself. First of all, she delivered an introductory lecture on psychology and then she talked to the ladies in the evening about self-esteem.
R: What kind of conversation took place with the psychologist?
P: Though this psychologist didn't know much about disabled women's issues, we understood each other. She was the only one I talked to before the seminar who said people shouldn't be sympathetic towards people. When she organised the conversation with disabled women, they told about their problems. For example, one woman told her, "I cannot be a mother and a woman. I always worry that I am worse than a healthy woman." Other women told about their experiences of healthy women having the same problems. And this psychologist helped them to understand that it does not depend on the fact if you are in a wheelchair or on crutches or healthy. They could have the same problems. She had the same viewpoint as we had.
(P: Dana)

That is, the **psychological barrier as "disabled"** was focused on to be removed in order that they feel themselves as women in front of disability. Female member B of a Kazakh urban area says this increased her self-esteem:

It was very interesting for me and I felt that I am equal to ordinary people. And of course the most important thing for me was that I feel equal to other persons.

This is the feeling that they had never experienced in the isolated and individual environment at home. They realized that they are not destined to stay passive but can be active as other non-disabled women. They noticed that society made them passive, not their impairment.

Aside from this psychological impact, the seminar contained lots of **practical skills** and exercises to protect their rights. In addition to the self-esteem training, two more training courses were arranged within the framework of this seminar: self-defence training and dance in wheelchairs. The self-defence skills made them realise that they have rights and that violence is wrong. They can take active measures against such violence. For instance, they were taught to shout "Fire!" when encountering any danger of violence. Then some person near by will feel the danger and come and help her. They exercised shouting out loud, "Fire! Fire!" They learned to gain back their own will and control in their lives through this training. The third training of dance also caught the attention of the participants. This idea came from Finland:

> *After Dana returned from Finland, she told me about the dance group in wheelchairs. Then I couldn't believe that. But when I watched that in her video, I thought that was a fascinating show and I think that was the reason why she included that in the seminar.*

> *It was so much fun when Dana told us that we were going to meet a choreographer. I couldn't imagine that it's possible for us to dance. We got interested and when we got some results, we got interested even more. (...) Those were the most pleasant classes (Female member B of a Kazakh urban area).*

She continues, "All of these training sessions were very helpful for us." These training sessions in which the participants became active subjects facilitated to change their mentality. They started to feel that they could do different things which they had been deprived. Many started to see opportunities rather than desperation.

Moreover, the visual materials were actively introduced by using the videotapes that the Finnish participants gave to the local coordinator in the previous seminar and that Dana shot by herself when she visited Japan for a conference with a grant from the Abilis Foundation. She stressed the process to reach to the level of Finland rather than the gap with Kazakhstan, which successfully conveyed the more important message:

> *Dana brought a video from Finland and I was surprised to see such people. In Finland you have universal accessibility to all places. But in Kazakhstan, we have so many difficulties. Even Dana cannot enter her house because there are some stairs. There were so many devices for accessibility, elevators, ramps and different devices for disabled people. For example, I also cannot go upstairs and [a person] helps me every time. It was a great discovery for me to see the comparison between our country and Western countries. Our people think that the situation is better in the West because the government takes better care of them. They get bigger allowances than in our country. But it was a surprise for me that they also had to fight for their rights. Maybe 40, 50, or 60 years, they have been fighting for their rights. They didn't receive everything sitting at home. Then **I understood that we should fight**, and it was a great encouragement for me to fight and to go on (Female member B of a Kazakh urban area).*

> *Yes, we were surprised when watching the video in the seminar. People in wheelchairs could get on the bus, and they could even use the subway. The subway is under construction in Almaty, but the local authority has not taken this into account. (...) So if I am to say briefly, disabled people need two changes: changes in architecture and*

engineering in the city so that the government can equip ramps and the employment of disabled people so that they can work. We don't insist on financial help. Only few of our association members are employed. Some have a store and some have other enterprises. But these are just single examples (Female member C in a Kazakh urban area).

Even though the differences were introduced, most of the seminar participants did not fall into the trap to compare negatively. The gap was used to understand the possibility of the disability movement. Participants started to feel positive about fighting for their rights after this seminar by getting to know that there is a means to change the discriminating society, while the reality had been something to accept:

> *I didn't even know that we could fight for improving the attitude of society towards us. We were talking about economic discrimination, psychological discrimination and equality with others. Now I know that I ought to demand other treatment from people to me. Now I know that I should decide my problems by myself. Previously, I felt uneasy to ask help from somebody to do something for me. But now I know that I should solve problems on a personal level, and I should also go to the government. Thus the seminar made a great impression on me. I, of course, would like to participate in other seminars and also like to involve other people (Female member C in a Kazakh urban area).*

Participants felt the empowerment at an individual level and also became interested in collective and political activities. Those people who had been isolated and thus "passive" started to feel like helping others, which is a major change. **When they were given opportunities, they can become as active as any other non-disabled peers.**

A few participants did not change their mentality and remained passive by thinking "they are rich and we are not so rich" (Female member D in a Kazakh rural area). Except for the few who did not experience much an impact, participants managed to change the mentality. This is rather natural that people react in different ways because people are different from each other. **Remaining passive because there is no other choice and remaining passive with their own choices is different.** This is the clear border between discrimination and the rights approach. Their choices are to be respected after self-awareness of their rights. Dana made a great impact on the lives of these women by showing different opportunities, regardless of the decisions made after the seminar. In this way, Dana succeeded in localising the ideology to meet the needs of the constituency, delivering the information forward to those who were the farthest away from it and empowering them with the paradigm change:

> *Over the four days of the seminar, our mentality has changed a lot because previously when I was talking to these women, they didn't understand that there is discrimination in Kazakhstan. For example, this one woman went to the local government, and she was treated well, and the [mayor] was very kind to her. She didn't know that, for example, in Finland, if you are treated with sympathy, it's considered to be discrimination. And I told them that sympathy is not a very good way to treat discrimination. After the seminar, everybody has changed. At the end of the seminar, we were going down to the stairs, and one woman shouted, "What a discrimination! Stairs!" Before the seminar, she thought it's no problem, "Oh, no problem, somebody will help me" (Dana).*

The first impression from the seminar was the realisation ability. We could do many things. We could work more and harder. We were the persons who were the persons to ask for money, who were supposed to beg for money. We can also be active. Then I realized that we should do some kind of self- education. We should solve our problems. We can lead an active way of life, not just sit at home (Female member B of a Kazakh urban area).

A collective effort cannot be achieved without the constituency to understand that this is a collective and political issue. The conceptualisation of discrimination and power is the sign of their awareness of their rights. In this sense, this seminar was an important step forward to the creation of the disability movement for claiming their rights.

Society Should Be Changed

However, empowering the constituency alone is not enough because the surrounding environment should also be changed. Therefore, Dana's DPO tries to make an **influence also on society.** This was considered impossible by many other chairpersons participating in the Finnish project due to the multiple layers of discrimination against disabled people and the difficulties of the activities of NGOs in their local context. During the seminar period organised by Dana's DPO, a visit to a shopping mall was arranged so that the participants could experience shopping after a long time, while society could face severely disabled women for the first time. Both parties have to interact in the same physical space in order to break the prejudice and mainstream disabled people. This was an eloquent example of her activities that try to both empower the members and change society.

Another way to influence society is to **make use of the mass media** to actively deliver information about disabled women. This is an indirect encounter between society and severely disabled women. Yet, the advantage is that the mass media can increase the impact in terms of the number of involved people. Some journalists were invited to this seminar event:

We invited this journalist because we know her favourite topics. She sometimes evokes sympathy and sometimes shocks and sometime she wants to write something extraordinary. Knowing this, we invited her to the seminar so that she would be interested in the sex of disabled women, martial arts and dances in wheelchairs. We drew attention of society like this because after this article many people looked at us as women who could do a lot of things (Dana).

This DPO prepared well and studied what are the tentative interests that catch the attention of the journalists. With the result of their study, they prepared a written form of press release paper about the seminar and delivered it to journalists:

We tried to write it in such a way as to hook our journalists because they are reluctant to participate in such events. Only if a person is raped or injured or robbed, they come there. They came to the seminar and they liked everything and they said it was interesting. They also said, "Next time when you organise a seminar, we won't come. Invent us for more interesting things." Now I know about journalists. They should be educated in some other way. Some other measure should be taken to change them (Dana).

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However, the dancing class was shocking enough for the journalists to pay attention to. The DPO used this opportunity to deliver the real meaning of the seminar to the journalists:

> *The dancing skills caught the attention of journalists. That's what reporters want to hear. After that, we explained to the journalists that we are not that weak. We are dancing. We can dance. But you know, to be able to dance, I have to go up the stairs. In order to be able to use self-defence, we need to know our rights. (…) Step by step, we achieved our goals (Dana).*

Several articles were published. Although some articles still carry a sympathetic feeling towards disabled people, this DPO tries to train the mass media little by little. In general, journalists write what they want to write and the objects remain as objects (see Chapter 4.1.2). However, this DPO tries to affect the content of the media so that their real messages are properly delivered to society. Other chairpersons are happy only with the coverage in some mass media regardless of the content. Dana, however, actively affects the way of writing. In other words, Dana is **making an impact on the media as a subject.** In this way, their existence started to be known. Subsequently, the membership has increased dramatically through the media coverage. By the use of the nation-wide media, they now have members in rural areas as well as in urban areas. The number of members has reached 100 by now.

Another active involvement of society is seen in their own **publication**. The DPO has published a book on the lives of disabled women in Kazakhstan because they feel the lack of information about disabled women:

> *In 19**, when I got this injury, there was such a concept in society that there is no disabled person in society. Only in 1989 when there was no iron curtain anymore, information started to flow and the first DPO began to be established. But even at that time, there was no gender approach to this problem and that's why for a long time we haven't had any source of information. I think there is no research done in Kazakhstan (Dana).*

The copies were delivered to the local authorities and different organisations dealing with disability issues. In order to make all these come true, she thoroughly planned the ways to make an impact on the members and society and included a detailed budget of transportation, assistants and the publication cost of the books when applying for a grant of money from the Abilis Foundation. She was not restricted to the Western framework of the project but reflected their needs. With the stance of the Foundation that it does not interfere with the activities, Dana put the learned **political model in a localised way**.

Her organisations also started an **information campaign** by producing four articles and two TV programmes on reproductive rights of disabled women. Dana is different from the majority of DPO chairpersons because she challenges the "impossibility." She focuses more on reasons why things are thought to be impossible. She started her activities from studying about the reality, which was the major difference from other DPO activities and the Finnish project. Her subjective experiences also played a role as a severely disabled woman in a wheelchair. However, she did not reconcile with that fact and further developed the objective information about disabled women, which made her arguments convincing. Dana adjusted the independent living philosophy

according to the identified collective needs of disabled women in her country. The adjustment she made was unique in the sense that she challenged the barriers one by one in time-, money-, and energy-consuming ways which other local DPOs has not tackled before, as they are "impossible" or "too difficult." She **combines both the urgent needs of the members such as humanitarian aid and more political activities such as seminars and an information campaign**. She has noticed that humanitarian aid alone is not the solution because the problems remain. She thinks such a social safety net should be institutionalised by the government because DPOs cannot do everything universally. Such activities are always patchy because the capacity of DPOs is limited. Nevertheless, she did not deny the acute needs of humanitarian aid in the era of "transition" when disabled people were totally ignored in the process of "development." Humanitarian aid alone could reinforce the passivity of disabled people and does not help them to escape from the vicious circle. Therefore, her DPO fills the gap of services wherever possible and uses the political model at the same time. The political approach namely includes the empowerment of disabled women and lobbying to the government by involving the mass media. That is, she combines activities of the first and third generations when using the analytical tool of the generation theory of Korten (see Chapter 1). Her DPO reflects the genuine needs of the constituency and the international movement that promotes the third and fourth generation activities. This type of combination is an interesting implication towards other DPOs in the disability sector in Kazakhstan. Whether it is theoretically correct or not, the needs of service provision and intervention on individual psychological aspect remain unsolved in practise, if mere a political approach is focused.

Making a Difference in Central Asia

Her organisational activities prove that **even a small DPO can make a change** to society rather than reinforcing the reality. Despite the difficult and restrictive environment of Central Asian DPOs, the political model has proved to be applicable to some extent. Dana proved this. Even one person can make a change little by little towards the disability movement and towards the ultimate goal of equality, since movements are not only about actions but also common ideas, purpose and understanding (Barker, Johnson and Lavalette, 2001).

Kynnys now tries to make another project proposal to apply for money from the Finnish Foreign Ministry to appoint Dana as the local coordinator to continue cooperation in the field of disabled women in Central Asian countries. Thus her future activities are expected to play a big role across borders. One concern could be **the role of Dana as a leader**. Without exception, she has been empowered through the organisational activities. She has been exposed to information from different countries. She has visited several countries by participating in international conferences on disability. In this regard, if not enough attention is paid, her position as a leader will enlarge the gap with the members in a short time. Strong leaders play a big role when the overall disabled population is made passive. For instance, the leaders can show the role model and lead the movement. However, the **dissemination of information and decentralisation of power** are always the other side of the coin.

In ex-Soviet states, the political model of disability has room to play a role for the paradigm change. On the one hand, society needs to change. On the other hand, the empowerment of disabled people is necessary. Thus the political model in which disabled people themselves are the main subjects can be the strategy towards equality, as non-disabled people are ignorant of the whole disability issue. In Uzbekistan, however, the political restriction is too strong that **explicit**

types of political activities are extremely difficult when the government totally controls even the mass media. Uzbek DPOs rather need to start building a relationship with the government than fighting against it, which is the key to their sustainability at the moment. The political approach instead could be used for empowering their constituency to be ready for the future when the restriction is to be alleviated. **Implicit types of political action** such as facing the prejudice in daily lives by going out from home are as important as the explicit political action. This kind of implicit action also challenges the power structure. In this regard, the political approach has a great implication even in politically restricted countries such as Uzbekistan. When it comes to Kazakhstan, the example of Dana shows the small but significant space for the political model in a localised strategy to change society. Thus the political approach is definitely one of the future strategies in Central Asia along with the diverse activities that correspond to different individual needs.

The **local context** should be taken into account when employing the political approach because the empowerment of disabled people is far from reality at the moment in Central Asia. Palubinskas (2003) introduces the formula of empowerment: Empowerment (E) is the product of autonomy (A), direction (D), and support (S), or $E = A \times D \times S$. When the empowerment of Central Asian disabled people is put into this formula, empowerment is difficult to be achieved at present because of the deficiency of all three criteria: little autonomy of disabled people in their lives, little direction due to the environment and the induced passivity and little support from anywhere as they are isolated. To gain autonomy, Central Asian disabled people need to be self-aware of their rights and gain control over their lives. To gain direction, they have to understand the rights perspective. Money, time, and energy are necessary for enough support for both individual and organisational empowerment. These supports are at the moment provided mainly through temporal and individual development cooperation projects by international donors and NGOs in addition to a too small pension from governments. However, these supports are not enough and sustainable. Furthermore, society in terms of the context is not ready to co-exist with empowered disabled people. Therefore, a fundamental social and structural change in the form of mainstreaming (M) is another criteria for them to be empowered because social barriers such as the attitude of society including family, discriminating governmental policy and practice and physical inaccessibility remain huge problems even though each individual is going to be empowered. In respect of Deaf people, mainstreaming by society as a linguistic minority rather than disabled people is relevant. Therefore, $E = A \times D \times S \times M$ is the formula for empowerment for disabled people because society plays a significant role in the context of the disability movement towards equality because their vulnerability is systematically created in society. I acknowledge that this formula is too simplistic to grasp the whole picture of the empowerment process. However, it is theoretically important to point out that **academic discourse tends to forget the environmental focus that deeply affects the process of empowerment**.

Mainstreaming, however, does not take place automatically because at the moment disabled people are hidden and invisible. The mainstreaming of disabled people is difficult at present firstly because decision makers are ignorant of this issue, secondly because such decision making at a national level takes time and thirdly because policy can be rhetoric as any other rhetorical laws in Central Asian reality. Thus, a top-down approach towards equality has been difficult. This is the **room for DPOs** of Central Asian disabled people with a right-oriented approach. Both DPOs and disabled people need capacity building efforts to make sure that their voices are heard

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and that sustainable changes are made in the mainstream policy and practice on the basis of their voices.

The study of STAKES (2003) investigated those "traditional" activities towards disability with welfare and charity approaches and concluded that individual projects cannot make changes. It continues that this mainstreaming rather than individual projects is especially important for disability issues due to the following reasons: individual development projects cannot make big enough changes firstly because the needs of 10% of the population cannot be met by such individual efforts, secondly because sustainable and stable change is necessary and thirdly because disabled people should not be separated and specialised from the human rights perspective. The study is trapped into the pitfall because it measures the result within the typical project cycle. The effect of a project especially in the disability sector cannot be measured within the project timeframe when the problem of discrimination is so massive. Particularly when a project concerns psychological changes, the visible change takes place slowly. As the example of Dana proves **rights-oriented projects can make a difference** towards mainstreaming slowly but significantly when the political model is integrated into the local context. She showed the activeness and possibilities of the disabled population in such politically constrained countries to empower themselves both as individuals and as a group. Implementation of the political model takes a longer time, more money and more energy at present in Central Asia. When all these specificities of the local context are taken into account, however, applying the political approach in practice is possible.

Summary
Activities of Dana are highly suggestive in the sense that she challenges the structure that makes and reinforces the vulnerability of disabled people rather than accepting reality. Her challenge to include severely disabled women into their activities proves that a time-, money- and energy-consuming methodology is the only way firstly to include the most discriminated population under current discriminating reality. This effort then leads to their participation through the paradigm change from an object to a subject in their individual life and also in the collective activities. The empowerment of individual disabled persons is not the only arena of their activities. The DPO members also try to change their environment that degrades their lives. Her experiences showed the possibilities of the political model in Central Asia. At the same time, her example reassures the difficulties for making a difference when the massive mechanism against disabled people is resistant to any change.

4.4. Roles of Kynnys in the Globalisation of the Disability Movement ~Ideology, Ownership and Direct Money Transfer~

This part analyses how the Kynnys project positively influenced the creation of the disability movement in Central Asian countries[15]. "No one is 'against' disability rights" (Blaser, 2001:594). However, the way how to secure the rights is still an open question. This Kynnys project gives hints to elaborate the way how to globalise the disability movement rather than disability which could be the paradoxical outcome of some international intervention (see Chapter 4.2.1). Without exception, the Kynnys project also faced mistakes and misunderstanding in its process as was mentioned in Chapter 4.2.2. However, it did play important and suggestive roles through this project that are three-fold: ideology transfer, ownership transfer and direct money transfer. These

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[15] Influence of this Kynnys project on Finland is mentioned separately in Appendix 4.

three steps are discussed in order to find implications for the future intervention of the West in the disability sector and most probably also to other sectors dealing with the rights of minorities, which is the aim of this part.

Ideology Transfer
First of all, ideology transfer rather than service provision or the certain Finnish model transfer was the main activity throughout this project. The significance of this activity is that Kynnys managed to **transfer the political model of disability**. That is, individuals and disabled people as a group are empowered which are the prerequisite to create their own movement in the future. This political model had an impact on Central Asians to understand the importance of paradigm change from objects to subjects. Central Asian project participants realised that daily difficulties are social problems and not individual problems. In other words, they are aware of their rights. This ideology transfer is important in the sense that the concerned people identify their own issues to be solved and find a suitable solution under the local specific context where they live. The philosophy that "they know about themselves the most" is running through this ideology. This is especially relevant in this kind of international intervention because the local culture is so different from the one that Westerners are familiar with. More precisely, the **Western disability movement has the objective of independent living, while that sort of individualistic goal is not necessarily suitable in an Asian context where the family concept is totally another one**. Kynnys did not highlight this independent living but the political model so that the final decision making to create their ideal way of living was left for the responsibility of the Central Asians. This is relevant because Chapter 3 proved that the vulnerability creation mechanism is similar between Western countries and ex-socialist countries and therefore the rights perspective can contribute to figure out the social discrimination and its structure. Thus this ideology transfer is of use. When it comes to the actual context specific experiences, Finnish activists are inexperienced. Only the concerned people know their own experiences and thus have the expertise on their issues after understanding the paradigm change. Therefore, the actual work was left for the Central Asians to deal with. This strategy created enough room for the Central Asians to think over their ways once the rights perspective is applied in their context. This was the first and biggest role of the Kynnys project in the globalisation of the disability movement.

Ownership Transfer
This first role leads to the second theme of ownership because the paradigm change from objects to subjects follows ownership. However, the ideology transfer should be prior to this ownership because ownership is tricky. This theme of ownership is well epitomised in the well known slogan in the international disability movement since a decade ago (Charlton, 1998): "**Nothing about us, without us**." This slogan is widely used by international agencies such as the UN and the World Bank and also by DPOs such as Disabled People's International. This slogan stresses the **representation and participation** of disabled people in the decision-making process to control their own lives. It was highlighted in the study of STAKES (2003) that being disabled is an advantage in this disability movement because disabled people have the expertise on disability. This world trend has pitfalls which became clear from the above Central Asian case. First of all, this slogan and international trend of involving representatives in decision-making generalises disabled people as "us." However, as has been clarified, **disabled people have huge diversity**. For instance, chairpersons and general members have a big gap in between even in the small framework of DPOs. The independent living movement in the West and its international engagement in developing countries in general is criticised "because members tend to be middle

class, the poor are often left out, or their needs are misinterpreted to fit the priorities of Western disability activists" (Werner, 1998). Therefore, when the direct beneficiary of a seminar is targeted to chairpersons, the final beneficiary of general disabled people does not necessarily gain power due to the gap. This representation and ownership question of the final beneficiary is the first pitfall if not enough attention is paid to it.

Secondly, disabled people tend to have an internalised negative image of the discriminating society and to believe many things impossible for them though they are possible. For instance, the study of STAKES (2003:50) analyses that the "inadequate treatment" of development cooperation activities in disability is due to the lack of awareness of the targeted community:

> *The answer the team heard from various directions was: "Partner countries do not bring it the [disability issue in development] up, communities do not demand it, people with disabilities do not have a voice and donors do not consider it."*

Therefore, including these disabled people in decision-making process is a **false representation** because they have not had the chance to be aware of their rights and possibilities and to raise their voices. Involving a disabled person is not enough. The involved disabled people have to be directed to the rights perspectives rather than the hitherto predominant medical model and workability model of disability, for example in a Central Asian context. White (1996) warns of the potential harm of "participation" depending on "who is involved, how and on whose terms." Careless leadership and representation can cause bureaucracy rather than democracy. **Participation is thus not a simple panacea but a "dynamic process" that should be elaborated** (ibid.). When ensuring the needs and objectives, special attention should be paid to clarify if the disabled people have internalised social oppression and needed something within this limited understanding of their lives or they need it for their long-term objective of equality. Therefore, before giving total control and ownership over their issues, self-awareness is indispensable when it is still missing. Kynnys played a role in this part with its intervention in Central Asia though it turned out that some seminar participants were already familiar with the themes and did not need the training. This mechanism under "participation" is relevant to other groups of people fighting for their rights such as women, children, poor people and ethnic minorities. Different groups of people use this slogan for claiming their control. However, when they are involved in the decision-making process without prior training, their reality could be reinforced as a result of the false representation. In this sense, the above arguments are of relevance to other disadvantaged and stigmatised groups of people as well as to disabled people.

The third pitfall happens when ownership is confused, for instance, between that of the Finnish side and that of the Central Asian one, in this specific case. When the central focus is Central Asian disabled people, Finnish disabled people are to be withdrawn at some point in its intervention because they are not "we" but "they." In this sense, the withdrawal of the Finnish side was brave to avoid the dependency of the Central Asian party and to give maximum freedom of choice and responsibilities to them. However, this clear cut ownership does not mean that the relationship stops all together. As has been stressed, disabled people in so-called developing countries are doubly discriminated against and so vulnerable. Therefore, **both moral and financial support is much more necessary than any other disadvantaged minority groups**. In this regard, the next third point becomes important.

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Direct Money Transfer

Last but not least, direct money transfer is another transfer that could follow the above two. Direct money transfer refers to the money transfer on the basis of total trust and thus without or with little binding conditions for the usage of the money so as to decentralise the power of planning, implementation, monitoring and evaluation to the very concerned people. With this transfer, money is directly allocated to the concerned people rather than through Western development agencies including Western NGOs. Especially the money flow is expected for activities of the political approach because donors pay less attention to such activities (van Rooy, 2000). One international donor agency in Central Asia, for instance, said "We don't give money to seminar activities because we cannot measure the result of them" (Staff B of international NGO in an Uzbek urban area). The change could be psychological and thus it is true that the result could be hard to be visible in the short term. However, that **very psychological change is the source of the following big changes in the long run especially in the minority movement**. In this sense, activities of the political approach should not be underestimated. Once again, the first two should be prior to this third transfer because mere direct money is nothing more than a source of corruption if enough conditions are not carefully prepared. This money transfer took place outside the Kynnys project framework because the money technically came from the Abilis Foundation, another Finnish DPO. The main decision makers in this foundation, however, overlap with the Kynnys organisation. In this sense, this can be included in the role that Kynnys played. The Kazakh DPO received funds for organising the Almaty seminar under some pressure from Finland, which is not the best possible scenario because the **incentive also belongs to an important aspect of ownership**. When it comes to Dana's grant, the foundation proved its strength: trust in the ability and their local knowledge to implement the project. In this way, Dana could carefully think of the budget to be able to tackle the local obstacles in different kinds of accessibilities. She learned the political model and took the rights issues seriously. She felt the strong ownership and responsibility for society so that the change would be made in the way she and her colleagues collectively wanted. Participation was carefully made possible for one of the most disadvantaged groups of disabled people. As a result, the trust and direct money transfer increased the capacity of the project participants to identify their needs with sharp insight. This transfer also had an impact on increasing organisational management skills that would be useful for further development in the creation of their disability movement. This third step of direct money transfer, in theory, follows the fourth step in which local DPOs and disabled people are empowered enough to create and carry out their own way of the disability movement. However, Western intervention will be necessary for a long time for the disabled people in "developing countries" to reach this level.

Summary

In conclusion, the following discussion around the word "transfer" summarises the roles of Kynnys. The word "transfer" seems to be a one-way action from one point to the other. It thus sounds like only one party has the absolute power. However, as has become clear in the above discussion, it is actually crucial to secure the ownership and autonomy of the other. Only at the right time when the other party is ready and actively seeks for certain things, the transfer could take place. It is especially true of the second step onwards. In this sense, it is more of a word of partnership in this context because both parties are indispensable to attain the goal of the globalisation of the disability movement. These three roles that Kynnys played are highly suggestive and theoretically important towards the future intervention from the West in any "developing countries."

The material support, however, should not be undermined in the process of the movement. When "daily survival" is the concern of disabled people, mere movement cannot meet their needs or even attract any member of the constituency to take part in the movement to start with. This study focused on the activities of the political model of disability because the paradigm change and ownership is extremely relevant in the creation of the disability movement. This part thus summarised the roles of Kynnys in terms of this specific model. However, as vulnerability is multi-layered, the activities of the political model cannot cover many needs. Therefore, multiple interventions including material and medical support should not be ignored in addition to the implementation of the political model of disability. This argument will be elaborated more in the concluding chapter.

Chapter 5. Implications towards Equality

This is the concluding chapter. Firstly, the main findings of this research are summarised. Subsequently, I look back this study and analyse the roles of the study and the validity. Finally, practical recommendations to different actors for their future policy and practices are introduced on the basis of the collected voices of the disabled research participants.

5.1. Main Results of This Study

The purpose of this study was to investigate the complex reality of Western NGO intervention in the disability sector in a Central Asian context. Especially the political approach was the central focus. In order to elaborate on the organisational experiences, I had to investigate the local background conditions because otherwise reality cannot be grasped and located in the context. The final goal was that this thesis, including its process, contributes to the disability movement and their equality. With this goal in mind, the key questions for this research have been 1) What are the main factors of the mechanism making disabled people vulnerable in Central Asia? How disabled people could be empowered? 2) What is the reality of Finnish NGO intervention in Central Asia from the perspective of the disabled people themselves? And 3) Could disabled people in Central Asia consider the political approach as their future possibility? These are the questions that this study has sought to answer. This sub-chapter tries to fulfil my aims for this study by summarising the findings. The main findings of this study are three-fold: vulnerability creation mechanism for disabled people, heterogeneity of disabled people and then implications towards equality. These findings answer the key questions.

First Finding: Vulnerability Creation Mechanism

Firstly, this study articulated the main factors of the vulnerability creation mechanism for disabled people in Central Asia through the deep and personal interviews over the last four years. This study found that there are many layers of mechanism trapping disabled people to reinforce their deviant role and vulnerability in their society. This study especially focused on seven main layers that compose the massive mechanism.

One of the layers is the **impact of the Soviet Union history** that labelled disabled people as "invalid" who are not eligible to work when workability was essential for their ideology. Especially physically disabled people were excluded from this ideological social structure, while blind and deaf people were entitled to work in certain workshops meant for them. That is, disabled people were physically segregated from the mainstream of society: physically disabled people were institutionalised, while deaf and blind people lived in isolated workshop complexes. This Former Soviet Union policy that "there is no disabled person in the Soviet Union" left deep prejudice against disabled people because society was manipulated to believe that there is no disabled person. Not only this psychological barrier but also the physical barrier was the product of Soviet times because the isolation meant indifference to the needs of disabled people in the physical environment. In this way, the Soviet Union constructed an unfavourable environment against disabled people.

Another layer that this study found is the **current governmental policy and practice** that is the continuum of the Soviet regime in the sense that the current regimes took over the segregation policy and practices. This policy is well epitomised in their medical practices that confuse impairment with illness and injury. With this practice, impairment is abnormal firstly because it

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is not the "normal" healthy condition and secondly because it is not cured. In this way, the abnormality concept of impairment is systematically created through the governmental medical practices that follow the medical model of disability. This study clarified that disabled people under these Central Asian regimes are deprived of their work opportunities due to the legacy of the Former Soviet Union. Furthermore, the financial crisis became the excuse for cutting down privileges and for hiding information. As a result, disabled people suffer from financial poverty along with many other kinds of poverty. In addition, wide-spread corruption deteriorates their position. In this way, disabled people are systematically made ignorant of their rights from the intentional choices against them.

The third layer is the **profound prejudice** that has been deeply rooted due both to the Soviet legacy and to the current policy and practices. Disabled people frequently face prejudice in their daily lives even from their relationship with their family members and close friends who have internalised the social prejudice. This prejudice limits the opportunities of disabled people because of low expectation towards them. Through relationship with the closest surrounding people, disabled people gradually lose power in their own lives and internalise the negative image of themselves. This is the dependency creation mechanism. Their daily life experiences reinforce vulnerability.

The fourth layer is a **lack of means for disabled people to escape from the mechanism.** Three major turning points in lives, education, employment and family life, are the opportunities for non-disabled people to empower their position in society, which is not true of disabled peers. Disabled people are deprived of such opportunities in these turning points which reinforce the differences from non-disabled peers. Especially establishing a family is even more difficult for disabled women compared with disabled men. This socially created deprivation makes disabled people feel vulnerable due to the clear differences from their non-disabled peers. Disabled people lack a mean to escape from the mechanism when they are trapped.

The fifth layer is the **isolation** of disabled people from society. All the above layers force disabled people to be isolated from society and to stay at home. This physical isolation makes it difficult for society to pay attention to the disability issue. At the same time, this isolation individualises the vulnerability where each disabled person starts to normalise the reality as an individual tragedy rather than as a social issue. This isolation also leads to the further prejudice of society towards disability issues and makes a vicious circle of the mechanism that continues to put disabled people down. Disabled people are trapped in this vicious circle and consequently become objects in their own lives.

The sixth layer is surprisingly **DPO activities** that are expected to play a role in improving the lives of disabled people. Unlike Western initial organisations for disabled people, Central Asian organisations are represented and headed by disabled chairpersons and the parents of disabled children. They are the concerned people, which is the great difference with the discriminative history of Western organisational activities. However, due to the induced **passivity** of disabled members before the engagement in organisational activities, most probably only chairpersons are empowered through the activities. Due to the passivity and inaccessible environment in many senses with limited resources, DPO activities tend to focus only on those who are walkable. Furthermore, DPOs tend to meet the needs of the unaware members and organise charity-oriented events rather than activities of the political approach. Charity activities make disabled people

remain passive and dependent because it reinforces the hierarchical relationship between givers and takers. This organisational life, therefore, is another layer of the vulnerability creation mechanism that reinforces the status quo. Some DPOs try to improve the lives of members with a more politically-oriented approach. However, the above-mentioned different layers of the mechanism hamper their efforts.

The seventh and last main layer pointed out in this study is **international intervention** in the disability sector in Central Asia. Despite the big impact of international intervention, it tends to fit into the limited framework that each government defines for the area of activities allowed for NGOs to play. The governments are tolerant of charity and service provision activities, while they take strong measures against those challenging the structure. That is, activities from the political approach hardly attract attention of the international community to tackle. Consequently, the essential structural change does not take place with current international intervention that rather reinforces the reality with limited impact.

In this way, these major seven layers plus minor multiple layers of vulnerability creation mechanism hampers disabled people to be mainstreamed in Central Asian countries. That is, discourse concentrating only on the individual, social or political aspect is not enough because all factors are intertwined and create disability. Despite the context-specific conditions, this mechanism was witnessed in all the five countries. This was a learning process for me to have found out the similarities despite the big differences among the countries. At the same time, this mechanism is amazingly relevant to the Western countries as well because the environment greatly affects the quality of life of disabled people. (see Appendix 4).

This finding articulates the fact that this vulnerability issue of disabled people should be solved in a holistic approach by involving many different actors both directly and indirectly influencing the lives of disabled people in such a negative way. This point is going to be elaborated further in the third finding.

Second Finding: Heterogeneity of Disabled People
The second finding of this study is the heterogeneity of disabled people. Having investigated the social mechanism by deep and personal interviews, the study clarified that the life of each individual disabled person is unique from each other despite the existence of the mechanism. This heterogeneity can be analysed from two different aspects: environment and personal characteristics. The first factor is their environment. As was clarified in the first finding, the social environment tends to determine the lives of disabled people in Central Asian countries. That is, the environment is an important aspect in the lives of disabled people. The environment of each disabled person, however, is very different from each other in terms of the attitude of their family, family composition, geographical location, activities of DPOs they belong to, government policy and practices and so forth. Despite the similarities especially in the historical experience of the Soviet Union, the five Central Asian countries are different from each other. For instance, Kazakhstan and Uzbekistan have a different environment for disabled people especially in terms of the tolerance of the activities of the citizens. In this study, I chose Kazakhstan and Uzbekistan to investigate disability issues more intensively than other Central Asian countries. The essential principle not to be tolerant of any antagonistic activities is common to both governments. However, Kazakhstan allows more space for freedom of speech compared with Uzbekistan where the coping strategy of people is typically self-censorship being

afraid of negative consequences and harassment from the government. Self-censorship was also witnessed in Kazakhstan. The degree, however, was bigger in Uzbekistan, at least in my interviews. Under the Uzbek government pressure, disabled people in Uzbekistan were more careful about being critical about their own government in my interviews. They have critical views about the government, which became clear only after they made sure about the confidentiality prior to the interviews. Kazakh disabled people were as critical as disabled people in Uzbekistan and expressed the criticism to me. However, the Kazakh research participants trusted me much more easily on the confidentiality issue. Another difference stemming from the same environment is the degree of passivity, which can be also explained by the tolerance of the governments. Research participants in Uzbekistan were more passive in the changes that they wish. They wait for things to happen. On the other hand, research participants in Kazakhstan were more active for the changes. More people try to make changes by themselves. This study assured from these differences that disabled people in Uzbekistan are more pressured to be isolated and passive compared with the peers in Kazakhstan. As these examples show, the governmental environment makes differences. When it comes to the environment in terms of family, the attitude of parents makes a great difference in the self-image: the family with low expectation tends to make disabled members dependent. All the other dimensions of the environment make differences, which contribute to making the lives of disabled people unique from each other despite the strong tendency to become vulnerable due to the massive mechanism. In this regard, studying about the social environment and context is indispensable for any studies of vulnerable groups including Disability Studies.

Individual characteristics also make their lives heterogeneous even if they live in a similar environment. Disabled people are not only disabled or impaired but also women, children, mothers, wives, middle aged, Uzbek or Kazakh, or active in nature etc. Disability should not be separated from the rest of the changing and/or permanent characteristics that compose their lives. Deaf people with a capital D also claim a different identity as a linguistic minority in a phonocentric world and do not consider deafness as impairment. Disabled people are, first of all, human beings who have got many different characteristics and positive aspects in life in addition to impairment and/or disability at a different time, place and occasion. That is, the existing mechanism against disabled people does not necessarily lead all disabled people to feel abnormal all the time. They are too often isolated, which hides both collective and individual experiences. However, many disabled people live active lives as mothers, husbands, women or young persons under the veil of isolation. At some other time, they suffer from discrimination not only against their impairment but also against sex, race and/or age. This study assured that this multiplicity should not be undermined to solve individual difficulties especially of minorities such as disabled people facing racism, sexism and heterosexism (Morris, 1991). That is, multiplicity should be paid attention to because the human rights of disabled people are interdependent with other human rights. Individualities in terms of both material and psychological needs stemming from their different impairments should not be ignored. Therefore, on the one hand, involving non-disabled peers is important not to exclude disabled people as different. At the same time, involving different minorities to solve different kinds of discrimination as a whole is another important way forward. In this way, disabled people as a group are mainstreamed. On the other hand, the individual needs should also be met. The individuality as the other end of the spectrum of the collective experiences of discrimination gives important implications for the future strategy of the disability movement, which is mentioned further in detail in the following finding number three.

Third Finding: Implications towards Equality

The third finding has implications towards equality on the basis of the collected voices of disabled people in this study. This study tried to focus on the activities of the political model that is a theoretically strong strategy for filling the gaps in the activities of DPOs in Disability Studies and those of NGOs in Development Studies. This rights-oriented political approach which had been avoided due to the fear to contradict with the local government policy actually turned out to be applicable, to some extent, under certain conditions in Central Asia. The example of Dana in Chapter 4.3 explicitly proved that the political approach has possibilities to be implemented in this region. The self-awareness training, campaigning through the mass media and voluntary activities for improving their quality of life are all explicit political actions. In addition, interviews proved also that implicit political actions have been gradually taking place in the daily lives of the research participants. For instance, going out from home to face the prejudice is seemingly subtle but actually significant behaviour of the political approach. These "everyday tacit and behaviour as resistance against the powerful" also belong to the political action (Skelton and Valentine, 2003:131). This is, first of all, a very important finding in itself is that this approach works to some extent. However, this model has not succeeded in fulfilling the daily material needs of the people concerned, which is a shortcoming. The daily material needs are the most acute needs. In this regard, critiques might argue that this model is the ideological way out for Western donors not to increase the development cooperation money. This model shows one of the directions and solutions towards equality rather than the globalisation of disability. Due to this complexity, however, this approach has to accompany certain conditions to be implemented in a proper way. This part tries to summarise some implications from this political approach to different target groups: to individual disabled people, to disabled people as a group, to society and to international donors including NGOs.

The first important target group of the political model is undoubtedly **disabled people** themselves, as this model aims at the empowerment of individuals with the paradigm change from objects to subjects in their lives. This paradigm change is a goal in itself but a process at the same time. Disabled people should be aware of their rights and feel the power to control their lives. This change from passivity to activity is the key to a successful implementation of the political model so that the disability movement is directed to equality. Without awareness of the constituency, the disability movement loses legitimacy. With awareness, the constituency might still choose to be passive, which is another story. Every single disabled person does not need to act in the same way after self-awareness. Nevertheless, this awareness for their choices needs to be understood to enlarge their possibilities. This psychological change is probably the most important implication towards equality because the movement starts from it.

The second target group is **disabled people as a group**. The empowerment of disabled people as a group through collective voices is another aim of this political model. The individual approach to meet the needs of individuals, for instance, the specific needs of blind people, is important to be fulfilled. However, collective voices to fight for their rights cannot be achieved when the power of DPOs is scattered around because disabled people are a minority to start with. Their voices are hard to be heard which is an assured fact as its starting condition. In this respect, conflict among DPOs decreases the collective power of disabled people as a group. In the social movement theory, the role of such organisations is big to create the movement and also to maximise the impact of the movement. Each DPO needs to have freedom of choice for their activities and variety, which is the strength of genuine civic activism. As the first finding

indicated, the multi-layered solution is necessary for tackling the multi-layered mechanism. That is, the variety of activities including service provision, material support, rehabilitation and medically-oriented treatments are all important, though inclination and concentration only on these aspects cannot change the status quo. An additional political approach to the variety is important so as to change the discriminating structure with collective efforts. That is, the hitherto discussion of dichotomy between service provision and rights-oriented activities is not binary. The dichotomy is too small in scale. In fact, they are both indispensable in the rights discourse.

The third group is **society.** Each person in society has to recognise the fact that they reinforce the disability if they are not aware of the rights of disabled people. Indirect reinforcement of ignorance worsens the quality of life of disabled people and vigorously maintains the status quo. Society needs this consciousness that they actually take part in the vulnerability creation mechanism also by doing nothing. It is society that makes disabled people vulnerable. This implication needs to be penetrated so that the political model would work smoothly.

The fourth group is **international donors including NGOs**. Chapter 4.4 clarified three implications towards international donors in theory and in this practice: ideology transfer, ownership transfer and direct money transfer. As has been repeatedly mentioned earlier, a variety of activities is essential to solve the difficulties of disabled people at many different levels. Among them, the political approach needs to gain more visibility to be included in one of the major activities. When applying this approach, these three criteria should be cleared up in order. Firstly, the ideology of the political model needs to be understood properly. The inclusion and involvement of any disabled person without proper understanding can lead to false representation because her/his view is limited due to the internalised medical model of disability. Secondly, ownership should be properly transferred from an international actor to the people concerned. Special attention is needed for not homogenising the people concerned because disabled people are heterogeneous. For instance, chairpersons and disabled members have a big gap in between even in the small framework of DPO activities. This dynamic process of "ownership" and "participation" should be carefully secured for the people concerned. Lastly, direct money on the basis of trust needs to be transferred to the partners especially for implementing the activities of the political approach, once the above two criteria are cleared up. Trust in expertise and local knowledge becomes important so that the disabled people in "developing countries" can identify their issues, plan their activities and create their movement in the way they want. The last point is a theoretical argument. However, it is highly suggestive. Furthermore, resources allocated to meet the material needs of the people concerned are also important along with support for the political model. Such aid needs to be coordinated among donors.

Last but not least, it is important for **all actors in society** to realise that even a small change can make a difference, as everybody has something to do with disability by taking some action and/or by not taking any action in this issue. The accumulation of small things at different levels by different actors makes up the massive mechanism against disabled people. That conversely means that the accumulation of such small steps makes a big, positive change, which was articulated in this study.

5.2. Looking back on This Study

I would like to look back on this study to figure out the roles and validity of this study in this sub-chapter.

Roles of This Study

I strongly believe that this study filled gaps between existing literatures in several ways. The roles could be sub-divided into the roles of different aspects in this study: methodological roles, academic roles in Disability and Development Studies and practical roles.

First of all, this study succeeded in **listening to the hidden voices of disabled people** who have been largely unheard. In this way, the personal experiences and troubles of this vulnerable group of people were introduced as social issues. This was an important step especially in the minority movement of the disability movement as it aims at social and structural change. Another role that this study played in terms of methodology is that the **research participants increased their self-esteem** through participation. I have not elaborated this fact in any statistical form. However, I observed that some people gained confidence after being paid attention to and also being able to help me. Many expressed to me at the end of the interview, "It is nice to know that someone is doing research into our lives." The third role in the methodology is that this study focused on **both the individual and collective aspects**. These two aspects succeeded in understanding the complex reality of their lives not only as disabled people but also as people with many other different characteristics. In this sense, this study managed to avoid the pitfall to generalise too much any group of people in a too simplistic theory. These three points are the roles in the methodology.

Secondly, this study played roles in academic terms. This study proved that the **social model of disability is, to some extent, applicable** not only in Western society but also in ex-Soviet countries. As the hitherto literature concentrates mostly on Western countries especially on the US and the UK, this **newly cultivated geographical area of Central Asia** gives great insights into the existing literature. This focus on Central Asia is rather new in Disability Studies and in Development Studies. Little is known about disabled people in Central Asia in both studies. In this sense, this focus filled some gap. Another important role is the focus on the **vulnerability making mechanism** in poverty. The **vicious circle** can be used for other minority studies in a context-specific manner. Especially discussion of ownership and participation are directly applicable to any other minority studies. In this sense, this study had good **implications for poverty reduction discourse and minority discourse**. The third role in the academic field is that this study supports the argument that the **political approach** leads to sustainable activities, because the targeted group can build capacity and hold ownership in its process. Therefore, once again this study is interesting for any minority or vulnerable groups-related studies.

The third roles are in the practice of disabled people in Central Asia towards equality. This study clarified the vulnerability creation mechanism in their society. This finding is meaningful in a few ways. Firstly, with this mechanism, disabled people in Central Asia can make sure that disability is a social creation rather than an individual tragedy. Subsequently, **they can tackle the articulated main barriers** to be removed to secure their rights. In these respects, this finding is going to be useful in practice. Further practical points are to be mentioned in the following

Chapter 5.3. In conclusion, **this study filled gaps both in academic literatures and in practices** in significant ways.

Validity of This Study

When it comes to the validity of this study, both the external validity and internal validity need to be examined. This part seeks to answer the question, "**What is this research valid for?**" rather than "Is this valid research?" because validity is not binary (valid or not valid) but "a process of interrogation" (Aguinaldo, 2004:130). Firstly, **external validity** questions about the quality and quantity of data. In terms of the quality of the data, I believe that this study went well thanks to the disabled research participants who trusted me. I feel that most of the interviewees trusted me and spoke honestly about their experiences. They understood that I am an independent researcher who keeps their confidentiality. I felt so from the fact that they honestly raised their voices and criticised what is wrong with the government in countries where self-censorship is the coping strategy in their daily lives. A few government officials spoke only rhetorically about the lives of disabled people as if there was no problem at all. This could be interpreted as dishonesty, but I feel that it also reveals an important aspect of their reality that the government is so strong that they are not supposed to criticise it as government officials. Aside from these few government officials, I managed to listen to their honest feelings and experiences. As my findings based on the voices of disabled people, my study is valid in terms of the reality from the viewpoint of the disabled people.

However, it would have been better if I could have involved more the extremely hidden groups of disabled people such as mentally disabled people and people with learning difficulties. Finding these people was difficult due to the multiple discrimination against them in Central Asia. Furthermore, I could have visited Central Asia when the climate is severer. I have experienced close to 40 degrees and minus 5 degrees during my stay, which did not cover the whole seasons. I intentionally chose mild seasons to conduct my fieldwork for my practical convenience. However, if I visited there in the very hot or cold seasons, I could have learned more about the reality of the lives of disabled people. I could have visited at such a time at least once among my visits so as to experience it rather than listening to them describing the severity. The third improvement that I would make is about my visit to rural areas. Due to the big gap in urban areas and rural areas, I visited rural areas to understand their reality. However, the stay in rural areas was less than that in urban areas. I feel that I should have allocated more time because those are the places where most of the disabled people live in each Central Asian country. At least, statistically more population live in rural areas, which indicates a higher number of disabled people in rural areas compared with the number in urban areas. It was difficult firstly because of the practical difficulties to visit there with few choices of transportation. Secondly, it was hard for me and for my research assistants to maintain our health in those areas, as my assistants were also from urban areas. In order to respect the local culture, I ate everything that was offered in each home. Even when everybody ate with their hands from one big plate, I followed their ways. I feel that facilitated me to gain their trust. However, different water in rural areas hit my health and that of my assistants very badly sometimes. This health condition partially restricted my period of stay in rural areas. However, naturally I wanted to learn more about their lives in rural areas. Nevertheless, the study succeeded in listening to the voices of disabled people also from rural areas. In this sense, the findings are valid.

When it comes to the quantity of the data, vast data was collected to fulfil the aims of this study. Especially the data was collected to cover the diversity of the disabled population which managed to avoid generalisation of the population. Furthermore, this study followed the Finnish intervention project from the beginning till the end over the last four years. Thus the data was collected in a different time frame, which added an interesting flavour to investigate the changes over time. However, four years is not enough time for elaborating the long-term effect of this project. In this sense, this time frame was the difficulty.

Secondly, **internal validity** questions if the research accurately examines the set questions (Murray, 2004). As is clear from the above, this study accurately answered the set questions on the basis of the collected data. The hidden voices of disabled people were brought up, which was the most important significance in this study. The only significance that the study aimed at and was left without an explicit answer was the effect towards making social policy. To investigate this thoroughly, simply more time was necessary. However, the psychological change started to follow the disability movement, which implicitly forecasts the possibilities for disabled people to make an impact on policy making in the future. Moreover, the practical recommendations in the following try to contribute to this aspect by future-oriented implications. In this sense, the study did not forget this significance among others. Therefore, the study is valid for answering the set questions.

5.3. Recommendations

When academics remain only in theories, it is a failure especially in my academic disciplines of Disability Studies and Development Studies. This sub-chapter is, therefore, devoted to connect the findings with practices so as to try to contribute to meet the needs of different groups of people who kindly shared their experiences with me in this study. I focus on making recommendations to four different groups: local actors, Western actors, policy makers and academics.

To Local Actors

Local DPOs in the study wanted to know the following two themes when I asked the research participants to articulate what they expect from this study: how to eradicate discrimination in society and how to influence the government. As summarised in the above findings, different layers of the local conditions reinforce these DPOs to remain part of the mechanism of the discrimination. Thus firstly changing the paradigm of DPOs themselves from the medical model and workability model to the political model of disability is necessary. In order to do that, the constituency should be empowered and self-aware of their rights. Without mobilising their own constituency, DPOs have difficulty in making an impact because their support justifies and legitimates the activities of the DPOs. Therefore, starting from their own constituency will be an important first step towards equality. When disabled people are empowered, society has to change at the same time so as to welcome disabled people into society. A constant and holistic effort is necessary because society constantly tries to reinforce the reality and pressures them to go back to the vicious circle. This resistance in society means a holistic approach is necessary to eradicate the discrimination. That is, the capacity of DPOs itself is not good enough to correspond with this huge mechanism. Therefore, different actors have to support DPOs.

Among different relationships with different actors in society, the studied local DPOs wanted to know how to influence the governments. Due to the legacy of the Former Soviet Union, Central Asian people tend to think that everything depends on the decision of the governments under these authoritarian regimes. Therefore, it was natural for them to answer that they firstly would like to know how to deal with their governments as they are the strongest and the most influential actor among all. At present, Central Asian DPOs have been working under a very restricted environment. All countries sought for authoritarian governments to a different extent after independence so as to prioritise stability over freedom. Yalcin (2002) defends that this was a temporarily understandable solution in the beginning stage of independence. Uzbekistan fears to give power to the parliament which has had no experience of democratic decision making, which is the justification for the authoritarian institution in which power is centralised in the president. The analogy of parliamentary responsibility is applied also to the arena of civil society because civil society has played little role in their history, which arouses scepticism towards their activities. Consequently, responsibility is not much given to them. This tradition and current politics determine the arena where civil society could work. To be "democratic," the parliamentary system and civil society were introduced in these countries. However, the actual significance is limited as the responsibility and a freehand is not given to them. The political restriction is tighter in Uzbekistan than in Kazakhstan. Therefore, DPOs cannot play a significant role in such a limited space with the limited approach of charity. Thus what they need to do before fighting against the governments is to establish a relationship with them so that the governments accept the role of civic activism in their society. Dana in Chapter 4.3 took both direct and indirect approaches for building this relationship with the government. She visited local authority to let government officials know about the existence of the disability issue, which is a direct means to influence the government. She also empowers disabled members and uses the mass media to mobilise general awareness in society on this issue, which are the indirect means. Once again, it should be remembered that multiple and holistic approaches are necessary because any individual effort is small in front of this massive mechanism. Thus cooperation among DPOs to gain visibility of the disability issue is going to be even more important. The Kazakh example of a TV programme making among different DPOs is suggestive. Cooperation with different NGOs will also be important for their common objective to gain their space of civic activism in society. Gaining trust from the governments to secure an arena is the first and the most urgent goal for NGOs in general. The governments have to understand the diversity in a democratic society, which sometimes ends in conflicts. Such conflictive situations need to be normalised as a process of democratic change rather than wiping all "opposition" from the scenery. The healthy development of democracy can be seen in the very diversity.

To Western Actors
The importance of the political model and possibilities of disabled people need to be reassured among Western actors. In order to employ this political model in which disabled people are the central actors, each Western actor needs to pay attention to some specificities of the disability sector. First of all, **projects and programmes in the disability sector cost much more money** due typically to the existing discriminating environment. The beneficiaries too frequently do not have the means of accessibility to the premises where the project takes place due to the deficiency of accessible public transportation, money to pay for the transportation, assistance, equipment and information about the project. They also often lack enthusiasm to go out. In order to overcome all these obstacles in each discriminating society, simply more resources are necessary for any project involving disabled people. Disability-specific projects necessitate much

more resources because people are deprived of their prerequisite opportunities to be equal with non-disabled peers. However, the lack of resources is too often the reason for excluding disabled people from development project activities in general. This is totally wrong because disabled people have rights to be equal and because at least every 10th person in this world is disabled. All projects, therefore, have to include the disability aspect to reflect their needs.

Furthermore, Western NGOs are squeezed into the framework of the project cycle by their donors in which disabled people are not mainstreamed. For example, transportation costs are often prohibited from being included in the project budget. Western NGOs should appeal to each government structure and foundations supporting their activities to pay attention to this fact that disabled people need more money and support for any project due to social discrimination. Otherwise, project activities only benefit those who are not in acute need of these activities. At the same time, these noticed obstacles have to be informed to society in the targeted countries so that the local actors become aware of this issue to be mainstreamed.

Service and material provision is only a temporary solution and criticised for not making fundamental structural change (see Chapter 1). However, disabled people need such support due to the current severely discriminative reality because too many impairments stem from malnutrition and a poor financial environment. **Disability and poverty is deeply related**. The material needs of the people concerned are stressed throughout this study, though donors tend to allocate money "according to the (psychological) needs of the donor countries" (Hofstede, 1991:218). Humanitarian aid is necessary for disabled people who are ignored in the market economy system, especially during the "transitional" period. At present, humanitarian aid comes and goes without systematic control to be delivered to all. Distribution is patchy and frequently overlaps. The **coordination of humanitarian aid among donors** or the appointment of a person in charge of equal distribution is necessary to increase the effect of this type of aid. As service provision is necessary and is known to create dependency, it should be **combined with the political approach** so that the consequence is not dependency.

Another specificity is the **importance of information delivery** because disabled people are too often physically isolated from society and cannot get hold of relevant information about their lives. This tendency becomes stronger for those who are in more disadvantaged groups such as severely disabled people, people with learning difficulties, disabled women and disabled people in rural areas. Deaf people also cannot often get enough information due to the lack of sign language interpreters, and blind people without Braille publication means. Each activity of a DPO has a limitation in itself because only a limited number of people can participate in it at one time. Two possible follow-up activities should be implemented so that the effect of the activity continues: the participating people can deliver information to others or activities are held as many times until all the others get to know the same knowledge. The latter option is "unrealistic" due to the limitation of different resources. Thus, hitherto Western actors have chosen the first way of activity meant for a limited number of people. Nevertheless, Western actors tend to forget monitoring or further effort so that the information reaches the final beneficiaries of general disabled people. As a result, information remains only within the circle of the small number of participants or in worst cases fades away when theories are not put into practice. In this sense, any training needs to encourage further information delivery and preferably needs to prepare some further means for the locals to be able to carry out this activity. As disabled people suffer too frequently from the lack of information, this activity should be focused more. Information

delivery to the final beneficiaries is important also not to separate chairpersons and their constituencies. Transparency and accountability prevents the personalisation of the DPOs. Collective decision making is impossible without proper information shared among the members. Thus information delivery should be paid more attention to in any Western development cooperation project, especially in disability specific projects.

To Policy Makers

This part is dedicated to the policy makers both in Western countries and in Central Asia. The investigation on the lives of disabled people has relevant implications for other vulnerable groups of the population because the vulnerability of disabled people shares some common features with other vulnerable groups such as women, ethnic minorities, and HIV/AIDS positive persons[16] (Gupta, 2004; Albertyn, 2003; Karlsen and Nazroo, 2002). The commonalities are as follows. Firstly, **eradication of the vulnerability is justified** within equal rights discourse. No one is against equality. However, **clear implications for implementing** rhetorical national and/or international policy of equal rights into reality of the vulnerable population is frequently missing. This is the second commonality. As a result and thirdly, the reality is reinforced or even deteriorated being trapped in **multiple-layers of vulnerability creation mechanism** frequently rooted deeply in history and social norms. The people concerned, therefore, experience various kinds of inequality, stigma and/or discrimination due to the socially constructed "normality" which is against the vulnerable people. They tend to have a higher risk for inequalities and disadvantages against other characteristics because they tend to lack information. For instance, disabled people have a higher risk of becoming HIV positive or physically and sexually violated as women (Yibeltal, 2004). Fourthly, a **vulnerable group of people are heterogeneous** and not all feel vulnerable all the time due to the multiplicity of the individuals and their environment. Finally and fifthly, there are **context-specific differences** on top of the above universalism. These five aspects are commonalities for other vulnerable groups of people.

On the basis of the interviews of disabled people in Central Asia and the above summarised commonalities, the implications for policy makers towards the vulnerable population could be summarised as follows. Firstly, **indigenous knowledge** is important. Policy makers need to listen to the population concerned by paying attention to their variety. Secondly, policy makers also need to pay attention to **creation of knowledge.** Critical investigation of the expressed needs by elaborating further the mechanism and context behind the needs contributes to identify the major reasons why certain people are vulnerable. Thirdly, to make **policy with multiple approaches** to correspond with the multiplicity of the vulnerability creation mechanism by involving also the non-vulnerable population in the discourse is important to tackle the massive problem of vulnerability. One powerful strategy would be to add the activity of ideology change with the rights perspective to hitherto activities. The political approach is suggestive. Finally and fourthly, **more resources** are necessary to cover the deficiency of prerequisites for equal opportunity because the problem is that the people concerned cannot participate in limited but seemingly available activities due to the lack of the prerequisite conditions.

To Academics

Disability is a complex phenomenon with multiple layers of mechanism reinforcing the status quo. Therefore, multiple approaches are needed to eradicate it. Research is one way to contribute

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[16] In a Western context, HIV/AIDS positive people comprise an important part of the disability movement.

to the social change, as academics are also one group of the "users of political power" (Vehmas, 1999). Researchers carry responsibility not to reinforce the reality of discrimination by actively involving disabled people in the studies. However, involving them is not enough because we have to understand the social mechanism as well as their lives to comprehend this social creation. Disability issues always need a social aspect to explain the reality because otherwise disabled people might be blamed for their difficulties as them being "passive" or "lazy." Most of them are systematically forced to look so in contemporary society. Disabled people are as creative as others, as clever as others, and as stupid as others! When they are given equal opportunities as their non-disabled peers, we can see that they are part of us. They are not special or abnormal. Thus, researchers should not make disabled people special but try to find the mechanism why they are made to look special so that the findings can lead to social change. Obviously, the social factor is not the only barriers and difficulties. For some disabled people, impairment is. Thus, equal treatment without attention to impairment is discrimination because they cannot then get equal opportunities, while the mere medical model is also discriminative. All the approaches including individual, social and political ones are needed for equality. Academics should make clear about their standpoint so as to reflect the practices. Otherwise theories are useless.

Disability is one form of social oppression. For many disabled people, disability is not the only oppression that they face in their daily lives. Discrimination against sex, race, age and many other aspects of human beings co-exist with disability. This is the reason why researchers in Disability Studies claim that the politics of disablement is about far more than disabled people (Barnes, 1996-b). Researches have to challenge all this oppression in different forms or at least acknowledge it if elaboration is impossible. Researchers in Disability Studies need to step back to grasp the bigger picture of social oppression. On the other hand, researchers in other studies need to add the disability aspect because as long as a study concerns human beings, disabled people occupy one tenth of the target population in principle.

I have three immediate dimensions that I would like to see in the near future research: discrimination against mentally disabled people and people with learning difficulties, a religious implication towards disability discourse and the significance of direct money transfer as a form of development cooperation. In my study, I focused on disability and to some extent gender in Central Asian countries. I acknowledge that disability is diverse. Due to the political and historical constraints in Central Asia, mentally disabled people and people with learning difficulties were highly hidden that I did not have more chance to be able to listen to their experiences. I managed to talk with parents of mentally disabled children and children with learning difficulties. Finding them has been very difficult. I wanted to meet them more because they face severe discrimination even among disabled people in Central Asia. This is one aspect for further research in the future. Another dimension is the religious implication. The religious aspect was not elaborated vigorously in this study partly because it was not mentioned so often by the research participants and partly because I needed then one more thorough research to investigate such a huge theme. The religious human rights have not been secured in ex-Socialist countries (Horvat, 2004). However, Islamic way of thinking has become more visible after the Perestroika period in Central Asia. I particularly wanted to know more about the Islamic significance in disability discourse. Western disability discourse criticises the role of religion due to the conceptualisation of sins in disabled people (Hirst and Michael, 2003). The Islamic impact, however, is hardly known in disability discourse except for few articles of religious persons without an empirical study (Al-Qaradawi, 2003; Musse, 2002). It is thus another theme in the

further empirical research. The third aspect is the significance of direct money transfer as the Abilis Foundation exemplified in this study. The Abilis Foundation gives grants only to those projects in which disabled people control the whole activities and the underpinning idea goes well with equal opportunities, independent living, human rights and economic self-sufficiency of disabled people. Service provision alone has been criticised due to its failure to challenge the structure. The direct money transfer with minimum control of donor countries is a new form of intervention by trusting the capacity and possibilities of the local target population. Is that the ultimate way for the Western actors to be able to support local civic activities in the way that they do not disturb the ownership of the local population? In theory, this can support the local activism. In practice, however, it can create another mechanism to cause the dependency of the people concerned along the line with service provision. The long-term effect of this intervention has not been investigated in this study since it was not the central focus. These three aspects are the immediate themes for the further research.

Epilogue

While finalising my writing, Asian tsunami catastrophe took place. It has caused devastation to many countries. The following international cooperation to relief the disaster and to support the reconstruction process is now amount to the level that our history has never experienced before in terms of money. I sincerely hope that the cooperation will be of even little help for the future of those who suffered from this catastrophe.

When it comes to the disability issue, the world attention is too little in spite of the fact that 600 million people around the world face various kinds of discrimination, as the findings clarified part of their reality. It should be stressed once again that the findings and the recommendations are on the basis of the interviews of Central Asian disabled people. Each research participant was isolated from each other and had extremely limited influence on society, let alone the international community. In this way, international community has paid far little attention to this issue. I hope that this study succeeded in bringing up their experiences and feelings to the readers. Especially I would be happy if the readers could change the prevailing negative image towards disabled people, if any, into positive one or at least understand that the superficially negative image is socially constructed. Furthermore, I hope the readers have gained even a slight responsibility for disability issues on their own part, which is then one step forward towards equality. Equality for disabled people is a huge goal due to the deeply rooted discrimination both in "developed" and "developing" countries. Disability is a universal problem. In this sense, all countries are developing in disability discourse. That is why each one has to carry the responsibility. When it comes to myself, my effort from the academic side to support the disability movement towards equality especially in developing countries does not end here. I will continue to be engaged deeply in this field of disability and development to make my humble contribution.

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Appendix 1. Information Sheet *(Printed with official University letterhead)*

Information Sheet

Project Title: The Impact of the Intervention of NGOs for QOL of Disabled People in
Developing Countries ~From the perspective of the social and political models of disability~
Investigator: Hisayo Katsui (Ph.D. Student)
Phone: +358-40-7236680 E-mail: hisayo.katsui@helsinki.fi

I am a Japanese student at Helsinki University, Finland, studying for a Ph.D. in Social Policy and Development Studies. For my Ph.D. Thesis, I am studying the experiences of those who are members of non-governmental organisations (NGOs) of disabled people both in Finland and in Central Asia.

The purpose of this research is firstly to explore the hidden aspect of people's experiences in this reality. From the experiences, impact of the intervention is clarified as the second purpose. I believe that the clarified information will be useful for the organisations to improve their activities if there is any room for improvement. Also the information will be helpful for any other NGOs that are working for disabled people and for disadvantaged groups of people. With those purposes, I have a strong interest in the experiences of disabled people in NGOs.

I wonder if you would be willing to take part in my study for attaining those purposes.

Your participation will be in the form of interviews and observations. During these interviews, questions will be asked and tape-recorded regarding your experiences about being a member of NGOs. At the same time, I will observe any relevant events and meetings, which are also tape-recorded. These tapes or written data will not be shared with anybody including members of the NGOs, but the final report with no names will be available at the end of the study if you or your organisation would like to have a copy.

If you agree with participating in my research, would you please fill in the attached informed consent form? If you have any questions, please do not hesitate to contact me at the above phone number.

Sincerely Yours,

Hisayo Katsui
(Signature of the researcher)

Appendix 2. Informed Consent Form *(Printed with official University letterhead)*

Informed Consent Form

Project Title: The Impact of the Intervention of NGOs for QOL of Disabled People in
Developing Countries ~From the perspective of the social and political models of disability~
Investigator: Hisayo Katsui (Ph.D. Student)
Phone: +358-40-7236680 E-mail: hisayo.katsui@helsinki.fi

I would like to agree to participate in the above named project.

I understand that there will be no risk for the current NGO activities to me resulting from my participation in the research. I also understand that the information may be published, but my name will not be disclosed.

I understand that I am free to deny any answer to specific questions during the interviews. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty.

I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

_____   _____

Participant   Researcher

                                         _____

                                             Date

Name (please PRINT)
_____

Address
_____

Telephone
_____

Appendix 3. TV Programme Topics

1. Terminology and ethics towards disabled people: How can we address them? What can humiliate human dignity?
2. The mass media and problem of disability: Good and bad sides in highlighting disability issues, discrimination and stereotypes.
3. Modern approaches towards disability issues: medical and social
4. State and disabled people: issues of social protection of disabled people, problems and perspectives
5. Issues of accessibility to public places and information: What is accessibility and how accessibility issues can be solved?
6. Opportunities in education: can a young disabled person have an education?
7. Integrated education: to what extent is it possible? Viewpoints of teachers, parents and schoolchildren.
8. Disability and limitations in employment: issues of employment from the point of view of disabled people and employers.
9. Culture and creativity of disabled people: achievements and attitude of society.
10. Sports activities of disabled people: achievements and attitude of society.
11. Disabled children's families: problems and hopes.
12. Disabled women and girls: double discrimination and its manifest.
13. What are equal opportunities for disabled people?
14. HR and disabled people: viewpoints of DPOs on HR and disabled people.
15. Mentally disabled people: their status, rights and safety.
16. Limitations in fulfilling HR, related to psychic diseases: threat posed to society and discrimination.
17. Social control over fulfilment of HR by people with psychic disorders.
18. International standards related to disabled people and domestic legislation.
19. International campaigns related to disabled people.
20. Individual rights and freedom.
21. Social and economic rights.
22. Social protection of disabled people.
23. DPOs and Disabled People's Movement for equal rights and opportunities.
24. Free topic for dispute: viewpoints on disabled person's milieu.
25. Summary: wishes and thanks.

Appendix 4. Impact of the Kynnys Project in and beyond Finland

The impact on the Finnish side has not been included in the main text of this study because it was not the central focus. However, I found it very interesting how Finnish and Central Asian actors perceived similarities in their problems despite their different background conditions. Thus I decided to include this part in an Appendix for those who are more interested in reading this aspect.

After the completion of the project, Finnish participants D, E and F feel that **Finland and Central Asia are similar**:

> *This is a cliché, but people think in a similar way as we do. I didn't experience with those [Central Asian] people that there is a wall between us. In every country, we meet a minority of the population there and we understood each other in what we are talking about. For example, women and violence is similar in Finland, too. It's not to that extent anymore, but, for example, when a disabled woman has a baby, it does not lead to violation but it does cause lots of things. I can say that the **problems are very similar but the intensity is different** (Finnish Participant F).*

The Finnish participants felt the **relevance** of this activity on the basis of their own experiences as disabled people. All the seven Finnish participants felt positive about the experiences, when they think back.

However, the overall impact in Finland is rather small because of the series of very similar organisational problems as Central Asian DPOs experience such as the lack of information delivery, the passivity of members, and competition among DPOs. First of all, all Finnish participants except for the project secretary have failed to keep contact with the Central Asian participants and even with other Finnish participants due to "laziness", "busy daily lives" and "lack of information from staff at the management level of Kynnys." Those who did not participate in the last Almaty seminar knew little about what happened in Central Asia after their intervention a few years back. In other words, they did not follow the impact of their own project that they were part of. **Information delivery** especially between those in management and those in local offices are a "big problem" in Finland as well:

> *Actually, I heard very little about anything! There is not much information coming to this area. (...) Board members know surely, but we are a random visitor to the project and traveller. So it was that trip and then our life continues. (Finnish Participant D).*

> *In [a city], we know about our own things, while Helsinki knows their own things. It's sad. But if they think in a different way, we do in different ways (Finnish Participant B).*

That is, Finnish DPOs are also bureaucratic:

> *It's in vain to criticise any DPOs on the bases of the fact that their organisational structure is Soviet-like because if we want to criticise, we can. But the corresponding big DPOs in Finland are quite bureaucratic, too. (They are) Hierarchical really, though we*

live in a very democratic country. [Three names of Finnish DPOs] and those who have so many members. They are all hierarchical (Finnish Participant A).

Even Kynnys, which is quite a small DPO, has a bureaucratic structure:

He (Kalle) is the opinion leader and he has lots of ideas and he develops them. And others implement them. It's like that. It's the same everywhere. Those who develops ideas don't do the practical work, do they? (...) I would not have thought of this kind of idea to have such a project in Central Asia if Kalle didn't develop it. I just joined the idea right away. We need such idea makers and then we need those crazy people who don't have ideas but implement the ideas (Finnish Participant A).

She argued the importance of a certain bureaucracy or a framework to manage a group of people to implement some ideas in practice. However, information delivery which could make this structure work in a democratic way is not ensured between those at the management level and other staff, let alone members. Therefore, sharing experiences and information is a big problem in Finland as well as in Central Asia.

Passivity is another similarity. Most of Finnish disabled people are induced to be passive despite the existing mechanism which could change the discriminative reality:

Kyrgyz Participant C: What happens if a person is discriminated against? Do officials know about it immediately when it occurs?
Finnish Participant G: In Finland, there is a law to prohibit discrimination. We have it in the legislation. At the moment, there was no person who wrote a criminal report to inform that they are discriminated against. So we could believe that there is no such isolation. But this is a problem in Finland that disabled people haven't filled in the criminal report, even when they are discriminated against. Well, this is a bit problematic. We could require a change but this happens very rarely. You could bring it to a court, but this is very rare.
(Discussion took place at the Helsinki Seminar on 5.9.2001)

You cannot be satisfied when things are wrong. This is the biggest problem here that too many disabled people are satisfied though things are wrong (Kalle Könkkölä, lecture at the Helsinki Seminar for Tajik Participants on 12.5.2002).

This Finnish DPO also encounters with very similar problems such as the lack of information delivery, passivity of members, and competition among DPOs, while Finnish people experience similar difficulties such as the medical way of thinking, family dependency, ignorance of society and isolation. In this sense, **Central Asia is a mirror for Finnish people** to learn from because both the social and organisational problems are similar.

The overall impact of this project on the Finnish side remained minimal due to the similar constraints as in Central Asia. The Finnish side can also prepare further means within the framework of such a project to deliver the information to Finnish members and society. Evaluation report only to the Ministry of Foreign Affairs, the financier of the project, is not enough to make better use of the personal experiences of the Finnish participants.

Today, disability activists around the world are overloaded. On top of the daily struggles in personal and organisational lives, they are involved in the making of new Standard Rules of UN, Global Partnership on Disability and Development of the World Bank, International Disability and Development Consortium of Europe, similar consortium of Northern Europe and/or many other international cooperation work. Furthermore, more and more criteria are recommended to be implemented. The political model is one of such additional tasks to be included to make interventions effective. When the activists are overloaded, additional task pressures them even more because their capacity is limited. Thus both national and global disability movements acutely need more disability specialists, especially from the younger generation, at different cooperation levels. Nevertheless, decentralisation of the power is difficult around the world due to the specificity of disability and that of organisational activities: coerced passivity of many disabled people and empowerment only of those involved deeply in the organisational activities. Therefore, the findings of this study on Central Asia are relevant in many senses to the disability movement around the world.