

Presentation for ISTR Fifth International Conference

"Transforming Civil Society, Citizenship and Governance: The Third
Sector in an Era of Global (Dis)Order"

Disability NGOs and International Perspectives

**~Political, Economical and International Explanation for the Need of
“directly applicable aid and advice”~**

Hisayo Katsui

MSc. In Disability Studies

Ph.D. candidate in Department of Social Policy

and Institute of Development Studies

at Helsinki University

Any comment on this paper is welcomed to

E-mail: hisayo.katsui@helsinki.fi

Introduction

~Why do Central Asian people want more practical and directly applicable aid and advice?~

“The empowering process may need to be gradual. In the process of planning and implementation, disabled people are given training and encouragement to ultimately empower themselves” (Wiman, 1996:177).

This is the theoretically correct argument for the development project in the field of disability. Disabled people have been excluded from decision-making process on their own lives in all part of the world, which has reinforced the reality of discrimination until now. Therefore, disability discourse is very sensitive about the representation of disabled people and highlights their participation as the important criteria for alternative approach.

The voices of disabled people/ -disability activism started to be heard more in 1990s. As a result, many policies and rules are proffered every year. Nevertheless, "in the reality very few things has <sic> 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). Too many governments are uninterested in disabled people (UN, 1999-2000). Therefore, international organizations and national organizations increasingly promote the activities of NGOs as providers of social welfare services (Deacon, 1997; Wiman, 1996 and Hertzberg, 2000).

Both in the development and disability discourse, researchers and activists started to assert the need for more political approach which challenges the fundamental problem in the structure (see Development in Practice, Vol. 10 number 3&4 on the development discourse, and Könkkölä and Sjövall, 1993. on the disability discourse). Joseph (2000), for example, explains that the political aspect is fundamental for development. He argues 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 in the structure. He continues that instead of neo-structuralism, ethical principles, cultural values and concern for the quality of life should be the starting point rather than “optional extras.”

This PhD research¹ has been conducted to follow the intervention of a Finnish disabled people's organization (DPO) in Central Asian countries. The interventions aim at improvement of the lives of disabled people in Central Asia through ideological transfer rather than the predominant provision of services. This DPO, Kynnys, therefore, tries to put the above-mentioned theoretically correct approach into practice. In more precise words, Kynnys trusts the local partner DPOs in their organizational capacity to continue their activities and to make it sustainable on their own account. That means Kynnys withdraws right after the series of training seminars where they transfer the ideologies of equal human rights treaties especially UN conventions and independent living, for instance. The timetable of the project has been and will be as follows.

7.1998	Preliminary Visit to Kyrgyzstan and Kazakhstan
4.2000	Preliminary Visit to Uzbekistan and Turkmenistan
9.2000	Seminar Trip to Kyrgyzstan and Kazakhstan
3-4. 2001	Seminar Trip to Uzbekistan and Turkmenistan
9.2001	Seminar in Helsinki, inviting 5 representatives from each country to Finland
4. 2002	Preliminary Visit to Tajikistan
9. 2002	Seminar Trip to Tajikistan
2003	Final Seminar in Kazakhstan

The researcher participated in seminars in Uzbekistan, Turkmenistan, and Helsinki². Interviews from the two seminars revealed that Central Asian people with disabilities have understood the ideologies very well and raised self-esteem as a result. Therefore, positive psychological change was observed in both seminars. However, many claimed that implementation of the ideologies into their practice is unrealistic and preferred more practical and directly applicable aid and advice rather than ideologies and theories.

This paper tries to understand the reasons **why Central Asian people want more practical and directly applicable aid and advice.** The first chapter concentrates on the economic explanations. The second chapter focuses on political reasons. Chapter three describes supplementary reasons in regard to international agencies with the case study of Kynnys. Finally, a concluding remark introduces the differences among different countries so as to go beyond the pitfall of the explanation, which accuses only the Soviet Union for their reality.

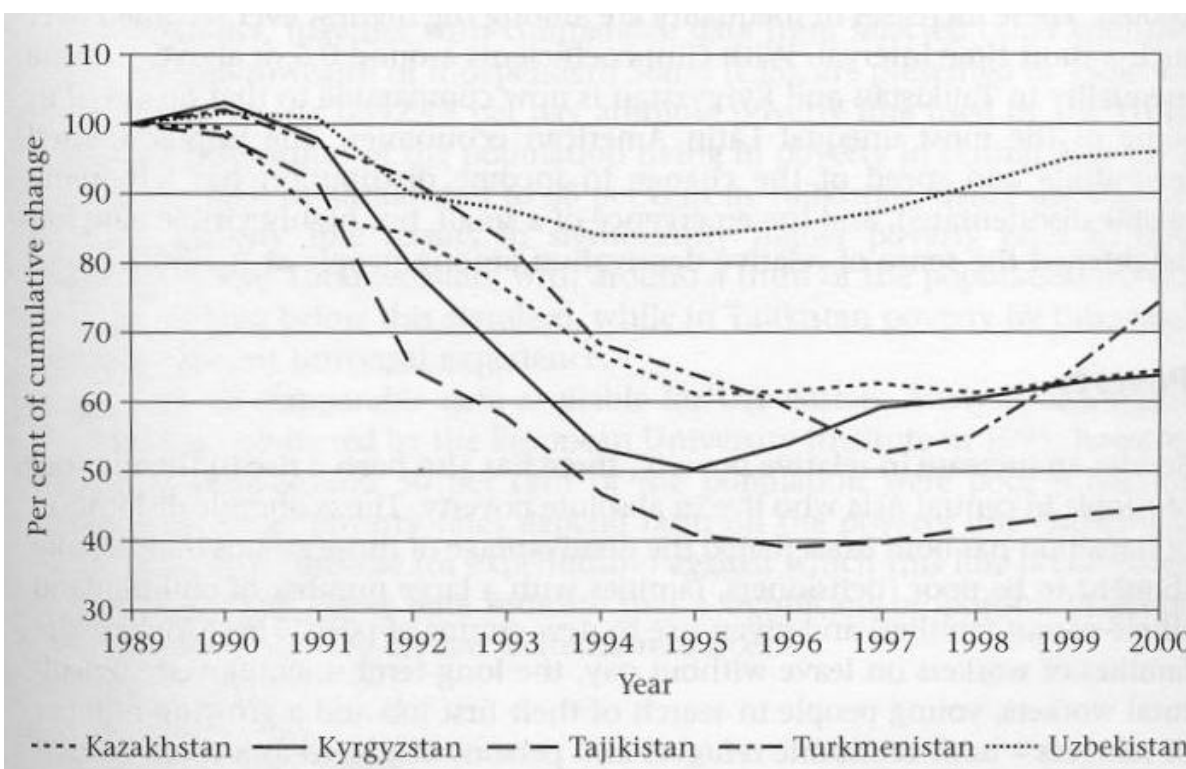
¹ This research is still on going and due to 2004. Any comments at this stage are highly appreciated.

² The agendas for these seminars are introduced in the end of this paper as Appendix 1.

1. Economic Constraints Partly Explains Why

Until independence in 1991 from the Soviet Union, all Central Asian countries had been under the totalitarian system with the control of Moscow. Virtually all aspects of lives were subjugated to Soviet ideology. Their economy was also planned by and for Moscow (Carley, 1995). Therefore, 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. The turmoil of Russia has worsened the situation (Falkingham, 2002). Table 1. shows the change in real GDP in Central Asia between 1989-2000, which well describes the economic situation in this region since the independence.

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



Source: Falkingham, J. (2002) "Poverty, Affordability and Access to Health Care." In M. McKee, J. Healy and J. Filkingham (eds.) *Health Care in Central Asia*. Open University Press. Buckingham. P42-56.

As this table describes, the overall economic situation has not been positive. Thus many people do not have money even for their medical services. One survey in 1996 showed that 25% of people in Kyrgyzstan (20% in Urban and 29% in Rural) could not use 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).

As for disabled people in this region, the economical reality is even more severe because of the big inequality between the poor and the rich. Uzbek people with disability claimed their severity of lives in the interviews. For instance, in regard to the medical services, Participant m³ uncovered the reality:

“When you come to the 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.’”

As for the pension, the funds are so meager that disabled people cannot live with dignity.

“Look the truth. Best communication is through Internet. Internet connection costs 1100 cym, but is it possible for disabled people (to pay)? More than one dollar per hour, but you know that pension is 5000 cym. Think about this (Participant j).”

On top of the economic constraints both at collective and individual levels, the attitude people inherited from Soviet Union reinforces the reality because they still believe that the governments will improve the situation but not themselves.

W: ... This is a so-called Soviet thinking.

Z: Which is?

W: I told in my speech, too.

Z: Ah, the state is moving things.

W: Yes, state is moving things. They are waiting what to come next.

Z: Does it mean that people are passive?

W: Yes. Disabled people are waiting that they can have more pensions. That is they are waiting for more and more pension but waiting for it to happen. Perhaps they cannot work. I don't know what is that. Perhaps they don't want to. It may also be psychological stage that they cannot think that disabled people could also work because in Soviet Time, people didn't work.

(W: Participant W, Z: Researcher)

That is, there is a very low incentive of donating money among disabled people to their collective movement of Civil Society. People just wait for something to happen.

In regard to the tax legislation, Central Asian countries do not distinguish clearly 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

³ The researcher has interviewed to participants of the series of Kynnys seminars both in Central Asia and in Finland. After careful consideration of possible ethical issues, informed consent form was made. Those Central Asian people who were willing to talk with the researcher have been the participants for this research work. "Participant x (x with small letter)" is a participant from Uzbekistan, while "Participant X (X with big letter)" is a participant from other Central Asian countries.

general although the rates are adjusted in many exceptions. For instance, the rate is 30% in Kazakhstan and 35% in Uzbekistan, but Central Asian countries accept “far less” tax deduction compared with Western countries. Value-added tax is also legally exempted. However, NGOs have great problem for this exemption because they have to apply for the VAT refund. Property tax is to be paid only if an NGO conduct some business activities. The rate is ½ % of the value of the property in Kazakhstan and 4% in Uzbekistan.

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 donation should not exceed 1% of taxable income in Uzbekistan and 2% in the other countries. These tax legislations are not encouraging people from companies to donate for NGO activities (Horton and Kazakina, 1999: 52-53). Cooper (1999:224) argues,

There are no (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. Participant C revealed contemporary tax policy:

C: All the tax relieves are abandoned. So we don't have them anymore. We used to have them, but it used to be so that if you have 51% of disabled people working in your organizations, almost all the tax was abolished. As a result of this legislation, everybody was looking for disabled people to work. In this way, every disabled person was working even those people couldn't go away from home, before. And in the end, so many companies just stopped paying taxes because they legally were not obliged to because they had many disabled people working. So the tax return for the government, of course, dropped. So that's why they had to. After a few days, all those disabled people were unemployed. They didn't have work places anymore.

Z: Did you work at that time?

C: No. I was asked to, but I had my own business to do.

Z: When was that? When the tax thing was stopped?

C: A few years ago, it was abolished.

Z: When it was started.

C: I don't remember, but it was sometime after the independence.

(C: Participant C, Z: Researcher)

This chapter has summarized the economic reality around disabled people and DPOs in Central Asia, which hampers the practice of their ideology transfer. The next chapter focuses on one of the options that Cooper mentioned above: governmental/ political constraint.

2. Political Constraint Explains More

Not only do economic factors directly discourage the growth of Civil Society in Central Asia, political difficulties also hamper their activities. The historical perspective explains the reality. In this chapter, the history of civil society development in this region is firstly described, after which the severe reality of political culture is focused.

2-1. A History of Civil Society Development in Central Asia

~Pre -Soviet Period and Soviet Period~

Civil Society had been totally unknown and non-existent until the twentieth century in Central Asia. Before the Soviet rule, the way of living made stronger identity consciousness among Central Asian people rather than ethnic or national identity. People recognized themselves either as sedentary or nomads, both of which were highly authoritarian or feudal in the nature of their management. Kinship culture and tribalism were very strong even before the Soviet era (Carley, 1995).

During the Soviet era, Moscow controlled everything. 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).

Civil Society was non-existent, and so were disabled people except for deaf and blind people. During the Soviet rule, disabled people were not allowed to exist anywhere.

“...history of our country, Soviet Union. The constitution said there was no disabled person in our country. In the Soviet Union, there was not any invalid (disabled person), only invalids they included in the law were deaf and blind. Rest of them, they were not invalids. Only deaf and blind. So others are not. In Soviet Union there was some resolution for the invalids where they live, not in the society but apart, in some houses where nobody could see them (Participant c).”

Therefore, organizations of disabled people were naturally also non-existent. This regime caused ignorance on civil society activities and contributed to the lack of management culture in the current societies.

On top of this highly totalitarian system, which prohibited the activities on civic level, Soviet legacies have also been discouraging the development of civil society. Carley (1995) points out that Soviet ideologies are deeply penetrated in the society, corruption, absence of legitimate legal structure and environmental devastation as the most significant legacies. The effects of these legacies are to be discussed further in the following sub-chapter.

2-2. Development of Civil Society since Independence

The collapse of the Soviet Union in 1991 was the significant turning point for the development of civil society in Central Asia. Citizen's organizations were non-existent in 1991, but have increased in magnitude in all five Central Asian countries. The number of citizen's organizations is now estimated to have grown to 3000 (Handrahan, 2000:18).

At present, the number of NGOs and that of NGOs in Disability Sector in the respective countries are as follows:

Table 2. Number of NGOs and Disability NGOs in Central Asian countries

	No. of NGOs	No. of Disability NGOs
Kazakhstan	699	75
Kyrgyzstan	1001	126
Tajikistan	595	48
Turkmenistan	138	9
Uzbekistan	465	74

Sources: (www.cango.net/db ; graph by the author.)

As the number show, the development of Civil Society in Central Asia has been very rapid. However, Handrahan (2000:18) implores the need to elaborate the reality behind the number saying “though donors place great importance on NGOs to buttress democracy, rhetoric about democracy assistance often focuses mainly on the quantity of NGOs.” The following sub-chapters investigate the reality of Civil Society development beyond the increasing number of NGOs.

2-3. Reality of Political Culture toward Civil Society

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 to take a generation at least for meaningful and long-term change to be possible. (Omit) 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).

Even if the number of NGOs rapidly increases, it does not necessarily mean the prosperity of civic actions in Central Asia. Despite of the good constitutions to secure freedom of citizens, their reality remains far from rhetoric. The Uzbek constitution (See Appendix 2), 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.” Nevertheless, the government discriminates authentic NGOs and restricts their activities with harassments. The Soviet legacy of the lack of legitimate legal culture partly explains this phenomenon as people very easily ignore the constitution. A significant example is the registration system where government-controlled NGOs (GONGOs) have much less trouble to register, while authentic NGOs are very frequently denied (Polat, 1999). In 1998, Kyrgyzstan had 700 NGOs, of which only 300 were considered to be active while the others were just ghost organizations (Horton and Kazakina, 1999). In 1995, one survey showed that 47.1% were still government-controlled although more and more NGOs were independent from the government control and began to replace government-oriented agencies (Bekturganova, 1997). In regard to NGOs in the disability sector, the Uzbek government is quite tolerant to aid type of activities, whereas those NGOs which touch politics are pressured to close down (Polat, 1999). In Turkmenistan, only sports related organizations for disabled people were allowed to exist and all the others were pressured to close down (Participant Q). Kangas (1995) claims that especially Uzbekistan, Tajikistan and Turkmenistan are restrictive and make little effort for the growth of Civil Society. Therefore, the activities of NGOs are still under very tight control of each government.

All these countries have quite strong, authoritarian governments controlling many aspects of the countries. Freedom House, for instance, categorizes all Central Asian countries as “not free⁴” countries in its annual report (Eurasianet, 2001). It lists also what it calls “The Worst of the Worst.” Turkmenistan was one of the five countries under this category. Many examples of “political prisoners” have been constantly witnessed in various literatures (Amnesty International, 2001; IHF, 2001; IHF, 2000; Olcott, 2000). The political regime has been causing lots of troubles and restrictions for the activities of NGOs in Central Asia. This political background is one of the explanations why the number does not necessarily reflect what Westerners expect it to.

⁴ “Not free” means their residents are denied basic political and civil rights.

2-4. Organizational Capacity of Authentic NGOs

Due to the economic and political environment, activities of NGOs have been restricted. Consequently, many local NGOs are still either GONGOs or apolitical organizations. When explaining the objectives of the Kynnys project, Finnish activist, Kalle Könkkölä, mentioned,

We decided that the main idea is to transport our experiences in creating organizations. In fact they have organizations but like to make them real organizations. And then speak about human rights organizations (Kalle Könkkölä).

This sub-chapter deepens the concept of NGOs in Central Asia and witnesses quite a difference in their nature compared to Western ones.

Mininni (1998) describes the nature of authentic NGOs as follows: “Groups were often comprised of just a few people with a charismatic leader whose personal vision formed the organization’s mission. These strong and inspiring personalities, while important in jump-starting independent action, would later pose obstacles to groups making the transition to a more structured organization with a clearer mission and more defined goals.” Fieldwork interviews reveal the organizational structure with hierarchical relationship where the leader is on the very top of decision-making process and information access. Chairpersons and general disabled people have totally different status especially in Uzbekistan and in Turkmenistan:

I am a normal person, so I cannot maybe reach the managers. I don’t like to be in contact with the management level people with the higher circle. But because I am quite a normal person, so to everybody who is below the management level, I was quite friendly with. Because you have to be quite official when you are talking to the managers and directors, I am not interested in this at all (Participant Q).

This hierarchical structure leaves very little to majority of people to benefit from, whereas the local host of one country has had absolute power throughout the project. The following example tells the whole nature of the relationship between information and power. The following is the conversation between the researcher (Z) and Participant q:

Z: Did you have any chance to talk about what you want to hear in the seminar, for example, to (name of the local coordinator)?

q: No, I didn’t have any chance. I knew about the seminar one day before the seminar. We came on the day when the seminar had to start. I didn’t know about the programmes that will be discussed in the seminar, about themes.

Z: How about your boss? Did he know about this seminar?

q: He knew about this one week in advance, but he was not serious about that. Maybe he is indifferent to that. Maybe he doesn’t need that. He doesn’t want me to talk about this, but

this is the reality. He is a healthy person, that's why. He is not interested. So he is not interested in this so much.

Many participants who are not leaders of regional DPOs did not know about the seminar itself until a few days before; in some cases such as Participant q until one day before the seminar. Leaders of regional DPOs got the information about one week earlier, whereas the local host got the information about half a year before the seminar. That is, information is firstly halted in the hands of the most “powerful” person such as the local coordinator, and then stops again at “relatively powerful” people such as regional leaders. In this specific context, the amount of information is proportional depending on the hierarchy: the higher people get more information earlier.

Organizational management and democracy is very different from what Northern/ Western NGOs are used to. Another example is the permission to talk with “the guests (=Finnish participants)”. Participant q revealed that there was only one Uzbek participant who was allowed to talk with the guests during the seminar period. This example tells a lot about the power of limited number of people in this country.

“They also have other problems. They would like to tell about this (their lives) as well and to talk about that with Finnish people. I don't know how (name of the local coordinator) can decide about that. What would be his decision if we can have possibilities to talk with our guests? For right now, one of the participants is given the opportunity to speak, but maybe that would be the only one but nobody else”

Due to the Soviet legacy, management capacity is missing among NGOs. Moreover, people wait for something to happen. Kynnys asked Central Asian partners what are the interesting themes to discuss when they meet up in Helsinki. However, Central Asian coordinators did not answer and just came to Helsinki, let alone the majority of disabled people who had little information about the seminar. Kynnys trust the organizational capacity and willingness of people. The expectation of Kynnys was not met.

In conclusion,, the increasing number of NGOs in Central Asian countries does not equal to the development of civil society. The reality is different from the expectation upon NGOs because “(t)he cultural and political inheritance of Central Asian states is a barrier to democratization” (Prtridge, 1999). The concept of civil society in Western term is not applicable to Central Asia.

3. Constraint from International Agencies Supplementary Explains Why

3-1. Paradoxical Outcome from the Good Intention of International Agencies

Another layer of explanation can possibly answer the raised question, “why do Central Asian people want more practical and directly applicable aid and advice?” Since the collapse of Soviet Union, NGOs from Northern/ Western countries started to engage with local organizations in development cooperation. “They (Northern/ Western NGOs) equated the creation of local NGOs in the short terms as a tool to engender the development of a viable civil society in the long term” (Luong, 1999). Local NGOs are expected to facilitate the democratization in these authoritarian regimes. Many scholars and practioners admit the great role that North/ West plays in the area of organizational development and infrastructure (Mininni, 1998; Bekturganova, 1997), connecting isolated local NGOs (Galbraith, 1997; Luong, 1999), financial contribution, information provision, and navigation of local NGOs (Bekturganova, 1997; Luong, 1999).

However, due to the above-mentioned reality, there is a 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 organization that attempts to analyse the situation and master its specific characteristic is a rare exception (Kuratov, 2002:12).

Northern/ Western intervention has been unintentionally and ironically causing non-democratic outcomes in Central Asia. The simplest consequence that stems from the ignorance of the local reality is the proliferation of government-oriented NGOs because donors demand to increase the number of NGOs without checking the reality. Handrahan (2000:19) accused the Northern/ Western partners for their little consideration on the choice of local NGOs. She suggests that the North/ West should take time to examine the NGO profile.

Even if the Northern/ Western intervention managed to be engaged with authentic local NGOs, they still cause paradoxically non-democratic result under the political conditions in Central Asia. Under the circumstance where any activities for political and social change is tightly restricted, local NGOs priorities more the fund-raising activities toward Northern /Western NGOs. As Northern/ Western community is willing to allocate funds for NGOs in Central Asia, this is a less incentive for the local NGOs to make more effort to be engaged with the antagonistic government or with local people in their community. That means local NGOs pay more attention to international needs rather than local needs, which subsequently leaves out government and people from their activities

by cooperating with North/ West. Cooper (1999) describes that local NGOs are “project-driven” without long-term sustainability. Consequently, Polat (1999) argues that Western influence is little for the governments. Cooper (1999) introduces the result of one survey where Kyrgyz urban people showed lower interests on the activities of NGOs compared with rural population although Kyrgyz cities have been attracting the interests of international agencies the most in Central Asia. He continues to explain this phenomenon by arguing that hitherto failure of international support has degraded the image of NGOs. As a result, local NGOs are increasingly isolated from the local environment rather than fostering the aimed democracy (Luong, 1999).

Moreover, North/ West intervention could cause negative competition among local NGOs for external assistance such as funds, information and connection (Richter, 1999). Because of the restrictive environment, access with North/ West community determines the sustainability or success of a local NGO. Therefore, tensions come up among local NGOs rather than better relationship among them. “One element of social capital that is crucial for community building is a sense of trust among members of society. Part of the Soviet legacy, however, is distrust” (Luong, 1999). Under the above-mentioned circumstance, the Northern/ Western models are hard to apply to the reality in Central Asia (Mininni, 1998). Partridge (1999) points out that it takes long time for the North/ West to understand this region. This layer of reality, therefore, also supplementary explains the reason why.

3-2. Reality of International Cooperation in Central Asia ~Case Study of Kynnys~

As has been discussed above, the needs of Central Asian people with disabilities were quite different from theoretically correct ideological transfer. There is a big gap between the Kynnys policy and the reality of Central Asia. On the one hand, Kynnys tries to follow the theoretically correct “participatory model” and leaves lots of room for the local actors so that they themselves could discuss and construct their future in the way they want. Kynnys believe the management capacity of the local actors. Kalle Könkkölä, Finnish activist in Kynnys, says:

Of course, they have difficulties. They have difficulties even more. But we can't go to Central Asia and change central Asia. These 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 the bed. Independent in which culture you are living, people want to get out of the beds, absolutely. There are some universal structures. But then, how they want, that's different. They have to think about that. Like how is the family system and how are the culture, economic possibilities and so on. So we give them materials to find their own way.

On the other hand, Central Asian people lack management capacity due to the Soviet legacy. Under the circumstance, putting ideologies into practice is very difficult due also to the limited finance and restricting political conditions. For instance, Finnish people taught Central Asian people with disability about how Finns appealed to the politicians about their needs. However, in Central Asia, such political activities are illegal and even threaten the lives. Due to these different stages of democracy between Central Asia and Western countries, Western examples as “material” are not necessarily applicable to Central Asian context.

Polat (1999:153) argues:

The Western theory of civil society and democracy is extremely important and useful, but its application in Central Asia is only possible if local customs and traditions are thoroughly taken into account.

Who understands the local customs and traditions thoroughly? The answer would be the local people in concern. Saves et al (2002:90) also indicates the same message:

Ownership is a key issue. People must feel a true sense of pride and ownership in the overall programme of health-sector reform in their country. The coordination role must be placed in the hands of nationals of the country, and international and bilateral agencies must respect this.

In sum, some Western examples are not useful in Central Asian context, but Kynnys policy of participation is to be respected in theory. Nevertheless, it is also true that majority of Central Asian participants of the project, who are not policy makers nor academic theorists but general disabled people, wanted more practical help rather than ideologies.

This phenomenon could be analysed in a few different ways. First of all, one possibility is that the general disabled people are simply ignorant about participatory model which empowers them in theory. Therefore, they seek for the instant, visible change in their lives rather than waiting for the long-term effect of empowerment. This could well be the case because Kynnys did not mention clearly their purpose of choosing ideological transfer rather than traditional aid. Their severe reality made the Central Asian people feel impatient especially after knowing the more established care and service system including independent living in Finland, although it took several decades for Finns to have reached to this level. Uzbek Participants f and h say:

“In your country it’s possible, but in our countries, it’s impossible yet unfortunately...You have more opportunities because you are in Europe and we are in ex-USSR, in Asia. Asia is Asia (Participant f).”

“I want to have a similar story in my life, maybe to go to beautiful country like that (Finland) (Participant h).”

Another possible analysis would be the fact that their reality is too different from Finland that Finnish theories sound useless in spite of the understanding of theories themselves. Participant L explains why studying theories only is not useful:

When theories are not implemented into 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 proved to be waste of time, if I don’t do anything. So I will pay most attention to the mechanism of the implementation to the practice (Participant L).

Many others also feel the ideologies does not change the reality:

“We can speak about many things here now, but they can’t go out from this place and tell about that outside to play in democracy (Participant a).”

“I just want to say we don’t want to create something which doesn’t come true, but real idea (Participant s).”

“Frankly saying, I don’t expect any result from this seminar. Or I think that everything will rest just here, in this (seminar) hall, and that will be the end of everything (Participant q).”

In both analyses, what is overlapping is the severe reality of disabled people. The environment is surely hampering the implementation of the ideologies into practice. Then the next question is what is actually the “practical aid and advices” in such states of totalitarian governments? Constance Hambalula (2002) from Zambia answered in a seminar when a person from Finnish Foreign Ministry asked, “What is the good development cooperation from North to South?” She claims that despite of the long history of North-South cooperation, the result is minimum. She explains that pumping money into South is not changing situation due to the rigid governments. Good development cooperation is, therefore, the one that enables to open the “deaf ears” of local politicians. That is, changing the fundamental nature of existing politics is her answer to the raised question. Coincidentally, “system-wide approach” also recommends the change not only in minor ad hoc groups but also in the system in the reform of health sector in Central Asia:

- *Each country has undergone a comprehensive political, social and economic transition, so that the impact of ad hoc minor changes to the health care system have had marginal or even no impact without changes in the other components of the system.*

- *Policymaking and management capacities were not well developed in the Central Asian republics, since these functions were carried out in Moscow. A systematic planning approach in each of these republics has helped to develop these capacities.*
- *A comprehensive and participatory process has contributed to the development of a democratic culture (Saves et al, 2002:88).*

Kynnys is aiming for policy-oriented ideological transfer rather than traditional aid that does not challenge the fundamental problems. In this regard, its strategy tries to involve different actors for the policy-making and thus is similar to the above theory. However, how disabled people feel and experience the reality is still unclear, especially in terms of the effects of the intervention in practice. These different layers of theories and practice need to be researched further to seek for the more focused reality from the perspective of disabled people.

Concluding Remarks ~ Soviet Union Is Not the Reason Anymore! ~

General picture of civil society in Central Asia has been overshadowed. Central Asia cannot be totally separated from the too big influence of ex-Soviet Union. All countries lack freedom of speech, freedom of media and freedom of organizational activities. 10 years have not been enough to reach democratic society but enough to make a difference among these countries. Kyrgyzstan and Kazakhstan have made greater effort for the development of Civil Society and have been more tolerant and open to the pluralistic society. For instance, both countries have many political parties, whereas Uzbek government controls all the parties (Kangas, 1995). Both countries are not restrictive to the activities of human right organizations, while Uzbekistan heavily harasses their activities (Horton and Kazakina, 1999). Kyrgyzstan seems to be even more open to democracy partly because President Akaev is the only president in Central Asia who does not have the background of traditional elites of Soviet Union (Kangas, 1995). Kyrgyz domestic NGOs genuinely lobbied for the Civil Code and established it in 1996, which is the only successful example in the region (Horton and Kazakina, 1999). When it comes to the registration process of NGOs in Uzbekistan and in Kazakhstan, it is very restrictive, takes ages and complicated in Uzbekistan, and as expensive as 150 USD which equals to 1.5 months salaries in Kazakhstan (Horton and Kazakina, 1999). Whereas, its process is quite simple and affordable (5 USD) in Kyrgyzstan (Cooper, 1999). This Kyrgyz example is encouraging to the further development of Civil Society in this region. Kyrgyz participant P believes in the role of NGOs:

I have a very high opinion of NGO in the sense that they are very good for civil society, for awareness because during the 70 years of Soviet Rule, the only way was to sit and wait what does the government would give you and what the authorities would give you. So everything

used to come from above. It wasn't the concept of you on your own trying to achieve your own goals (Participant P).

The effort of Kynnys and partner organizations in Central Asia continues for attaining their goal of equality. As quality of life of significant number of disabled people is relevant around the world, this theme is very important. In order not to follow the same track of discriminative history AND present of “developed” countries, this theme is urgent and necessary to be looked into. Otherwise, Northern/ Western DPOs could just spread the negative connotation of “disability” globally, instead of empowering the disabled people.

Appendix 1. Agenda for the Kynnys Seminars

Agenda in Uzbek and Turkmen seminars:

- *International Human Rights and Fitting them in national legislations
- *Disabled Persons' Individual Development
- *Disabled People's Rights in Finland
- *Implementation of Independent Life and Its Principle
- *Personal Assistance as a Support of Disabled Persons' Independence
- *Disabled Women—Double Minority—
- *Independent Living Centre and Their Programme
- *Disability Movement in International Context
- *Role of NGO as Protection of Disabled People's Rights

Agenda in Helsinki seminar:

- *Standard Rules ~presentation of each country on their understanding~
- *What is the Independent Living Movement?
- *How to Establish an Independent Living Centre?
- *Group Work on Independent Living
- *Presentation on the above Group Work
- *Relationship of Independent Living Centre with other DPOs
- *Vision of Future of International Disability Movement and Significance of the National Movement
- *Independent Living Centre and other DPOs versus Authority
~Including influence on making law~
- *Visit to one of the following: Rehabilitation Centre,
Organization of Blind People, Organization of Developmental Disabled People, Children Hospital and Women's Group
- *Barrier Free Environment
- *Excursion to Try out Public Transportation in Helsinki
- *Visit to Exhibition of Support Devices in Tampere
- *Evaluation and Feedback

Appendix 2. Uzbek Constitution on “Public Associations” under Part 3 “Society and Individual”

Chapter 13. Public associations

Article 56. Trade unions, political parties, and scientific societies, as well as women's, veterans' and youth leagues, professional associations, mass movements and other organizations registered in accordance with the procedure prescribed by law, shall have the status of public associations in the Republic of Uzbekistan.

Article 57. The formation and functioning of political parties and public associations aiming to do the following shall be prohibited: changing the existing constitutional system by force; coming out against the sovereignty, territorial integrity and security of the Republic, as well as the constitutional rights and freedoms of its citizens; advocating war and social, national, racial and religious hostility, and encroaching on the health and morality of the people, as well as of any armed associations and political parties based on the national or religious principles.

All secret societies and associations shall be banned.

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.

Interference by state bodies and officials in the activity of public associations, as well as interference by public associations in the activity of state bodies and officials is impermissible.

Article 59. Trade unions shall express and protect the socio-economic rights and interests of the working people. Membership in trade unions is optional.

Article 60. Political parties shall express the political will of various sections and groups of the population, and through their democratically elected representatives shall participate in the formation of state authority. Political parties shall submit public reports on their financial sources to the Oliy Majlis or their plenipotentiary body in a prescribed manner.

Article 61. Religious organizations and associations shall be separated from the state and equal before law. The state shall not interfere with the activity of religious associations.

Article 62. Public associations may be dissolved or banned, or subject to restricted activity solely by the sentence of a court.

From <http://www.pravo.eastlink.uz/english/resources/doc/constitution.php3#313>

Reference

- Amnesty International. (2001) Kazakstan. On www.amnesty.org/ai/nsf/index
- Bekturganova, B. (1997) Kazak NGOs Struggle for Influence. On www.isar.org/isar/archive/ST/kasinfluence47.html
- Carley, P.M. (1995) "The Legacy of the Soviet Political System and the Prospects for Developing Civil Society in Central Asia." In Vladimir Tismaneanu (ed.) *Political Culture and Civil Society in Russia and the New States of Eurasia*. M.E. Sharpe. London. P.292-317.
- Cooper, J. (1999) "The Real Work: Sustaining NGO Growth in Central Asia." In M.H. Ruffin and D. Waugh (eds.). *Civil Society in Central Asia*. University of Washington Press. London. P214-231.
- Deacon, B. (1997) *Global Social Policy ~International Organizations and the Future of Welfare~* SAGE Publications. London.
- EurasiaNet Human Rights. (2002) Freedom House Report Focuses on Muslim Countries. On www.eurasianet.org/departments/rights/articles/pp122801
- Falkingham, J. (2002) "Poverty, Affordability and Access to Health Care." In M. Mckee, J. Healy and J. Filkingham (eds.) *Health Care in Central Asia*. Open University Press. Buckingham. P42-56.
- Galbraith, C. (1997) Disability Leader Focus on Coalition Building in Kazakhstan. On www.isar.org/isar/archive/ST/kazdisable461.html
- Handrahan, L.M. (2000) "Formation of 'GONGOS' in Kyrgyzstan Raises Questions about NGO Aid." In Give and Take, summer 2000. On www.isar.org/isar/GT13.pdf
- Hertzberg, A. (2000) *Disability in Nordic Development Cooperation ~Synthesis Report Prepared for the Nordic Conference~* Centre for Health and Social Development.
- Hambalula, C. (2002) Discussion in a seminar "Taking African Disabled along with the Flow of Development" of Africa 2002 in Helsinki on 19.4.2002.
- Horton, S. and Kazakina, A. (1999) "The Legal Regulation of NGOs: Central Asia at a Crossroads." In M.H. Ruffin and D. Waugh (eds.). *Civil Society in Central Asia*. University of Washington Press. London. P34-56.
- IHF (International Helsinki Federation of Human Rights) (2001) Mission to Central Asia (Kazakhstan, Kyrgyzstan and Uzbekistan). www.ihf-hr.org
- IHF (International Helsinki Federation of Human Rights) (2000) *Human Rights in the OSCE Region: the Balkans, the Caucasus, Europe, Central Asia and North America*. www.ihf-hr.org
- Joseph A., J. (2000) "NGOs: fragmented dreams." *Development in Practice* vol.10 no.3 and 4. p390-401.
- Kangas, R.D. (1995) "State Building and Civil Society in Central Asia" In Vladimir Tismaneanu (ed.) *Political Culture and Civil Society in Russia and the New States of Eurasia*. M.E. Sharpe. London. P.271-291.
- Kuratov, S. (2002) Kazakhstan NGO Chooses Goals and Partners with an Eye on the Long Term. On www.isar.org/isar/GT13.pdf
- Könkkölä, K. and Sjövall, G. (1993) "Independent Living and Personal Assistant Services in Finland." In Duncan, B. and Brown, S. (eds.). *Personal Assistance Services in Europe and North America*. Rehabilitation International and World Institute on Disability. California. P7-14.
- Könkkölä, K. Personal Interviews at Helsinki on 3.10.2000, 25.11.2000, 14.3.2001 and 9.5.2001.
- Könkkölä, K. (2000) "Disability coming on the front-line in development." *Zeitschrift Behinderung und Dritte Welt* 1/2000. P16-19.

- Luong, P.J. (1999) "The NGO Paradox: Democratic Goals and Non-democratic Outcomes in Kazakhstan." In Europe-Asia Studies Nov, 1999. On www.findarticles.com
- Mininni, M. (1998) Making a Difference: Early Interventions at the Grassroots. On www.isar.org/isar/archive/GT/GT1Mininni.html
- Olcott, M. (2000) Regional Study on Human Development and Human Rights –Central Asia. On www.undp.org/hdro/Olcott2000.html
- Partridge, B. (1999) Caucasus/Central Asia: Report Calls Western Approach 'Too Arrogant.' On www.rferl.org/nca/features/1999/08/F.RU.990803130129.html
- Polat, A. (1999) "Can Uzbekistan Build Democracy and Civil Society?" In M.H. Ruffin and D. Waugh (eds.). Civil Society in Central Asia. University of Washington Press. London. P.135-157.
- Richter, J. (1999) Civil Society or the Third Sector? On www.isar.org/isar/archive/GT/GT4Richter.html
- Savas, S., Gedik, G. and Craig, M. (2002) "The Reform Process." In M. McKee, Healy, J. and Falkingham, J. (eds.) Health Care in Central Asia. P.79-91.
- UN. (1999-2000) Fundamental Rights of Disabled Persons are violated around the World. DPI Press Release SOC/4528.
- Uzbek Constitution. On <http://www.pravo.eastlink.uz/english/resources/doc/constitution.php3#313>
- Wiman, R. (1996) The Disability Dimension in Development Action. ~Manual on inclusive planning~ Gummerus Printing Oy. Saarijärvi.