Session 3　“Value Created by Transnational Networking of Persons with Disabilities”

**Kuroda**/ In this session, we will focus on the seemingly miraculous case of collaboration attempted by Persons with Disabilities groups in Pakistan and Japan. It is pleasing to have such an opportunity to think about what each of us should do to realize an inclusive society based on the case. For this purpose, we have three guest speakers. Mr. Shafiq from Pakistan and Mr. Kadota from Japan will talk about their collaborative case from each point of view, followed by a presentation relevant to domestic issues and the general conditions of PWDs in Pakistan by Ms. Nagata. She is from Nagoya Gakuin University and was formerly the country representative of UNESCO Pakistan.

**Nagata**/ Welcome to Japan, Mr. Shafiq. It’s been five years since we met last. First, I would like to share the general situation of Pakistan with the audience. At the upper right (of the slide 1) is the national flag of Pakistan in green which is Islamic colour, with the crescent moon of Islam. At the lower left is the symbol for persons with disabilities, often used in Pakistan and the Middle East. (Slide 1)

Please note that Pakistan is an Islamic country. It is a multi-ethnic country comprising various ethnic groups such as Sindhi, Baloch, and others from various countries. With respect to language, Urdu is the national language, but only about 8% of the population uses it as their mother tongue. Punjabis are the largest ethnic group. Mr. Shafiq is a Punjabi and his mother tongue is Punjabi. Pakistan is an unusual country, in that only about one person in ten uses the national language as their mother tongue. It is more like a complex community than a nation-state.

The literacy rate of the population aged 10 years and above is 58 percent, according to the statistics of 2015, meaning that about 60 percent of the population can read and write, and the rest especially many elderly persons are illiterate. Incidentally, Punjab, where Mr. Shafiq comes from, is the most developed area in Pakistan. Therefore, I think, the literacy rate there is much higher than this statistic shows. As its political system, Pakistan has a set of Parliament and Assembly, thus it is a democratic country like Japan, and this is different from many other Arab countries which have a single-party system. (Slide 2-3)

In Pakistan, one of the causes of disability is poverty. There are also problems faced by persons with disabilities including malnutrition, especially insufficient micro-vitamins, and the lack of access to medical services. Especially in Pakistan, immunization of polio vaccine is insufficient, and Pakistan has the highest prevalence of polio in the world. Islamic extremists are against the polio vaccination. There are also disabilities caused by traffic accidents and hereditary disabilities caused by marriage between very close relatives (i.e. cousin marriage).

There are discrimination and violence against women, as well as against men. When a person becomes disabled, the family falls into poverty circle. They cannot go to school, cannot find a job, cannot get married, and cannot lead a social life. A barrier-free environment has not been sufficiently developed; they often face a social discrimination; and especially women with disabilities are faced with severe and compound discrimination. The legal system is under-developed, and its enforcement is limited.

Data from the old national census of 1998 shows 2.49% of the total population to be persons with disabilities. Unexpectedly, the number of persons with disabilities has decreased in the new census-thus I use this 1998 data. The actual number of persons with disabilities is not reflected in this kind of national statistics. There is a tendency that the number of women with disabilities is significantly small. Throughout the country, there are probably more than 531 schools for special needs education. More than 200 NGOs and organizations of persons with disabilities are supporting the education of children with disabilities.

Under the 18th Constitutional Amendment, the autonomy of provinces was strengthened and the national-level “Ministry of Social Welfare and Special Education” was abolished, and responsibility for education and welfare for persons with disabilities was devolved to provincial governments. This has caused disparities among provinces and ethnic groups. There is also an overwhelming disparity between rural and urban areas. (Slide 4-8)

As regards laws to support persons with disabilities, very well-known ones include the national policy concerning persons with disabilities enacted in 2006, and the law concerning public transport and barrier-free transport enacted in 2009. At present, efforts are being made toward establishing an anti-discrimination law, but having already left Pakistan, I am not sure about its details. Pakistan signed the Convention on the Rights of Persons with Disabilities (CRPD) in 2011, when I was Country Director of UNESCO Pakistan. (Slide 9)

Let me mention a little about the network impact. International network of persons with disabilities by Duskin, the ESCAP (United Nations Economic and Social Commission for Asia and the Pacific), and the APCD (Asia-Pacific Development Center on Disability) are good examples of effective ones. Persons of high capacity, such as Mr. Shafiq, are great at obtaining funds by making excellent use of networks. He did gain a magnificent amount of funds from the World Bank. Networking with other countries is vital at the State Parties Conference of CRPD. Creating networks means building up “social capital”. In Pakistan, there are active networks of CBR (Community-based Rehabilitation) and CBID (Community-based Inclusive Development) in Sindh province near Karachi. (Slide 10-13)

**Kuroda**/ Thank you for speaking about the general outline of issues and other problems surrounding persons with disabilities in Pakistan. Ms. Nagata also mentioned networks. Now, following Ms. Nagata, Mr. Shafiq will give his presentation. He has participated in Duskin Leadership Training in Japan from 2001, and he is currently president of Milestone (Society for the Special Persons). There was a major earthquake in Pakistan, but overcoming its adversity, he established independent living centers. He also plays an important role in the disability movement in Pakistan.

**Shafiq**/ What I would like to share in my presentation is not about focusing on disabilities alone but about general society as well. Life starts. Every human starts life here. When we are born, we cannot eat, we cannot walk, we cannot change the world. Life starts this way for every human being. The network starts with different things; the first network is made by male and female, and then life starts. And then the network is diversified and there are many, many networks, like food networks, road networks, cell phone networks and a lot of networks we can see in our daily lives. So networks are very important for any life cycle. To make good networks, we need collaborations. Collaborations always have different shapes, powers, and objects. Different parts are combined to create collaboration. When we have a good collaboration, we can have a smooth network. (Slide 2-3)

An inclusive society means having many colours of life together like collaborations – to cooperate with each other to make a smooth inclusive society. When we create a sustainable inclusive society, we usually need social entrepreneurship. The independent living movement is privileged to start a new entrepreneurship, which creates various kinds of business opportunities and services. It sustains the IL (Independent Living)-based movement as well. There are several services of social entrepreneurship that we consider, such as personal assistant services, peer counselling, assistive devices, etc. There are many services that we can introduce as social entrepreneurship.

I think we were lucky. I got the opportunity to be selected to participate in the Duskin Leadership Training Program, and I established cooperation and relationship during my training. I was lucky to visit the Human Care Association. I met my teacher, Mr. Shoji Nakanishi, president of the Human Care Association, and learned a lot about the international politics of disability movements there, such as DPI (Disabled Peoples’ International) and the Asia-Pacific Network on Independent Living. And then I was very lucky to go to the Mainstream Association, where I met my mentor, Mr. Shunji Kadota, its president. Then, when we organized the first seminar in Pakistan, we met a person who was fully committed to his profession. When he arrived at the airport in Pakistan, he started fixing wheelchairs at the airport. It was Mr. Saito from Saito Kobo. Because of his support, Pakistan now is making wheelchairs, and maybe this year we plan to have electric wheelchairs too.

We also have a project with JICA (Japan International Cooperation Agency) and JIL (Japan Council on Independent Living). JIL has provided 500 electric wheelchairs to community members. Now, in my city, more than 500 persons with severe disability are using electric wheelchairs. Lahore, Pakistan, has accessible buses with a ramp now. This is the impact of the JICA project. There are many things going on. All these things started from the beginning with networking, then collaborations, and then the start of the inclusive society, which we have yet to achieve. Until now what we have achieved because of the networking is the exchange of knowledge and information. We have received a lot of resources from Japan: human resources, financial resources, technical resources, and technology.

This kind of collaboration created a strong network between the Pakistani and the Japanese disability movements. Not only Milestone but also many other organizations are influenced by the Japanese disability movement. In Pakistan, we found that CBR and IL were working in different directions, and then we realized that there is no need for competition. The destination is the same; we are just using different ways. The destination is independent living for persons with disabilities.

In Pakistan, we have a CBID network, as Ms. Nagata mentioned. This network is not creating a new philosophy, but a collaboration with each other, sharing resources and reserves and technologies as well. This has created a huge harmony in the Pakistani disability movement. Now the Pakistani disability movement is moving smoothly towards a rights-based law, the Pakistan Disability Act, which is in process, and hopefully, this year, we will have that law in Pakistan. Now I would like to share with you a short video about Milestone activities. (Slide 4-6)

(Video Show)

Whatever we have is because of networking between the Milestone and the Pakistani disability movements and the Japanese disability movement. We know our educational standards are lower and we have fewer health facilities. Human capital is very important if a nation wants to rise. We want to utilize our youthful population. What we need is education, training, resources, and dreams, which we have got from the Japanese disability movement. Thank you very much. (Slide 7)

**Kuroda**/ Mr. Shafiq talked about networking, and I realized once again that having a common goal is very important. That goal is independent living for persons with disabilities. We also saw the various activities of Milestone, and the starting point for all of this was the Duskin training program. Next, we would like to hear from Mr. Kadota, president of the Mainstream Association. Mr. Kadota accepted Mr. Shafiq as a trainee from 2001 to 2002 and still keeps supporting him after the training has finished. Mr. Kadota does not use the word “support”, but rather he says he has been working together with friends in Asia.

**Kadota**/ We operate an independent living center called the Mainstream Association in Nishinomiya City. In 2003, we aimed to help establish an independent living center in Asia, and it all started in Pakistan. First, around December 2001, JSRPD (Japanese Society for Rehabilitation of Persons with Disabilities) asked us to accept some trainees. Mainstream Association does not accept trainees for sporadic short-term training of only one to two weeks. The reason is that we think it important to create a human relationship. If it is just to give lectures in a teacher-student style, reading books would be enough. But our approach is: In the beginning, we go out just to play and to enjoy ourselves together, so we can become well-acquainted with each other as friends; then about a month later, training starts. And we accepted Mr. Shafiq from Pakistan. But maybe he was too serious. One month later he left Mainstream Association, saying, “There’s a ghost in the room of this independent living center!” We felt it was unfortunate that he had left, but later we decided to talk again in May. By that time, he had become interested in independent living centers. I think, perhaps some other centers skillfully got him interested in the centers. Not us. Anyway, he said he wanted to start an independent living center and asked me to visit Pakistan. Our talk this time ended with an ambiguous promise.

Later, the DPI World Assembly was held in Sapporo, where I met Mr. Shafiq again, and we talked all night long in the same hotel room for about 4 to 5 days. I asked him then if he wanted to start an independent living center, but at that time he was still not sure and said he also wanted to become a university professor. I told him to let go of the idea of becoming a university professor, because it is impossible to run a center as a sideline. But he said he needed to make a living, so I told him that I would provide the living expenses that he needed. That is how things started. Around October 2002 we decided to hold a seminar in Pakistan in February 2003. We supported him by donating 300,000 yen, which was half of the necessary cost of 600,000 yen and the seminar was organized. These three major encounters with Mr. Shafiq gave me the opportunity to visit Pakistan. The Pakistani people often talk with a touch of exaggeration, but they went so far as to say that although a lot of persons with disabilities have gathered for sporting events, it was unprecedented in the history of Pakistan that the seminar with the theme of human rights and workshops would gather this many people. I thought it was interesting to work as a missionary and to convey ideas of independence support and self-decision to overseas countries. This was the beginning, and it led me to rent an office there and start activities.

**Kuroda**/ I would like to ask Mr. Kadota to continue by answering questions. I feel that the Duskin Training program is bringing about social impacts. Please make a comment about that point, and also about the continuation of relationships after the training is finished. You said that you do not use words such as “follow” or “support,” but rather that you develop a friendly relationship with others.

**Kadota**/ I think that the Duskin Ainowa Foundation is conducting a wonderful program, and we enjoy being a part of it. I am afraid, however, that the Duskin program is weak about “follow-up,” and so we are involved in the program this way: When they decide to establish an independent living center after training, that is when we come in. The Mainstream Association accepts Duskin program trainees every year. They come from various countries including Korea, Nepal, Cambodia, and Mongolia. Mr. Samith and Ms. Lin who gave their presentations here yesterday are also graduates. They are working together in collaboration with various countries through the Mainstream Association.

We are not, however, teachers forever. We are overtaken very quickly. Members from Asian countries are very smart, so there is much more for us to learn from them. When the DPI World Assembly was held in Seoul, Korea, in 2007, those who had received training through the Duskin program were invited to the Assembly. There, they talked about creating a network of Asia’s IL centers born from Duskin. I wish I could say “born from Mainstream Association,” but actually it was Mr. Shafiq’s initiative. This network currently is active under the name of “Kokorozashi Network”, which means will or intention in Japanese. In one of their activities, for example, they went to Cambodia and organized a seminar and an event called “TRY” to promote independence. As they became active in various countries, the network became more developed. The word “network” may sound exaggerated, but come to think of it, it is simply a gathering like a circle of friends that support each other. It’s a casual network, something like a big family.

**Kuroda**/ This is indeed wonderful, miracle-like case, but was this possible because it was Mainstream and Milestone, or is this kind of network possible for other organizations as well, or does another already exist, and what are the issues? I would like Ms. Nagata to comment on these points, referring to generalizations.

**Nagata**/ About the question of if any organization can do the same and bring the same effect, well I think the probability is fifty-fifty. What is needed for the creation of an effective and meaningful network? The two gentlemen covered very interesting stories, but I listened to them very carefully to grasp what lies behind their stories. The first asset is People (human resources), of course, followed by Funds and Technology. As for people, individuals with leadership, such as Mr. Kadota and Mr. Shafiq, are needed. Otherwise the network will not continue. Second is the money (financial resources), which, surprisingly, tends to be ignored and not noted. Networks may sound like a free of charge item, but they need funds. Without a mechanism to raise funds, it is difficult to sustain continue networking and activities. Third is technology, such as electric wheelchairs, as mentioned earlier. Japan needs to provide technical information. With the backing of “people,” “money” and “technology,” networks will be successful to an extent. Pakistan, however, is a large country with twice the population of Japan. Many ethnic groups live in the country, and they are somewhat like independent entities, so to speak.

There are some impressive Pakistani disability leaders, including Mr. Shafiq, here, but I feel there are still too few people who have leadership skills. The very first requirement is leadership, and without leadership, the network will not succeed. Mr. Shafiq is good at mobilizing financial and other resources by using networks, but just maintaining networks also cost money. Say you attend a conference in Japan, the conference finishes, but the money may or may not be available, and you do not know when you will meet again. This is not good at all. In the next sessions of this Forum, there will be presentations by persons who may possibly be able to provide financial support, so I wish good luck for Shafiq-san.

**Kuroda**/ People, money and technology – they are indeed necessary. I realized once again that if people do not strive to work hard on these three matters, it will be difficult to continue a network. Now I would like to ask the audience if there are any questions. If you have a question, please raise your hand.

**Questioner D**/ I have a question for you, Mr. Shafiq, about the funds you gained from the World Bank. Please tell us what kind of efforts you made at that time. Also, I would like to know the current status of the Global IL network that you are working on.

**Shafiq**/ In 2005, we had a big earthquake in Pakistan. In only 49 seconds, 80,000 people lost their lives, and 15,000 people became disabled. About 750 people got spinal cord injuries. In Pakistan, there was not a sufficient medical care system at that time. Left behind were persons with disabilities and persons who got spinal cord injuries, and they started dying. At that time JIL and other stakeholders sent us some financial support and some equipment that was needed for people with spinal cord injury. Our activities were soon visible to the state government, and Mr. John Wall, the World Bank Country Director, Pakistan, was also there. They realized that only the Milestone team had the ability to teach persons who were newly identified as persons with disabilities about self-management and how to maintain independent living after becoming disabled. Then there was an idea about introducing the independent living philosophy or concept soon after any disaster.

We made a combination of doctors and IL experts; then we managed the camp. In the camp, there were students from Muzaffarabad University, who had suffered spinal cord injury, and we started sharing with them the idea of independent living. People from the Mainstream Association, Human Care, and a lot of other people came to Pakistan to support our camp activities. That was the turning point, because the Prime Minister’s office recognized that our camp was the best, and John Wall was watching us working together. Various connections and networks created an opportunity with the Japan Social Development Fund. We used seven million US dollars for local capacity-building, in order to deal with the disaster and economic impartment. We also provided 1152 wheelchairs to newly-disabled persons, 1500 white canes, and 600 cell phones for deaf people and created the first network of deaf people in Pakistan. Because of this funding and activities, right now we have more than 30 independent living centers, and more than 200 disabled persons’ organizations (DPOs), all over Pakistan. Our strategy is to create self-help organizations first and do the capacity building, turn these into DPOs, and then at the final stage, turn them into independent living centers. They then can provide services to communities using the tax money from the government, because we want to complete the charity model in Pakistan. We want to utilize the tax money, our money, to make the sustainable social security system such as Japan has.

Actually, we follow the Japanese disability movement in many ways. Yes, we have a huge population and fewer resources, but I think that one day we will achieve many things, similar to Japan. If we see Japan from South Asia, Japan is the marker of the disability movement, and the center of the disability movement not only in Asia, but in the world. No other country shares their resources, human resources, and knowledge, with other countries, as Japan does. There is no other country in the world whose persons with disabilities or activists are visiting other countries to empower them. There is no other country that is transferring technology like wheelchair-making.

But there is one negative thing: The Japanese disability movement needs to be highlighted in a more powerful way to the rest of the world. Projects are very big tools to enhance financial benefits, and social benefits as well. It is a big business, because 10 percent of the world’s population, one billion people, are persons with disabilities. It is a huge consumer market. Why not look at it as a business to create a new social market, to create new economic resources for humankind? We have a very strong network which is underway: WIN（World Independent Living Center Network）. If the center of WIN could develop its secretariat here in Japan, it could involve Europe and America and other countries too. Now is the time to show Japan as a country of progress in front of the world. Lastly, I thank Duskin very much, which selected us to be here to explore all these opportunities.

**Kuroda**/ Before we conclude, I would like to ask Mr. Kadota and Ms. Nagata to give us a final word or a message that you should not miss.

**Kadota**/ It has not been so long since the IL centers started to be built in Asia, and for most of them, information was dispatched from Japan. IL centers are being established in Latin America as well. Since they started from Japan, I would like you to take more interest in them and actually go and visit them. It is not easy to set up an IL center in a developing country, where they do not have enough resources. When you see them work very hard there, you will be inspired to work harder. When we started our IL center, it was not easy for us either; the more we put our efforts into it, the more it cost us. The centers never ask for money, but it is not disrespectful at all to give them money. I do hope that you will visit them and share the same feeling with us.

**Nagata/** When Mr. Shafiq participated in the Duskin Leadership Training program, at first no one knew what kind of person he was. However, he is a huge success today, and has become an indispensable person in the field of disability activities. Duskin produces graduates every year, but not all of them are successful. If there are 10 trainees, at least one, or perhaps two to three persons, become huge resources when they go back home to their own countries. Today, I see private sector and corporation representatives in the audience. Training people is an investment for not only Duskin, but also for you as well. Please do continue your support for many years to come. Money is needed very much. It is not rude at all to provide money. I learned this during my 30-year service at the United Nations. Funds are needed, funds for the creation of human resources, funds for the provision of technology. If anyone present is able to provide support, please do so continuously.

**MC**/ This concludes Session 3. Thank you very much.