

## LESSON 4

### PARTICIPATION AND EMPOWERMENT OF PERSONS WITH DISABILITIES

This lesson is dedicated to a field visit to a local organization of persons with disabilities (DPOs) so as to listen to the experiential knowledge and local disability expertise in the country.

- A list of Kyrgyz DPOs is attached at the end of this module. The teacher can use the list and select a suitable DPO to pay a visit with the trainees.
- Alternatively, guest lecturers from an organization of persons with disabilities can deliver their presentations at the premises of the training.
- For the trainees, it is useful to read some of the life stories of empowerment written by Kyrgyz persons with disabilities in the following before visiting the DPO.
- For the trainees, it is also useful to read the life stories on the roles of DPOs before visiting the DPO.
- In case neither visiting a DPO nor inviting a guest lecturer from a DPO is possible, please read all the life stories and do the exercises with the trainees as instructed.

#### **Content of Lesson 4**

4.1. Life Stories of Empowerment

4.2. Role of Organisations of Persons with Disabilities

## 4.1. Life Stories of Empowerment

### 4.1.1. Life Story of Dastan Bekeshev, a Blind Member of Parliament in Kyrgyzstan



I was born in Bishkek, Kyrgyz Republic, on November 22, 1983. When I was born, I had impaired vision, but still could see something. As I was told later, it had been a doctor's fault that I was born partially sighted. Still hopeful for a miracle, my parents brought me to Moscow twice to have a surgery performed on my eyes. But there was no miracle, and I lost my sight completely after being diagnosed with glaucoma.

My parents were desperate and asked themselves if I could live on my own when I grew up, because I was blind. Dad started teaching me at the age of three, explaining how to write letters and draw pictures. And I, being almost totally blind, tried to draw some scribbles. This gave me an ability to "read" a vehicle registration plate, because I could feel the shapes of the numbers and letters. When I was six, I started attending a boarding school for blind and visually impaired children. Dad learnt how to read in Braille to teach me, and I used to train with him at home. He realized that it was only knowledge that could help me in life. And today I tell the students and schoolchildren who I meet at schools and universities, who visit the parliament on the tours that I arrange with my assistants, that knowledge is a key to success.

I graduated from the high school with honours and started attending the Kyrgyz Russian Slavic University in Kyrgyzstan. When I submitted my documents to apply for the university, I thought that I couldn't pass the admission exams since we had used old textbooks during my school years. But I had been an avid reader, and that literally saved me because I had expanded my knowledge by reading the books beyond our curriculum. And even today, though I have to spend a lot of time for my work at the parliament, I still find some time to read interesting and useful books.

I was an excellent student. I used to record the lectures on my recorder and also ask my friends to read some textbooks aloud. In my second year at the university, I started using the computer and then it was my turn to help my friends to do various assignments.

When I was in high school, I set a goal for myself to get involved in politics and help people like me, who have some physical impairments. To make this dream come true, I knew that I needed to start working in public service from the very bottom to understand the basics of its operation. After the graduation, I chose public service and found a job at the state tax agency where I spent one year. During my first months, I had to establish myself there, relying on my friends' assistance who would visit me after their work was over and help me categorize the documents at my disposal. Later, my co-workers would be stunned to see me finding a required document all by myself, because I knew exactly where it was stored.

In 2007, I left the tax agency for the Ministry of Economy where I spent three years working in different positions. Since I was blind, I could not be promoted due to the existing legislation restrictions. I would be successful at promotion interviews, and then be told that I simply could not work. But I had been told the same when I was studying at the university. I always had to prove the contrary.

In 2010, I was elected as Member of the Kyrgyz Parliament for the first time. This happened because I was active and pushed for the necessity to have a representative of the community of persons with disabilities elected to the parliament. During my tenure, I introduced a huge variety of bills, including bills on the issues of persons with disabilities and their rights. In 2011, I was able to convince the Government and President to sign the UN Convention on the Rights of Persons with Disabilities, and now I'm working on its ratification. Today, Kyrgyz legislation on elections has a rule which provides a quota for two persons with disabilities to be included into the pre-election party lists. The Law on Education also provides quotas for people with disabilities to study free of charge at universities. Kyrgyz legislation has norms on sign language interpreters, Braille publications and many other issues.

In 2015, I was elected to the parliament for the second time, and I still keep raising the issues on people with disabilities and their rights.

#### 4.1.2. Life Story of Marina Fegele, a Founder of an Organisation of Persons with Disabilities in Osh



I was born on November 7<sup>th</sup> in 1975. I studied at an ordinary school in the city of Osh. In 1991, December 11<sup>th</sup> I was in a car accident. As a result, I acquired physical disabilities and was granted the disability category of the first group. In 1998, I got married and shortly after that gave birth to a daughter. But my daughter had a congenital disability, a digestive tract (gastrointestinal tract), and lived for a very short time before passing away.

In 2000, I had a son. However, I broke up with my husband and began to "look for" myself. After a very long period and many attempts to get a job, in 2005, I finally found a job. I began to work at an ice cream shop. Then I opened a small business and sold household goods and consumer goods, such as matches, cigarettes, seeds, sweets and so on.

In 2010, I was invited to work as an operator at the social taxi of an organization called "Smail. Kg". This was part of the project, "The World Outside the Window". And from that time onwards, my career started to fly. In early 2011, I became the head of the club "Integration" for young people with disabilities. In November of the same year, I went to Japan on the program "Integration and empowerment of persons with disabilities in Central Asia" of JICA with the financial support of the Ministry of Finance of the Kyrgyz Republic.

Having received a lot of positive and productive knowledge, in August 2012, I legally registered the organization of persons with disabilities, "Integration". Since that time, I became the director of the organization. I began to plan projects and write project proposals. Our first project was supported by an organization of persons with disabilities called "Equality". Subsequently we won project funding from Abilis Foundation with the project entitled "Women's Initiatives for Peace". We taught young persons with disabilities, human rights, computer literacy and writing and implementing project proposals.

I'm constantly learning at training and seminars. I raise my level of knowledge and share my knowledge with others. However, sometimes it seems to me that my level of

knowledge is very limited, and I need to constantly gain new skills and knowledge. It would then be a true success when I share the knowledge with others!

#### 4.1.3. Life Story of Ukei Muratalieva



What is success? To be honest, all success stories scare me because success is an axiom. Traditionally, success is attributed to a man in Kyrgyzstan.

But all the same, there are women who achieve their goals. The truth is that you, as a woman, will have to constantly prove and prove what in general you can and how.

Naturally, no matter what gender identity you have, you need to show your quality, will and diligence. But that's not all. It is necessary to have a serious reserve of intellectual and business qualities to be able to build something without outside help.

When I say intellectual opportunities, I mean that it is necessary to progress in a concrete situation, to study, and to know. Especially when it comes to business, all the qualities that are listed above are actually attributed to masculinity in my opinion.

I studied to some extent. By the way, I went to school with difficulties. The aspirations of my mother, Ziynagul, helped me to get admissions. Perhaps today's presents would be different. Mathematics was difficult. So were chemistry and physics. I was good in the lessons of literature and history. I liked painting and drawing because it was my dream to become an artist. I love beautiful things and graphic drawings especially. My five years in the university was not very easy and interesting. I have followed my heart based on my own feeling of love and decided what to do with whom. If you cannot love something, it's rather a clear sign to look for your own way.

When you feel that something is going wrong, yes, really, there are days, weeks and months, when it seems like everything is wrong. No, you do not need to kill yourself. You do not need to blame your fate either. You just need to breathe. Do not worry. It

will not be worse, if you have reached the bottom. In fact, congratulations. After all, the time has come for you to go to the surface.

It goes the same in business. All of these are our dreams of work, fashion and much more. Once it seemed to us that those were not attainable and not possible. When we opened our organization of persons with disabilities, we felt absolutely helpless. It seemed to us that our capabilities were not enough to open an organization and work. There were people and organizations that supported, believed in and guided us. All what we have today is because once in our life there were people who believed in us and supported us in our endeavours.

When we just started sewing our ecological bags, it seemed to us that people did not need us. We wondered how to compete in the competitive world. And what did we do in the end? We began to try, endlessly to experiment. It does not matter what happens tomorrow. What is important is what we are doing now. Every detail of the colour and texture is chosen with feelings.

Yes, there were times when it seemed that all of this was nonsense. It was not true. We attach the taste and joy of life to ourselves. Today we have expanded our capabilities through the work we do. We continue to try, develop, study and expand. Do you remember how it all began? It all began with dreams.

#### 4.1.4. Life Story of Aigul Mitalipova



I am Aigul Mitalipova, 36 years old. I am the director of the organization, Biz Bizgebiz Osh. Together with Altynbek Nurbayev, we founded the organisation in October 15th 2016. Leaders of similar organizations of people with disabilities supported us to establish our organisation in Osh. Altynbek was appointed as the founder and I became the director of the organisation.

I lead all organizational and reporting activities. We were supported to visit Bishkek. We organised concerts. We also took part in seminars and trainings on the protection of the rights of people with disabilities.

We, unfortunately, do not have an office space. If we had an office, we would invite all people with disabilities to talk with their parents and relatives, so that they would integrate the member of the family with disabilities into society. Often family members are ashamed of their children with disabilities. Sometimes they are subjected to domestic violence, and in fact people with disabilities have feelings that they cannot always express themselves. We would also like to organize for our female members, who are half of the members, to engage in needlework and small businesses. Of course, like many citizens our members need housing.

When I was 19 years old, I had an accident. I was involved in a car accident. It was not only strong physical pain, but also spiritual because I felt that all of my dreams were broken at once. At that time I was a second-year student of the medical faculty of a university. For 12 years I did not go anywhere, because I was ashamed to go out into the street, and into society as a whole.

At the age of 32, I was taken on as a cashier in one of the supermarkets in Jalal-Abad. It was a new turning point, a new beginning. I began to feel the pulse of life again. I met many good people who accepted me as an equal member. In early 2016, I settled down in Osh city and started working at the passport office. This work was within the framework of a project providing temporary work for people with disabilities. For the first time in my life, I received a high salary of 20 thousand soms. I was very happy. Now I am engaged in the affairs of the organization. Recently the teachers of Osh State University said that I will be a good psychologist, after listening to my guest lecture to them in the framework for EU Social Protection System Programme. They encouraged me. Next year I will try to become a psychologist.

- After reading the four life stories, the trainees can discuss the similarities and differences between the lives of persons with and without disabilities.
- For advanced trainees, they can further analyse why there are different impacts on the lives of persons with and without disabilities based on the learnings of Lessons 1-3.

## **4.2. Roles of Organizations of Persons with Disabilities**

Persons with disabilities have many different identities depending on the context where they are located. Sometimes they are mothers, and other times they are teachers, for

instance. Therefore, they do not necessarily feel that they are persons with disabilities depending on different situations.

When they feel that they are persons with disabilities? That is, when they feel the identity as persons with disabilities? It is often when they are treated differently from peers without a disability. For instance, when siblings without a disability go to schools, while a child with a disability from the same family is not sent to school, this child most likely feels that s/he is different from other siblings through her personal experiences. Such personal feelings and experiences often remain personal when s/he is isolated. This was studied on the first day in Lesson 1 when we studied the vicious circle.

- The teacher can go back to the picture of the vicious circle again and recap.

This personal tragedy discourse changes when s/he meets another person in a similar or same situation. When they meet each other and share their personal experiences among them, they often realise that they are not alone. The collective experiences gradually make them realise that it is not the personal tragedy but more structural and systematic mechanism that is against them to be treated on an equal basis with others without a disability. When there are several people with similar discrimination experiences, they start to form their own groups and organizations. Sometimes the aim is peer-support and psychological empowerment, other times it is to conduct some activities together. When the groups and organizations start aiming towards changing a discriminating society with some activities, they grow into a disability and/or other social movement. This is how social movement theory proceeds when it is applied to the context of persons with disabilities. Groups and organizations of persons with disabilities play different roles in the lives of persons with disabilities.

- Please read the following two more life stories that highlight the roles of DPOs.

#### 4.2.1. Life Story of Seinep Dyikanbaeva



My name is Seinep and I was born and raised in Bishkek, Kyrgyzstan. I have a good family, my family, especially my mother Tamara, accept me as a person and not a disabled. Therefore, my life is full and interesting as human life with goodness, challenges,

happy times, problems and positive contents. I am human and I do live a normal human life. It is interesting... So, let us get started....

When I was born in post-Soviet Kyrgyzstan, my mom was doing great things with medical and social integration. I grew up watching her help others and I saw children with disabilities as people.

When I was five years old, I said to my mom, "I see many children with disabilities and they are so isolated. There is no joy in their life...they have no access to education and services." I said, "They are constantly neglected by others, and I want to change this!" My mother said, "If my daughter thinks about these options, why am I not doing something more about this?" She then decided to start an organization for people with disabilities. My mom hoped to start in 1992, but parents were not sure about how NGOs could protect the right of children with disabilities. There is a complex relation between the state bodies and parents who have children with disabilities.

During the time when I was 6-8 years old, I studied at "Umut—Nadejda" that provides great support to children with disabilities, especially children with multiple disabilities. I am very thankful to Rehabilitation Center of "Umut – Nadejda" for that time of my life. That aimed to take the next step—we had a big wish to improve the situation around disability issues and involve families, people, and the state to solve problems. We wanted to carry out many activities to empower persons with disabilities and their voice in Kyrgyzstan—like the national parental network "Janyryk", which we later created in 2012. There is now a network of colleagues working on disability issues.

A few years later in 1995, the organization was founded and registered under The Association of Parents of Disabled Children (APDC). From February 28 2017 it was renamed, "The Public organization of Parents of Children with Disabilities (ARDI)". From this time, it was started without financial support and resources. The Rehabilitation Center of "Umut—Nadejda" was the other main organization for people with disability, and they had been working for 25 years, even during the Soviet period.

When we first started, it was very difficult because we did not have any information—we had no internet connection and consequently no resources. We started working with parents and supporting them through psychological consultations, even though this was limited as well.

Today, there are many organizations using our experiences and information to work in this field. We are able to share the idea that people with disabilities have the same rights as any other citizens.

I never saw another person with a disability in public places when I was a child. I spent a lot of time alone. There was a huge lack of accessibility in public places. Now the situation is better, but when I was a child, I only ever saw other children with disabilities when I went to the Rehabilitation Center of "Umut – Nadejda".

Today, I see people with disabilities openly and it is not just because of our organization's success, but of everyday people who are trying to do something about this issue. I believe that the situation is improving. Now everyone says that we all have the same rights. For instance, we had a project on [inclusive education](#) where we went to different schools and talked to children. We asked them what their thoughts on people with disabilities were. In the earlier years, we usually had negative responses, but now the children were saying that they wanted to help and support people with disabilities.

Getting an education was difficult. As a child with a disability myself, trying to go to an ordinary school was almost impossible. Along with having a disability, I was older than my classmates. Normally you start at seven and I started at ten, so they wanted to put me in a different program. They said that I could only get home education, which was insufficient because my level was much higher than what the teacher was teaching me. My teacher told me that she would testify for me to get higher education so I could go to high school. I was finally able to get into ordinary school and the first month was very difficult for me, but because my teacher and classmates were so supportive, I was able to catch up quickly.

Moreover, I am full of thanks to the teachers and professors in the Rehabilitation Center of "Umut – Nadejda", comprehensive school #27, Bishkek Humanitarian University and American University of Central Asia (AUCA) that helped me to get a good education.

Additionally, I am inspired by people's success stories. I like being able to talk about more than just the problem—I like talking about the ways in which to solve the problem. And when I listen to my friend's stories about how they got married, especially girls because it is much harder for them to create families, it makes me really happy.

I am also inspired by the success of people's professional lives—I listen to these stories and then share them with everybody back home! One of the most incredibly inspiring people is Kalle Könkköla, leader of the Abilis Foundation and Threshold organization in Finland. He was the first person who saw my leadership skills and he is the director of a documentary film entitled "Seinap's Songs."

Currently I work for "Ravenstvo" as the coordinator of the Central Asian network of women with disabilities and work as the public councillor of the Minister of Education and Science in the Kyrgyz Republic.

Honestly, in my life I have met so many wonderful people in my motherland and other countries. I am pleased that I have graduated in 2012 with a Bachelor's Degree in Law of the American University of Central Asia (AUCA) and have advancements in my job and life. However, it is not nice to tell about one's own success stories. Therefore, I would like to just say that I am full of thanks to my God that my life story can become a motivation and useful for someone else.

If you want to know more about me and my activities in "ARDI" please visit <http://ardi.kg/> and my public work is on rights of children and people with disabilities see

<https://www.facebook.com/seinepdyikanbaeva> there publicly access [news](#), events and other related information about people with disabilities and current activities and in the [book](#) Our Time Is Now by Shelia Kinkade, Paperback – November 1, 2005.

#### 4.2.2. Life Story of Gulmira Kazakunova



I am Gulmira Kazakunova, currently the head of the Public Association "Union of Disabled Issyk-Kul region "Equality".

At the age of 18 years old, I was kidnapped for a marriage. At the age of 19, as a second year student of a medical institution, I was completely paralyzed. I could not move my legs, hands, and head. For six months, I was hospitalized and could not move at all. By that time I was expecting a baby. A month later my daughter was due to be born. Unfortunately she died two days after the caesarean delivery. It seemed that my life was over. I did not go out for six years.

But after a few years I met people who had a disability and helped others and began to quietly go out onto the street. I was re-admitted to continue my studies, as by that time I already could move with the help of a cane. When I graduated from the medical institution, I entered into a university and started studying at the medical department.

I also began to work in an organization of people with disabilities. In 2000 I was invited by Save the Children UK to play the role of a field researcher in its project, "Access of disabled children to social services in the Issyk-Kul region". I saw that in the regions people with disabilities face many problems and there are no organizations supporting them.

In 2004, I left Bishkek for the city of Karakol, where I did not know anyone. I met people with disabilities, set up an initiative group and then registered an organization.

Since then, 13 years have passed. Over the years we have achieved a lot, though, of course, there have been mistakes and failures. But the main thing is that we speak for our rights as one voice.

In 2010, our organization became a partner of the Finnish foundation, Abilis Foundation. We often talk about the problems, difficulties and challenges faced by persons with disabilities. Unfortunately, the society has not yet noticed the contribution that they can make for the development of the country, so that our country becomes a country of equal rights and opportunities.

For my work, I often travel around the regions of our country, and I see and face people with disabilities who are trying to restore and realize their civil rights. They create organizations, enterprises, and workplaces. Some are also engaged in private entrepreneurship and try to escape from a difficult life situation with dignity.

Today, people with disabilities try to exercise their rights, from free movement to access to education, medical services, employment, etc.

Today, people with disabilities will organize training courses on their own in various professions, create social enterprises that generate income, create children's habilitation and rehabilitation centres, and incorporate "special" classes into mainstream schools.

In 2009, our NGO "Equality" started an income generating work in the form of a social taxi. The purpose of creating this service was to provide for persons with disabilities of the first category, such as wheelchair users and crutch users, affordable transportation services, because public transport is practically inaccessible for us. Girls with disabilities were employed as operators. At the moment, our taxi operates in the city of Karakol and is one of the city's leading taxis, as the operator's services are fully automated. This is just one example.

There are many such examples throughout the country:

- The Stimul Center implements a project to assist the employment of 20 young people with disabilities in the Leilek district.
- "Kolbaby" Public Foundation deals with the training and employment of mothers with children with disabilities.
- An NGO, "Dream Dream - Equal Opportunity", employs people with disabilities in the "Bublik" coffee shop and in the confectionery shop.
- An NGO, "Women of Central Asia", trains girls with disabilities in sewing modern national clothes in Batken region.
- An NGO, "Nazik kyz", implements a number of projects like "Independent ladies", "Training girls with silk screening and employment", "Sewing ecological shoes and employment of girls with disabilities".
- An NGO, "Mumkunchuluk", is engaged in breeding chickens and selling eggs in the city of Naryn.

- An NGO, "Smile", conducts trainings on business planning for young people with disabilities at the age of 16 to 25 years.
- An NGO, "Umut Shamy", trains persons with disabilities, adolescents and young people with disabilities in culinary business in the city of Batken.
- An NGO, "Baldar Omur Bulagy", trains people with disabilities in beekeeping in the village of Tyup of Issyk-Kul oblast.

These are only small examples of what persons with disabilities do to live, work and be happy and give joy to others.

- The trainees are divided into small groups and discuss the following questions:
  - What are the roles played by DPOs? Why are DPOs needed?
  - How can social workers collaborate with DPOs?
- Each group makes a presentation on the discussion.