



Training course module

Introduction to Disability Studies: Social and human rights-based approaches to disability, empowerment and participation

5 credits for one-week-intensive-training

By Abilis Consulting

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INTRODUCTON

TO WHOM?

This module is primarily meant for the pre-service and in-service training of social workers, para-professionals, staff at rehabilitation centres, non-governmental organisations and international organizations who deal with social protection of the population.

A trainer on this topic can use this module for both beginners and advanced trainees. Some of the assignments have the marking of “advanced” for further challenging trainees on some issues more critically.

MAKING OF

The content was developed by the EU Social Protection System (EU-SPS) Programme through Abilis Consulting in close collaboration with the Kyrgyz Ministry of Labour and Social Development and social work university lecturers in Bishkek and Osh.

The EU-SPS, led by the Finnish National Institute of Health and Welfare, together with OECD Development Centre, supports eleven developing partner country governments and national expert institutions in their efforts to develop inclusive and sustainable social

protection systems in close co-ordination with other international partners. In Kyrgyzstan, the EU-SPS capacity development work is implemented between 2017 and 2018.

During the first phase of EU-SPS work in Kyrgyzstan in early 2017, the social work discipline curricula of Kyrgyz universities at the Bishkek University of Humanities and Osh State University were analysed by Professor Marjo Kuronen, the chairperson of the Finnish National University Network for Social Work. Based on the professional analysis and recommendations and the teaching module of Dr. Hisayo Katsui, who is a university lecturer in disability studies at Helsinki University, the trainings of trainers (ToTs) were planned and implemented with local disability experts such as Seinep Dyikanbaeva, Marina Fegele, Tolkunbek Isakov, Gulmira Kazakunova, Aigul Mitalipova, and Ukei Muratalieva.

The first ToT was held between 2nd and 6th October 2017 in Bishkek University of Humanities with its lecturers. The second ToT was held between 9th and 13th October 2017 in Osh State University with university lecturers from four Osh-based universities. The aforementioned local disability experts with disabilities were invited as guest lecturers. The one-week-intensive ToTs in Bishkek and Osh included an interactive discussion on the context-specific needs of Kyrgyzstan in realizing disability rights. The identified needs are incorporated into this module.

PRACTICAL TIPS

The module has many practical tips for the teachers.

- The tips are mentioned after this sign.

The module includes recommendations to invite local guest lecturers with disabilities who have experiential knowledge on some specific issues. The list of organizations of persons with disabilities (DPOs) will help the course organizer in identifying suitable guest lecturers for the teaching course. Similarly, some video links are recommended to show to the trainees.

Some of the tips are meant for advanced trainees.

CONTACT OF THE AUTHORS

If you have any question, please turn to Dr. Gulmira Kazakunova (ravenstvo-ik@mail.ru) in Kyrgyz and Russian, or Dr. Hisayo Katsui (hisayo.katsui@helsinki.fi) in English.

Dr. Katsui conducted her PhD study (2000-2004) on the disability movement in Central Asian countries including Kyrgyzstan and an evaluation study on the development cooperation projects of Threshold Association in Central Asia, especially in Kyrgyzstan and Kazakhstan in 2008. She has also closely followed the development of disability rights promotion in Central Asia through Abilis Foundation work as Research and Development Manager since 2012. She has a good number of academic publications on

the disability situation in Central Asia. Katsui is Adjunct Professor in Disability Studies at the University of Helsinki.

Dr. Kazakunova is Executive Director of Public Association Ravenstvo, a Kyrgyz organization of persons with disabilities. She is a medical doctor by profession. She has extensive knowledge on disability rights in the local context and valuable relationships with high-level-government officials in line Ministries and local stakeholders. She has a highly respected position in Kyrgyzstan. She is a wheelchair user.

CONTENT

Lesson 1: Introduction to Disability Studies

Lesson 2: Frameworks of Disabilities

Lesson 3: Disabilities in Practice in Kyrgyzstan

Lesson 4: Participation and Empowerment of Persons with Disabilities

Lesson 5: Independent Living

Attachments

- Video Links
- List of DPOs and Their Contact Information
- Evaluation Survey

LESSON 1

INTRODUCTION TO DISABILITY STUDIES

This lesson is dedicated to the very first introduction to disability studies, focusing on social and human rights-based approaches to disability, empowerment and participation.

Things to prepare:

- A flip chart paper
- Papers and pens for trainees

The Content of Lesson 1

- 1.1. Exercise 1: Disability Concept
- 1.2. Exercise 2: Disability Relevance
- 1.3. Global History of Disability Rights
- 1.4. Disability Studies and Different Approaches to Disabilities
- 1.5. Exercise 3: Life Game
- 1.6. Discussion on Discrimination and Vicious Cycle

1.1. Exercise 1. Disability Concept

First of all, trainees are asked the following question: **Which words you think of when you hear “disability”?**

Task 1.1. Individual work

Trainees are asked to write down all the words that come to their mind when they hear the words “disability” or “disabilities”. A few minutes are given until they exhaust their ideas.

Task 1.2. Small group work

Subsequently, trainees are asked to form a small group to discuss what were common and what were different among them.

Task 1.3. Discussion of the whole group

The teacher asks trainees what kinds of words came to their mind and writes them down on the flip chart paper.

- A paper is better than a blackboard, as this will be used once again at the end of the module. (If a blackboard is used, do not forget to take a photo of it to record the answers of the trainees.)
- The teacher can first ask what were common words in the small groups. Then the teacher can ask what were different. It is usually easier to express what are common.
- When the words are presented and written on the flip chart paper, the teacher informs the trainees that these words represent different ways of approaching disabilities that we are going to study today.
- The teacher can also inform them that this is the starting point before taking this course. After this course, their perception about disability will change. The change will be clear when the teacher will ask the same question after the course and compare the answers before and after the course. The teacher therefore asks each trainee to keep the piece of paper to be able to compare their development at the end of the course.

1.2. Exercise 2. Disability Relevance

Trainees are asked the following question: **Why is disability relevant to you?**

Task 2.1. Individual work

Trainees are asked to write onto their own papers why disability is relevant to them.

Task 2.2. Small group work

Subsequently, trainees are asked to form a small group of a few persons to discuss what were common and what were different among them.

Task 2.3. Discussion of the whole group

The teacher asks the trainees to present their ideas and writes them down on the flip chart paper.

- At this stage, many might think that disability is relevant to them because of the social work profession that they are/will be engaged in, as persons with disabilities are one of the targeted groups for social work services in the country.
- The teacher can explain an analogy of gender equality. The teacher can ask from the trainees what is needed when men and women are culturally and socially treated differently and they have gendered roles which hinder women from becoming more active part of society. The teacher asks if empowering women is enough and discloses that it is not enough if men do not change. Both concerned

and marginalized group of people and the people around them have to change to realise the gender equality. Likewise, disability-related equality between persons with and without disabilities is similar to gender equality. If persons with disabilities get special services and supports, that is not enough, when the society does not change. This is one of the reasons why you, as current or future social workers, are relevant to disability discourse as an integral part of making the change.

- Also the teacher informs the trainees that 1 out of 7, that is 15%, of the population are persons with disabilities.¹ If family members are included, those who are directly affected by disabilities are easily half of the population.
- Likewise, the aging population of the world has brought the issue of disability close and relevant to everybody as when one gets old, s/he usually acquires some disability.
- Accidents, natural disasters and man-made disasters are also other typical ways of acquiring disability, which is relevant to anybody.
- The teacher can conclude by saying that there are many relevant points to all of us to disabilities. This understanding of disability is important for the trainees to motivate them to study disabilities during this course.

1.3. Global History of Disability Rights

The historical development of disability rights is the next topic, as understanding of the history makes the trainees comprehend changes in the definition of disabilities over time and current approaches to disabilities much easier.

1948	The Universal Declaration of Human Rights
1975	Declaration on the Rights of Disabled Persons
1981	International Year of Disabled People
1982	World Programme of Action Concerning Disabled People
1983-92	UN Decade of Disabled People
1993-02	Asia and Pacific Decade of Disabled Persons (2003- Second decade; 2013- Third decade)
1993	UN Standard Rules on Equalization of Opportunities for Persons with Disabilities
2000-09	African Decade of Disabled Persons (2010- Second decade)
2003-12	Arabic Decade of Disabled Persons
2006	UN Convention on the Rights of Persons with Disabilities
2013	UN High-level Meeting on Disability and Development
2015	New Sustainable Development Goals

¹ WHO and World Bank. (2011) Global Report on Disability. WHO. Geneva.

The UN has adopted various international conventions and rules that are to promote the equal rights and opportunities of persons with disabilities during these years starting from The Universal Declaration of Human Rights in 1948.

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

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non- self-governing or under any other limitation of sovereignty.²

In this Declaration, persons with disabilities are not explicitly mentioned in any Article, except for Article 25:

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

Nevertheless, the words such as “all human beings” and “everyone” could be interpreted to include disabled people as “other status”. That is, at this point, disability was not highly recognised as being a significant minority yet. Similarly, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights, adopted in 1966, did not have any articulated statement on persons with disabilities, except for the expected connotation in “everyone.”

Disability came into the mainstream with the Declaration on the Rights of Disabled Persons in 1975 and with the UN International Year of Disabled Persons in 1981. In the following year, the World Programme of Action Concerning Disabled People was published. This Programme set “the guidelines for a world strategy to promote the adoption of effective measures for the prevention of disability, rehabilitation and the achievement of ‘equality’ and ‘full participation’ of disabled persons in social life and development.”

The World Health Organisation (WHO) made a distinction between impairment, disability and handicap in 1970s, which was included in the World Programme of Action:

² United Nations. (1948) Universal Declaration of Human Rights. Available at <http://www.un.org/en/universal-declaration-human-rights/> Accessed on 27.11.2017.

Impairment: Any loss or abnormality of psychological, physiological, or anatomical structure of function.

Disability: Any restriction or lack (resulting from an impairment) [sic] of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap: A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal, depending on age, sex, social and cultural factors, for that individual.³

In this way, handicap is considered to arise as a direct consequence of individual impairment in this model.⁴ Therefore, this classification leads to medical and administrative solutions of the cure or rehabilitation of persons with disabilities from the viewpoint of scientific authenticity. This International Classification of Impairment, Disability and Handicap (ICIDH) had been the predominant definition of these terminologies until very recently. ICIDH has been named **medical model of disability** in disability studies due to its medically-oriented understanding of disability.

In spite of the mainstreaming of disability in international policies, persons with disabilities were not satisfied with this international trend. **Persons with disabilities started to organise themselves in 1960s and 1970s.** This coincides with the time when other social movements were created to pay attention to differences and vulnerable minority groups. The disability movement was one of these such social movements to seek equal rights with others.

Some activists with disabilities started to argue that they need much more than the medical 'facts' in order to understand disability as a collective experience in society which goes beyond the existence or experience of individual persons with disabilities. Accordingly, persons with disabilities started to assert their own needs by establishing organisations of persons with disabilities which enable the collective voice of persons with disabilities to be heard. The tension between persons with and without disabilities became decisive in the International Year of Disabled People in 1981. A number of persons without a disability had an agenda of their interests, such as residential care, which was clearly different from the expectation of persons with disabilities. Therefore, some persons with disabilities started to focus on their own and real problems apart from the mainstream events, while persons without a disability were spending their time on "irrelevant" issues.⁵

Persons with disabilities stress that their experiences must be expressed in their words and integrated in the consciousness of mainstream society.⁶ In this way, the disability movement was concerned to alter this medical conception and to empower persons with disabilities with the global slogan of "**Nothing about us, without us**". In its process,

³ Despouy, L. (1993) Human Rights and Disabled Persons. New York. United Nations.

⁴ Oliver, M. (1990) The Politics of Disablement. Macmillan. London.

⁵ Hasler, F. (1993) "Development in the Disabled People's Movement." In Swain, J., Finkelstein, V., French, S. and Oliver, M. (eds.). Disabling Barriers-Enabling Environments. SAGE Publications. London. P.278-284.

⁶ Morris, J. (1991) Pride against Prejudice. The Women's Press. London.

social model of disability was formed which challenges the very assumption of "normality" and re-defines disability as social oppression.⁷ The comparison of ICIDH and the following definition clarifies the difference between these two models. The Physically Impaired against Segregation and Disabled People's International defined:

Impairment: *the lack of part or all of a limb, or having a defective limb, organ or mechanism of the body.*

Disability: *the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers.*⁸

With the great efforts of the global disability movement and participation of a number of representatives of persons with disabilities from around the world, the United Nations adopted the Convention on the Rights of Persons with Disabilities in 2006, which entered into force in 2008. This Convention, which is a legally binding instrument when ratified, has brought several added values to the discourse of disability rights. First of all, the making of the Convention was an empowerment process in itself participated in by a large number of persons with disabilities. This has brought visibility of disability into the discourse of human rights and that of development. Secondly, the Convention has set clear definitions and general principles, such as disability, non-discrimination and reasonable accommodation, that broadened the human rights agenda not only restricted to state-individual relationship but also to inter-personal relationships. Disability has clearly entered into the mainstream discourse of both human rights and development. As a result, a human rights-based approach to disability has been promoted. Thirdly, procedural advances are made in the Convention with a clear national monitoring framework for implementation involving organizations of persons with disabilities.

⁷ French, S. (1994) "What is Disability?" In S. French (ed.). On Equal Terms. Butterworth-Heinemann Ltd. Oxford. P. 3-16.

⁸ Finkelstein, V. and French, S. (1993) "Towards a Psychology of Disability." In Swain, J., Finkelstein, V., French, S. and Oliver, M. (eds.). Disabling Barriers- Enabling Environments. SAGE Publications. London. P.28.

In the Convention, the key concepts are defined as follows:

“Disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.”

“Discrimination on the basis of disability as any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including a denial of reasonable accommodation.”

Reasonable accommodation means “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.”

In 2013, for the first time in UN history, the UN General Assembly focused on disability and development at the High-level Meeting on Disability and Development, where heads of states made further promises of their commitment to the realization of disability rights in their respective contexts. The Outcome Document of the High-level Meeting facilitated the inclusion of disability into the Sustainable Development Goals (SDGs) adopted by the member states of the UN couple years later in September 2015. Clear references to disability and also to vulnerable people were made in the SDGs, unlike in the Millennium Development Goals preceding the SDGs, due to which many national and international efforts then did not pay much attention to the inclusion of persons with disabilities. Indeed, the SDGs have the slogan of “leaving no one behind” that finally and explicitly mainstream persons with disabilities to the discourse of global development.

1.4. Disability Studies and Different Approaches to Disabilities

Disability studies is a relatively newly established academic discipline and researched mostly in Social Sciences and Humanities. In disability studies, disability is examined as a social, cultural and political phenomenon. It is different from medical research on disability in Medical Science where disability is defined as an abnormal health condition that should be medically treated and rehabilitated.

In fact, there are many approaches to disabilities that represent different ideological backgrounds, in addition to aforementioned medical, social and human rights-based approaches to disabilities. The following table summarises the main different approaches to disabilities, that can be reflected with what words came to your mind in the first exercise.

Table 1. Different Approaches to Disabilities⁹

Model/Approach	Cause	Solution
Traditional	Misbehaviour of family or that of oneself in former life	Punishment/Guilt
Charity-based	Unmet needs	Provision
Medical	Impairment	Rehabilitation/Treatment
Religious	God's will	Acceptance
Social	Discriminating society	Social change
Political	Asymmetrical power	Participation
Human rights-based	Violation of rights	Human rights-oriented action

In the traditional approach, disability is understood to be caused by a misbehaviour of family or that of oneself in a former or present life. Therefore, the punishment of impairment was imposed and the person with a disability needs to feel guilty for the cause. This is still a very common approach around the world today.

In the charity-based approach to disability, disability is caused by unmet needs and persons with disabilities are often pitied. Therefore, meeting often material needs by some benevolent giver(s) is a solution for the challenges faced by persons with disabilities.

In the medical approach to disability, as has been already presented, impairment and medical diagnosis is the cause of problems. Therefore, medical treatment and rehabilitation is the solution to make persons with disabilities as "normal" as possible.

In the religious approach, it is the God's will that causes disabilities. Therefore, persons with disabilities need to accept all difficulties.

In the social approach, it is the oppressing and discriminating society that is the problem. Therefore, solution is to change the society to inclusive and barrier-free in both physical and attitudinal terms.

In the political approach, an asymmetrical power relationship between persons with and without disabilities is the cause of the reality. Therefore, it is solved by more participation and the political power of persons with disabilities.

In the human rights-based approach, violation of human rights is the cause for disability. The solution therefore is to achieve human rights through human rights sensitive means and actions.

⁹ Katsui, H. (2012) Disabilities, Human Rights and International Cooperation: Human Rights-Based Approach and Lived Experiences of Ugandan Women with Disabilities. VIKE. Helsinki. P.4.

- After the introduction of all the approaches, the teacher can go back to the flip chart paper where the answers to the first exercise question are written down so as to see which approaches are reflected in the answers. The teacher can summarize which approaches are most predominantly represented among the trainees.
- The teacher can ask the trainees which approaches are common in this country. The teacher can also ask the trainees if there are any combination of approaches in the country, as these approaches are not totally independent from and exclusive to each other.

1.5. Exercise 3. Life Game

Life Game

- 4 volunteers are asked to stand in line (or alternatively, four papers can be removed from on the wall). The four represent “man without a disability”, “man with a disability”, “woman without a disability”, and “woman with a disability”. Each volunteer holds a paper with one of the four group s/he is representing written down.
- Not the volunteers, but all trainees participate in deciding answers based on the realities in the country (not how it should be)
- One step forward for a positive answer to a question
- One step backward for a negative answer to a question

Question 1. One fine day, after a long wait of nine months, your character is born.

How does your family feel when they see who you are? Are they happy? Make your moves.

Question 2. Now you are a bit older, and it is time to start thinking about school. How likely is it that you will be able to attend school? Make your moves.

Question 3. Now you are 20 years old. You would like to get married, or form a relationship. How much do you think this will be possible for you? Make your moves.

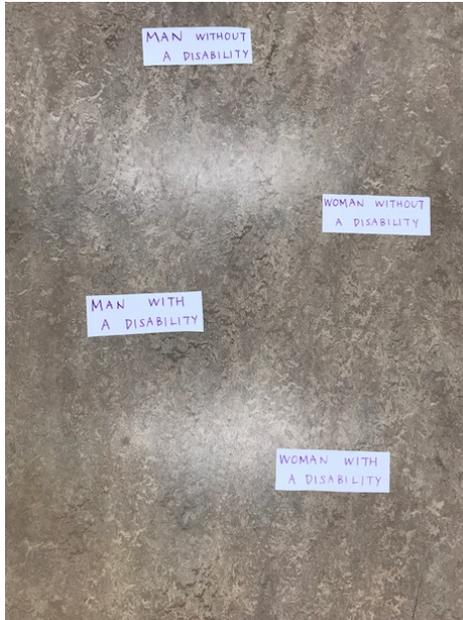
Question 4. You want to make some money. You try to get a job. How easy will it be for you to find one? Make your moves.

Question 5. Many in your age group are having babies. How much will this be a possibility for you? Make your moves.

Question 6. Now you are in your 40s and you have a lot of experience of life.

You want to help your community by becoming involved in local politics. How likely are you to achieve this goal? Make your moves.

Picture 1. A Result Example of the Life Game Exercise



- The teacher encourages trainees to discuss each case for each question, rather than make them reach an easy consensus, if there are different opinions. In case opinions are divided, the teacher can be creative in making the move by moving it forward only half a step or remain in the same position when both alternatives are strongly possible under different circumstances. The idea of this life game is not to generalize all men with disabilities as homogenous groups, for instance. Therefore, the discussion is vital in understanding heterogeneity and diversity among men with disabilities, for instance, and among all the groups.
- The Life Game is also not to reinforce the understanding that everyone has to get married, have children and so forth. Life is very different for each other, regardless of the culturally understood life cycle where people are expected to play certain roles. This critical view should also be introduced to the trainees.
- After the last question, gaps among the four groups are usually very obvious. Very often, the man without a disability tends to move far ahead, which is followed by the woman without a disability and man with a disability. The woman with a disability tends to lag far behind all the other three groups. With this result, trainees visually see the gaps of opportunities available to different groups. The teacher then problematizes this phenomenon that different groups cannot enjoy equal opportunities.
- At the same time, the question can be posed to the trainees that they have certain stereotypes for different groups of people, as has become clear from the result of

the Life Game. For instance, trainees might have less expectations of persons with disabilities to fulfil their potential and opportunities.

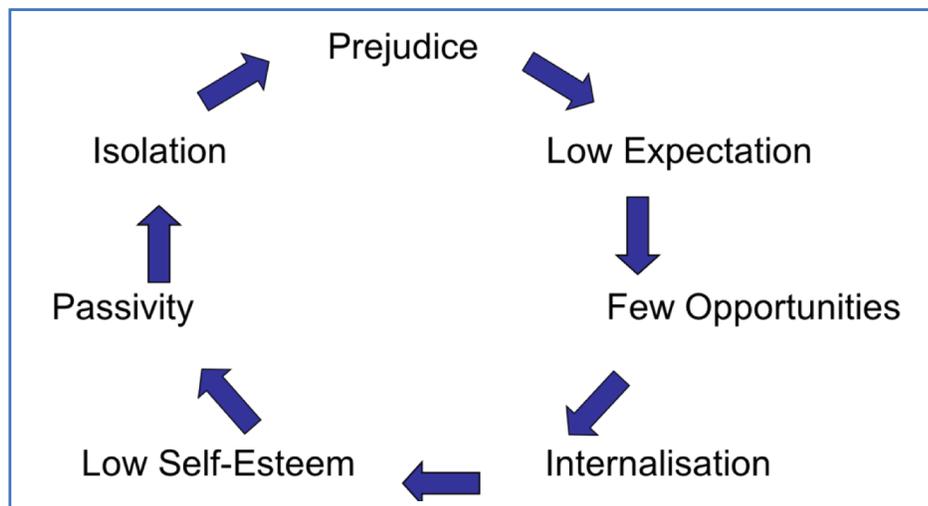
1.6. Discussion on Discrimination

After the Life Game, it is easy to move onto the discussion on discrimination.

- The teacher can ask the trainees how discrimination is manifested in the country and why. It is useful and helpful, if the teacher can connect their answers to the aforementioned different approaches to disabilities.

After the discussion, the teacher can present the following vicious circle experienced and observed in Central Asian countries.

Picture 2. Vicious Circle¹⁰



People in society often have a prejudice against persons with disabilities, which leads to a low expectation to them. When expectation is low, persons with disabilities have fewer opportunities, for instance for continuing their studies or having relationship. When opportunities are limited, especially compared with siblings without a disability and/or peers without a disability, persons with disabilities start internalizing the negative image that society has on them and start thinking that the problem comes from oneself. Their self-esteem, therefore, is low, which makes them passive and for instance to rather stay at home than to encounter prejudice and discrimination in society. They often become very isolated, which leads to a prejudice of people in society. The vicious circle goes around and around to reinforce the status quo where persons with disabilities are

¹⁰ Katsui, H. (2005) Towards Equality: Creation of the Disability Movement in Central Asia. Helsinki University Press. Helsinki. P.90.

discriminated against. At some stages of this circle, intervention has to be made to make positive changes.

- The teacher can ask the trainees what they can do to change this reality as social workers.

The Convention stipulates that discrimination on the basis of disability includes denial of reasonable accommodation. **Reasonable accommodation** can be explained in the following picture. When the height of three girls are different, reasonable accommodation to watch something together is to provide them with different boxes to stand on, so that all can watch it on an equal basis with each other (on the right side of the picture). When the same boxes are provided to all whose height are different, it is not fair for the smaller ones, as they might not be able to watch it.

- The teacher can put this into a context of inclusive education, for instance. When a child with a disability is physically placed in a school without any reasonable accommodation, that is a violation of human rights, as s/he might have some educational needs that should be accommodated.
- The teacher can ask the trainees to think of what kinds of reasonable accommodation can be provided to persons with disabilities in their work. They (metaphorically the boxes) can be assistive devices for persons with physical disabilities, sign language interpreters for Deaf persons, personal assistants to blind persons and so forth. This point of reasonable accommodation needs to be understood properly through solid discussion.

Picture 2. Reasonable Accommodation

