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## Changing the paradigm of disability from stigma to equity in university social work education in Kyrgyzstan

Hisayo Katsui, Gulmira Kazakunova and Mina Mojtahedi

### **Abstract**

The main aim of this paper is to tease out the historical and deeply rooted ethical standards, spirituality and social values that have long supported the social service system in Kyrgyzstan, which, today, faces pressure to align with the United Nations Convention on the Rights of Persons with Disabilities. The data is based on an intervention conducted as part of the EU-Social Protection Systems Programme (EU-SPS) in Kyrgyzstan between 2017-2018 where 30 university lecturers were part of. Interviews both to the Kyrgyz trainers with disabilities and trainees of the university lecturers as well as follow-up survey conducted in 2019 form important part of data for this paper. We firstly investigate the conventional ethical standards, spiritual explanations and social values related to disabilities within the Kyrgyz social protection system and social services. We elaborate on the Kyrgyz context of the societal ethics, spirituality and values around disability in the Kyrgyz university education for social workers. Secondly, we analyse the transformation of the perception of disability among the university lecturers. We conclude this paper with a discussion on the negotiation between a charity-based approach that reinforces the stigmatization of disability and a human rights-based approach that promotes paradigm change, to contribute to global discourse of social change towards disability inclusion.

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### **Introduction**

Discourse on disability in many parts of the world, especially in the global North, has been historically predominated by a medical approach where persons with disabilities are considered abnormal or deviant, and/or they have been marginalized (Oliver, 1990). With such a reductionist approach, persons with disabilities have been stigmatized (Goffman, 1963, 2017) due to the difference in social contexts (Coleman-Brown, 2017), and opportunities for people with disabilities to participate in society are limited compared with peers without a disability (WHO and World Bank, 2011). A relatively new academic discipline, Disability Studies, has

been established by the disability rights movement. This introduced an alternative understanding of disability, namely the social model of disability (Oliver, 1990; Finkelstein and French, 1993 etc.). This social approach gradually changed the paradigm to one in which the oppression of society is seen as the problem rather than the individual with a disability (e.g. Barnes, 1991; Shakespeare, 2018). The approach has been developed in parallel with a human rights-based approach to disability (Katsui and Kumpuvuori, 2008). The latter approach is embodied in the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), of which the global disability movement played a large role in the development. In the human rights-based approach, human rights principles and ethical values such as participation, equality and non-discrimination, and self-determination are enshrined and central (Katsui, 2012). Although as many as 180 UN member states have ratified the CRPD today, full implementation is still not yet realized in these countries. The Kyrgyz government is one of the most recent countries to have ratified the CRPD. Nevertheless, Kyrgyzstan still has a strong legacy from the Soviet Union, which widely implemented a policy of segregating persons with disabilities from society.

The majority of research in the field of disability has been conducted in the context of the global North (Grech and Soldatic, 2016; Grech, 2011; Katsui, 2012). Bell (2017: 406) criticizes this phenomenon and labels it “white disability studies”. Although there is a growing body of literature investigating the historical, cultural and local context of disability in different geographic locations, as well as an increasing number of authors from the global South (e.g. Watermeyer et al., 2019) as well as global North authors writing in collaboration with authors from the global South (Grech and Soldatic, 2016; Chataika, 2018), there are still gaps in evidence from countries in the global South (Grech and Soldatic, 2016; Katsui, 2012). Thus, the understanding of disability and persons with disabilities is generalized to apply also to the Global South. Grech refers to this as “myths” (2011: 89), and more detailed accounts of disability in the Southern context are called for.

As for Kyrgyzstan, there is limited research investigating disability (Hallberg, 2016; Alybaeva, 2007; Katsui, 2005). Existing literature on disability primarily focuses on the social problems faced by persons with disabilities, such as segregation, education, employment and family. There is a paucity of literature on ethics and values related to disability in the provision of public service, particularly the social services sector, despite this being a sector that directly impacts the realization of rights of persons with disabilities. For example, social work – a discipline and profession that aims at enhancing the wellbeing of individuals – risks further marginalizing persons with disabilities if social work relies on a reductionist approach or as a

response to deficits rather than using a more holistic approach based on participation, social integration and equal citizenship (Hiranandani, 2005; French Gilson and DePoy, 2002; Meekosha and Dowse, 2007). Morgan (2012: 218) suggests that such a holistic approach, namely disability studies, is transformative in social work education by “evaluating the extent to which societal structures, processes and cultures are disabling and the identifying strategies to remove these barriers and promote more inclusive environments and practices”.

The main aim of this chapter is to tease out the historical and deeply rooted ethical standards, spirituality and social values that have long supported the social service system in Kyrgyzstan, which, today, faces pressure to align with the Convention. This chapter focuses on social work as an example of public service where ethical standards and social values are of utmost importance for ensuring the equity of persons with disabilities. The data is based on an intervention conducted as part of the EU Social Protection Systems Programme (EU-SPS) in Kyrgyzstan between 2017 and 2018 and its follow-up survey. Thirty university lecturers participated in two or three trainings in the framework of the programme and provided feedback after each training. Six persons with disabilities, who are representatives of cross-disability organizations of persons with disabilities, were recruited to be trainers. These trainers were interviewed both individually and in a group, and they completed feedback surveys during the course of the programme. The interviews were held a few times per trainer with a disability between these trainings, often in the evenings or in the mornings, to reflect upon their learnings, learnings of the university lecturers, and perceptions on disabilities. They took between 30 minutes and one hour. In addition, a follow-up, anonymous survey was completed by the university lecturers during the summer of 2019 in order to collect more information on spirituality, ethical standards and social values. Ten participants completed the survey. These data were analysed with thematic content analysis technique to highlight and support some of the arguments in this chapter.

This chapter first investigates the conventional ethical standards, spiritual explanations and social values related to disabilities within the Kyrgyz social protection system and social services. We elaborate on the Kyrgyz context of the societal ethics, spirituality and values around disability in the Kyrgyz university education for social workers. Second, we analyse the transformation of the perception of disability among the university lecturers. We conclude this chapter with a discussion on the negotiation between a charity-based approach that reinforces the stigmatization of disability and a human rights-based approach that promotes paradigm change, and try to present implications of the study beyond Kyrgyzstan and common Kyrgyz practices.

## **The Kyrgyz context: Understanding disability through spirituality and the Soviet legacy in Kyrgyzstan**

Kyrgyzstan is an interesting country where social customs reflect an intersection of Islamic and Soviet influences. This section of the article analyses the spiritual influences, which are largely from the Islamic religion. Most of the population is Muslim, although Islam is not a national religion in Kyrgyzstan. Most of the research participants mentioned the impact of the Islamic religion on their understanding of disability and their behaviour towards persons with disabilities. Research participants 7, 8 and 9 mention that disability is considered the result of sin committed by the person with a disability, their parents and/or relatives, and, thus, a form of curse or punishment by God. Persons with disabilities are pitied (research participant 6), which is manifested in charity and donations by people without a disability to persons with disabilities. This is viewed as a virtue in their religion (research participants 5, 6, 7, 9, 10). In this spiritual understanding of disability, persons with disabilities are positioned as a hierarchically lower group of people than others in society and as objects of charity.

When it comes to the Soviet influence on the conceptualization of disability, the following interview statement exemplifies the extent to which it has affected persons with disabilities.

The USSR didn't respect the law or the rights of people. People were not the central focus then. For instance, the International Year of Disabled People of the United Nations was not publicized but was covered up in the Soviet Union. Instead we were told, "There are no disabled people"; "There is no problem".

(Uzbek person with disability E in an urban area, cited in [Katsui, 2005](#): 43)

Of course, this does not literally mean that there were no persons with a disability in the former Soviet Union. But rather, it means that persons with disabilities were excluded in the Soviet ideology and thus had no place in society. There were a few exceptions among persons with disabilities who were well educated and employed. However, positive cases of inclusion and empowerment among persons with disabilities remain in the minority.

Due partially to Soviet ideology, ableism ([McRuer, 2006](#)) was a dominating value in the Soviet time, in which all citizens were expected to work and uphold the ideology of communism. Depending on their impairment, persons with disabilities were categorized into three groups. This categorization system was used primarily for those who were temporarily sick or injured and who could return to work after medical treatment and rehabilitation. Thus, people with disabilities were expected to be cured after treatment and rehabilitation, despite the fact that their impairments were a permanent condition. Nevertheless, they were expected to recover

after treatment so that they were able to work again. This “equal treatment for all” policy rather than “equal opportunities for all” was reinforced by the categorization system. This medical approach to disability in the form of defectology was predominant in the Soviet Union. According to defectology, persons with disabilities were often considered to be “abnormal”, first, because they were not healthy and, second, because they were not cured after receiving treatment. In the Soviet Union, the concept of “invalid” was introduced to describe those persons with disabilities who were not considered employable and who were sick. Research participant 8 recalls, “Until recently, the ‘medical model of disability’ was dominant, in which disability was regarded as a purely medical issue, referring to disability as only the individual’s problem and requiring only medical intervention.”

On the one hand, the Soviet social protection system for persons with disabilities was highly sophisticated in providing services such as segregated boarding schools for children with disabilities and institutions for adults with disabilities, rehabilitation and medical treatment, medications, recreation and monetary compensation. On the other hand, the very same system segregated persons with disabilities and maintained an unethical division between persons with and without a disability. Therefore, because persons with disabilities were unseen and hidden, either institutionalized or isolated at home, society came to perceive that there were no persons with a disability. In this way, many persons with disabilities were excluded from society, and exclusion was normalized in recent history. As a result, prejudice, stigma (Goffman, 1963, 2017) and physical inaccessibility still remain a major Soviet legacy in the lives of persons with disabilities in former Soviet states such as Kyrgyzstan (Katsui, 2005).

Today 2.8% of the population of Kyrgyzstan are categorized as adults and children with disabilities according to the population census of 2015. The number has been steadily increasing over the years, which is nevertheless far from the 15% that the World Report on Disability (WHO and World Bank, 2011) indicates based on a large-scale collection of scientific evidence. The institutionalization of children and adults with disabilities is widely practiced still today (UNICEF, 2011), while many of those staying at home do not receive proper education and thus subsequent employment opportunities. Although local organizations of persons with disabilities advocate for the human rights of persons with disabilities, the negative attitudes of both persons with and without a disability that is based on a spiritual conceptualization of disability and the Soviet legacy are still a big challenge.

## **Social protection programmes for persons with disabilities in Kyrgyzstan**

The social protection system in the Kyrgyz Republic remains strongly influenced by social ethics and values based on spirituality as well as on the Soviet legacy. This is manifested in a reliance on welfare services, direct cash transfers and institutional care for vulnerable members of society, as mentioned above. Persons with disabilities continue to be divided into three categories: first, second and third categories depending on the severity of their impairment and the ability to work. For instance, wheelchair users and blind persons are considered to be unable to work and so are categorized in the first group. Deaf persons belong to the third category and are considered to be able to work in occupations such as carpentry or shoemaking. Persons with disabilities receive a monthly disability pension, which however is too small to meet the average daily expenses, and thus persons with disabilities become financially dependent on their families and relatives. Social services include home visits from community-based social workers (2,760 home-visit service users in 2017), who help with household chores and provide hot meals, and the availability of special institutions (2,325 inhabitants in institutions in 2017). Consequently, public services still continue to perpetuate the segregation and isolation of children and adults with disabilities either in institutions or at home, instead of supporting them to be part of society on an equal basis with others. Social justice for persons with disabilities is too often not realized (Bickenbach, 2009: 105–110), and persons with disabilities are not provided the same opportunities as their peers without a disability. This means in practice that there is no place for persons with disabilities to make decisions about their own lives, for example, on what to eat, when food is provided by community-based social workers. In this way, many persons with disabilities continue to be passive and isolated from society. The research participants described this as due to the social ethics and values perpetuating the lower status of persons with disabilities in society.

Certain reforms have taken place over the past 20 years since independence, but the intention of the government to establish a modern social protection system is complicated by the need to dismantle the current set of measures before establishing new ones. For instance, in the case of disability services, a number of institutions for both children and adults with disabilities are planned to be dismantled in order to realize the rights of persons with disabilities as stipulated in Kyrgyz legislation. At the same time, new types of services that support children and adults with disabilities to live in the community must be developed to replace the services provided through institutions. A representative of an organization of persons with disabilities has pointed out that the legal illiteracy of young persons with disabilities is a major problem, since many

do not know what benefits they are entitled to, and how and where to get them (Interviewee 23, cited in [Katsui, 2018](#): 4). The ideology of independent living based on human rights principles and ethical values is not well understood or known by either duty-bearers or rights-holders.

In Kyrgyzstan the term “social worker” is currently used to describe a professional providing many levels of social work and social protection. Social workers work at one of two public service administrative levels: village self-government community workers and district (*rayon*) social workers. The duties of the village community worker include the delivery of hot meals, services at home such as cleaning and washing clothes, and tasks such as paying bills. These services are delivered to persons living alone who have difficulties leaving their home, for instance, because of mobility limitations. Village community workers serve 12–14 elderly persons or persons with disabilities in urban areas, 10–12 in rural areas and 8–12 in remote, harder-to-reach areas. The duties of the district social worker are to monitor the delivery of services and provide annual reports on the services provided. In addition, the district social worker is responsible for identifying persons in need of social services, assessing their needs and registering them for services.

Currently, approximately 1,000 village self-government community social workers work in Kyrgyzstan, of which 250 are specialized in child protection, including the protection of children with disabilities. Their salary is rather low (5500 KGD = 80 USD/month), which leads to a lack of interest among university graduates to select social work as their degree, especially in urban areas where the cost of living is high. This in turn means that often unqualified employees fill social worker positions. In general, the turnover for social workers is high, especially in urban areas. However, the high unemployment rate in rural areas motivates social workers to stay in their profession and provides them employment in their home localities. A major problem is that social workers are not trained in disability-related issues and are not familiar with the social model of disability or a human-rights based approach and the application of these to social work.

Today, universities that provide social work as an academic discipline are given the responsibility by the government to educate social workers in independent living principles for persons with disabilities in the community. Moreover, the Kyrgyz government enacted a new law in 2018 introducing new professions, including personal assistants, physiotherapists and occupational therapists, with the aim of supporting persons with disabilities to live in the community. In other words, training for social workers will shift from reinforcing marginalization towards providing services that support persons with disabilities to live in the



community, now that the CRPD has finally been ratified by the Kyrgyz government. However, universities lack the capacity to apply the human rights-based approach in social work because their teaching approaches focus on social values and ethical standards in conjunction with the aforementioned spirituality that undermines the social model and human rights-based model of disability.

### **EU Social Protection Systems Programme in Kyrgyzstan and its outcomes**

The Kyrgyz Ministry of Labour and Social Development requested help from the Finnish government to build the capacity of social workers to apply the social model of disability. In response to this request, the EU Social Protection Systems Programme (EU-SPS) – a global programme designed to support the government’s capacity to develop inclusive and sustainable social protection systems in ten developing countries – was implemented in Kyrgyzstan in 2017–2018. After the legal change approving new professions such as personal assistants, physiotherapists and occupational therapists, a working group, including a representative of a cross-disability organization of persons with disabilities, was established in the beginning of 2018 to discuss these new professions. The Kyrgyz universities that provide social work as an academic discipline are responsible for creating curricula for the new social work professions. To support the universities, the EU-SPS intervention trained 30 university lecturers of social work, including the members of the aforementioned working group, on disability rights and the social model of disability, and more broadly on disability studies.

The Kyrgyz curriculum for social work has been based on the medical approach to disability where disability has been taught in the form of defectology and the ontology of impairment (Vehmas and Mäkelä, 2009; Shakespeare, 2006).

My ideas about disability before the trainings were heavily coloured by the medical point of view. Because I believed that people with disabilities should be cared for in special institutions, where special conditions are created for them.

(Research participant 6)

Furthermore, the background of some of the university social work lecturers is in medical sciences, which further promotes a medical approach to disability. Other aspects including social and human rights-based approaches to disability were included to a limited extent, as the curriculum focuses more on managing and supervising social workers than working at the grassroots level with service users such as children and persons with disabilities.

In the EU-SPS intervention in Kyrgyzstan, the first consultation meetings and interviews took place in early 2017 to identify the precise needs of local university lecturers, social workers and the Ministry of Labour and Social Affairs. Based on the consultations, a curriculum was developed for the university social work programme. Thirty university social work lecturers were trained in the new disability studies curriculum in one-week intensive trainings sessions for trainers (ToT) in universities in Bishkek and Osh in late 2017. One further training session was held in Bishkek in early 2018, to which lecturers from both cities were invited.

As an outcome of this ToT, a teaching module on disability inclusion that is specific to the Kyrgyz context was created. Since 2018, the trainees have been educating other university lecturers, social workers and university students in the subject using the new teaching modules. A final wrap-up meeting took place at the end of 2018 in Bishkek, to which representatives from both cities as well as relevant other stakeholders were invited. Data was collected throughout the trainings from participatory observation and personal and group interviews. Oral feedback was also continuously noted during the interactive and participatory trainings. For instance, several questions were asked during the trainings, after which the answers were collected and analysed. After each training, a feedback questionnaire was completed by the participants to determine what they had learned, what areas required further improvement, and what the participants would like to further develop. Furthermore, an anonymous and voluntary survey was conducted in the summer of 2019 as a follow up. Only ten participants voluntarily completed the survey, despite regular reminders.

The basis of the new curriculum produced in the EU-SPS intervention was that disability is not an ontological inferior condition; instead the curriculum focused on the relationship between individuals and society and a holistic understanding of disability as a social phenomenon in which persons with disabilities are equal members of society. Local representatives of cross-disability organizations of persons with disabilities, who are persons with disabilities themselves, were guest lecturers teaching disability studies to the Kyrgyz university lecturers based on their personal and collective experiences. They were representatives of their cross-disability organizations. That is, “experts by experience” (Sosnet, 2017: 8) were utilized as a local resource for the disability inclusion social work training. The added value of “experts by experience” is that trainees could learn from the lived experiences of the guest lecturers and that the inclusion of persons with disabilities as lecturers exemplifies the equal relationship between persons with and without a disability.

A Kyrgyz university education pertaining to disability prior to the trainings reflected the deeply rooted social values, ethical standards and spirituality related to disability. All of the

interviewed social workers and university lecturers confirmed that training on disability in general, and disability rights in particular, is quite rare and very limited. Therefore they tend to unknowingly reinforce the stigma, though with “a good heart”, as the social workers themselves put it.

After the first trainings, the lecturers’ perceptions towards disability changed quite dramatically. At the beginning of the first one-week training in 2017, Kyrgyz university lecturers were asked to list words that are related to disability. They associated “disability” with words such as impairments, dependence, limitations, physical restrictions, “not having a full life”, wheelchair and medical care. At the end of the training, the same question was asked, and the words associated with disability included discrimination, “we can change”, ethics, equal opportunity, mainstreaming and identity. These words epitomize their profound change in understanding disability in Kyrgyz society. When different approaches to disability were introduced to them, the university lecturers themselves recognized that they had internalized the historically and socially predominant ethical standards, values and spiritual understanding of disability in which children and adults with disabilities are objects of both charity and medical interventions. The research participants reflected on the change as follows:

At the moment in Kyrgyzstan rights as well as service provisions for people with disabilities are poorly implemented. Ignorance leads to inaction on the part of the public sector as well as the general public... After the training, I began to believe deeply that ... [we can] increase our knowledge about disability and train young people to better understand it (disability).

(Research participant 5)

I think that the rights of people with disabilities to equality and full inclusion in society, inclusiveness, must now be recognized on a large scale. This approach to disability, based on human rights, requires a complete change in the traditional attitude towards people with disabilities. After the trainings, I am even more convinced that the outdated practices of paying benefits, medical rehabilitation and institutionalization needs to be carefully reviewed.

(Research participant 8)

After two years of these ToTs, with the great help of the university lecturers and local disability activists, a set of teaching modules for disability inclusion was produced to fit the specific needs of the Kyrgyz context. As an outcome of this EU-SPS programme, the trainees started

to teach disability not only through defectology but also with human rights principles and ethical values on inclusion. A new element in the revised teaching modules was that the local guest lectures who were persons with disabilities were treated as important and equal colleagues. In this way, the university lecturers changed their teaching curriculum to incorporate new values and beliefs to promote the inclusion of children and adults with disabilities instead of reinforcing negative stigma.

**Concluding remarks:            discussing the paradigm change from stigma to equity**

This chapter tried to shed light on the historical and deeply rooted ethical standards, spirituality and social values that have long supported the social service system in Kyrgyzstan, which is currently under the pressure to change. As Vehmas and Mäkelä (2009:52–53) argue,

The first and right thing to do would appear to be to change the social arrangement of the context, if possible. However, social structure, practices, arrangements, value structures and so on are notoriously difficult and slow to change. This is quite understandable since they are collectively created and maintained, and also historically deep-rooted.

The outcomes of the EU-SPS verified that such interventions do not automatically translate into a large social change in favour of persons with disabilities, as the university training of social workers is only a small part of the public service production chain. The “collectively created and maintained” structure is generally hard to be deconstructed, as Vehmas and Mäkelä (2009:52–53) rightly put it. When the statutory structure of social protection systems as well as society do not facilitate the equity of children and adults with disabilities, a charity-based approach is often the way in which children and adults with disabilities obtain the necessary support. For instance, community-based social workers of the public sector continue to provide standardized help to children and adults with disabilities in a non-emancipatory way without taking into account the decisions of individuals with disabilities.

A charity-based approach has been heavily criticized (cf. Barnes, 1991; Murphy, 2000). Katsui (2012: 23–24) summarizes the criticism against it as follows:

Charity organisations and a charity-based approach have historically served to innovatively fill the gaps of existing needs. Nevertheless, this approach has been heavily criticised because it gives the impression that the problems have been solved, it does not challenge the fundamental structure, which is the root cause of the situation,

and further, because of the mechanisms inherent in it, which takes away the decision-making power and/or ownership from the beneficiaries.

A charity-based approach is prevalent not only among charity organizations but also in the public sector in Kyrgyzstan and beyond. Many children and persons with disabilities are dependent on charities for their survival, especially when they are isolated and made passive (Katsui, 2005). When the capacity of many grassroots persons with disabilities is extremely weak, they themselves often become part of the mechanism reinforcing a charity-based approach and the stigma attached to it. They often internalize a negative image of oneself and remain passive. On the other hand, the general public, including social workers of the public sector, perceive that charity is very good, which is an “observed paradox” (Shakespeare, 2006:153). In other words, “Charity becomes an indispensable aspect of realities of many persons with disabilities” (Katsui, 2012:135). The change in the social environment of charity that carries the stigmatic values thus is a priority. Ikäheimo (2009: 88) argues:

It would be politically wise to point out loudly and clearly the radical ways that people will remain socially excluded simply because of the lack of adequate cognitive response by relevant people in their social environment. It is only when this form of exclusion becomes an explicit part of the public imagination that effective remedies can be expected.

The social environment, including the presented social values, ethical standards and spirituality, continues to be undermined by many governments, including the Republic of Kyrgyzstan, because one of the most influential, though usually unstated, assumptions of social policy is that “it is always cheaper, more efficient, and publicly acceptable to provide resources that respond to individual functional deficits, than to modify the physical and social environment in which they live” (Bichenbach, 2009:110).

One of the modest but meaningful outcomes of the EU-SPS is the established collegial relationship between university lecturers of social work and local disability activists. The created teaching module encompasses guest lecturers of local disability activists as “experts by experiences” (Sosnet, 2017: 8). This exercise entails changes in the social value system: moving away from stigma that is profoundly based on spirituality and the Soviet legacy towards a more equal relationship between persons with and without a disability. The guest lecturers with disabilities are no longer objects of charity but prominent lecturers in higher education. This element has the potential to trigger the intended paradigm and value change

from a charity-based approach to a human-rights based approach. As the social environment in Kyrgyzstan is largely based on a charity-based approach to start with, it is high time to pay closer attention to the values, ethics and spirituality behind existing support mechanisms for children and adults with disabilities so as to understand the root causes of the status quo.

As this study shows, investigation of the social and historical background in terms of ethical standards, social values and spirituality is helpful in understanding the persistent discriminatory reality faced by persons with disabilities in any context and further provides opportunities to build new ways forward. This finding has wider implications not only in Central Asian countries that share a similar historical background with Kyrgyzstan but also in other parts of the world. The necessity of holistic disability studies and accommodation in the social work discipline has started to be addressed by scholars in different contexts (Morgan, 2012; Holler and Werner, 2018; Sniatecki et al., 2018). The ratification of the CRPD by 180 countries has meant that many countries face a variety of transformative challenges when social values and ethical standards do not comply with the principles of the CRPD. The evidence presented in this chapter contributes to this worldwide discourse on social change in disability inclusion and provides a practical example of change established in higher education institutions in Kyrgyzstan.

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