SITUATION ANALYSIS:
Children and Adolescents with Disabilities in Kyrgyzstan

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Abbreviations

CCA	Commission on Children's Affairs
CSD	Child Survival and Development
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CISSA	Corporate Information System for Social Assistance
COVID-19	Coronavirus disease of 2019
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
CSO	Civil Society Organizations
ECD	Early Childhood Development
ECDI	Early Childhood Development Index
ECEC	Early Childhood Education and Care
EIEI	Early Identification and Early Intervention
EU	European Union
FCSD	Family and Children Support Department
FGD	Focus group discussion
SAYAPCS	State Agency for Youth Affairs, Physical Culture and Sports
HIV	Human Immunodeficiency Virus
ICD-10	International Classification of Diseases, version 10
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health for Children and Youth
ILO	International Labour Organisation
IPR	Individual Programme of Rehabilitation

KIHS	Kyrgyz Integrated Household Survey
KII	Key informant interview
MBPF	Monthly Benefit for Poor Families with children
MESKR	Ministry of Emergency Situations of the Kyrgyz Republic
MICS	Multiple Indicator Cluster Survey
MLSD	Ministry of Labour and Social Development
MoES	Ministry of Education and Science
MoH	Ministry of Health
MSB	Monthly Social Benefit
MSEC	Medical-Social Expert Commission
NGO	Non-governmental organization
NSC	National Statistics Committee
OOS	Out-of-school
OPDs	Organisations of persons with disabilities
PMPC	Psychological Medical Pedagogical Commissions/Consultations
Qº	Quintile
SDG	Sustainable Development Goals
SitAn	Situation Analysis
UNDP	United Nations Development Programme
UNICEF	United Nations Children’s Fund
USAID	United Stated Agency for International Development
VET	Vocational Training and Education
WB	World Bank
WHO	World Health Organisation

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EXECUTIVE SUMMARY

While this Situation Analysis is of particular interest to various stakeholders in Kyrgyzstan – government officials, policy makers, professionals in various areas, scholars and researchers – it should be noted that the most valid contributions of the study were provided by children with disabilities themselves, and their families, who shared their life experiences with the team. Their varied accounts are testament to families and children's tenacity, and parents´ unconditional love for their children, despite extreme difficulties.

Findings

Kyrgyzstan ratified the Convention on the Rights of Persons with Disabilities (CRPD) in May 2019, but implementation mechanisms have not been put into motion yet and persons with disabilities and the organizations that represent them do not yet feel the impact of the ratification of the Convention on their lives. An Action Plan for implementation of the CRPD has been developed, and a Council of Disability Issues has been established; however, many initiatives have been delayed or stopped over the last 2 years.

As reported by persons with disabilities themselves, the language used to refer to them is stereotypical and, in some instances, derogatory. The legal and policy framework is insufficient to adequately protect the rights of persons with disabilities, including children. Two of the principal concepts of a CRPD-complaint legislative framework are missing entirely from the existing legislation: reasonable accommodation and universal design.

Accessibility is granted in several legal documents and the national programme "Accessible Country 2021-2040" has been developed and published for public deliberations but not yet approved due to political and COVID-19 circumstances. While civil society tries to influence policy revisions and environmental accessibility through activities such as monitoring of public spaces, their voices are not considered. In addition, low public awareness of the rights of persons with disabilities outweighs the limited efforts that are made to create an accessible environment.

The definition of disability in Kyrgyzstan (Law nº 38, 2008) continues to reflect the medical model and provides conflicting guidance. On the one hand, persons with *"limited health functioning" are defined as persons with "health disorders with persistent impairment of bodily functions resulting from illnesses, trauma or defects, and having as consequence limitations of functioning and calling for social protection and rehabilitation".* On the other hand, it defines *"disability",* as a *"socio-legal status presuming the existence of persistent physical, psychic or mental impairments"* (Article 1).

The process of early identification and early intervention – when it exists - is fragmented between departments, lacks specific expertise, and does not count on the participation of parents, caretakers, and their environment. Having a child identified as having a disability often requires that parents navigate through a costly and emotionally difficult process, often without support. Information about their rights is not provided at the medical or welfare levels, and they are faced with a lack of/incorrect diagnosis, requests for bribes from professionals, and cumbersome administrative procedures.

The health care system is committed to ensuring the quality of its services considering the needs of people. However, persons with disabilities are not viewed as a group of service users of the health care system similar to the rest of the population. Rather, health care professionals relate to persons with disabilities as impersonal carriers of a disease, which is needed to qualify them according to regulation, and do not take into consideration the emotional or social charges of experiencing a disability.

The rehabilitation programme for persons with disabilities, developed by the Medical and Social Expert Commission, is not provided with the necessary high-quality habilitation and rehabilitation knowledge and services needed in the field and persons with disabilities themselves largely do not know they have the right to a rehabilitation plan. Outdated medical rehabilitation services are not readily available to everyone and social, psychological, educational, and other types of rehabilitation are not carried out due to the lack of specialists, equipment, and methods.

Age-appropriate assistive devices of acceptable quality – that might aid in enhancing participation - are difficult to obtain, particularly in rural and remote areas due to the lack of person-centred approaches, absence of choice and long waiting periods.

In policy and in practice, mainstream and special education are considered separately, preserving the segregation of children with disabilities. Access to education by children with disabilities is dependent upon a disability registration form and the whim of school personnel. Parents who want their children to access segregate settings (and reportedly receive specialized education adequate to the type of disability) must pursue a disability registration card. A special school will not enrol a child without it but may refuse enrolment even if a child has it.

Likewise, parents who do not want to send their children to segregated settings (often away from home) will not pursue a disability registration, unless they need the monthly benefit to purchase medicine or services. In this case, children can only enrol in a mainstream school if the school director and/or the teacher agree to it, which often requires the payment of a bribe.

Adolescents and young adults with disabilities face significant difficulties in accessing employment as school-to-work transition is not adapted to persons with disabilities, opportunities in vocational training and rehabilitation are scarce, the public employment service is generally not sensitive to the specific needs, and the quota system of reserved workspaces is not reinforced.

Social protection schemes do exist, specifically in the monthly social benefit which targets children with disabilities, as well as others. However, there are access barriers, the benefit levels do not reflect the differentiated needs and are considered inadequate. Personalized social services have been promoted with the introductions of “personal assistants” and a contractual opening for third-sector providers of public services. Coverage and adequacy of these services, however, remains below the perceived needs.

Study participants reported on the persistence of negative attitudes towards disability in Kyrgyz society. Service providers have low awareness on the issue of disability or are guided by traditional and medical models of disability. Civil society organizations promote information about different types of disabilities but remain restricted to promoting the rights of persons with a particular impairment. Families do not receive enough information to be able to make informed decisions and are vulnerable to potentially biased support of the non-governmental sector’s group communication and education, the family’s place of residence, social status, etc.

Data collected for this Situation Analysis indicates that children and adolescents with disabilities in the justice system, either as victims of crime or alleged perpetrators, are not provided with sufficient safeguards to protect them against victimisation and manipulation.

There is widespread institutionalisation of children with disabilities, lack of support to families, financial discrimination, lack of access to accessible and affordable services, with a particular disadvantaged situation for children with mental disabilities. The national deinstitutionalization programme has been developed and is being implemented almost exclusively by civil society. Reportedly, state bodies are not actively involved or are reluctant to engage. Thus, deinstitutionalization is hampered by a lack of intergovernmental interaction, a lack of qualified specialists and social services, indifferent or negative attitude of society towards children with disabilities, lack of systematic and complex support for children leaving residential institutions and lack of adequate alternative care services, such as specialised fostering, respite services, etc.

However, it should be noted that many parents of children with disabilities who participated in the study indicated strong reluctance to send their children to institutionalized care, be it "orphan homes" or specialized schools as often suggested by professionals. This reported sense of protection and lack of willingness to separate their families, should be further developed by providing families of children with disabilities with the necessary supports and services at the local level.

Recommendations

This Situation Analysis identified a series of recommendations. Each is identified according to short-, medium- and long-term priority, and each indicates the stakeholder(s) better placed to lead on each. Below is a summary list:

Promote a unified approach to identification, based on the International Classification of Functioning (ICF) Members from the 3 existing mechanisms that identify children with disabilities, delays or in difficult life situations, together with professionals fully familiar with the International Classification of Functioning (ICF) and international experts should formulate a plan of collaboration that retains their professional expertise but expands their reach and level of oversight, aiming to streamline the existing processes, and develop mechanisms and protocols of cooperation that aim at supporting all children and families along the life-cycle.

Early Identification and Early Intervention (EIEI) mechanisms need to be set up, efficiently and professionally, with support from the Bishkek and Osh children's hospitals. While the legislation envisions that the identification of children with disabilities be done at the local level, participants in this study indicate this is not possible due to the low technical capacity of professionals at the local level. Thus, it is important that a temporary solution be found.

Develop a whole-of-government approach towards inclusive education and life in the community. Social – and educational – inclusion are the responsibility of the entire government. It is recommended that UNICEF develop a Country Office working plan related to children with disabilities that is cross-sectoral, including Education, Child Protection, Social Policy, Local Governance and Health, and can serve as a platform to: (1) exemplify how multiple sectors should work together with one common goal, such as EIEI and implement inclusive education; (2) encourage multiple ministries to gather efforts around one aim (I.e., EIEI and inclusive education).

Upscale community-based support structures. Persons with disabilities and their families must be supported in creating the necessary local conditions that can help respond to their psycho-social needs. When they already exist, day care centres should be retrofitted to be inclusive of all children with disabilities regardless of their accessibility needs, disability status, age or other. When they do not exist, financial and human resources should be allocated for their development.

Inform families of children with developmental delay or disabilities about rights and account for benefits. Develop a centralized, transparent mechanism by which parents of children with disabilities have access to information regarding their rights. The mechanism should include a system of anonymous reporting of instances of bribery associated with service provision, leading to legal action and restitution.

Talk about disabilities as a human characteristic. Using existing awareness campaigns from across the region, adapt and conduct a national awareness campaign that starts to dispel the myths that surround disability in Kyrgyzstan and serves to provide basic and accurate information to the general population.

Learn from the pandemic to build back better. Conduct an urgent evaluation of the conditions under which each family was able to receive and retain their child – usually in a separate or segregated setting –at home, during COVID-19 confinement, and develop a plan of family support with the purpose of continued family (re) unification post-pandemic.

Conduct an evaluation of services at residential institutions where children with disabilities remained during COVID-19 confinement, and identify the bottlenecks for family (re) unification, aiming for a targeted planning for de-institutionalization of children with disabilities.

Ensure safety, protection, and a loving environment in institutions. Develop clear and transparent protocols to prevent and react to violence against children in residential care. Protocols should deal with issues such as age-and gender-appropriate training in understanding and recognising violence, complaint mechanisms, protection against victimisation and rehabilitation and include mechanisms by which children can place an anonymous complaint to an independent monitor with the authority to act immediately (including but not limited to removing the child from the setting).

Reassess the concept of inclusive education. Consider halting the project of development of a "Concept and Program for Inclusive Education in the Kyrgyz Republic" until a full review of the documents is made against normative frameworks, to ensure "inclusive education" is, in fact, the end result of the project and in alignment with international norms – not "integration". Stakeholders involved in the development of an inclusive education strategy should engage in a study visit to a country with an advanced Early Identification/Early Intervention and Inclusive Education System

Comply with the United Nations mandate. It is recommended that UNICEF take the lead- within the UN Country Team structure – on issues related to childhood disability. An easy first step would be to create a working group on disability, with representation from all UN organizations and international NGOs/Donors, to develop a common plan for support of the ratification of the CRPD.

Nurture a strategic cooperation between government services and the third sector. NGOs and DPOs that provide services to children with disabilities and their families should develop a plan for devolution of responsibilities to central and local authorities. Because a lot of the know-how is currently concentrated within civil society, capacity development activities should take place to ensure wide-spread technical capacity.

Review all law for CRPD compliance. Engage in a thorough legislative review, with the involvement of international experts and the national representative organisations of persons with disabilities, to address substantive rights of persons with disabilities under the CRPD, as well as procedural mechanisms for implementation, monitoring and reporting.

Enable National statistics services to report on disabilities, discrimination, and inclusion. UNICEF should ensure wide understanding of the distinction between the data governments usually want (for disability pension purposes) and the data MICs provides (a range of possible functional limitations in the child/youth population that may or may not directly indicate a degree of disability), and engage in capacity-building, including with the National Statistics Committee, to empower government officials to make decisions that are inclusive of persons with disabilities.

- Consider the possibility of having a second wave of household surveys completed in those households identified has having a person with a reported functional limitation, to gather more specific and reliable information related to their bio-psycho-social status as it relates to their functional limitation, while advancing the possible synergies between the concept of functional limitation and service/benefits provision for persons with disabilities.
- Consider the possibility of having a "functional limitation" survey included in the next population census to determine a more accurate prevalence rate of persons with a functional limitation (essential for planning service provision and benefits allocation).

Work on getting the CRPD on the ground. Adopt the Initial Action Plan for CRPD implementation without further delay and ensure its implementation and monitoring by delegating tasks, earmarking human and financial resources and introducing a transparent mechanism for monitoring implementation.

Report routinely against CRPD obligations. Considering the obligations of Kyrgyzstan under CRPD Article 33, develop measures to establish a robust mechanism for implementation and monitoring of progress towards the CRPD. There should be two independent components of the mechanism:

- Inter-agency structures, curated by a designated focal point within the government and including a coordination mechanism, such as the recently established National Disability Council. The structures should have dedicated mandates and resources, enjoy sufficient visibility, and can be replicated at the regional levels.
- An independent monitoring mechanism, including the Ombudsman's Office that should be specifically designated to perform CRPD monitoring functions, and supported in fulfilling its tasks. Efforts to receive A-status Paris Principles' accreditation by the Ombudsman should be ongoing.

INTRODUCTION

UNICEF commissioned a Situation Analysis on children and adolescents with disabilities in Kyrgyzstan to assess and analyse the situation with respect to the realization of the rights of children (0-17 ages) and adolescents (10-19 ages) with disabilities according to the International Classification of Functioning (ICF), Disability and Health for Children and Youth (WHO) in Kyrgyzstan.[1] The Convention of the Rights of the People with Disabilities (CRPD)[2] has been ratified by the Republic of Kyrgyzstan on 16th of May 2019.[3] The rationale for this Situation Analysis is to inform stakeholders, both governmental, civil society and development partners, as to the current situation with regards to the fulfilment of children and adolescents with disabilities' rights.

The study identified the barriers and bottlenecks in the provision of quality and inclusive services for children and adolescents with disabilities as well as the gaps in the policy environment and evidence base. The study fills an existing void: while some literature exists on the topic of disability in Kyrgyzstan, this is not focused on the issues that are of primary importance for children and adolescents.[a]

It is expected that this Situation Analysis will inform various stakeholders. Primarily, the report is to provide evidence and guidance for future policy formulation and service provision to the Government of the Kyrgyz Republic. It shall also inform UNICEF, as well as other international development partners both multilateral and bilateral, in advising the government and focussing their capacity building efforts. Finally, the report is directed to the broader civil society, including organizations of people with disability, child rights activists and representatives of youth and parent´s organizations.

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[a] In addition, the research undertook an analysis of the enabling environment for the development of an Early Identification and Early Intervention Programme aiming to identify the necessary actions required to improve the scope and quality of EIEI services available. This has been provided in a separate (unpublished) document.

METHODOLOGY

The scope of the research, as it relates to children and adolescents with disabilities in Kyrgyzstan was to:

1. Undertake a desk review.
2. Analyse the policy environment vis-à-vis CRPD compliance.
3. Determine barriers and bottlenecks impeding the fulfilment of rights by children and adolescents with disabilities.
4. From the above (3), detail the barriers and bottlenecks impeding the fulfilment of rights by children with disabilities ages 0 to 8.
5. Assess existing stakeholder and enabling environments with a view to support the fulfilment of rights by children and adolescents with disabilities.
6. From the above (5), details the stakeholders and enabling environments with a view to support the fulfilment of rights by children with disabilities ages 0 to 8.
7. Assess existence, availability, accessibility and participation in disability-inclusive services.
8. Map existing EI/EI services with a view to capitalize and expand existing practices.
9. Review existing data and to what extent it is used with a view to identify gaps.
10. Develop recommendations for policy and action related to children and adolescent with disabilities' fulfilment of rights.
11. From the above (4, 6, 7, 8, 9 & 10) develop an analytical report to strengthen EI/EI
12. From the above (10), detail recommendations with a view to accelerate EI/EI policy and program.

The Situation Analysis was tendered in December 2019 and encountered a series of significant challenges due to obstacles related to the COVID-19 pandemic. Field-based data collection was postponed or severely constricted due to the ongoing Covid-19 pandemic. Therefore, the methodology was adapted to respect the social distancing measures.

First, a "System Analysis" was conducted. It was focused on duty-bearers and was conducted as a study based on literature and legislative review, covering publications from 1995 up to 2020, online interviews and focus-groups with experts, including professionals, government authorities, and representatives from child rights organizations and organizations of persons with disabilities). More than 350 documents were reviewed, in-depth interviews with 20 government officials and civil society representatives were undertaken, 6 focus groups with government and/or civil society groups were conducted.[4] On 16th of December 2020, the System Analysis was presented to members of government and civil society and given feedback was incorporated onto the written report. While conducting the study, government had been planning a number of reform initiatives related to the rights of children with disabilities, as discussed in the report. While the report aims to take them into account, only those conducted before the 1st of December 2020 were considered.

A second phase, focused on rights-holders, and leading to this "Situation Analysis" was undertaken in February of 2021, by conducting four –case studies and ten focus groups with parents and children with and without disabilities. The tools had been defined in detail in the Inception report and are replicated in the annexes 2. They have been previously used in other countries in the region. Furthermore, a first set of FDG and KII were used to refine tools (pre-test). This additional data gathering was undertaken in various regions as displayed in Table 1. The recruitment of participants was undertaken via organizations of persons with disabilities. A list of representatives of organizations of persons with disability (OPD) was compiled, both at national and regional level, and discussions were held to get a cross-section of study participants that would be able to cover the diversity both in terms of regional spread, gender balance, urban-rural coverage, and types of impairment. Based on this, local OPDs served as conveners for the groups of children and parents. The specific cases, as documented in the Annex "case studies" of this report to were taken from participants in the focus groups. The data generated in these encounters was used to corroborate, correct, and deepen the System Analysis. The case studies are biographical reconstructions of the lived experiences of four children and their families regarding disability, their journeys through the existing institutions and mechanisms, as well as their perceptions and aspirations. They are presented in the annexes and referred to briefly throughout the text.

The study has been managed by the UNICEF country office, with the technical assistance of the UNICEF Europe and Central Asia Regional Office (ECARO). In an open tendering procedure, a team composed of international and national experts had been contracted. The division of labour within the team entailed Paula F. Hunt as team leader, Jóse-Manuel Fresno as advisor on research methodologies, Janina Arsenjeva as legal expert, Rakhat Orozova as social services expert and coordinator of the field research, Stefan Meyer as social protection expert and project coordinator, and Skye Bain and Ana-Matilde Monteiro as research assistants. The study had been supervised in the respective steps of revised proposal (January-May 2020), Inception Report (May-September 2020), System Analysis (October-December 2020), and Situation Analysis (January-March 2021), undergoing reiterated steps of fact-checking, constructive criticism, and quality assurance. The Inception report has undergone an exhaustive ethical review undertaken by an external ethical review board. The Situation Analysis has been revised internally by the UNICEF country office and had been submitted to external quality assurance.

While the study did not foresee a formal governance mechanism to involve stakeholders both governmental and from civil society, various stakeholders were involved in the design and implementation of the research. The findings of the System Analysis were presented to several high-level representatives, including from government, organizations of persons with disabilities and child right activists, in an online discussion session on the 16th of January 2021. Written feedback was requested by all participants, based on the draft System Analysis. All interviewed duty-bearers, UNICEF staff, and right-holders have been given the opportunity to validate the results of this study, during the online validation meeting, in writing, or during the in-person data gathering process in both phases of the research.

Table 1: Locations of study with right holders

# FGD	Geographical area	Urban/ rural	North/ South	Participants	No
FGD 1	Naryn oblast, Naryn city	Urban	North	Children with disabilities	8
FGD 2	Issyk-kol oblast, Tonsky rayon, Bokonbaevo village	Rural	North	Children with disabilities	6
FGD 3	Osh oblast, Nookat rayon	Rural	South	Children with disabilities	8
FGD 4	Batken oblast, Kyzyl kia city	Rural	South	Children with disabilities	7
FGD 5	Chui oblast, Tokmok city	Rural	North	Children without disabilities	8
FGD 6	Naryn oblast, Naryn city	Urban	North	Parents of children with disabilities	6
FGD 7	Issyk-kol oblast, Tonsky rayon, Bokonbaevo village	Rural	North	Parents of children with disabilities	6

FGD 8	Osh oblast, Osh city	Urban	South	Parents of children with disabilities	8
FGD 9	Batken, Kyzyl kia city	Rural	South	Parents of children with disabilities	8
FGD 10	Chui oblast, Tokmok city	Rural	North	Parents of children without disabilities	7

The present document is the report of the Situation Analysis completed as described in the second phase (above).[5] Full description of the research methodology and a deeper analysis of the systems in Kyrgyzstan were developed in the Inception Report and System Analysis which were intermediary deliverables to this document. The questionnaires for interviews and focus groups are reproduced in the annexes.

In general, political developments in Kyrgyzstan during the research – namely general elections in October 2020, civil unrest, and a presidential election in January 2021, together with the related stand-still, change in leadership and restructuration of government departments – led to some delays and difficulties in accessing key informants and data. Names of ministries and government agencies reflect government structure prior to January 2021.

1. POLICY FRAMEWORK FOR DISABILITY IN KYRGYZSTAN

This chapter discusses the situation and the response by public institutions, in respect to articles 1-4 and 7 of the Convention on the Rights of Persons with Disabilities (CRPD).

Kyrgyzstan is a landlocked country in Central Asia. It borders China, Kazakhstan, Tajikistan, and Uzbekistan. The majority of the population lives in rural areas, to the north (around Bishkek) and to the west (around Osh). According to the National Statistics Committee (NSC), there are approximately 6.5 million people in Kyrgyzstan, of which 38% are below age 18 (2.5 million children).[6] According to UNICEF, 43.1% of children under 6 years old live in households below the poverty line and 119,000 children had both parents living abroad.[7]

Table 2: Basic population data in Kyrgyzstan

	Nº	Per cent
Total population of Kyrgyzstan	6,523,529	100%
female	3,285,923	50%
male	3,237,606	50%
Children	2,456,101	38%
Female under 18	1,199,101	48.8%
Male under 18	1,257,120	51.2%
Poor population (2019)	1,312,808	21%
Extremely poor population (2019)	35,836	0.54%
Recipients of state benefits related to disability*	57,204	0.87 %
Persons with disabilities since childhood*	31,688	0.48 %
Persons with disabilities from general illness*	7,183	0.11 %
Survivor's recipients (for each disabled family member)*	18,333	0.28 %

Source. National Statistics Committee stat.kg/ru/statistics/ Date of reference 12.08.2020 and (*) National Statistical Committee of the Kyrgyz Republic. (2019). Social trends in the Kyrgyz Republic 2014-2018: Extract of Disability Data.

The World Report on Disability (2011) indicates that approximately 15% of the global population lives with some type of disability, while the number of children ages 0 to 14 years old "experiencing moderate or severe disabilities" is approximately 5.1%, of which 0.7% "experiencing severe difficulties.[8] The prevalence rates in middle- and low-income countries varies and can be as high as 12.7%. Likewise, the rate of children at risk of a disability (globally) varies between 14% and 35%. In Kyrgyzstan, as elsewhere in the region, an estimation of prevalence rates is challenging due to the manner of classification.

The globally variance in the ways in which "disability" is understood, measured and officially captured in data sources is likely one of the explanations for the global disparities in the prevalence rate of children with disabilities (14 to 35 %). In most countries, data on persons with disabilities will vary, particularly administrative data, as different sectors operationalize "disability" differently (e.g., as a benefit recipient, as a person with a health condition, as a person who requires special education).

At the end of 2018, the total number of recipients of state benefits as related to disability (57,204) made up approximately 15% of the total recipients of state benefits (365,227). According to official data, 57,204 persons were official recipients of state benefits in Kyrgyzstan. They were qualified as "persons with disabilities since childhood" (31,688), "persons with disabilities from general illness" (7,183), or "survivor's" recipients (for each family member not able to work) (18,333). Thus, only 67.9% of those state benefits (31,688 + 7,183) were awarded to persons with disabilities themselves.

Caution is needed when interpreting data as reported above and in the following sections of this report. Receiving a disability benefit is not an adequate proxy for the total number of persons or children with disabilities or disability prevalence.[9]

1.1. Legislative commitments

In the framework of the localization of the Agenda 2030 and the Sustainable Development Goals (SDGs), the Kyrgyz Republic reaffirmed, in 2020, adherence "to the global commitment to "leave no one behind," with a particular emphasis on and prioritisation of the most vulnerable social groups"[10], while admitting that persons with disabilities are among the most discriminated against people in Kyrgyzstan, and gaps remain in the ability to disaggregate data on the basis of disability.[11]

By signing (21 September 2011) and ratifying (16 May 2019) the United Nations Convention on the Rights of Persons with Disabilities (CRPD) the Kyrgyz Republic committed to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity".[12] The realisation of the CRPD is subject either to immediate application for civil and political rights (such as the freedom from torture, violence and abuse, or respect for home and the family) or progressive realisation for economic, social and cultural rights (such as education, health or social protection). In all cases, the right to protection from discrimination in all areas of life is subject to immediate application.[13]

Shortly after the ratification of the CRPD, Government Order No. 143-r of 21 May 2019 established an interagency working group for implementation of the CRPD[14], tasked with drafting a proposal for an Initial Action Plan for implementation of the CRPD in 2019-2022 and a proposal for programme "Accessible country" ("Доступная страна") aimed at elimination of discrimination against persons with disabilities in various areas and improvement of accessibility of infrastructures. The proposal for the Action Plan was submitted in March 2020[15] and, following the political fluctuations, the interagency working group was disbanded. Later in the year, a new body, the National Disability Council, consisting of many of the same people, was established, holding its first meeting in December 2020.

Two of the principal concepts of a CRPD-complaint legislative framework are missing entirely from national legislation: reasonable accommodation and universal design. Parents of children with disabilities report a complete lack of consideration of their children's needs for accommodations (reasonable or otherwise) in medical and educational facilities, in transportation and rehabilitation services and products.

Also, as reported by participants in this study, and confirming previously reported[16] accounts, the language used to refer to disability or persons with disabilities, and the language often used to speak to persons perceived to have a disability and their families are stereotypical and often derogatory. Parents of children with disabilities reported that their children are perceived as less deserving of attention, care, or services than other children, and are often viewed by their peers, and professionals they come in contact with, as having a contagious condition.

As found in the in-depth analysis of the Early Identification and Early Intervention (EIEI) mechanisms in Kyrgyzstan, ensuring the rights of children with disabilities is problematic from a lack of early identification and early intervention system, to a lack of family support services. The findings from the data collection conducted with rights-holders, and of the "shadow" report[17], are in support of those already reported in the

Concluding Observations of the Committee on the Convention on the Rights of the Child adopted in 2014, that deplores widespread institutionalisation of children with disabilities, lack of support to families, financial discrimination, lack of access to accessible and affordable services, noting a particularly disadvantaged situation of children with mental disabilities.[18]

Additionally, Kyrgyzstan has not ratified the Optional Protocol to the Convention on the Rights of Persons with Disabilities, the Optional Protocol to the Covenant on Economic, Social and Cultural Rights (2013) or to the third Optional Protocol to the Convention on the Rights of the Child (2014). These separate treaties allow individual complaint mechanisms to be put in place. In Kyrgyzstan, they do not exist. International law protects the right of children with disabilities to participate in the making of decisions that concern them.

1.2. Definition of disability

Since the adoption of the CRPD in 2006, there has been an effort to understand disability through the lens of human rights, or the bio-psycho-social model of disability. Children and adolescents with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and children with disabilities are, according to the Convention on the Rights of the Child (CRC), "children first", a human right that extends to all children.

Box 1: What is disability?

Article 1 of the CRPD describes persons with disabilities as "those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

However, the description of persons with disabilities proposed by the CRPD results from a progression, over time, of the way in which disability has been understood. Thinking about disability has evolved substantially; the three main models used to conceptualize disability are:

The oldest and most outdated, the 'charity model' model, conceptualizes disability as a punishment or tragedy, usually with the intervention of a god. Under this model the individual is seen as needy and pitiful, and can only find salvation through the mercy, love and care of others.

The 'medical model' is arguably the most common; this model conceptualizes disability as a physiological condition of the individual, a condition, illness, or disease that needs to be treated and cured, with assistance from health professionals.

The most recent model, the 'social model' evolved from an increased understanding of the barriers that prevent participation of persons with disabilities. It maintains that disability results from interactions between an individual with specific physical, intellectual, sensory, or mental health impairments and the surrounding social and cultural environment. Disability is understood as a socio-political construct, whereby the attitudinal, environmental, and institutional barriers that inherently exist within society systematically exclude and discriminate against persons with disabilities.

The Social Model (also known as the bio-psycho-social model) is in line with the human rights-based approach, or human rights model of conceptualizing disability, and is consistent with the World Health Organization's International Classification of Functioning, Disability and Health, more commonly known as the ICF. The ICF (and ICF- CY) conceptualizes a person's level of functioning as a dynamic interaction between her or his health conditions, environmental factors, and personal factors. It defines functioning and disability as multidimensional concepts relating to:

The body functions and structures of people.

The activities people do and the life areas in which they participate.

The factors in their environment that affect these experiences.

The social model acknowledges the importance of context and environment in enabling or disabling individuals from participating effectively within society.

Source: Situation Analysis: Children with Disabilities in Kosovo[19]

In Kyrgyzstan, the umbrella legislation regulating the rights of persons with disabilities is Law No. 38 on the Rights and Guarantees of Persons with Limited Health Functions, adopted in 2008 and amended in 2009, 2016 and 2017.[20] This was a welcome departure from the standard Soviet-times legislation on social protection of 'invalids' (in the original) that served, in some variations, as blueprint for disability legislation in Kyrgyzstan and its neighbouring countries. Law No. 38, in its 2017 revision, includes important elements such as discrimination on the basis of disability; accessibility; the status of sign language interpreters; and political rights, among others. However, it does not yet fully live up to the CRPD normative framework and there is confusion with regards to the terminology of Law No. 38 (2008)[21]. On the one hand, the title of the Law addresses persons with "limited health functioning" that are defined as persons with "health disorders with persistent impairment of bodily functions resulting from illnesses, trauma or defects, and having as consequence limitations of functioning and calling for social protection and rehabilitation". On the other hand, the same law defines "disability", as a "socio-legal status presuming the existence of persistent of physical, psychic or mental impairments" (Article 1).

The term "disability" is only used in relation to prevention, or in discussions around awarding a disability group I, II or III to adults, based on severity of impairment. In all other instances, the Law uses the formulation "limited health functioning" or some variations thereof. Children under age 18 are included in the category "child with limited health functioning" (Article 1). The draft Action Plan for implementation of the CRPD seems to be one of few exceptions, where the terminology is based on the CRPD and "persons with disabilities" ("инвалиды" "люди с инвалидностью") is used.

At the time of this research, the consistent reference to "limited health functioning" ("ограниченные возможности здоровья") and the impairment-focused definition of disability, point at the continued reliance on the medical model of disability in Kyrgyzstan. The significant focus on prevention of disability also suggests a lack of clear distinction between the rights-based approached to disability championed by the CRPD and the general population health framework that should apply to persons with and without disabilities.

Thus, the definition of disability in Kyrgyzstan is not in alignment with the CRPD and is problematic in three ways: first, it does not take into consideration that disability is not a legal status, but rather a living condition that is heavily influenced by the environment; second, it does not take into consideration that qualifying persons with disabilities according to a severity level is unlawful, as it is counter to the individual nature of living with a disability; third, the current definition of children with disabilities is solely focused on the medical impairment (health-related) and ignores the psycho-social aspects of experiencing disability.

As referred to above, the agreements conveyed by the CRPD have also promoted a different way of identifying disability – as a functional limitation – more in-line with the social model of disability.

One such tool in the determination of disability, to be used in addition to others, is the use of the ICF and ICF- Children and Youth version (ICF-CY). Participation is one of the critical elements of ICF and one not taken into consideration by Kyrgyz legislation (see more in section 2.6). It is defined as 'a person's involvement in a life situation'.[22] This definition includes the concept of involvement, which may further be defined as 'taking part, being included or engaged in an area of life, being accepted or having access to needed resources'.[23]

Various reports – often contentious- related to the implementation of the ICF emerged during the research for this study. While piloting has taken place and an action plan drafted, professionals that participated in this study reported that only a very restrict number of health professionals in Kyrgyzstan are familiar with the ICF and can, in practice, exercise their professional know-how in multi-disciplinary teams of people. In direct contradiction, the VNR report concludes that progress towards introducing elements of the ICF in assessing disability and developing an individual programme of rehabilitation (IPR) has been achieved (SDG 1).[24]

Children with disabilities

With regards to children with limited health functioning (henceforth, children with disabilities), the Code "On Children" includes various provisions that affect them. Disability is considered to be among factors "objectively disrupting person's functioning and their psychological state due to inability to independently overcome it", and children with disabilities are automatically included in the definition of children in "difficult life situations" (Articles 5 and 25).[25] The system of protection of children in "difficult life situations", including children with disabilities, comprises the central government, a representative child protection agency (the Ministry of Labour and Social Development (MLSD)), district-level commissions on children's affairs (children's affairs commissions under the district authority) the Family and Child Support department (at the territorial division of MLSD), and the executive branch of the local authority responsible for social affairs. Other provisions that target children in "difficult life situations" (including children with disabilities) include the design of the individual child protection plan (Article 36) and placement in residential care as a last resort measure (Article 37). Lastly, as guarantee of the right to education of a child "with limited health functioning unable to receive education in educational establishments under general conditions", it foresees the creation of special groups, classes, or rehabilitation centres (Article 10(6)), and learners with "limited health functioning" are subject to quota in higher education (Article 10(7)).[26]

The Code "On Children" mandates the Ombudsman of the Kyrgyz Republic to monitor, analyse and control the realisation of rights, liberties, and lawful interests of children by the state bodies (Article 23).[27] The 2017 report of the Ombudsman of the Kyrgyz Republic indicated that children placed in residential state care are excluded from statistics on children in "difficult life situations" since residential placement is considered as a resolution of the said difficult situation. Children with disabilities and children from poor families are also often excluded from statistics.[28]

1.3. Determination and assessment of disability

Several commissions and consultations are responsible for determining disability and formulating development plans, some of which are further detailed in a separate analysis of the EIEI practice elaborated in the context of this study.

Table 3: Institutions for disability determination and formulation of rehabilitation plans

Institution	Function, mandate, tool	Reports to
MSEC	Disability assessment and determination, principally medical Determines legal status (categories I, II, III and child with a disability) as well as eligibility for benefits, social protection measures and rehabilitation services	MLSD
PMPC	Multidisciplinary teams to develop an education pathway for the child	MoES
CCA	Decisions on tutelage and institutionalization	district administration
FCSD	Case management functions related to identification, registration, and the development of Individual Child Protection Plans	District division of MLSD

KEY: MSEC: Medical-social expert commission; PMPC: Psychological Medical Pedagogical Commissions/ Consultations; CCA- Commission on Children's Affairs; FCSD: Family and Children Support Department.

Medical Social Expert Commissions (MSEC)

Resolution. 68 of the Government of the Kyrgyz Republic regulates the determination and assessment of disability ("person with limited opportunities of health" in the original) is the responsibility of one of the 27 Medical Social Expert Commissions (MSEC) under the Ministry of Labour and Social Protection. Two of them are specialized, working in the South and North of the country, and four of them are specific to psychiatric, ophthalmic and physiatrists (tuberculosis). People apply to the examination by the commission after treatment in primary health care organizations or based on referral from secondary health care organizations[29]. The MSECs are then responsible for establishing the "structure and extent of restriction of activity of the citizen, and also determination of measures of rehabilitation and social protection" (Art 1.1).

However, as extensively reported by parents of children with disabilities who participated in this study, the only MSECs that seem to function adequately are those in large cities (Bishkek and Osh), which are quick to respond to parents and doctors' concerns, and do not require out-of-pocket payment. Local MSECs either do not exist, do not reach the rural areas, do not have adequate human or technical expertise or simply refer parents to another MSEC in Bishkek or Osh. More importantly, parents in every small town FGD reported instances of bribery when applying for a determination of disability. While this is supposed to be a procedure free of charge, parents have been asked to contribute with anything from money (cash, "first 3 pensions"), to goods (honey, sheep). When advised – by an NGO or the MSEC in Bishkek – to follow up with an official complaint, parents are reluctant to do so due to fear of retaliation.

For a person to be recognized as having a disability, several conditions must be met: (1) the person must have a permanent disorder of the body functions or systems, caused by a disease, or a consequence of illness or defect, in accordance to the International Classification of Diseases-10,[30] (2) the disorder must result in activity restrictions (either complete or partial loss of the ability to self-care, move independently, "communicate, to control the behaviour, to study or be engaged in labour (sic) activity" (1.2.a), and (3) require measures related to social protection, including rehabilitation. As described above, adults with disabilities will be further categorized under groups I, II or II depending on the severity of the impairment, and persons up to 18 years old will be categorized as "child with limited opportunities of health".

According to Order n.675, the assessment procedure is described as follows:

1. A person undergoes a complete physical examination by a physician who determines the disease, injury or defect that cause the permanent restrictions;

2. The person presents the health expert of the MSEC the documentation provided by the attending physician (step 1 above);
3. The person enters a comprehensive health assessment (hospitalization);
4. The person is assigned (or not) a disability status;
5. In case of recognition of disability, the MSEC develops the Individual Programme of Rehabilitation.

However, a report given in interview by the chairperson of an NGO indicates that a simplified assessment procedure has been implemented for children, a procedure that indicates children can be assessed without the required hospitalization. In addition, the initial requirement that all children with disabilities be re-assessed yearly has been revised. In some cases (e.g. autism) the first assessment is valid for 5 years and, if confirmed, it is then provided indefinitely.

As confirmed by the participants in this study, and reported by United Nations Development Programme (UNDP) in 2016, various obstacles exist in assessing and determining disability.[31] Lack of coordination and monitoring of the process of assessment across ministries, and between ministries and OPDs, and issues related to accessibility, assistive technology, and provision of services as anticipated in the law continue to be barriers.

However, parents and NGOs indicated that the greatest barriers to assessment and determination of disability status are:

1. lack of technical capacity of doctors and frontline workers combined with the lack of a mechanism of Early Identification and Early Intervention;
2. lack of knowledge – by professionals and the general population - with regards to delays and disabilities which prevents them from seeking or retaining help;
3. lack of transparency and professionalism within most responsible structures at Oblast and local levels.

Psychological Medical Pedagogical Commissions/Consultations

Once a child of age 3 and above has been identified as having a disability, the legislation envisages that an education plan be devised by the Republican, Bishkek city or any of the 24 regional Psychological Medical Pedagogical Commissions/Consultations (PMPC) under the Ministry of Education and Science (MoES). Their responsibility is to recommend the form of education that a child with a disability should receive (special or mainstream), based on a complex diagnostic. Two commissions are stationary (Bishkek city and Republican) and work permanently throughout the year and the regional consultations provide their services – for one week - before the start of the academic year (August) and at the end of the academic year (May)[32]. According to a Republican PMPC representative, the Regional PMPCs are composed of doctors, teachers, special school professionals, auxiliaries, etc. and operate upon parental request.

The PMPC assessment is based on guidelines for enrolment of children with disabilities in education developed by the MoES in 2008.[33] According to these guidelines, the enrolment of a child in school is based upon a list of diseases that is used to determine whether the child can enrol in a mainstream school or, alternatively, be provided home-schooling.[34] Likewise, the guidelines determine placement in special schools. The educational assessment is based on a medical diagnosis, parent and doctor's information, and tests conducted by the PMPCs, as needed. A child may be sent to a clinic to establish a diagnosis, or to a specialized institution in the decision-making process.[35]

While a UNDP study[36] indicated that assessment of children is difficult due to the regulation of the PMPCs, our research indicates that there is no common understanding of the role and the actual procedures undertaken by PMPCs. While PMPC representatives are adamant that they follow established procedures with changes made to account for local contexts, parents of children with disabilities reported no contact with PMPC except in the instances where they are actively seeking that their child be placed in a special school. Otherwise, parents whose children with disabilities attend their local school indicated that the decision to enrol was taken by the school director and the teachers, often involving the payment of a bribe. The predominantly exclusionary effect of the action of the PMPCs has recently been reconfirmed in a research, that called for an abolition of the very institution of the PMPC, if inclusive education was to be promoted.[37]

1.4. Quantifying children and adolescents with disabilities

One important aspect for quantifying children and adolescents with disabilities in Kyrgyzstan, or elsewhere, is the availability of reliable data; in order to determine the size of any sub-set of the population it is crucial to know the exact size of the entire population. In Kyrgyzstan this presents an issue since the Multi-Indicator Cluster Survey (MICS) indicates that 1.8% of children (1.8% male and female, 1.3% urban and 2.1% rural, 4% mother with functional difficulties) were not registered at birth, and only 73.7% of mothers were able to show birth registration documents of their children during the MICS survey. This is one of the reasons why calculating the entire population of children with disabilities in Kyrgyzstan is problematic.[38]

Another reason is related to data sources and their reliability. In Kyrgyzstan - as in many other countries in the region – official data on the number of children with disabilities is that which corresponds to the number of children (with a disability) who receive a state benefit. However, because the data reported by a government source (in Kyrgyzstan, the National Statistics Committee) is gathered by various administrative services, there continues to be the possibility of finding conflicting data, as demonstrated below.

Table 4 aggregates data reported by the same source (NSC) but gathered from different agencies. Then, the number of "children with disabilities under 18" from Table 4 again used by the NSC for comparison purposes (see Table 5), although the data used is from 2 different administrative sets: for the years 2012 to 2016 the data refers to social trends (source 1), while for years 2017 to 2019 it refers to social welfare (source 3).

Table 4: Number of children with disabilities according to different data sources

	NSC Source	2012	2013	2014	2015	2016	2017	2018	2019
Children with limited health functions from childhood	1	24,549	25,882	27,024	28,270	29,561			
	2							30,000	29,000
% from total number of people with limited health functions	1	16.9	16.4	16.3	16.2	16.4			
% from total population according this age	1	1.2	1.3	1.3	1.3	1.3			
Children with disabilities under 18	1	25,346	26,672	27,450	28,200	29,317			
	2						30,000	31,000	
	3				28,200	29,317	29,948	29,834	32,013

Source 1- Source "Social Trends in the Kyrgyz Republic 2012-2016," Issue 13, p. 104 Bishkek 2018, available at http://stat.kg/media/publicationarchive/4d455bc5-357c-49c7-a735-3ac469a69e89.pdf retrieved 20 March 2021

Source 2- Statistical yearbook 2014-2019, National Statistic Committee, Chapter "Income level," page 112, available at http://stat.kg/ru/publications/statisticheskij-ezhegodnik-kyrgyzskoj-respubliki/ retrieved 20 March 2021

Source 3- Statistical yearbook 2015-2019, National Statistic Committee, chapter "Social welfare." Page 179 available at http://stat.kg/ru/publications/statisticheskij-ezhegodnik-kyrgyzskoj-respubliki/ retrieved 20 March 2021

Table 4 (above) and Table 5 (below) are illustrative examples of how unreliable data on "disability" can be, how variance is introduced by means of administrative data, and how difficult it might be to correctly answer the question "how many children with disabilities are there is Kyrgyzstan". Nevertheless, for the purposes of discussions in this Situation Analysis and aware of its limitations, this research will use data reported by the NSC.

The existing data from the NSC indicates that the overall number of children with disabilities has grown steadily overtime, from 20660 in 2007, to 32013 in 2019. However, this variation in the number of children recipients of a disability benefit should not be interpreted as a variation in the number of children with disabilities in the country.

Data as reported in Table 5 – although they vary according to source – indicate that approximately 1,3% of the children in Kyrgyzstan are children with disabilities, a percentage that has remained stable since 2013.[39] However, this figure considers only children eligible for monthly social benefits. This number does not correspond to the total number of children with disabilities in the country.[40] Indeed, even when compared to the expected global estimates that only take into consideration children with moderate and severe disabilities, the Kyrgyz estimate is severely undermined.[41]

According to official data (Table 6 below), in 2019 there were 4 categories of children receiving a state benefit related to disability or "children with limited health functioning" (column A):

1. children under 18 years old (Column B);
2. children under 18 years old with Cerebral Palsy (column C);
3. children born to mothers with HIV-AIDS (column D);
4. children with HIV (Column E).

Thus, in 2019, there were a total 32013 "children with limited health functioning" (thus, receiving a state benefit related to disability). This number included 26514 "children under 18 years old", 5017 "children under 18 years old with Cerebral Palsy", 95 "children born to mothers with HIV-AIDS" and 387 "children with HIV".

Table 5: Number of children [with disabilities] between 2007 and 2019

	Children [with disabilities] under the age of 18												
	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
Number of children with disabilities, people	20,660	20,842	21,194	22,359	23,565	25,346	26,672	27,450	28,200	29,317	29,948	29,834	32,013
Share of children with disabilities in the total number of people with disabilities, in percent	18.0	17.3	16.9	16.7	16.5	16.9	16.4	16.3	16.2	16.4	16.3	16	16.5
Share of children with disabilities in the total population of the corresponding age, in percent	1.1	1.1	1.1	1.1	1.2	1.2	1.3	1.3	1.3	1.3	1.3	1.3	1.3

Source: Source National Statistics Committee. http://stat.kg/ru/statistics/zdravoohranenie/ [table 5.02.00.28.]

Table 6: Children receiving state disability benefits, in 2019, by gender & oblast

	Including														
	A-Children with disabilities			B - children under 18			C- Children under 18 with cerebral palsy			D- Children born to mothers with HIV-AIDS			E- Children with HIV		
	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female
Total	32,013	15,096	16,917	26,514	12,496	14,018	5,017	2,393	2,624	95	42	53	387	165	222
Bishkek city	3,120	1,625	1,495	2,502	1,310	1,192	600	308	292	11	3	8	7	4	3
Chui oblast	4,792	2,214	2,578	3,906	1,789	2,117	838	402	436	43	20	23	5	3	2
Talas oblast	1,749	922	827	1,571	828	743	174	92	82	2	1	1	2	1	1
Naryn oblast	2,169	1,075	1,094	1,833	915	918	336	160	176	0	0	0	0	0	0
Issyk-kul oblast	3,520	1,910	1,610	2,946	1,602	1,344	570	305	265	2	1	1	2	2	0
Osh oblast	5,889	2,296	3,593	4,607	1,782	2,825	950	388	562	14	2	12	318	124	194
Batken oblast	2,867	1,402	1,465	2,493	1,219	1,274	372	181	191	2	2	0	0	0	0
Jalal-Abad oblast	6,971	3,299	3,672	5,943	2,807	3,136	1,008	478	530	9	7	2	11	7	4

Source: statistics provided by the National Statistics Committee (2021), based on data provided by Ministry of Labour and Social Development for the year 2019. Key: T – total; M – Male; F – Female

Available data (from 2017 and 2019) disaggregates children with disability in Kyrgyzstan by "condition/disorder" according to the International Classification of Diseases, version 10 (ICD-10) system of disease classification, despite government reports that indicate the normative framework was amended according to the ICF. Thus, while the amendment of the normative framework might have taken place this is not yet reflected in the available data provided in official records. As available, disaggregation is not provided by ICF code (i.e., body functions, body structures, activity and participation or environmental factors) nor does it indicate the quantification of the problem (i.e., no problem, mild problem, moderate problem, severe problem, complete problem, not specified or not applicable) but it is reported by the ICD10 code – which should not be interpreted as "having a disability" (as per the CRPD) or a "functional limitation" (as per the Washington Group or the Child Functioning Module 1).

Box 2: The difference between the ICD 10 and the ICF

ICF belongs to the WHO family of international classifications, the best known member of which is the ICD-10 (the International Statistical Classification of Diseases and Related Health Problems).

ICD-10 gives users an etiological framework for the classification, by diagnosis, of diseases, disorders and other health conditions. By contrast, ICF classifies functioning and disability associated with health conditions.

The ICD-10 and ICF are therefore complementary, and users are encouraged to use them together to create a broader and more meaningful picture of the experience of health of individuals and populations. Information on mortality (provided by ICD-10) and information about health and health-related outcomes (provided by ICF) can be combined in summary measures of population health.

In short, ICD-10 is mainly used to classify causes of death, but ICF classifies health.

Source: (WHO, 2002, p. 3)

Further reinforcing the idea that governmental numbers do not reflect the real number of children with disabilities in Kyrgyzstan, data collected by the 2018 MICS[42] puts the percentage of children reported to have a functional difficulty at 8.7%.[43] However, it is important to note that there is no possible comparison between the two data sets. On the one hand, government data refers only to children who have been identified - through a narrow process of medical observation/diagnosis - as having a disability and are eligible for a disability pension. On the other hand, MICS methodology does not survey for a static medical condition (e.g., blindness or deafness) and does not ask a respondent if they have a disability. Rather, it surveys for levels of difficulty, if any, in separate domains. In other words, MICS does not count disability. It indicates how many persons in a given population have no difficulty, some difficulty, a lot of difficulty or cannot do at all in questions related to seeing, hearing, walking, fine motor, communication, learning, playing and controlling behaviour. However, because it does not measure context or environment, the MIC Survey alone cannot determine disability.[44]

With regards to children ages 5 to 17 years old, in 2018, 8.9% of children had functional difficulties in at least one domain, with percentages higher for boys (9.2%) than girls (8.7%), in direct contrast with the findings in younger children.[45] The percentages for rural (9.6%) and urban (7.5%) areas followed the trend found for younger children. MICS data also indicated that, the older the child, the least likely they were to be reported as having a functional difficulty. No direct relationship between percentage of reporting and the mother's education was found, as for younger children, but a direct relationship between the wealth index quintile and reporting was noted: the higher the wealth quintile the less likely was the reporting of a functional difficulty.

2. REALIZING THE RIGHTS OF CHILDREN WITH DISABILITIES

Realizing the rights of all children – including children with disabilities – requires that universal public services are inclusive - be accessible for all and adapted to the specific needs of each and everyone, including children with disabilities. However, as described below, the lived experiences of children with disabilities in Kyrgyzstan indicate that an enabling environment is not developed or inclusive.

The motto "Nothing about us without us" is at the heart of the CRPD philosophy, reminding decision makers and persons with disabilities that nothing that affects the lives of persons with disabilities can be done without their direct and active participation. However, meaningful participation is conditional on the creation of an enabling environment including respect for their personhood, non-discrimination and equal treatment, fear from suppression and intimidation, provision with support for living in the community, access to information and provision of reasonable accommodation.

2.1. Early Identification and Early Intervention (EIEI)[b]

The first 5 years in the life of a child are crucial for their growth. Young children learn about themselves and the world around them by interacting with objects and persons, parents and families.[46] However, each child has a unique experience, and progression through their milestones can be obstructed.[47] Early Identification and Early Intervention of children with disabilities or those at risk of a disability or delay is well documented as a systemic approach to service delivery that is centred on support for children and their families.[48] It aims to ensure children acquire and use behavioural competencies and social interactions in order to maximize their participation in home and school. EIEI is the first step in identifying barriers to access and participation and promoting full involvement in all activities and daily routines.[49] For children who present with disabilities or developmental delays and their families, EIEI is an essential mechanism is ensuring that children are supported in participation, and that families have at their disposal the essential services required to enhance their potential.

Box 3: Access to EIEI – a case study

Timur* was diagnosed with Down syndrome at birth and his parents considered themselves lucky to have had such an early diagnosis as they found that this was not the norm. His family fought against negative attitudes and a lack of information to give him a good quality of life and an inclusive education.

For more details: read case study D in annex

At the time of the conclusion of this study, Kyrgyzstan does not have a policy for implementing early EIEI at the national level. The education, health and social protection sectors provide some services to children with delays or disabilities and their families, but mostly in a fragmented way. The review of the existing services shows that identification is dominantly conducted by medical workers; thus, due to a lack of cross-disciplinary knowledge, the range of possible intervention is limited to medical services. However, even within the health care system there is a lack of mechanisms to orient horizontal and vertical interactions between

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[a] An in-depth review of the EIEI services in Kyrgyzstan was completed in the course of this research.

levels. Together, these shortcomings support the findings from a significant number of studies that have suggested that a comprehensive, coordinated, multidisciplinary, interagency early intervention service program should be developed, in order to reduce the likelihood of developmental delays and increase the ability of families to meet the special needs of infants and young children to overcome dominant medical model.

As reported by participants in Focus Discussion groups conducted for this study, at the present time, there are discussions regarding the role of various professionals within an EIEI mechanism, both as it currently happens and their potential roles in the future.

As reported by parents of children with disabilities, delays and disabilities are seldom diagnosed at birth due to a lack of adequate screening, medical competence, and/or adequate equipment. With regards to Down's Syndrome and other intellectual disabilities, parents still request health professionals to engage in medical/pharmaceutical interventions because there is a lack of understanding of the conditions.

> *Parent of a deaf child suspected her child's hearing loss when she was around 3 months old. Doctors in her city (Naryn) recommended that she goes to Bishkek, but she could not afford the trip. The child was only seen by a specialist at age 4.*

Health department professionals are the experts in the development of the physical body – they both diagnose and treat problems of development in childhood which are aspects of disability and developmental such as epilepsy, heart defects, low weight and problems of the gastrointestinal tract. Health professionals are essential in determining if a child has (or is at risk) an impairment. But, to determine a disability, they should be encouraged to work in collaboration with others, including rehabilitation professionals such as the LFK (physiotherapists), speech therapists, assistive technology specialist and others who have a complementary skill-set and are essential in teaching and re-teaching physical skills after there has been a disruption from some impairment. As described below (and in many other accounts) doctors who diagnosed children as having a disability or delay do not refer them to other professionals.

> *A parent recalls that when she gave birth to a child with Down's Syndrome no one told her about it. She noticed the medical nurse crying when they left the hospital. As the mother started observing developmental delays over the next 7 months, she took her child to Bishkek for testing. However, the specialist advised the mother to not spend a great deal of money (5000 soms) on genetic testing, because it is already seen the child has Down Syndrome. She was told to "spend your money on treatment and medicine instead of unnecessary test".*

Likewise, it is very important to involve other specialists and promote cross-sectoral collaborations with, for example, social workers and preschool teachers, particularly on a community level. Social workers have the most experience and knowledge on where community resources are and how to access them. They should be skilled in managing complex situations, coordinating care and often have training in providing emotional and practical support to families.

> *One parent reported that the Individual Programme for Rehabilitation written by MSEC all say the same thing: "The child needs rehabilitation in their locality". There are no other recommendations or descriptions. "Our social workers don't even understand the diagnosis, how can they provide rehabilitation?"*

Early childhood development (ECD) specialists and teachers have the most experience in teaching children's skills for learning and for life, as they are often engaged in teaching small children's skills of dressing, eating independently, washing their hands and face and using the bathroom, as well as social and emotional skills. Children with developmental difficulties might need different techniques to help them to learn these skills but experience has shown that early childhood teachers understand these techniques very quickly and can apply them.

Coordination between all relevant authorities and organisations is key.[50] There is no mapping of the existing services and an identification of gaps. This is needed, to ensure that at least the three key sectors (health, education, and social protection) collaborate at the central and local levels throughout the life cycle. Likewise, more reflection on ensuring rights and guaranteeing coverage with services is needed, including a focus on financing and notwithstanding the mode of delivery, be it via public services or third sector providers financed by public commission. The main target should be not wait until children reach pre-school to involve education professionals.

2.2. Early Childhood Education and Care (ECEC) and Education (Art. 24)

The CRPD Committee stresses the value of early childhood education for children with disabilities, noting that they are more likely to transition smoothly into pre-primary and primary inclusive education settings if they are identified and supported early. For this, close and continuous coordination between all relevant authorities and organisations is key.[51]

Box 4: Access to education – a case study

Ermek* went to several examinations before he was finally diagnosed with autism. Whilst all institutions would push towards putting him into an institution of special education, the insistence of the family together with a significant investment did allow him to participate in mainstream education.

For more details: read case study A in the annex

The right to education for children with disabilities in Kyrgyzstan is officially enacted and an international obligation (due to the ratification of the CRPD). However, in practice, it is not offered to many children with disabilities[52] despite the Constitution of Kyrgyz Republic 2010 guaranteeing that every citizen has right to education (Art.45)[53] and the Law on Education, 2003 (Art.4).[54]

One of the main objectives of the Education Development Strategy 2012-2020 (EDS 2012-2020) was the implementation of inclusive education[55], and identified pre-school education as one of key governmental priorities[56]. Likewise, the National Development Strategy of the Kyrgyz Republic for 2018-2040, includes the commitment to form a system of continuing education and the implementation of social inclusion[57] through the development of a legislative environment that accepts the diversity of educational needs of the population. The new early childhood educational standard on "Pre-school Education and Child Care", approved on June 29, 2020, was developed based on the Diary of Child Development (developed in 2016 by the Kyrgyz Academy of Education, with experts from the Health sector and support of UNICEF), elements related to gender and peace/social cohesion, and should include an inclusive approach and the accessibility of pre-school services for children with disabilities.[58]

Despite the Kyrgyz government approval (July 19, 2019) of the Concept of Inclusive Education and the Programme of its Implementation in 2019-2023 (Decree № 360)[59], the current legislative and policy framework of the Kyrgyz Republic is inadequate for the realisation of inclusive education and contrary to CRPD's Article 24, as the education of children with disabilities is considered only in separate forms: special groups, classes or organisations with the goal to provide treatment, education and training, social adaptation and integration into the society.[60] This law does not contain a definition of inclusive education, nor does it have measures for the provision of alternative communication modes in education. There is neither obligation to promote the learning alternative communication modes by teachers, nor measures to employ teachers with disabilities. In addition, it does not regulate access to assistive products. However, the Law on Rights and Guarantees of Persons with Disabilities envisages that "people with hearing and visual impairment are provided by the services of a sign language interpreter in educational organizations" (Art.3)[61] - the state is thus obliged to train sign language interpreters and teachers, 'defectologists' and speech therapists.

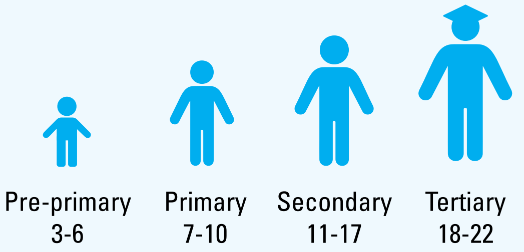
The ensemble of legislation on preschool education, vocational training and higher education is not disability-inclusive and calls for revision.[62] Therefore a legal revision of the most recent education-related law and norms, it is strongly recommended.

Data on access to education

In 2018, 39.5% of household heads completed secondary, 25.3% professional primary/middle and 25.1% higher education, reflecting a well-educated population that likely places a high value on education. Compulsory education includes 1 year of pre-primary and 9 years of primary and secondary education, with primary education starting at age 7.[63]

Figure 1: Schooling system in Kyrgyzstan

Official school ages by level of education



School-age population by education level

Pre-primary	629,002
Primary	519,775
Secondary	724,083
Tertiary	516,666

- Compulsory education lasts 10 years from age 6 to 15
- For primary to post-secondary education, the academic year begins in September and ends in May

Source: UNESCO. (n.d.). Education and Literacy Kyrgyzstan. Retrieved from http://uis.unesco.org/en/country/kg (UNESCO, n.d.)

Overall, 39% of children ages 36-59 months (39.7% male and 38.3% female, 47.3% urban and 35.2% rural) and 47.4% of 3-5 years old (46.4% male and 48.6% female, 55.8% urban and 43.7% rural) are attending early childhood education.[64] This number is higher (49.4%) for children with functional difficulties.[65] The Early Child Development Index measures the percentage of 3-4-year-old children who are developmentally on track in literacy-numeracy, physical, social-emotional and learning, providing an Index Score (ECDI) indicated that, in 2018, only 71.7% (68.2% male and 75% female, 75.8% urban and 69.8% rural)[66] children were on track.

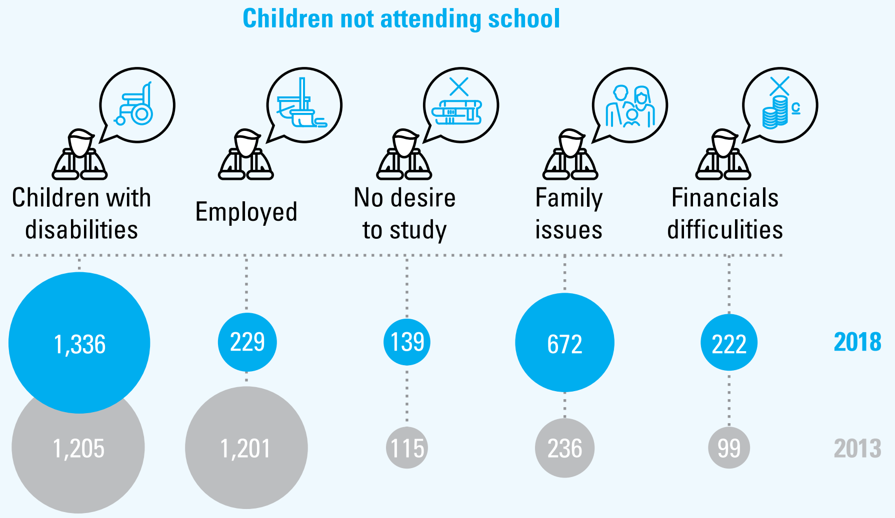
No data was found that indicates participation and completion rates disaggregated by children with disabilities or functional limitation. Likewise, the existing data on out-of-school children in Kyrgyzstan is problematic, as it is unclear whether the data available by UNESCO considers the number of students with disabilities in special schools or only those attending mainstream schools. In any case, the rate of out-of-school (OOS) children is larger among children whose mother reported a functional difficulty, at age 7 (1.5% vs 1.3%) and age 10 (1.6% vs 1.0%), and declines as wealth index quintiles (Q) grow: (Q1-1.7%, Q2 – 1.6%, Q3 -0.5%, Q4-0.4%, Q5 – 0.7%), with the exception of the highest quintile.[67]

When asked about the reasons for not being in school, the response most often given by out-of-school children (as reported in the VNR – below) is having a disability - the percentage of this response has increased between 2013 and 2018, demonstrating that the system has become less inclusive of children with disabilities, as can be seen in Figure 2.

Interestingly, our research revealed that having a disability is not, in itself, the reason for children with disabilities to be out of school. Rather, negative attitudes of professionals towards children with disabilities and/or lack of necessary conditions are the most cited reasons for children with disabilities to be out of school. Some of the parents (Bokonbaevo rural village), reported:

- "previous school director didn't accept children with visible disabilities",
- "there is no individual program",
- "don't have a proper wheelchair and nobody at school will help to move from class to class",
- "teachers informed they cannot control the situation [seizures] home education was not provided",
- "teacher cannot pay special attention to her".

Figure 2: Reasons why out-of-school children are not in school



Source: (Government of the Kyrgyz Republic, 2020d) Voluntary National Review VNR 2020, pg. 54 (image)

The reasons given in the urban areas (Kyzyl Kia city) are not much different, reflecting a system-wide lack of knowledge and professionalism. For example, parents reported:

- "went to specialized school but was met with bullying, especially from older children",
- "every day go to school with my child and moves his wheelchair from one class to another",
- "Due to systematic epilepsy attacks the school dropped the child to get home education",
- Child wasn't accepted by specialized school",
- "teachers didn't accept child with cerebral palsy (...) other children would be shocked and scared".

An additional obstacle to enrolment and attendance - and a very important factor to consider, as reported by parents - when placing children with disabilities in the local school (or helping them stay in school) is the payment of a bribe to a school director to allow enrolment, or to a teacher (called a "hat") to ensure adequate attention is given to the child while at school. As indicated above, bribery of professionals involved in education, early identification and early intervention, and health (as described below) is a frequent obstacle to the social inclusion of children with disabilities in all areas of life.

Existing system of education for children with disabilities

According to MICS 2018, preschool education covers only 39% of children ages 36-59 months in Kyrgyzstan[68], a low coverage despite the increase from 22.7% in 2014. Half of children from high-income households attend preschools compared to 12% of children of low-income households. In addition, only 83 out of the 2144 (3%) children ages 3-5 years attending early childhood education in 2018 had functional difficulties[69].

To widen access to preschool education,

community-based kindergartens for children of 3-5 years old were established in rural areas of Kyrgyzstan. Another alternative is the one-year preschool programme "Nariste" (480 hours), in the year prior to entering the 1st grade. However, despite its declaration of inclusive principles, the programme establishes criteria for the inclusion of children with disabilities based on diagnoses - to participate, children must go through PMPC assessment. Therefore, for many children with disabilities, attending special preschool is the only chance to get preschool education, with the system providing services for children with speech, intellectual, vision, hearing and musculoskeletal system disorders or impairments. At the present time, there are 14 special pre-schools (11 of which are located in Bishkek) that cater to 1775 children.

Many nongovernmental organizations such as "Luch Dobra", "Sunterra", "Hand-in-hand", "Ymyt-Nadezda", and "Association of Parents of Disabled Children" established centres for children with disabilities of pre-school age, including programme-development, specialist training and infrastructure adaptation. Some include children without disabilities in an attempt to create an inclusive culture in their setting.

Data related to education in Kyrgyzstan, often does not include or refer children with disabilities because they are mainly placed in segregated settings. While there is data on the number of special schools and of children with disabilities in each special school/residential institution for children with disabilities, information on education programmes and quality of teaching is rare. The participants of this study could not provide specific or reliable information, or documented descriptions. Reports from Bokonbaevo village indicate that the support children with disabilities receive in school is varied. One youth said:

> *"Due to illness, I often miss school, but my teachers and classmates always provided me with help and support. I went to Bishkek for treatment and then came back and caught up with the programme. I am currently studying in college. Here, too, everyone understands. I have no difficulties in my studies. When my legs swell, I can safely leave the classroom" (boy, 17 years old, studying law).*

Another student confirmed receiving support:

> *"When my classmates are doing physical training, I sit in the classroom, as the teacher exempted me from these lessons" (boy, 16 years old).*

A third student reported that he entered school when he was 6 years old and should now be in 4th grade. However, he is in 1st due to spending several years in zero class. He does not have an individual plan.

> *"When I come to school, the teacher gives me an assignment and sends me home. She says I don't feel well, I am sick. But that is not true. I want to study with other children. They stay and continue to learn. I feel very sad about it. I have to return home only receiving assignments" (boy, 10 years old).*

As demonstrated throughout this report, data related to children with disabilities is scarce and varied according to the reporting source. According to data from the nongovernmental sector, only 1/5 of all children with disabilities go to school[70]. Official statistics indicate that only 305 children with disabilities of schooling age attend mainstream schools, but information related to the substance and quality of the education provided is scarce. Likewise, a recent report by a human rights organization claims that less than one out of three children with disabilities have access to any kind of schooling.[71]

Types of education available to children with disabilities

The MoES considers "correction classes" a way of widening access to education to children with disabilities and prevent their institutionalization. In 2019, the total number of students in correction classes in 4 schools in Bishkek was 200; in 2020, this number increased to 289. Despite a course on inclusive education being required by the state[72], many teachers continue to advocate for correction classes as the best way of teaching children with disabilities. Thus, special education is the main form of education for children with disabilities, although parents would prefer to send their children to mainstream classes.

At present time there are 14 special schools for children with different types of disabilities which work according to the standard regulation on Special Educational Institutions for Children and Adolescents with Mental or Physical Disabilities[73] - for the last 25 years, regulatory legislation, programmes, materials, didactical base and learning resources (textbooks) have been unchanged. In many schools, children with disabilities live full-time, and are separated from their families. If a child is admitted to a special school, the possibility of transferring to a mainstream school is no longer considered, with the exception of isolated cases with considerable efforts by the parents. This constitutes a violation of CRPDs' Articles 19, 23 and 24.

In October 2018, the government adopted the resolution No. 477 On Approval of the Regulation on the Organization of Individual Education at Home[74], that states that children with developmental disabilities are eligible to access individual education at home upon PMPC recommendation. Teachers from local schools go to the child's home and provide an education plan based on state educational program. However, teachers are not trained on how to adapt individual programs, use adapted teaching methods, and modify/adapt learning materials. A boy who receives home education reported:

> *"I don't go to school because my mother cannot spend half the day in schools carrying me from class to class. She needs to work. And I became heavy. (…) School is not far. I would like to go to school with other children" (boy, Kyzyl Kia).*

In Nookat city, a girl who also receives home education does not know what grade she is in; the teacher who escorted the girl to the FDG would not say, only that she is teaching her basic literacy. In the same city, two parents reported that their children received home education.

> *"I would like to send my daughter to school, but it is difficult for her to walk, I think she cannot move like other children. We are satisfied that the teacher comes home and teaches her to count, read and write. My daughter likes to draw".*

> *"My daughter has a home education. Teachers come to our home, but my daughter cannot study for a long time. Our lessons should be short".*

While the literature reviewed for this study, and the information gathered from various professionals, places much emphasis on the role of PMPCs in the placement of children with disabilities within education, information gathered from parents and youth with disabilities provides a different view. While NGO representatives indicated that children are often taken to Bishkek for the PMPC because the local consultations are not operative, lack of information about the PMPCs was widespread among parents of children with disabilities, as reported in FGDs.

In one village in the rural north, 6 parents of children with disabilities ages 15 to 19 had never heard of the PMPC; most children had never attended school or had dropped out shortly after primary school. Likewise, in a city in the urban north, no parents reported being familiar with PMPCs. On only 2 occasions (throughout the entire data collection) did parents report engaging with the PMPC: on both occasions, parents received recommendations to place their children in a specialized school, which the parents declined due to not wanting their children away from home.

In Naryn city, a family sends their daughter to school every day in a taxi that they pay for themselves. In the same city, another parent sends his child to a mainstream school but reports that there are no adapted programmes for him.

> *"Often teachers call from school and ask me to take my child out, as he beat other children. Sometimes other students complain my son tore their notebooks. I buy them new ones. But I noticed that they began to ask me to buy a notebook even if my child was not at school" (parent, Naryn city).*

A boy reported:

> *"Teachers know that study is difficult for me. Sometimes they give me concessions, but in general I have a very difficult time. My mother always supports me. She helps me do my homework, talks to teachers" (Boy, 12 years old, Kyzyl Kia).*

Of concern is a lack of information about the quality of education provided in segregated settings; however, reports by stakeholders indicate that even young adults with disabilities who leave special schools do not know basic literacy and numeracy skills.

Transition to work and employment (Art.27)

According to the literature, the transition from school to work remains a key challenge for adolescents with disabilities. After compulsory education, adolescents and young persons with disabilities enrol in higher education or vocational training and education (VET) schools, or directly engage in unqualified employment, frequently informal. However, while the youth who participated in the FDGs had dreams and aspirations for future employment, none mentioned the pathway they would take to achieve them. Recent MICS data reveals that more than one out of three children with functional difficulties are involved in child labour, whereas for their peers without functional difficulties, the ratio is only one out of four.[75]

In response to the right of work of young persons with disabilities, the government has to regulate and facilitate bridging education pathways, that will allow these students to achieve continuous educational progression and lifelong professional development.[76] However, legislative stipulations of the right to work and on school-to-work transition are still underdeveloped. The recent law on education does not consider employability, vocational rehabilitation and active job-placements.[77] In addition, there is a specific challenge related to the employment of children who leave care institutions where no assistance or support is provided, other than their enrolment in technical colleges,[78] but specific National Plans that promote vocational training that is inclusive of persons with disabilities are non-existent and, in the mainstream Vocational Training and Education (VET) policies, disability is barely considered.[79]

The national public employment service is obliged to oversee the 5% quota and offer job-placements for persons with disabilities, including adolescents. However, in practice, there seems to be a general lack of understanding of the law. Specific 'traditionally-adequate' occupations are often imposed on young persons with disabilities in their professional orientation- blind adolescents are directed towards massage and deaf adolescents towards sewing.[80]

Despite an uncertain future and not many examples of persons with disabilities who are independent and successfully employed, all children and youth with disabilities who participated in this study have dream and hopes for a bright future, similarly to children and youth without disabilities. Their wishes for the future were as diverse as the children themselves:

> *to become a doctor, a teacher, a military officer, a pharmacist, a seamstress, a car mechanic, IT specialist, professional chef, accountant, dancer, professional singer, etc.*

However, parents of children and youth with disabilities did not have positive outlooks for their children's futures. While some parents reported not thinking about the future because of associated worry, other parents reported worrying about what would happen to their children once they died.

No data is available in Kyrgyzstan on salary levels and the comparison between persons with and persons without disabilities. However, disability rights advocates claim that there is a significant cleavage in the pay levels, often leaving households with persons with disabilities in additional stress to achieve a decent living standard, as compared to their peers without disability.[81]

Likewise, parents and caretakers of children with disabilities should be able to pursue employment, and, thus, access their right to work. Adaptation also refers to the facilities for this target group. In contrast to this provision, the practice in Kyrgyzstan often obliges parents, particularly women, to prescind of paid employment: Project-related surveys report that only one out of four mothers with children with disability is in full-time employment.[82] However, nearly all mothers of children with disabilities who participated in FGDs reported being the caretaker for their child, almost exclusively. The post of "personal assistants" instated in 2019, as discussed in section 2.4 of this report, has slightly alleviated their income situation. However, the lack of communal services prevents mothers to engage in gainful activities, and, in some cases, their remuneration as personal assistants locks them in on a low level of take-home pay.

2.3. Health (Art. 25)

CRPD Article 25 guarantees the right of persons with disabilities to the highest attainable standard of health, on an equal basis with others. It obliges the States Parties to ensure equal access to healthcare services, that must be gender- and age-appropriate[83] and protects the right to both general health services and disability-specific services, including early identification of health needs, timely interventions, and prevention of secondary impairments[84] to be provided as close as possible to people's own communities, including in rural areas.

The Kyrgyzstan Republic's constitution guarantees the universal right to health protection, with free medical services provided by, and under the responsibility of, the State (article 47) and to a healthy environment (article 48), with minimum levels of health and labour protection being set for citizens in socially vulnerable situations (article 9).[85] In addition, it prohibits medical, biological or psychological experiments without a person's expressed and verified voluntary consent, legislating the provision of informed consent (article 22).[86] This centralized health-care system guarantees access to a range of free services, prioritizing hospital and curative care (rather than preventative), with significant regional imbalances in accessibility and quality[87]. Access to health is based on a 3-level model[88] of insurance and all citizens have access to the Basic Public Health insurance, that is State-guaranteed and includes provisions for specific populations, including children with disabilities

The Kyrgyz health system has received praise for the promotion of family medicine and by the priority given to its funding. However, challenges remain, such as the overtreatment and hospitalization of children,[89] the underdevelopment and centralization of the field of child and adolescent mental health[90], the lack of medical professionals in remote rural areas, the low level of qualification of medical personnel and equipment, and heavy workload combined with low wages, high outflow of the health providers, and poor governmental cooperation[91].

Health policy towards disability

Since 1996, a number of strategic programs have tried to increase the efficiency of healthcare facilities and attention to patients' needs, with particular emphasis on health protection of mother and child, primary health care and cardiovascular disease[92]. In 1997, a new system of compulsory health insurance started to be implemented and the compulsory health insurance fund was created[93]. This was followed by the development of clinical protocols and an increase in the quality of primary health care, especially to the most vulnerable groups of the population, exempted from co-payment. The range of medical services provided free of charge at the outpatient level for persons with disabilities was expanded. However, the validity of the treatment and diagnostic measures and their compliance with the very few clinical protocols developed by the Ministry of Health (with support from UNICEF) and introduced into clinical practice was limited.

Persons with disabilities are entitled to two hospitalizations per year, free medical services, and drug benefits.[94] The goal of promoting evidence-based medicine that helps to develop and provide quality health services for persons with disabilities was set in The National Programme of Reforming Health Care System in Kyrgyz Republic 2006-2010. It provided the development of clinical protocols, such as a clinical protocol for the treatment of child cerebral palsy, in which the ICF principles were applied. The National Health Care Reform Programme of Kyrgyz Republic 2011–2016 (extended until 2018) aimed at orientating the health care system to the needs of people and some diagnoses related to the assignment of disability status and congenital malformation monitoring system were developed, patient registers established, qualifications and skills of personnel drafted, and the training of medical workers done according to approved clinical protocols in the field.

The new Programme of the Government of the Kyrgyz Republic for the Protection of Public Health and Development of the Health Care System for 2019-2030 was signed on December 20, 2018. Its main goal is to strengthen people-centred systems that ensure public health and provide quality services throughout the lifecycle, and aims to reduce rates of disability (primary, secondary), of preventable diseases and of morbidity and disability (primary, secondary), with a focus on socially significant diseases[95].

Access to services by persons with disabilities

As reported by professionals and indicated in the literature, at the primary level, persons with disabilities are entitled to receive health care services provided by a group of family doctors, family medicine centres and a limited number of general practitioners' centres. In small villages with a population of 500-2000 people, primary services are provided by feldsher-obstetric services, often by middle level health professionals only. With regards to the provision of health services to children with disabilities it is reported that, regardless of registration, access to quality care services is poor, as the current system (with weak cross-sectorial coordination at central and community levels) remains focused on treating illness or disorders. This poses difficulties for early identification and targeted family support measures[96].

In general, when asked question related to their health, children and adolescents with disabilities who participated in FGDs did not understand the physiological origins of their impairments. None could explain why they had a disability registration, and some did not see themselves as "disabled". Some of the children reported going to other cities to receive medical treatment but could not explain what it was. In a city in the urban south the youth reported receiving a massage at home, going to a rehabilitation centre because "there we get treatment", or spending half a year at the hospital for treatment. One hospital in Bishkek seems to be the preferred treatment location, although there are reports that parents must pay for it.

Overall, health services are not available to children with disabilities, and certainly not available for free as legislated. Almost all parents involved in the study indicated that:

1. Local health professionals who recognize the potential for a delay or disability are reluctant to inform parents as soon as possible.

   "Doctors in Kyzyl Kia didn't want to recognize my child is disabled and always said that development is normal. They explained some development delays by premature birth" (parent, Kyzyl Kia)

2. When local health professionals refer parents to another hospital (Osh or Bishkek) for further observation/treatment they cannot/will not explain why that was needed. There is a lack of technical knowledge by medical professionals.

   "my child was diagnosed with cerebral palsy and the neurologist recommended a very strong and expensive medicine after which she became thin and sedentary. (…) family doctor said specialist could not give that medicine without proper tests (…) Republican health centre said local treatment was absolutely not correct" (parent, Kyzyl Kia).

3. local health professionals expected a bribe in order to identify an impairment (which must be completed to adequately pursue a disability certificate).

   "If I want to get treatment in Bishkek local medical doctors do not provide me proper tests and referral documents" (parent, Naryn city)

   "When I wanted to hospitalize my daughter in Nookat, they ask 5000 soms that I should give directly to doctor, even my daughter has a high temperature. In Bishkek the hospitalization is free. Then I complained to the akimiat (…) they refused to help me" (parent, Nookat).

   "When I come to policlinic with my child doctors always ask us to bring syringe, medications and other things. I know that all these things should be given free" (parent, Nookat).

4. Children with disabilities are not seen as general health care rights-holders, only as persons who require specialized care.

   "I'm always upset when I go to the doctors. I go to the doctors with the question that the child cannot breathe at night, has fever of something like this. The answer is always the same: 'What do you want? It's Down Syndrome'. Local doctors recommend only vitamins" (parent, Kyzyl Kia)

In addition, many parents report that the process of examination in Kyrgyzstan is complicated and bureaucratic. On the one hand there is a lack of specialized medical workers in rural and remote areas, limited set of diagnostic services, clinical standards and protocols, tools, long distance to secondary medical services, indifferent and negative attitudes of medical doctors. Research[97] on access to services provided by the health care system to persons with disabilities identified the lack of specialised medical workers - outflow of qualified personnel from rural to urban regions and abroad[98]. On the other hand, parents are often are not aware of the right to health and stereotypical or negative attitudes of medical workers towards persons with disabilities are barriers to access to health. In particular, there are reported indifferent and indulgent treatments and specialists looking at patients with disabilities as outcasts or with disdain, providing unequal treatment[99].

> *"Sometimes local medical specialists are afraid of doing massage to my child" (parent, Naryn city).*

> *"Every time I go to the doctors, they blame me for giving birth at 40". (parent, Kyzyl city).*

Research has shown that poor quality health care given to persons with disabilities in Kyrgyzstan can lead to their premature death.[100]

2.4. Habilitation and rehabilitation (Art. 26)

CRPD's Article 26 addresses the right to habilitation and rehabilitation. It stresses the multidisciplinary nature of (re)habilitation that should aim at attaining the maximum independence and inclusion of the person in all aspects of life. As with the right to health rehabilitation for all persons with disabilities should be community-based[101] and, recognising the shortage of rehabilitation specialists as the main barrier to access individualised high-quality rehabilitation, Article 26(2) calls for the development of rehabilitation corps.

Rehabilitation must be based on the multidisciplinary assessment of individual needs and strengths and be person-centred, goal-oriented, gender-sensitive and fit to achieve the purpose of including the person in the society on an equal basis with others. The OHCHR stresses that rehabilitation must always be based on the needs of the persons and not depend on official recognition or certification of disability.[102] The CRPD prohibits discrimination in accessing rehabilitation and obliges states to provide persons with reasonable accommodation, which may include modifications to the standard protocols of delivery of rehabilitation services, to meet the client's requirements.

Box 5: Access to (re)habilitation – a case study

Saltanat* has cerebral palsy and epilepsy. Her mother has dedicated great efforts to learning rehabilitation methods and raises funds for treatment abroad. Therefore, Saltanat's quality of life has improved, and she is able to communicate. While her mother learned about early intervention and rehabilitation late, she hopes that modern technologies can help her daughter´s ability to communicate and interact with others.

For more details: read case study C in the annex

In Kyrgyzstan, the rules on providing citizens with the technical devices for social rehabilitation do not depart from the CRPD core principle of person-centeredness and choice – but, most rehabilitation centres were, in 2018, reported to be private and dependent upon the payment of fees, with public (free-of-charge) centres in Bishkek and Ak-Suu and a new one being established in Jalal-Abad (to assist a residential institution for children, in the development of personal independence skills).[103]

Law No. 38 on Rights and Guarantees of Persons with Disabilities defines rehabilitation as the

> *"adoption of a set of medical, psychological, pedagogical, educational, professional and social, and measures for restoration of abilities for domestic, social, professional and other activities of an individual with limited physical or mental health functioning".[104]*

Habilitation was not defined or mentioned in the Law No. 38, but in the recent Concept on Inclusive Education, as

> *"the application of a set of measures of a medical, social, educational, pedagogical, psychological and professional nature, with the aim of forming the individual's absent abilities for domestic, social, professional and other activities".*[105]

As of 2019, occupational therapy and physiotherapy (requiring higher education qualifications), as well as social assistant, personal assistant, and occupational therapy assistant, are part of the national classification of occupations, as well as defectologists and oligophrenopedagogy (pedagogy used in teaching children with intellectual disabilities). However, most rehabilitation workload is still reliant on doctors who may not have the necessary training, knowledge, or skills, with a single fully qualified occupational therapist in the country.

Individual Program of Rehabilitation (IPR)

According to the literature, an Individual Program of Rehabilitation (IPR) including medical, psychological, pedagogical, educational, social and environmental, social and labour, social and cultural rehabilitation is developed, upon determination of disability and based on the results of examination by MSEC (see section 1.3 above). All services that are included in the IPR are guaranteed by the state. According to the Law n° 38, the main areas of rehabilitation for persons with disabilities include:

- restorative medical measures, prosthetics, and spa treatment;
- vocational guidance, training and education, assistance in job placement, industrial adaptation;
- socio-environmental, socio-pedagogical, socio-psychological and socio-cultural rehabilitation, social adaptation;
- physical culture and recreational activities, sports.[106]

As for (re)habilitation services for children and adolescents with intellectual disabilities (such as behavioural therapies, speech-language therapies, counselling), clients are often referred to private services in their IPRs, due to shortage or near absence throughout the country. For children with disabilities, the examinations for an IPR can be very stressful and report that specialists ask children to do some exercises but do not explain what they observe and what are results of these exercises. Parents do not participate in examination.

Stakeholder interviews reiterate what most persons with disabilities know and report: not everyone who needs it has an IPR that outlines the entitlement to rehabilitation services. In some cases, people don't even know what and IPR is, or find the paperwork overly complicated. In addition, the system presupposes that the applicant knows exactly what product or service they require, where to get it, and what the procedure is. Since, in reality, the general level of understanding and ability to work the system is low for many persons with disabilities, the access to assistive products and services remains limited.

A 2008 monitoring report on the rights of persons with disabilities as patients in the Issyk-Kul region confirmed that 94% of persons with disabilities surveyed were not aware about their entitlement to an IPR; this is corroborated by more recent personal experiences of parents of children with disabilities in the Kyrgyz Republic, as well as interviews with professionals.[107] Many rehabilitation services, guaranteed by the state law, are not available because, at present, there are no (re)habilitation specialists such as occupational therapists, speech therapists, vocational rehabilitation specialists or special teachers.[108] Thus, the services that should otherwise be provided are not even included in the IPRs.

When available, the focus is on medical rehabilitation, which is provided by the health care system, in detriment to other types of rehabilitation such as professional, psychological and social rehabilitation. Even with this focus, medical rehabilitation is not carried out fully, due to a lack of medical and technical means of rehabilitation. Reportedly, the result is a total deficit of rehabilitation services and provision of assistive technologies.

Parents who can afford it will pursue treatment in Osh, Bishkek, or even in other countries (Russian Federation, Uzbekistan and Kazakhstan). Others will stop treatment due to lack of financial resources or because they cannot access the health services due to lack of infrastructure. Moreover, children with disabilities and parents reported that rehabilitation services that were provided when the children were young and were discontinued when the children grew older.

One youth reported that he had received medical rehabilitation, but it had been discontinued:

> *"during the last two years I don't receive any treatment, although my back and legs hurt. I don't like massage, it can be very painful, but I need to get it. Therefore, I have to go to Ak-Suu, where I received treatment every year. But I have not gone there in a long time" (boy, Bokonbaevo village)*

One parent reported paying 8000 soms per month for speech therapy, an amount that most parents cannot afford. Doctors in the Russian Federation recommended that she stop the therapy and work with her child at home. She did not report this to her local doctor.

In Kyzyl Kia some children temporarily received services from a speech therapist. Parents paid between 50-100 soms per session to a therapist from a special school. However, the therapist stopped coming to the village and now works in the school full time, as private sessions are not profitable.

Box 6: Good practice: Development of a multisectoral rehabilitation programme in Tajikistan with support of the World Health Organisation

The 2010 polio outbreak in Tajikistan showcased the serious shortcomings of the country's rehabilitation system with nearly universal lack of access to modern rehabilitation services and products. Supported by WHO, Tajikistan developed its two-phase National Rehabilitation Programme: preparatory phase 1 in 2013-2016, and phase 2 in 2014-2019. The key strategic objectives of the programme are (1) strengthening rehabilitation services, (2) human resource development, (3) developing community-based rehabilitation and (4) policy development.

During the programme, nearly 90% of children affected by the 2010 polio outbreak received rehabilitation services, 138 health and rehabilitation professionals were trained in dealing with consequences of polio, further 8 specialists were trained for supporting the Ministry of Health in building long-term rehabilitation capacity, and occupational therapy units were built within the national rehabilitation centres. The WHO Priority Assistive Products List was used to adopt the first national list of priority assistive devices that includes 30 key products, using a dynamic participative approach.

Sources: (Mishra et al., 2018; WHO, 2017, 2018)

Non-governmental involvement in service provision

Perhaps due to a lack of state engagement, the non-governmental sector has become increasingly engaged in service provision and many NGOs in Kyrgyzstan provide services to persons with disabilities and even established rehabilitation centres. There are currently more than 50 private rehabilitation centres in Kyrgyzstan that provide different services for children and adults with disabilities. Their development is viewed as an essential step in providing the necessary educational, social and (re)habilitation services that the state does not provide to families with children with disabilities. Parents who have a good financial situation often hire private (re)habilitation professionals and these services have – reportedly - become very popular in the last few years. The appropriateness and safety of private interventions for the child are not always objectively measured and adverse effects are a real risk.

Creating rehabilitation centres can support in moving away from the "petitioners" to a new "human rights" level of activity, focusing on adaptation to new technologies (Internet, email, social networks, media projects) and consolidate efforts of similar organizations (networks, coalitions, associations) that can model new and innovative practices. However, such high level of ownership by NGOs can also mask the reality of the experiences lived by persons with disabilities and create a false sense of success that may result in continued government inactivity and incapability to provide quality services. However, as suggested by government officials, cooperation between the governmental and non-governmental organs is important because they provide an opportunity to exchange experiences and motivate the state to act.

Assistive technology

The CRPD definition of "universal design" and "accessibility" do not exclude the use of assistive technologies (products and services) by persons with disabilities and impose an obligation on States Parties to make assistive technology available at affordable cost (Article 20(b)). Governments should include them in the coverage of national health insurance or social protection schemes and consider other incentives, such as tax/duties reductions, stimulation of locally produced assistive products of high quality and investing in research. In order to meaningfully realise their obligation under the CRPD, states must ensure that the assistive devices are user-centred and age-appropriate, and trained personnel is available for prescription, fitting, user training and maintenance of products.[109] The obligation to provide them is a core obligation under the CRPD [110]and the state cannot use financial consideration to justify denial to essential assistive products.

Box 7: Access to assistive technologies – a case study

Amir* had several examinations before the extent of his hearing impairment (3-4 degrees) was determined. His parents had to take him out of mainstream school and enrol him in specialized school so that they could afford the installation and upkeep of cochlear implants.

For more details: read case study B in annex

The Law No. 38 of Kyrgyz Republic regulates access to assistive products or, as it calls them "technical and special devices".[111] However, the wording of the Article reflects Soviet-times legislation on social protection and does not seem to have been altered recently. It stipulates that persons with disabilities are provided with "orthopaedic and prosthetic products, technical assistive devices and other specialised devices" by the state, except if the disability is the resulted of an employer's wrongdoing, in which case the employer is financially responsible for provision of assistive products. It also obliges the state to provide schools for pupils with disabilities that require specific assistive devices such as special script printers, sound-enhancing technology, signalisation, etc. Technical rehabilitation is provided by the Republican Institution of Prosthetic and Orthopaedic Products. This institution works under the MLSD.

However, as reported, age-appropriate assistive devices of acceptable quality are difficult to obtain, particularly in rural and remote areas due to the lack of person-centred approaches, absence of choice and long waiting periods. In addition, there is a lack of consistent import chain which means that even if the financial burden is not an obstacle, child-size wheelchairs or communication devices may not be available in the country. One parent reported buying orthopaedic shoes for their child, at a cost of 4500 soms. They are purchased in Bishkek, but they have to be paid by the family.

The concerns over lack of access to assistive products was a repeated theme during the stakeholder interviews, and there were several accounts similar to the following statement from a stakeholder:

> *"One 3-year-old girl with Down syndrome needed the hand prosthesis, while her mother applied for such prosthesis from the institutions her daughter was provided a 10-year old's prosthesis."*

In addition, a representative of the parents' organisation of children with cerebral palsy reported that the authorities' failure to consistently involve the NGOs in tendering processes, resulted in the purchase of mobility equipment unsuitable for the intended users' age and requirements. This is particularly concerning for children with cerebral palsy for example, as standard adult-sized wheelchairs are known to increase the risk of scoliosis and decrease the child's function.

A mother reported:

> *"couldn't get a wheelchair for my daughter and local social workers and doctors explained that there is no need" (parent, Bokonbaevo village).*

After she placed a complaint the authorities provided them with a wheelchair, but it is not adequate for her child.

Personal Assistants

According to state policy, the main responsibility in supporting children with disabilities is given to parents, but this has been done without adequate supports being available. Organisations of parents of children with disabilities have been raising the issue of personal assistants since 1996 but only in January of 2019 as the Kyrgyz Government, created the position of personal assistant.[112] According to Decree No. 556, a personal assistant can be assigned to a child with a disability by the local department of social protection, based on a need expressed in the MSEC report. One of the parents, guardians or close relatives of the child can become a personal assistant and is paid an allowance. Also, a person who becomes a personal assistant is considered an employee and accumulates years of work that will count for their social security benefits. Thus, the care work is credited as seniority with regards to pensions entitlement in the social security.

At the time of this research for this study (2021), in Kyrgyzstan, there are approximately 6,000 children with personal assistants[113]. As reported by stakeholders and government officials in discussions, it is expected that attributing the role of personal assistant to a parent or caregiver will incentivize de-institutionalization or, at least, act as a deterrent for institutionalization. However, it should be noted that reporting on the remuneration of personal assistants of children with disabilities was not straightforward as the data seems to change according to source and/or the time period being reported.

Due to the lack of existing supports to personal assistants, of skilled trainings related to disability and of information regarding this provision, this has not yet had an impact on deinstitutionalization. It should also be mentioned that parents of children with disabilities who are placed in institutions were not informed about their right to apply for a personal assistant position, reportedly to avoid having them take severely disabled children out of the institutions.

Unfortunately, because the current legislation only covers children (up to age 18) many young persons with disabilities lack the support that can be provided by a personal assistant. As reported in FDG:

> *"I think that for children with severe disabilities like my daughter not only one but several assistants are needed: she cannot go to the toilet on her own, take a bath, but we are deprived of this right because our child is over 18 years old" (parent in Bokonbaevo).*

Accessibility (Art. 9) & personal mobility (Art. 20)

Accessibility is one of the pivotal rights enshrined in the CRPD. As well as a self-standing right, it is also a precondition for persons with disabilities to live independently and fully participate in the society on an equal basis with others. The Convention treats failure to provide access as a form of discrimination regardless of whether the perpetrator is a public or a private entity. The Kyrgyz legislative framework, particularly in Law No. 38, Law No. 6 on "On copyright" (Article 20)[114] and in the adoption of the Concept of digital transformation "Digital Kyrgyzstan 2019–2023"[115] there are a number of provisions but, despite a robust legislative framework, the research for this study confirms that the realisation of the right of persons with disabilities, including children with disabilities, to accessible environments, is lagging behind. The Kyrgyz government itself admits that physical infrastructures in many schools in the country remain inadequate for pupils with and without disabilities.[116]

Study participants reported that accessibility is mostly understood in a very narrow manner, with physical accessibility for persons with mobility impairments understood best, and requirements of other impairment groups mostly ignored.

Likewise, when designing accessible solutions, requirements of children with disabilities are often forgotten in favour of adults' requirements. Ensuring accessibility, is not realised in practice and rarely goes beyond ramps at the entrance to a building, excluding a large proportion of persons with disabilities.[117] In FGDs, at least 5 parents reported that their children did not attend school due to lack of an assistive device, or were fitted with wheelchairs that were not for someone their size.

Since 2015, the Administrative Code of the Kyrgyz Republic has foreseen sanctions for building design that does not include accessibility features for persons with reduced mobilities (Articles 470, 470-1, 475-1).[118] However, OPDs monitoring of public buildings (ministries, court, schools) in Bishkek showed partial inaccessibility of 5 out of 11 buildings, with no building being fully accessible for persons with different impairments. OPDs also reported nearly complete lack of accessibility of public transport, urban infrastructures and roads, and communication (no interpretation in sign language on public TV, no Braille signings in public places, difficulties in accessing Braille literature). Monitoring of new infrastructures for accessibility for persons with disabilities foreseen in the legislation does not take place systematically and has no consistent participation of experts with disabilities. There are no references to universal design, standards or sanctions and failure to provide accessibility is not included in the definition of discrimination.

In March 2017, the President of the Kyrgyz Republic signed the Law on Accession to the Marrakesh Treaty, which entered into force in the Kyrgyz Republic in September 2017.[119] The Kyrgyz Republic became the first country in the post-Soviet area to join the treaty and make the necessary changes to copyright legislation. Accession to the Marrakesh Treaty obliges the inclusion in national law of provisions allowing the reproduction, distribution, and delivery of published works to the blind and visually impaired in accessible formats through limitations and exceptions to the rights of copyright holders. However, the state does not publish literature in other formats (audio literature or books in Braille). Only minor publications are carried out with the support of international foundations in the framework of educational or cultural projects.

2.5. Social Protection (Art. 28)

The CRPD recognises the right of persons with disabilities and their families to adequate standard of living and social protection. This translates into the obligation to provide persons with disabilities and their household with social protection measures, that can be either transfers for minimum incomes or person-centred social services.[120] Also, to mitigate situations of poverty and ensure the principle of non-discrimination, the State is to consider disability-related expenses.[121] In that respect the CRPD links clearly to the international aspiration expressed in the Agenda 2030 (SDG targets 1.3 on reducing poverty and 10.2 on reducing inequality, both of which are to be disaggregated by disability status).[122]

In the last decade, the Government of the Kyrgyz Republic has seen a dynamic period in policy formulation in social protection[123] and has adopted and implemented several state programmes to support persons with disabilities.[124] A major paradigm shift towards a system of universal child grants, elaborated in 2017 by Government and authorized in 2018 by Parliament, had been stopped and reversed during implementation.[125] Currently the government plans to create a National Model of Social Protection and a Long-Term Concept of Social Protection Development Plan until the Year 2030, which would incorporate international best practices.[126] In general, disability has not yet been considered systematically in the domestic social policy debate.

More than 1.2 million people in the country - 22 % - are living below the national poverty line.[127] Poverty reduction has been slow since the late 2000's, but has improved in general over the last five years.[128] Child poverty is an issue, with more than one out of four children living in poverty.[129] Rural and remote areas are more affected by poverty, although the gap is closing.[130] Employment does not necessarily protect from poverty, particularly in larger households.[131] However, despite the global evidence related to the vicious cycle of poverty and disability[132], solid data on the degree to which children with disabilities in Kyrgyzstan are exposed to poverty and social exclusion are scarce. The Kyrgyz Integrated Household Survey

(KIHS) does provide some disaggregated data by disability status: 0.9% of the total population lives with some kind of disability and poverty is more prevalent among households that include persons with disabilities, which reflects the additional associated cost and low levels of labour-force participation among persons with disabilities.[133]

Non-contributory assistance is principally provided mainly via two benefits: Monthly Benefit for Poor Families with children (MBPF) and Monthly Social Benefit (MSB).[134] Whilst MBPF is directed to poor families and can be accessed by passing a significant administrative hurdle of means testing, the MSB, as a "categorical programme", is directed to beneficiaries with certain objective conditions as certified by the social administration, amongst which are persons with disabilities, including children, as well as orphans and mothers of large families (7 children). The average disability benefit for children with disabilities (end of the year, in som) was 3000 (around 37 USD) for all disability categories, in 2014-2017, with an increase to 4000 som (around 50 USD), in 2018.[135] There is also a lump sum birth grant, as one-off payment. In view of the heavy procedure of means-testing to access social assistance, the targeting towards the poorest quintiles is rather unsuccessful.[136]

The social protection system cannot fully provide support for the poor and faces several challenges, among them an insignificant impact of living standards, low coverage of those in need and, particularly important with regards to children with disabilities, the insufficient development of qualified social services.[137] In general, the social protection system for children with disabilities has access barriers, the benefit levels are inflexible to differentiated needs and are considered as inadequate. The design rather promotes retraction from employment, as opposed to fostering active inclusion. The amounts of the disability benefits do not reach the subsistence minimum considered as a basic minimum income needed for decent life.[138]

For the most part, parents of children with disabilities did not report knowing about and/or accessing social services except for applying for a disability benefit in order to be able to afford medicine and care. Some parents were told by the doctors in Osh and Bishkek how to apply for a disability certificate, and some were provided with the necessary documents to apply at the local level. However, as reported above, the process is not clear, and a bribery payment is expected at various steps in the process. Parents who have a good economic situation do not apply, and some parents reported being pressured by their own families to not apply, due to the stigma associated with having a child with a disability in the family.

Case management and social work

Two main bodies responsible for child protection operate in the Kyrgyz Republic: the Commission on Children's Affairs (CCA) and Family and Children Support Department (FCSD). They were established to determine the future of children who are "in a difficult life situation".[139] CCAs are interdepartmental ad-hoc committees at municipal or district level that are convened to discuss the situation of each child, in order to approve individual child protection plans developed by the FCSD.[140] As reported by a parent:

> *"Once we were invited to the city administration. There was some kind of commission. They examined my daughter for 10 minutes, asked her to walk around. After that, they registered her. I don't know how they found us, probably from the hospital. She also began to study. They came to us from school, saw that our daughter could study and sent a teacher to our home. Now the teacher sometimes comes to us and teaches our daughter" (parent, Nookat city)*

According to the Code of the Kyrgyz Republic On Children, which is established in the territorial divisions of the Ministry of Labour and Social Development, the FCSD is expected to have a preventative function, engage in case management, ensure the rights of children in difficult life situations and act as child protection officers.[141] The scope of their assigned functions is extremely wide, which requires not only relevant expertise among agency employees but also an adequate number of employers to address them. Currently, there are no standards of workload for employees of the FCSD. Approved staff cannot effectively carry out the full range of their specified tasks and the agency does not have sufficient resources to perform its functions.

Person-centred social services

Personalized-social services remain underdeveloped in Kyrgyzstan, despite recent legislative provisions for personal assistance. Both in terms of spending and beneficiaries, residential institutions remain the primary form of social service.[142] Kyrgyzstan lacks a legislative framework for the provision of social services according to a guaranteed minimum level of services for specified vulnerable groups.[143] Access to social services has improved in recent years, in part due to the procurement of services from non-state actors though a government-financed social procurement plan[144]. Despite this increase, the lack of professionals working with children with disabilities, combined with low public awareness of child disability, heavily conditions service provision.

At implementation level, there is an overlap of roles and responsibilities between MLSD staff and social protection experts employed by local government, be it village self-government community workers or district (rayon) social workers: Social workers of MLSP and social workers of local authorities have the same functions, mostly providing care for elderly people, and attention to children is very limited by both profiles.[145] Increasingly, social services include home visits to adults with disabilities (not children) from community-based social workers, but these services have also been criticised to add to isolation at home, rather than integration into the community, in a type of home-based micro-institutionalization.[146]

A transition from Soviet-legacy assistance based on institutions towards community-based support services requires, in addition to political will, a change in the skills set and capacities of the social workforce, by ensuring social workers possess the required skills, training and resources.[147] Legally, a first step has been made by the legal change that approved new professions such as personal assistants, physiotherapists, and occupational therapists.[148] Furthermore, supported by international cooperation, the government should soon be able to generate better data on social assistance coverage, impact and service quality, through the newly developed Corporate Information System for Social Assistance (CISSA) which is an information and administrative systems for social protection run by MLSD.[149]

2.6. Living independently

Ensuring participation

Non-discrimination and equality of opportunity are among the general principles of the CRPD and are a cornerstone of the human rights-based approach to children with disabilities. However, the CRPD envisions supports – as needed – to ensure participation, among them reasonable accommodation which is understood in Article 2 as:

> *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.*

Article 16 of the Kyrgyz Constitution prohibits discrimination on the basis for disability and allows for positive action measures to achieve de facto equality. The 2008 Law on the Rights and Guarantees of Persons with Disabilities contains a definition of discrimination, understood as

> *any distinction, exclusion or limitation, on the basis of disability, that has as object or result the reduction or denial of acknowledgement, realisation or implementation, on an equal basis with others, of all human rights and basic freedoms in the political, economic, social, cultural, civil or any other sphere.*[150]

The only other mention of discrimination in the Law is found in Article 2 that lists prohibition of discrimination on the basis of a disability as one of the basic principles of state disability policy. Reasonable accommodation is not defined nor included among types of discrimination; there is no reference to mechanisms of implementation or monitoring, and no mention of sanctions for violations of the anti-discrimination principles.

For children with disabilities, provision of reasonable accommodation may include alternative assessment of learning instead of standardised assessment systems, provision of sign language or alternative communication modes in education, or age- and gender-appropriate accommodations in the justice system. Further, the CRPD prohibits direct and indirect discrimination, harassment, discrimination by association (for example, of parents of children with disabilities) and intersectional discrimination on two or more characteristics.[151] Thus, such practices as physical punishment or institutionalisation, disproportionately affecting children with disabilities, are a form of discrimination.[152]

The lack of legal foundations and mechanisms to address discrimination lays a fertile ground of widespread discrimination against persons with disabilities, including children. Discrimination against persons with disabilities is documented by both international and national monitors.[153] In particular, NGOs that participated in this study confirm that despite daily instances of discrimination of persons with disabilities, no cases have been brought before the court, most likely due to the low level of understanding of discrimination among judiciary and persons with disabilities, and the lack of robust procedural safeguards and of people's trust in legal remedies. During FGDs with parents, some commented that the reason why no complaints are ever filled is because they are afraid of retaliation, particularly if they live in a small town.

In addition, parents of children with disabilities and children with disabilities themselves reported active bullying by adults and other children (including health and education professionals), discrimination and harassment by medical professionals, and an utter lack of understanding regarding children's rights. In Naryn city, for example, parents report that doctors place disability blame on them by telling them that "fathers drink alcohol, don't read the Koran, chew naswai" and mothers "did hard work during the pregnancy or washed clothes in cold water". These observations are given by health professionals to parents as potential reasons for a disability.

Equal recognition before the law, protection from violence and ill-treatment

Equally relevant to persons with disabilities in Kyrgyzstan is the full inalienable right to equal recognition before the law. Article 12 of the CRPD indicates that no one shall be restricted of their legal capacity, that some persons might need supports to exercise it (and it is the State's responsibility to provide it), and safeguards must be put in place to ensure this right. However, according to the Civil Code of Kyrgyzstan, a person who cannot understand the consequences of their actions can be declared legally incapacitated.[154] As such, Kyrgyzstan practices the system of substituted decision making, whereby a person's legal capacity can be removed and their power to make decisions replaced by that of a guardian. This substitution may affect all areas of the person's life, including consent to medical treatments, financial decisions, the right to marry and to have children and the freedom of movement.

As reported during the stakeholder interviews, many children with physical and intellectual disabilities have little chance for enjoyment of their full legal capacity at age 18. The removal of legal capacity and transfer of decision-making powers to their guardian (usually the person who has been responsible for their wellbeing prior to reaching the age of 18) is quasi-automatic and rarely challenged. Many parents of adolescents with disabilities are too overwhelmed with their daily challenges to plan far ahead and question the practice of stripping the rights of young persons with disabilities at the age of 18.

Denial of legal capacity may result in an array of human rights violations, many of which have been corroborated during the Situation Analysis, including the impossibility to make decisions about one's reproductive, educational, training, financial or leisure decisions or enter into inheritance rights. More importantly, the denial of legal capacity allows the transfer from a children's residential home to an adults' residential home at 19 years old without taking the person's wishes into account.

Closely related to this issue, is the obligation for effective access to justice for persons with disabilities, including through the provision of age-appropriate accommodations to enable participation at all stages of the legal process.[155] The Kyrgyz Criminal Procedure Code includes a set of provisions to ensure the rights of persons with disabilities and children in criminal proceedings.[156] As of early 2021, a draft Resolution to regulate the provision of sign language interpretation to persons with disabilities was being deliberated. As such, there seems to be a basic normative framework in place to provide disability- and age-related accommodations for children and young persons with disabilities in the justice system.

Despite these provisions, the civil society monitoring conducted by the NGO Coalition revealed violations of the rights of children and young people in the justice system, such as failure to provide age-appropriate accommodations to ensure safety and freedom from (repeat) victimisation and violence against children in the juvenile justice system.[157] As reported by the Foundation "Oasis", there is an over-representation of children from marginalised groups, including children with disabilities, among children in conflict with the law.[158] Some of the common issues under scrutiny include forcing children with mental disabilities to commit criminal actions, failure to take disability into account in proceedings, and unduly severe punishments for petty crimes committed by children from marginalised groups.

> *X, born in 2005, resident of Osh, is a person with a disability as per MSEC certification has been sentenced to one year of probationary control and penalty of 87 000 som for a theft of five mobile phones. X's father who is also a person with a disability and out of work at the time of incident, is unable to pay the penalty. He insists that X became a victim of external pressure to commit the offence.*[159]

CRPD Article 16 protects persons with disabilities against exploitation, violence and abuse both within and outside the home.[160] The measures that the States must take to prevent and address it should be gender- and age-sensitive and include monitoring of all facilities and programmes designed to serve persons with disabilities. The CRC Committee General Comment No. 13[161] reminds that children with physical, sensory, learning, psychosocial disabilities, and those with acquired and/or chronic illnesses or serious behavioural problems/disabilities are likely to find themselves in vulnerable situations, exposing them to violence. Girl children are often at a higher risk of violence, including sexual violence, forced/early marriage, sterilisation, virginity testing or "honour" crimes. In one particular instance in the FDGs, a mother – who reported not understanding what Down's Syndrome is – worried that her (girl) child would not be able to defend herself in the case of a rape.

Many of the children with disabilities who participated in FDGs and their parents reported instances of violence perpetrated against them and/or bullying without any consequence. Other parents reported being afraid of leaving their children unattended, including at school.

> *"Other boys often take my crutches away from me. Once I hit the boy with a stone. He began to steel my crutches even more actively. I was very angry. I told my mom. She did nothing." (boy, Bokonbaevo village).*

Other groups of children in vulnerable situations include children in alternative care, children from minority backgrounds, poor children, children involved in hazardous forms of child labour and children separated from their caregivers as the result of complex and chronic emergencies. Any combination of these and other factors increase the child's vulnerability to violence.[162]

In Kyrgyzstan, instances of torture and inhuman or degrading treatment and punishment against children are regularly reported by independent monitors and civil society, although official information on the subject remains scarce.[163] Boys in residential care and juvenile justice system are most vulnerable to torture and ill-treatment at the hands of (or plotted by) state officials. Additionally, poor living conditions, neglect, and deprivation of children with disabilities in residential care may amount to violence against children, as per the CRC definition.

At the same time, investigations to allegations of violence and ill-treatment of children belonging to marginalised groups remain an exception rather than a rule. According to interviewed experts, children with disabilities, especially those living in care, take abuse as a norm, have no experience of complaining against abusers and being rarely believed. An opaque legislative base,[164] lack of effective response protocols in the institutions and, often, outright conflict of interest (where the institution is both the child's legal guardian and the perpetrator) result in the number of complaints being dismally low: according to official data[165], it was measured in single digits in the period 2010-2012, and no complaint reached the courts. In 2015, over 70% of child inmates in a juvenile detention centre reported having been subjected to torture[166]. However, this information was not disaggregated by disability. As the result of international pressure, Kyrgyzstan acknowledged the serious problem of violence against children and announced plans to strengthen the legislation on domestic violence to better protect, children, women, persons with disabilities and older persons.

Respect for home and family (Art 23) and being included in the community (art. 19)

The CRPD recognizes that every person with a disability, including those who might have a psychosocial disability, has a right to live independently and be included in the community.[167] This translates into having the right to choose where and with whom to live and having control of their lives, ensuring community services and facilities for the general population should be available on an equal basis to persons with disabilities and be responsive to their needs. However, the right to live independently and being included in the community is, in Kyrgyzstan, difficult to realize for both children and adults with disabilities due to a life-long approach to institutionalization.

Kyrgyzstan is, reportedly, the country in Central Asia with the largest number of children with disabilities in residential care. Additionally, "there are still many children with disabilities learning in special primary schools (…) Kyrgyzstan shows the highest percentage [enrolment in special schools] at 97 per cent."[168] Many residential care institutions for children with disabilities (also considered "special schools" due to their obligation to provide education) are a part of the education system and the responsibility of the MoES. While neighbouring countries have moved towards more inclusive practices in the last decade, Kyrgyzstan continues to educate children with disabilities in segregated settings, whether in "special schools" or in segregated settings within mainstream schools. In 2018, a data base of residential care institutions was setup[169], and is to be maintained by MLSD (currently under revision). It includes many elite schools among alternative childcare institutions.

Residential care for both children and adults in vulnerable situations – including children with disabilities - is a prevalent matter in Kyrgyzstan, with several governmental bodies involved in managing institutions: the Ministry of Health (MoH) manages institutions for children under the age of 3 ; the MoES manages institutions for orphaned children and adolescents, and boarding schools for children, including those for children with disabilities; and the MLSD, in coordination with local governments, manages institutions for children and adults with severe disabilities, and institutions for the elderly.

One attempt to prevent institutionalization of children with disabilities was the development of the concept of case management (see chapter 2.5 above). In addition to a lack of case management and adequate follow-up by social workers, the alternative report of NGOs indicates that, in Kyrgyzstan, there is an active practice of sending children with disabilities to special boarding institutions,[170] based on an extrajudicial procedure, by use of the decision of the PMPC.

Since 2012, improvement in both legislation and procedures allowed for a small reduction in the number of children in residential care. However, the same legislation and procedures are not applicable to children with disability, whose placement in an institution (referred as boarding schools) is not dependent on a court decision, but rather on the conclusions of the PMPCs.[171] In a 2020 document, approximately a third of all children with disabilities in Kyrgyzstan are reported to be institutionalized[172] in the aforementioned boarding schools for children with speech, vision and hearing difficulties or in neuropsychiatric hospitals.[173]

The system of state guardianship, which includes the placement of children with significant physical or mental disabilities in psycho-neurological boarding schools (residential institutions) currently violates of the rights of children with disabilities as, in practice, government agencies do not take any steps to keep children with disabilities placed in residential institutions in touch with their families, and children are placed in residential institutions without considering the potential geographic barriers.[174] Indeed, a recent account of the situation in institutions denounces widespread violations of the rights of the children. Frequently, shortage of personnel and specific training amounts to lack of individualized attention and care and neglect. Furthermore, there seems to be a widespread practice of overmedicalization with psychotropic drugs, as well as forced psychiatric hospitalization.[175]

Children who don't have an intellectual impairment, but have disorders of the musculoskeletal system, hydrocephalus or other impairments are often placed in psycho-neurological boarding schools that limit their physical capabilities. As reported by stakeholders interviewed for this study, these residential institutions focus on physical care, not on ensuring intellectual development and social integration. In general, their classes focus on everyday skills, rather than provision of primary education.

As reported in focus group discussions, when leaving a residential institution, children receive only personal "spravka" (certificate). Documents confirming the child's right to property, cash, living space, pension, savings, writ of execution for the collection of alimony, and other documents are not issued. Children with disabilities' own opinions about their choice of educational/vocational profile is often not taken into account. The low level of education in residential institutions, the lack of information about the state benefits[176] and the lack of housing and material support, make it almost impossible for children with disabilities in residential institutions to access higher education.[177] Thus, as reported by stakeholders, the practice of sending youth with disabilities to the vocational training system is primarily due to considerations to provide children with accommodation and food. Providing a hostel, food for children, scholarships, the possibility of obtaining a profession and further employment, make vocational schools attractive to the heads of institutions.

For children and adults with disabilities and for the elderly, another type of institution referred to as either boarding houses or nursing homes (for children 0 to 3 years old) are available, for those who are in need "of specific services" and can be placed in temporary or permanent institutionalization.[178] As seen in the table below, the number of persons (either adult or children) in these institutions remained stable between 2014 and 2018 despite an effort to optimization and restructuring of institutions.[179] In 2018, the government presented an information gateway in which residential institutions as well as their inhabitants can be tracked.

Table 7: Nursing homes for the Elderly and Disabled

	2014	2015	2016	2017	2018
Number of boarding houses	15	16	16	16	16
for the elderly and adults with disabilities	11	11	11	11	11
for children with disabilities	4	5	5	5	5
Number of places in boarding houses	2,854	2,812	2,812	2,862	2,862
for the elderly and adults with disabilities	2,290	2,290	2,290	2,340	2,340
for children with disabilities	564	522	522	522	522
Number of people living in boarding houses	2,343	2,410	2,409	2,378	2,386
elderly and adults with disabilities	1,915	1,958	1,955	1,931	1,952
children with disabilities	428	452	454	447	434

Source: Disability data from National Statistical Committee of the Kyrgyz Republic. (2019). National Statistical Committee of the Kyrgyz Republic. (2019). Social trends in the Kyrgyz Republic 2014-2018: Extract of Disability Data. Table 8.6, p.5 (National Statistical Committee of the Kyrgyz Republic, 2019b)

Interestingly, parents of children with disabilities who participated in FGDs did not know about PMPCs and many actively avoided placing their children in residential care. Even in the instances when someone recommended that a child attend a special school, parents were reluctant to send the children. Perhaps because the participants in the research for this Situation Analysis were recruited with the help of NGOs (that can be indicative of a support system being in place, even if rudimentary), parents and children did not have much experience with institutionalization. Some parents reported that their children attended special schools for a short while but have left due to bullying by older children. A mother reported that, in order to have her child attend a special school, the entire family moved to Bishkek in order to remain together. Another family considered moving but could not afford to and the child is attending the local school.

De-institutionalization efforts

As previously mentioned, a family and child protection programme was approved in 2017. One of the keys tasks of this programme was to reform the system of residential institutions for children, ensuring the right of children to live and be raised in a family. The action plan for the implementation of this programme includes tasks for the return of children to their families, including through the creation of the institution of fostering and guardianship. The residential institutions themselves are subject to optimization and restructuring.

One of the crucial aspects in building conditions for de-institutionalization is developing inclusive education. However, none of the parents of children with disabilities and children without disabilities that participated in this study knew about inclusive education. Moreover, despite reports that children with disabilities are not accepted by local schools and parents are forced to send their children to boarding schools to get basic education, this does not seem to be the case. The few parents who reported considering sending their child to a special/boarding school considered doing it because of the potential for their child to receive treatment (not education) and stay in a large city upon graduation. In addition, one parent reported on discrimination from a specialized school who refused to accept her child because she is both blind and deaf. The special school is Osh indicated that they did not have an open place.

While the Ombudsman and the National Centre for the Prevention of Torture each monitor children's homes once a year, stakeholders interviewed agree that this is not sufficient and more frequent and regular monitoring should take place at the local level.[180] Despite efforts since 2017, the institutionalization of children seems to remain problematic, and the 2019 Annual Report from the National Centre for Prevention of Torture recommends that, to meet the Government's Action Plan for the Prevention of Torture 2019-2021, measures that focus on family-type care or community-based care placement of children with disabilities are necessary, as well as the prevention of further institutionalization, by providing families with the necessary resources to care for their children.[181]

Housing is an important step for the provision of an independent life to persons with disabilities. The state guarantees that persons with disabilities in need of improved living conditions are registered by local authorities and provided with living places in accordance with legislation[182], and that living quarters occupied by persons with disabilities are to be equipped with special means and technologies in accordance with an Individual Programme Rehabilitation.[183] Likewise, children with disabilities who are orphans or deprived of parental care and living in residential social service institutions will be provided with living quarters after reaching the age of 18, if envisioned in their individual rehabilitation programme. However, this article is declarative as no children are provided their own living quarters after leaving the residential institutions. As noted throughout this report, Kyrgyz society assumes persons with disabilities cannot live independently. That is why there are no cases where persons with disabilities buy their own homes. Persons with disabilities, especially those identified with a mental or psychosocial disability live with their parents, relatives, or continue living in institutions.

The group of persons who are entitled to improved housing conditions include children with disabilities living in residential social service institutions, if the Individual Programme of

Rehabilitation provides for the opportunity to lead an independent life when they reach eighteen years of age.[184] However, the legislation does not define "self-service" and "the ability to lead an independent life" nor how the procedure for assessing the needs of persons leaving special service institutions is carried out. In addition, due to a lack of approval of the programme of "Accessible Country", universal design of buildings and living infrastructure is not fully implemented yet. Despite significant support by donors such as the European Commission or United Stated Agency for International Development (USAID), the barriers to life in the community, such as insufficient adaptation or insufficient community-based support structures, remain, and the process to defund institutions and redirect means towards communal services has not yet gained traction.[185]

Day care and psycho-social support

Article 19b of the CRPD includes the obligation of governments to provide children with disabilities and their families with a range of services and to "prevent isolation or segregation from the community".

Parents of children with disabilities reported feeling unsupported and isolated; some reported feeling despondent and unhappy, fearing for their own future and the future of their children. In Nookat city, parents reported not having any type of support. They did not know of any parent organization that they could turn to. With the exception of New Year (when they received sweets and oranges) and Disability Day in December (when they received 500 soms), they were not acknowledged by anyone.

> *"When we were invited to this focus group discussion, on Friday we begun to prepare ourselves since Friday. Nobody asks us about the disability of our children. Even now, after this group, I feel myself much better as I had the possibility of being heard" (mother, Naryn city).*

In Nookat city, discussions were halted due to the distress of parents in FDG when discussing their children's future.

> *"This is the first time someone asks me about the life of my child. My child was given to me by Allah" (mother, Nookat city).*

Learning about disability is essential in understanding and predicting the future. Parents of children with disabilities who participated in FDGs often reported not knowing what their child's disability was, how to care for them, and how to self-care.

> *"If I put dishes on the table a little bit loudly my child begins to scream, cry, and talk for a long time. I am afraid that my neighbours believe that I beat my child, which is not true. I and the whole family cry in such situations. Neighbours don't understand child disability" (mother, Naryn city).*

> *"When fatigue and resentment accumulate, we go crazy. When we complain to our relatives, on the contrary, they spread gossip about us and our situation" (parent Naryn City).*

> *"I know that I'm aggressive and cannot control my emotions. My father often says that sitting at home is the reason for the breaking of my psyche. But I'm not suicidal" (boy, 17 years old).*

> *"My child often hits me. I cannot understand why. I want to know what is causing this behaviour" (parent, Naryn city).*

> *"I never go to visit someone (relatives, friends, neighbours) because I cannot go to the toilet by myself. Officially I can only go one place and it's under the ground" (boy, 16 years old).*

Likewise, having a safe place where to engage in peer support, be heard and learn about their rights, is critical for both children with disabilities and their parents.

> *"They asked support from NGO "Kadam" but their capacity is limited. They need a centre where they can get respite services and everyone can come together and talk" (parent, Naryn city).*

In Kyzyl-Kia city, parents also mentioned needing a day care centre where children could spend time together. Interestingly, they were adamant that this should be a day-care for a few hours and not a residential institution for long-term placement.

> *"Once, they really wanted to complain to national security service that various specialists (psychiatrist, teacher) constantly demands money from them (…) but in the end, they did not dare" (parent, Naryn city).*

In Bokonbaevo village, parents noted their children do not have a place where they can socialize or engage in extra-curricular activities. Some of the parents are part of a national WhatsApp group of parents and know that in Bishkek there are many activities for children with disabilities to engage in; however, in their village there is nothing for them to do.

In the same village, children reported having an opportunity to go to a "centre" when they were younger but now (ages 15 and above) could not attend anymore. Only in Kyzyl-Kia city did some children report attending the centre "Umid" where they could – before the COVID-19 pandemic – engage in arts and crafts.

Broad participation in life and leisure (Art. 29 & 30)

A tradition of institutionalization, failed and delayed efforts for de-institutionalization and a lack of support services to enable independent living are further compounded with dominant negative attitudes, image and understanding of disability. There are no systematic services provided by the community in Kyrgyzstan. The MLSD carries out a state social order, in the course of which a number of public organizations can apply to provide community services to persons with disabilities. However, the coverage of these projects is small, the projects themselves are not sustainable, the project implementation time is limited to one year. Combined, these obstacles contribute to the invisibility of persons with disabilities. A recent study[186] found that the majority of survey participants (61%), regardless of the type of settlement, rarely meet persons with disabilities on the street or public places and few more than a third (37%) had seen them in their places of residence. Half of the adult respondents (50%) reported feeling discomfort and inconvenience when dealing with a person with a disability. The proportion of students who experienced such feelings when dealing with a person with a disability, were significantly lower: 39 per cent.

As mentioned previously, parents of children with disabilities fear for their safety. A lack of knowledge about disability, starting at birth, was reported as a barrier to service by parents and negative attitudes were reported by children with disabilities themselves.

> *"Some people in our neighbourhood offend my child. One woman said that children with Down's Syndrome do not live long. I don't want to talk to her anymore. I don't understand why people are so cruel. Until they themselves face this, they will not understand it" (mother, Nookat city).*

> *"Many people think our society is tolerant. It's a lie. This is not true. The only place where I feel accepted is the mosque. They are only interested in your name and that's it (…) outside the mosque, society is wary of the disabled" (boy, 17 years old, Naryn city).*

The CRPD recognizes full and effective participation of persons with disabilities in society on an equal basis with others (Art.1). Participation is one of the general principles running through the convention. However, participation of persons with disabilities in decision making related to their lives is not identified in the Kyrgyz legislation. Only the Code of Children in Kyrgyz Republic[187] mentions that one of the key principles of child's rights protection is ensuring the child's right to express his or her opinion when making decisions concerning his or her fate. However, some reports revealed instances of denial of information to children about their own health, and failure by the schools to establish a safe and trusting space where children can share their concerns, problems, and complaints.

The absence of the concept of participation in the national legislation further limits persons with disabilities in their rights to receive information from state agencies. Thus, parents of children with disabilities are not fully informed about the disability and the rights of their child with a disability (see EIEI Analysis[188]), are not included in the process of decision making of health and rehabilitation plans, or even living arrangements.

Some deaf and hard-of-hearing students are doubly disadvantaged as they learn some form of sign communication at the boarding schools - generally Russian sign language - but parents do not, making communication between deaf students and their own family often impossible.

Children and adolescents with disabilities have the right to form and express their views about situations that concern them (such as family life, school, health, play, relationships) and should be provided with an enabling environment to do so, with consideration to their age and maturity. They also have the right to be represented in organisations whose role is to facilitate, promote and secure their individual autonomy and active participation. To enable participation of children with disabilities, they must be provided with reasonable accommodation, and their views must be given due weight.

However, children with disabilities in Kyrgyzstan often do not participate in the decisions that affect their lives. In part, this is the result of traditional family values based on obedience and respect for the parents. However, parents, teachers and the society in general hold low expectations of children and young persons with disabilities, which contributes to the situation. For example, in Naryn city, parents were reluctant to send girls to the FGDs. Even NGO professionals that work with children with disabilities maintain and transmit traditionally discriminatory gender rules, as they allow FGD seating arrangements that place boys in predominantly dominant positions.

According to reports gathered in interview,

> *a 10-year old child with a disability in general education has been transferred to a special school at the demand of their parent who is also a person with a disability with positive personal experience of this special school. According to the parent, the child would be better off in the special school, whereas the child's own views were not asked during the transfer procedure.*

Likewise, disability-rights advocates report that,

> *When asked if they would like their child with an intellectual disability to advocate for their rights and be active when the child has reached 18, the parent answered that they don't think the child will have the capacity to understand or participate in public life, including in elections.*

Legislation does not guarantee the full participation of persons with disabilities in the cultural life of society but rather, each cultural institution determines its policy in relation to persons with disabilities, based on a charity approach. Theatres, museums, circus and other cultural organizations distribute free tickets to their performances among persons with disabilities, even if the infrastructure of their buildings is not adequate to the needs of persons with disabilities. In addition, the public spaces of cultural institutions are not equipped with multimodal means of information transmission (Braille, kinaesthetic signals, typographical translation.). Music and dance schools seldom include children with disabilities.

Sport with participation of persons with disabilities develops separately from mass sport. In 2015, the National Paralympic Committee was established in Kyrgyzstan, with the main goal to ensure sports activities are as accessible and affordable as possible to persons with disabilities. In addition, the committee set itself an important task - to increase the responsibility for representing Kyrgyzstan in international competitions and united several sports federations. However, sports are not inclusive, and persons with disabilities who play sports in Kyrgyzstan are segregated from others.

The State Agency for Youth recently launched a contest of youth and child-friendly cities, that considers a detailed set of 26 indicators in six dimensions, namely youth participation, culture, and leisure, safety, health, education, and difficult life situations.[189] In practice, the programme of child friendly cities does not, for now, seem to develop a specific action on mainstreaming inclusiveness into their programming.[190]

Friendships of children with disabilities

The realization of the rights of children with disabilities can best be illustrated by their own accounts of their lived experiences, in school, in play, with their friends and families. For comparison purposes, an FDG was held in Tokmok city, with 8 youth ages 13 to 18 (2 girls and 6 boys). All FDG participants attended school, all helped their families with house chores, and all reported having friends. Indeed, most of their time is spent with friends and siblings. All children were involved in making decisions that concerned them, were oriented towards their future and lead active lives.

In comparison, children with disabilities who attended FDGs in 4 different locations, had very different experiences. While some children had attended primary school, they had dropped out. Others were involved in home education, but most did not attend school. Some never had. Those who reported having friends were also those children who were in school (classmates) highlighting the importance of school not only as an academic setting but also for children's socio-affective development. Some of the children reported helping their parents with household chores. For most of their days children with disabilities are with their parents – most often the mother – and siblings.

> *A 10 years-old boy spends most of the day at home with the older brother. He cannot walk independently. His relatives help him to move outside the house, inside the house he can move himself.*
>
> *A 16 years-old girl attends school every day, then spends most of her time at home helping her mother with daily routine.*
>
> *A boy, age 16, has many friends at school; he is very communicative and doesn't have problems building new relationships. His close friends are those that go to school with him. Their village is located far from school – 30 km – and the local authority and parents together rent transport to get them to and from school. He said:*
>
> *"I think my disability is not visible. People don't see any difference. Sometimes I play with other children and try to show that I can do everything, even if it is sometimes painful".*
>
> *"Once I saw a swing on the playground and decided to ride it. One girl saw me and wanted to ride next to me. But her parents saw my wheelchair and started telling her to not come close to me as if I'm contagious or a terrorist. We are given a piece of paper that says we are disabled. But many people think that it is a given that we are unbalanced. You see, I am a bit rude, but I am balanced!" (girl, 17 years old).*
>
> *"My daughter doesn't have any friends. It is difficult to move from 3rd floor apartment, that is why she spends her time with younger siblings. Sometimes our relatives ask me to bring my daughter; they would like to spend time with me" (parent, Nookat city).*

Traditionally, in Kyrgyzstan, boys are more active than girls, and engage in clubs and organized sports more often than girls. This was true for all participants in FDGs. However, children with disabilities were more often isolated from others, spent more time with their immediate family and lacked friendships and social interactions.

3. CROSS-CUTTING ISSUES

3.1. Awareness-raising (Art. 8)

The CRPD recognizes the importance of awareness raising of the society (including specialists of services, families, communities, neighbourhoods and mass media) about disability.[191] Awareness raising promotes respect for rights and dignity of persons with disabilities; the overcoming of stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life; and the awareness of the capabilities and contributions of persons with disabilities. Disability is considered not as a physiological pathology or defect of the body, but as "the social effect that results from the negative attitudinal and environmental barriers imposed on persons with impairments that prevent them from fully enjoying their rights".[192] However, the construction of disability is formed based on peoples' experience, beliefs, and values, and many factors influence this construction. The prevalence of positive or negative attitudes towards disability in the public understanding affects how society response to persons with disabilities. In Kyrgyzstan, the understanding of disability is varied from moral/traditional/medical to social/cultural/diversity.

Government agencies do not raise awareness about disability among the society and the country lacks a comprehensive national strategy for raising awareness about disability and/or a plan to combat stereotypes about persons with disabilities. Professionals working in government agencies have little knowledge of different cultures of disability, which is an obstacle to the provision of quality services.[193]

Traditional views of disability

Since the year 2000, more than 60 research studies on disability have been conducted in Kyrgyzstan. Such interest is explained by the long movement to the ratification of the CRPD. Many research papers consider awareness of the society towards disabilities, existing stereotypes and public attitudes as barriers that persons with disabilities meet in access to services. However, most of these studies view disability as a personal characteristic, not as a result of social interaction. Disability in the local research context is presented mostly as a defect, deficiency or illness.

Research in Kyrgyzstan presents disability from various perspectives, but our research confirms other studies.[194] that present disability as a purely negative phenomenon, in line with the medical model. The more recent study "On attitudes of the society towards children with disabilities" found that the range of ideas and understanding of disability among respondents does not have variability, which represents stereotyped normative ideas.[195]

As described by parents who participated in FGDS, service providers who interact with children with disabilities tend to perceive the child in terms of the physiological aspects of the child that "deviate from the norm" and justify classifying the child as "disabled" or "incapable". Among the definitions given by study participants, a number of them represented a "diagnosis" of a person's health status with a disability and a subsequent "functional problem". Descriptions such as "serious health problems", "terminally ill", "sick person", "has a bodily defect", "hands, legs do not work "," a person with a physiological deviation", "lacks an organ "," born with a defect "," s/ he has a breakdown of the body "," cannot fully function "," physical capabilities are limited "," is not able to live independently", "needs care", were common. Medical staff referred to persons with disabilities as "A person who cannot do anything himself/herself, cannot work; s/he cannot live on his/her own, s/he needs care".

Professionals such as social workers and teachers declaratively express their understanding of disability based on the existing legislative framework but admit not knowing how to work with children with disabilities. They do not know the difference between different types of disabilities and assume that all disabilities are an invariable functional impairment and deviation from the norm. Most teachers express fear of teaching children with disabilities, show prejudice and a lack of understanding regarding the importance of social inclusion and the positive possibilities of early intervention. Social workers and teachers noted that they have not been trained on disability issues and few teachers receive any information about an inclusive education. Medical workers differentiate disability based on a classification of diseases, and also differentiate between the level of "danger" of persons with disabilities. Thus, they recalled the risk of aggression and "inappropriate behaviour" of persons with nervous and mental illnesses, in particular schizophrenia, while other types of disabilities were perceived at a "comfortable" level of interaction. However, one of the study participants noted that even patients who are "comfortable" in terms of interaction with doctors can turn out to be unpredictable and dangerous. Service providers tended to idealize child disability but attributed severe disabilities to functional illiteracy and/or lack of parental love.

Awareness raising is key to combat stereotypes that lead to discrimination against persons with disabilities. However, there are no specific legal documents where awareness raising In Kyrgyzstan is considered as a human rights implementation. In addition, the plan of implementation of the CRPD in Kyrgyzstan does not include any task to develop and realize a national disability awareness strategy and/or plan to tackle stereotypes about persons with disabilities and raise awareness about disability and the rights of persons with disabilities. Persons with disabilities themselves have little involvement in covering disability issues in the public sphere, due to antiquated ideas that persons with disabilities are not able to express their voice, make decisions or act, leading to the assumption that they are not competent. The involvement of persons with disabilities in all spheres of life, their activation and participation in decision-making concerning their lives, representation of the views of persons with disabilities themselves and their active participation in research will change the perception of disability in society and gain new resources for understanding and accepting disability.

In the media, disability is most often viewed from only one perspective: as a characteristic of a person and not as a result of social interaction. Disability is presented as a kind of defect, inferiority, or equated with a disease (illness). Thus, the media often demonstrate negative attitudes, while reflecting society's attitude.

3.2. Disability and other vulnerabilities (Art. 6 & 11)

In Kyrgyzstan, abduction of women and girls for the purpose of forced marriage, especially in rural areas, is regularly reported by civil society and is rampant, with over 20% of marriages being the result of abduction and 6% the result of forced marriages.[196],[197] According to official data, nearly 10% of young women aged 15-19 are married, while the share of women aged 20-24 officially or unofficially married before the age of 18 is 12.9% in 2018, and represents an increase compared to 2014.[198] Both practices have been repeatedly condemned by the international community.[199] However, existing data makes no mention of women and girls with disabilities, and whether the same practices impact them. International research in Eurasia, however, confirms that girls and women with disabilities are at an increased risk of sexual violence than girls and women without disabilities. Moreover, accessing justice for sexual crimes is most difficult for girls and women with intellectual disabilities and mental health problems.[200] Although left unspoken, this was clearly a concern of mothers with girls with disabilities, who carefully refer to fears of rape and demonstrated concern over allowing their children to do anything unsupervised.

The CRPD, in its article 11, calls upon states parties to take measures to protect persons with disabilities in situations of risks, including man-made or natural disasters.[201] Whilst armed conflict has ceased over the last years, Kyrgyzstan remains particularly exposed to natural disasters, which might increase due to climate change.[202] Likewise, migration generates situations that call for protection, inclusive for children with disabilities. The National strategy for comprehensive safety from disasters and emergencies does not include a perspective on inclusion of persons with disabilities[203] and the Ministry of Emergency Situations of the Kyrgyz Republic (MESKR) has yet to include the perspective of disability mainstreaming into their action.

Kyrgyzstan has a significant level of migration, both internal, as well as out-migration and in-migration. A distinct feature is the feminization of the migratory flows.[204] This creates a phenomenon of children left behind. "An estimated 12% to 17% of the Kyrgyz population are migrant workers, with many parents unwilling or unable to take their children with them"[205]. The relation between migration and disability in Kyrgyzstan is under-researched. There seems to be a relation between the high institutionalization of children with disabilities and the fact that labour migration generates a significant number of children left behind.[206] On the other hand, migrants with disabilities are often particularly vulnerable. A regional report of national human rights institutions, thus, reminds that "migrants with disabilities often become the victims of exploitation and forced begging".[207]

3.3. Disabilities and COVID-19

Kyrgyzstan, like the rest of the world, has been dealing with the impact of the COVID-19 pandemic. This crisis has impacted all aspects of life, from health to economic and social spheres. Information about COVID-19's impact on children and, more specifically, children with disabilities has been scarce since the beginning, with each country responding differently to the crisis and with persons with disabilities generally being left behind.[208]

In the early stages of the pandemic (April 2020), reports indicated that, as relates to the overall support of persons with disabilities, Kyrgyzstan received praise for relaxing the administrative requirements for those already receiving benefits, facilitating continued access with a one-year extension of cash-transfer to beneficiaries.[209] In addition, for the cities of Bishkek and Osh a one-time provision was set, of in-kind/voucher assistance regarding food, medical supplies and financial assistance, for low-income families with children and children and adults with disabilities (no information was provided on the number or beneficiaries or on the assistance value).[210] However, an August 2020 report indicated the closing of the Obereg Children's Rehabilitation Centre, with the building being transferred from the state to a municipal territorial administration, without a clear indication of what happened to the 60 children followed by the centre.[211]

UNICEF completed an analysis of the situation of children in residential institutions in April, May and September in order to gather information on support needs. According to interviews, out of the 10800 children in residential institutions at the start of 2020, only approximately 1400 children were left in institutions in May. Out of the 1400, approximately 430 were children with disabilities. As reported, this shift in the number of children from segregated settings to their families indicates that more than 9000 children were in residential institutions (of various types) due to lack of family conditions or lack of services in their area of residence but could – given adequate supports – be reunited with their families. This is true for both children with and children without disabilities. MLSD reports that, as of 15 October 2020, the number of children in residential institutions was 3273 and 1165 children with disabilities have been sent back to their previous placements.

The government responded to the crisis with a number of social protection measures, such as emergency food security programme,[212] deferral of utility payments, and the delivery of pensions at home.[213] Disability allowances as cash transfer to persons with disabilities, both children and adults, have been prolonged automatically.[214]

Remote learning and access to information during pandemic/emergency

As is the case with education, remote learning in emergencies must also be tailored to the environment and to the population it aims to reach. Early reports (April 2020) indicate that all education institutions were closed to prevent the spread of the COVID-19 virus and the Anti-Crisis Plan of the MOES was implemented to ensure remote learning. The last term of the school year was planned to take place remotely, through the "translation of online learning resources and TV lessons to Uzbek and Tajik languages and provide sign language translation to all TV lessons to ensure their accessibility to ethnic minorities and children with disabilities".[215] As of June 2020, the transcripts of lessons that allowed for subtitle translation and sign language interpretation were being handled by UNICEF volunteers[216]. In late March 2020, the Global Partnership for Education (GPE) helped the Ministry of Education "develop online learning platforms and contents in local languages for all children, including children with disabilities, by subject and levels of education, following the educational plans and syllabuses for all grades. The grant also supported the development of gender-responsive instructions for caregivers on different kinds of learning and play activities to do at home, broadcast on the radio, TV and in print"[217].

In spite of these efforts by the Kyrgyz Government, educational institutions and private service providers initial data indicated that the "educational coverage of children with disabilities is low (11.7% of the total number of children with disabilities between the ages of 0 and 7)"[218], in line with research conducted in other countries.

The beginning of the new school year happened on September 1st for first-grade students, in a presential mode. For second- to sixth- grade students, reopening was scheduled for October 6th but has since been postponed. It should be noted that most resources consulted with regards to the crisis response in Kyrgyzstan were not disability-inclusive and/or disability-specific.

4. CONCLUSION

This chapter summarizes the situation of children and adolescents with a particular emphasis on the point of view of rights-holders.[219]

4.1. Answering the research questions

No research questions were provided in the ToR. However, the questions below were proposed by the team in the Inception Report. They are based upon the set of Key Questions recommended in UNICEF's Toolkit: New Generation Situation Analysis. The short answers provided below each question are based on the results of all three analysis (Systems Analysis, EIEI analysis and Situation Analysis).

For duty-bearers

1. To what extent is the government planning/taking steps to ensure a disability-inclusive legislative/policy environment?

The government of Kyrgyzstan is planning a number of changes in policy that do refer specifically to children with disabilities and/or the rights of persons with disabilities. However, there is no indication that legislative and policies reforms are disability-inclusive.

2. What is the governments approach to the ECEC and Education of children and adolescents with disabilities? Is it CRPD compliant?

As documented extensively, the Kyrgyz government approach to children with disabilities in education, ECEC, health and rehabilitation, transportation, communication and accessibility is not CRPD compliant. The few services available to children and adolescent with disabilities are either not free, not accessible, or not inclusive. Thus, not compliant with the CRPD.

3. To what extent is there a robust EI/EI mechanism and set of practices that follows the social model of disability and is CRPD complaint?

There is no EI/EI system in place in Kyrgyzstan. There are a series of unrelated and uncoordinated services, that do not yet constitute a mechanism. As previously mentioned, most of the services available to children and adolescent with disabilities are either not free, not accessible, or not inclusive. Thus, not compliant with the CRPD.

For duty-bearers and rights-holders

4. To what extent are children and adolescents with disabilities and their families prevented from participating in society on an equal basis with others?

The barriers to full or partial participation are extensive, from attitudinal to environmental. Not only is the legislative/policy landscape non-inclusive, but services needed to support and promote the rights of persons with disabilities do not exist. Families feel isolated from their extended families and communities, and children and adolescents with disabilities do not have access to the same rights as other children, even in rural communities.

5. To what extent are existing services disability-inclusive? What are the gaps, barriers, bottlenecks and opportunities to make them so?

Existing services are not disability-inclusive. The main gaps are likely due to 1) a lack of general knowledge about diversity (in all its forms), and 2) lack of knowledge about disability that is not steeped in stereotypes and misconceptions.

1) The legislative landscape does not provide for umbrella policies that enforce the rights of all citizens, including those with disabilities and/or including children with and without disabilities.

2) Not only is the legislation mostly silent with regards to the rights of persons with disabilities but professionals are not knowledgeable about issues related to disability and/or inclusion. Even health professionals who should be the ones prepared to identify, assess and refer children at risk of a delay or disability are misinformed, and reportedly lack professional empathy and ethical guidelines.

6. Are the existing social protection measures disability-inclusive? What are the gaps, barriers, bottlenecks and opportunities to make them so?

Persons who are identified has having a disability are entitled to a disability-related benefit. However, the process is cumbersome, unclear and most parents who have children with disabilities are unfamiliar with the identification/registration process. In addition, because being registered as a person with a disability does not entitle them to free and inclusive services and might, on the contrary, lead to separation of children from families – as is the case with an implied relationship rehabilitation and special schools – many families of children with disabilities do not pursue an official disability registration or status.

7. What capacities (institutional, financial, human) exist/are needed at the national, oblast and local levels to address the inclusion of children and adolescents with disabilities?

It is not possible to answer this question with certainty because a financial analysis was not done. Further, while the research included a variety of participants that provided both rural and urban viewpoints, it is likely that there is great variance among and between oblasts and local levels which was not captured in this research. However, from the reports by duty-bearers and rights-holders, it can be deducted that a great deal of technical capacity – at all levels - is needed to overcome the traditional medical model of disability.

One persistent variance is that of the level of professionalism of health professionals in the Children's Hospital in Bishkek (very good), in comparison to local professionals (very poor), often reported by parents of children with disabilities.

For rights-holders

8. To what extent are physical, communication and information accessible to children and adolescents with disabilities?

All parents of children with disabilities and children and adolescents with disabilities themselves reported that Kyrgyzstan is not an accessible country, at the legislative and environmental (physical, communication and information) levels.

9. To what extent are children and adolescents with disabilities, their families and representatives heard and taken seriously?

Children and adolescents with disabilities and their families are not heard or taken seriously. Children and adolescents are not viewed as holders of rights and, while their parents do take them seriously, they often decide what is best for them. Fortunately, many of the parents of children with disabilities who participated in this research have a very strong sense of family and unity that translates in their refusal to place their children in institutional care. This is particularly important, because it points to institutionalization as a governmental practice, rather than a family practice (as alluded to by some professionals). In addition, refusing to place children with disabilities in institutional care is increasingly difficult to the societal pressure - parents of children with disabilities reported not having any social networks to lean on, and being berated by the professionals whose job it is to educate and support them.

NGOs and OPDs who work to promote the CRPD are supportive of children with disabilities and their families and have often intervened with government, to promote and advocate for needed legislation and services. They have also developed services for children with disabilities due to a lack of government intervention but are limited in capacity, both financial and human.

10. Is the existing data being used for decision-making, and children and adults with disabilities and their families consulted in decisions concerning them?

It is expected that this comprehensive research can provide a solid base of data to be used in decision-making by the UN family and the Kyrgyz

Government. However, Kyrgyzstan has a long tradition of research related to the rights of persons with disabilities, that does not seem to have impacted decision-making thus far.

For many research participants, their participation in focus discussion groups was the very first time someone showed an interest in their lives, the obstacles they face and their potential contributions to society.

4.2. Lessons learnt

Definition, determination, and identification of disability

In Kyrgyzstan, as in many other countries in the region, there is very little knowledge about disability, the CRPD-complaint mechanisms for identification and assessment of disability (or functional limitation) and the ways in which the use of the ICF can contribute to the adoption of the social model of disability. Trans-disciplinary technical capacity is needed to address the necessary paradigm shift from a medical to a social model of disability.

Early Identification and Early Intervention (EIEI) & collaboration

Trans-disciplinary work to support EIEI mechanisms is a reported challenge in Kyrgyzstan as elsewhere. This collaborative way of working must start with legislation that clearly outlines the ways in which multiple sectors work together with one aim but must go beyond the legislation to ensure professionals are capacitated to work across disciplines. In addition, adequate EIEI mechanisms must consider the child over the life cycle and be able to anticipate progress and transitions overtime, in medium- and long-range.

This lack of collaborative initiatives and programmes is also visible in other arenas, including a lack of common agendas and efforts by donors and other stakeholders, related to supporting the government of Kyrgyzstan in upholding the CRPD.

Support to children with disabilities, their parents and families

Shame, lack of understanding and knowledge, and lack of adequate support contribute to the social isolation of children with disabilities and their families. Understanding disability from a bio-psycho-social perspective can help to ameliorate anxiety in parents when they are faced with having a child with a disability. This might include learning about the medical causes/ consequences of an impairment, learning about their children's rights, or having a support group that can provide moral and psychological support in addition to services. In Kyrgyzstan, as in other countries, parents report social isolation as a burden to already difficult financial and physical circumstances.

Awareness raising

Closely related to 3 above, negative attitudes towards people with disabilities are based on a perspective of deficiency and are pervasive. Tackling stereotypes and discrimination must include a two-prong effort: on the one hand, there has to be a general population sensitization campaign that portrays children with disabilities as children first; on the other hand, there has to be an educational effort that ensures all professionals who work with children and families have adequate knowledge about disability, from the social model perspective. This is directly related to 1 above - Definition, determination, and identification of disability.

De-institutionalization

Although a tradition in Eastern Europe and Central Asia, the institutionalization of children from vulnerable populations – including children with disabilities – has declined over the last 10 years. However, although some decline has taken place in Kyrgyzstan, children with disabilities continue to remain in institutions, even when all other children return to their families (such as the case during the Covid-19 pandemic). Interestingly, and contrary to a large sector of professionals who blame institutionalization on parent abandonment, this was not the reported case in this research. An important lesson with regards to de-institutionalization can be leaned: the process of de-institutionalization must take into consideration- first and foremost- the family and the support services they need. Only after taking into consideration the (perceived) aptitude of the system. As is the case in Kyrgyzstan, many parents of children with disabilities placed in specialized schools (institutions) would not have placed their children and keep them away from home if the local schools had been obliged to enrol them.

ECEC & Education

Inclusive education is not commonly understood by all professionals in every country. Multiple understandings exist and many different programmes and initiatives are being implemented in the name of "inclusive education". However, to partially respond to this lack of clarity, the CRPD Committee has provided all State Parties with a clear roadmap towards inclusion in its Article 24 – General Comment n°4 on the Right to Inclusive Education. Thus, all governments – including Kyrgyzstan - who have signed and ratified the CRPD have an obligation to adhere to this roadmap, regardless of national or international pressures and financial donations. Only a CRPD-compliant vision of inclusive education can be truly respectful of the rights of all children – including children with disabilities.

Data Collection

Data collection and the use of data for decision-making are challenging in Kyrgyzstan, as elsewhere. While the use of MICS has provided valuable information with regards to children and parents with functional limitations, the data has not been fully explored and is not adequately utilized. This is directly related to 1 above. While potentially important data is gathered and reported in MICS, the government of Kyrgyzstan continues to focus its expenditures on data gathered by means that are not CRPD-compliant, thus creating a data landscape that is unreliable, confusing and under-utilized. When introducing the MICS child functioning module, UNICEF should simultaneously embark in an effort to reform the social benefit scheme that is associated with a purely medical identification procedure. The introduction to the social model of disability, the change in disability identification (and introduction of the ICF), and data collection related to functional limitations (MICS), would be better used and understood as a three-prong initiative.

5. Recommendations

Taking into consideration the findings reported above, the recommendations of this Situation Analysis are written under the assumption that the Kyrgyz Government and its partners are committed to upholding the CRC and CRPD and placing children at the centre of their national agenda. As such, children with disabilities are considered children first, worthy of enjoying all their rights, living with their families, in a dignified and respectful way.

The recommendations below are aimed at all stakeholders - Central and local Government, the UN Country team and donors, NGOs and OPDs. However, for each recommendation, a "Responsible institution/organization" has been identified as the lead in implementation, with support of others.

All recommendations should be read and understood as part of a package of recommendations and not as independent and one-off actions. Lastly, although all actions are considered necessary, an order of priority has been established (short-, medium- and long-term) in order to provide a possible outline for an Action Plan.[220]

5.1. Definition, determination, and identification of disability

The definition of disability in use in Kyrgyzstan as well as the mechanisms by which disability is assessed and identified are not in compliance with the CRPD and are not sufficient to ensure the rights of children with disabilities are fulfilled.

Rec.1 (short term & urgent) – Members from the 3 existing mechanisms that identify children with disabilities, delays, or in difficult life situations – together with professionals fully familiar with the ICF and international experts – should formulate a plan of collaboration that retains their professional expertise but expands their reach and level of oversight. Using the ICF as their model, professionals should streamline the existing processes and develop mechanisms and protocols of cooperation that aim at supporting all children and families along the life-cycle.

- MoH, MLSD, MoES, NGOs and OPDs technical staff including but not limited to MSEC, PMPCs, case managers, social workers, paediatricians and disability specialists, ICF experts.

5.2. Early Identification and Early Intervention (EIEI)

Rec.2 (short term & urgent) – While the legislation envisions that the identification of children with disabilities be done at the local level, participants in this study indicate this is not possible due to the low technical capacity of professionals at the local level. Thus, it is important that a temporary solution be found that assures an EIEI mechanism is set up, efficiently and professionally, with support from the Bishkek and Osh children's hospitals.

Rec.3 (short term & urgent) – EI/EI that leads to social (and educational) inclusion are the responsibility of the entire government. It is recommended that UNICEF develop a Country Office plan related to children with disabilities that is cross-sectoral (Education + Child Protection + Social Policy + Health) and can serve as a platform to: 1) exemplify how multiple sectors should work together with one common goal (i.e., EIEI and implement inclusive education); 2) encourage multiple ministries to gather efforts around one aim (i.e., EIEI and inclusive education).

- MoH, MLSD, MoES, NGOs and OPDs technical staff including but not limited to MSEC, PMPCs, case managers, social workers, paediatricians and disability specialists, ICF experts, UNICEF and UNCT

5.3. Support to children with disabilities, their parents and families

Being able to feel supported and understood, and learn from others with similar life experiences, is critical to develop resilience and autonomy. Thus, creating spaces that provide children with disabilities and their families with support – including psycho-social support – is critical in promoting and enabling independent living while securing conditions for support in the de-institutionalization process.

Rec.4 (short term & urgent) – persons with disabilities and their families must be supported in creating the necessary local conditions that can help respond to their psycho-social needs. When they already exist, day care centres should be retrofitted to be inclusive of all children with disabilities regardless of their accessibility needs, disability status, age or other. When they do not exist, financial and human resources should be allocated for their development.

Rec.5 (short term & urgent) – Develop a centralized, transparent mechanism by which parents of children with disabilities have access to information regarding their rights. The mechanism should include a system of anonymous reporting of instances of bribery associated with service provision, leading to a legal action and restitution.

- Government of Kyrgyzstan with UN Country Team

5.4. Awareness raising

The Kyrgyz population has a genuinely negative attitude towards people with disabilities based on a perspective of deficiency. The process of deinstitutionalization and inclusion into community life and the workplace must go along with awareness raising in mass-media, social media and popular events, to promote alternative perceptions of disability based on images of capacity and diversity.

Rec.6 (short term & urgent) – using existing awareness campaigns from across the region, adapt and conduct a national awareness campaign that starts to dispel the myths that surround disability in Kyrgyzstan and serves to provide basic and accurate information to the general population.

- Government of Kyrgyzstan with UNICEF and UNCT

5.5. De-institutionalization

Despite parents’ reluctance to send their children to residential care, many parents are encouraged to do so under the belief that specialized or boarding schools provide better living conditions, and specialized health care, rehabilitation and education to children with disabilities. According to recent information, close to 9000 children out of the approximately 11000 in residential institutions at the start of 2020, left segregated settings and were in confinement with their families during the COVID-19 pandemic. This indicates that:

- Approx.. 9000 can – and do – stay home with their families for long periods of time, making their institutionalization unnecessary.
- the remaining approx. 1500 children in institutional care are – mostly – children with disabilities.

Rec. 7 (short term) – engage in urgent evaluation of the conditions under which each family was able to retain their child at home during the COVID-19 lockdown and develop a plan of family support with the purpose of continued family (re) unification.

Rec. 8 (medium term) – Engage in an evaluation of services at residential institutions where children with disabilities remained during confinement, and identify the bottlenecks for family reunification, aiming for a targeted planning for de-institutionalization of children with disabilities.

Rec. 9 (short term) – Develop clear and transparent protocols to prevent and react to violence against children in residential care. Among others, protocols should deal with issues such as age- and gender-appropriate training in understanding and recognising violence, complaint mechanisms, protection against victimisation and rehabilitation. Furthermore, they should envision a mechanism by which children can place an anonymous complaint to an independent monitoring body with the authority to act immediately (including but not limited to removing the child from the setting).

- MLSD, Ombudsperson Office, NPM and UNICEF

5.6. ECEC & Education

A great deal of effort, human and financial resources have been deployed to develop a Concept and Programme for Inclusive Education in the Kyrgyz Republic, in partnership with USAID, UNICEF, Soros and EU. However, the resulting Resolution #360 does not follow the spirit or letter of CRPD Article 24 – General Comment #4 or SDG4.

Rec. 10 (short term) – Consider halting the project until a full review of the documents is made, against normative frameworks, to ensure "inclusive education" is, in fact, the end result of the project and in alignment with international norms – not "integration" or the perpetuation of a continued segregated environment with "special schools" as pseudo-mechanisms for inclusive education.

- MoE, EU, Soros, USAID and UNICEF

Rec. 11 (short term) - Organize a study visit to a country with an advanced Early Identification/ Early Intervention and Inclusive Education System (i.e. Portugal or Cyprus) with the purpose of:

  - promoting the exchange of knowledge and innovations related to trans-disciplinary work with a view to support children and families through the life-cycle;
  - promoting the exchange of knowledge and innovations, in order to create an in-house pool of government officials willing and able to advocate for an education system that is in line with CRPD Article 24 (GC 4) and SDG 4.

- MoH, MLSP, MoE and UNICEF

5.7. Collaboration and cross-sectoral engagement

According to reported information, donors and international organizations (including UN agencies and international NGOs) do not have a common agenda and/or concerted efforts related to supporting children and/or persons with disabilities.

In addition, NGOs and OPDs have taken over responsibilities towards service provision that are, in fact, Government responsibility.

Rec. 12 (short term) – It is recommended that UNICEF take the lead - within the UN Country Team structure – on issues related to childhood disability. An easy first step would be to create a working group on disability, with representation from all UN organizations and international NGOs/ Donors, to develop a common plan for support of the realisation of the CRPD, creating spaces for all stakeholders to intervene while under one common goal in line with the principles of the Global Partnership for Effective Development Co-operation and SDG17.

- UNICEF and UNCT

Rec 13 (medium term) – NGOs and DPOs that provide services to children with disabilities and their families should develop a plan for devolution of responsibilities to central and local authorities. Because a lot of the know-how is currently concentrated within civil society, capacity development activities should take place to ensure wide-spread technical capacity.

- NGOs, OPDs, UN Country Team and government technical staff

5.8. Full legislative review against CRPD

Following the ratification of the CRPD, an inventory of the exiting instruments supporting or impeding its effective realisation is required. The Kyrgyz Republic is required to ensure that the ensemble of its legislative instruments is in line with the CRPD and can be used to develop practical implementation measures. While some efforts to analyse the Kyrgyz law against the CRPD has been made (e.g. report of the Expert Group "Plus"; IDLO analysis of the situation of persons with disabilities), the next step is a complex approach leading up to a schedule of systematic revisions of key laws in light of the CRPD.

Rec. 14 (short term) – Engage in a thorough legislative review, with the involvement of international experts and the national representative organisations of persons with disabilities. The review should address substantive rights of persons with disabilities under the Convention, as well as procedural mechanisms for implementation, monitoring and reporting.

- Government of Kyrgyzstan with UN Country Team

5.9. Data Collection

While MICS provided valuable information on the situation of children and women in Kyrgyzstan, including some data on functional limitations of the overall population, the data is limited when seen through the lens of disability, not very helpful for decision-making related to persons with disabilities, nor for targeted programmatic responses.

- Because the official definition of disability in Kyrgyzstan (medical model) and the concept of functional limitation used in MICS (social model) are not congruent, MICS results need to be analysed and carefully reported;
- Although there is an attempt to disaggregate all data by with/without a functional limitation, the sample is often too small to warrant reliable data;
- None of the data specific to persons with a functional limitation is disaggregated further (gender, region, wealth quintile, etc.);
- The addition of questions related to depression and anxiety might provide a false proportion of persons considered to have depression and/or anxiety because the benchmark used in the survey is not commensurate with the international definition of "depression" and "anxiety" (DSM-5).

Rec. 15 (short term)- It is imperative that UNICEF ensures a clear distinction between the data governments usually want (for disability pension purposes) and the data MICS provides (a range of possible functional limitations in the child/youth population that may or may not directly indicate a degree of disability), and engages in capacity-building, including with the National Statistics Committee, that empowers government officials to make decisions that are inclusive of persons with disabilities but also take into consideration other populations that may also require changes in their environment in order to fully participate in Kyrgyz society.

- UNICEF & NSC

Rec. 16 (medium term) – Consider the possibility of having a second wave of household surveys completed in those households identified by the MICS as having a person with a reported functional limitation, to gather more specific and reliable information related to their bio-psycho-social status as it relates to their functional limitation, while advancing the possible synergies between the concept of functional limitation and service/benefits provision for persons with disabilities.

- Government of Kyrgyzstan and NSC

Rec. 17 (long term) – Consider the possibility of having a "functional limitation" survey (e.g., Model Disability Survey) included in the next population census in order to determine a more accurate prevalence rate of persons with a functional limitation (essential for planning service provision and benefits allocation).

- Government of Kyrgyzstan and NSC

5.10. National implementation and monitoring of the CRPD

Rec 18 (short term) – Adopt the Initial Action Plan for CRPD implementation without further delay and ensure its implementation and monitoring but delegating tasks, earmarking human and financial resources and introducing a transparent mechanism for monitoring implementation.

- Government officials, National Disability Council, UN Country Team

Rec 19 (short-term) - Taking into account the obligations of Kyrgyzstan under CRPD Article 33, develop measures to establish a robust mechanism for implementation and monitoring of progress towards the CRPD. There should be two independent components of the mechanism:

1) Inter-agency structures, curated by a designated focal point within the government and

including a coordination mechanism, such as the recently established national disability council. The structures should have dedicated mandates and resources, enjoy sufficient visibility, and can be replicated at the regional levels.

2) An independent monitoring mechanism, including the Ombudsman's Office that should be specifically designated to perform CRPD monitoring functions, and supported in fulfilling its tasks. Efforts to receive A-status Paris Principles' accreditation by the Ombudsman should be ongoing.

Participation of diverse representative organisations of persons with disabilities and their families must be ensured in all implementation and monitoring mechanisms, and organisations' expertise and time should be recognised and compensated.

- Government officials, National Disability Council, UN Country Team

CASE STUDIES

Case A: Access to education for a child with autism

Ermek was born in 2009. The family lives in a village, in Osh oblast, far from Osh city.[c] The young parents did not identify any delays, perhaps because he is their first child. When he turned 3 years old, the mother noticed that he reacts unusually to noise, with sharp movements, and he is not comfortable with a large number of people around. In addition, Ermek has a speech delay. The doctor at the local medical centre could not explain these symptoms and sent the family to a neurologist at the inter-regional children's clinical hospital, located in Osh city.

The mother continued to observe Ermek for some time and realized that the help of a neuropathologist was needed; he was frequently in a stressful state, cried a lot, and was uncontrollable. The neuropathologist immediately informed - "right from the doorway, without any deep assessments" - the parents of a diagnosis of tuberous sclerosis. Ermek's parents began to search the internet for information about this diagnosis, but the description they found did not match their child's developmental symptoms. They were sceptical of the competence of the doctor.

> *"It seemed that Ermek was once frightened. In order to relieve this fear, we went to the moldo [a servant of the mosque] so that he would carry out his own procedures to get rid of the fear".*

After a while, the parents saw an advertisement of a private centre of Nogoibaeva[d].

> *"The doctor had a small children's house in the corner of her room. When we entered her room, my son immediately, without anyone noticing, went to the house and sat down in it. The doctor said he had symptoms of autism. This was the first time I heard this diagnosis".*

Ermek's parents could not accept this diagnosis and were resistant for a long time. Over the next six months, he had private lessons with a speech therapist. Finally, the parents decided to go to Bishkek, where the diagnosis could be officially confirmed. They went to the "Hand-in-Hand" centre, frequently mentioned on the internet. Unfortunately, at that time, all specialists in the centre were participating in a conference and did not have the possibility to assess him. The representative of the centre referred the parents to a psychiatric hospital, but they did not have the opportunity to visit the doctor because there was a long line of other parents with their children. They decided to go to the Republican Centre of Maternity and Childhood Care to a very well-known neuropathologist in the country. But to get an appointment with him, it was necessary to make it a month in advance.

> *"We had to look for acquaintances to get an appointment with him. He told us that Ermek has a psycho-speech delay and signs of autism and prescribed us a lot of neuro-tropics. But our son couldn't drink any pills or syrups, so we didn't give him any medicine".*

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[c] The name and location have been disguised to ensure anonymity.

[d] The Centre for the Hearing and Speech Development has existed since 2005. Since November 28, 2008, it received the status of the NGO "Centre for the Hearing and Speech Development ". The organization conducts training and development of children with disabilities: children with hearing impairment, children with Down's Syndrome, children in the autism spectrum, children with cerebral palsy, and children with various forms of intellectual disabilities - Source: https://medik.kg/ky/clinic/tsentr-razvitiia-slukha-i-rechi-no-goibaevoi72/

Ermek's parents returned to Osh and he continued to receive speech therapy. Later, they heard about a centre in Osh where children with autism could get ABA-therapy[e]. They began to visit this centre 5 times per week. Ermek and his mother spent 2 hours per day to travel to the centre, and 2 hours to return home. They paid 300 soms for every session and some money for public transport.

> *"When my eldest son was one and a half years old, I gave birth to the next child. I spent a lot of time with the youngest, so I think I missed the development of my older child. If I had noticed earlier that the child has signs of autism, something could have been done."*

It was difficult for Ermek's parents to cover all expenses related to ABA sessions, speech therapy and transport services. Moreover, they observed only a little progress - their son began to sit. The young mother decided to get educated as a speech therapist herself in order to provide treatment to her child. She found information about private professional development courses (72 hours), which were organized in Bishkek, took the courses, and received a certificate as a speech therapist.

> *"I began to apply my acquired knowledge to my son. All our walls were hung with pictures of animals, letters, coloured cards, etc. My hard work with my son yielded results. My son began to repeat phrases after me and then started building sentences. I really wanted my son to go to kindergarten."*

Access to education

There is only one kindergarten in the village. The local kindergarten accepted Ermek because his family is well known. His grandfathers and grandmothers from both sides are well-respected persons in the village. The director of the kindergarten said:

> *"We had experience accepting children with mild speech disorders before. But this boy was the first case of a special child. I accepted him because he has a very educated family. His grandparents and parents are well-respected people in our village. I could not refuse. But when he came to kindergarten, from the very beginning, he behaved in a special way. He laid down on the wet floor behind the sink; the teachers tried to get him out of there. The children did not communicate or play with him. He did not talk, so we did not understand what he wanted. We also noticed that he didn't look people in the eye; he looked away. My teachers didn't know how to work with such a child. I would not have taken such a child if I had not been friends with his family. Our village is small, and everybody knows each other. How can I refuse to accept him? We intuitively understood that such children need to communicate in society with their peers, but when there are 30 children in a group, we must pay attention to each child, and it is difficult to accept such a child. Honestly, there are no such children in the village except him, and I am weak to God. I would not take such a child because it is difficult with him."*

When Ermek was 6 years old, the parents decided to send him to mainstream school. There are no special schools in this rayon, and parents did not want to separate their son from the family. The mother went to all private schools in Osh city. No school would accept a child with autism. Finally, one school agreed to enrol him when the mother promised that she would pay extra for the teacher. Ermek spent three hours per day in school, although all other students spend the whole day there. There were only 5-6 children in his class, and that was very comfortable for him.

When he turned 8 years old, the parents decided that he had to get a quality education. They wanted Ermek to communicate with his peers and to learn something. They decided to contact the local school. The school administration said that it was necessary to register him as a child with a disability. When Ermek went in front of the commission, the doctor asked the mother what diagnosis he should mention. The parents asked for "moderate autism" because this would

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[e] Applied Behaviour Analysis (ABA). NGO "Smile.kg" centre, working on the project of ABA implementation with the support of Soros Foundation.

make it possible to enrol in a mainstream school instead of a specialized school for children with intellectual disabilities.

The teacher explained that it is very difficult to teach Ermek:

> *"This child behaves incomprehensibly. He never does assignments or participates in the lesson. Often, he is shut down and withdrawn. He doesn't like it when children make noise. Sometimes he can only use felt-tip pens all day. The mother works with him at home. I have a lot of experience in school, but I have never met such a child in my practice. Honestly, I don't know how to approach him and what he can learn in school. His mother plays a big role in his life. Not all these children have such parents interested in their education. I believe that for such children, it is better to study in specialized educational institutions. Their specialists know how to work with them. There, children study on a lightweight program".*

Ermek's mother thinks that he needs a tutor because he needs constant supervision. But when she applied to the social protection authorities, she was told that the personal assistant is provided only for childcare; it has nothing to do with education. The social protection specialist explained:

> *"They can get a personal assistant, but for this, the child must spend one month in a psychiatric hospital. The parents refused to do this because, as they explained, it could make the child's situation worse".*

The parents reported:

> *"We don't need 5000 soms [salary of personal assistant]; we wanted to get the professional support of a tutor for our child at school".*

At the present time, Ermek studies in primary school, although, according to his age, he should be in secondary school. There is no individualization of the program. Therefore, he does not show success at school. His parents continue to make great efforts to ensure he is following the program. The grandparents comment:

> *"We, grandparents and parents, are successful and respected in our community because we have high education. My son has a unique profession in Kyrgyzstan. Education allowed us to have a higher quality of life, to build a big house, and to stay afloat. If our eldest grandson does not receive a qualified education, then he will not be able to build his future. Therefore, our family directs all our earnings to ensure that he goes to school."*

Case B: Assistive technologies for a child with a hearing impairment

Amir is 16 years old and lives with his family in Issyk-Kul Oblast[f]. When he was born, his parents didn't identify any developmental delays. However, when he was two and half years old, his mother's brother told her that he thought Amir had a hearing problem. He had served in the army where he was shell-shocked and this experience helped him to assume that Amir may not be able to hear. The next day, the mother took Amir to the paediatrician and otolaryngologist in the local city polyclinic, but the local doctors did not have the equipment to determine his hearing level. So, the family decided to take him to the doctor in Bishkek. The surdologist at the children's' hospital told them that Amir had a deafness in the 4th degree, meaning total deafness. Amir's parents were shocked because they did not notice any abnormalities in his development. They did not believe this diagnosis and decided that the hospital had very old diagnostic equipment.

> *"I know that parents often blame doctors, and the lack of qualified treatment of their children becomes a reason for disability. I cannot say for sure but, when my child was young, he had pyelonephritis. The doctors recommended a very strong antibiotic, and his hearing impairment is the potential consequence. I think that, before his illness, my son spoke and heard well. So, when I was told that he is deaf, I did not believe it. Now I think it is due to a doctors' mistake during my child´s treatment."*

The parents took Amir to Kazakhstan, where there is an equipped hearing diagnostics centre. There, doctors identified 2-3 degrees of deafness in one ear, and 3-4 degrees in the other. They recommended treatment and a hearing aid. Amir's parents started saving money for the "Oticon" hearing aid. When they had saved enough, they went back to Kazakhstan and bought it.

When his mother was a student, she actively participated in a youth volunteer program where they provided support to marginalized groups of the population. Within this program, some students were invited to the boarding school for deaf children in Bishkek to provide recreational events. Volunteers stayed at their school for several days.

> *"I was very shocked at how poorly the children in this institution lived. They had cold rooms, poor food, a strict, almost prison-like regime, and caregivers who were always screaming. I understood that children shouldn't live in such conditions. I decided that if I ever had a child, I would never send him/her to such places".*

This life experience was very important in helping Amir's mother make her decision about the type of education her son should have. She decided that even though he had hearing impairment he would study in a mainstream school. However, the family had to move to Bishkek because Amir was not accepted by any local mainstream school. In Bishkek, he began to study in a private school. He learned to read and write, but he didn't speak. The mother spent a lot of time teaching him herself. The teachers complained that they didn't know how to teach a child who doesn't speak and did not pay attention to him during lessons.

> *"Experts say that a language environment is needed for the development of a child. My child did not have it. He was always alone and other children did not communicate with him. He was pretty and neat but sitting alone at the last desk".*

Every year Amir's hearing worsened, and he lost all his previous knowledge. Therefore, his parents decided to change schools. They found a more expensive private school where, they believed, their child would learn better. They even paid extra money for additional lessons and the mother actively participated in all events. They also bought a more expensive and comprehensive hearing aid for 7,000 euros. But, when he turned 10 years old, the doctors identified him as profoundly deaf. Amir's mother decided to not inform the school because she wanted to keep him in a mainstream school.

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[f] The name and location have been disguised to ensure anonymity.

One day Amir's mother met a child with a cochlear implant. She was very interested in this technology and tried to find information about it. She found that the Austrian Charity Fund working in Bishkek brought used cochlear implants from Europe and installed them in children from developing countries. After a long discussion and reflection, the family decided to pursue the possibility of fitting Amir with cochlear implants. They did not want to accept the deafness of the child as final and asked for financial support. The Austrian fund covered 50% of the cost of the surgery (doctors came to Bishkek) and the family paid 18000 euros for the cochlear implant and speech processor. The state didn't provide any financial, organizational or social support and the parents didn't register Amir's disability.

> *"The problem of registering disability in our country is that children with 3-4 degrees of hearing impairment could get it [disability status] but only if they study in a specialized school. If these children attend mainstream school, they cannot get disability status. We couldn't prove that my child is disabled, and there are some expenses for assistive technologies that we pay ourselves; that is why we needed the pension."*

The parents explained that making the decision about implants was the most difficult in their life. The father said that many parents are not well informed about the reality of cochlear implants:

> *"If parents think that their child has a chance to hear, they will sell everything: their house, all their sheep, cars, in order to install a cochlear implant but, they don't know that installation is not enough. There needs to be constant monitoring and control of the device. I read on the internet about all the pluses and minuses. I was a little bit against my wife's decision. But we decided to go ahead."*

Fitting Amir with cochlear implants didn't change his life. He was still alone at school, didn't show academic progress, and didn't actively communicate with people around.

> *"Studying in a mainstream school was my wife's whim. She wanted him to study with his non-disabled peers. I said: 'Stop torturing the child. He needs to be transferred to a specialized school where he will really study and communicate with children like him'. We pay for education in a private school, but there is no result of this education. I rent an apartment for my family in Bishkek, but I live in (…) where I have a job. The separation of my family was difficult. We paid a high price for no results."*

After several visits to a specialized school, the parents decided to send Amir there. He said that it was very stressful because he didn't understand sign language.

> *"In this school, no one speaks, and at the beginning, I felt that I had nothing to do there. I don't understand these children. I wanted to become a leader in this school, but there are guys here who study from the first grade, they all know each other and trust each other more than beginners. The school is hell."*

Amir's mother decided to get a professional certificate as a sign language interpreter in order to communicate with her son. She successfully attended qualification courses on sign language interpretation in Moscow. But Amir doesn´t feel comfortable using sign language.

Amir spends the whole day at school. He wakes up at 6 a.m. and leaves the home at 6.30 because the school is located far from his house. They have classes in the morning until the afternoon. After lunch, they do their homework supervised by caregivers (not teachers). But because there is no one interested in this job, they stay several hours in one room due to the lack of staff to provide supervision. When he went to private school, he went to the swimming pool, played volleyball, was in English courses, and his life was very busy. But in this specialized school his life is limited.

In school, he has only one friend who can speak. He feels that in his previous school he was excluded because of his disability but, in the current school, he is not accepted by other people who have more severe disabilities. He doesn't feel that he is a part of this community. He often tells his mother that she made a mistake and that his disability is a consequence of her improper care of him in his early childhood. He feels sorry for himself, and does not like his life, since he cannot communicate with the deaf or with 'ordinary' people.

Once the parents decided to organise a birthday party for their son and invited all his classmates from the specialised school. The father was shocked because he had never seen so many deaf people together.

> *"I am a man but, after the party, I cried because my son became an adult and I'm afraid for his future. What will his community be? How will his life be?"*

The mother said that they have been told many times that they need to accept their child's disability, but she cannot. His disability is always on her mind.

After 5 years of using the speech apparatus, it became outdated and stopped working. Therefore, it needed to be replaced. The family took a bank loan to be able to buy a new one, for 16,000 euros. They also needed to buy a new speech processor because the old did not accept an accumulator. The new one runs on batteries, and each battery works 1,5 days. Six batteries cost 300 soms. If there are no batteries, then Amir cannot hear anything. Every month they spend about 2000 soms only on batteries. That is the reason why the family decided to fight for registration of disability, since the one condition for disability indictor was followed: Amir studies in a specialised school. The disability pension helps them to buy batteries, a microphone that needs to be changed every 6 months (120$), and jumper wires (100$).

> *"If a cochlear implant is fitted in a child, the parents must learn how to properly care for it, dry it, clean it, and regulate it. I know that in other countries there are many services where parents can get information and help. There aren't any such services in our country. We need to learn everything from the internet".*

In Kyrgyzstan, the state doesn't provide services for cochlear implantation. This area of services is covered by private sector. The cost of implants is very high (18.000 euro and up) and many families can´t afford the expenses. Lack of information among parents also contributes to inflating prices and dishonest practices.

The installation of cochlear implant is not sufficient; the cochlear implant processor must be well tuned for good hearing. This should be done by a professional audiologist, regulating the electrical signals that are sent to the cochlear implants.

> *"I remember one mother who was so glad that her child will hear well, but she didn't know that during surgery doctors installed a cochlear implant but the speech processor would only be installed in a month, when the scalp heals. Her child would not hear until the speech processor was installed. Poor families… they are not well informed about implantation process".*

There are no audiologists in the country and only two surdologists. When Amir's mother went to Osh with her son, one surdologist began to ask her questions about cochlear implants.

> *"I think that doctors should know more than parents, they are the professionals. I was surprised by the doctor's detailed questions".*

Amir currently studies in the 10th grade (according his age he should be in 9th grade but his previous education setting allowed him to skip one grade). After finishing 10th grade he cannot continue to study because the specialized school does not have 11-12th grades - there are no children willing to continue their studies. With an incomplete education, Amir will not be able to pass the general education test and get a higher education. His mother dreams of him receiving a secondary vocational education in IT technologies, but he has no desire to study in this area.

Amir noted that he was stressed when he entered both mainstream and specialized schools. In the first case, he could not communicate with others because he couldn't speak, and teachers didn't pay attention to him. In the second case, he could not communicate with peers and teachers because he doesn't use sign language. He has had many discussions with his mother. He reported that he didn´t want to change schools but his parents forced him to move to the specialized school to access technologies that are, otherwise, very expensive. His family wants him to be accepted by both types of the society: people using sign language and others.

Amir's parents reported that some charity organizations- such as the Qatar Fund- help with surgeries and cochlear implants but they cover only a few children in Kyrgyzstan, some of whom will face problems with rehabilitation. The head of the NGO "Development" corroborated this report:

"Providing hearing assistance is a business. Every day, every hour… Access to assistive technologies is not under state control, and that is why deaf people try to survive. If you hear, you are accepted by society, you could get quality education, find a job, build a family. If you don't hear, find money for batteries. You are excluded from the society".

Case C: Rehabilitation of a child with cerebral palsy

Saltanat[g] is an 14-year-old girl living with her mother in a rural area of Osh Oblast. She has been diagnosed as having cerebral palsy and epilepsy. Saltanat´s mother remembers having some signs during her pregnancy that could indicate she was at risk of giving birth to a child with development delays. When she was in the 34th week of pregnancy, her doctor told her that the size of the foetal head circumference of the baby did not correspond to the expected at that stage in the pregnancy. She was also prescribed an antibiotic during pregnancy, as she was often ill. She had a caesarean section. When she gave birth, her doctors informed her that Saltanat would not survive and therefore she shouldn´t "get too attached" to her. She remembers being told this on several occasions over time.

Shortly after being born, Saltanat´s father left the family. Her mother did not believe that her child had any delays. When she was 10 months old, Saltanat fell ill with chickenpox. One night, she was injected with a medication 4 times and, after that, began to have severe convulsions. She was hospitalized, where she was diagnosed with cerebral palsy and epilepsy. She received a long treatment with neuro stimulants, but the treatment did not work, and the convulsions continued.

Saltanat´s mother took her to Moscow where the doctors reported that the previous treatment was wrong and had severely damaged her brain. Because Saltanat needed treatment in Moscow, her mother asked the media for help. The collection of charitable funds helped to get treatment in Moscow, after which she needed complex rehabilitation. Upon returning to Kyrgyzstan, Saltanat's mother asked the social protection department for help in rehabilitation, and they offered to send her to a residential institution, telling her mother that they could help with her daughter´s institutionalisation.

Refusing to place Saltanat in institutional care, her mother decided to move to Moscow to work as a babysitter and earn money for Saltanat´s rehabilitation, leaving Saltanat at home with her grandmother. Soon after her the grandmother fell and broke her hand, and Saltanat´s mother returned to look after her daughter. She tried to find useful information about possible rehabilitation options and applied to the local authorities for financial support to go to Italy where Saltanat could get the surgery she needed. She asked them to cover the cost of the surgery which was $10000 USD (about 89000 som). The local authority gave 3000 soms (approximately $33 USD). One businessman helped her and gave 6000 euro, which allowed her to get the surgery.

However, the surgery was not enough. As Saltanat grew up, her muscle spasticity changed. This affected all bodily functions and her development slowed down. Her mother began to search all possible means of rehabilitation and applied to the nearest rehabilitation centre in Osh. However, this was not a positive experience:

> *"I regret going to this centre. During the massage, my daughter suffered a dislocated hip joint. The rehabilitation therapists work according to the old Soviet rehabilitation methods: massage, electrophoresis, etc. They massage to stretch the muscles. This is not only very painful for the child, but also has a short-term effect. After a while, the muscles contract again. All children get the same scheme of treatment, despite there being different types of cerebral palsy".*

After this experience, Saltanat´s mother decided to learn methods of rehabilitation that she could perform to Saltanat. Through this effort, she learnt BDA (Biomechanical Developmental Approach), a therapy aimed at returning to the path of spontaneous development of children/persons with disabilities through the improvement of existing and development of new functions. Step by step she learned how to do everyday rehabilitation procedures that help Saltanat to have a better quality of life.

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[g] The name and location have been disguised to ensure anonymity.

> *"I know that my daughter will never walk, get out of bed, be able to say the word "mom," or even go to school, but my task is not to improve her, but to try to ensure that her condition doesn´t worsen."*

Saltanat's mother adopted approaches to caring for her that aim at making sure her situation doesn´t get worse. She believes that doctors prescribe many nootropics to children like hers, which stimulates the brain activity causing epileptic seizures.

In addition to BDA, she began to use mask breathing, paying attention to Saltanat´s nutrition and began to teach her to read by showing her cards with objects, letters, words, etc. In the beginning, she didn´t see any results but, one day, Saltanat began indicating the correct card with her gaze. This made her mother very happy.

> *"Of course, this experience cannot be strictly defined as reading. But I think this is a success. If my daughter can select with her sight a card with animals, flowers, objects, then the same approach can be used in everyday life."*

Saltanat´s mother began to come up with adapted books for her daughter about Africa, Australia, and other subjects. This way of "reading" later became useful when they went to specialists. Saltanat looked to the correct cards, and this gave the doctors some idea of her development.

Later on, Saltanat's mother got acquainted with the Doman's method, a series of rehabilitation and developmental methods for children with developmental delays and for children with full development.[i] All the rehabilitation measures that her mother tried have had positive results for Saltanat. Her seizures have decreased to only 1-2 times a month, instead of the previous 30 seizures a day.

Saltanat´s mother found that in the rehabilitation centre in Osh city there was a cabinet for social, psychological and educational rehabilitation established by a local NGO "Smile.kg". Here, Saltanat had the possibility to use their services. More importantly, her mother was able to acquire useful knowledge on childcare from the centre's specialists. Unfortunately, the centre is located in the city away from the village where the family lives.

Saltanat mother found that she can learn but said that she started teaching her too late. Saltanat is excluded from society and spends all day at home with her mother. She doesn't have the possibility to see other people, peers or even neighbours.

> *"People didn't believe that my daughter understood anything or could show her emotions. But I think that if I had begun to teach her earlier, she might have somehow be able to communicate with people and show what she wants. Unfortunately, I learned about early intervention very late."*

Saltanat´s mother believes that modern technologies could help her daughter to express her desires, feelings and emotions, and is collecting money for an eye tracker and LINKa.[j] This eye tracking technology is a way for those with cerebral palsy to control a communication device or an adapted computer with just their eye movement. It allows them to speak, read, write, and interact with the world around them.[k]

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[i] To know more about the Doman-Delacato method "patterning", see https://bdatherapy.com/ and https://www.domaninternational.org/

[j] LINKa is program that uses a speech synthesizer to help people with speech and musculoskeletal disorders communicate with the world.https://linka.su/

[k] https://www.tobiidynavox.com/learn/user-conditions/cerebral-palsy/gaze-interaction-and-cerebral-palsy/

Case D: Early identification of Down syndrome and access to education

Timur[I] is a 12 year old boy identified as having Down syndrome. He lives in Bishkek with his family. When he was born, the paediatrician at the maternity house identified that he had Down syndrome but initially decided to not inform his mother. After staying at the maternity house for two days, the paediatrician invited Timur´s father to come in and informed him that Timur was born with Down syndrome. The doctor explained that she didn´t want to disturb Timur´s mother out of fear that her distress would cause her breastmilk to disappear.

> *"I think that this is a unique situation because I know that many parents are not aware that their child has Down syndrome for a long time, even until the child is 5 or 7 years old. It was lucky that this paediatrician was on duty on the day of his birth".*

The paediatrician referred the family to genetic and cardiology testing. When Timur's parents got the results of the genetic test, they were shocked. Nobody from their local polyclinics explained to them what they should do after receiving such diagnoses.

> *"While I was communicating with our family doctor she behaved very rudely, blaming us for having a baby with Down syndrome. It annoyed her that such an incident happened on her site".*

After several visits with this doctor, Timur´s parents decided to change from state polyclinics to private clinics. However, the doctors there although very polite and respectful, were also not fully aware about Down syndrome.

Timur´s father didn't want to tell people about his son´s disability. He said that the family wasn´t ready to celebrate their son´s birth yet or invite people to meet him. Timur's mother said:

> *"I realized that he did not want to admit that we had a son with a disability. It upset me a lot. Of course, we were recommended to send the child to an orphanage. But this is my child; I wanted to raise him myself. When our son was one year old, I organized his birthday party and invited all our friends and colleagues. My husband didn't know about that. When they all came and saw our son, we carefully told them what Down syndrome is".*

At the time of Timur's birth there were no protocols for the treatment of Down syndrome. Timur´s parents searched for information on the Internet, asked other parents who have children with Down syndrome, and asked specialists. The level of awareness about Down syndrome was very low at the time, and most of the other parents they met hid their children with Down syndrome at home.

Once Timur´s mother reported to the doctor that his hands and legs were too short. The doctor replied that they could not stretch his legs and arms and that the most important thing for them to do as parents was 'to teach the child to walk with those legs and eat with those hands'. When another mother complained to the doctor with the same issue, the doctor recommended "Pikovit" vitamin promising that it would help to stretch child's legs and hands.

Timur was also diagnosed with two heart defects at birth. But his parents didn't know how to deal with this. In addition, his parents learned from the internet that children with Down syndrome are also at risk of a visual impairment.

> *"We did not know where and when to seek medical help. Timur feels discomfort when we show him to doctors, so we did not go to medical organizations. He already is 12 years old but we still have not tested his eyesight".*

The family was informed by the paediatricians that Timur can get a pension if he is registered as a child with a disability. Timur´s father was against his son having this "label" but, after much persuasion from Timur´s mother, he

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[I] The name and location have been disguised to ensure anonymity.

eventually agreed that it is just a word, and the money would be needed to buy medicine. When Timur was 3 years old they applied to the MSEC for registration of his disability status.

> *"The representative from MSEC told us that our child needs to spend 20 days in the hospital; only after that they could register his disability. We didn't agree with this condition and explained that we have done all the required tests. The genetic test is very expensive (about 5000 soms) but we did it, and it proves that our child has Down syndrome. Why did he need to be hospitalized? After long negotiations they agreed to register his disability. I think that we were the first family in the country who fought against this stupid rule".*

Timur´s disability status, does not help the family access any services, only provides access to the pension.

> *"I know that some parents get vouchers to Ak-suu rehabilitation centre in Issyk-Kul oblast but, in our case, nobody told us what we should do or how get these vouchers".*

Timur´s parents reported that at the MSEC the specialists "treat the applicants with an authoritarian, unpleasant attitude and constantly scold their parents".

Access to education

Providing Timur with an education was very important to his family, but he wasn't accepted by any kindergarten. They eventually convinced a preschool teacher from a local kindergarten to accept Timur, on the condition that no one would know about the agreement or about his disability. The teacher was afraid that other parents would complain to the administration and she would lose her job if they found out. She promised to accept Timur in the kindergarten, but his parents waited for a long time and nothing happened.

They decided to ask Timur´s grandmother to teach him at home, as she was a preschool teacher. His grandmother agreed and left her job to teach Timur and help in his development. After several weeks teaching Timur one-to-one, his grandmother decided that he should spend some time with his peers. Her idea was to establish a small private kindergarten where children with and without disabilities could play and learn together. They rented a small house and invited 5 children - 3 with Down syndrome and two children without disabilities. Over the years, this group has expanded. Timur's grandmother recruited other preschool teachers and started accepting children with other disabilities (autism, cerebral palsy and ADHD[m]).

When Timur was 8 years old, the family decided to send him to mainstream school and his mother took Timur to PMPC. Timur was not granted access to mainstream education although another child with Down syndrome undergoing the same process was provided access.

> *"The PMPC didn't give us permission for our son go to mainstream school. They said that my child had a mental retardation. But another girl with Down syndrome was sent to a mainstream school. I asked them why one child with Down syndrome can go to school, while another child with the same diagnosis cannot. They explained that my son had visible characteristics of Down syndrome, while there were no visible signs of Down syndrome on the girl's face. I was shocked. Of course, because that girl is Asian and my son is European there could be differences in their faces. The director of the PMPC was trying to explain to me that my child has a Down "illness", while the other girl has a "syndrome". This can´t be true! I slammed the door and never went to the PMPC again".*

After this experience, the family decided to open their own private school. At present time, Timur studies with a few other children with Down syndrome at the centre managed by his parents and grandmother. This school doesn't have a registration or license yet, but they believe that they will get a license. The family does not want to send him to a specialized school.

Timur has two best friends who also have Down syndrome. He spends a lot of time with them. He likes to cook, so his parents dream about

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[m] Attention-deficit with hyperactivity disorder

establishing a professional cooking course for people with Down syndrome in the future. His mother said that they don’t pay attention to negative attitudes of the society and try to create an inclusive environment around their son.

> *“Several years ago, we didn’t even think that our children could study or get married. We discussed their futures with other mothers, and we couldn’t understand what a woman and a man with Down syndrome could do if they stayed together. Now we strongly believe that they can have sexual relationships like other people, can build families, and maybe we will even have grandchildren. Of course, our children are not accepted by the whole society; they cannot go to public sport clubs as they do not allow them to attend; sometimes children in playgrounds fight them; doctors don’t know how to treat our children. Children like them are sent to special kindergarten and schools”.*

ANNEX 1:

LIST OF QUESTIONS FOR KIIS AND FGDS WITH DUTY-BEARERS

Duty-bearers – policy makers

1. Could you please describe your job profile and where your job fits within the existing structure of your region/town?
2. Can you please describe your specific professional responsibilities towards children with disabilities?
3. Can you please describe the most important measures the government has developed for children? Social inclusion? Children with disabilities? (Please ask each category – children, social inclusion, children with disabilities - separately and pause between each to obtain an answer)
    a. What are the international conventions, national laws and by-laws that the government applies to set these national policies? (Please probe for the integration of government policies with the Convention on the Rights of Persons with Disabilities (CRPD), Convention on the Rights of Children (CRC), Convention on the Elimination of Discrimination against Women (CEDAW), etc.)
    b. Do you feel there is sufficient awareness about these instruments in your department? Has training on these instruments been organised?
4. Can you please elaborate on the government's strategy, work plans, timeline, and budget to implement the national policies that are specific to children with disabilities? What is the role of each ministry in this regard? [Please probe separately for each mentioned policy in question 3 above]
    a. If interviewee mentions "action plans": please probe to find out if action plans have been costed and budgeted and include standards, monitoring and/or evaluation mechanisms
5. Can you please describe, to the best of your knowledge, what are the different types of public services that have been implemented for children with disabilities in your geographic area? (Please collect details of the different types of services as described).
    a. What can you tell us about their quality? How do you know?
6. Do you think that government's policies and action plans to serve children with disabilities should be different depending on the type of disabilities? (sensory, learning, physical, combined] or their severity?
    a. If yes: Who should be responsible for determining the type, severity and associated needs of each impairment? How?
7. Can you please describe the existing inter-ministerial/interdepartmental coordination between different areas of government on the subject of children with disabilities? (Please probe for coordination between Social Welfare, Education, Health, Vocational Training, Public transport, Labour, Sports and Culture, etc.)
8. To the best of your knowledge, is there policy regulating accessibility to public facilities and information (including public website) based on universal design?
    a. If yes: can you describe what it says?

9. To the best of your knowledge, how accessible are the public facilities [buildings and inside infrastructure] in your geographic area for children with disabilities?
10. To the best of your knowledge, is there enough available data/ information on persons with disabilities for evidence-based decision making?
11. To the best of your knowledge, what are the challenges you face in legislating and/ or enforcing implementation of services for children with disabilities and their families, and what are the possible measures to overcome these? Please ask to elaborate.
12. Do you think there is a need for protocols [i.e. process and procedure for treating and/ or serving] or guidebooks for providing services to children with various forms of disabilities?
13. Do you think that you have enough trained professionals on issues related to disability issues to ensure proper implementation of policies nation-wide?
14. To what extent do you think the rights of children with disabilities are being fulfilled in your geographic area? Please elaborate.
15. Could you please give us any example of good practice related to legislation, policy or service provision for children with disabilities?
16. What do you think is the general public's view (awareness and attitudes) of children with disabilities?
17. Do you have a family member or close friend who is a person with a disability?
    a. If yes: how much has this person influenced your professional work?
    b. If no: Would you allow your son/daughter to be friends with, marry or constitute a family, living independently with a woman or man with a disability? Why or why not?
18. What are your views on having people with different disabilities in the executive committees working on disability within various ministries/departments?
19. Do you know any DPOs or other organizations working on the rights of children with disabilities in your area? Which ones?
20. What are you views on the role played by the Organizations of People with Disabilities (OPD) or other development partners in raising awareness, doing advocacy and research, and monitoring the rights of children with disabilities in Kyrgyzstan?
21. To what extent are Disabled Persons Organizations supplementing the government's efforts to serve children with disabilities in Kyrgyzstan?
22. Are the rights of children/adults with disabilities being fulfilled in your community? Why or why not?
23. How are children/adults with disabilities viewed by other professionals such as yourself?
24. How would you describe the level of awareness and attitude towards children/ adults with disabilities in ….? [Please collect information for each of the following separately]
    - General population
    - Government
    - Non-governmental Organizations/Civil Society Organizations
    - Disabled People's Organization
25. What are some of the misconceptions regarding children with disabilities that you encounter most often in your work?
26. Do you have colleagues who are persons with disabilities themselves?
27. To what extent are the contributions of children with disabilities valued and taken as important contributions in your work? (good, average, weak, not existing)
28. To what extent are children with disabilities accepted as full members of your community?
29. To what extent are children with disabilities included in the social life of your community? What are the main challenges they face?

   a) Who is responsible for ensuring opportunities for social inclusion in your community?

   b) What is your role in ensuring opportunities for social inclusion for children/adults with disabilities in your community?

Duty-bearers – service providers

1. Could you please describe the type of service to children with disabilities you provide? Please collect information for each separately.
2. Which children with disabilities generally come to receive your services? [Please probe for the social and economic background of the children and check whether these are children with specific types of disabilities].
3. Do they travel to see you? How?
   a. If not: Do you travel to see them?
4. Is your service/expertise essential in determining specific services and/or cash benefits that children with disabilities (or their families) receive?
5. To what extent is your work setting friendly to children with disabilities? [E.g. ramp, accessible toilet, safe playgrounds, etc.]
   a. If it is: Could you please give us examples of initiatives taken to make the infrastructure friendlier for children with disabilities? How have these been financed or resourced? [probe for the role of the government, community, private donations, projects funded by any NGO/CSO/ Other Organization, etc. in this regard]
6. What are the challenges you face in working with children with disabilities and their families, and what are the possible measures to overcome these? Please ask to elaborate (the facilitator should guide the discussion on what type of obstacles do they face such as economic, health, social access, stigma, infrastructure, big number of children in classes, cultural barriers etc.)
7. To what extent have you and others in your work setting been trained to work with children with disabilities?
   a. If training is mentioned: Can you please describe the training? Who provided the training? How effective was it?
8. What other specific training and/or supports would you need to improve your work with children with disabilities and their families?
9. To what extent do you think children with disabilities and their families are encouraged to seek your services?
10. What is your role in raising awareness regarding children's rights to access existing services?
11. Do you have any collaboration with other service providers outside of your immediate area of expertise? Please ask to describe and elaborate on collaboration.
12. To what extent do the families pay from pocket to get some/all types of services for children with disabilities?
13. To what extent are there budget allocations for services for children with disabilities this year? Is this allocation sufficient? What are the different heads of the budget? [E.g. salary, infrastructure, training, equipment, awareness promotion, performance measurement, M&E, etc.]
    a. If 'no': do you think separate budget allocation is needed? Why or why not?
14. As far as you are aware, have there been cases of children with disabilities experiencing physical and/or emotional abuse [E.g. mocking, physical, intimidation, etc.]?
    a. If 'yes': by whom? What are the measures you take to prevent physical and emotional abuse of the children with disabilities?
15. Are there any service providers in the community than cannot accommodate children with disabilities within their service provision? Please elaborate.
16. How do you provide services to children with disabilities in remote areas? Please describe

17. How would you describe the level of awareness and attitude towards children with disabilities in general?

18. To what extent are the rights to health, education and protection for children with disabilities fulfilled where you live?

19. Do you have any procedures for identification of children with disabilities including any early detection and prevention services at local level?

    a. If 'yes': could you please describe such procedure?

    b. If 'no': to what extent do you think such procedure would be useful?

20. Could you please give us any example of good practice related to your service delivery for children with disabilities?

21. In your view, can children with disabilities be included in society? Why or why not?

22. To what extent do you receive any support related to the services you provide to children with disabilities from local officials in the form of guidelines or other means? Please elaborate with examples.

23. In your view what kind of support (additional or new) do you require for proper service provision to children with disabilities from the: (i) government, (ii) non-government organizations, and (iii) communities?

Duty-bearers – OPDs/NGOs

1. Could you please describe the type of activity or a service to children/adults with disabilities and their families your organization provides? Please collect information for each separately.

2. Does your organization provide direct services related to health, education, employment, protection, rehabilitation, provision of assistive technology or other disability-specific services?

3. Does your organisation participate in the policy-shaping (e.g advocacy activities)? At what level (municipal, national)?

    a. If yes: could you estimate proportion of time and investment for service provision and for policy-shaping activities?

    b. If yes, how do you involve children with disabilities in policy-shaping activities?

    c. Is your organisation funded to participate in policy-shaping?

4. What types of persons with disabilities (children/adults) generally come to receive services provided by your organization? [Please probe for the social and economic background of the children and check whether these are specific types of disabilities].

5. Do they travel to see you? How far do they come? Do you cover remote/rural areas?

    a. If not: Do you travel to see them? Who pays for your travel costs? How often do you make house visits?

6. To what extent do the families pay out-of-pocket to get some/all types of services for persons (children/adults) with disabilities?

7. To what extent is your work setting friendly to persons (children/adults) with disabilities? [E.g. ramp, accessible toilet, safe playgrounds, etc.]

    a. If it is: Could you please give us examples of initiatives taken to make the infrastructure friendlier for persons (children/adults) with disabilities? How have these been financed or resourced? [probe for the role of the government, community, private donations, projects funded by other NGO/CSO/Organization, etc.]

8. What are the challenges you face in working with persons (children/adults) with disabilities and their families, and what are the possible measures to overcome these?

9. To what extent have you and others in your organization been trained to work with persons (children/adults) with disabilities?

    a. If training is mentioned: Can you please describe the training? Who provided the training? How effective was it?

10. What other specific training and/or support would you need to improve your work with persons (children/adults) with disabilities and their families?

11. How are persons (children/adults) with disabilities and their families made aware of the services you provide? Are persons (children/adults) with disabilities and their families referred by other professionals (teachers, doctors, etc.) to seek your services? Please ask to elaborate if a procedure is mentioned.
12. Where does the funding needed to support your organization work come from? Does your organization have a specific budget allocation for services for persons (children/adults) with disabilities?
13. As far as you are aware, have there been cases of persons (children/adults) with disabilities experiencing physical and/or emotional abuse [E.g. mocking, physical abuse, intimidation, etc.]?
14. If 'yes': by whom? What are the measures you take to prevent physical and emotional abuse of persons (children/adults) with disabilities? Does your organization provide legal advice or specific child protection measures?
15. How would you describe the level of awareness and attitude towards persons (children/adults) with disabilities, in general, in the geographic area where you work? Please describe.
16. To what extent are the rights to health, education, employment and protection for persons (children/adults) with disabilities fulfilled the geographic area where you work? Please describe.
17. Do you have any procedures for identification of persons (children/adults) with disabilities, including supporting early detection and prevention at local level?
    a. If 'yes': could you please describe such procedures?
    b. If 'no': to what extent do you think such procedures would be useful?
18. In your view, can persons (children/adults) with disabilities be included in society? Why or why not? What are main challenges for their inclusion? And the main opportunities for improvement? Please elaborate with examples.
19. To what extent do you receive any support related to the services you provide to persons (children/adults) with disabilities from local officials or other professionals/service providers in the form of guidelines or other means? Please elaborate with examples.
20. In your view, what kind of support (additional or new) do you require for proper service provision to children with disabilities from: (i) government, (ii) non-governmental organizations, and (iii) communities?

Duty-bearers – residential institutions (and special schools)

1. Could you please describe your job profile and what are your general responsibilities towards the children with disabilities in your care?
    a. IF BOTH CHILDREN & ADULTS WITH DISABILITIES IN THE SAME INSTITUTION:
        i. Do you have different responsibilities towards children and adults with disabilities?
        ii. Do you have two separate facilities (or areas of the same building) for children and adults with disabilities, or are all beneficiaries together in the same space?
    b. Do you have separate facilities (or areas of the same building) for boys and girls, or are all children together in the same space?
2. Can you please describe your institution? (Please record the answer exactly as given; do not probe or ask for elaboration)
    a. Is the infrastructure of your institution accessible to children/adults with disabilities?
        1. If yes: Can you please describe the accessible features?
        2. If no: How do children with disabilities have access to the entire institution?

   b. Does your institution have an isolation room for use by children with disabilities who have behavioural difficulties?

3. What types of services do you provide? (Please probe for differences between orphanage, social protection services, education/special school, vocational education, job training, residential, full-day, day-care, occasional care, etc.)
4. Which ministry is responsible for your budget? Are all the costs of running your institution covered in your official budget or do you receive donations (in cash or in kind) from others?
   a. If yes: who provides your institution with financial support? And other types of support? Please describe.
   b. Is your budget sufficient to provide minimum services to all of your beneficiaries?
   c. How much do families/parents pay out-of-pocket to your institution for the care of their children with disabilities on a monthly basis?
   d. If no: what are some of the services and provisions that you would like to ensure but for which you do not have enough money in your budget? Please describe.
5. How many CHILDREN are in your institute, in total? (Please specify how many females and how many males)
   a. How many children with disabilities are in your institute?
   b. How many types of disabilities are represented? And levels of severity?
   c. Are all children with disabilities together in the same space or do you have some children with disabilities who are isolated from others?
6. Do you accept children without disabilities at your institute?
   a. If yes, please describe the process.
7. How many CHILDREN with disabilities stay in your institution overnight?
8. How long do they usually stay? (Probe for week-days, all month, only during school semester, all year except holidays, all the time, etc.)
9. Do you have separate sleeping and hygiene (toilets, showers) arrangements for girls and boys?
10. How many go home to visit their families? How often do they go home? How do they travel to go home?
11. Do their families come to visit them? How often? How do they travel here? Do they bring gifts to the children when they visit?
12. How many staff do you have in total?
    a. How many are women and how many are men?
    b. How many of them are professionals and how many are support staff (such as cleaning and cooking)?
    c. How many staff usually stay in the institution overnight? Are they men, or women, or both?
13. What types of professionals do you have in your staff? (probe for physicians, psychologists, psychiatrists, therapists, social workers, teachers, etc.)
    a. What type of training specific to disability have your staff undergone? How often are they retrained? Does the training offered to them include safe restraint techniques?
    b. Do you have disability specialists to match every type and/or severity level of disability in your care? How many and what type of specialties do they have?
    c. When/if needed, can you ask for external professional expertise to support your work? Is there a specific procedure? How long does it take for a reply or support?
14. How are the children with disabilities placed in your care? Are they placed here by a government agency or do they come on their own (brought by family)? Please describe the various ways by which you receive new beneficiaries. (Please record answers exactly

as given and probe as needed to clarify)

15. When you receive a new child what assessments does the intake process include? Please describe the process from the time that a new person is identified as a potential client for your institution.

16. Do you assess for impairments/disabilities when needed/requested?

    a. If yes: What tools do you use? Who is responsible for the assessment results? How long does the assessment process take? What do you use the results of the assessment for?

    b. If no: Why not?

17. Does each child in your care have a plan of care/therapy?

    a. If yes: Who is responsible for developing the plans?

    b. If yes: Do the plans for children include an education component?

    c. If yes: Do the plans include a work rehabilitation plan?

    d. If yes: Do the plans include positive behaviour modification and/or other types of behaviour management methods? Can you give an example?

    e. If yes: Do the plans include administration of psychotropic medications? Shock therapy? Isolation?

    f. If yes: Who monitors the plans of care? How often?

    g. If no: How do you answer to each person´s individual needs for care and services without individual plans? Please elaborate.

18. How often does one of the children with disabilities in your institution complete a treatment/care plan and is successfully returned to their family? In the last year, how many children with disabilities have "graduated" from your institution?

19. Do the children with disabilities who are in your care attend an education programme?

    a. If yes: do they go to a regular school or do you have your own education programme?

    a. If they go to a regular school: Do they follow the regular curriculum?

    b. If they go to a regular school: Do they take graduation exams as all other children?

    c. If they go to a regular school: can the children who graduate pursue other studies?

    d. If institution has its own programme: why do the children not attend a regular school?

    e. If institution has its own programme: Do you think they should attend a regular school? Why or why not?

20. Can you please describe the most important measures the government has developed for children with disabilities? Do you know which are the international conventions, national laws and by-laws that the government applies to set these national policies?

    a. If they mention the CRPD or the right to independent living: what is your opinion about this right?

21. Are the rights of children with disabilities in your institution being fulfilled? Why or why not?

22. How are children with disabilities viewed by others in your community?

23. How would you describe the level of awareness and attitude towards children with disabilities in .....? [Please collect information for each of the following separately]

24. General population

25. Government

26. Non-governmental Organizations/Civil Society Organizations

27. Disabled People's Organization

28. What are some of the misconceptions regarding children with disabilities that you encounter most often in your work?

29. To what extent are the contributions of children with disabilities valued and taken as important contributions for their community?

30. To what extent are children with disabilities accepted as full members of their communities?

31. To what extent are children with disabilities included in social events in the surrounding community? What are the main challenges they face?

32. Who is responsible for ensuring opportunities for social inclusion in your community?

33. What is your role in ensuring opportunities for social inclusion for children with disabilities in your community?

34. To what extent do children with disabilities have access to essential services that can support them to live as independently as possible once they leave your institution? What types or services exist?

    1. What other types or services still need to be developed?

    2. Who is responsible for ensuring services exist, are accessed and of quality?

35. What happens when the young person is too old to continue living in the institution?

    a. Is there a transition plan (professional orientation, independent living skills training, housing support)?

    b. Is the young person transferred to an institution for adults? How does this happen?

    c. What happens to the young person's legal capacity? Is it intact, or are they under guardianship?

36. In your view what kind of support (additional or new) do you require for proper service provision to children with disabilities from: (i) government, (ii) non-government organizations, and (iii) communities?

ANNEX 2:

LIST OF QUESTIONS FOR FGDS WITH RIGHTS-HOLDERS

Methodological note prepared for interviewers and facilitators - Ethical considerations[n]

Persons with disabilities are not "weak", "helpless" or "useless". They do not "suffer" from a disability and are not "victims" of a disability. In addition, persons with disabilities may or may not be a part of a "vulnerable population", depending on their individual circumstances. Making generalizations regarding persons with disabilities based on stereotypes is wrong, and often serves to perpetuate the charity or medical models of disability. The social model of disability enshrined in the CRPD promotes persons with disabilities as fully deserving, autonomous and independent people.

Often, persons with disabilities will say that they just need "an opportunity to be myself and participate with my peers". As a young woman from the Philippines will tell you, "value us for who we are and what we can do, not by how we look and what we cannot do".

When communicating and/or working with persons with disabilities, common sense, sensitivity and basic interpersonal skills should be used. Children asking questions about persons with disabilities is a typical part of development, attitude formation and learning values. Therefore, it is important to teach children (even the very young ones) the most adequate ways of speaking to and about persons with disabilities.

The CRPD promotes the use of person-first terminology when referring to persons with disabilities. Therefore, you should say "a child with a disability" instead of "disabled child" to emphasize the individual as the primary subject. In addition, you should use terminology that is not demeaning and does not carry derogatory or negative meanings. Thus, you should say "child with polio" for example, and not "polio affected child".

In all cases, be respectful of the person you are talking to or about. When in doubt, ask the person her/himself which is their preference, or ask an Organization of Persons with Disabilities (OPD) in the area. When distinguishing between children with and children without disabilities, do not use the term "normal".

The following are some basic rules of etiquette to follow throughout the research:

1. ASK BEFORE YOU ACT – when in doubt, ask a person with a disability how they would like to be addressed or how you should refer to their impairment or disability;
2. Do not speak about a person with a disability as if they are not present, cannot hear you, or cannot understand you;
3. In all cases, refer to people by their names – do not describe persons with disabilities as "the little blind girl" or "the man in crutches";
4. Do not talk to adults with disabilities as if they are children and cannot fully understand you or act on their own – even people with communication limitations can understand and take their own decisions;
5. Speak from a position that is comfortable to anyone – if needed, sit down or crouch to be at eye level;

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[n] Adapted from: UNICEF (2015). Disability Orientation (video). Retrieved from https://www.unicef.org/66434.html

6. Every person has the right to make their own decisions – if someone uses a wheelchair it may seem easier or faster to decide where/ how to go on their behalf. But, making decisions is a right and you should give the opportunity and time needed for independent decision-making;
7. Don't think in terms of stereotypes, thinking that all persons with disabilities are tired, angry, frustrated, depressed, sick or vulnerable. Persons with disabilities are just people with their own individualities; do not attribute their behaviour to their disability;
8. TREAT PERSONS WITH DISABILITIES THE WAY YOU WOULD LIKE TO BE TRAETED – respectfully and attentively, not with pity or paternalism.

FGD with children and adolescents with disabilities

Guidelines for FGD Facilitators

- For the benefit of a productive discussion please try to limit the size of a group to a maximum of 10 between the age of 14 and 19. However, please do not exclude children with disabilities who have expressed willingness to participate in the discussion.
- Please introduce yourself with warm greetings, tell your name, explain the purpose of the meeting, and intended use of the study findings. Please explain that the participation in the study is absolutely voluntary and this discussion does not involve any biological/ medical examination. Please record the names and addresses of the participants for quality control purposes.
- Please read and explain the questions in simple language that can be understood by a child and be mindful about the composition of the group (by age, gender, types of disabilities, etc.). Explain the questions, if needed.
- In all questions, examples are provided for the benefit of the facilitators. Please use only these examples to avoid influencing/ leading the answers of the participants.
- Please ensure that the children are not asked or probed to reveal any personal, confidential or intimate details about their life and that all children are participating in the discussion. Encourage participation by all children as much as possible but, do not engage any one child directly or force a response. Take note of those who do not respond.
- It is desirable that children with disabilities participate in the FGD on their own. However, this restriction may be relaxed in some cases (e.g. communication impairments, etc.) and a caregiver/ family member may be allowed to accompany the child
- The Focus Group Discussion should last between 60 and 90 minutes.

Questions

1. Could you please describe the activities you generally do in a day? [Discussion should bring out the extent of involvement in different types of normal daily activities like going to school, doing school homework, taking part in sport activities, helping in various household chores, hobbies, involvement in any paid or unpaid 'work', etc.]
2. Could you please describe the persons with whom you spend most of the time in a day? What are the things you do with them? What else would you like to do? [Discussion should bring out the type, role, and extent of the involvement of the caregivers in the daily life of the children; probe for differences between answers from boys and girls]
3. What is the one thing you like to do most? [E.g. spending time with family members and friends, playing games with others, pursuing own hobbies, visit to different places, going to social or cultural events, etc.]
4. Do you go to school or receive any type of education?
    a. If yes, go to school: Could you please describe what you do in the school/ institute you go to and how do you like it there? [Discussion should bring out the children's experience in the school/ institute, their likes and dislikes about the place, behavior of- and cooperation

received- from the teachers and/ or staff, methods of teaching/ training/ caring used, interaction with other children, availability and ease of access to infrastructure, any barriers in accessing the school/institute, and any other good or discriminating practices at the school/ institute that the children feel]

   b. If yes, receive education but do not go to school: Can you describe the type of education you receive? (Discussion should bring out what they are learning, who is teaching them, where, how often, etc.)

   c. If not, don't go to school or don't receive any education: Why not? (Discussion should bring out reasons why the child does not attend, such as parents do not wish to send them, schools refuse to enroll, accessibility barriers, etc.)

5. How often do you go to the doctor/nurse? What do you like about going there? How do you wish it would be different? [Discussion should bring out the frequency of visit, type of the health service received, like and dislikes about the place and the services, ease of access of the infrastructure, behavior of- and cooperation received- from the staff/ practitioner, any barriers in accessing the institute, and any other good or discriminating practices in the place that the children feel.]

6. Could you please describe your experience participating in community activities with other children and adults? (e.g. sports, games, religious festivals, marriages, funerals, etc.)? [Discussion should bring out why they want to participate, the extent of their participation, whether someone from the community or family members helps them in participation, reaction of the community members regarding their participation, any barriers in the participation, whether they want to participate more or less, etc.]

7. How many of you have friends? [Note those who do not] What can you tell us about your friends? [Discussion should bring out whether the children have any friends in the neighborhood and/ or in the school/institute, whether they have any friend(s) without disabilities, do they play with them regularly, what kind of games they play, how they feel about their friends, how they feel when they go to the friend's house, etc.]

8. Could you please describe the last time that someone made you feel sad or upset? [Discussion should bring out whether they have experienced negative incidences like mocking or bullying, what they do when they feel sad, if anyone (caregiver, friend, community member, etc.) help in this regard, etc.]

9. How often/many times are you allowed to make your own choices/decisions? [Discussion should lead to whether they can choose living at home with their family; the school they go to; the doctor/nurse they visit with; the activities they do with friends, family and others in your community, etc.].

10. What do you want to do/be when you grow up? [Discussion should bring out their aspiration, how they feel it can be fulfilled, types of guidance or assistance they want from their family, friends, community members, teachers, government and other organizations, etc.]

11. Could you please describe whether you have received any assistance/ information from an organization outside of your family or school?

   a. Of those who say yes, ask to describe the organization. [Discussion should bring out type, role, and extent of involvement of these organizations in the life of the children. Note: Organizations can be off different types like Non-government Organization, Civil Society Organization, Faith-based Organization, Community-based Organization, Disabled People' Organization, Organization working for people with disabilities, etc. Children may or may not distinguish between different types of organizations like NGO, CSO, OPD, etc. FGD coordinator may explain these concepts in simplest form with examples, if required, for the ease of the discussion. Please make sure that the exact type of organization is not asked unless the children are sure about it. Please record the children's answer exactly as given.]

b. Once a few children describe organizations, ask the others who did not answer, again.

FGD with children and adolescents without Disabilities

Guidelines for FGD Facilitators

same as above

Questions

1. Could you please describe the activities you generally do in a day? [Discussion should bring out the extent of involvement in different types of normal daily activities like going to school, doing school homework, taking part in sport activities, helping in various household chores, hobbies, involvement in any paid or unpaid 'work', etc.]
2. Could you please describe the person with whom you spend most of the time in a day? What are the things you do with him/ her? What else would you like to do? [Discussion should bring out the type, role, and extent involvement of the caregiver in the daily life of the children and probe for differences between answers from boys and girls]
3. Could you please describe any other persons (other than the primary caregiver) with whom you spend some time in a day or sometimes? What are the things you do with him/her/them? What else would you like to do with him/her/them? [Discussion should bring out the type, role, and extent of involvement of the other family and non-family members in the life of the children]
4. What is the one thing you like to do most? [E.g. spending time with family members and friends, playing games with others, pursuing own hobbies, visit to different places, going to social or cultural events, etc.]
5. Could you please describe what you do in the school/institute you go to and how do you like it there?
6. How would you like your 'dream'-school to be? How do you compare your 'dream'-school with what your school is like now? [Discussion should bring out the children's experience in the institute, their likes and dislikes about the place, behaviour of- and cooperation received- from the teachers and/ or staff, methods of teaching/ training/ caring used, interaction with other children, availability and ease of access to infrastructure, any barriers in accessing the institute, and any other good or discriminating practices at the school/ institute that the children feel]
7. How often do you go to the doctor/nurse? What do you like about going there? How do you wish it would be different? [Discussion should bring out the frequency of visit, type of the health service received, like and dislikes about the place and the services, ease of access of the infrastructure, behaviour of- and cooperation received- from the staff/ practitioner, any barriers in accessing the institute, and any other good or discriminating practices in the place that the children feel.]
8. Could you please describe if you participate in community activities with other children and adults (e.g. sports, games, fair, religious festival, marriage, funeral, etc.)? [Discussion should bring out why they want to participate, the extent of their participation, whether someone from the community or family members helps them in participation, reaction of the community members regarding their participation, any barriers in the participation, whether they want participate more or less, etc.]
9. How many of you have friends? [Note those who do not] What can you tell us about your friends? [Discussion should bring out whether the children have any friends in the neighbourhood and/ or in the institute, whether they have any friend(s) with disabilities, do they play with them regularly, what kind of games they play, how they feel about their friends, how they feel when they go to the friend's house, etc.]
10. Could you please describe whether you have received any assistance/ information from an

organization outside of your family or school?

   a. Of those who say yes, ask to describe the organization. [Discussion should bring out type, role, and extent of involvement of these organizations in the life of the children. Note: Organizations can be off different types like Non-government Organization, Civil Society Organization, Faith-based Organization, Community-based Organization, Disabled People' Organization, Organization working for people with disabilities Children may or may not distinguish between different types of organizations like NGO, CSO, OPD, etc. FGD coordinator may explain these concepts in simplest form with examples, if required, for the ease of the discussion. Please make sure that the exact type of organization is not asked unless the children are sure about it.]
   b. Once a few children describe organizations, ask the others who did not answer, again.

11. Can you tell us about times when you were afraid, or have not felt safe/ secure? [Discussion should bring out why they feel afraid, where they feel afraid most (at home, outside home, at the institute, at the health facility, in the community or social events, etc.), what they do when they feel afraid, does anybody (caregiver, friend, community member, etc.) help in this regard, etc.]
12. How often/many times are you allowed to make your own choices/decisions regarding: living at home with your family; the school you go to; the doctor/nurse you visit with; the activities you do with your friends, family and others in your community?
13. What do you want to do/be when you grow up? [Discussion should bring out their aspiration, how they feel it can be fulfilled, types of guidance or assistance they want from their family, friends, community members, teachers, government and other organizations, etc.]"

FGD with parents (caregivers) of children and adolescents with disabilities

Guidelines for FGD Facilitators

- For the benefit of a productive discussion please try to limit the size of a group to a maximum of 10 persons. However, please do not exclude caregivers/parents of children with disabilities who have expressed willingness to participate in the discussion.
- Please introduce yourself with warm greetings, tell your name, explain the purpose of the meeting, and intended use of the study findings. Please explain that the participation in the study is absolutely voluntary and this discussion does not involve any biological/ medical examination. [Please record the name and addresses of the participants for quality control purposes.]
- Please read and explain the questions in simple language and be mindful about the composition of the group (by age, gender, rural/urban, etc.). Explain the questions if needed but avoid influencing/ leading the answers of the participants.
- Please ensure no one is asked or probed to reveal any personal or confidential or intimate details about their life or that of their child.
- Discussions should take between 90 and 120 minutes

Questions

1. What is your relationship to the children with disabilities you are representing in this discussion? (Please record if mother/father or caregiver; in the case of a caregiver, record the type of relationship – sibling, aunt, grandfather, social worker, case manager, etc.). How many other children do you have? Is your child with a disability the first, last or middle child?
2. Could you please describe your children with disabilities in your own words?

3. Do your children have disability certificates? What are the official disability categories or types? (mark down the exact response given)
4. Can you describe the process you went through in order to get information abou
5. When did you first realize your children had specific difficulties? Who helped you diagnose the disabilities? How old were your children at the time of diagnosis?
6. Can you describe the process you went through in order to get information about your child's disability? Who helped you?
7. Can you please describe your child's regular day? [Please probe for going to school, doing homework, playing, working, etc. and enquire about his/her involvement]. Do they do all these things alone or with assistance? [Probe for specifics as to who, what, how frequent, etc. is the assistance].
8. What do your children like to do most? [or] What are his/her hobbies? How and how often do they do them? Do you encourage their choices? Do you sometimes help them in doing these things/ pursuing hobbies? How?
9. Are you the person who spends most of the time with your children at home and provides care?
    a. If 'no', who spends most of the time with your children and provides her/him with necessary assistance? What is the relationship between the person and your children?
10. Do you know who your child's friends are? Do you encourage your children to make new friends? Why, why not?
    a. If parent knows some friends: How and how often do your children interact with the friend(s)? What do your children do with his/her friends? Are his/ her friend's children with and without disabilities? Do your children go to his/her friend's place sometimes? Do the friends also come to your place? Please probe.
    b. If 'no': why do you think your children don't have friends? Do you think there is any specific reason your children do not want to interact with other children and vice versa?
11. Do your children participate in social or community life on a regular basis? (e.g. sports, game, fair, religious festival, marriage, funeral, etc.)
    a. If 'yes': Do his/her friends or any community member(s) help in the participation? How do they help? Do you take part in social or cultural events or community as a family along with the child? How often? Do your friends, neighbours, or community leaders pose obstacles to your child's participation in community life? Could you please elaborate on your response?
12. Are your children attending any educational institute?
    a. If 'yes': what is the type of school? (e.g. Early child development centre, mainstream school, day school for children with disabilities, day care centre for people with disabilities, vocational training centre, residential school for children with disabilities, etc.)
    b. If the child is attending a mainstream school: Which grade are your children currently studying? Have your children skipped any grade?
        i. If 'yes': Why have your children repeated any grades?
    c. If the child is NOT going to any educational institute currently: Have your children ever attended any preschool, school or institute?
        i. If 'yes': what was the type of the institute? What was the grade last attended by your child? Why are your children not going there at present? Whose decision was it to take your children out of school? Would you like your child to continue his/her education?
13. Could you please tell us how your children describe his/her experience in school?

[Please probe how the child narrates his/her experience regarding behaviour or cooperation from teachers, friends, classmates, etc.]

14. To what extent do you believe that the school/ institute is fulfilling your children's learning needs? Please describe.
15. How often do your children visit a health facility/ medical practitioner? What are the main reasons for taking your child to a facility/ medical practitioner? [Please probe for regular health check-up related to disability issues and other health issues, immunization, emergency care, etc.]
16. Where do you generally take your children for treatment/ health check-up? Please describe type of the facility/ doctor. Why do you take your children to this particular facility/ doctor? Please explain. Do you always accompany your child? If 'no' who takes your child to this place?
17. If your children are not visiting any facility/ doctor regularly, what are the reasons? Do you think your children should get health check-ups more often? Have you ever faced any challenges or difficulties in accessing heath facilities/ services?
18. Do you know if your child has ever been subjected to mocking, bulling or abuse, by adults or other children?
    a. If 'yes': how often? What did you do about it? [Only for girl children with disabilities] Were the instances of [mocking, bulling or abuse] directly related to the fact that your children are girls? Please explain.
19. Do you know who [person/organization] to go to for help if your child is being abused?
20. What does your child want to be when they grow up?
21. What do you want your child to become in adult life? How do you think your child can achieve this?
22. Who has a responsibility to support your child in fulfilling their dream?
23. Do you think your child has more, less or the same rights as all other children? Why?
24. Does your child have the support of an assistant in order to complete some of her/ his daily tasks, such as going to school?
    a. If yes: who pays for this assistant? How and how often does the assistant report to you (parent/caregiver)?
25. What are the things you/caregiver do with your children, on a regular day, that your child could not do alone? Do you think you spend enough time with your children? Does this take you off from other tasks including caring for other children? Do other family members spend time with your children regularly?
    a. If 'yes': who, how and how often?
26. Are your children members of any sport, youth club or such community group?
    a. If 'yes': could you please describe this group and his/her participation there?
    b. If 'no': what are the reasons for not participating in the social or community life regularly? Please describe.
27. Does your child have an individualized educational Plan?
    a. If yes: Do you participate in developing the individual education plan in school?
        i. If yes: do you think you are an equal partner in creating the individualized education plan for your child?
    b. If no: why not?
        i. If no: As anyone ever talked to you about the learning needs of your child?
28. Do you think your children can access all parts of the school without help (e.g. building, toilet, classroom, etc.)? [Interviewer please probe for availability of infrastructure like toilet, ramp. etc. that is friendly to persons with disability]
29. How do your children get to school? Do your children face any difficulties in getting to school? Please describe.

30. In your views, are your children happy to attend this school? How do you know?
31. Do you feel satisfied with the services received from the medical facility/practitioner you generally see? Please probe
32. How far do you need to travel to go there?
33. How is the condition of the infrastructure? (Please probe about availability of infrastructure friendly for people with disability)
34. Are the different types of services required for the children available in the facility? (e.g. general physician, paediatrician, physiotherapy, etc.)
35. Are you satisfied with the quality of medical treatment and counselling provided?
36. Do you get all medicines required/ prescribed by a doctor from there?
37. Can you do the medical/ laboratory test(s) there?
38. How much do you need to spend (from pocket) in the facility to get services? Do you think it is OK? Could you please elaborate on the response?
39. Do you have concerns regarding your children's safety? What are those concerns? Please elaborate.
40. Have you ever received any assistance from an organization? Could you please describe the types of assistance? Was the assistance received free or did you have any out-of-pocket expenses? [Probe for Government, Community-based Organization, Community-Based Rehabilitation Services, Non-government Organization, Civil Society Organization, Faith-based Organization, Community-based Organization]

Parents (caregivers) of children and adolescents without disabilities

Guidelines for FGD Facilitators – same as above

Questions

1. What is your relationship to the children you are representing in this discussion? (Please record if mother/father or caregiver; in the case of a caregiver, record the type of relationship – sibling, aunt, grandfather, social worker, case manager, etc.). How many other children do you have?
2. Could you please describe your children in your own words?
3. Do any of your children have specific difficulties? How do you know? How old were your children when you first noticed the difficulty? Have you taken them to a doctor/ nurse?
4. Can you please describe your child's regular day? [Please probe for going to school, doing homework, playing, working, etc. and enquire about his/her involvement]. Do they do all these things alone or with assistance? [Probe for specifics as to who, what, how frequent, etc. is the assistance].
5. What do your children like to do most? [or] What are his/her hobbies? How and how often do they do them? Do you encourage their choices? Do you sometimes help them in doing these things/ pursuing hobbies? How?
6. Are you the person who spends most of the time with your children at home and provides care?
    a. If 'no': who spends most of the time with your children? What is the relationship between the person and your children?
7. Do you know who your child's friends are? Do you encourage your children to make new friends? Why, why not?
    a. If parent knows some friends: How and how often do your children interact with

the friend(s)? What do your children do with his/her friends? Do your children go to his/her friend's place sometimes? Do the friends also come to your place? Please probe.

b. If 'no': why do you think your children don't have friends? Do you think there is any specific reason your children do not want to interact with other children and vice versa?

c. Are his/ her friend's children with disabilities?

   i. If no: Why not?

8. Do your children participate in social or community life on a regular basis? (e.g. sports, game, fair, religious festival, marriage, funeral, etc.)

   a. If 'yes': Do you take part in social or cultural events or community as a family along with the child? How often?

9. Are your children attending any educational institute?

   a. If 'yes': what is the type of school? (e.g. Early child development centre, mainstream school, day school for children with disabilities, day care centre for people with disabilities, vocational training centre, residential school for children with disabilities, etc.)

   b. If the child is attending a mainstream school: Which grade are your children currently studying? Have your children skipped any grade?

      i. If 'yes': Why have your children repeated any grades?

   c. If the child is NOT going to any educational institute currently: Have your children ever attended any preschool, school or institute?

      i. If 'yes': what was the type of the institute? What was the grade last attended by your child? Why are your children not going there at present? Whose decision was it to take your children out of school? Would you like your child to continue his/her education?

10. Could you please tell us how your children describe his/her experience in school? [Please probe how the child narrates his/her experience regarding behaviour or cooperation from teachers, friends, classmates, etc.]

11. To what extent do you believe that the school/ institute is fulfilling your children's learning needs? Please describe.

12. How often do your children visit a health facility/ medical practitioner? What are the main reasons for taking your child to a facility/ medical practitioner? [Please probe for regular health check-up related to disability issues and other health issues, immunization, emergency care, etc.]

13. Where do you generally take your children for treatment/ health check-up? Please describe type of the facility/ doctor. Why do you take your children to this particular facility/ doctor? Please explain. Do you always accompany your child? If 'no' who takes your child to this place?

14. If your children are not visiting any facility/ doctor regularly, what are the reasons? Do you think your children should get health check-ups more often? Have you ever faced any challenges or difficulties in accessing heath facilities/ services?

15. Do you know if your child has ever been subjected to mocking, bulling or abuse, by adults or other children?

    a. If 'yes': how often? What did you do about it? Were the instances of [mocking, bulling or abuse] directly related to the fact that your children are girls? Please explain.

16. Do you know who [person/organization] to go to for help if your child is being abused?

17. What does your child want to be when they grow up?

18. What do you want your child to become in adult life? How do you think your child can achieve this?

19. Who has a responsibility to support your child in fulfilling their dream?

(ADDITIONAL QUESTIONS IF TIME ALLOWS)

20. Are your children members of any sport, youth club or such community group?
    a. If ‘yes’: could you please describe this group and his/her participation there?
    b. If ‘no’: what are the reasons for not participating in the social or community life regularly? Please describe.
21. How do your children get to school? Do your children face any difficulties in getting to school? Please describe.
22. In your views, are your children happy to attend this school? How do you know?
23. Are you satisfied with the quality of medical treatment?
24. Do you have concerns regarding your children’s safety? What are those concerns? Please elaborate.
25. Have you ever received any assistance from an organization? Could you please describe the types of assistance? Was the assistance received free or did you have any out-of-pocket expenses? [Probe for Government, Community-based Organization, Community-Based Rehabilitation Services, Non-government Organization, Civil Society Organization, Faith-based Organization, Community-based Organization]

ANNEX 3:

PARTICIPANT INFORMATION SHEET AND CONSENT / ASSENT FORM

For Focus Groups of Parents and Legal Guardians

Title of Research Project: Situation analysis on children and adolescents with disabilities and participatory analysis of the early identification and early intervention programme

Introduction/Study Overview

UNICEF and Fresno are working to improve UNICEF programmes. We are interested in challenges related to children with disabilities. We want to understand the opportunities and challenges children with disabilities face. We also are interested in how people think about public services, such as health care providers, schools, and social services, and how they should be involved and improved. We are asking permission to speak with you. The purpose of this study is to help UNICEF develop and improve programs. We want to address the needs of children with disabilities in Kyrgyzstan.

We wish to ask if you would kindly participate in one of our focus groups. We believe that your based on your experience and expertise you could provide insight into the situation of children with disabilities for the proposed of this research.

Procedures

The group discussion will take approximately [2 hours], but may take longer if you have more to share. We may ask you about your experiences as parents with a child with disabilities, the handling of when the disability was first identified, the support provided by all kinds of public services as well as the life in the community. We will also ask you questions about your opinions. We also want to know your thoughts about your child´s experiences at school. We want to record the group session [IF YOU ARE RECORDING yes], in order to capture all of your thoughts. The recordings will be written down afterwards.

Confidentiality

We will not disclose your name or any identifiable information from you. Members of the research teams will be the only ones to listen to the recorded interviews and discussions. They will also be the only ones to view the full written transcripts or survey questions.

Risks and Discomforts

There are few risks to participation. Some aspects of your experiences may be uncomfortable to talk about. You do not have to answer any questions that are uncomfortable. You are free to stop the discussion at any time. We aim to protect your privacy. In the group discussion, others hear what you say.

Benefits

This study is designed to improve UNICEF programs related to children with disabilities. We want to inform new programs that meet needs of boys and girls with disabilities. The study results may be used to improve public policies and programs related to children with disabilities.

Compensation

Participants will not be offered payment for being in this study. A compensation for the travel cost will be given in the amount of 300 som

Contact Information

If you have any questions or concerns about this research or the rights of the participants you may contact. If you have any questions about your rights as a participant in this research study, please contact [Rakhat Orozova [telephone number 0773710775]].

Assent: If you are willing to participate, please fill in the above questionnaire and consent sheet.

1. I confirm that I have read and understand the information sheet dated _________ [insert date] explaining the above research project and I have had the opportunity to ask questions about the project. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐

3. I understand that my responses will be kept strictly confidential with the exception of cases that might reveal that a specific child needs protection. ☐

   I give permission to the members of the research team to use the information that I will share with them provided that my responses are confidential. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.

4. I understand that my participation will not take more than 4 hours of my time and those of the child I am responsible for, including the travel to the place of meeting with the researcher and the travel back. ☐

5. I understand that my participation and those of the child I am responsible for could cause negative emotions to us because of the remembering of our experience. ☐

6. I agree to take part in the above research project. ☐

7. I agree the information about the age, the psychical and physical conditions of the child and the services provided to her/him/our family [underline the true] to be shared with the researcher provided that these details are confidential. ☐

8. In my capacity of a parent/foster parent/legal guardian [underline the true] of _______ ______________________________ [insert the name and the family name of the child] I agree she/he to take part in the above research project under the same conditions. ☐

_________________________ _________________ _____________________

Name of Participant Date Signature

_________________________ _________________ _____________________

Name of person taking consent Date Signature

To be signed and dated in presence of the participant

Copies:

Researcher's contact details: (Name), (phone number).

Once this has been signed by all parties, the participant should receive a copy of the signed and dated participant consent form, the information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be placed in the project's main records (e.g. a site file), which must be kept in a secure location.

Focus Groups for Children and adolescents (12 years of age and above): Participant information sheet and Consent Assent Form

(The text will be translated and rendered child friendly in Russian/Kyrgyz and designed to make it reader friendly)

Title of Research Project: Situation analysis on children and adolescents with disabilities and participatory analysis of the early identification and early intervention programme

Hello! We are a group of researchers from Kyrgyzstan, Spain, Portugal and Estonia. UNICEF asked us to help them understand if children with disabilities in Kyrgyzstan are treated well and if their rights are respected. We will write a report at the end of the research in (month depending on revised timeline) and we will take into account your experiences and opinions.

We want to know about your experience in your daily life, including things like your family life and your experiences in education, in health care and your community and social life.

We are going to meet children and young people from 12 to 19 years old, both girls and boys. We will talk individually to some of them and organise group activities with others. These will take up between 60 and 90 minutes.

Do you want to join us? You can decide to participate or not; it is not compulsory and there will be no consequences if you decide not to. You can even decide now to participate and then change your mind later.

Your parents/caregivers also have to be informed and agree for you to participate. But be aware that they will not be present during the talks or group activities. They will be just next-door and will also meet the researcher in separate meetings. We want to have their opinions too!

The information that you will share with us will be anonymous, unless you tell us that somebody or something threatens you and we must tell this to "Social Protection" or to the Police. Otherwise, nobody will know that it came from you. We will not take any picture or post information online. We will keep the documents that are about you and your opinions in a safe place and we will destroy them after the end of our research.

And finally, if you decide to participate but after that you feel uncomfortable, not at ease and you need help, feel free to let us know. We will listen very carefully to you!

You can call one of the members of our research team, (name), at (phone number).

You can always contact the social services XXX here: XX and at this number: XX (the information sheet will be customised with the relevant contacts for the location). Or call the national phone line for children at: 111 - helpline for children under the Ministry of Labour and Social Protection

Thanks and it will be a pleasure to meet you soon!

1. I confirm that I have read and understand the leaflet about this research and how children will be involved in it and I have had the opportunity to ask questions about the research. ☐
2. I understand that my participation is not compulsory and that I am free to withdraw at any time without giving any reason and without any negative consequences. In addition, if I do not wish to answer any particular question or questions, I am free to refuse. ☐
3. I understand that my responses will not be shared with people outside the research team with the exception of cases that reveal that I or other individual children need protection. ☐
4. I give permission for members of the research team to know what I have said without knowing my name. I understand that parts of what I will say could be included in the report without being connected with me personally. ☐
5. I understand that my participation will not take more than 4 hours of my time including the travel to the place of meeting with the researcher and the travel back. ☐
6. I understand that the talks with the researcher could cause negative emotions to me because of the remembering of my experience. ☐
7. I agree to take part in the above research project. ☐
8. I agree the researcher who will talk to me to know my age, how I feel and the activities I am currently involved in under the condition that these details will not be shared with anyone else. ☐

______________________	______________	__________________
Name of Participant	Date	Signature
______________________	______________	__________________
Name of person taking consent	Date	Signature

To be signed and dated in presence of the participant

Copies:

Researcher's contact details: (name), (phone number).

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be placed in the project's main records (e.g. a site file), which must be kept in a secure location.

Focus Groups for children

Title of Research Project: Situation analysis on children and adolescents with disabilities and participatory analysis of the early identification and early intervention programme

Introduction/Study Overview

UNICEF and Fresno are working to improve UNICEF programmes. We are interested in challenges related to children with disabilities. We want to understand the opportunities and challenges children with disabilities face. We also are interested in how people think about public services, such as health care providers, schools, and social services, and how they should be involved and improved. We are asking permission to speak with your child. The purpose of this study is to help UNICEF develop and improve programs. We want to address the needs of children with disabilities in Kyrgyzstan.

We wish to ask if your child would kindly participate in one of our focus groups. We believe that his or her experience and expertise will provide important insights into the situation of children with disabilities for the proposed of this research.

Procedures

The group discussion will take approximately [2 hours], but may take longer. We may ask your child about his/her experiences, the support provided by all kinds of public services as well as the life in the community. We will also ask him/her questions about his/her opinions. We also want to know the thoughts about your child´s experiences at school. We want to record the group session [IF YOU ARE RECORDING - yes], in order to capture all of your thoughts. The recordings will be written down afterwards.

Confidentiality

We will not disclose your name or any identifiable information from you or your child. Members of the research teams will be the only ones to listen to the recorded interviews and discussions. They will also be the only ones to view the full written transcripts.

Risks and Discomforts

There are few risks to participation. Some aspects of the experience of your child may be uncomfortable to talk about. Your child does not have to answer any questions that are uncomfortable. He/She is free to stop the discussion at any time. We aim to protect the privacy of you and your child. In the group discussion, others hear what your child say.

Benefits

This study is designed to improve UNICEF programs related to children with disabilities. We want to inform new programs that meet needs of boys and girls with disabilities. The study results may be used to improve public policies and programs related to children with disabilities.

Compensation

Participants will not be offered payment for being in this study. A compensation for the travel cost will be given in the amount of 300 som

Contact Information

If you have any questions or concerns about this research or the rights of the participants you may contact . If you have any questions about your rights as a participant in this research study, please contact [Rakhat Orozova [0773710775]].

Assent: If you are willing to participate, please fill in the above questionnaire and consent sheet.

1. I confirm that I have read and understand the information sheet dated ________ [insert date] explaining the above research project and I have had the opportunity to ask questions about the project. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐
3. I understand that the responses of my child will be kept strictly confidential with the exception of cases that might reveal that a specific child needs protection. ☐

   I give permission to the members of the research team to use the information that my child will share with them provided that these responses are confidential. I understand that my name or that of my child will not be linked with the research materials, and no member of my family will be identified or identifiable in the report or reports that result from the research.
4. I understand that the participation of my child will not take more than 4 hours of my time and those of the child I am responsible for, including the travel to the place of meeting with the researcher and the travel back. ☐
5. I understand that my participation and those of the child I am responsible for could cause negative emotions to us because of the remembering of our experience. ☐
6. I agree to take part in the above research project. ☐
7. I agree the information about the age, the psychical and physical conditions of the child and the services provided to her/him/our family [underline the true] to be shared with the researcher provided that these details are confidential. ☐
8. In my capacity of a parent/foster parent/legal guardian [underline the true] of ________ ______________________________ [insert the name and the family name of the child] I agree she/he to take part in the above research project under the same conditions. ☐

______________________	______________	__________________
Name of Participant	Date	Signature
______________________	______________	__________________
Name of person taking consent	Date	Signature

To be signed and dated in presence of the participant

Copies:

Researcher’s contact details: (Name), (phone number).

Once this has been signed by all parties, the participant should receive a copy of the signed and dated participant consent form, the information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be placed in the project's main records (e.g. a site file), which must be kept in a secure location.

Case studies - Information sheet and Consent Form for Parents and children

Title of Research Project: Situation analysis on children and adolescents with disabilities and participatory analysis of the early identification and early intervention programme

Introduction/Study Overview

UNICEF and Fresno are working to improve UNICEF programmes. We are interested in challenges related to children with disabilities. We want to understand the opportunities and challenges children with disabilities face. We also are interested in how people think about public services, such as health care providers, schools, and social services, and how they should be involved and improved. We are asking permission to speak with your child. The purpose of this study is to help UNICEF develop and improve programs. We want to address the needs of children with disabilities in Kyrgyzstan.

We wish to ask if your child and your family would kindly participate in one of our case studies. Case studies are in-depth investigations of the situation of concrete children with different disabilities and their families (caregivers). The main purpose of case studies is to listen to the voices of children with disabilities.

We believe that experience of your child and expertise will provide important insights into the situation of children with disabilities and sharing their voices for the proposed of this research.

Procedures

The case studies will include deep interview of your child and family (caregivers) that will take approximately 2 hours, but may take longer. We may ask your child and you (family) about his/her experiences, the support provided by all kinds of public services as well as the life in the family and community. We will also ask questions about his/her and your opinions. We also want to know the thoughts about your child´s experiences at school. We want to record this information, in order to capture all of your and his/her thoughts. The recordings will be written down afterwards.

Confidentiality

We will not disclose your name or any identifiable information from you or your child. Members of the research teams will be the only ones to listen to the recorded interviews. They will also be the only ones to view the full written transcripts.

Risks and Discomforts

There are few risks to participation. Some aspects of the experience of your child may be uncomfortable to talk about. Your child does not have to answer any questions that are uncomfortable. He/She is free to stop the sharing information at any time. We aim to protect the privacy of you and your child.

Benefits

This study is designed to improve UNICEF programs related to children with disabilities. We want to inform new programs that meet needs of boys and girls with disabilities. The study results may be used to improve public policies and programs related to children with disabilities.

Compensation

Participants will not be offered payment for being in this study.

Contact Information

If you have any questions or concerns about this research or the rights of the participants you may contact. If you have any questions about your rights as a participant in this research study, please contact [Rakhat Orozova [0773710775]].

Assent: If you are willing to participate, please fill in the above questionnaire and consent sheet.

1. I confirm that I have read and understand the information sheet dated _________ [insert date] explaining the above research project and I have had the opportunity to ask questions about the project. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐
3. I understand that the responses of my child will be kept strictly confidential with the exception of cases that might reveal that a specific child needs protection. ☐

   I give permission to the members of the research team to use the information that my child will share with them provided that these responses are confidential. I understand that my name or that of my child will not be linked with the research materials, and no member of my family will be identified or identifiable in the report or reports that result from the research.
4. I understand that the participation of my child will not take more than 5 hours of my time and those of the child I am responsible for. ☐
5. I understand that my participation and those of the child I am responsible for could cause negative emotions to us because of the remembering of our experience. ☐
6. I agree to take part in the above research project. ☐
7. I agree the information about the age, the psychical and physical conditions of the child and the services provided to her/him/our family [underline the true] to be shared with the researcher provided that these details are confidential. ☐
8. In my capacity of a parent/foster parent/legal guardian [underline the true] of ________ ______________________________ [insert the name and the family name of the child] I agree she/he to take part in the above research project under the same conditions. ☐

_________________________	_________________	_____________________
Name of Participant	Date	Signature
_________________________	_________________	_____________________
Name of person taking consent	Date	Signature

To be signed and dated in presence of the participant

Copies:

Researcher's contact details: (Name), (phone number).

Once this has been signed by all parties, the participant should receive a copy of the signed and dated participant consent form, the information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be placed in the project's main records (e.g. a site file), which must be kept in a secure location.

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213 Data from the ILO´s Social Protection Responses to COVID-19 Dashboard https://www.social-protection.org/gimi/ShowWiki.action?id=3417

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219 This study had two objectives, both of which have been fulfilled resulting in three related documents. First, a systems analysis which provides an overview of the system from the perspective of duty-bearers, was conducted. Second, an analysis of the EIEI programme was conducted. Third, using the first two analyses as a starting point of inquiry, a Situation Analysis was conducted from the point of view of rights-holders, in which the main claims of duty-bearers and finding from the EIEI analysis were confirmed and/or denied. As previously mentioned, the processes were interlinked, with methodologies feeding into all three sets of data.

220 More importantly, the recommendations included in this Situation Analysis are slightly different than those previously provided in the Systems Analysis that had been written as an intermediate product.. This is because they take into consideration what children with disabilities themselves and their families have highlighted as their priorities.

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