SITUATION ANALYSIS
Children with Disabilities in Kosovo
November 24, 2017
Written by Paula Frederica Hunt & Vjolica Belegu-Caka
at the request of UNICEF KOSOVO

*For UNICEF: Hereafter, references to Kosovo in this document shall be understood to be in the context of the United Nations Security Council resolution 1244 (1999)

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This report is dedicated to all the children in Kosovo.
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<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tr>
<td>AI</td>
<td>Administrative Instruction</td>
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<tr>
<td>AT</td>
<td>Assistive Technology</td>
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<td>CBR</td>
<td>Community Based Rehabilitation</td>
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<td>CRC</td>
<td>Convention on the Rights of the Child</td>
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<td>COD</td>
<td>Centre for Social Orientation</td>
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<td>CSO</td>
<td>Civil Society Organization</td>
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<td>CSW</td>
<td>Centre for Social Work</td>
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<tr>
<td>DPO</td>
<td>Disabled Persons Organization</td>
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<td>ECD</td>
<td>Early Childhood Development</td>
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<td>EI/EI</td>
<td>Early Identification/Early Intervention</td>
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<td>EC</td>
<td>European Commission</td>
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<td>EMIS</td>
<td>Education Management Information System</td>
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<td>EU</td>
<td>European Union</td>
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<td>FGD</td>
<td>Focus Group Discussion</td>
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<td>GC</td>
<td>General Comment</td>
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<td>GDP</td>
<td>Gross Domestic Product</td>
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<td>GIZ</td>
<td>German Development Agency</td>
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<tr>
<td>ICF</td>
<td>International Classification of Functioning</td>
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<tr>
<td>ICF-CY</td>
<td>International Classification of Functioning, children and youth</td>
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<tr>
<td>ICT</td>
<td>Information and communication technology</td>
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<td>IE</td>
<td>Inclusive Education</td>
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<td>IEP</td>
<td>Individualized Education Plan</td>
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<td>IQ</td>
<td>Intelligence Coefficient</td>
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<td>ISDY</td>
<td>Institute for Sustainability And Development of Youth</td>
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<td>KAP</td>
<td>Knowledge, Attitudes and Practices</td>
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<td>KAS</td>
<td>Kosovo Agency of Statistics</td>
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<td>KDF</td>
<td>Kosovo Disability Forum</td>
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<td>KII</td>
<td>Key Informant Interview</td>
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<td>KOMF</td>
<td>Coalition of NGOs for Child Protection in Kosovo</td>
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<td>MDE</td>
<td>Municipal Department of Education</td>
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<td>MICS</td>
<td>Multiple Indicator Cluster Survey</td>
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<td>MLSW</td>
<td>Ministry of Labour and Social Welfare</td>
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<td>MEST</td>
<td>Ministry of Education Science and Technology</td>
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<td>MoH</td>
<td>Ministry of Health</td>
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<td>M&amp;E</td>
<td>Monitoring and Evaluation</td>
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<td>NGO</td>
<td>Non-governmental organization</td>
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<td>NSPWD</td>
<td>National Strategy on the Rights of Persons with Disabilities</td>
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<td>OI</td>
<td>Ombudsperson Institution</td>
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<tr>
<td>Acronym</td>
<td>Definition</td>
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<td>OGG</td>
<td>Office of Good Governance</td>
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<td>PwD</td>
<td>Person with a disability</td>
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<td>RC</td>
<td>Resource Centre</td>
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<td>SEN</td>
<td>Special Education Needs</td>
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<td>SitAn</td>
<td>Situation Analysis</td>
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<td>SL</td>
<td>Sign Language</td>
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<td>SO</td>
<td>Special Olympics</td>
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<td>SW</td>
<td>Social Worker</td>
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<td>ToT</td>
<td>Trainer of Trainers</td>
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<td>UD</td>
<td>Universal Design</td>
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<td>UN</td>
<td>United Nations</td>
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<tr>
<td>(UN) CRPD</td>
<td>(United Nations) Convention on the Rights of Persons with Disabilities</td>
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<td>UNICEF</td>
<td>United Nations International Children’s Emergency Fund</td>
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<td>W3C</td>
<td>World Wide Web Consortium</td>
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<td>WHO</td>
<td>World Health Organization</td>
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GLOSSARY

**Acquired disability**
A disability arising from some external cause, such as injury in an accident, illness or use of substances such as medications or illicit drugs.

**Accessibility**
Accessibility describes the degree to which an environment, service, or product allows access by as many people as possible, particularly people with disabilities.

**Activity limitations**
In the ICF, difficulties an individual may have in executing activities. An activity limitation may range from a slight to a severe deviation in terms of quality or quantity in executing the activity in a manner or to the extent that is expected of people without the health condition.

**Assessment**
A process that includes the examination, interaction with, and observation of individuals or groups with actual or potential health conditions, impairments, activity limitations, or participation restrictions. Assessment may be required for rehabilitation interventions, or to gauge eligibility for educational support, social protection, or other services.

**Augmentative and alternative communication**
Methods of communicating that supplement or replace speech and handwriting – for example, facial expressions, symbols, pictures, gestures, and signing.
**Assistive devices; also assistive technology**

Any device designed, made or adapted to help a person perform a particular task. Products may be specially produced or generally available for people with a disability.

**Developmental disability**

Also referred to as ‘child disability’. An impairment typically first evident before or during birth or during infancy, childhood or adolescence. Defined relative to age-specific norms. May be genetic or acquired, and usually lasts throughout a person’s lifetime. May cause difficulty with language, mobility, learning and independent living. Examples include autism spectrum disorders, cerebral palsy, hearing loss, intellectual disabilities and visual impairment.

**Disability**

In the ICF, an umbrella term for impairments, activity limitations, and participation restrictions, denoting the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors).

**Disabled people’s organizations (DPO)**

Organizations or assemblies established to promote the human rights of disabled people, where most the members as well as the governing body are persons with disabilities.

**Early intervention**

Involves services and supports which aim to support young children who are at risk of developmental delay or young children who have been identified as having developmental delays or disabilities. It typically focuses on populations at a higher risk of developing problems, or on families that are experiencing problems that have not yet become well established or entrenched.

**Education – inclusive**

Education which is based on the right of all learners to a quality education that meets basic learning needs and enriches lives. Focusing particularly on vulnerable and marginalized groups, it seeks to develop the full potential of every individual.
Functioning
An umbrella term in the ICF for body functions, body structures, activities, and participation. It denotes the positive aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors).

Impairment
In the ICF loss or abnormality in body structure or physiological function (including mental functions), where abnormality means significant variation from established statistical norms.

Intellectual impairment
A state of arrested or incomplete development of mind, which means that the person can have difficulties understanding, learning, and remembering new things, and in applying that learning to new situations. Also known as intellectual disabilities, and formerly as “mental retardation” or “mental handicap”.

International Classification of Functioning, Disability and Health (ICF)
The classification that provides a unified and standard language and framework for the description of health and health-related states. ICF is part of the “family” of international classifications developed by the World Health Organization.

International Classification of Functioning, Disability and Health - Children and Youth Version (ICF-CY)
A version of the ICF that takes into account the characteristics of the developing child and the child’s interaction with the surrounding environment. Recognizes that functioning and disability interact in particular ways with children's development, for example as children learn or establish new relationships.

Mainstreamed services
Services available to any member of a population, regardless of whether they have a disability – for example, public transport, education and training, labour and employment services, housing, health and income support systems.
Medical model
Views disability as an attribute of a person, arising as a result of a health condition or injury. Managing disability is thus primarily a matter of professional medical care, with treatments and services to help the individual adapt to given circumstances.

Participation
In the ICF, a person’s involvement in a life situation, representing the societal perspective of functioning.

Personal assistant
An individual who supports or assists a person with disability and is answerable to them directly.

Persons with disabilities
Persons with long-term physical, mental or sensory impairments that, owing to barriers that exist in society and the environment, may limit their ability to effectively participate in society and enjoy equal status with those who do not have such impairments.

Prevalence
All the new and old cases of an event, disease, or disability in a given population and time.

Reasonable accommodation
Necessary and appropriate modification and adjustment not imposing a disproportionate or undue burden, where needed in a particular case, to ensure that persons with disabilities enjoy or exercise, on an equal basis with others, all human rights and fundamental freedoms.

Rehabilitation
A set of measures that assists individuals who experience or are likely to experience disability to achieve and maintain optimal functioning in interaction with their environment.

Risk factor
A risk factor is an attribute or exposure that is causally associated with an increased probability of a disease or injury.
**Schools – inclusive**

Children with disabilities attend regular classes with age-appropriate peers, learn the curriculum to the extent feasible, and are provided with additional resources and support depending on need.

**Schools – integrated**

Schools that provide separate classes and additional resources for children with disabilities, which are attached to mainstream schools.

**Schools – special**

Schools that provide highly specialized services for children with disabilities and remain separate from broader educational institutions; also called segregated schools.

**Social model**

Views disability as a result of a social environment that does not meet the needs of individuals with impairments. Such individuals are disabled in the sense of being excluded from full participation because of physical, organizational or attitudinal barriers. Managing disability is thus primarily a matter of social change aimed at removing such barriers.

**Universal design**

The design of products, environments, programmes, and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.

**Vocational rehabilitation and training**

Programmes designed to restore or develop the capabilities of people with disabilities to secure, retain and advance in suitable employment – for example, job training, job counselling, and job placement services.
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for every child, play
EXECUTIVE SUMMARY

This Situation Analysis of Children with Disabilities in Kosovo took place from December of 2016 until December of 2017, and aimed to: identify the main causes of child rights violations in Kosovo, particularly violations of the rights of children with disabilities vis-à-vis the Convention on the Rights of Persons with Disabilities and, assess the barriers and opportunities for access and participation of children with disabilities. The study was based upon the assumption that children with disabilities are children first, the future of Kosovo, and worthy of dignity and respect in the entire territory. Disability was defined according to the social model of disability, as the result of an interaction between a person’s impairment and the environmental obstacles they face and that prevent them from accessing life's opportunities on an equal basis with others.

Designed as a qualitative study, the research included a desk review and identification of stakeholders through a snowball effect. Throughout the 12 months of the study, over forty-five (45) Key Informant Interviews (KII) and twenty-seven (27) Focus Group Discussions (FGDs) were held in 7 locations: Ferizaj, Gjakova, Prizren, Mitrovica North, Prishtina, Fushë Kosova (Roma Mahalla), Graçanica (Roma Mahalla). In total, sixty-two (62) children with disabilities, fifty-two (52) children without disabilities, fifty-nine (59) parents/caregivers of children with disabilities, and fifty-eight (58) service providers of children with disabilities participated in the FGDs. Particular attention was paid to ensuring the participation of children with disabilities and families from the Roma, Ashkali and Egyptian communities in Kosovo.

Situation analysis findings

As documented below, the number of persons with disabilities in Kosovo is unknown. While data has been gathered in the last few years, both in the Census and through administrative means, there is no accurate number that can support data-driven decision-making because multiple definitions of disability are in use by multiple institutions and stakeholders.

The identification of persons with disabilities follows the medical model and is based on a medical opinion regarding an impairment, rather than a holistic assessment, that takes into consideration the assessment of multiple professionals from a variety of disciplines/sectors. Existing legislation regulating the identification of disability does not focus on children, and is almost always used to provide a cash benefit. Often, children with disabilities are only identified when they reach school age and attempt to enrol in school, at which time intervention is already too late to have a lasting impact on their development. Further, the existing practices do not lead to individualized plans that are responsive to each child’s impairment and environmental barriers, and do not address the need for integrated, continuous services for the child and the family, to support proper development and life-long goals.
Existing legislation, while currently being revised and amended, is not cohesive and encompassing of all aspects (bio-psycho-social) of the life of children with disabilities. It is not implemented at local levels, budgets for implementation do not exist or are small and, more importantly, existing mechanisms for enforcing implementation are not fully functioning. The implementation of legislation and service provision is obstructed by a lack of commitment, human and financial resources, and a continued lack of understanding of disability from the social perspective by professionals. Despite the existing anti-discrimination law, children with disabilities are discriminated against daily, in particular, children that suffer from multiple disadvantage factors. Disability is still understood as a medical condition, and not a human rights issue, and professionals are not trained to mainstream disability in their own daily practices. In addition, the professional role of social workers is not clearly defined, nor fully supported.

Kosovo does not have a Child Protection Law and the existing laws that provide protection do not clearly include children and are not disability-inclusive. Thus, prevention, response and monitoring of abuse and neglect are not made explicit or enforced. Children with disabilities in Kosovo are at a high risk of being abused and/or neglected that children without disabilities and most children and families do not know their rights under the law, how to protect themselves, or how/to whom to report instances of abuse or neglect. Further, the existing protection mechanisms do not explicitly include children with disabilities. Children with disabilities from the Roma, Ashkali and Egyptian communities are at exceedingly high risk of vulnerability.

The concept of Inclusive Education (IE) is, in Kosovo, understood in its most restricted way. Inclusive Education is understood as the provision of access to education to children with disabilities (i.e. enrolling children with disabilities in regular schools, often in attached classes) and not as ensuring the conditions for full participation of children with disabilities in the teaching/learning process. There is no common understanding of Inclusive Education among stakeholders and thus no agreement as to a way forward in developing inclusive practices. Early childhood development, school-readiness, pre-school and kindergarten are not included within the broad understanding of IE and are not taken into consideration when developing education plans. Pre-service and in-service teacher preparation curricula are not harmonized and in-service teacher training has been provided by many NGOs over the years, without a cohesive plan of action, and has resulted in a fragmented understanding and practices of IE.

The health care system in Kosovo does not mainstream disability throughout its plans of action. Screenings, early identification and intervention of children at risk of delay or disability, do not exist and the medical model of disability has been perpetuated by medical professionals. Prevention and risk analysis has not included children with disabilities, and school health programmes, parent education and local interventions have been carried out by NGOs often with international donor funds without government support, quality control or ownership. Re-habilitation in Kosovo is provided by NGOs and only to a very small and specific group of children. Many of the support services required for ensuring independent living are not available. The work related to disability has been largely carried out by small groups of disabled
persons that have a common interest in a specific impairment. While there is a renewed effort to make disability all-inclusive in Kosovo, this effort does not always acknowledge that children have specific needs that cannot be addressed in legislation, policy and services developed for adults. Throughout, children with disabilities and their families have been largely absent from dialogue, and children with disabilities and their families are not informed of their rights, or what few services are available to them.

The recommendations below have been aggregated by perceived level of urgency (priority), as well as by the system level and/or corresponding institution that is most likely to be able to respond to the needs identified above.

SITUATION ANALYSIS RECOMMENDATIONS

CENTRAL-LEVEL RESPONSIBILITIES

Priority 1A: Making children (with disabilities) a priority

The highest priority in Kosovo with regards to ensuring the fulfilment of the rights of children with disabilities is for Parliament and respective line ministers to ensure that all children, including children with disabilities, become a visible part of Kosovo’s agenda for development. Upholding the rights of persons with disabilities is a question of political will and should count with the involvement of Parliament (all 14 Parliamentary Committees), and the Prime Minister’s Office, on all issues related to children with disabilities, starting with adopting measures that address social norms and attitudes that affect the identification and service provision to children with disabilities.

A first step should be to invest on developing the capacity and political will of the Gender, Human Rights and Missing Persons Parliamentary Committee to ensure that all sectors are disability inclusive and all decision-making is responsive to the voices of children with disabilities. Under the leadership of the Gender, Human Rights and Missing Persons Parliamentary Committee, support all 14 Parliamentary Committees in guiding line ministries to develop clear reporting mechanisms, assignments, roles and responsibilities, to ensure coverage of all necessary services to children with disabilities by the most appropriate line ministry, including the allocation of adequate financial resources to implement legislation (starting with an earmarked budget to service provision to children, including children with disabilities).

Mechanisms such as the creation of a budget code and specific grant for social services, should be in place to enforce legislation at municipal level and provide additional financial resources to those municipalities that present higher levels of efficient and effective service provision to children with disabilities, as measured by the number of children from vulnerable populations (children with disabilities including children from Roma, Ashkali and Egyptian communities) fully included and participating with majority children. Require regular reports from line ministries, the Office for Good
Governance, as well as the Kosovo Disability Forum, and the National Council on the Rights of Persons with Disabilities on their activities related to inclusive and effective service provision for children with, including budgets.

**Priority 1B: Social model of disability**

CONCURRENTLY with making children with disabilities visible, is ensuring that the definition of disability included in the CRPD should be included in all central and local level legislation that is directly related to children and persons with disabilities and enforced as the “working definition” used by all line-ministries (and corresponding municipal institutions) when determining eligibility of disability. To ensure harmonization, all methodology, criteria, and tools needed to determine eligibility for services and benefits should be developed across central and local authorities. This is essential in ensuring that the rights of all children with disabilities are equally recognized and fulfilled regardless of their place of the assessment team initiating the process.

Child identification, assessment and eligibility should be considered an integrated, holistic, and multidisciplinary approach, conducted by a mobile team of expert professionals, with case-management lead from MEST, with close cooperation with MoH, MLSW, CSWs, but as early in the child’s life as possible (school age is too late) with close collaboration with Early Identification/Early Intervention (EI/EI) methodologies. The teams should be trained on ICF-CY parameters – functional assessment - and take into consideration all three aspects of the bio-psycho-social model of disability when making eligibility determinations, ensuring re-evaluations are required on as-needed basis, as per team determinations (fit-for-purpose) for each case.

An integrated, holistic and multidisciplinary approach based on functional assessment makes permanent disability criteria inadequate an unnecessary. The Office of Good Governance and line ministries should engage in a revision of cash benefit provisions and ensure that cash is provided to children with disabilities based on actual need, and not provided to families as a poverty-alleviation mechanism. Consider creating a system that utilizes existing financial resources to provide needed services, and that fewer cash benefits are used to cover for specialized services that do not generally exist in all communities (i.e. voucher system).

**Priority 2: Legislation that is aligned with CRPD and enforced**

Ensure laws and policies reflect the spirit of the CRPD. With the participation of persons with disabilities, establish a monitoring system within each line ministry and across ministries to track the development and enforcement of strict anti-discriminatory policies that ensure the rights of all children, in all arenas of life, in particular children from the most disadvantaged groups, and children at risk of discrimination due to multiple disadvantages (i.e. girls with disabilities, children with delays or disabilities from remote rural areas, children with delays or disabilities from the Roma, Ashkali and Egyptian communities). Enforce existing legislation by providing training in Sign Language to employees in public office who can support adequate communication between the deaf community and professionals. Complete the process of development of the Child Protection Law by engaging in broad consultations with all stakeholders,
particularly children and youth, who will be the main recipients of the provisions included in the law, and **ensure that the law is disability-inclusive and envisions mechanisms to prevent, monitor and respond to abuse/neglect of children with disabilities.**

Provide adequate financial and human resources to the Office of Good Governance (as Secretariat of the National Council for the Rights of Persons with Disabilities) and the Ombudsperson Institution, including capacity development opportunities related to the rights (and rights’ violations) of children with disabilities and their families, with a special focus on children with disabilities from the Roma, Ashkali and Egyptian communities. Financial and human resources are necessary to coordinate the development and implementation of legislation including the upcoming National Plan on the Rights of Persons with Disabilities.

The international community should insist on the implementation of existing legislation that is **aligned with the CRPD**, and the design/implementation/monitoring of quality services as **conditions for cooperation and financial support** with central and local level government. All UN system agencies, the EU Delegation, and international donors should advocate for better coordinated actions by being more strategic in their spending (human and financing resources), and investing in the education of decision-makers, starting with trainings on the bio-psycho-social model of disability.

Decision-making should be informed by a **longitudinal data-collection process** to include a nationally representative household survey and/or census that can collect data related to child disability prevalence (functional ability), starting at age 0. Data gathered on functional ability and limitations can assist local authorities to improve provision of services to children with disabilities and their families. If a baseline, nationally representative household survey and/or census is not possible in the short-term, consider holding a Multiple Indicator Cluster Survey (MICS) with a module on child functioning in 2019. Consider creating a central database on children with disabilities, that can identify children with disabilities by their birth registration number and ensure that all line ministries and municipal institutions have access to and responsibility towards the reliable and accurate data-entry on functional ability to ensure that, up-to-date information for decision-making is available.
DECENTRALIZATION OF RESPONSIBILITY
implementation & service provision

Priority 3: Identifying high quality services

Service provision that is of high quality and inclusive of children with disabilities requires human resources, as well as the creation or re-allocation of existing financial resources. To determine what services exist, need to be developed and/or improved three actions should be taken concurrently:

a. Engage in a mapping of existing services for children with disabilities and their families and identify pockets of good-practice, and needs. Include all current and planned projects by UN organizations and others. Ensure coordinated efforts are happening at the ground level and connect-the-dots between all stakeholders; Existing good practices at the local level, many of which are based on the “human factor” should be identified, properly documented and analysed for replication and sustainable use;

b. Carry out an assessment of capacities of all education professionals (including early childhood development and pre-school professionals) who work, even in peripherally, with children with disabilities and provide an adequate set of recommendations for minimum standards, advocating for its immediate establishment. This should include assessing the capacities of teacher preparation institutions (and support as needed) to provide pre- and in-service teachers preparation for inclusive education, in accordance with the standards set forth by the CRPD Article 24 (and General Comment # 4 on the Right to Inclusive Education);

c. Engage in Knowledge, Attitudes and Practices (KAP) research focused on professionals and service providers. Focusing your attention on this sub-set of the population could provide stakeholders with an important baseline regarding professionals, vis-à-vis different categories of children with disabilities and their families.

Priority 4: Capacity Building for high quality services
at municipal/local level

Based on the three actions above, advocate with the responsible institutions to invest in targeted capacity development for professionals to support the development of multi-disciplinary teams of experts (permanent and mobile at municipal and local levels) that can support parents and families of children with disabilities across all aspects of life, including: social assistance, rehabilitation, inclusion into regular schools, accessing disability-inclusive health services, and securing assistive technology devises.

Invest in the capacity development of early childhood development and pre-school professionals, teachers and other education professionals to work in, and help
All teachers must be adequately trained on child development and child-centred pedagogy and differentiated instruction that can support them to teach all students in a regular classroom. Teachers and education professionals must also be trained to identify the occasions when they require the support of other teachers or specialized professionals, and they must be compelled to utilise mechanisms for collaboration and cooperation among professionals.

Provide basic training on **disability mainstreaming to all Human Rights teams/officers at the municipal level.** Emphasize the need and advantages of a multi-sectoral approach to activities related to disability and social inclusion, with lead from Human Rights teams/officers, and ensure the best models for working directly with families and children with disabilities are in place. Concurrently, improve inter-sectoral coordination by clearly **defining the coordination mandate of municipal CSWs**, and strengthen their capacity through the provision of adequate human and financial resources. **Create mechanisms for reporting** coordinated actions leading to the identification, assessment and service eligibility of children in vulnerable situations (both temporary and long-term), especially children at risk of delay or disability, poverty, violence or exploitation, or abandonment, and from the Roma, Ashkali and Egyptian communities. **Expand the role, capacities and responsibilities of social workers for case management** to ensure they reach all children, including children with disabilities, everywhere in the country, including children from the Roma, Ashkali and Egyptian communities.

**Priority 5: Providing high quality services**

Accelerate the development of an **early identification and early intervention (EI/EI)** system that is respectful of the definition of disability according to the social model, is **conducted by teams of multi-disciplinary professionals, and leads to service provision in inclusive settings.** Extend and expand existing home visiting efforts to the Roma, Ashkali and Egyptian communities, and school health programmes to screen school-age children for potential functional limitations in the domains of hearing, seeing, movement, communication, learning and behaviour/emotion throughout the life cycle using standardised protocols.

Ensure children with disabilities have access to **early childhood development and school readiness opportunities**, and initiate transition of children with disabilities from attached classes and resource centres to regular schools; investigate the potential usefulness of resource centres to support transition; **clarify the role of general education teachers**, special education teachers, teacher assistants and others within an inclusive education system in Kosovo.

Create a health care system that is proactive instead of reactive. Invest in **health promotion and health education, including parent education on child development** and ensure that preventative and universal measures such as vaccination and screening for functional limitations are done to identify needs before they occur, and **encourage outreach by family doctors and local community health centres.** All health care professionals should have minimum knowledge regarding functional assessments.
according to the International Classification of Functioning and the bio-psycho-social model of disability, leading to a greater understanding of their role within the scope of the multidisciplinary methodology of identification and assessment of disability.

**Priority 6: Monitoring high quality services**

Strengthen the capacity of NGOs and DPOs in general, and the Kosovo Disability Forum in particular, to speak on behalf of children with disabilities with only one voice and without the political pressures of particular (impairment specific) constituencies. Because children have needs and strengths that are specific to their age and level of development, the Kosovo Disability Forum should be provided with opportunities to develop their capacity related to child rights, including by engaging in consultations with children with and without disabilities on issues that relate to them (and of their choosing).

*Children with disabilities and their families should be an integral part of any monitoring and evaluation process* related to legislation development and enforcement and/or service delivery. Children with disabilities and their families should be involved in establishing a system of monitoring and evaluation of services, leading to a ranking system that can provide the information necessary for quality-driven decision-making. Further children with disabilities should be able to report, anonymously, on instances of abuse/neglect, ensuring that their reports are taken seriously and complaints are followed through. In addition, Violence Prevention activities should be continued and expanded to educate professionals and the general public on the right to protection of children with disabilities. Ensure all children and their families, particularly those in vulnerable or disadvantaged communities (i.e. Roma, Ashkali and Egyptian communities) are aware of their right to protection and of the ways in which they can claim their rights.

Encourage a collaborative working model that includes the World Health Organization (WHO), MoH and municipal level health professionals responsible for service provision to children with disabilities to ensure that local level responses are done according to international standards. The MoH should assume responsibility for the coordination of all activities related to health care, to ensure a cohesive and coordinated approach to service provision. A set of guidelines for donors, NGOs and DPOs should be prepared to ensure all financial and human resources provided to the health system fall within the standards set forth by the WHO, and take into consideration WHO’s Community Based Rehabilitation Guidelines for Persons with Disabilities.
COMMUNITY RESPONSIBILITY

Priority 7: Nothing About Us Without Us

Increase the capacity of children with disabilities and their families, and empower them to demand their rights through public discussions and dialogue with authorities. Special attention should be given to engagement with children and their families in the Roma, Ashkali and Egyptian communities. The international community should condition all funded or partially funded disability-related activities to include monitoring and evaluation activities led by children with disabilities and their families, in collaboration with the DPOs who can represent them.

Create multidisciplinary teams that include community member who are knowledgeable about the communities in which they live (i.e. Roma mediators, Ashkali and Egyptian community leaders, persons with disabilities) and are able to communicate effectively and without prejudice with community members.

Support DPOs/NGOs in providing awareness and education with regards to children’s rights to the population in general, and 1st line professionals, in particular; support DPOs in acquiring the skills and knowledge necessary to engage in mix-methods, participatory research and M&E activities, thus contributing to the Kosovar research community. Ensure that DPOs/NGOs create an information network that can provide information, referral and support to all children with disabilities and their families.

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The last chapter of the report presents the findings and recommendations according to the identified barriers and associated CRPD articles, and expands on some of the recommendations included in this executive summary. In both cases, it is expected that this Situation Analysis, while only a description of the situation of children with disabilities in Kosovo in a particular moment in time, can provide an incentive and road-map to the development of Action-Plans.
for every child, love
I. INTRODUCTION

Objectives

The main objective of this Situation Analysis is to summarize, analyse and document current facts and observations, leading to an appraisal of the life of children with disabilities in Kosovo, particularly the status of the fulfilment of their universal rights under the Convention on the Rights of the Child (hereafter, CRC) and the Convention on the Rights of Persons with Disabilities (hereafter, CRPD), based on existing data and additional qualitative research conducted in this study.

Methodology

The Situation Analysis was initiated with a desk review of the available literature related to children with disabilities in Kosovo. The desk review served to compile and analyze existing and available data of relevance for children with disabilities in Kosovo.

Data from the desk review was augmented with qualitative data gathered in over 45 Key Informant Interviews (see full list in Annex 1), as well as 27 Focus Discussion Groups held in 7 locations (see full list in Annex 2) over the course of 9 months. Key Informant Interviews (KIIs) were held with available key relevant governmental stakeholders tasked with monitoring and implementing children with disabilities’ rights and with key NGO counterparts. Some stakeholders were identified through an expert panel organized with the purpose of ensuring the Situation Analysis was representative of the situation on the ground, others were identified in the desk review, while others were identified by other key informants during the interviews (snow ball effect). Focus Discussion Groups (FDGs) were held in 7 locations (Ferizaj, Gjakova, Gracanica, Fushe Kosova, Prishtina, Prizren, and Mitrovica North), attempting to provide a geographically representative view of the situation. Protocols for the FDGs were developed collaboratively based upon previous work completed in 6 other counties (for the full FDG methodology and tools see Annex 4). As much as possible, data gathered was disaggregated by gender, age, administrative unit, type of reported disability, and living arrangements (i.e. residential/non-residential institution), and information about the situation of children from minority groups (Roma, Ashkali and Egyptian) was gathered in 2 sets of Focus Group Discussions held in specific communities.

The data gathered was used with two main purposes: first, to identify the main causes of child rights violations, particularly violations of the rights of children with disabilities vis-à-vis the CRPD; second, to assess the barriers and opportunities for access and participation of children with disabilities. Causal and determinant analysis
were completed, often concurrently. The causal analysis followed a 5-step procedure: 1) Initial identification of immediate, underlying and structural causes based on the literature and data reviews; 2) Identification of causes based on international literature; 3) Initial discussion of causes during Key Informant Interviews; 4) Identification of additional causes based on interviews and focus group discussions; 5) Final validation of the causality analysis. The second type, focused on identifying barriers and bottlenecks for access and participation.

This report was developed in line with UNICEF’s principles and SitAn Guidelines’, and the resulting analysis is baseline evidence for policy advocacy and programming, looking at children with disabilities in institutions, children with disabilities currently in the education system and, where possible, children with disabilities out of education or institutions. Within the broad desk review that focused on children with disabilities, special attention was given to identifying documents relating to ‘invisible’ children, such as those aged 0-3, Roma, Ashkali and Egyptian, as well as Kosovo-Albanians and Kosovo-Serbs boys and girls, to the extent that such documents exist.

**Constraints**

The participants in the FDGs carried out in this study constitute a convenience sample. All children with disabilities interviewed and/or their families (except those in FDGs facilitated by Balkan Sunflowers and Ideas for Partnership Centre) receive some kind of support from HandiKOS. Therefore, it is difficult to determine up to what point were the FDG attendees unbiased in their reports related to service provision (often carried out by HandiKOS). However, identifying FDG attendees through the use of a different methodology would have been extremely difficult, as proven in North Mitrovica (see Annex 3 for tools and methodology). Likewise, Balkan Sunflowers and Ideas for Partnership Centre, the NGOs who facilitated the FDGs with children with disabilities and families from Roma, Ashkali and Egyptian communities identified FDG participants from their own networks of service provision.
for every child, happiness
II. OVERVIEW OF THE SITUATION OF CHILDREN WITH DISABILITIES IN KOSOVO

Kosovo context

Kosovo is a mountainous landlocked country in which agriculture, forestry and mining are the main occupations. Unemployment is very high, at a rate of 30.5% according to the Labour Force Survey for the first quarter of 2017\(^2\), and the economy is largely dependent on international aid and remittances. Kosovo remains one of the poorest countries in Europe, with per-capita GDP of about €3,393 per capita (in 2016), which is about a tenth of European levels.\(^3\) The population is “composed of Kosovo Albanian (92%), Kosovo Serbs 4%, and other minorities such as Bosnians, Gorani, Turks, Roma, Ashkali, and Egyptians (4%). The Albanian, Serbian, Bosnian, Turkish, and other languages are spoken. The main religions are Islam, the Orthodox church, and the Roman Catholic church”\(^4\). Kosovo has 38 administrative municipalities and, since 1999, a UN presence (Interim Administration Mission in Kosovo, its Agencies and Programmes) on the basis of the United Nations Security Council Resolution 1244. The Parliament of Kosovo adopted the resolution for independence in 2008 but Serbia refuses to recognize Kosovo as a state.

In 2009, Kosovo adopted a decentralized mode of governance. However, and according to UNICEF’s Programme of Cooperation for 2016-2020, “the pathway to translate into realities is confronted with serious political, social and economic challenges. Also, the current political context reveals that the change in the development assistance landscape is complicating the growing inequity and youth unemployment in Kosovo. In spite of these challenges, the on-going decentralization process has brought about two major policy changes and the local level. They include the transfer of competencies of handling social and human services, and the social welfare budget. The existing policy framework is not sufficiently translated into social well-being for Kosovars. To address these challenges, there is a need to identify new ways of engaging stakeholders for progressive realization of children’s rights. Kosovo institutions have incorporated the Convention on the Rights of the Child in Kosovo’s Constitution which reflects the highest legal foundation for children’s rights. With this strategic step forward, the Kosovo institutions have expressed their readiness and good will to adopt
this international act and to make its legislative system compliant with international standards and to translate it into systems and services for children based on available resources." The decentralization process is challenging because municipalities often lack technical and financial resources to meet state requirements. Transfer of budgets from central to local level is also, reportedly problematic, impacting negatively social protection and the fulfilment of children’s rights, as local institutions do not prioritise resources and their own budget incomes for social protection services. The 2015 Stabilization and Association Agreement was signed between the EU and Kosovo, opening the pathway for reforms towards EU accession, including the protection and promotion of the rights of all children as a key European Union objective.

Long-term ethnic tensions between Kosovo’s Albanian and Serbian populations make reconciliation at community level a challenge, particularly in Mitrovica region/Northern part. Northern Kosovo’s health and education infrastructure are financed from Serbia, operating under Serbia laws; social protection (and centres for social welfare) use both Serbian and Kosovo laws, report to both Kosovo and Serbia, and the police are part of the Kosovo police (headed by an ethnic Serb chosen in the northern municipalities). Thus, depending on where they are resident, individuals can seek services from Kosovan or Serbian administrative institutions (or both).

**Children with disabilities in Kosovo**

According to the findings from this and other desk reviews, as well as the reports from many stakeholders interviewed, the situation of children with disabilities in Kosovo has improved overtime, particularly in the last 5 years, although many challenges remain to be addressed. Despite unreliable data, a situation analysis completed in 2011 indicated that only a small per cent of families with children with disabilities received a social pension of approximately 103 Euros per month, considered by parents of children with severe disabilities to be inadequate to provide necessary expendable supplies and medications. Inflexible curricula, lack of trained professional staff, lack of transportation, were identified as major obstacles for inclusion, despite a rising number of children with disabilities attending regular school.

The 2013 EC Kosovo Progress Report recognized improvements in the legislative framework related to persons with disabilities, as well and administrative instructions related to education. However, the report also reports that public building and spaces remain inaccessible to persons with disabilities and the collaboration between government and disabled persons organizations should improve. The equivalent 2014 report again expresses concern over access to education, health care and rehabilitation, as well as need for continued support between the Office of Good Governance (OGG) and the National Council for Disability. The 2015 report reports that, despite appropriate legislation, service delivery to persons with disabilities continues to be challenging and “the rights of persons with disabilities continue to be hindered by inadequate support and health services, and poor accessibility.” Again, lack of implementation of the action-plan is reported as well as “the unsubstantiated removal of more than 1000 members of the deaf community from the disability pension scheme is a concern. The National Disability Council has so far failed to
promote the rights of persons with disabilities and needs stronger support from the government’s Office for Good Governance to enable it to exercise its coordinating role in implementing the strategy and action plan. The concerns expressed in the 2016 report were similar but, as documented below, the situation has now changed.

Likewise, the 2015 Ombudsperson Institution Annual Report indicates that, “the situation of children with disabilities in Kosovo is very difficult. Lack of transportation to attend school is not the only barrier they are facing. From the complaints investigated through the years and information obtained from representatives of institutions and NGOs, it appears that they are facing numerous difficulties and barriers in all areas of life.” The report includes barriers related to education, health and social protection, ranging from lack of individualized education plans, lack of free health services and materials including assistive technology, and lack of day care centres, rehabilitation and other social protection measures. The 2016 Ombudsperson Institution Annual Report indicates “no visible progress.” Challenges and obstacles to social inclusion remain in the areas of inaccessible infrastructure in all public venues despite a few improvements, employment, lack of sufficient essential medicines, lack of access to education and professional staff, etc.

According to data gathered in interviews with representatives from the Ombudsperson Institution and the European Union Office in Kosovo, future financial support for actions related to persons with disabilities will be conditional upon the immediate action, by the Kosovo government, on recommendations provided by the Ombudsperson Institution. Therefore, it is expected that linking financial support to the actual implementation of international human rights in Kosovo, will serve as incentive towards positive progress.

The representative of the Ombudsperson Institution (OI) who attended the FDGs reported that the situation of persons with disabilities continues to remain a challenge. Despite the fact that there is a legal framework for inclusion of persons with disabilities their situation is not satisfactory. Although the law on pre-university education guarantees inclusive education, children with disabilities face different problems, starting with learning issues because of the lack of school assistants. The provision of assistants for children with disabilities remains with the family of the child with disability because the schools do not have assistants. Children with disabilities have difficulties in accessing school infrastructure, schools do not have toilets for children with disabilities. Children with disabilities face the problem of access to road infrastructure. Also, the challenge for them remains poor health and social services. The OI within its Department for Protection from Discrimination and the Department for the Protection of Children’s Rights addresses complaints filed for the violation of the rights of children with disabilities. In addition, investigations regarding the violation of the rights of children with disabilities by the Ombudsman Institution are opened also ex officio, and they are treated in accordance with the legal and constitutional mandate of the Ombudsman Institution.

According to the OI, one of the biggest barriers to protection of the rights of children with disabilities is also a general lack of information about their rights, by children themselves, their families and the general public. Families of children with disabilities
do not see the OI as a place where they can address their concerns, while in many of the cases they cannot provide evidence on their right’s violation. There is a very small number of families that approach OI but the department for protection against discrimination in the OI has close cooperation with civil society organizations that are involved in protection of the rights of children with disability.

A new Situation Analysis commissioned by UNICEF in 2016\(^\text{18}\) found that children with disabilities are one of the most marginalised groups in Kosovo. Lack of data is found to be the main constraint in addressing their needs as well as a lack of definition of disability. It is difficult to determine how many children with disabilities are in Kosovo, who and where they are, and what types of services are needed and provided. Research, analysis and reporting on implementation is insufficient, and the number of qualified professionals is equally scares. Inter-ministerial or inter-sectoral cooperation is non-existent or insufficient to address the issues related to children with disabilities and “protection of children with disabilities is not prioritized in budget allocations, meaning that resources are lacking for implementation of policies, laws and strategies in the health, social welfare and education sectors\(^\text{19}\)\(^\text{20}\). Infrastructures are not accessible, including some public institutions, and social norms also affect children with disabilities and their families.

As expected when analysing the lives of children, school and social interactions take centre-stage with all children who participated in FDGs for this study, both children with and children without disabilities. Among the 52 children without disabilities who participated in FDGs, 52 attended regular school on a regular basis, at least half attended extra-curricular activities, and all reported having a wide circle of family and friends with whom they participated in social events. However, the overall situation of the 62 children with disabilities (see Annex 2 for more information) who participated in the FDGs for this study, is quite different according to their own reports. While their dreams and aspirations are very similar to those of children without disabilities (i.e. football/ basketball player, actor/ess, police officer, teacher, singer, doctor) their life and school experiences – the means to reach their aspirations - are very different. Out of 62 children, 26 are fully or partially dependent on a caregiver for dressing, eating, and toilet needs. At least half of the children cannot go to school alone, and at least 12 children are dependent upon others for communication needs (including 2 children who require a SL interpreter).
Defining and quantifying children with disabilities in Kosovo

Definition of Disability

Traditionally, disability has been understood as a medical condition that needs to be addressed or a vulnerability that can be improved by a charitable action. Since the adoption of the United Nations Convention on the Rights of Persons with Disabilities (henceforth, CRPD) in 2006, there is an effort to understand disability through the lens of human rights, or the bio-psycho-social model of disability. Children 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.

What is Disability22?

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”22.

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 out-dated, 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 people 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.

According to the Kosovo National Strategy on the Rights of Person with Disabilities 2013-2023 (hereafter the NSPWD), persons with disabilities in Kosovo are defined as in the UNCRPD and “include those who have long term physical, mental, intellectual and sensory impairments which in interaction with various barriers could hinder their complete and effective participation in society on equal basis with others.” However, as observed in other countries of the Balkan region, while the normative definition of disability is aligned with the CRPD, it is not put into practice.

As reported by the Office of Good Governance and the Kosovo Disability Forum, both the main legislation related to persons with disabilities and associated methodologies of identification, assessment and eligibility for purposes of disability service provision, are under revision to address the existing limitations. This creates opportunities to identify existing expertise in Kosovo, as well as best-practices at the local level that might, in combination, help to address some of the obstacles. Obstacles in fulfilling the rights of children with disabilities start with the lack of a definition of disability (and eligibility criteria) that take into consideration each child’s functional abilities in relationship to the environment in which they live. The need for a definition of disability that looks at each child individually and in relationship to environmental factors, and leads to services that are fit-for-purpose, is not yet widely recognized in Kosovo.

As determined by the 59 parents/caregivers in 7 locations who attended FDGs for this study, families that have children with disabilities usually have an average of 3 children, although only one child with a disability. Forty-one (41) out of forty-three (43) children received a medical diagnosis of impairment (which is equated with disability) sometime between ages birth to 13 years old by a medical professional. Causes of impairment are varied, from Autism, Blindness, Cerebral Palsy, Deafness, Epilepsy, Hydrocephalus, Intellectual Impairment, Muscle Dystrophy, Spina Bifida, various physical impairments, and “psycho-motor retardation” (as frequently reported). However, in no cases were there indications that environmental factors had been taken into consideration when determining “disability”. As reported in most municipalities, the majority of children had their impairments diagnosed in the University Clinic Centre in Prishtina, due to the lack of expertise at the local level, or were sent abroad.
(Albania, Macedonia, Germany, Turkey and Serbia). A similar situation was reported in Mitrovica North, whereby children were sent to Serbia (Belgrade, Kragujevac, Nis), Russia and the Ukraine for diagnosis.

Quantifying disability in Kosovo

According to the results of the 2011 Kosovo Population and Housing Census\(^{25}\), there were 1,739,825 persons in Kosovo at the end of April 2011, evenly divided by males and females. Almost 1/3 of the population (661,586) lives in urban areas. Out of the 1,429,174 population over 10 years old, 8.2% are graduates (of which 3.0 are women), and 29.9% have an upper secondary school degree (10.7% are women), 35.1% have a lower secondary school degree (20.14% are women), and 17.18% only have a primary school degree (9.98% are women). 5.7 of the population over 10 years old have no formal education/no completed education level who knows how to read and write (3.06% are women), and 3.8% are illiterate (79.7% are women). The largest majority of the population declared Albanian has their ethnic/cultural background (1,616,869), with Bosniak and Serb as distant second and third choices respectively. This is also reflected in their choice of mother tongue.

Over ten percent (10.3) of the population (179,648) is under the age of 6 years old, and there are an average of 5.9 persons per household. Overall, in 2011, there were 592,046 children under the age of 18 years old, making Kosovo one of the countries in the region with the largest (proportional) under-18 population. However, as can be seen below, a very small proportion is counted as children with disabilities. Trying to move away from a purely medical/impairment–based way of conceptualizing disability, the 2011 Census uses questions that take into consideration the reported functional ability of each respondent. Thus, the 2011 Kosovo Population and Housing Census gathered data related to disability by utilizing a set of questions that tried to quantify the number of persons reporting a *long-lasting difficulty*, rather than asking about disability (social model vs. medical model of disability).

According to the 2011 Census\(^{26}\), the number of children ages 0 to 14 years old by *number of long-lasting difficulties*\(^{27}\), with only one difficulty reported is 2,811. There are 1,308 children ages 15-19 years old with one difficulty reported, and 1,397 young adults ages 20-24 also with one difficulty reported. The numbers increase between the ages of 55 and 69 and then decline once again. In all categories, the number of reported males is higher than females.
### SITUATION ANALYSIS

#### Children with Disabilities in Kosovo

<table>
<thead>
<tr>
<th>Age</th>
<th>None</th>
<th>One</th>
<th>Two</th>
<th>Three</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-14</td>
<td>484,279</td>
<td>2,811</td>
<td>271</td>
<td>216</td>
<td>487,577</td>
</tr>
<tr>
<td>15-19</td>
<td>173,377</td>
<td>1,308</td>
<td>141</td>
<td>106</td>
<td>174,932</td>
</tr>
<tr>
<td>20-24</td>
<td>159,828</td>
<td>1,397</td>
<td>136</td>
<td>106</td>
<td>161,467</td>
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<tr>
<td>25-29</td>
<td>139,372</td>
<td>1,658</td>
<td>142</td>
<td>96</td>
<td>141,268</td>
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<tr>
<td>30-34</td>
<td>128,074</td>
<td>2,175</td>
<td>192</td>
<td>101</td>
<td>130,542</td>
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<tr>
<td>35-39</td>
<td>121,365</td>
<td>3,163</td>
<td>256</td>
<td>128</td>
<td>124,912</td>
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<tr>
<td>40-44</td>
<td>103,858</td>
<td>3,827</td>
<td>306</td>
<td>151</td>
<td>108,142</td>
</tr>
<tr>
<td>45-49</td>
<td>89,551</td>
<td>4,876</td>
<td>402</td>
<td>159</td>
<td>94,988</td>
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<tr>
<td>50-54</td>
<td>73,820</td>
<td>6,026</td>
<td>560</td>
<td>219</td>
<td>80,625</td>
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<tr>
<td>55-59</td>
<td>57,574</td>
<td>6,978</td>
<td>714</td>
<td>273</td>
<td>65,539</td>
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<td>60-64</td>
<td>44,300</td>
<td>7,569</td>
<td>838</td>
<td>341</td>
<td>53,048</td>
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<tr>
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<td>7,559</td>
<td>952</td>
<td>415</td>
<td>44,056</td>
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<td>70-74</td>
<td>25,369</td>
<td>6,920</td>
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<td>75-79</td>
<td>15,601</td>
<td>5,197</td>
<td>832</td>
<td>514</td>
<td>22,144</td>
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<tr>
<td>80+</td>
<td>10,593</td>
<td>4,702</td>
<td>825</td>
<td>658</td>
<td>16,778</td>
</tr>
<tr>
<td>Total</td>
<td>1,662,091</td>
<td>66,166</td>
<td>7,582</td>
<td>3,986</td>
<td>1,739,825</td>
</tr>
</tbody>
</table>

**Table 1** – Usually resident population by number of long-lasting difficulties (2011 Kosovo Population and Housing Census – Table 3.3828)

The data gathered in Table 2 below is the most approximate data to that which could have been gathered by more traditional questions such as “do you have a disability”. Please note that Table 1 (above) only has total numbers while the original table provided in the Census also provides a disaggregation between males and females.

<table>
<thead>
<tr>
<th>Age</th>
<th>&quot;Deafness or severe hearing impairment&quot;</th>
<th>&quot;Blindness or severe visual impairment&quot;</th>
<th>&quot;A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying things&quot;</th>
<th>&quot;A learning or intellectual disability&quot;</th>
<th>&quot;A long standing psychological or emotional difficulty&quot;</th>
<th>&quot;Other, including any long standing illness&quot;</th>
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</thead>
<tbody>
<tr>
<td>0-14</td>
<td>355</td>
<td>431</td>
<td>1,050</td>
<td>684</td>
<td>616</td>
<td>865</td>
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<tr>
<td>15-19</td>
<td>123</td>
<td>155</td>
<td>513</td>
<td>348</td>
<td>351</td>
<td>418</td>
</tr>
<tr>
<td>20-24</td>
<td>200</td>
<td>127</td>
<td>562</td>
<td>315</td>
<td>385</td>
<td>398</td>
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<tr>
<td>25-29</td>
<td>191</td>
<td>135</td>
<td>608</td>
<td>318</td>
<td>456</td>
<td>522</td>
</tr>
<tr>
<td>30-34</td>
<td>212</td>
<td>146</td>
<td>926</td>
<td>334</td>
<td>536</td>
<td>708</td>
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<tr>
<td>35-39</td>
<td>245</td>
<td>220</td>
<td>1,312</td>
<td>366</td>
<td>738</td>
<td>1,178</td>
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<td>40-44</td>
<td>321</td>
<td>299</td>
<td>1,644</td>
<td>351</td>
<td>780</td>
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<td>45-49</td>
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<td>488</td>
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<td>294</td>
<td>725</td>
<td>2,068</td>
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<tr>
<td>50-54</td>
<td>564</td>
<td>732</td>
<td>2,587</td>
<td>312</td>
<td>693</td>
<td>2,915</td>
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<td>55-59</td>
<td>687</td>
<td>946</td>
<td>3,211</td>
<td>284</td>
<td>667</td>
<td>3,430</td>
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<td>60-64</td>
<td>928</td>
<td>1,073</td>
<td>3,515</td>
<td>340</td>
<td>595</td>
<td>3,817</td>
</tr>
<tr>
<td>65-69</td>
<td>1,197</td>
<td>1,170</td>
<td>3,745</td>
<td>368</td>
<td>464</td>
<td>3,764</td>
</tr>
<tr>
<td>70-74</td>
<td>1,434</td>
<td>1,189</td>
<td>3,757</td>
<td>451</td>
<td>456</td>
<td>3,172</td>
</tr>
<tr>
<td>75-79</td>
<td>1,365</td>
<td>1,091</td>
<td>3,054</td>
<td>403</td>
<td>313</td>
<td>2,177</td>
</tr>
<tr>
<td>80+</td>
<td>1,712</td>
<td>1,233</td>
<td>2,902</td>
<td>439</td>
<td>358</td>
<td>1,682</td>
</tr>
<tr>
<td>Total</td>
<td>9,935</td>
<td>9,435</td>
<td>31,567</td>
<td>8,133</td>
<td>8,133</td>
<td>28,611</td>
</tr>
</tbody>
</table>

**Table 2** – Usually resident population with at least one long-lasting difficulty by age (2011 Kosovo Population and Housing Census – Table 3.3929)
However, the 2011 Census also gathers data related to the number of people who report having difficulty in performing daily activities, and the degree of the difficulty. Thus, table 2 below provides data with regards to **degree of difficulty in doing daily activities** – some difficulty, a lot of difficulty, cannot do at all - data that is much more aligned with the definition of disability included in the CRPD, as well as data that can serve a more immediate purpose because it can be used to determine what types of services are needed to respond to what types of difficulties.

As can be seen in Table 2 (above), 880 children ages 0 to 19 were reported as having **some difficulty learning remembering or concentrating**, 694 were reported having **some difficulty dressing, bathing or getting around inside the home**, 614 were reported having **some difficulty going outside the home alone to shop or visit a doctor**, 510 were reported having **some difficulty working at a job or business or attending school or college**, and 599 were reported having **some difficulty participating in other activities**.

Likewise, 520 children ages 0 to 19 were reported as having **a lot of difficulty learning remembering or concentrating**, 398 were reported having **a lot of difficulty dressing, bathing or getting around inside the home**, 614 were reported having **a lot of difficulty going outside the home alone to shop or visit a doctor**, 510 were reported having **a lot of difficulty working at a job or business or attending school or college**, and 599 were reported having **a lot of difficulty participating in other activities**.

As expected, the numbers of reported children listed in the **cannot do at all** category is much higher than in the two previous categories. The listed activities do not take into consideration developmental benchmarks and are those generally asked of an adult, and simply adapted to all ages in this census. Therefore, the data should be interpreted with caution. 1,043 children ages 0 to 19 were reported as **cannot do at all** in the category **learning remembering or concentrating**, 1,103 children were reported as **cannot do at all** in the category **bathing or getting around inside the home**, 1,376 children were reported **cannot do at all** in the category **going outside the home alone to shop or visit a doctor**, 2,040 were reported **cannot do at all** in the category **working at a job or business or attending school or college**, and 1,908 were reported **cannot do at all** in the category **participating in other activities**.
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<tbody>
<tr>
<td><strong>SOME DIFFICULTY</strong></td>
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</tr>
<tr>
<td>Learning, remembering or concentrating</td>
<td>601</td>
<td>279</td>
<td>312</td>
<td>328</td>
<td>430</td>
<td>700</td>
<td>788</td>
<td>1,215</td>
<td>1,622</td>
<td>2,115</td>
<td>2,412</td>
<td>2,656</td>
<td>2,446</td>
<td>1,784</td>
<td>1,572</td>
<td>19.26</td>
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<tr>
<td>Dressing, bathing or getting around inside the home</td>
<td>460</td>
<td>234</td>
<td>262</td>
<td>311</td>
<td>413</td>
<td>583</td>
<td>711</td>
<td>950</td>
<td>1,219</td>
<td>1,556</td>
<td>1,907</td>
<td>2,117</td>
<td>2,209</td>
<td>1,853</td>
<td>1,718</td>
<td>16.503</td>
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<tr>
<td>Going outside the home alone to shop or visit a doctor</td>
<td>396</td>
<td>218</td>
<td>264</td>
<td>327</td>
<td>437</td>
<td>664</td>
<td>869</td>
<td>1,113</td>
<td>1,489</td>
<td>1,836</td>
<td>2,09</td>
<td>2,254</td>
<td>2,085</td>
<td>1,521</td>
<td>1,209</td>
<td>16.792</td>
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<tr>
<td>Working at a job or business or attending school or college</td>
<td>337</td>
<td>182</td>
<td>208</td>
<td>269</td>
<td>385</td>
<td>541</td>
<td>724</td>
<td>938</td>
<td>1.07</td>
<td>1.172</td>
<td>1.115</td>
<td>962</td>
<td>747</td>
<td>465</td>
<td>326</td>
<td>9.441</td>
</tr>
<tr>
<td>Participating in other activities</td>
<td>400</td>
<td>199</td>
<td>233</td>
<td>285</td>
<td>420</td>
<td>618</td>
<td>762</td>
<td>945</td>
<td>1.189</td>
<td>1.405</td>
<td>1.228</td>
<td>1.050</td>
<td>686</td>
<td>496</td>
<td>11.381</td>
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<tr>
<td><strong>A LOT OF DIFFICULTIES</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Learning, remembering or concentrating</td>
<td>346</td>
<td>174</td>
<td>185</td>
<td>214</td>
<td>258</td>
<td>328</td>
<td>400</td>
<td>509</td>
<td>594</td>
<td>728</td>
<td>933</td>
<td>984</td>
<td>1,102</td>
<td>895</td>
<td>967</td>
<td>8.617</td>
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<tr>
<td>Dressing, bathing or getting around inside the home</td>
<td>279</td>
<td>119</td>
<td>109</td>
<td>131</td>
<td>146</td>
<td>244</td>
<td>285</td>
<td>319</td>
<td>412</td>
<td>466</td>
<td>620</td>
<td>718</td>
<td>840</td>
<td>751</td>
<td>934</td>
<td>6.373</td>
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<tr>
<td>Going outside the home alone to shop or visit a doctor</td>
<td>305</td>
<td>145</td>
<td>165</td>
<td>190</td>
<td>251</td>
<td>357</td>
<td>418</td>
<td>534</td>
<td>690</td>
<td>886</td>
<td>1,162</td>
<td>1,283</td>
<td>1,314</td>
<td>1,128</td>
<td>1,163</td>
<td>9.991</td>
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<td>247</td>
<td>171</td>
<td>177</td>
<td>228</td>
<td>297</td>
<td>465</td>
<td>569</td>
<td>750</td>
<td>911</td>
<td>1,050</td>
<td>1,127</td>
<td>1,090</td>
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<td>693</td>
<td>586</td>
<td>9.397</td>
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<tr>
<td>Participating in other activities</td>
<td>250</td>
<td>147</td>
<td>154</td>
<td>192</td>
<td>255</td>
<td>375</td>
<td>481</td>
<td>628</td>
<td>674</td>
<td>862</td>
<td>1,014</td>
<td>1,041</td>
<td>980</td>
<td>699</td>
<td>612</td>
<td>8.364</td>
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<tr>
<td><strong>CANNOT DO AT ALL</strong></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Learning, remembering or concentrating</td>
<td>712</td>
<td>331</td>
<td>340</td>
<td>367</td>
<td>394</td>
<td>456</td>
<td>478</td>
<td>474</td>
<td>611</td>
<td>659</td>
<td>850</td>
<td>1,095</td>
<td>1,286</td>
<td>1,294</td>
<td>1,583</td>
<td>10.930</td>
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<tr>
<td>Dressing, bathing or getting around inside the home</td>
<td>615</td>
<td>288</td>
<td>244</td>
<td>249</td>
<td>255</td>
<td>273</td>
<td>237</td>
<td>281</td>
<td>319</td>
<td>369</td>
<td>473</td>
<td>613</td>
<td>739</td>
<td>763</td>
<td>1,102</td>
<td>7,020</td>
</tr>
<tr>
<td>Going outside the home alone to shop or visit a doctor</td>
<td>988</td>
<td>388</td>
<td>361</td>
<td>362</td>
<td>396</td>
<td>492</td>
<td>475</td>
<td>550</td>
<td>755</td>
<td>926</td>
<td>1,235</td>
<td>1,553</td>
<td>1,800</td>
<td>1,679</td>
<td>2,147</td>
<td>14.105</td>
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<tr>
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<td>646</td>
<td>743</td>
<td>925</td>
<td>1,280</td>
<td>1,461</td>
<td>1,846</td>
<td>2,544</td>
<td>3,266</td>
<td>4,066</td>
<td>4,772</td>
<td>4,722</td>
<td>3,909</td>
<td>3,900</td>
<td>36,120</td>
</tr>
<tr>
<td>Participating in other activities</td>
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<td>604</td>
<td>591</td>
<td>669</td>
<td>830</td>
<td>1,126</td>
<td>1,284</td>
<td>1,687</td>
<td>2,297</td>
<td>2,830</td>
<td>3,555</td>
<td>4,165</td>
<td>4,236</td>
<td>3,548</td>
<td>3,682</td>
<td>32,408</td>
</tr>
</tbody>
</table>

Table 2 – Population by long-lasting difficulty in doing daily activities, by age, degree of difficulty (2011 Kosovo Population and Housing Census – Table 3.40)
Despite the efforts for the 2011 Census, there is limited data related to the number of persons/children with disabilities in Kosovo. Most household surveys currently on schedule in Kosovo collect data on the adult population or, at most, children ages 15 years old and up, completely disregarding the child population. Thus, it is very difficult to collect data that is statistically significant at a national scale. The National Council of Statistics (with representation from all ministries) is responsible for providing Kosovo Agency of Statistics (KAS) with a 5-year plan for data collection that, thus far, does not include a survey that will include children. A different source of statistical data, “PRISM (2011) estimates the disability population (sic) as between 150,000 to 180,000 or 7% of the entire population. For the vast majority, their lives are plagued by poverty, isolation, and social stigma. PRISM (2011) states that 95% of the almost 1,000 PWDs that they interviewed were totally dependent on someone else for their daily living activities. Persons with disabilities in Kosovo therefore constitute one of the most vulnerable sections of the population”.

Several of those interviewed for this situation analysis agreed that children with disabilities are one of the most marginalized groups in society in Kosovo. However, one of the key constraints to addressing their needs is a lack of knowledge about how many children with disabilities there are in the country, where they live and what their particular needs are. According to information received from the Ministry of Labour and Social Welfare, three types of data are available with regards to persons with disabilities, although the two data sources are not triangulated: first, because evaluation for a disability cash benefit is initiated by municipal centres for social work, every municipal centre keeps a record of every case that is initiated. Second, the central level assessment commission that reviews the municipal cases, keeps a record of every case that is approved for disability eligibility (permanent disability status). Finally, the MLSW keeps a record of every person who is receiving a disability cash benefit.

Information is available from the Ministry of Labour and Social Welfare (see below) on the number of children with disabilities receiving social assistance, but the criteria for this assistance are extremely strict and not necessarily all children who would be eligible receive it. There are also figures from the Ministry of Education, Science and Technology on the number of children with disabilities attending school, but this does not include children who are not attending (see annex 4).

Data collection is made even more difficult because there is no harmonization of mechanisms and systems among ministries. While the MLSW collects data on disability benefits but not on the specifics of each person’s functional abilities (what leads to the benefit), the MEST is collecting data according to “special educational needs” (not functional abilities or disability in the traditional sense), according to a list of 10 types of impairments: autism, communication and language impairments, Down’s Syndrome, emotional and behaviour disorders, hearing impairments, intellectual impairments, learning difficulties/disorders, multiple impairments, physical impairments, and visual impairments. While the information is collected at the school level, and may be used in the future for purposes of funding, it is highly unlikely that the data is reliable or rigorous since it lacks adequate supporting documentation.
Some of the interviewees for this study (MEST and MoH) reported plans to harmonize data collection by upgrading data collection systems to use civil/birth registration numbers (a number provided to each citizen by the Ministry of Internal Affairs), thus facilitating data triangulation. However, plans are still in preliminary stages of development. The widespread, multidisciplinary and cross-ministerial use of the ICF would create conditions for more reliable and accurate data collection for decision-making.

Due to administrative complexities in the Mitrovicë/Mitrovica region and other Serbian majority municipalities, there is little data regarding children with disabilities. The Center for Social Orientation (COD) produced in 2013 a report\textsuperscript{32} that claims that there are, in Kosovo, many persons with disabilities in situation of social isolation, deprived of right for equal education and employment, with limited access to health services, public services and information, deprived of equal participation in public and political life\textsuperscript{33}. According to the report, persons with disabilities from Serbian communities are unaccounted for - the majority Serbian municipalities were not included in the Kosovo 2011 Census, nor in the 2011 Serbia Census. According to the same report, “although there are no official data on the exact number of persons with disabilities in the municipality of Mitrovica, COD, through its research came to the information that there are 432 persons with disabilities in the municipality, which are the data from the Centre for Social Work, Municipality of Mitrovica and associations of persons with disabilities. Number of persons with disabilities [by] disability category: Physical disability- 58; Hearing and speech impairment – 80; Blind and visually impaired – 107; Multiple sclerosis – 29; Intellectual disability – 50; Psychosocial disability – 28; Children with disabilities – 80 (there are no data on the type of disability)\textsuperscript{34}.

There is no standardized data collection on children with disabilities in any of the 5 municipalities included in the FDGs, although having rigorous data is seen as an essential means for informed decision-making. The experience of identifying children with disabilities to participate in the FDG in North Mitrovica highlighted a few issues of interest with regards with identification and associated quantification of children with disabilities in Kosovo. As reported, it was difficult to identify children with disabilities, particularly those 15 years and older, because inclusive education started in the 2009/2010 school year and the generation that was enrolled in school started with this system and hasn’t yet reached the age between 15-17 years old. Thus, it is likely that in this case, having a more inclusive system helped in the identification of children with disabilities but only at the preschool or primary school enrollment, when it was compulsory for children to undergo the assessment of “Inter resorne komisije” (municipal evaluation team), established in 2010.
Identification, assessment and determination of disability eligibility in Kosovo

Different sets of legislations regulate who is considered to have a disability (depending on the type of impairment) and there is no overarching legislation to regulate identification, assessment and determination of disability. As can be seen below, the existing legislation assumes that a given impairment is already suspected, before an assessment is initiated, and assessment is conducted only to determine eligibility for cash benefits and rights.

Identification, assessment and eligibility of disability in Kosovo is restricted to 3 types of impairment: visual impairment, hearing impairment, and para/tetraplegic. These are the only 3 types of impairment (and associated disability) for which there is regulation (see below). According to the reports given by the OGG and the various DPOs interviewed for this study, the existing legislation was developed as a response to the strong lobby and advocacy of the three largest disability groups in Kosovo, each of them representing very specific groups of persons with specific disabilities, with a strong emphasis on the needs of adults with disabilities. Thus, while the existing landscape shows that the disability agenda in Kosovo has been led by DPOs, there is now a strong effort to ensure that legislation is articulated as a national strategy, takes on a more encompassing and inclusive quality, and pays attention to the needs of children with disabilities.

In addition, legislation also exists for children/persons with a permanent disability, covering those with physical, sensorial or a mental impairment, although no regulation exists for determining identification and assessment of mental impairment. In all cases, a medical commission is responsible for determining eligibility. In addition to a restrictive legislation, there is a significant deficit in the number of professionals that can diagnose complex types of disabilities including those anticipated in the legislation, including autism. Therefore, there are significant gaps in the identification of children with disabilities.

According to the service director of the Children and Adolescent Mental Health services at University Clinical Centre of Kosovo, most parents will initiate a disability assessment procedure with the aim to secure a financial cash benefit. Provision of services, even those that can be provided free of charge within the health system are not usually a priority for parents. Lack of early identification/early intervention services is a main challenge in ensuring that parents are knowledgeable about child development and able to identify atypical behaviours and delay in meeting appropriate milestones. Often (almost daily) parents will request an autism spectrum evaluation while being unaware of the many possible sensory-processing problems that can resemble autism but are, in fact, due to a lack of proper stimulation. In addition, because every process of assessment must start with an Intelligence Quotient (IQ) measurement, permanent disability status is highly dependent upon performance that is dependent on the setting, mood and conditions of the testing environment and not necessarily on actual individual performance overtime.
Law N° 04/L-092 For Blind Persons, of 2012, provides the framework for the identification of blind persons and for their protection under the law. Persons are deemed blind or visually impaired by a Medical-Social Commission constituted by a mix of vision specialists and professionals in the social sciences and DPOs who determine cash benefits and services. Blind persons must have an appointed guardian on record. The legislation covers employment, exemption from fiscal obligations, monthly “compensation” based on the minimum salary but of no less than 100 Euros (Art. 7), personal assistance as deemed necessary, housing support, free health care services or at a reduced cost. With regards to education, blind persons are entitled to education in a public institution, Braille, relief, enlarged text, acoustic and digital materials, as well as tiflo equipment. Likewise, information is to be available in various modes. Rehabilitation is to occur in centres, and blind persons can participate in sports and cultural events free of charge. Public transportation is free or at a reduced cost, and phones are to be outfitted with adequate software. The legislation is silent of the specific needs of children. According to the Kosovo Association of Blind and Partially Sighted Persons director, the legislation envisions two types of financial compensations: For persons who are found to be 100% blind, the cash benefit associated with the disability is of 125 Euros, with an additional 125 Euros for payment of a personal assistant, if needed. However, a person who is found to be 95% blind, is only entitled to the 125 Euro cash benefit associated with the disability.

Law N° 05/L-067 on the Status and the Rights of Persons with Paraplegia and Tetraplegia sets out provisions for persons who have lost mobility in the lower or upper and lower extremities. Persons are deemed to be beneficiaries under the legislation by an evaluation committee (MoH, MLSW and one member of a representative DPO). The law sets protection and established freedom of expression and access to information. As with the law above, beneficiaries receive compensation and, depending on assessment, may receive an additional 50% to “prevent decubital injuries” (Art. 7), and may choose to have a personal assistant (again, based on the assessment). Also, as above, beneficiaries are exempt from fiscal burdens, including those associated with a vehicle. Education is to be accessed in both public and private schools and health care is to be accessed free of charge, including home health services when necessary. Equipment is to be provided also free of charge. Likewise, electricity and public transportation are to be free of charge or at a reduced cost, and housing needs prioritized. The legislation is silent of the specific needs of children, such as early identification and early intervention, transitions through the life cycle (early childhood, school-readiness, kindergarten, primary, lower, and upper secondary, tertiary, the world of work), living and social skills, the importance of play, of living in the family, of social interactions, of mediated learning, etc.

Regulation GRK N. 15/2014 on Provision of Services in Sign Language in the Republic of Kosovo defines the rules and procedures of services in sign language in Kosovo. It applies to all public institutions who are obliged to provide appropriate services based on needs and requests. Services are to be provided by the OGG in cooperation with the Kosovo Association of the Deaf, who are also responsible for conducting trainings for institutions and persons. Sign language instructors are to be trained, certified and accredited.
It should be noted that there is no Law that specifies the identification and protection measures of persons who are deaf or hard of hearing, as is the case with the Law for Blind Persons or the Law of Persons with Paraplegia and Tetraplegia. In a country where legislation takes centre stage with regards to ensuring the rights of persons with disabilities and taking into consideration the fact that the deaf community has been instrumental in advancing the rights of persons with disabilities in Kosovo, this is an oversight that is reportedly politically motivated. As documented below, there is a concerning and currently unexplained case of approximately 1,000 deaf people in Kosovo who have been stripped of their right to receive social assistance on the grounds of permanent disability, which requires immediate attention and a resolution that takes into consideration the rights of all persons who are deaf, including children. According to the Deaf Association of Kosovo, the status of permanent disability (see below) is directly related to one’s ability to work. Thus, because deaf persons are seen as being able to be employed (even if that is not the reality in Kosovo) they do not qualify for permanent disability status or the associate cash benefit.

According to the Office of Good Governance, the National Program for the provision of Sign Language Services (2013-2016) was developed for the protection and promotion of the rights of deaf persons, including deaf children, aiming to increase their participation in all spheres of life, by promoting the removal of communicative obstacles, ensuring the full participation of deaf persons in the future. As a result, the government has approved the Regulation on the provision of Sign Language Services and the Administrative Instruction on the provision of Sign Language Services (see below) that constitute the basic documents that have enabled access to Sign Language Services to all deaf persons in the country. In addition, those who remain identified as deaf persons are beneficiaries of the disability pension scheme within the Law 04 / L-131 on State Pension Funds and the number of beneficiaries can be obtained from the Evaluation Committee within the MLSW.

“Permanent disabled children of physical, mental and sensory forms are considered the children from their birth up to 18 years old with permanent residence in Kosovo, who are completely disabled for carrying out daily activities without the other person's help.”. Permanent disability is a necessary condition for a child’s family (birth or foster family) to receive material support in the form of cash. Children with a permanent disability are those who are blind and those who have mobility limitations, cannot perform daily tasks such as feeding, clothing, or personal hygiene, or “carry out physiological needs” (Art.6).

The status of permanent disability (type and level of severity of physical, mental or sensory impairment) is attributed by the Ministry of Labour and Social Welfare, after a medical evaluation committee takes place. The committee is made up of 5 members, 4 professionals from the medical sciences (paediatrics, ophthalmology, physician, neuropsychiatry or psychiatry), and one social worker. The person/family initiating the assessment must have a medical certificate establishing the impairment and a medical record must be provided. The municipal Centre for Social Work initiating the evaluation, is responsible for assessing the social environment of the person undergoing assessment, and also issues the final decision, retroactive to the date of request for evaluation. The Coordinator of the MLSW Assessment Commission
interviewed is very aware of the need to align the current procedure with the social model of disability espoused by the CRPD. Likewise, he confirmed that the resulting 100 Euro cash benefit is very modest, and often used as a poverty-alleviation benefit rather than to purchase necessary services (that often do not exist). However, the MLSW has to follow procedures established in administrative instructions.

However, the decisions related to the status of “permanent disability” are, at best, controversial. Throughout this study, many of the professionals interviewed in government and civil society as well as various FDG participants (CSW professionals - Gjakova), health care professionals (Ferizaj), and others responsible for assessment and/or case-management of children considered to have a “permanent disability” see the legislation as discriminatory. First, the legislation starts at age 1 year-old while many children are born with severe impairments that require immediate intervention. Second, the legislation discriminates towards all other persons and children with disabilities perceived to have a “lower severity level” of disability because it excludes them from the assistance scheme and from all cash and/or service assistance. Third, the methodology in use to identify “permanent disability” does not take into consideration the lack of information related to disability that is still the norm in Kosovo, or the lack of outreach services that can help families to identify children at risk of a developmental delay or children with disabilities.

As reported, criteria for “permanent disability” is quite stringent although data differs depending on source and depending on the year/quarter for which data is being reported. In addition, as families of children with disabilities become better informed about their rights and responsibilities, they are also becoming more demanding with regards to not only diagnosis but also treatment alternatives and environmental accessibility. The judgment provided by a “permanent disability” assessment (yes or no) is no longer sufficient.

The Medical Commission in the Ministry of Labour and Social Welfare is responsible for determining the type and level of severity of disability for purposes of social assistance scheme. However, other reports (DPO Down Syndrome – Prishtina) indicate that the Ministry of Labour and Social Welfare determines the status of “permanent disability” based on a health certificate diagnosis or medical report from the University Health Centre (State Hospital) that is issued by a team of 3 doctors. Also, the DPO Down Syndrome reported that, evaluation commissions at the Ministry of Health (MoH) are often discriminatory because children with a suspected disability are not given priority over other children.

Because legislation is focused on type of disability, entitlements are different and specific to the impairment. Further, according to the 2016 Ombudsperson Institution Annual Report, “as was reported in the Ombudsperson’s Annual Report of 2015, persons with disabilities with the same diagnosis, after the reassessment by the medical commission are removed from the list of pension beneficiaries for persons with disabilities, because according to the assessment they do not meet the criteria required. Persons with disabilities continue to raise questions about the precision of the work of the medical commission, because when conducting reassessment medical commission does not assess the applicants according to the diagnosis of professional doctors, but it assess them according to their subjective perception.”
As reported by participants in this study (Gjakova and Ferizaj), there is a need for a unified approach towards defining disability, defining criteria for diagnosis, categories and level of severity, as well as standard methodologies and procedures on how to ensure the assessment of children with disabilities leads to useful service-provision orientation. According to FDG participants, there is a need to provide families with children with disabilities within formation and trainings to help them in understanding the type of disability that their children have, and how/where to get further guidance on services and support. Further, there is a need for standard guidance for each expert involved in evaluation and assessment of children with disabilities, including psychologists, social workers, teachers, doctors paediatrician, speech therapists, audiologists, physical therapists, occupational therapists, etc., so that there is a common and multidimensional understanding and cooperation among them. Assessment and eligibility procedures in Mitrovica North follow Serbian guidelines. It is reported that some parents from Mitrovica North go to Kragujevac, Kraljevo, Nis, Belgarde, Novi Sad and other cities for both diagnosis and tertiary care.

With regards to the evaluation of children thought to be in the Autism Spectrum Disorder, diagnosis is based on an interview instrument and observation of the child behaviour, and often the child psychiatrist will recommend them for therapy at the centre for autistic children. However, there is an admitted lack of specialized knowledge and capacities for a detailed diagnostic of autism (and even some other categories of disabilities), services or treatments. According to the child psychiatrist from the University Health Centre in Prishtina, “Indeed we do not make a detailed diagnostic but more of a superficial evaluation of the child. Sometimes due to the parent’s request and stigma, the doctor makes only the prescription of the symptoms, but they do not prescribe the diagnosis as autism. There are cases when after the therapy the child makes a significant progress so, when he gets in front of the evaluation commission the child looks like he doesn’t have any problem, thus he does not qualify for the assistance”. As confirmed by the Autism Association representative, there are cases when the paediatrician does not know what autism is, and cannot fully confirm the diagnosis before a longer observation of the child’s behaviour and attitudes.

In addition to the above-mentioned assessment procedure, each municipality also has an Education Assessment Team responsible for assessing the child’s education-related capacities, and provide guidance on both the more appropriate school setting (special school, special classroom attached to a regular school or a regular classroom) for each individual child as well as the main content in each child’s individualized Education Plan (henceforth, IEP). Education Assessment Teams were born out of necessity, because it was felt by the responsible professionals at the Ministry of Education that the existing assessments for disability (as described above) did not provide information that could be used to guide the placement and/or IEP for each child with a disability (see more details below in the education section). As can be seen in this study, holistic, child-centred assessments aiming at adequate service provision and rights protection are not yet done in Kosovo, in any sector.

Lack of coordinated efforts and/or mechanisms that can ease the process of identification, assessment and eligibility were reported by all stakeholders. While the MEST reports good working relationships with both MoH and MLSW, no coordinated
actions exist between or among them. The MEST often identifies children with special education needs (who may or may not have a disability), there is no functioning mechanism by which the identified children can be referred for rehabilitation services by the MOH. In addition, some children with disabilities who are identified by the MEST as needing assistive technology (AT) devices (such as hearing aids, for example) can only have access to such AT from the MEST while this is clearly the responsibility on the MLSW. However, no referral mechanisms exist to ensure follow up from identification of needs to provision of services by another ministry.

The fragmented approach to disability highlighted above results in many rights not fulfilled and leaves many children excluded, a situation that is fully acknowledged by many stakeholders during Key Informant Interviews, but it is expected that the new law related to disability under development will address these issues. It is expected that the existing Concept Document\textsuperscript{42} that is meant to supersede all the above Laws (blind, tetra/paraplegic, permanent disability, etc.) will have been fully developed into law by the end of 2018, providing a more inclusive and socially appropriate approach to disability. The Concept Document lists many of the challenges and obstacles to social inclusion that have been identified in this study but is fairly silent on the issues specific to children with disabilities. In its most favorable option for a way forward into reforms, the document continues to highlight the need for “strengthening and renaming of the medico-social commission is indispensable, which will place the focus not only on the medical but also on the social aspects of each situation individually. The Commission would also assess the degree of disability and remaining job ability for adult persons as well as their social and environmental situation. Also, the commission will also assess the state of the children”\textsuperscript{44}. However, no suggestions are provided as to what the responsibility of the commissions should be in determining the support services needed to ensure the appropriate development of children with disabilities, from pre-birth and into independent adulthood. The document does not emphasize the findings from this study, and that lead the below recommendations with regards to assessments that are completed by inter-sectoral, multi-disciplinary teams of professionals that focus on holistic views of the child through the life-cycle (as proposed by the CRPD).

As seen above, the identification of persons with disabilities is regulated and focuses exclusively on 3 groups of impairments, while assessment of disability is medical in nature, and eligibility aims at the provision of a cash pensions (not service provision). The limitations of the assessment of disability in use in Kosovo has long been discussed and understood in Kosovo. All health professionals, most education policy makers and most donors interviewed for this study mentioned (with varying depths of understanding) the need for an identification, assessment and eligibility package of methodology and tools that is aligned with the CRPD, and in accordance with the International Classification of Functioning (ICF) and a multidisciplinary approach. Some of the professionals interviewed have been a part of various efforts to introduce the ICF in Kosovo, some of which have started as early as 2010\textsuperscript{45}. However, it was difficult to pinpoint with accuracy why, despite various efforts throughout the last decade, with wide involvement of the education, health and social welfare sectors and financial support from multiple donors, these efforts have not lead to concrete results. Many of those interviewed for the study (OGG, MoH, MLSW, WHO, etc.) expressed
willingness to join forces, once again, and renew efforts to ensure identification, assessment and eligibility are multidisciplinary, inter-sectoral and have a holistic view of the child according to ICF parameters.

Legislation, Coordination& Monitoring

In Kosovo, as in many other countries in the region, children with disabilities are not a legislative or political priority. Quite often, children with disabilities are seen as part of the larger “vulnerable population” for whom specific laws and policies are developed. According to many of the interviewees for this study, fulfilling the rights of children with disabilities to social protection, education, health, etc., will require that children with disabilities be visible at the highest level of political involvement: the Parliamentarian agenda. According to the Association of Kosovo Municipalities, only the Parliament of Kosovo can require ministries, collegia, the council of Mayors, and municipal authorities to ensure implementation (and enforcement) of actions that might directly impact the lives of children with disabilities in Kosovo.

National legislation

As of the time of this report, Kosovo has not gained full international recognition, nor the ability to officially sign or ratify any of the UN Conventions that outline human rights. Despite not having the authority to sign/ratify any international treaties, Kosovo has demonstrated its intention to do so as soon as international law allows it, and its efforts are recognized by the UN family, the EU and others. In 2013, a UNICEF commissioned report indicated that Kosovo has developed a strong legal framework to promote an inclusive society, particularly inclusive of children with disabilities, a commitment demonstrated in the development of legislation and policy such as the National Action Plan for People with Disabilities 2009 – 2011, the Strategy and National Action Plan on Children’s Rights of Kosovo 2009-2013, the Strategic Plan for Organizing Inclusive Education for Children with Special Educational Needs in Pre-University Education in Kosovo 2010 – 2015 and the Kosovo Education Strategic Plan 2011-16. However, according to the same report, the legal framework lacks clarity because of the co-existence of laws with both a medical and a social approach to disability.

In 2014, the UNICEF Study on the compatibility of existing legislation with the Convention on the Rights of the Child found that “the legislative framework for children in Kosovo is largely in harmony with international and European standards. The Convention on the Rights of the Child (CRC) was incorporated into the constitution of Kosovo in 2008. The framework is in harmony with the Convention on the Elimination of all Forms of Discrimination Against Women, the Convention on the Rights of Persons with Disabilities and 18 other UN instruments, and with European norms such as the European Convention on Human Rights, the European Social Charter, the Lanzarote Convention on the Protection of Children Against Sexual Exploitation and Abuse and the European Convention on Recognition and Enforcement of Decisions concerning Custody of Children and on Restoration of Custody of Children and the
European Guidelines on child-friendly Justice. On the other hand, a number of rights and obligations recognized by the CRC are still not part of any law currently in force in Kosovo”.

All legislation that is meant to uphold the human rights of Kosovo’s citizens, including those below, are based upon a set of three laws that lay out all rights for all citizens: The Anti-Discrimination Law, the Law on Gender Equality and the Law on Ombudsperson. However, as highlighted by some interviewees, the package of laws as originally developed contradicts some of the existing laws and directives aimed at upholding the rights of persons with disabilities, and can create obstacles to the fulfilment of their rights.

**Coordination**

**National Strategy on the Rights of Persons with Disabilities 2013-2023 (NSPWD)**

Despite not having signed or ratified the UNCRPD, Kosovo has had National Action Plans on Persons with Disabilities since 2009. The National Disability Action Plan for the Republic of Kosovo 2009-2011, represents the “first attempt to harmonize Kosovo legislation with the Universal Declaration of Human Rights and international covenants on human rights in the disability sector”, and identifies several groups of persons with disabilities at a higher right of vulnerability, such as children with disabilities, for whom specific actions (detailed in the Action Plan) need to be developed and implemented.

The current *National Strategy on the Rights of Person with Disabilities 2013-2023* (henceforth, NSPWD) is an “important mechanism to ensure that principles that are embodied in the United Nations Convention on the Rights of People with Disabilities are incorporated in the policies and programs that impact the life quality of People with Disabilities in the Republic of Kosovo”. Its goal is “to promote, protect and ensure the complete and equal enjoyment of all human rights and fundamental freedoms by all the persons with disabilities and to promote respect for their inherent dignity”.

The document aims to provide guidance to all government sectors, and calls for actions which are specific, measurable, achievable and ruled by budgeted action plans with clearly defined timelines. It requires that all governmental institutions work in non-discriminatory ways, and emphasizes collaboration with Disabled Person’s Organizations and civil society. Further, the NSPWD is based upon existing regulation and also regulates all upcoming legislation related to persons with disabilities in Kosovo. According to this document there are three sets of laws dedicated to upholding the rights of persons with disabilities. They are:
Specific Laws

- Law on Material Support for Families of Children with Permanent Disability, No. 03/L-022.
- Law on Vocational Ability, Rehabilitation and Employment of People with Disabilities, No. 03/L-019.
- Law on Blind People

Laws that contain provisions related to persons with disabilities

- Law on Construction, No. 04/L-125
- Law on Labour No. 03/L-212;
- Law on Construction, No. 2004/15
- The anti-discrimination law, No. 2004/3
- Law on the Social Assistance Scheme in Kosovo, No. 2003/15
- Law on pre-university education 04/L-032
- Law on Construction, No. 04/L-075

Administrative Instructions and Regulation

- Regulation No. 2000/66 on Benefits for War Invalids of Kosovo and for the Next of Kin of Those Who Died as a Result of the Armed Conflict in Kosovo:
- Administrative Instruction on the Application Procedures for the Acknowledgment of the Rights for Vocational Ability, Rehabilitation and Employment of People with Disabilities No. 03/2010

There are 5 priority fields within the NSPWD strategy, each with its own strategic objective, as follows:

**Strategic Objective 1:** Improvement of the provision of health services for Persons with Disabilities;

**Strategic Objective 2:** Functional and genuine welfare and social security system as well as the provision of equal opportunities for the employment of persons with disabilities;

**Strategic Objective 3:** Creating conditions for all inclusion in education and professional support for children with special needs;

**Strategic Objective 4:** Equal access to legal protection as well as provision of services in the local level for the fulfillment of the right of persons with disabilities;

**Strategic Objective 5:** Creating equal opportunities to access, communication, participation as well as in creating or setting up a unified system of data on persons with disabilities.”
According to the NSPWD, progress has been observed in various areas of the life of persons with disabilities since 2009, such as an increase in the number of children with disabilities in education, a positive trend in the education system towards inclusive practices, and improved access to shelter services for persons with disabilities. With regards to data collection, the NSPWD raises the issue of the need for stronger engagement between responsible institutions to address the challenges in collecting data on persons with disabilities including the continuous monitoring of the situation.

In addition to the above, the Institute for Sustainability and Development of Youth – Kosovo identifies two additional laws as of primary importance for persons with intellectual and psychosocial disabilities:

- Law No. 03/L-007 on Non-Contentious Procedures
- Mental Health Law


The Action Plan on the Implementation of the National Strategy on the Rights of People with Disabilities (2013-2015) (henceforth, Action Plan 2013) acknowledges areas of improvement that have been agreed by persons with disabilities and the government of Kosovo in the 5 areas mentioned in the NSPWD above and provides “concrete actions and specific time limits (...) for the following three years”, and contains “specific actions, goals, measurable, specific, achievable and realistic indicators, responsible institutions for the implementation of each activity, time limits and budgetary lines within each activity”. The summary below highlights those activities that have the greatest potential to impact the lives of children with disabilities.

Under Strategic Objective 1, “Improving the Provision of Health Services for Persons with Disabilities”, activities are related to identifying the needs of children with disabilities, ensuring health staff are adequately trained to address the needs (including rehabilitation services) and persons with disabilities informed of their rights, and accessibility and necessary medical supplies are provided. A lot of emphasis is given to early detection, identification and prevention of disability, including the training of medical staff, parent education regarding the importance of early intervention, vaccination, and provision of medical supplies.

The Action Plan on the Implementation of the National Strategy on the Rights of Persons with Disabilities in the Republic of Kosovo (2013-2015) – Progress Report (henceforth, Action Plan 2013 Progress Report) states that the Centre for Family Medicine Development developed a curriculum for specialized education that incorporates the rights of persons with disabilities, while the Centre for Continuing Nursing Education conducted 8 training (in 2014) for “family nurses covering specific subject matter in regard to training and health care delivery” for persons with disabilities. The handbook for home visiting (collaboration between MoH and UNICEF), and 50 health staff were trained on early identification of babies with developmental delays. Guidelines for parents were developed, and vaccination rates...
reached 97% (with awareness campaigns ongoing). Constraints in implementation were identified: lack of comprehensive health care analysis, shortage of medicine and expandable materials, lack of training of medical staff, and poor early identification/early intervention activities.

Strategic Objective 2, “Functional and genuine welfare and social security system as well as the provision of equal opportunities for the employment of persons with disabilities” focuses on amending, completing or implementing legislation, such as the Law on Pensions for Persons with Disabilities Nr. 2003/23, and ministerial memorandums. The document also includes “establishing and running [functional] centers for children and adults with disabilities”, described as seven community based houses, as well as training for experts working in the centres. Activities related to employment focus on amending the Law on Vocational Ability Rehabilitation and Employment of Persons with Disabilities, and prioritizing employment opportunities for persons with disabilities and their families.

With regards to Strategic Objective 2, the Action Plan 2013 Progress Report indicates that Law n° 04/031 on Government Sponsored Pension Schemes was passed and, according to Law n° 02/L-17 on Social and Family Services, licensing of family service providers has been done as well as unspecified amendments in Law n° 03/L-019 on Vocational Ability, Rehabilitation and Employment. The Office of Employment reported progress in employment of persons with disabilities, and the Centres for Vocational Education and Training certified 43 persons in 2014. Further, 7 out of the 8 planned community homes have been upgraded (one more in construction), “and after its construction Persons with Intellectual Disabilities and working staff will be transferred from SIS to Shtime”. The identified obstacles to implementation are: difficulty in providing rehabilitation services, low monetary value of the pensions for persons with disabilities, and carrying out employment laws.

The - education - Strategic Objective 3, “creating conditions for all inclusion in education and professional support for people with disabilities”, is the largest and most detailed of the sections in the Action Plan 2013. It starts with acknowledging a need to research on persons with disabilities in education, as well as sign language needs. It envisions developing home-schooling programmes, data collection in regular schools, standards for inclusive schools and universities, appointing inclusive education coordinators in the Municipal Departments of Education (MDEs), capacity building of municipal authorities, defining a special line and funding formula for children with special needs, appointing, instructing and training evaluation teams in seven municipalities as well as municipal coordinators, employing and training itinerant teachers and support teachers. Further, the activities detail the development and implementation of early intervention programmes for children with special needs as well as a database and awareness campaigns, training education staff and parents in early intervention, and plan the establishment of centres for Early Identification/Early Intervention (EI/EI). The Action Plan 2013 includes reorganizing and staffing, as needed, resource centres to support children with special needs in regular schools and setting up a network of resource centres with national coverage, as well as employing sign language instructors and class assistants for deaf children. The resource centres are envisioned to have evaluation teams as well as provide (unspecified) new
services by trained professionals. Resource centres are also tasked with monitoring the integration of children with disabilities, supporting the establishment of inclusive education teacher’s forums, as well as teaching (given training) children with severe and multiple disabilities. The vocational practice of university students is to take place in resource centres and schools where children with disabilities attend. The Action Plan 2013 envisions training of teachers in abilitation, rehabilitation programmes and increasing the number of subjects related to inclusive education, and open an inclusive education teacher programme at the university, while ensuring in-service training of all teachers. Awareness raising, and disseminating materials promoting inclusive education, round up the plan.

Reporting on Strategic Objective 3 includes research on early childhood development, the training and placement of 3 sign language interpreters in regular schools, as well as the “adoption and implementation of the Index for Inclusion at primary and lower secondary schools as well as 8 preschools”. A national education gathering system is inclusive of data on children with disabilities and child-friendly school standards implemented. At the municipal level, 25 municipalities have appointed inclusive education officials, 13 had established evaluation teams and 4 capacity building workshops have been held, with municipal officials. Evaluation teams in resource centres are functional, and have received 4 training workshops (one of which on sign language). One of the resource centres has received a 100 thousand Euro donation from use in hearing aids and other equipment, from the University of Anatolia (Turkey). As expected, a lot of the burden related to inclusive education falls onto Resource Centres that have accredited 20 training programmes and provided internship opportunities. Some inspectors and school directors have received training on monitoring Individualized educational plans, and a total of 3100 teachers and educators were trained on inclusive education. A financing formula is being elaborated with a working group. Seven “teacher educators and 7 teaching assistants” have been hired (presumably to work with children with disabilities – unspecified location). And, lastly, awareness campaigns are ongoing. The identified challenges in implementation are: shortage of revisions in programmes for home, residential and treatment education; standards for tertiary education; employment of travelling teachers and assistant teachers, development and implementation of programmes and/or establishment of centres for early identification/early intervention.

The Strategic Objective (4) “creating the legal infrastructure to respect and fulfil the rights of persons with disabilities” is dedicated to activities related to legislation, some of which mentioned above. In addition, it envisions drafting the Law on Paraplegics and Tetraplegics, amending the Anti-Discrimination Law, the Law on Road Transport, issuing various legal acts and sub-legal acts, and administrative instructions. It also includes ensuring there are specialized staff in correctional and probation services and facilities and training of various civil servants on the specific rights and needs of persons with disabilities, as well as providing sign language services, and documents in Braille as needed.

Within Strategic Objective 4, progress is reported in legislative changes, such as the draft on the Status and the Rights of Persons with Paraplegia and Quadriplegia, the approval of the draft law on Protection against Discrimination, the Draft Law on
Gender Equality and the Draft law on Ombudsperson. Al 12/2014 was approved, as well as Draft Al 18/2013 on Personalized Education Plan and Regulation n. 02/2013 on medical-social commissions for persons with disabilities. Al UA 07/2012 on professional assessment of children with special needs, Al 15/2012 for early childhood care and education, and Al 23/2013 on Resource Centres were approved. Correction officers were trained on human rights with an emphasis on persons with disabilities, and 20 Sign Language interpreters were trained on legal interpretation. Criminal Code and Criminal Procedure Code are now provided in Braille. Identified barriers to implementation are: adoption of draft laws, shortage of trainings for probation and police officers, and sign language services within judiciary and security fields.

Strategic Objective 5, “creating equal opportunities to access, communication, participation as well as in creating or setting up a unified system of data on persons with disabilities”\textsuperscript{75}, again includes research activities related to accessibility and awareness campaigns. It envisions the construction of ramps, accessible toilets in public buildings, retrofitting schools and universities, providing assistive technology equipment to schools as well as transportation, sign language, Braille and other alternative communication to children with disabilities, infrastructure of public venues, and adapted public vehicles. In strategic objective 5, sports and cultural activities for persons with disabilities are mentioned, as well as the inclusion of youth with disabilities in activities targeting youth, broad cooperation, and, as above, the development of software, compliance with W3C information standard, training of information officers, use of screen readers and writers, and the training of persons with disabilities on the use of ICTs and AT.

Finally, the Action Plan 2013 Progress Report indicates that, in the area of Strategic Objective 5, 8 institutions were subjected to infrastructural interventions (although 7 are not adequate to persons with all types of impairments), an assessment of public health accessibility was carried out (only 25% are accessible), 12 DPO representatives were trained, two classrooms were equipped with ICT hardware and software, and 3 people were provided text-to-speech software. Passports, IDs and driver licenses are now provided to persons with disabilities free of charge and, the Paralympics commission took part in capacity development trainings and collaboration opportunities. Challenges identified are: lack of knowledge about local-level needs of persons with disabilities, lack of infrastructure accessibility and adaptability of public transportation.

As seen above, the Action Plan 2013 is quite comprehensive and ambitious (particularly given the allocated budgets) and inclusive of children. While this study takes on the perspective that the situation of children must be considered through the life-cycle, it also takes into consideration that actions should start as early in life as possible. The Action Plan 2013 takes children and young people into consideration throughout. However, regardless of how much effort has been placed in addressing some of the most relevant and necessary actions in Kosovo currently, some others are omitted. Clearly, only a restricted number of persons with disabilities is taken into consideration in the document. While the Action Plan 2013 does not make exceptions, and speaks of persons with disabilities in general terms, it only makes specific mentions of activities, actions, legislation and accessibility needs of persons with sensory of
physical impairments. There are no specific items related to persons with intellectual impairments, persons with mental disabilities, persons with mild disabilities, or children with learning disabilities (to name a few) who, as a whole, are likely a larger proportion of the total number of persons with disabilities in Kosovo, as opposed to just those with physical and sensorial disabilities. The omission of actions related to a broader spectrum of disability in the legislation and Action Plan 2013 is acknowledged by government and civil society alike, and reflects the current lack of engagement by the wider group of persons with disabilities of Kosovo, within political activism.

The Action Plan also envisions monitoring, reporting and implementing mechanisms that are discussed in the section below.

**Implementation and Monitoring**

The National Council for Persons with Disabilities is an inter-ministerial committee with governmental and civil society representation. The National Council is scheduled to meet twice a year to take stock of the implementation of the National Strategy and Action Plan on Persons with Disabilities but, in 2016 met only once to approve the draft EU Country Report. The Council is constituted by: Deputy Prime Minister (chairman), Director Co-chaired by the Head of Disability Kosovo Forum (co-chairman), Director of Office of Good Governance, DPOs and representation from various line ministries (i.e. Ministry without Portfolio, Ministry of Labour and Social Welfare, Ministry of Health, Ministry of Education, Science and Technology, Ministry of Local Government Administration, and Ministry of Environment and Spatial Planning) and representation from six NGOs who dedicate themselves to issues of disability (HandiKOS, Handicap Kosova, Association of Deaf Persons, Autism Association, Blind Association of Kosovo, Down Syndrome Association).

The Kosovo Disability Forum of DPOs, is a newly created umbrella organization with representation from the 8 largest NGOs in Kosovo, is seen by most stakeholders interviewed for this study as the mechanism by which many of the challenges might be addressed. With observer status in the European Disability Forum, the Forum sees its agenda as one of intervention and not as a political vehicle (as the National Council). The Forum’s most immediate aim is to ensure the discussions of the drafted concept note (currently in public discussions) for an all-inclusive disability law are successfully completed (although the concept note was initiated before the official creation of the Forum, the NGOs included in the Forum were those who developed the concept note). It is expected that the concept note will quickly give way to a draft law, and to a new law by the end of 2018. The Forum is reportedly recognized by the government as the organization that represents all persons with disabilities, a great responsibility taking into consideration that it is composed by 7 organization with very specific missions and interests (groups of persons with specific impairments).

There is a lack of documented research and analysis of the situation on children with disabilities in order to assess where Kosovo stands in the implementation of the laws that include provisions related to children with disabilities (KOMF Conference on child rights protection of children with disabilities, 3 Dec 2015). Likewise, there is no close cooperation between the Ministry of Health, Ministry of Education, Ministry of Labour and Social Welfare and the Ministry of Finance, as key partners to advance issues related to children with disabilities, (Conference on Children with disabilities, 3 Dec 2015).
The Action Plan 2013 includes 8 activities related to monitoring, reporting and implementing mechanisms. Activities focus on cooperation among government and DPOs, annual reporting on progress, unspecified active participation of persons with disabilities in decision-making at the municipal level, information gathering and dissemination, analysis of municipal structures vis-à-vis implementation of the Action Plan 2013, drafting local action Plans, and informing local authorities of their obligations.

However, and according to observations from the various stakeholders interviewed for the study, including the Ministry of Local Governance, implementation of the National Strategy and Action Plan at municipal level is occurring ad-hoc, and results from monitoring have been ineffective in expanding coverage or producing positive change. Thus, at the time of this report, only 14 out of 38 municipalities have municipal Strategies and Action Plans for persons with disabilities. They are: Drenas, Hani I Elezit, Ferizaj, Fushë Kosova, Gjilan, Kamenica, Lipjan, Partesh, Podujeva, Prizren, Skenderaj, Suhareka, Vitia, and Vushtrri. Even though the National Strategy and Action Plan has been in effect since 2013 (and expired in 2016), less than one third of all municipalities in Kosovo are upholding the rights of persons with disabilities as legislated.

Several reasons were suggested by interviewees as to the lack of implementation of programmes and activities aimed at fulfilling some of the needs experienced by children with disabilities, which is possibly associated to the lack of municipal action plans on persons with disabilities.

First, lack of actions associated to decentralization efforts was the most commonly cited reason for lack of implementation of these and other legislative directives: 1) lack of financial resources that should have been provided to municipal authorities along with governance responsibilities; and, 2) a lack of transparent accountability mechanisms that ensure coordination exists between central and municipal levels, and is fully functioning.

Second, it is agreed that while municipal strategies and action plans are desired, they are not a required condition for the provision of services. Thus, two other reasons for lack of implementation are often cited: 1) lack of political will to place children with disabilities as a political priority that renders children with disabilities invisible; 2) lack of a central budget allocation/grant marked for social services which would provide municipalities with the necessary financial allocations to initiate social service provisions. However, as can be seen below, financial allocations are not the main constraints to implementation, since the education and health sectors both include central grants and these two sectors still present significant challenges.
for every child, hope
III. PROGRESS AND CHALLENGES IN REALIZING RIGHTS

Below, the progress and challenges observed during this study are presented according to the relevant articles that constitute the CRPD. A quote from the CRPD is provided at the start of each section to situate the findings within the relevant CRPD Article. However, it should be noted that many of the findings are cross-cutting and do not “fit” precisely within a specific right. Rather, they are relevant across multiple articles (e.g. violations on the right to accessibility - CRPD Art.9 – restrict the right for participation in political and public life – CRPD Art. 29 – and restrict the right to participation in cultural life, recreation, leisure and sport – CRPD Art. 30).

Cross-cutting rights and obligations

General obligations

1. States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties (…) undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines; (g) To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost; (h) To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities; (i) To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights. (…) with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law. (…) States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations. (…) – CRPD Article 4
The CRPD is clear with regards to normative procedures but also with regards to the ways in which the CRPD is meant to be implemented. While the CRPD expects the “progressively the full realization of these rights”, service provision is expected to accompany legislation reviews. Overall, in Kosovo there has been an effort to ensure that the legislation that was developed after 2008 is in alignment with the spirit of the CRPD. However, implementation is extremely difficult and, although interviewees often indicate that decentralization has been the main obstacle for implementation the analysis below outlines various barriers and bottlenecks, not all of which are associated with the process of decentralization.

Right to equality and non-discrimination

States Parties recognize all persons are equal before and under the law and entitled without any discrimination to the equal protection and equal benefit of the law; (...) prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds; (...) take appropriate steps to ensure that reasonable accommodation is provided; (...) specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination – CRPD Article 5

Law N. 05/L-21 on the Protection from Discrimination makes specific mention of “Failure of a reasonable adaptation/accommodation for persons with disabilities - in accordance with their specific needs, is deemed discrimination on the grounds set out in Article 1 of this Law, unless when is an undue burden on the person who is obliged to provide and this is not in contradiction with the legislation in force, by considering due to this purpose such factors as the use of available public resources, participation in social and public life and ensuring access to the workplace and suitable working conditions” within Article 4, under types of unequal treatment. Article 19 again mentions reasonable accommodation of persons with disabilities in relation to employment. However, the entire Law is disability-friendly and can be used to argue in favour of non-discriminatory practices for persons with disabilities, including children with disabilities.

In addition, the Government of Kosovo has passed, in 2017, a regulation that ensures anti-discrimination protection within all ministries and municipalities, to ensure full implementation of Law N. 05/L-21 on the Protection from Discrimination.

Discrimination is experienced in the service provision that families with children with disabilities have access to. While families with children with disabilities do not pay out-of-pocket for the services they get in public institutions, in the majority of cases specialized services available in public institutions are scarce, and not available in the entire municipalities. In most cases, there is a lack of medications in clinics and sometimes even those in the essential lists. When services exist, families usually have to wait long hours and/or travel to the large cities for more specialized medical examinations. Therefore, most families are obliged to seek private specialized services which are extremely expensive for the families, mostly of which have a very low living standard and poor conditions.

Health care professionals who participated in this study reported that the cash benefit that families of children with permanent disabilities receive “is nothing” by comparison to the expenses that most families incur in ensuring the services children need (when said services are available, which is seldom). The discriminative nature of the criteria that
requires that children with disabilities be identified as *more than 85% impaired* leaves many children with severe disabilities and high levels on service need outside of the assistance scheme: “*We are not just violating the rights of children with disabilities but we are stepping with both feet onto their human rights*” (physician, Ferizaj region).

Free legal Aid in Kosovo is regulated by the *Law on Free Legal Aid in Kosovo*, in order to create a functional system for free legal aid in civil, penal, minor offences, and administrative procedures, through which an effective access is secured in justice for the citizens that do not have enough financial means. It is offered in all of the territory of Kosovo, through 5 regional offices in these types of cases: juridical information and advices related to legal procedures compilation of paperwork and whole other technical assistance that has to do with completion of the case representation of civil, penal, administrative and minor offences procedures. Women, children, elders, people with disabilities, and other disadvantaged or excluded people have been the focus of legal aid.

Free legal aid is also available to ensure the legal protection of persons receiving social assistance and persons who are unemployed, although this service is not very well known among most marginalized citizens as reposted by the representatives of Prizren and Prishtina legal aid offices in FGDs. Reportedly, services can be provided also to families with children with disabilities who have been denied social assistance, and also in ensuring children remain with their families: “*recently there are many cases when the Commission for Social Welfare in the Ministry rejects the families from all other social assistance schemes, if they benefit from one scheme already. For instance, there is a family of 7-8 members living in very poor conditions who have a children with disabilities as well, who benefits from the social assistance scheme, but has been deprived from benefiting from the scheme for families that have children with disabilities, which is very discriminative. These families do not even have access to basic information about their rights based on the existing legal framework and how to access the right institutions and mechanisms for help*” (lawyer, Prizren). Reportedly, in Kosovo, there are no lawyers specialized in children's rights and no training specific to this area. Likewise, there are no lawyers specialized on disability but, as mentioned by other professionals, the “permanent disability” law is very discriminative.

**Right to Awareness-Raising**

State Parties undertake to adopt immediate, effective and appropriate measures: (a) to raise awareness throughout society including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities; (b) to combat stereotypes, prejudices and harmful practices (...); (c) to promote awareness of the capabilities and contributions of persons with disabilities; 2. Measures to this end include: (a) initiating and maintaining effective public awareness campaigns (...); (b) fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities; (c) encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention; (d) promoting awareness-training programmes (...). – CRPD Article 8
Stigmatization, prejudice (and discrimination) of children with disabilities is largely present in most communities in Kosovo. The most prevalent and illustrative example is that of “autistic children.” As suggested above (see section on evaluation for Permanente Disability status) and below (see Education section) the evaluation procedures of children thought to be in the Autism Spectrum Disorder continuum reported are lacking, are unprofessional, and discriminatory due to the lack of professionals training of the staff. Children are often described, talked about, and recommended for evaluation as the “autistic boy” or “autistic girl” even before a medical diagnosis has been initiated, which predisposes the staunchest professional to think about a child in a certain way and look for indications to prove an assumed theory. Even in the cases when diagnosis is inconclusive or incomplete, the stigma associated with autism is so prevalent that in all cases of data collection throughout this study (both FDGs and KIIs) all professionals referred to children thought to be in the autism spectrum as “autistic children,” without regard for their rights as children first, even in the cases where they were describing children whose diagnosis had not been established. On the other hand, most professionals complained that parents were not keen to have their children evaluated for either cash benefits or education placement, without recognizing that parents’ reluctance is, at least, partially due to the lack of professional expertise demonstrated and reported.

Special education teachers in Gjakova region reported on efforts made, in 2002, to identify children with disabilities with the purpose of ensuring they were having access to education and during which it was found that many parents were hiding their children: “There were cases when even the closest neighbours were not aware that there was a child with disability in the next house.”

In 2013 the situation is still grim and families continue to report stigma and discrimination: “The group of mothers reported that for some the stigma within their local communities was so strong that they were reluctant to approach local health centres for advice and support. Most of the mothers reported that the child’s disability was identified late and none had the opportunity to benefit from an early stimulation programme until they had access to the HandiKOS centre. For some therefore it meant that the first help they received was not until the child was six or seven years of age”\textsuperscript{79}. “One of the mothers of a child with Downs Syndrome was told by a health worker in the child’s early years that the child was unlikely to survive. The mother reported that she felt unwelcome at times at the local health facility. This added to her sense of isolation and a feeling that the child did not exist in the eyes of the authorities”\textsuperscript{80}.

Many FDG participants (Gjakova) reported that there are still cases where children with disabilities are stigmatised, bullied, and mocked by other children, by school directors who refuse to make accommodations (as reported in Ferizaj), as well as cases with some families who hesitate to identify their child has a child with disabilities due to stigma and fear of discrimination. Joint efforts by pre-schools, and by special/regular classrooms have helped in dispelling stigma and educating families of children with and without disabilities: “the presence of children with disabilities itself in various events and activities helps in the awareness raising of the entire society”\textsuperscript{60} (pre-school director, Ferizaj).
As reported by the Prishtina MDE representative to FDGs, awareness raising efforts need to target the entire population of Kosovo. “We have problems with parents of children without disabilities who still need to understand and accept the fact that children with disabilities have the rights on inclusive education”.

Right to Accessibility

To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communication technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. – CRPD Article 9

Law № 2004/15 on Construction mentions disability only once, and never refers to Universal Design or disability-inclusive regulations and article 12 establishes that “technical conditions for construction buildings used by disabled persons” is to be set by administrative instruction. However, Administrative Instruction 33/2007 that regulates technical requirements of accessibility of public buildings and public infrastructures such as roads and traffic lights, and provides rules as to building size and layout of rooms, entrances, ramps, etc., took 3 years to be developed and approved. Architectural, electric, plumbing, engineering aspects are regulated and a requirement when obtaining a building permit.

However, according to a survey conducted in Prishtina and Prizren, “the real situation is that administrative instruction remains on paper and municipalities do not follow procedure for applying these technical requirements”83. The research suggests that when attempts to make changes are made, they are limited to the level of appearance, and inspections of construction sites do not enforce the Administrative Instruction. Public toilets or public transportation that can accommodate a person with a disability are rare or non-existent and sidewalks are equally in disrepair and, as of 2015, no adapted public transportation existed in Kosovo. As reported, in Ferizaj, the Family Health Centre is not accessible to children with disabilities (with the exception of a ramp at the entrance) despite it being a newly constructed building.

In Prishtina, measures have been taken by the Mayor’s Office to remediate some of the issues with public roads and sidewalks. According to the representative of the Municipal Directorate of Capital Investment who participated in the FDG, since 2013 the municipality has started to make budget allocations for improving access to infrastructure for persons with disabilities such as building ramps, adapt traffic lights for blind persons, elevators, etc. They have been reconstructing the long street and according to the design plan, some 200 meters of sidewalk with a non-slippery textured pavement shall be adapted for blind persons in Garibaldi Street, in Prishtina city, and they will continue with this in other parts of the city in the future: “We are far from other countries in this respect but some initiatives have been undertaken by the municipality to improve the access for persons with disabilities”.

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However, accessibility goes beyond roads and building construction. It is necessary to ensure that mobility issues are discussed and addressed in addition to Universal Design guidelines, Sign Language and Braille signage, sound signals, tactile surfaces, etc. While enforcement of technical guidance is important, addressing accessibility issues starts with educating legislators, technical staff and inspectors about the rights of persons with disabilities. As seen below, the right of children with disabilities to education is often violated due to a lack of adequate infrastructure, and social inclusion is made difficult.

The director of the CSW in Gjakova region reported that “a person with disability alone cannot do any independent work in our town as they can not move freely in the municipality due to lack of proper infrastructure”. FDG participants agreed that initiative to making the environment friendly to children with disabilities are modest. “There are some ramps built in town but there is a lack of access in most of institutions, nor toilet, or safe playgrounds. The situation is even worst in the rural areas”.

The representative of the Prishtina municipal Directorate for Capital investments mentioned that the directorate has undertaken some initiatives to contribute to access to infrastructure for persons who use a wheelchair, and for blind and deaf persons, but efforts are not satisfactory. However, each ministry has to plan about the needs for access to infrastructure. Reportedly, the interventions they do are mainly focused on entrance of older buildings because it is difficult to adapt the interior. However, in the new buildings, the access for people with disabilities is planned at the designed phase of the project. There is also, reportedly, work being done in some streets in the city although this report was highly contested by DPO representatives in the same FDG.

HandiKOS and GIZ have partnered on projects focused on improving accessibility in the city of Prishtina but, unfortunately, issues related to accessibility are, for the most part, understood in the most restrictive way: accessibility is understood as infrastructural changes made to address the perceived needs of persons who use wheelchairs. Reportedly, AT has been provided by donors on ad-hoc basis and the MoH and MoH and MLSW have worked with HandiKOS in providing maintenance of wheelchairs and crutches. Glasses and hearing aids were, in the past, donated by some USA donors but those projects have now ended. According to interviews with Ministry of Health staff, assistive technology is not the direct responsibility of any one ministry, which lends accountability almost impossible to enforce.

Right to equal recognition before the law

States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law (…) enjoy legal capacity on an equal basis with others in all aspects of life (…) shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity (…) provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will
and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests (…). States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs (...). – CRPD Article 12

In Kosovo, Law Nº 03/L-007 on Non-Contentious Procedures regulates legal capacity of persons with disabilities (adults), with both full and partial guardianship or placement in an institution. The decision is taken by a judge and supported by 3 medical experts, and the person has the right to be heard and/or appeal a decision. The appointed guardian can be a family member or a professional from the Centres for Social Work

According to reports from the Institute for Sustainability And Development of Youth (ISDY) and others, Law Nº 03/007 on Non-Contentious Procedures is not included in the National Strategy on the Rights of Persons with Disabilities 2013-2023 list of laws to be revised or amended. However, it should be, since the right to legal capacity impacts many other rights.

All 43 parents of children with disabilities who participated in 5 FDGs during this study report that although they are not knowledgeable about all rights of children with disabilities, they know that their existing rights are not being safeguarded and laws are not being implemented in non-discriminatory ways. In Gjakovan, Ferizaj and Prishtina, parents reported that essential care and services are not adequate, their children’s rights are not respected, and existing laws are not implemented. In Prishtina municipality, parents in both urban and rural areas report having poor relationships with social workers, and lacking of information or support. A few families openly reported having little faith that the state will take care of their children if needs arises. Like a father in Ferizaj said: “I pray to God that my son does not live after I pass away as there will be no one to take care of him.”

While parents in Mitrovica North reported needing to get knowledge of the existing laws, parents in Gjakova and Prishtina have very low expectations (and aspirations) of their children as they report that they are not able to meet their most basic needs. All expressed much love and affection for their children as well as the will and desire to continue to provide what is needed to the best of their ability, but they are clearly despondent in face of the lack of governmental support.

**Right to adequate standard of living and social protection**

States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability. 2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right
without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures: (a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs; (b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes; (c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care; (d) To ensure access by persons with disabilities to public housing programmes; (e) To ensure equal access by persons with disabilities to retirement benefits and programmes. – CRPD Article 28

In Kosovo, Centres for Social Work bear the brunt of the responsibility with regards to identifying persons who need social protection, either permanently or temporarily, including persons with disabilities. Social Work is a fairly new profession in Kosovo, even though a similar profession existed during the ex-Yugoslav state, although with a very different job profile. According to information gathered in key informant interviews and focus discussion groups, there are some 2,600 families in Kosovo receiving some sort of social benefit, including social work support, with approximately 1,700 in Prishtina municipality, where the Centre for Social Work has existed since 1999. Social Workers are responsible for 46 different types of clients, of which children with disabilities is only one. Some of the services they are supposed to provide include supporting adoption, fostering, investigate cases of domestic violence, street children, etc.

With a focus on social work focused on children with disabilities, it is important to note that while the job profile of a social worker includes a good portion of outreach and referral to services, the lack of financial resources to travel through a municipality and perform home visits, combined with a lack of technical capacity to identify and refer children at risk of a disability or delay, have been pointed out as challenging. However, despite an acknowledgement that Centres for Social Work do not have the necessary conditions to perform to their expectations, CSW (and social workers personally) are tasked with gate-keeping responsibilities that greatly impact the lives of children with disabilities. As reported by the Assessment Commission at the MLSW responsible for determining eligibility for “Permanent Disability” status, only children who have been found to have a medical impairment and have turned in an application with a CSW can come before the Commission. In addition, the Social Worker who initiates a case at the municipal level is also responsible for completing the psycho-social portion of the bio-psycho-social assessment that is currently envisioned by the National Strategy and Action Plan for Persons with Disabilities, although there is no evidence gathered for this study as to what that process entails.

Social Workers are supposed to be able to identify children who need further assessment or medical follow-up, ensure referral to appropriate services, liaise with schools and communities, re-evaluate existing cases, liaise with MLSW, MoH, MEST and others as needed, and advise families when/if a decision is contested. In addition, as reported by the CSW in Prishtina, the work of the SW does not end at eligibility.
Even in the cases when children are not found eligible for cash assistance, children and families will still have needs to be met, and follow up is required. Capacity building of staff, including communication strategies for children with disabilities and their families is a high need within the municipality.

The Law on Social and Family Services of 2005 regulates the provision of services for persons and families in need of support and persons in need are, among others, “children without parental care, children with antisocial behavior, (...) physical illness or disability (…), mental disability” (Art 1- 1.3). It establishes the conduct and responsibilities of the municipal Centres for Social Work, including the roles and responsibilities of each in determining who needs, who is entitled to, and should get assistance. The best interest of the child rules all determinations related to children and their families. Families and children in need of support are to be registered at municipal level, visited periodically by a Social Worker and, when necessary the Centre for Social Work can act as guardian of a child. The amendment of the law in 2012 includes the licensing of NGOs that can provide social and family services. Overall, the changes are largely administrative, although there is an addition of provisions for “children with asocial behavior”.

While much of the work related to social protection falls onto Centres of Social Work it should be noted the lack of human resources able to properly address the plight of children with disabilities has been reported as a main challenge since the enactment of the law. In 2013, a UNICEF report indicated that “(...) significant lack of trained resource personnel and the dearth of training in the area of disability. Apart from promoting appropriate foster care for a handful of children with disability the feeling was that little was being done to assist children with disabilities. With fifty four (54) different categories of persons being assisted by the Centre of Social Work the needs of children with disabilities has a low priority. However, the Centre for Social Work is in the process of establishing a new team of Psychologists who may be in a position to help families with children with disabilities. Moreover, with the new requirements for accreditation the plan is that all Community Social Workers will be relicensed over the next five years”. Likewise, a 2014 report indicated “a major shortfall in the availability of social work staff, if a quality service were to be achieved. All areas of work were under pressure but in particular, child protection, juvenile justice and cases of domestic/gender based violence”. While financial responsibility falls within municipalities, Directors of Health and Social Welfare may not fully understand or value the role of social workers within the system which leads to under-resourcing them in many municipalities. Human, financial and material resources are scarce and the same report indicated that the nature and extent of the qualifications of social workers was undetermined. “In addition to the work of the CSWs, a number of NGOs deliver specific social work services, largely in the field of work with children and families. These services relate to policy and practice development, and some specific social work interventions, particularly residential care of children. NGOs are also involved in training of both their own staff and of staff involved in practice developments. Many of the NGOs currently operating in Kosovo are informed by individual and collective experience of social work elsewhere in Europe. Consequently, staff of NGOs have a different vision for social work from that held within municipalities and within the relevant Ministries”. Parents also have a different view of what the role of a Social Worker should be, as compared to their experiences: “The social workers are very
rude if/when they come for monitoring of the Children with disabilities who are on the social assistance scheme, they made me drag my granddaughter from her wheel chair to convince them she cannot stand on her feet” (grandmother/caregiver, Prizren).

Law N. 4/L131 on Pension Schemes Financed by the State regulates various pensions, including the “permanent disability” and “work disability” pensions. As the title indicate, the first is paid to persons who are deemed to have a permanent disability by “based on the decision of relevant body of the Ministry” and the second “persons who suffer injury at work or acquire occupational illness during the employment relationship, who meet the criteria set forth by this law, and invalids of work” (Art.3). While the “permanent disability” pension is to be paid to citizen between the ages of 18 and 65 years old (thus excluding children), the “work disability pension” is to be paid to citizens under the age of sixty-five who have been recipients of a work disability pension under an older law. Thus, being work-related, this also excludes children (or their families) from the pension scheme.

Law N. 2003/15 on Social Assistance Scheme in Kosovo regulates social assistance in the form of a financial payment for families at risk. At the time of development of the law, payments could be as much as 75 Euros or as little as 35 Euros per month/per family. Families eligible for social assistance may include children with disabilities, and do consider a caregiver of a person with a permanent disability as not employable (thus counting as an eligible dependent). However, a person with a disability receiving a disability pension does not count as a dependent family member for purpose of calculating the cash amount of be disbursed (while a person with a disability due to a war injury – war invalid –does count as a dependent). Following the MLSW decision to increase social assistance benefits by 25% as of November 2015, reportedly, social assistance payments can be as much as 150 Euros or as little as 50 Euros per month/ per family as of January of 2017.

According to Law N. 03/L-022 on Material Support for Families of Children with Permanent Disability, which aims at protecting children with a permanent disability, material support is provided to families with children with permanent disabilities to enabled them to “live a more normal life in conditions that guarantee their dignity and make their lives easier” (Art. 3). A cash allowance is provided to birth or foster parents of children with permanent disabilities (identification and assessment procedures above). In 2010, the law was supplemented with instructions as to how to file a resubmission of request. In 2014, an Administrative Instruction was passed to clarify rules for re-application as well as identification and elimination of fraud.

Law n. 04/L-096 on Amending and Supplementing the Law N. 2003/15 on Social Assistance Scheme in Kosovo, refines the regulations of the original law, set responsibilities within municipal case managers, and extends coverage to families with young children (under 5 years old) or orphans under the age of 15 years old. However, the amendments and supplements do not substantially change the situation of families with children with disabilities.

Despite the above mentioned laws, the social protection measures outlined in the National Strategy for Persons with Disabilities (NSP WD) do not take into consideration various subsets of the population of persons with disabilities. First, it does not take
into consideration the needs of families with children with disabilities that often live under the poverty line due to various expenses (i.e. specialized doctors, specialized services, assistive technology, care for non-ambulatory children, loss of income) that cannot be surpassed regardless of the employment status of the parents. Second, it does not take into consideration and elderly population of persons with disabilities that, due to their age and their lack of relevant education and training, are not able to join the workforce. Third, by placing the burden of social protection measures onto the employability of persons with disabilities, the NSPWD strategic objective fails to recognize the government’s responsibility towards one of its most vulnerable populations: children with disabilities who are not, at present, being prepared to enter into a relevant workforce, now or in the near future.

Specific assistance of €100 per month for families of children aged 0-18 with permanent disabilities was introduced in 2009. However, the Ministry of Labour and Social Welfare has struggled to finance this scheme, as it appears that selection criteria is very tight: “Children with permanent physical, mental and sensory form of disability” are those “who are totally unable to perform daily life activities without the care of other person.” Meanwhile, as soon as a child turns 18, the payment is reduced to €65, the standard benefit for adults.

According to HandiKOS, in 2013, “the Ministry of Labour and Social Welfare supports 2,985 families of children with permanent disabilities (ages 1-18) with the social assistance scheme of 100 Euro per month, and 17,000 persons with disabilities (ages 18-65) through the pension scheme of 60 Euros per month”. However, parents of children with disabilities interviewed in the same year reported that although they were “appreciative of the cash assistance programme offered by the government they also expressed the frustration that such assistance was only offered in cases of ‘permanent disability’. One mother spoke about having to wait two years to obtain a wheelchair to allow her to be able to take her daughter to the regular school. Whatever support they received from the institutions in terms of social assistance was regarded as inadequate.”
The number of families receiving the benefits has been falling in recent years. At the end of 2015, only 2,528 families were eligible. Between quarter three and quarter four of 2015 the number of families fell by 217: in Pristina alone it fell from 280 to 95. The 2,528 families is less than half of the 6,172 children registered with special needs in the education system at the beginning of the 2015-16 school year. In 2014, according to NGO PEMA, only 2,898 children benefitted from this financial assistance across Kosovo. However, according to the same source, “there are roughly 20,000 children with disabilities in Kosovo who suffer from social exclusion and/or neglect in their daily life, forcing them further into social, economic and political marginalisation. These children need specialised support and care to help them reach their potential and lead more fulfilling lives”.

According to data gathered in the FDGs organized for this study, 39 parents of children with disabilities (out of 59) reported receiving cash assistance under the provisions of Law N. 03/L-022. And, while cash assistance is deemed largely inadequate taking into consideration the services needed by children with disabilities, it is an issue of contention among all parents interviewed. While, on the one hand, the 100 Euro amount is, reportedly, not enough to cover for children needs, on the other hand, is necessary to offset expenses in families already overburden by poor conditions, since the majority of the families reported living in difficult economic conditions. In Prishtina, some families reported surviving from the charity of family members living abroad, while in Mitrovica North 7 out of 9 mothers who attended the FDGs are unemployed and one other requested a change in her work shift in order to be able to be home when her child is home. Six (6) families in Ferizaj were adamant in reporting that they receive no cash assistance because although their children have a disability they are not deemed to be “permanent.” One foster care parent reported receiving 250 Euros of cash assistance for their foster care child with disability.

In Prizren, a grandmother (who cares for her 4 grandchildren) mentioned that despite her very poor conditions she tried to send her granddaughter for treatment everywhere in the country as she cannot imagine being able to send her abroad without any institutional support. Before her grand-daughter turned 18 years old, the family received 100 Euro as a cash benefit from the social assistance scheme, “which is not even enough to pay for her diapers”. Now that the girl has turned 18 years old, she has been moved to another pension scheme that provides a monthly pension of 75 Euros. “What kind of law is this? This is against every human rights as we could hardly manage with 100 Euro…now what can we do with 75 Euro??” The grandmother further mentioned that they are deprived of benefiting from other social assistance schemes even though they could qualify because of the poor conditions they live in. The girl was 14 times operated in the state hospitals but without any results. She mentioned further about the difficult times they had when she had to carry her granddaughter (by bus) to Peja for a surgery as she couldn’t afford more comfortable transport. She further stated that she could do anything to have her treated, but they have lost faith that her health can improve. “I pray to god for this child every time I put her to bed, and fear what shall happen to her when I’ll be gone”.

Further discrepancies are found when comparing regions/districts that are majority Serbian with other parts of the country, or when comparing benefits across types of impairment. For example, in Mitrovica North, all parents who attended the FDG
reported receiving 100 euro cash assistance for children with disabilities from Kosovo government, but also receiving 65 Euros from Serbian government, despite how challenging and painful the process can be. As one mother reported: “*It took 2 years for my child to convince the Health Evaluation Panel to qualify for the cash assistance scheme, under justification that her child is not sufficient disabled to benefit from the scheme*”. In Mitrovica North, reportedly, cash assistance is also provided for children with severe disabilities and for other levels of disability depending on the situation. Assistance varies between 40 and 120 Euros per month, although blind children can get a scholarship of 250 Euros per month. If attending school, cash benefits can be paid up to age 26. According to the representative of the Centre for Social Work in Mitrovica North who attended the FDGs, in addition to a cash benefit for a child with a severe disability from the Serbian government, the family also receives a child allowance of 70 Euros per month (given to all children up to age 18) and children with disabilities and families can also benefit from cash allowances given by the Kosovo institutions such as the cash benefit paid to families with children with permanent disabilities.

On the other hand, in Prishtina, the parent of a child with multiple disabilities reported that he quit applying for 100 Euros assistance and, instead, is applying for 250 Euro that is provided if a child is blind. According to his report, CSW was not happy with his decision and was uncooperative to the point of threatening the father with court if he persisted. “*He wanted to sue me at the court for “fraud” because I asked to quit the assistance of 100 Euro that my daughter received from the assistance scheme for families with children with disabilities, and apply for the other assistance for blind persons because it was more beneficial for my daughter. The social worker went so far that he wanted to ask me through the court to pay back the whole money that my girl received till now before we apply for the new assistance scheme. I had to involve other people to explain him the situation and our right to make the best choice that is legal for my daughter’s case and he stopped with this ridiculous idea*” (father, Prishtina).

Finally, the legal representative for HandiKOS reported that, in recent years, persons have been prevented from claiming benefits from two or more assistance schemes, which is also discriminatory. For example, blind people are not allowed (by the Law for Blind Persons) to benefit from other state sources, if they already benefit from this assistance scheme. However, there are blind persons who have worked before becoming blind, were tax and pension contributors, and should be able to claim their rights. In Gjakova, one mother stated her child only receives assistance due to his blindness although he has multiple/complex disabilities.

As can be seen above and confirmed by many of the stakeholders interviewed for this study, service provision is almost exclusively done by NGO’s such as HandiKOS, Caritas and a few others. Families of children with disabilities, civil society, and government officials all consider NGOs as the main referral point for service provision for children with disabilities, despite the fact that they operate with very small, short-term, project-based budgets. It is well accepted by all interviewed that NGOs are responsible for providing services to children with disabilities, despite this being a local governance responsibility108 – to provide for the social protection of all its citizens. Previous research completed in North Mitrovica reports109 similar circumstances.
While there is an evident lack of social services especially when it comes to children, the Centre for Basic Rehabilitation funded by an NGO provides services to approximately 60 children. Sign language interpretation is provided through the Inter-municipal Association of Deaf and Hard of Hearing but supported living, transportation of children with disabilities, and personal assistant services do not exist. Likewise, the Network of Rights Watchers also reports that approximately 40% of all respondents are using institutional services. Of those, 85% of respondents are completely or partially satisfied with the services but most parents reported that they “encountered difficulties or inability to realize all form of anticipated support (…) as well as difficulties with the provision of services which have already been established in that area, but for which there are insufficient capacities.”

Medical professionals, social workers, teachers and school officials, and word-of-mouth among parents and families often refer children with disabilities to one of the NGOs in closest proximity to the children needing services, regardless of the identified need/strength of the child, with few exceptions: children with visual impairments are usually referred to the Kosovo Association of the Blind or the special school for the blind in Peja, while children who are deaf or hard of hearing are referred to the Deaf Association of Kosovo or the special school for the deaf in Prizren. Children who are perceived has having a physical impairment, or a complex or severe disability, are usually referred to HandiKOS that often has to further refer elsewhere, due to its lack of technical capacity and resources to provide highly specialized services to children with complex impairments and often complex needs. Children who are identified to have an intellectual impairment related to Down’s Syndrome are usually referred to the Down Syndrome Kosova, while most children with a complex intellectual impairment are usually referred to the Centre for Child and Adolescent Mental Health at University Hospital. Most services are provided ad-hoc, without a proper assessment, plan of intervention or follow-up.

**Highlight on Roma and Ashkali children with disabilities**

Nine (9) Ashkali children (5 girls and 4 boys) and 6 Roma children (3 girls and 3 boys) with disabilities attended the FDGs in 2 Roma and Ashkali communities. There were no participants from Egyptian community. Out of the 15 children, 12 children come from urban areas and 3 from rural areas. Children were of different age groups. The youngest child was 3 years old and the oldest was 14 years old. Only two Ashkali children could participate independently because either they had speaking difficulties or they were too shy to communicate. For other children information was gathered from their parents who accompanied them in FDG. 2 of the Roma children could not communicate by themselves and info was gathered through the caregivers. The children had various types of disabilities, some severe and complex. Children come from big families, usually with 3 up to 9 children. The 9 Ashkali children attended the FDGs with their caregivers, all of whom were mothers and all fluent in Albanian language. 7 caregivers attended the FDG with Roma children. Three were mothers, one father, one grandmother, and two siblings. Those who could communicate were speaking Roma language, with very little use of the Serbian language.
All children come from very poor families. In both communities, mothers were unemployed (and the majority of the mothers could not read or write) and fathers worked from time to time with not regular income, mostly doing physical labour. Ashkali mothers reported that sometimes help their husbands collect bottles and cans from garbage containers. Ashkali families reported that they have water supply and sewage system installed at home, but not regular water supply, while Roma families reported having no water supply and no sewage. While most Ashkali families live on minimal social assistance, Roma Children reported that sometimes they don’t have enough food to eat. One of the caregivers (grandmother) reported that no one is supporting the Roma community, including those who live in extreme poverty. They try to support each other within the community but that is not enough as everyone is trying to survive on their own. She further asked the facilitators of the FGD to convey the message to the authorities that they should send at least some urgent packages with food and basic hygiene for those in extreme poverty.

Most parents of both Ashkali and Roma children reported that they were never visited by any social worker, neither do they know where the Center for Social Work is, except those parents who received benefits for children with disability and have periodic visits for re-assessment. Only two families receive a cash benefit associated with disability (blindness), one in Ashkali and one in Roma communities. One Ashkali mother reported that she applied twice for this scheme and was rejected with no justification. However, most caregivers were not aware of the benefit scheme for families with children with a permanent disability, and were not aware of how to apply, or how to prepare the documentation. When asked about their rights more broadly, and those of the children, parents reported not knowing what their rights are. Some Roma parents receive social assistance related to unemployment and child allowances although it was not clear from which institutions they receive it, but were not fully informed about all possibilities of material support within Kosovo institutions, particularly with respect to children with disabilities. One of the Roma caregivers who is disabled himself and a single father, reported that he is responsible for 7 members in their family, none of them employed, and with no water or sewer in their house.

7 of the 9 Ashkali children in the FDG are completely dependent on their mothers for basic needs such as eating and using the toilet. The familial situation of Roma children was markedly different from Ashkali in that 2 of the 6 families were single parent homes. In one case, two children live with separated parents. In the other case, the caregiver is a father (deaf) who takes care of three sons, 2 of which have disabilities. One child has an intellectual impairment and the other a physical impairment due to burns to the body while trying to warm themselves with a fire. The mother reportedly abandoned the family due to illness, and the father is forced to leave the children at home alone when he has work. Lack of adult supervision may also be the cause for another child to have lost an eye in an accident with scissors. A child with Down Syndrome was born to deaf parents and she spends most of her time with her grandparents.
Right to child protection measures

The section below includes the Right to Freedom from Exploitation, Violence and Abuse – Article 16, the Right to Living Independently and Being Included in the Community – Article 19 and, the Right to Respect for Home and the Family – Article 23.

States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects. (...) prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive. (...) promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs. 5. (...) put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted. – CRPD Article 16

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that: (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement; (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs. – CRPD Article 19

States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others (...) Persons with disabilities, including children, retain their fertility on an equal basis with others. (...) States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children
with disabilities and their families. 4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents. 5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting. – CRPD Article 23

According to the Child Protection Index for Kosovo10, the “child vulnerability index” score for Kosovo11 is 0.56 out of a possible 1.0. This score places Kosovo in the second position among 9 countries in the region, lower than Serbia, but higher than all others: Georgia (0.49), Bosnia and Herzegovina (0.47), Romania (0.47), Bulgaria (0.40), Albania (0.34), Moldova (0.34) or Armenia (0.26)12. With regards to the child protection scores on disability, Kosovo ranks eighth (second to last) of all 9 countries13 in the Child Protection Index14. Kosovo’s highest score on disability is in the area of law and policy (0.688) while all others are significantly low. “Although Kosovo scores relatively high in law and policy actions for disability (0.688), its services (0.375), capacity (0.100) and accountability (0.167) scores are significantly lower. Coordination mechanisms, like law and policy, speak to Kosovo’s strong legal and regulatory provisions (0.667)”15. While Kosovo does not yet have a Child Protection Law (see below), ensuring the rights of children in Kosovo, including children with disabilities and the right to child protection, has been outlined in the National Strategy and Action Plan for Children’s Rights 2009-201316. The National Strategy is based on the main principles of the CRC (non-discrimination, child participation, full potential of the child, and best interest of the child) and should be applicable to all children, including children with disabilities. While progressive in 2009, taking into consideration the CRPD was newly developed as well, the document is somewhat limited in scope in that it envisions that appropriate legislation guarantee the rights of “children with limited or partial mental or physical abilities from the age of 0 to 18”17. Further, while it envisions the need to address issues related to education, healthcare, social welfare and juvenile justice for all children, it is silent on some of the most pressing child protection issues concerning children with disabilities: such as freedom from exploitation, violence and abuse, living independently, and the right to live in the family.

Accountability is an issue that has been addressed in various ways, including in discussions and actions related to the inter-sectoral nature of child protection and the need for multi-sector and multi-agency actions18 aimed at ensuring the protection of all children, including children with disabilities that have led to the creation of plans and protocols. Among them stands the Working Protocol: Inter-Sectorial Collaboration in Child Protection Cases19 that aims to “standardize, unify and coordinate the work of all agencies who are, or should be, working together to protect children”20. Because the protocol is set upon the principle of protection for all children at risk, and risk assessment includes various vulnerabilities, the Protocol is inclusive of all children with disabilities regardless of the type of impairment they may have.
According to the Ombudsperson Institution Annual Report of 2015, the child protection law has been under drafting since 2013. And “it should be followed with the quicker drafting and adoption of the Strategy and Action Plan for the rights of the child for 2016-2020. The process for drafting these documents started after the assessment of the Strategy and Action Plan for the Rights of the Child (2009 - 2013), completed by the United Nations Fund for Children (UNICEF) in the first part of 2015”\textsuperscript{122}. Indeed, the Child Protection Law is needed, and has been under drafting for some time. However, it will have to be re-submitted by the Government to be reviewed, but at the time of writing of this report (1\textsuperscript{st} draft) the Assembly of Kosovo was dissolved (on 11 May 2017) due to the announcement of general elections and a new Assembly has not yet been appointed. All draft laws at the process of review at the time of dissolution are considered unfinished by the next legislative.

In the Mitrovica North FDG, concerns related to violence in the family were highlighted in the discussions. Social Workers reported that children with disabilities often create an added stress to fragile families and the issue of divorce among parents who have children with disabilities has gone unaddressed. A social worker who is also a mother of a children with disabilities said: “I have a child with disability and have sent him everywhere for treatment. In this journey, I have met many women with children with disabilities, and almost every second of them was divorced as a consequence of no support from their husbands and violence at home. In my opinion, some 70\% of marriages are dissolved because of disability of a child. In most of cases husbands give up from their responsibilities”.

As reported by service providers in Gjakova region, there are no systematic home-visiting programmes for children with disabilities. Professionals from CSW are obliged to visit families receiving social assistance once every 6 months but there is no home-based service provision. HandiKOS does provide some home-based services that are, at the time of the report, being supported by Save the Children but, unless it is institutionalized, this type of support is not sustainable as NGO priorities and financial and human resources are likely to change.

Unlike in other countries in the Balkans, there are very few people (including children) in residential institutions in Kosovo. As reported by the MLSW and SOS Children’s Village in Prishtina, the SOS Children’s Village is the only accredited programme in Kosovo to provide care to children who are abandoned by their families, as well as support to families who are at risk of abandonment. At the time of the interview and visit to the location, out of 13 children under the age of 3 years old, only one was a child with a disability. In the family-based care homes where care is provided to children ages 4 and above, out of approximately 40 children, 6 are children with disabilities. All children attend regular school and only once they had a case of a child who was temporarily “pushed out” from school due to academic difficulties. The SOS Children’s Village hires qualified professionals such as psychologists, pedagogues, social workers, and others to support children in their care and families attending the counselling services.

The director of Special Institute in Shtime stated that there are no children with disabilities placed in their institute, but he knows that there is a daily care centre where
are placed some 10 children with “severe mental retardations”. To his knowledge, with regards to the institutions in the municipality, there is no specialised staff to provide services nor do they know how to deal with children with disabilities. "I think there should be a National Framework to provide clear guidelines, obligations, responsibilities and accountability on how to deal with these categories of children, as things will never work as long as we leave this only in the hand of NGOs. There is no adequate nor specialised staff in our institutions to deal with children with various categories of disabilities. There is a need for systematic capacity building. Even in my Institute there is a lack of adequate staff, because the employment has been done without any professional criteria, and the point is that you cannot dismiss these people until they get retired. I consider that people with disabilities are most discriminated categories, although some progress has been made compared to previous time but it is far from being good. The responsibility need to start from the family first, not to hide cases of children with disabilities and other family members. There are cases that were hidden from the society for even 25 years, and the case is identified only after the death of one of the parents, and the other parent who is old and cannot take care of his child then he/she seeks help from the Centre for Social Work, who then addresses these cases to our Institute."

Although the above mentioned Child Protection Law remains in draft form, Child Protection measures, and alternative care measures, feature prominently in Articles 10 and 11 (respectively) of Law No. 02/L-17 on Social and Family Services. Although not specific to children with disabilities, the welfare of the child is to be considered first within the family context. Safeguards for removal of a child from the family are explicit, the procedures to follow in case of suspected need for protection, as well as reporting duties by various health care professionals. Article 11 regulates alternative placements for a child, in the instances where the birth family is found unable to care for the child or the child is abandoned. Again, although not specific to children with disabilities, it is not exclusive of children with disabilities either.

According to the 2011 Census, the following are the number of persons reported in institutional households:
<table>
<thead>
<tr>
<th>TYPE OF INSTITUTIONAL HOUSEHOLD</th>
<th>AGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Residence for students</td>
<td>0</td>
</tr>
<tr>
<td>Hospital, sanatorium, convalescent home</td>
<td>4</td>
</tr>
<tr>
<td>Establishment for disabled, psychiatric institutions</td>
<td>0</td>
</tr>
<tr>
<td>Old peoples home</td>
<td>0</td>
</tr>
<tr>
<td>Childrens home, orphanage</td>
<td>29</td>
</tr>
<tr>
<td>Military and police barracks</td>
<td>0</td>
</tr>
<tr>
<td>Prisons and reformatories</td>
<td>0</td>
</tr>
<tr>
<td>Monasteries, convents</td>
<td>0</td>
</tr>
<tr>
<td>Worker dormitory</td>
<td>0</td>
</tr>
<tr>
<td>Refugee camps</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
</tbody>
</table>

Tab. 3.52 - Population usually resident in institutional households by age, sex and type of institutional household

<table>
<thead>
<tr>
<th>TYPE OF INSTITUTIONAL HOUSEHOLD</th>
<th>AGE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1-15</td>
</tr>
<tr>
<td>Hotel</td>
<td>0</td>
</tr>
<tr>
<td>Residence for students</td>
<td>0</td>
</tr>
<tr>
<td>Hospital, sanatorium, convalescent home</td>
<td>33</td>
</tr>
<tr>
<td>Establishment for disabled, psychiatric institutions</td>
<td>2</td>
</tr>
<tr>
<td>Old peoples home</td>
<td>0</td>
</tr>
<tr>
<td>Childrens home, orphanage</td>
<td>38</td>
</tr>
<tr>
<td>Military and police barracks</td>
<td>0</td>
</tr>
<tr>
<td>Prisons and reformatories</td>
<td>4</td>
</tr>
<tr>
<td>Monasteries, convents</td>
<td>0</td>
</tr>
<tr>
<td>Worker dormitory</td>
<td>0</td>
</tr>
<tr>
<td>Refugee camps</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
</tr>
</tbody>
</table>

Tab. 3.55 - Institutional households by number of persons in the institutional household, sex of persons in the institutional household and type of institutional household
Children with disabilities without parental care are rarely adopted in Kosovo, and are likely to be placed in foster care. Foster carers receive a total of €250 to look after children with disabilities. In 2013, KOMF reported that “the protection of abandoned children with disabilities remains a challenge. Currently, in foster care there are nine (9) abandoned children with disabilities, whilst placed at residential houses there are six (6) abandoned children with disabilities. Placement of children in residential children’s houses (for a long time deprives the child’s right to grow up in the family and presents a violation of the rights of the child. Difficulties are presented also in finding adoption families for abandoned children with disabilities. Mainly were realized international adoptions for abandoned children with disabilities”.

According to data gathered by local NGO OFAP (ex. Italian NGO “Amici dei Bambini”) and Cooperazione Italiana allo Sviluppo, there are an average of 54 abandoned children per year in Kosovo, between the years 2009-2013. Child abandonment often occurs at birth and children may also be temporarily or permanently placed out of the family for a variety of reasons. In 2015, the Ministry of Labour and Social Welfare provided an overall figure of 1,279 children under guardianship in 2015, placed in alternative care, most of them in formal kinship care (immediate family), foster care families and residential children’s houses. However, often the child is not placed in foster care, but placed in residential shelter, although it doesn’t comply with the law. Centres of Social Work at municipal level are responsible for recruitment of foster carers, planning and service delivery, while final approval of foster families is centralized. Service standards have been established as a “guarantee of uniformity of children's rights among different Municipality”.

The NGO OFAP, has been operating in Kosovo since 1999 with a psycho-social support team offering services to children and families. In January of 2017, there were a total of 68 children placed in 28 active foster families in Kosovo. Of those, 9 are children with disabilities receiving a cash benefit from MLSW, although the number of unidentified children with disabilities in alternative family care is probably much higher. While MLSW administrative instruction regulates that each municipality should have 3 active foster families, at the time of the interview, 14 out of 38 municipalities had no foster families and most of the remaining ones only had partially met the objective. The main challenge reported is implementation at municipal level due to a lack of capacities and commitment of CSW’s on recruitment of new potential foster care families.

Foster care is also being developed in Mitrovica North to ensure children from the region who are temporarily or permanently without parental care are not moved from their communities. Currently there are 8 families being trained. It is planned that they will be paid approximately 200 euros per month, per child, and be given extra funds for other expenses. Foster families that take children with disabilities will be paid an additional amount from the MLSW Serbia. At the time of finalizing this report, the financial scheme was not yet in place.

Labour Law N. 03/L-212 specifies that one of the parents (or caregiver) of a child with a permanent disability is entitled to work part-time until the child reaches age 2 years old, as a transition between maternity leave and full-time work (Art.52).
The Coalition of NGOs for Child Protection in Kosovo – KOMF – is an umbrella organization with 22 member NGOs that advocate for child rights through awareness raising and legislation revision. While their focus is children in general, a few of their activities focus on children with disabilities. According to their spokesperson, lack of data greatly impacts the lives of children because decision-making takes place based on assumption, not on facts. In addition, the lack of a specific grant (from central to municipal budgets) that ensures municipalities have enough funds to justify prioritizing children’s needs within their action plans, was highlighted as the main reason why service provision for children with disabilities is inadequate and left to the responsibility of civil society. According to KOMF and Instituti GAP\textsuperscript{34}, while municipalities are provided with earmarked funding for education (13% or overall municipal grant) and health and welfare (9% or overall municipal grant), most of which is spent on wages and salaries, no funding is earmarked for social services.
States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to: (a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity; (b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential; (c) Enabling persons with disabilities to participate effectively in a free society. 2. In realizing this right, States Parties shall ensure that: (a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability; (b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live; (c) Reasonable accommodation of the individual’s requirements is provided; (d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education; (e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion. 3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including: (a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring; (b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community; (c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development. 4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities. 5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities. – CRPD Article 24
Progress towards Inclusive Education

“The overall process of inclusive education is a painful process for everyone, including children with disabilities, their parents and teachers” – representative MDE - Gjakova

The MEST has been committed to inclusive education since the early 1990’s. This commitment has been documented, and discourse has evolved over time, from access to education for children with disabilities (often in special schools) to the creation of inclusive schools, to a broader and more inclusive vision, one that considers systemic changes that necessitate the involvement of communities, cross-sectoral coordination and constant monitoring of implementation activities. Standards for early childhood and for child-friendly schools were established, and professional development efforts were undertaken, including those related to sign language assistants, inspectors, Individualized Educational Plan writing and monitoring, although implementation continues to be challenging.

Throughout the last 2 decades and despite many efforts, the responsibility for educating children with disabilities has fallen onto specialized professionals, initially those working in special schools, and more recently those working in Resource Centres. In practice, and as documented below, inclusive education is still very much focused on the integration of sub-sets of the student population (i.e. children with disabilities and/or students with special education needs) onto some mainstream schools, and it is still measured by the number of children with disabilities attending school. The responsibility for implementing Inclusive Education is still very much focused on education personnel whose experience has been within special education, and on providing support services to children with disabilities integrated in the mainstream, as opposed to the creation of an inclusive ethos. Interviewees acknowledged the challenges experienced by the Special Schools/Resource Centres in supporting children with severe disabilities, although “resource centres have played an important role in building the capacity of mainstream schools for inclusive education through the services offered by Itinerant teachers and through the training programs where in 2014 MEST has licensed 16 training programs”138. According to various observers, children with disabilities are faced with a range of challenges at school, including inadequate infrastructure, lack of personal assistants, lack of support from many teachers, and often a lack of individual education plans.137

The number of students with special education needs and/or children with disabilities in regular schools in Kosovo is unknown. However, it is likely much smaller than the 5,25% of SEN students in the total school population in some of its neighbouring countries in Europe138. According to UNICEF, “fewer than 20 percent of children are attending early childhood education programmes in Kosovo” and “in Kosovo, less than 1 in 5 children are developmentally on track in literacy-numeracy”139.
In addition, official statistics from 2015-16 suggest that more than 94 per cent of children registered with special needs attend regular classes but girls with disabilities are less likely than boys with disabilities to be attending school (see below). 140

According to the MDE, in Ferizaj, out of over 20,000 pupils only 184 are children with disabilities attending school, 33 in special education classrooms and 151 in regular
classes. However, the quality of education is reported to vary between location and schools depending on available material and human resources. Likewise, data provided by a representative of the MDE in Prishtina indicates that there are more than 60 institutions in the municipality, with over 50,000 pupils, out of which 400 have been identified as children with special needs.

The design of a web-based application for a more robust Education Management Information System (EMIS) was started in 2009 (joint project with the World Bank) and completed in 2012-2013, as part of an effort to address the lack of data for decision-making. Now, EMIS collects data on schools (public and licensed private), staff and children based on classroom data but does not allow for a robust data collection such as: year of birth, gender, ethnicity, disability, family constellation, distance from home to school, social assistance, etc., all of which are types of information the MEST considers important for decision-making. EMIS also captures the types of disabilities represented in each Resource Centre, based on a 10-types list of impairments: autism, communication and language impairments, Down’s Syndrome, emotional and behaviour disorders, hearing impairments, intellectual impairments, learning difficulties/disorders, multiple impairments, physical impairments, and visual impairments. However, data on disability, impairment or special education needs is not collected in regular schools due to a lack of reliability.

Pedagogical evaluations

Because disability eligibility procedures do not support education decision-making, the MEST produced a Guide to Professional Evaluation Teams to Assess Educational Needs of Children with Special Needs in the Municipality and has, currently, established 16 municipal teams for pedagogical evaluations, although reports vary as to the extent to which all teams are fully functioning. The teams may include a variety of professionals depending on need and availability, and documentation is regulated. A new evaluation methodology that is responsive to the functional ability of each child (according to ICF-CY) is planned, but the process is not yet finalized. While an administrative instruction exists to regulate evaluations, there is no obligation on the part of the parents or the schools in ensuring a pedagogical evaluation is completed. Thus, very often, children with disabilities are placed in regular classes without any instructional plans or education supports.

According to the MEST and staff from the evaluation team in Prishtina municipality, the process of a pedagogical assessment can be initiated by either the parent or the school where the child is enrolled. But reports vary greatly with regards to the process and outcome of evaluations and most of those who participated in this study reported that generally, deaf children and children with a visual impairment are referred to the two special schools that specialize in these particular impairments for further pedagogical assessment. The evaluation team in Prishtina municipality reported that they usually receive requests for evaluation of children who are perceived to have an intellectual impairments or severe learning disability. In the 2016/2017 school year, out of approximately 400 children with disabilities who attend regular schools, only 24 children were evaluated by the team in Prishtina municipality. Out of the 24
children evaluated, 16 recommendations to attend regular school were made, albeit with a personal assistant. As reported by parents in FDGs, in almost all cases personal assistants, while a recommendation from evaluation teams and often a school requirement conditioning enrolment, have to be paid for by the parents.

Furthermore, as reported, not all team members in all municipal pedagogical teams have sufficient and/or relevant training, which makes the results of pedagogical evaluations highly variable according to geographical area, and perhaps not entirely reliable. As reported during interviews and FDGs, evaluation team members are not being paid for the evaluation work done, work that they consider “very complex and a high responsibility task” (MDE representative). As reported by the head of the Pedagogical Evaluation Municipal Team in Prishtina, the roles and responsibilities of the team end once the evaluation report has been completed and provided to the parent, unless a re-evaluation is necessary at a later time. All other actions that might occur after the evaluation procedure has been concluded (discussions regarding placement, IEP development, monitoring or benchmarks, etc.) are the responsibility of someone else, likely the parent, school directors, teachers and others.

During the 5 FDGs with service providers for this study, teachers had many different concerns about municipal evaluation teams. They reported that there is only one municipal evaluation team for the whole of Prishtina municipality which has a very high population density. The evaluation team members are engaged in other daily duties (teaching, ambulances, or school management etc.), do not see their team membership as a part of their main professional duties and, therefore, complain that they are not paid for their work. Besides, there is only occasional attendance of more specialised health doctors in the evaluation teams. According to FDG attendees, only 50% of municipalities in Kosovo have established Municipal Evaluation Teams. There are cases when the evaluation team members sometimes do not report the realistic diagnoses of children, which impacts their further inclusion at school and the development of their individual plans. There are many children with disabilities applying for school, among them blind children, and this is a challenge for evaluation teams. Finally, the municipal evaluation team members claim to do not have harmonised standards for identification of types and categories of disabilities. They also need trainings on teaching materials for individual plan for children with specific education needs.

**Settings and instruction**

The psychologist who attended the FDG is Prizren region, who has been a member of the municipal evaluation team, believes that the concept of attached classrooms (special classrooms within regular schools) contributes the further segregation and stigma against children with disabilities that works as an obstacle to real integration. According to this professional (and others in other regions), for social inclusion to flourish, children with disabilities need to be exposed to the same environment, behaviours and attitudes as all other children in their age group with the support of well-prepared teachers (special and regular education teachers), guided by IEPs. The concept of attached classrooms in Kosovo, as in much of the region, is seen
as a necessary mid-step between special schools (segregation) and regular schools (inclusion). However, in reality, attached classrooms operate very much like segregated settings despite being in the same geographical space as a regular school. The 2 special education teachers who work in attached classes in Ferizaj report having 25 students of different types of disabilities in 2 classrooms, ages 7 to 22 years old. They reported that, although the classrooms are now called resource classes their practice had not yet caught up with the terminology. However, according to their professional observations, some children with disabilities could be transferred from their classrooms into regular classrooms, all with the exception of 2 children with severe disabilities. There was no given explanation as to why this has not yet happened.

As reported in the FDGs, in Vushtrri municipality, all existing attached special classes have also been transformed into resource classes. At the moment, they have 13 students with different types of disabilities and of elder age, who “cannot attend regular class” (MDE representative). The students are ages 19 years and older, who cannot go to a special school because the parents refused their enrolment. They have severe disabilities and are supported by a school psychologist, one support teacher, and one technician. Reportedly, there is a day care centre being constructed, that “these children can attend in the future” (MDE representative). Also, as reported by the same person, in the municipality, there are 5 children with disabilities in mainstream classes, while there is a lack of professional staff to work with them. However, all mainstream teachers have attended trainings on individual planning for children with disabilities. This report is the opposite of that provided by the representative from the NGO Kosovo Down Syndrome who reported that she personally knows of a child with Down Syndrome who attends a mainstream classroom without an IEP.

According to the Report on the Functioning of Resource Centres in Kosovo, Resource Centres in Kosovo are regulated by the Law on Pre-University Education (2011) and Administrative Instruction N.23/2013, and function directly under MEST supervision. They have two main functions: 1) “special school for students with severe and multiple disabilities and provision of accommodation for dormitories for those in need”; 2) to “provide support to mainstream schools in teaching students with SEN”. The existing 5 resource centres each have a specialization related to an impairment: one specializing in visual impairment, one specializing in hearing impairment, and three specializing in intellectual impairment/developmental delays. The 5 RCs supported over 80 schools in the school year 2015-2016, with over 200 students receiving support from itinerant teachers, who visit schools an average of 3-5 times a week. During school visits, itinerant teachers are supposed to perform a variety of tasks related to: IEPs, provision of materials, consultations with school staff, trainings, identification of students and pedagogical assessment, support teachers, and support students. In addition, half of the itinerant teachers who participated in the evaluation, have made family visits to identify cases for assessment, and support and advice parents.

According to the Prishtina RC director, the RC has a total of 38 staff, of which 4 are itinerant teachers. The 4 itinerant teachers support 108 children with disabilities in 28 schools, in 13 municipalities (around Prishtina), but do not typically support or work collaboratively with regular teachers who have children with disabilities in their
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Classes, due to: lack of teacher training, lack of willingness on the part of teachers and school administrators to create conditions for inclusion, and lack of enforcement of legislation on the part of municipal authorities. The RC in Prizren region – Nena Tereza – is the only institution for children who have hearing impairments. The centre currently has 81 children, ages 3 to 18 years old, in pre-school, primary and secondary school levels as well as 3 vocational training programmes. The RC functions as a boarding school, with 51 staff of which 2 are defectologists and 29 are subject-matter teachers, and the pre-school includes children with a variety of types of disabilities (but not deaf or hard of hearing) from the municipality. According to reports from FDG participants and interviewed members of the Deaf Association of Kosovo, the RC continues to operate as a special school with a dormitory, while reports of its outreach and support of children who are deaf and hard of hearing in regular schools (as expected of a RC) are varied. According to the Deaf Association of Kosovo, despite legislation that claims that sign language is supposed to be the language of instruction for deaf students, the reality is very different. Teachers do not, in the largest majority of cases, use sign language regardless of setting, including in the RC. According to the reports, there is a sign language instructor on staff supposed to provide training to the teachers but there is no willingness on the part of the teachers to learn it, and no administrative instruction that requires it. Thus, according to a teacher survey, less than 1% of all instruction is done in Sign Language. According to interviewees, it is not surprising that 66% of deaf survey respondents are illiterate after attending school. Teacher preparation programmes do not include any information on deafness or Sign Language and the Association is now working with the University of Prizren to include sign language in their programme.

Children with disabilities attending regular schools are often enrolled without having been identified as such, without a previous evaluation, or an individualized education plan, because enrolment is not dependent upon it and parents often do not want to (or know how to) initiate the process. CSW can identify children for evaluation, and parents or teachers can also request an evaluation. However, parents can (and do) enrol their children in the school of their choice, and do not have to abide by a teachers’ request for an evaluation. This was identified by many service providers as a challenge and an obstacle to inclusion. In addition, there are many children with either academic or social difficulties in regular classes, without adequate support.

As reported in Gjakova, the situation of children with disabilities in regular schools is highly problematic partially because the evaluation team that makes decisions related to the education of children with disabilities does not include the professionals who must enact those decisions. While the evaluation team defines the learning objectives that guide each child’s individualized education plan, many classroom teachers are reluctant to accept children with disabilities in their classrooms, even in the cases where there is a support teacher allocated to a specific child. As reported during an FDG: “If I am talking here with my colleague while you are facilitating the Focus Group Discussion do I interrupt or distract you? This is how it works in a class with a support teacher in the same class where I teach. It is difficult for a regular teacher to have another teacher in the class” – veteran teacher, 20 years in the classroom, advanced degree, in Gjakova.
Children with disabilities and their families reported that often they attend regular classes but do not receive the individualized support they require (and are entitled to) in order to participate in the process of learning. As reported by a caregiver in Pristina municipality, whose sister is attending the regular school in the grade 5, her sister’s teacher is not trying to involve her in the learning process, even though there are only 4 children in the class: “In principle, she is a good teacher for other children, but the point is that she doesn’t know how to deal with my sister. She is keeping her aside and alone in the class, separated from the other children by not involving her in the class activities. She has also asked us, the family members, to sit with our sister in the class. She doesn’t care if my sister doesn’t go to school at all, and she is not even taking any evidences when she is absent from the school”.

Parents such as the mother of a girl with a disability in Mitrovica North, expressed their frustration with education. As mentioned, she has bought the learning materials for her daughter who is attending mainstream school, but nobody is working with her individually. She reported that she is very disappointed as to how her daughter is treated at school, like everybody tries to be nice to her and feeling pity, without trying to support in her real inclusion: “I am fed up, and this is driving me crazy, it is not only my child that needs psychiatrist but I need psychological support as well as I am tired of false behaviour and not professional support for my child”. She further mentioned that “there are always some NGOs who benefit from our children with disabilities, who just invite our children in some events, but actually they do nothing except ending with taking some photos with our children and then leaving”.

In Gjakova, Ferizaj and other municipalities, regular teachers reported having no training related to children with disabilities. The teachers who reported having received some relevant training are those who have typically worked in special education classes. However, (special education) support teachers in most municipalities report having received extensive trainings related to children with disabilities over the years. Save the Children has been engaged in teacher training for inclusion, and by the end of 2017 will have provided support to 8 pre-schools and 18 primary/lower secondary schools on the use of the Index for Inclusion. Likewise, UNICEF supported in 2016 the development and modelling of the IE teacher training programme based on the ToT modules for in-service teacher training programme on IE with an emphasis on children with disabilities in cooperation with the Faculty of Education/Institute for Research and Development of Education, to provide a foundation for teacher training on IE that is grounded in a human rights-based approach. However, teachers reported that although there is one university course on inclusive education, teachers are not physically or psychologically ready to work with children with disabilities. Even in the instances where regular teachers are able and responsible for writing and implementing individualized education plans “the institution does not have a pedagogue nor a psychologist that could provide further support to this category of children” (director pre-school Ferizaj). Likewise, interviewees from the MEST and various donor organizations confirmed that many training opportunities have been provided over the years but there has been great difficulty in motivating and ensuring a change in practice in the field of education.
Parent and children’s perceptions of the education system

Perceptions related to the provision of education services vary drastically between parents and education officials. According to parents/caregivers reports gathered in 7 FDGs, out of 62 children with disabilities, forty-one (41) children with disabilities attend mainstream school although as reported by caregivers only a few of them have an IEP and, as reported by the caregivers, only a few teachers make the effort to implement them. Of those in mainstream school, two (2) children have a support teacher, and one (1) has a private assistant. Both children with Down Syndrome who attend mainstream school in Gjakova, do not have a support teacher, or IEPs. One mother says: “she attends regular school in the 9th grade, does not have a support teacher and she does not have an individual plan. We have requested support teachers from municipality but no response so far.” In both cases, parents want to send the children to the “special school Perparimi” (RC in Prishtina) for vocational training after age 17, so that they can, reportedly, gain some skills for employment and in the future become independent.

Twelve (12) out of 59 parents go to school daily with their children. Of those with children in mainstream schools, they are happy that their children attend regular school and spend time with other children. They report that the learning progress is very slow, but their children are happy to be among their classmates who support them in the class: “My son can never reach the learning outcomes and results as the other children in his class, but that was the decision of the evaluation team and the doctor that he should attend regular school, and we are in support of that decision” (mother, Prizren). The same 59 parents report having two (2) children with disabilities in special school, two (2) who attend an attached classroom, twelve (12) do not attend at all, two (2) that have never attended.

One parent from Ferizaj reported that her child attended mainstream school for five years but is now enrolled in an attached classroom. Reportedly, the reason is that the teacher stated that she could not handle her anymore, and the child’s sister was being ridiculed by her classmates in the regular school. Another parent whose child is no longer attending school (Prishtina) reported that his child initially attended an attached class which was 15 km from her village. Transportation was organized by the school and the child was very happy there. Following the new inclusive education process, school management recommended that the child be enrolled in a regular school, only 3 km away from her home. But, as the municipality did not provide transportation, she has not been able to attend for 2 years now. The father mentioned that the municipality offered him 20 Euros per month for transportation expenses (for him to drive his daughter to school), but he cannot afford this because he has to work (to support his family of seven), and there is no other person that can drive his daughter to school.

Also in Prishtina municipality, the only foster care mother who attended the FDGs reported that her foster child attended mainstream school until 2 years ago, when they moved to another house which is much further away from school. As there is no transportation provided by the municipality, the family tried to enroll the child in
the mainstream school closer to their new home but the school management did not accept her registration, stating that there was no place for her. She has been staying at home and not attending school ever since. Another parent in Prishtina reported that she enrolled her daughter in the mainstream school in their neighborhood for a short period, but then the teacher complained to the parent that she cannot take care of the girl and teach the other children at the same time, unless someone from the family stays with the child in the class. Because the mother could not afford this (she had another younger child to take care of), they were forced to withdraw the daughter from school. She has not attended since then.

Two parents in Prishtina have had different experiences although they also reported difficulties with transportation. However, they confirmed that both boys are very well integrated in the mainstream school, and are among the best pupils in the class. They further reported that they are happy with the teachers, and the way they treat their children. The director of the school has been very supportive by adapting a class in the first floor, and the toilet, as per the children’s needs. In Gjakova, another parent had a similar report: “Everyone at school tries to help him… friends and the teacher… the director has moved his class from the second floor to the first so my son could attend it.” (father, Gjakova).

**Quality of education**

Overall, parents are not happy with the progress of their children at school, and worry about what will happen when they complete primary and lower secondary, since their children have not learned the most basic things. In all five FDG locations there was unanimous agreement that school does not meet their children’s most basic learning needs and many parents reported that the children do not like going to school.

While parents and children identify the lack of technical capacity of teachers as a main obstacle, according to the desk review and confirmed by interviewees for this study, many trainings focused on children with special education needs or inclusive education have been provided to a variety of education professionals. Multiple donors have partnered with the MEST since 2008, but attempts at coordination of efforts have not been effective creating a lack of cohesive approach to training, particularly with respect to in-service training. Teachers and school administrators identify the lack of parent education and support, and a cumbersome system as obstacles to quality education, although every service provider interviewed and FDG participant mentioned the lack of adequate training as an obstacle to quality instruction.

Almost all children with disabilities who participated in the FDGs mentioned receiving educational support from Save the Children, HandiKOS, Caritas or other NGOs. In some cases, children reported that their only learning is done at the centers ran by NGOs, while NGOs report having been involved in supporting the education of children with disabilities in some capacity or other, at times working directly with MEST, and at other times working with children and their families directly. Tutoring, classroom support, direct instruction, counseling, are some of the education support services HandiKOS provides to children with disabilities in all municipalities represented in this study (with some funding support from Save the Children) although the modalities
vary, from home-based services, to learning support at the HandiKOS centre, to hiring a support teacher who provides support in a variety of ways.

The quality of education is also directly related to funding. As can be seen above, most human and financial resources that are allocated or being used, even peripherally, for children with disabilities is concentrated in segregated settings and acts as an active barrier to the full inclusion of children with disabilities within mainstream settings. While only one example for illustrative purposes in this study, the case of Vushtrri is a case in point: Not only are human resources allocated unevenly between a resource room that operates as a special classroom (13 students with 3 professionals) and mainstream classes (5 students and no professional), but transportation also illustrates the drain that segregated settings have on scarce municipal resources. As reported, the municipality has allocated a budget of 10,000 Euro for transportation of children with disabilities to school. Depending on the distance, they pay between 200 and 400 Euros per year to families with children with disabilities to ensure the transport of children attending regular school. However, the municipality provides a mini bus for the transport of children with disabilities that attend special school.

**Accessibility**

Accessibility of schools (both retrofitting existing schools and building new ones) has been a responsibility of the MEST since 2004. Norms and guidelines have been published, in accordance to existing Administrative Instructions (Technical Conditions of Constructed Buildings for the Access of People with Disabilities No. 07/2007). The existing guidelines were developed in collaboration with the World Bank and include European Union norms with respect to ramps, door size, accessible toilets and other accessible construction requirements. However, accommodation for persons with sensory impairments are not envisioned in any of the documents. While the MEST department in charge of accessibility is extremely proud of the new guidelines and of planned construction work, they are also well aware of the limitations and challenges of their daily work. The 7-people team (2 architects and 5 engineers) responsible for accessibility, are all self-taught on issues of accessibility and have never had any education or specific training on disability, CRPD requirements or universal design. It is important to note that the MEST is only responsible for construction of special schools. All other schools (building new and retrofitting) are the responsibility of municipalities.
Highlight on Roma and Ashkali children with disabilities

Out of 7 Ashkali school age children with disabilities who attended the FDG, only 1 child, an 11 years old girl with a mild physical impairment, was attending school. She attends regular school in 4th grade but she reported that she does not like her teacher or to go to school, because she sits alone in class, does not have friends, and other students tease and bully her: “I sit alone in the class...... I myself wanted to sit alone”. Her mother reported: “Yes, other children at school ridicule her, they call her invalid”. The two small children (both 3 years old) were not attending preschool/kindergarten. The other children up to 5 years old attend the kindergarten at Ideas for Partnership. One of the girls, who is blind, is interested in going to school but, as reported by her mother, was never enrolled in because the school for the blind is too far away. However, she has learned some Braille at Ideas for Partnership Centre. She sometimes goes alone out in the yard and to the toilet but not further. She does not like music at all. Another girl, 10 years old, was enrolled in regular school reportedly had to stop attending because she is “very nervous and can become aggressive”. The Ashkali caregivers where not aware on the rights of their children to inclusive education, and were never approached by anyone to inform them about the education opportunities in the regular school. They also have very little knowledge on their children’s rights and on the free service provisions they can get for their children with disabilities.

Three (3) out of 6 Roma children with disability who attended the FDG were attending regular school, in Serbian language but one of the children, a girl with Down Syndrome attends only one hour per day. Her grandmother reported that she was not learning anything at school: “There used to be a school for children like this but not anymore... and now in the regular school they don’t learn anything......she did not learn a single alphabet letter and she is 11 years old”. The 2 young children 3 and 4 years old were not enrolled in any preschool/kindergarten. One of the children, a 10 years old boy, was not attending school and he has never been enrolled in school. His brother answered like this when asked why he does not attend school: “He is troublesome in the class... he can’t use toilet alone and he is very nervous”. He also mentioned that their father is not keen to let his sons attend the school, as he could not take care of them and get them ready for school, thus would rather prefer them staying home. Those children that go to school also attend the education learning centre of Balkan Sunflow- ers. The learning centre provides text books and support children in learning activities. It should be noted that although the Roma children attend regular schools in Serbian language in Gracanica, they could hardly communicate in Serbian language in the FDG, and the community worker had to translate from Serbian into Roma and vice versa.
Right to health and rehabilitation

Right to Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall: (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes; (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons; (c) Provide these health services as close as possible to people’s own communities, including in rural areas; (d) Require health professionals to provide care of the same quality to persons with disabilities as to others (...) (e) Prohibit discrimination against persons with disabilities in the provision of health insurance (...) – CRPD Article 25

According to UNICEF, Kosovo is among the lowest ranking countries in the region with regards to maternal and child health. Based on the Multiple Cluster Indicator Survey, Infant Mortality Rate is estimated at 12 per 1,000 live births, while under five mortality rate is 15 per 1,000 live births. Infant Mortality Rate among Roma, Ashkali and Egyptian children is three times higher, estimated 41 per 1000 live births, while under five mortality rate is 49 per 1,000 live births (the probability of dying between birth and the fifth birthday). Additionally, according to the data reported from health facilities, Perinatal Mortality Rate (stillbirths and early neonatal deaths) has shown declining trend, estimated at 12/1000 births in 2015. In 2013, perinatal mortality was estimated at 16.2/1000 births, while in 2000 the Perinatal Mortality Rate was estimated at 29.1/1000 births (MoH 2016).

Psychologists at Family Health Centres should be able to take on a proactive role that can help to prevent conditions leading to disability. Parent education about child development is key to prevention as well as the development of a screening system that can track child development beyond vaccination.

According to interviews with the Ministry of Health (MoH), all primary, secondary and tertiary health services in Kosovo are free for all children. Service provision outside of public institutions is allowed and regulated by administrative instruction when the patient has a recommendation from a health official team (3 people), as well as urgent care that can be obtained in private clinics at the expense of the MoH. There is a national list of essential services/medications but, unfortunately, parents have to purchase medications that should be, by law, free of charge. All new-borns receive a vaccination card that allows them to get vaccinated for free, but all rehabilitation at the regional hospitals is very basic and almost non-existent at local levels. In a study commissioned by UNICEF in 2013, mothers reported that the health system...
did not maintain contact with children past their first year of life, and health services and medical treatment, particularly specialized treatment, were very expensive. According to interviews conducted with professionals from the Mother, Child and Reproductive Health division at MoH, specialist services provided to children with disabilities are done by referral of children to specific specialists. Treatment, habilitation and rehabilitation do not exist in all specialities (such as Cerebral Palsy, Autism, etc.) despite advances in identification, although home visiting nurses are meant to be able to identify and refer children younger than 36 months of age that are at risk of disability or delay.

Although home visiting efforts started in 2007, they have only expanded to seven municipalities (Prizren, Gjakova, Dragash, Fushe-Kosoce, Gjilam, Ferizaj, and Mitrovica South) at the end of 2016 (with 9 more at the end of June 2017), with UNICEF support being provided since 2013. Within the context of improving health and well-being of at risk children and the most vulnerable families, training has been provided to ensure that home-visiting nurses are able to identify children at risk of developmental delays and/or disabilities. In addition to delivering a package of integrated social services to over 7000 mothers and children, 5 centres and 9 community-based early childhood education centres in rural areas facilitate early detection and identification of children at risk of a disability or developmental delay.

According to interviewees, the nurses are supposed to complete both neo-natal and post-natal home visits and provide counselling to families, follow up with the development of the child and identify delays. If a child with a disability is identified, the number of visits will increase as needed and the nurse is responsible for reporting the family and child to the CSW, the Centre for Family Health Care, specialists as needed, and others. Nurses are not required to collect data on children with disabilities although data is shared, informally, with health development centres at the municipality. Thus far, services are highly dependent on the “good will” of municipal authorities and donor funding, although all services are supposed to be sustained by municipal budgets in the near future.

The Family Medicine Centre in Prishtina is responsible for coordinating home visiting and training home visiting nurses. The professionals interviewed report that the greatest majority of required services to babies (either related to an impairment or a disability) are, as much as possible, provided without incurring in a separation of the baby from the family. In total, there are 150 nurses trained, in 7 municipalities, with a great deal of effort being put into inter-departmental cooperation at the municipal level. In 2016, a total of 6,334 visits to children 0 to 3 years old, pregnant woman and RAE (Roma, Ashkali, Egyptian) communities were completed by 200 professionals (nurses, SW, kindergarten teachers, etc.). Home visits are supervised by professionals appointed by the directors of primary family health centre at the municipal level, who is responsible to report quarterly to an inter-departmental working group, who is also responsible for data collection. Kosovo home visiting nurses and other professionals were trained with UNICEF support, by professionals from the Albania Public Health Institute, from September to December of 2016. Training materials include a learning module on disability, that introduces disability from the perspective of disability and child developmental delay as a social phenomena.
Despite great efforts to create a network of home visiting nurses in Kosovo that can aid in the identification of young children at-risk, out of the 6,334 visits completed in 2016, there is no available data that can point to the identification of children with disabilities, although some children were identified as having developmental delays. Interviewees for this study were unsure as to the technical capacity of visiting nurses to properly identify children at risk, but pointed out that any suspected case of disability or developmental delay is communicated to a physician at the municipal health care centre who is also supposed to do a home visit.

But, home visiting alone will not be sufficient to address all needs related to the identification of children with disabilities and developmental delays. While there is a need to expand the network of home visiting nurses and institutionalize their professional role there is also the need to expand capacity of the entire health network as to the identification of impairments that may lead to disabling conditions. The Health Sector Strategy 2010-2014 mentions the needs of children with disabilities, but it does not go into detail. Whilst children with disabilities will clearly benefit from the broad provisions in the Strategy in the areas of prenatal and antenatal care, improved nutrition, and care in delivery, there also needs to be more focus in the Strategy on the specific needs of children with disabilities" 150, including the early identification and early intervention essential to the prevention of delays and disabilities.

In Gjakova & Ferizaj, each municipality has a CSW responsible for the preliminary identification of a child/person with a disability applying for financial assistance. The list with the necessary documentation is introduced to the Health Evaluation Panel at the MLSW that is responsible for the evaluation, the result of which is then communicated to the MLSW, the entity responsible for the disbursement of 100 Euros/month per qualified family. Family Health Centres also cooperate with schools and with the juvenile in Ferizaj, where there is one neuro-psychiatrist who is able to work with all types of disabilities and all children ages 1 to 18 years old and who is usually involved in the initial assessment and in prescribing treatment. Working in multi-disciplinary ways is still very new and somewhat problematic due to the differences in training of health professionals: some are able to participate in complex and multi-dimensional assessments while others equate disability with an IQ number. This variance in professional capacity also impacts who becomes eligible for a disability pension.

Reportedly, most children with disabilities who live in Mitrovica North have access to health services and rehabilitation in the Public Health Centre in Zvecan. Medications that are available can be had free of charge with a doctor’s prescription but children with more complex needs go to Belgrade or other cities in Serbia or abroad for treatment. There are no health-related home-services.

Save the Children reports that early identification in Prishtina municipality is generally done at the neonatal unit of the University Health Centre for infants up to 28 days of age. However, this is not possible in the rural areas, and does not help with the identification of disabilities that are not immediately visible upon birth. The DPO Down Syndrome reported that the Down Syndrome diagnosis was, until 3 or 4 years ago considered a new diagnosis. However, overall, early identification is reportedly
problematic as shown by a study that concluded that there is no integrated early identification mechanism in place in Kosovo. There are different institutions that have their different evaluation teams for their own purposes, but there is no integrated common strategy based on which the evaluation or early identification of children with disabilities would be conducted. In Prishtina, three parents stated that they believed that their children would not become disabled if the impairments had been identified earlier and adequate health services were provided at the time when first indications occurred. The situation of their disability has further deteriorated because there was no urgent treatment of their children by medical staff and lack of expertise to prevent further deterioration of the disability.

All health care service providers interviewed for this study, as well as those who participated in FDGs were adamant in reporting that health care services are free at state hospitals and local health clinics. Parents/caregivers of children with disabilities agree with this assessment, but also report that although all children should go to state hospitals for medical care, there are no specialized services available. Further, parents report that the quality of health services is worse in public clinics than in private clinics, with much longer waits, reported to be of many hours, and costs of specialized treatments are very high.

Working with professionals, raising their awareness and knowledge of disability was also mentioned by DPOs in FDGs. For example, the DPO Down Syndrome works with physicians on how to communicate with parents, how to explain the diagnose of their child especially to the mothers, as it is very difficult for them to accept that their child has down syndrome. There are many cases when the paediatrician communicated the diagnosis to the parents in a rude/uncaring way, often providing misleading information such as telling parents their child would not live longer than the age of 12 years old.

According to the children with disabilities who attended the FDGs for this study, their health care varies depending on the region. While children in Gjakova reported going to the doctor for regular health check-ups and more specialized services, children in Ferizaj reported not receiving any health care, neither for regular treatments (i.e. flu) nor for specialized care. One child in Prishtina region reported that “the nearest doctor is 4 kilometres away from our home…… the road is very bad…. we go to private doctor…. in the ambulances (state) there is only emergency”, while two deaf children from Prizren who attend special school reported that they have regular medical check-ups in the special school and, if there are more serious issues to address, then they are referred to the hospital and the interpreter accompanies them.

Confirming parent’s accounts, children with disabilities reported instances of travelling far distances, at times abroad, to seek specialized services related to their impairments. In Gjakova, two (2) children mentioned that more serious interventions like operations that were undertaken in Prishtina and Albania. Likewise, in Prishtina, three children (blind) have used health services outside of the country, either for diagnostic or treatment (Albania, Macedonia and Russia) and almost all the expenses were covered privately. Only one child reported receiving financial support from the Ministry of Health for an operation in Macedonia, in a private specialized hospital.
In Gjakova and Ferizaj most parents who attended FDGs reported taking their children to private clinics for visits that are disability-related, despite the fact that all private medical check-ups are paid out of pocket, often in a main city, sometimes even out of the country. Five (5) parents take children to private clinics they can barely afford: "My son needs lots of medical therapy. 100 Euro financial support is nothing for that" (mother, Gjakova). Two (2) parents have reportedly applied for MoH support to send their children for treatment abroad, and have been waiting for months for a response.

Parents from rural areas in Prishtina region report having to go to Prishtina (city) or abroad for health services. Often, they hire private services, and also pay for all medications: "I had to travel at least 5-7 km to the closest health centre and usually have to wait in a long queue for a medical check-up. There were cases when I had to go back home without being able to make any medical examination of my child because she got tired after a long travel and waiting in a queue, as no one had any consideration for us" (mother, Prishtina). Furthermore, parents in rural areas reported that they have stopped sending their children to specialized services (psychologist, psychiatrist, logoped, etc.) because they cannot afford it.

In Prizren, parents complained about both the expense and the quality of health care. All parents reported that, most times, children go to state hospital and public clinics because they cannot afford anything else, although the results are not encouraging. Two parents report their children had multiple surgeries with no significant results, and one mother believes that her child’s disability is due to the lack of knowledge of the attending physician when she was born: “I trust that her brain was damaged due to poor breast feeding as the doctors always insisted on this although she was too weak to breast feed on her own. Since then the girl’s brain was not well developed and then she started to have problems with eyes too”.

In Mitrovica North all parents take children to public health institutions. They have essential medications available but have to go to Belgrade for more specific medications, often at a higher price, because they are not available locally. For specialized treatments, they go to private clinics in large cities, often outside of Kosovo.

Despite reports such as those above and that indicate that not only the cost but also the quality of health care are questionable in Kosovo, the National Strategy on Persons with Disabilities (NSPWD) anticipates that the establishment of the Health Insurance Fund will change the existing difficulties experienced by persons with disabilities in accessing healthcare; therefore, the only provision in the NSPWD is the anticipation that the change in the ways in which healthcare is financed will improve the overall health provisions for persons with disabilities. But, in the health system, children with disabilities are not always provided with free medicine and other equipment to help improve their health, improve their mobility and offer them a life of dignity.151
Highlight on Roma and Ashkali children with disabilities

Only 4 of the 9 Ashkali parents could indicate the impairment or disability of their child. They indicated most of their children were born healthy and the problems appeared soon after their birth. Parents mentioned prematurity, fever, and difficulties during child birth, as the causes of disability. “She was born prematurely and then was kept in incubator for 2 months, and there her sight was damaged” (mother of a blind girl). Out of 6, only one of the Roma parents could indicate the impairment or disability, a brain tumour that led to blindness. The others could recall when they identified or noticed difficulties but could not say the diagnosis.

Ashkali parents reported that most of the children were partially immunized. They received initial immunization when they were born in hospital (all the children were born in hospitals), but then they were never visited by health workers for further shots and they did not send children for further immunization. One child has never been immunized according to the parents. In the Roma FDG only one caregiver, a sibling of two brothers with physical impairments, said that they were not vaccinated at all as they do not attend school regularly, where vaccination was usually done.

Parents send their children to Prishtina and Belgrade for specialised treatment but most of them cannot afford to pay for regular treatments. In their municipality, they attend health services for basic needs that are free of charge with exception of medications, which they must pay. They also reported that they must wait on long queues with other patients and there are no advantages for their children with disabilities. Roma Children themselves did not report visiting health services. Some parents stated that they had to send their children in Belgrade for specialised treatment (surgery) but it is too expensive for them and they often cannot afford it. As far as they know, there are no specialised services for children with disabilities in their municipality. One of the parents who had two children with disabilities said that she could not afford to send one of the daughters to the doctor although the girl has serious difficulties in speaking.

Right to Habilitation and Rehabilitation

States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes: (a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths; (b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas. 2. States Parties
shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services. 3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.
– CRPD Article 26

As reported by caregivers, in the municipalities included in this study, no home-visiting services are provided by either CSW or health care professionals. In Gjakova, some home visits are made by HandiKOS, while in Prizren home visits are done by both HandiKOS and PEMA. An analysis completed by KOMF in 2014 indicated that psychosocial and rehabilitative services for children with disabilities were provided in only 4 day centres in Kosovo (Peje, Ferizaj, Gjilan and Prizren). The day centres were, in 2014, a mix of governmental and non-governmental cooperation and municipal budgets expected to include them once the initial projects were over.

Children with disabilities in Kosovo face the barrier of a lack of day care centres where they can be treated, assisted or support for equal integration in society. No municipalities provide such support, which is exclusively provided by NGOs, and thus not sustainable. PEMa, an NGO founded in December 2013 set up four day care centres by 2015, which reportedly were “examples of best practice and established strong referral mechanisms with other institutions” However, the project’s European Union funding came to an end in 2015. Reportedly the centres are now struggling to survive without budgets. Addressing this requires government structures to provide material and budgetary support for such centres.

As reported by the Director of CSW in Gjakova region, day-care centres for children with disabilities that can provide rehabilitation services do not exist in his region, despite the municipality having made a plan that was denied by the central government. He considers day-care centres of utmost importance for the municipality because, at present, once a child is identified having a disability they have to be referred to an NGO for services, who are often who has initially identified the child and flagged him/her for assessment. As reported, Gjakova CSW does not have the capacity to undertake outreach activities or identify children with disabilities in the municipality; the CSW only works with families and children who approach them. “The municipality hasn’t foreseen any budget for provision of services for children with disabilities, they only pay salaries of staff and for other operational costs of the CSW”.

However, the NGO PEMa reports having opened day-care centres in four municipalities, providing services to approximately 350 children with disabilities over 6 years. Most of the services focused on psycho-social support, speech and language therapy, family support and family health. At the end of 2016, responsibility for the day-care centres were supposed to be transferred to municipal authorities.

All interviewees in this study with knowledge about provision of services to children with disabilities mentioned (with different depths of knowledge) HandiKOS as one of the longest-standing service providers in Kosovo. Its roots can be traced back to 1983, although their trajectory has changed overtime. The focus of the organization is
on persons with limited mobility, both in accessibility/assistive technology provision and in legal support. However, HandiKOS also engages in early identification and intervention due to its extensive network of partner organizations and staff involved. According to their director, HandiKOS has been in the field for 16 years, and while they created interventions and activities to address existing needs, these should have been taken over now, since many of their roles and responsibilities belong to governmental institutions and health/rehabilitation professionals. Now, HandiKOS has 58 staff full-time, country-wide, and more than 25 volunteers who work mostly on ad-hoc, as-needed basis. They also have 20 cars/vans, some of which adapted for persons with limited mobility. The staff works both centre-based and on itinerant basis. HandiKOS funding is a mix of donor funding, and service-provision tender from municipalities. As described, HandiKOS finds itself in a very difficult position in that it applies to government funding to provide services, while advocating for a change in service provision from NGO basis to government institutionalization.

As reported by parents (59 in 7 locations) during the FDGs, most children reportedly receive services by HandiKOS, with the exception of children in Mitrovica North and in the Roma and Ashkali communities, either at their own centres or at home. Services vary according to the location and the need of the child, but they focus on socialization, basic education support, physical rehabilitation and psychological support. Parents in Gjakova FDG reported that “We have requested from the municipality to support us through HandiKOS in providing more specialized medical staff in only certain days so we can bring our children for medical controls but they did not thing about this” (father, Gjakova). The blind and low vision children interviewed for this study (during the visit with the Association of Blind Persons) also reported receiving no services from HandiKOS because there is no reciprocal cooperation between HandiKOS and the Blind Association of Kosovo. In general, the situation of children who are blind and/or have low vision was described as different from other children because they receive a higher cash benefit related to the disability (250 Euros/month) and, apart from some general medical check-ups and treatments in the Kosova University Clinical Centre, there are no more specialized services available. For more specialized medical check-ups and interventions their parents have to send them abroad. Most children who are blind and/or have low vision go to the school for blind in Peja to learn Braille and orientation/mobility.

The Gjakova, Ferizaj and Prizren municipalities hold the right to contract NGOs for providing specific services, while CSW can only identify the type of service that the child needs to get but cannot provide the service, as they have neither capacities nor budget. Professionals at the CSW are aware of the challenges faced by NGOs and believe that without NGOs providing rehabilitation services “we have been left in a deep mud now” (SW Ferizaj). As reported by both professionals and a parent in Ferizaj, the lack of coordination and ownership by national and local government officials has had a great impact of the lives of children. For example, as reported by a parent, there is a deaf 8 years-old girl who had a cochlear implant at age 3 but no software or hardware servicing or upgrades. Now at age 8, and problems with her hearing device, the mother reported that they have visited several times doctors in both public and private clinics but have not been able to find anyone who can provide such a specialized service and the family cannot afford to pay for the reprogramming
of the hearing device. As reported by the research team involved in the FDG “the girl doesn’t hear and cannot speak and looks quite frustrated and aggressive when someone approaches her. She could not focus on any discussion and was playing with toys all the time, making big noises. Neither she nor her mother use any sign language”.

CSW cooperates with Save the Children and education institutions, while HandiKOS provides some physical rehabilitation services (125 children in Gjakova, 30 children with severe disabilities in Ferizaj, 30 children in Prizren), both at home and at their premises, although the NGO is overwhelmed with requests, operating with a small budget and dealing with a lack of expertise to work with children with impairments that go beyond their expertise with physical impairments.

In addition to rehabilitation services, most NGOs on the ground (Gjakova&Ferizaj) are largely responsible for all outreach and identification of children with disabilities and children at risk of a developmental delay, while Save the Children provides psychological support and public awareness. Caritas identifies children with disabilities (7 children with disabilities ages 7 to 22 years old in Gjakova) within the Roma Ashkali and Egyptian communities in the Gjakova region and mediate with HandiKOS for service provision. In Prizren, Caritas has held a project for 9 years that provides early identification and school-readiness support to children 0 to 6 years old (50 children currently). In Ferizaj, efforts related to early identification have been a joint CSW/HandiKOS effort.

Almost everyone and every organization does multiple things: education support and early identification, early identification and public awareness, health services and early identification, etc.

The Kosovo Association for the Blind and Partially Sighted has been advocating for the rights of visually impaired persons in Kosovo since 1947. Today the organization is engaged in both advocacy of rights of persons with visual impairments and service provision, as a licensed service provider of Braille, Orientation and Mobility, and Informational Technology for the Blind. The Association focuses on social integration and employment and was largely responsible for legislative advances in the last few years. As far as their data gathering abilities goes, the Association reports servicing around 500 children with visual impairments, of which 127 receive a cash benefit (95% to 100% blind). The Association, like HandiKOS above, functions with a mix of association fees, donor funds and government tender for services provided to persons with visual impairments.
Highlight on Ashkali and Roma children with disabilities

In the Ashkali group, the only services that they children get are from Ideas for Partnership NGO who provides some medication and some physical therapy. They are not aware of the services that HandiKOS can provide apart from two parents who reported that they received support from HandiKOS in the form of a special wheelchair and physical therapy for a short time. Except for the community learning centres support provided to Roma children, none of the children with disabilities receive any services, or know how to access services from an NGO.

Nothing About Us Without Us

The section below includes CRPD’s Right to Participation in Political and Public Life-Article 29 - and the Right to Participation in Cultural Life, Recreation, Leisure and Sport-Article 30.

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake:
(a) To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, (…) (b) To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including: (i) Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties; (ii) Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels. - CRPD Article 29

States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities: (a) Enjoy access to cultural materials in accessible formats; (b) Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats; (c) Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance. (…) enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.
(…) take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and
deaf culture. With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures: (a) To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels; (b) To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources; (c) To ensure that persons with disabilities have access to sporting, recreational and tourism venues; (d) To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system; (e) To ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities. – CRPD Article 30

In 2013, a UNICEF report on the life of children with disabilities, indicated that “DPOs tend to focus almost exclusively on the needs of their own members often to the point of criticising their fellow associations. After 20 years of governmental and international support one would have hoped that the DPO community would have been further developed. In practice, they appear not to collaborate and few are willing co-workers with government. But the DPO community is now confronting a new reality, the focus of funders is shifting to new lands, money is drying up, new DPOs are competing for the scare resources that are on the table. There is a real need for a visioning and repositioning exercise with the DPO community. The DPOs need to change their mind set. It should be of little surprise that the problems of lack of transparency, the need for democratization and decentralization, problems well known in the able-bodied community in Kosovo, should also affect the DPO community”157. However, the disability community in Kosovo is organizing and committing to work in partnership. In December 2016 nine DPOs (seven of which are members of the national Council for the Rights of Persons with Disabilities) signed the Declaration on Empowering the Forum158, “unifying the disability movement in Kosovo”. The aim of the Declaration is to reaffirm their commitment to improving “coordination of their work in a way which will enable them to become more representative and more effective in promoting persons with disabilities social and human rights and equal opportunities”.

According to the PERSON Kosovo Country Report on Legal Capacity159, “although civil society organizations (CSOs) established by people with disabilities and their family members exist in Kosovo, their approach towards the disability rights issues remains fragmented and is highly influenced by the narrow interests of certain disability communities, which these organizations represent. Furthermore, due to the lack of services for people with disabilities, most of the existing CSOs have been overwhelmed with the need to provide services for the community, thus leaving them very few opportunities to act as advocates for their rights. The lack of a unified voice that comes from the community of people with disabilities and their families makes this community vulnerable when it comes to advancing their interests in the policies, laws and services, for which the final beneficiaries are people with disabilities”.

As mentioned in two separate FDGs, stakeholders from various sectors do not usually have an opportunity to discuss, together, items of common interest. The FDGs
conducted for this study were often used for participants to exchange ideas and learn about each other’s work. Municipal representatives to the FDGs were often surprised by the engagement of DPOs and NGOs within the life of children with disabilities, while DPOs and NGOs saw the FDGs as opportunities to make their voices heard by government officials.

Participation in social life is extremely restricted for children with disabilities in Kosovo. While infrastructure certainly restricts their movements at home, school, in their communities and in accessing public institutions, societal attitudes seem to be a much bigger barrier. As seen above, discriminatory attitudes and bullying are predominant in school settings. If we take into consideration that much of a child’s like is spent in school, it is no wonder that children with disabilities and their parents report school life as very difficult.

When asked about the extent of their social and cultural life, children with disabilities who participated in FDGs had different answers. Two (2) boys mentioned that they don’t participate in any event outside of their family: “I do not go out….. I stay at home)... I do not join my family when they go out” (15 years old boy); “I do not go walking…. I stay at home with my brother” (7 years old boy). Others responded positively, indicating that they go out with family and friends and participate in community activities: “I go to the palace of culture to watch events... and I go to family parties” (11 years old girl). As observed by HandiKOS staff and some parents, children with more severe and visible disabilities (intellectual/ physical/sensory), do not seem to be involved in community activities or any cultural life apart from their families, close cousins or siblings, or only few friend from their neighbourhood. They do not feel safe to get separated from their mothers, or go far from their homes and their school area. Some of them are not very communicative at all, are shy and cannot express themselves without their mother’s support.

As reported by 59 parents who participated in FDGs, and confirmed by many of the children themselves, more than half of children are at least partially dependent upon a parent/caregiver to complete some basic life activities (feeding, hygiene, dressing, going to school, etc.). Eleven (11) out of 43 are completely dependent, while only 2 were reportedly able to live independently. Out of 43 respondents, 31 were mother, all of whom reported being the primary care givers of the child.

All 59 parents reported that their children spend most of their time with their most immediate families (in urban areas) such as mother/father, and siblings, although families in rural areas reported that their children also spend time with extended family members (aunts/uncles, cousins, grandmothers, etc.). Children in rural areas were also reported to have a wider circle of participation than children in urban areas, as neighbours and family members seem to be more understanding of their disabilities. When they are not in school, children spend time at home, watching TV, reading, listening to music, and playing with siblings. In all (59), 6 parents in 5 locations reported that their children have no friends, but only 3 reported that their child is confined to the house and rarely ever go out.

Out of the 62 children with disabilities who participated in FDGs, nine (9) reported having no friends, while most children reported that their friends are members of
their immediate family, such as siblings or cousins. Children with severe disabilities who attend school, only have friends from school, and almost all children reported having play time only at home. A 15 years old girl who had to drop out of school said: “I became sad, emotional when I see the school….. I am bored at home... I am used with activities (at school). I have no friends, I spend time only with my family at home....leaving the school made me feel sad.... I am separated from my girlfriends”. Two children, 8 years and 14 years old, who are blind, reported having no close friends and both reported feeling not fully accepted by other peers at school, while another girl in Prizren, who is deaf, reported that she has a lot of friends, but most of them belong to the deaf community. Another girl, also deaf and attending the same special school reported that she has a lot of friends among deaf people, but she does not have friends who are not deaf. She considers that social network is very important source for keeping people who are deaf linked to other people, and she is eager to get to know other people who are not deaf.

Unlike what is true for persons who are blind and persons who are para/tetraplegic, there is no law that regulates the identification of persons who are deaf or hard of hearing, and there is no legislation regulating service provision, other than Sign Language. Since 2013, Kosovo has had a National Programme on the Provision of Services for Sign language for Deaf Persons in the Republic of Kosovo (2013-2016), aiming to “create an inclusive society who will increase the participation of the deaf community in all areas of life in the Republic of Kosovo”. The national programme outlines both the provision of services in sign language (interpretation) and education in sign language (see education section above), and includes provisions for the institutional preparations related to providing services in sign language, access to education for deaf persons, training programmes, and awareness campaigns.

Throughout the 7 FDGs with parents/caregivers, there were multiple reports of instances of stigma, discrimination and bullying by both other children and adults, some of which, the children’s own teachers and attending physicians. In Gjakova one mother reported “It was difficult at school... my son was teased at school and he used to cry .. his teacher would keep him separated from other pupils in the class, not let him sit with others…. He was even beaten by the teacher for not being disciplined in the class” (mother, Gjakova). In Ferizaj two (2) parents reported their child mocked and ridiculed at school and “do not want to go anymore”, while another reported that “at school other children push him away, do not want to sit with him and call him stupid”, what made the child very unhappy and sad. A mother commented: “the school in the city has rejected my son, they did not want to accept him…. it was a catastrophe ... they said they did not want a sick child... parents and teachers rebelled... they did not allow him to enrol in the school”.

In Mitrovica North, parents mentioned several cases when their children were mocked, bullied, sometimes ridiculed, and even bitten by other children either at school or outside the school, in parks and other public places. This usually happens behind the back of the parents: “Look at her she walks like a grandmother” (mother of a girl with physical impairment). “Other children try to beat my son either at school or when we go out or to the park, because of his “strange behaviour”. There is no empathy from others for my son. Do i have to write it on his forehead that he is a “disabled
"child?" (mother, Mitrovica North). “My brother in law suggested to me several times that I get rid of my son by sending him to the orphans’ house. What can I say more” (mother, Mitrovica North).

In Mitrovica North, parents of children with disabilities spoke freely about their own needs for psychological support and counselling. Mothers, who are often the parent that spends the most time with their children, feel overburdened. As documented in broad literature\(^\text{162}\), parents often hesitate to go in public with their children, partly because of the bad infrastructure, and partly because they are embarrassed to be seen with their child, and have very restricted social groups. However, mothers seem to be the most devoted family member, and committed to addressing as much as possible of the needs of children, including health, education, socializing and participating in cultural events when they are available. As widely documented elsewhere, having a child with a disability often places an added stress on a marriage, causing parents to quarrel. Two of the caregivers in the FGD confirmed that they were divorced, partially because of the strain placed on their marital relationships, and are now single mothers who are taking care of their children with disabilities alone and under very difficult circumstances.

Many of the children with disabilities who attended FDGs reported instances of mocking and bullying. While one girl said that other children tease her at school - “Girls in the class tease me…. They stop me doing my class work…”, others said that nobody teases them at school and their pupils in the class are helpful with them. In Ferizaj, some children with visible disabilities have become object for bulling, mocking and teasing by other class mates and one child reported his wish to drop out from school because of the behaviour of other children and class mates. In Prishtina, reports are mixed. Two children reported that they feel they are very well accepted and also helped at school: “Friends are really careful, very kind with me and they take care of me” (boy, 12 years old); and, “, “Friends in the class are good with me…. they help me…. they help me carry the bag and also with schoolwork” (boy, 10 years old). However, some negative reports were also given: a girl reported that she is bullied in a verbal or non-verbal ways by her class colleagues: “they got my notebooks and throw them down”, while another girl reported “Well you get used to being made fun of…. once you get used to it than you handle it, those who don’t get used to it then they hardly handle it”.

In Prizren, two children mentioned that they are teased at school, and one girl sits alone on her school desk. HandiKOS staff reported that “There are cases of physical violence… also psychological violence... for example children (deaf) are not allowed to go out by their parents... they bring them to school but when they see that we use sign language they withdraw their children from the school because the parents do not want their child to use sign language…” A 10 years old girl reported: “There are children that make fun of you... they tell me I walk like a granny... these are grown up children.” A young caregiver (sibling) commented on children picking on her sister: “They hit her, push her... pull her hair... I have seen it and told them if I see you pushing my sister I will tell the pedagogue”. One of the girls attending an FDG reported on how other school friends behave toward her: “I have some problem with my friends... they exclude me on some things... for example I see they are talking about something and I go to them and I ask them what are you talking about and they say nothing…”.
Kosovo is a member of Special Olympics and since 2007 established as Special Olympics Kosova. The organization has approximately 200 athletes from various sports, and various municipalities in Kosovo, with children as young as 5 years old. For the last 3 years SO Kosova has started organizing inclusive activities where children with and children without disabilities play together, 1 day per week, 1 to 2 hours per session. According to the programme director, inclusive activities are extremely important because they help to increase the confidence of children with disabilities and change the negative perceptions of children without disabilities regarding their peers with disabilities.

**Highlight on Ashkali and Roma children with disabilities**

In both Ashkali and Roma communities it is reported that children spend most of their time at home, either with their siblings or parents and are sometimes left all alone. They reported no sporting activity or entertainment. Roma children report that they watch TV and are happy to attend the learning centre in their community where they spend time with other Roma children. Children with disabilities in Ashkali community are mainly isolated, even within their wider families. They don’t attend events in the family as reported: “*They are not welcomed in wider family ceremonies and events that is why we keep them at home*”. There are even reported cases when children are openly made fun of and ridiculed. A mother on the reactions of their community: “*They spill at him... they say things to him.... I take him inside the home.... what else can you do.*” Within the Roma group, most of children don’t have close friends. They are often kept isolated within their Roma community. Sometimes they are ridiculed and beaten by other children. “*Other children do not play with her not even Roma children.... they beat her and she becomes e aggressive and then she starts hitting other children....* (grandmother).

“*There is so much injustice inflicted on us.... for centuries till we remain completely marginalised, forgotten or bypassed. Nobody likes us ...We hardly survive, but I do not give up, as I have to take care of my deaf son and his children. Me and my husband every day travel from one place to other and check the garbage containers where we get most of clothes or other things for living and I am not ashamed for this*” (A grandmother, on the situation of Roma children).
for every child, care
IV.
KEY FINDINGS AND RECOMMENDATIONS

Taking into consideration the above findings, the recommendations from this Situation Analysis assume that children with disabilities are children first, the future of Kosovo, worthy of dignity and respect in the entire territory.

Defining and Quantifying children with disabilities in Kosovo

Finding: The number of persons with disabilities in Kosovo is unknown. While data has been gathered in the last few years, both in the Census and through administrative means, there is no accurate number that can support data-driven decision-making. The identification of persons with disabilities follows the medical model (by impairment), does not focus on children, and is almost always used to provide a cash benefit.

REC 1 – It is imperative that children with disabilities, become a visible part of Kosovo’s agenda for development. To ensure proper identification of children with disabilities in Kosovo it is recommended that the definition of disability included in the CRPD be included in all central and local level legislation that is directly related to children and persons with disabilities (particularly in social welfare, education, health and employment sectors), and enforced as the “working definition” used by all line-ministries and municipal institutions when determining eligibility of disability.

Responsible institution/organization: Parliament and respective line ministers.

REC 2 - Advocate with National Council of Statistics for the inclusion of a nationally representative household survey and/or census that can collect data related to child disability prevalence, starting at age 0, on a consistent basis (every 5 years) in order to: 1) gather longitudinal data regarding child disability in Kosovo; 2) gather data on functional limitations in Kosovo that can better assist local authorities to provide services to children with disabilities and their families. If a nationally representative household survey and/or census is not possible in the short-term, consider holding a Multiple Indicator Cluster Survey (MICS) with a module on child functioning in 2019

Responsible institution/organization: Parliament, National Council of Statistics, line ministries, international donors, Kosovo Agency of Statistics (KAS)

REC 3 - Consider creating a central database on children with disabilities, that can identify children with disabilities by their birth registration number and ensure that all
line ministries and municipal institutions have access to and responsibility towards the reliable and accurate data-entry to ensure that, up-to-date information for decision-making is available.

Responsible institution/organization: KAS and line ministries

Identification, assessment and determination of eligibility

Finding: The identification, assessment and determination of eligibility of disability is medical in nature, and based on a medical opinion regarding an impairment rather than a holistic assessment. Children with disabilities are often only identified when they reach school age, at which time intervention is already too late to have a lasting impact on their development. Further, the existing practices do not lead to individualized plans that are responsive to each child’s impairment and environmental barriers, and do not address the need for integrated, continuous services for the child and the family, to support proper development and life-long goals.

REC 4 - To ensure harmonization, methodology, criteria, and tools needed to determine eligibility for services and benefits, according to the bio-psycho-social model of disability enshrined in the CRPD should be developed across central and local authorities. This is essential in ensuring that the rights of all children with disabilities are equally recognized and fulfilled regardless of their place of the assessment team initiating the process.

Responsible institution/organization: Parliament and OGG

REC 5 - Child identification, assessment and eligibility should be considered an integrated, holistic, and multidisciplinary approach, conducted by a mobile team of expert professionals, with case-management lead from MEST, with close cooperation with MoH, MLSW, CSWs, but as early in the child’s life as possible. The teams should be trained on ICF-CY parameters, and take into consideration all three aspects of the bio-psycho-social model of disability when making eligibility determinations, ensuring re-evaluations are required on an as-needed basis, as per team determinations (fit-for-purpose) for each case.

Responsible institution/organization: OGG, MEST, MoH and MLSW and CSW

REC 6 - Change permanent disability criteria to ensure support is provided to all children who need it, regardless of Intelligence Quotient (IQ) or impairment. A multidisciplinary approach is necessary, starting as early as possible (school age is too late) with close collaboration with Early Identification/Early Intervention (EI/EI) methodologies (see below). Concurrently, revise cash benefit provisions to ensure that cash is provided to children with disabilities based on actual need, and not provided to families as a poverty-alleviation mechanism. Consider creating a system that utilizes existing financial resources to provide needed services, and that fewer cash benefits are used to cover for specialized services that do not generally exist in all communities (i.e. voucher system).

Responsible institution/organization: OGG, MEST, MoH, MLSW, MoF
Legislation, Coordination and Monitoring

Finding: Existing legislation, while being revised and amended, is not cohesive and encompassing of all aspects (bio-psycho-social) of the life of children with disabilities. Existing legislation is not implemented at local levels, budgets for implementation do not exist or are small, and existing mechanisms for enforcing implementation are not fully functioning.

REC 7 - Upholding the rights of persons with disabilities is a question of political will and needs an approach much like that was taken towards gender issues and minority issues. Therefore, it is recommended that an effort is undertaken to engage with Parliament (all 14 Parliamentary Committees) and the highest level of the Prime Minister’s Office on issues related to the rights of persons with disabilities, as outlined in the CRPD, particularly the social norms and attitudes that affect the identification and service provision to children with disabilities.

Responsible institution/organization: Parliament and government (Office of Prime Minister), EU, UNICEF, Ombudsperson Institution, DPOs and CSOs

REC 8 - Build commitment and capacity on disability according to the social model. Invest on developing the capacity (and political will) of the Gender, Human Rights and Missing Persons Parliamentary Committee to ensure that all sectors are disability inclusive and all decision-making is responsive to the voices of children with disabilities.

Responsible institution/organization: Parliament and government, EU, UNICEF, Ombudsperson Institution, DPOs and CSOs

REC 9 - Under the leadership of the Gender, Human Rights and Missing Persons Parliamentary Committee, support all 14 Parliamentary Committees in guiding line ministries to develop clear reporting mechanisms, assignments, roles and responsibilities, to ensure coverage of all necessary services to children with disabilities by the most appropriate line ministry, including the allocation of adequate financial resources to implement legislation (starting with an earmarked budget to service provision to children, including children with disabilities). Require regular reports from line ministries, the Office for Good Governance, as well as the Kosovo Disability Forum, and the National Council on the Rights of Persons with Disabilities on their activities related to inclusive and effective service provision for children with, including budgets.

Responsible institution/organization: Parliament, OGG, line ministries, KDF, EU, UNICEF

REC 10 - Re-examine and analyse relevant legislation through the lens of the social model of disability. Revise, as needed, all pieces of the legislative framework to ensure that laws, subsequent amendment(s), and associated administrative instructions are aligned with, and respectful of, Kosovo’s explicit and implicit international commitments.

Responsible institution/organization: line ministries
REC 11 - The international community should insist on the implementation of existing legislation that is aligned with the CRPD, and the design/implementation/monitoring of quality services as conditions for cooperation and financial support with central and local level government. All UN system agencies, the EU Delegation, and international donors should advocate for better coordinated actions by being more strategic in their spending (human and financing resources), and investing in the education of decision-makers, starting with trainings on the bio-psycho-social model of disability.

Responsible institution/organization: international organizations

REC 12 - Engage in a mapping of existing services for children with disabilities and their families and identify pockets of good-practice, and needs. Include all current and planned projects by UN organizations and others. Ensure coordinated efforts are happening at the ground level and connect-the-dots between all stakeholders. Advocate with the responsible institutions to support the development of multi-disciplinary teams of experts (permanent and mobile) that can support parents and families of children with disabilities across all aspects of life, including: social assistance, rehabilitation, inclusion into regular schools, accessing disability-inclusive health services, and securing assistive technology devices. Existing good practices at the local level, many of which are based on the “human factor” should be identified, properly documented and analysed for replication and sustainable use.

Responsible institution/organization: OGG, KDF and line ministries

Cross-cutting rights and obligations

Finding: Implementation of legislation and service provision is obstructed by a lack of commitment, human and financial resources and a continued lack of understanding of disability from the social perspective by professionals. Despite the existing anti-discrimination law, children with disabilities are discriminated against daily, in particular, children that suffer from multiple disadvantage factors. Disability is still understood as a medical condition, and not a human rights issue, and professionals are not trained to mainstream disability in their own daily practices. In addition, the professional role of social workers is not clearly defined, nor fully supported.

REC 13 - Establish a monitoring system within each line ministry and across ministries to track the development and enforcement of strict anti-discriminatory policies that ensure the rights of all children in all arenas of life, in particular children from the most disadvantaged groups, and children at risk of discrimination due to multiple disadvantages (i.e. girls with disabilities, children with delays or disabilities from remote rural areas, children with delays or disabilities from the Roma, Ashkali and Egyptian communities).

Responsible institution/organization: OGG and line ministries.

REC 14 - Despite decentralization, mechanisms such as the creation of a budget code and specific grant for social services, should be in place to enforce legislation at municipal level and provide additional financial resources to those municipalities that present
higher levels of efficient and effective service provision to children with disabilities, as measured by the number of children from vulnerable populations (children with disabilities including children from Roma, Ashkali and Egyptian communities) fully included and participating with majority children.

Responsible institution/organization: Parliament, line ministries, municipalities and Association of Municipalities

REC 15 - Provide basic training on disability mainstreaming to all Human Rights teams/officers at the municipal level. Emphasize the need and advantages of a multi-sectoral approach to activities related to disability and social inclusion with lead from Human Rights teams/officers, and ensure the best models for working directly with families and children with disabilities are in place.

Responsible institution/organization: Office of Good Governance, Ministry of Local Administration, municipalities and Association of Kosovo Municipalities

REC 16 - Increase the capacity of responsible professionals within each line ministry regarding accessibility and Universal Design. Ensure some professionals within each relevant line ministry have a broad understanding of reasonable accommodation vs. individualized accommodations, and financial and human resources are available to implement and monitor cost-effective Universal Design (UD), Assistive Technology (AT) and Information and Communication Technology (ICT) solutions that are costly to add after-the-fact.

Responsible institution/organization: Ministry of Infrastructure, Ministry of Finance, OGG, international organizations, local and international DPO's-CSO's.

REC 17 - Engage in Knowledge, Attitudes and Practices (KAP) research focused on professionals and service providers (as opposed to general population, children with disabilities themselves or their families – this information already exists). Focusing your attention on this sub-set of the population could provide stakeholders with an important baseline regarding professionals, vis-à-vis different categories of children with disabilities and their families. This information, collected based on a rigorous research methodology and properly documented, can lead to focused advocacy and tailored needs – based capacity-building of professionals.

Responsible institution/organization: OGG, KAS, local and international organizations

REC 18 - Improve inter-sectoral coordination by clearly defining the coordination mandate of municipal CSWs, and strengthen their capacity through the provision of adequate human and financial resources. Create mechanisms for reporting coordinated actions leading to the identification, assessment and service eligibility of children in vulnerable situations (both temporary and long-term), especially children at risk of delay or disability, poverty, violence or exploitation, or abandonment, and from the Roma, Ashkali and Egyptian communities.

Responsible institution/organization: MLSW, MoH and MEST, OOG

REC 19 - Expand the role, capacities and responsibilities of social workers for case management to ensure they reach all children, including children with disabilities,
everywhere in the country, including children from the Roma, Ashkali and Egyptian communities. Social workers should be provided with the resources to engage in outreach activities leading to service provision to children with disabilities within their own families, including the ability to coordinate the provision of adequate fora and spaces for all children to express themselves.


REC 20 - Support all responsible Ministries to introduce licensing of services and to create a mechanism of monitoring and evaluation of services; ensure the continuity of services, leading to a ranking system that can provide children with disabilities and their families with the information necessary for quality-driven decision-making;

Responsible institution/organization: all line ministries and international donors

Right to Child Protection

Finding: Kosovo does not have a Child Protection Law and the existing laws that provide protection do not clearly include children. Thus, prevention, response and monitoring of abuse and neglect are not made explicit or enforced. Children with disabilities are at a high risk of being abused and/or neglected and most children and families do not know their rights under the law, how to protect themselves, or how/to whom to report instances of abuse or neglect. Further, the existing protection mechanisms do not explicitly include children with disabilities. Children with disabilities from the Roma, Ashkali and Egyptian communities are at exceedingly high risk of vulnerability.

REC 21 - Ensure laws and policies reflect the spirit of the CRPD and that mechanisms exist to prevent, monitor and respond to abuse/neglect of children with disabilities at all levels and by all stakeholders; complete the process of development of the Child Protection Law by engaging in broad consultations with all stakeholders, particularly children and youth, who will be the main recipients of the provisions included in the law.

Responsible institution/organization: MLSW, OOG, PMLO (PM's legal office), UNICEF, KOMF, Ombudsperson Institution

REC 22 - Provide adequate financial and human resources to the Office of Good Governance (as Secretariat of the National Council for the Rights of Persons with Disabilities) and the Ombudsperson Institution, including capacity development opportunities related to the rights (and rights' violations) of children with disabilities and their families, with a special focus on children with disabilities from the Roma, Ashkali and Egyptian communities.

Responsible institution/organization: Parliament and international donors
REC 23 - Establish a system by which children with disabilities can report, anonymously, on instances of abuse/neglect, to ensure that children's reports are taken seriously and complaints are followed through.

Responsible institution/organization: MLSW

REC 24 - Continue and expand Violence Prevention activities and educate professionals and the general public on the right to protection of children with disabilities. Ensure all children and their families, particularly those in vulnerable or disadvantaged communities (i.e. Roma, Ashkali and Egyptian communities) are aware of their right to protection and of the ways in which they can claim their rights.

Responsible institution/organization: MLSW, OGG, DPO's - CSO's

**Right to Inclusive Education**

Finding: The concept of Inclusive Education (IE) is, in Kosovo, understood in its most restricted way: providing access to education to children with disabilities. There is no common understanding of IE and no agreement as to a way forward in developing inclusive practices. Early childhood development, school-readiness, pre-school and kindergarten are not included within the broad understanding of IE and are not taken into consideration when developing education plans. In-service teacher training has been provided by many NGOs over the years, without a cohesive plan of action, and has resulted in a fragmented understanding (and practices) of IE.

REC 25 - Initiate national dialogue to promote Inclusive Education that is respectful of the CRPD General Comment on Article 24: Ensure children with disabilities have access to early childhood development and school readiness opportunities, and initiate transition of children with disabilities from attached classes and resource centres to regular schools; investigate the potential usefulness of resource centres to support transition; clarify the role of general education teachers, special education teachers, teacher assistants and others within an inclusive education system in Kosovo.

Responsible institution/organization: MEST

REC 26 - The MEST should assume responsibility for the coordination of all activities related to teacher preparation (in-service and pre-service), school resourcing, and municipal support by stakeholders, to ensure a cohesive and coordinated approach to teacher preparation. A set of guidelines for donors, NGOs and DPOs should be prepared to ensure all financial and human resources provided to the education system fall within the standards set forth by the CRPD Article 24 (and General Comment # 4 on the Right to Inclusive Education);

Responsible institution/organization: MEST

REC 27 - Provide a forum for education officials (including early childhood development and pre-school professionals) and parents/families of children with disabilities to dialogue as to what an inclusive education system should entail. Whenever possible
dialogue should take place with parents and children with disabilities directly, as opposed to representatives; use existing structures such as School Boards, Teacher Council and Student Council to create school environments that are inclusive of all children, regardless of their individual characteristics.

Responsible institution/organization: MEST and international donors

**REC 28** - Carry out an assessment of capacities of all professionals (including early childhood development and pre-school professionals) who work, even in peripherally, with children with disabilities and provide an adequate set of recommendations for minimum standards, advocating for its immediate establishment\(^{164}\). This should include assessing the capacities of teacher preparation institutions (and support as needed) to provide pre- and in-service teachers preparation for inclusive education, in accordance with the standards set forth by the CRPD Article 24 (and General Comment \# 4 on the *Right to Inclusive Education*);

Responsible institution/organization: MEST

**REC 29** - Invest in the capacity development of early childhood development and pre-school professionals, teachers and other education professionals to work in, and help foster, an inclusive education system. All teachers must be adequately trained on child development and child-centred pedagogy and differentiated instruction that can support them to teach all students in a regular classroom. Teachers and education professionals must also be trained to identify the occasions when they require the support of other teachers or specialized professionals, and they must be compelled to utilise mechanisms for collaboration and cooperation among professionals.

Responsible institution/organization: MEST

**Right to Health and Rehabilitation**

**Finding:** The health care system in Kosovo does not mainstream disability throughout its plans of action. Screenings, early identification and intervention of children at risk of delay or disability, do not exist and the medical model of disability has been perpetuated by medical professionals. Prevention and risk analysis has not included children with disabilities and school health programmes, parent education and local interventions have been carried out by NGOs or with international donor funds.

**REC 30** - Create a health care system that is proactive instead of reactive. Invest in health promotion and health education, including parent education on child development and ensure that preventative and universal measures such as vaccination and screening for functional limitations are done to identify needs before they occur, and encourage outreach by family doctors and local community health centres. All health care professionals should have minimum knowledge regarding the International Classification of Functioning and the bio-psycho-social model of disability, leading to a greater understanding of their role within the scope of the multidisciplinary methodology of identification and assessment of disability.

Responsible institution/organization: MoH
**REC 31** - Encourage a collaborative working model that includes the World Health Organization (WHO), MoH and municipal level health professionals responsible for service provision to children with disabilities to ensure that local level responses are done according to international standards. The MoH should assume responsibility for the coordination of all activities related to health care, to ensure a cohesive and coordinated approach to service provision. A set of guidelines for donors, NGOs and DPOs should be prepared to ensure all financial and human resources provided to the health system fall within the standards set forth by the WHO, and take into consideration WHO’s Community Based Rehabilitation Guidelines for Persons with Disabilities.

Responsible institution/organization: WHO and MoH

**REC 32** - Create multidisciplinary teams that include community member who are knowledgeable about the communities in which they live (i.e. Roma mediators, Ashkali and Egyptian community leaders, persons with disabilities) and are able to communicate effectively and without prejudice with community members. Enforce existing legislation by providing training in Sign Language to employees in public office who can support adequate communication between the deaf community and health professionals.

Responsible institution/organization: MoH, local authorities and community leaders

**REC 33** - Accelerate the development of an early identification and early intervention (EI/EI) system that is respectful of the definition of disability according to the social model, is conducted by teams of multi-disciplinary professionals, and leads to service provision in inclusive settings. Extend and expand existing home visiting efforts to the Roma, Ashkali and Egyptian communities, and school health programmes to screen school-age children for potential functional limitations in the domains of hearing, seeing, movement, communication, learning and behaviour/emotion throughout the life cycle using standardised protocols.

Responsible institution/organization: MoH, MLSW and MEST

**Finding:** The work related to disability has been largely carried out by small groups of disabled persons that have a common interest in a specific impairment. While there is a renewed effort to make disability all-inclusive in Kosovo, this effort does not always acknowledge that children are specific needs that cannot be addressed in legislation, policy and services developed for adults. Throughout, children with disabilities and their families have been largely absent from dialogue, and children with disabilities and their families are not informed of their rights, or what few services are available to them.

**REC 34** – Strengthen the capacity of NGOs and DPOs in general, and the Kosovo Disability Forum in particular, to speak on behalf of children with disabilities. While the Kosovo Disability Forum is constituted by 7 NGOs/DPOs who are very knowledgeable
and capable with regards to persons with specific impairments, it is imperative that the rights of children with disabilities be advocated for by an organization that speaks on behalf of children with only one voice. Because children have needs and strengths that are specific to their age and level of development, the Kosovo Disability Forum should be provided with opportunities to develop their capacity related to child rights, including by engaging in consultations with children with and without disabilities on issues that relate to them (and of their choosing).

Responsible institution/organization: EU and UNICEF, KDF

**REC 34** - Increase the capacity of children with disabilities and their families, and empower them to demand their rights through public discussions and dialogue with authorities. Special attention should be given to engagement with children and their families in the Roma, Ashkali and Egyptian communities, Condition all disability-related activities funded (or partially funded) by the international community to include monitoring and evaluation activities to be led by children with disabilities and their families, in collaboration with DPOs who can represent them.

Responsible institution/organization: OGG and KDF, DPO's

**REC 35** - Support DPOs/NGOs in providing awareness and education with regards to children's rights to the population in general, and 1st line professionals, in particular; support DPOs in acquiring the skills and knowledge necessary to engage in mixed-methods, participatory research and M&E activities, thus contributing to the Kosovar research community. Ensure that DPOs/NGOs create an information network that can provide information, referral and support to all children with disabilities and their families

Responsible institution/organization: OGG, KDF and international donors

**REC 36** – Ensure that children with disabilities are included in all humanitarian response Plans of Action, such as Disaster Risk Reduction.

Responsible institution/organization: OGG, line ministries
for every child, a childhood
### Annex 1 – List of KIIs

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution</th>
<th>Position of Person within the Organisation</th>
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<tbody>
<tr>
<td>Dr. Brandão Có, MD, MPH</td>
<td>UNICEF</td>
<td>Country Representative</td>
</tr>
<tr>
<td>James Mugaju</td>
<td>UNICEF</td>
<td>Deputy Representative</td>
</tr>
<tr>
<td>Afrim Ibrahimi,</td>
<td>UNICEF</td>
<td>Child Protection Officer</td>
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<tr>
<td>Feride Dashi</td>
<td>UNICEF</td>
<td>Child Protection Officer</td>
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<tr>
<td>Kozeta Imami</td>
<td>UNICEF</td>
<td>Education Officer</td>
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<tr>
<td>Agron Gashi</td>
<td>UNICEF</td>
<td>Health &amp; Nutrition Officer</td>
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<tr>
<td>Dren Rexha</td>
<td>UNICEF</td>
<td>Social Protection Specialist</td>
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<tr>
<td>Arjeta Gjikolli</td>
<td>UNICEF</td>
<td>Data &amp; Management Officer</td>
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<tr>
<td>Sergio Tomsa</td>
<td>UNICEF</td>
<td>Communication and Information Specialist</td>
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<tr>
<td>Florije Kryeziu</td>
<td>UNICEF</td>
<td>Social Protection Officer</td>
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<tr>
<td>Jeton Siqeca</td>
<td>UNICEF</td>
<td>Innovation Lab Officer</td>
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<tr>
<td>Habit Hajredini</td>
<td>OGG</td>
<td>Head of OGG</td>
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<tr>
<td>Amrnda Berani</td>
<td>OGG</td>
<td>Senior Officer for Persons with disabilities</td>
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<tr>
<td>Lulave Behluli</td>
<td>MEST</td>
<td>Director of Special Education Needs Department</td>
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<tr>
<td>Fadile Dyla</td>
<td>MEST</td>
<td>Director of Department for Infrastructure and School Building</td>
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<tr>
<td>Enver Mekolli</td>
<td>MEST</td>
<td>EMIS officer</td>
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<tr>
<td>Gazmend Tahiraj</td>
<td>KAPIE</td>
<td>Project Coordinator</td>
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<tr>
<td>Merita Vuthaj</td>
<td>MoH</td>
<td>Director of Mother &amp; Child Protection Department</td>
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<tr>
<td>Muse Shigjeqi</td>
<td>MoH</td>
<td>Official for the rights of persons with disabilities</td>
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<tr>
<td>Albana Morina</td>
<td>Family Medicine Centre</td>
<td>Acting head of Primary Health Care</td>
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<tr>
<td>Ibush Fazliu</td>
<td>MLSW</td>
<td>MLSW Assessment (Health) Commission</td>
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<tr>
<td>Qazim Gashi</td>
<td>MLSW</td>
<td>Chief of the Disability and Elderly People Division</td>
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<tr>
<td>Salvador Elmazi Hysnije Maliqi</td>
<td>Ministry of Finance</td>
<td>Head of Budget Planning Department Budget analyst</td>
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<tr>
<td>Xheladin Hoxha</td>
<td>Kosovo Assembly</td>
<td>Director of Directorate for Legislation Standardization, Approximation and Harmonization</td>
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<td>Fehmi Hyseni,</td>
<td>Kosovo Assembly</td>
<td>Director of Directorate for Parliamentary Commissions Support</td>
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<td>Vebi Mujku</td>
<td>Centre for Social Work (Pristina)</td>
<td>Director</td>
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<tr>
<td>Sazan Ibrahimi</td>
<td>Association of Municipalities</td>
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<tr>
<td>Donjeta Kelmendi</td>
<td>KOMF</td>
<td>Executive Director</td>
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<tr>
<td>Bujar Kadriu</td>
<td>Forum of DPOs in Kosovo</td>
<td>Forum President</td>
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<tr>
<td>Alketa Lasku</td>
<td>Terre des Hommes</td>
<td>Deputy Country Representative</td>
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<td>Afrim Maliqi</td>
<td>HandiKOS</td>
<td>Director</td>
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<tr>
<td>Ahmet Kryeziu</td>
<td>Save the Children</td>
<td>Director</td>
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<td>Sami Uka</td>
<td>WHO</td>
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<tr>
<td>Ilir Begolli</td>
<td>National Institute of Public Health</td>
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<td>Flora Kelmendi</td>
<td>World Bank</td>
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<td>Edis Agani</td>
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<td>Visar Bivolaku</td>
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<td>Hilmi Jashari</td>
<td>Ombudsperson</td>
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<tr>
<td>Igballe Rahmani</td>
<td>Child rights Legal Officer</td>
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<td>Ivana Milosavljevic</td>
<td>Mitrovica North</td>
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<td>Ibadete Krasniqi</td>
<td>Amici de Bambini Kosovo</td>
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<tr>
<td>Gani Lluga</td>
<td>ASTRA Child rights research Agency</td>
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<td>Ramadan Gashi</td>
<td>Free Legal Aid Agency</td>
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<tr>
<td>Igballe Potera</td>
<td>Resource Centre “Përparimi” Prishtinë</td>
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<tr>
<td>Drita Cenaj</td>
<td>Primary school “Ismail Qemaili” Prishtinë</td>
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<tr>
<td>Arben Vitia</td>
<td>Municipality of Prishtina (Collegia for Health and Social Welfare)</td>
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<td>Rozafa Ukimeraj-Çuni</td>
<td>Ministry of Local Governance and Administration</td>
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<td>Liridona Preniqi</td>
<td>Municipality of Prishtina</td>
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<tr>
<td>Rukije Gashi</td>
<td>Kosovo Deaf Association</td>
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<td>Nebi Cakaj</td>
<td>Kosovo Deaf Association</td>
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<td>Andrew Russell, Nora Sahatciu</td>
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<td>Oliver Mains, Mimoza Jupa</td>
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<td>Matteo Corradini</td>
<td>Italian Embassy</td>
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<tr>
<td>Sebahate Beqiri</td>
<td>Down Syndrome DPO</td>
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<tr>
<td>Brigitte Koller, Rezarta Jashari</td>
<td>GIZ</td>
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<td>Drita Dushi</td>
<td>Special Olympic Athletes</td>
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<tr>
<td>Mimoza Shahini</td>
<td>University Clinical Centre of Kosovo</td>
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<td>Hilary Adams</td>
<td>HandiKOS</td>
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<tr>
<td>Ariana Shala</td>
<td>SOS</td>
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</table>

**Director of Department for Social Medicine**

**Senior Operations Officer on World Bank's Education improvement**

**Task Manager at EU Office Pristina Social Unit**

**Task Manager at EUSR Pristina Office**

**Ombudsperson**

**Ombudsman Institution**

**PO UNICEF**

**Executive Director**

**Director**

**Director**

**Director**

**Head of Collegia of Kosovo Association for Health and Social Welfare**

**Permanent Secretary**

**Head of Municipal (pedagogical) Evaluation Commission (Prishtina),**

**Executive Director**

**President of Kosvo Deaf Association**

**UN Development Coordinator UNKT Coordinator**

**Political Officer Human Rights Advisor**

**Deputy of Mission**

**Executive Director of Down Syndrome DPO**

**National Project Officer Social rights for vulnerable groups**

**Executive director**

**Head of Child Psychiatric Department**

**Consultant**

**SOS representative (Child protection)**
Annex 2 – Schedule and location of FDGs

In total 27 FDGs were conducted in 7 Locations:
1. Ferizaj
2. Gjakova
3. Prizren
4. Mitrovica North
5. Prishtina
6. Fushë Kosova (Roma Mahalla)
7. Graçanica (Roma Mahalla)

In Ferizaj, Gjakova, Prizren, four (4) Focus Group Discussions were held: one (1) with children with disabilities, one (1) with children without disabilities, one (1) with the parent/caregiver of children with disabilities, and one (1) with service providers to children with disabilities.

In Prishtina, six (6) Focus Group Discussions were held: two (2) with children with disabilities, one (1) with children without disabilities, one (1) with the parent/caregiver of children with disabilities, and two (2) with service providers to children with disabilities.

Mitrovica North, four (4) Focus Group Discussions were held: one (1) with children with disabilities, one (1) with children without disabilities, one (1) with the parent/caregiver of children with disabilities, and one (1) with service providers to children with disabilities.

In Fushë Kosova and Graçanica, two (2) Focus Group Discussions were held: one (1) with children without disabilities, one (1) with the parent/caregiver of children with disabilities.

In total, across all FDGs, the following is the total number of participants, by type:

62 children with disabilities
52 children without disabilities
59 parents/caregivers of children with disabilities
58 service providers of children with disabilities

Children with Disabilities in FDGs:

In total 62 children (36 Females, 26 Males) with disabilities participated.

By age groups:
Less than 6 years old: 6 children
6-10 years old: 19 children
11-14 years old: 28 children
15-17 years old: 8 children
18 years old: 1 child
By ethnicity:
Albanian: 38 children
Serbian: 8 children
Roma and Ashkali: 16 children

By location:
Rural: 25 children
Urban: 37 children

Children without Disabilities in FDGs:

In total 52 children (36 Females, 16 Males) without disabilities participated.
By age groups:
Less than 6 years old: 0 children
6-10 years old: 10 children
11-14 years old: 34 children
15-17 years old: 7 children
18 years old: 1 child

By location:
Rural: 13 children
Urban: 39 children

Parents/Caregivers of Children with Disabilities in FDGs:

In total 59 parents/caregivers of children with disabilities participated
Mothers: 42
Fathers: 10
Other caregivers: 7

By location:
Rural: 20
Urban: 39

Service Providers in FDGs:

In total 58 service providers participated.
By service domain:
Education: 22
Health: 8
Child Protection: 8
NGO (DPO and others NGO): 16
Others (infrastructure, private sector etc): 4
Annex 3 –FDG Tools and methodology

Selection criteria for participants in the FGDs for SitAn on children with disabilities

1. Children with disabilities
For the benefit of a productive discussion please try to limit the size of a group to a maximum of 10. However, please do not exclude caregivers/parents of children with disabilities who have expressed willingness to participate in the discussion.
The composition of the group should be selected by age, gender, region, urban/rural area, type of disability - the most important criteria is to ensure the children DO NOT ALL attend the same school, NGO, sports group, etc.

2. Children without disabilities
For the benefit of a productive discussion the size of a group should be limited to a maximum of 10. However, please do not exclude children who have expressed willingness to participate in the discussion.
The composition of the group should be selected by age, gender, region, urban/rural area - the most important criteria is to ensure the children DO NOT ALL attend the same school, sports group, or other activity group etc.

3. Parents/Caregivers of children with disabilities
For the benefit of a productive discussion the size of a group should be limited to a maximum of 10. However, please do not exclude caregivers/parents of children with disabilities who have expressed willingness to participate in the discussion.
The composition of the group should be selected by age, gender, region, urban/rural area, etc.

4. Service providers to children with disabilities
For the benefit of a productive discussion the size of a group should be limited to a maximum of 10. However, please do not exclude caregivers/parents of children with disabilities who have expressed willingness to participate in the discussion.
The composition of the group should be selected by age, gender, region, urban/rural area, health institutions, education institutions, relevant local government institutions, DPOs, NGOs, CBR, foster care, social workers, psychologists, pedagogues, etc.)
The most important criteria is that the participants work directly with children with disabilities or their families. These need to be professionals that have a sense of how the system works, not just themselves (as individual people) but the ability of the system in which they work to respond to the needs of children with disabilities and their families.
1: Focus Group Discussion with Children with Disabilities

Guidelines for the FGD Coordinators

- For the benefit of a productive discussion please try to limit the size of a group to a maximum of 10. 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 name 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, but 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. However, do not engage any one child directly or force a response. Note 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.

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 and if they are involved 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. 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 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?** [Discussion should bring out the children's experience in the school/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 school/institute, and any other good or discriminating practices at the school/ institute that the children feel]

6. **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.]

7. **Could you please describe if you participate 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 participate more or less, etc.]

8. **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.]

9. **Could you please describe the last time you were scared or afraid and why?** [Discussion should bring out why they feel unsafe or scared, where they feel unsafe or scared most (at home, outside home, at the institute, at the health facility, in the community or social events, etc.).]

10. **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 more than children without disabilities, what they do when they feel sad, if anyone (caregiver, friend, community member, etc.) help in this regard, etc.]
11. How 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.*

12. 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.*

Secondary questions to be asked only if time allows it.

13. Have you ever participated in any decision-making process, writing of any law or policy on the rights of children with disabilities, at school or other institutions?  
   a. If yes: Can you give an example of how you contributed to this process?

14. Could you please describe whether you have received any assistance/information from an organization outside of your family or school?  
   • 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 of 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, DPO, 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.*
2: Focus Group Discussion with Children without Disabilities

Guidelines for the FGD Coordinators

- For the benefit of a productive discussion please try to limit the size of a group to a maximum of 10. However, please do not exclude children 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. Please record the name 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, etc.). Explain the questions if needed, but 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. However, do not engage any one child directly or force a response. Note those who do not respond.
- It is desirable that children participate in the FGD on their own. If holding the FGD in a school, kindly ask any adults to leave the room.

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 and if they are involved 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 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 you like it there?** [Discussion should bring out the children's experience in the 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 institute, and any other good or discriminating practices at the school/ institute that the children feel.]

6. **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.]

7. **Could you please describe if you participate in community activities with other children and adults?** (e.g. sports, games, 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.]

8. **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 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.]

9. **Could you please describe the last time you were scared or afraid and why?** [Discussion should bring out why they feel unsafe or scared, where they feel unsafe or scared most (at home, outside home, at the institute, at the health facility, in the community or social events, etc.)].

10. **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 more than children without disabilities, what they do when they feel sad, if anyone (caregiver, friend, community member, etc.) help in this regard, etc.]

11. **How 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.]
12. **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.]

Secondary questions to be asked only if time allows it.

13. **Have you ever participated in any decision-making process, writing of any law or policy on the rights of children with disabilities, at school or other institutions?**
   a. If yes: Can you give an example of how you contributed to this process?

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

   - 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 of 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, DPO, 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.]

3: **Focus Discussion Group with Caregivers of Children with Disabilities**

   - **For the benefit of a productive discussion please try to limit the size of a group to a maximum of 10. 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.

Disability-related 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. 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?

Daily routine and care questions

5. 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].

6. 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?

7. 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?

Social life questions

8. 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?

9. 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, neighbors, or community leaders pose obstacles to your child’s participation in community life? Could you please elaborate on your response?

Education questions

10. 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?
         1. If ‘yes’: why?
   b. 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?

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

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

Health questions

13. 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.]
14. 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?

15. 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 health facilities/ services?

Safety and security questions

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

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

Rights, dreams and aspirations

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

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

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

21. Do you think your child has more, less or the same rights as all other children? Why?

*******************************************************************************

Secondary questions to be asked only if time allows it

22. 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)?

23. 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?

24. 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.

25. 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?
      ii. If no: why not?
   c. If no: As anyone ever talked to you about the learning needs of your child?

26. 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]

27. How do your children get to school? Do your children face any difficulties in getting to school? Please describe.

28. In your views, are your children happy to attend this school? How do you know?

29. Do you feel satisfied with the services received from this facility/ practitioner in general? Please probe the following issues that generally determines satisfaction

30. How far do you need to travel to go there?

31. How is the condition of the infrastructure? (Please probe about availability of infrastructure friendly for people with disability)

32. Are the different types of services required for the children available in the facility? (e.g. general physician, pediatrician, physiotherapy, etc.)

33. What is the quality of medical treatment and counselling?
   a. Are you satisfied with the quality of medical treatment and counselling provided?

34. Do you get all medicines required/ prescribed by a doctor from there?

35. Can you do the medical/ laboratory test(s) there?

36. 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?

37. Do you have concerns regarding your children’s safety? What are those concerns? Please elaborate.

38. 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]

39. How much do you know about the Convention on the Rights of the Child, the Convention on the Rights of Persons with Disabilities or the local legal frameworks that ensure the rights of children with disabilities in Kosovo?

4: Focus Discussion Group with service providers to children with disabilities

- For the benefit of a productive discussion please try to limit the size of a group to a maximum of 10. 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.

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? If not they do 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.].
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?
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.]
   i. 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.]?
   i. 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 that 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?
   i. If ‘yes’, could you please describe such procedure?
   ii. 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?
## Annex 4 - List of Peer-reviewers and Validation Workshop Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Municipality</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Brandao Cô, MD, MPH</td>
<td>Pristina</td>
<td>Head of Office – UNICEF Kosovo</td>
</tr>
<tr>
<td>James Mugaju</td>
<td>Pristina</td>
<td>Deputy Head of Office – UNICEF Kosovo</td>
</tr>
<tr>
<td>Arta Haliti</td>
<td>Pristina</td>
<td>Consultant</td>
</tr>
<tr>
<td>Sami Uka</td>
<td>Pristina</td>
<td>NPO-WHO</td>
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<tr>
<td>Afrim Maliqi</td>
<td>Pristina</td>
<td>Director - HandiKOS</td>
</tr>
<tr>
<td>Durim Gashi</td>
<td>Pristina</td>
<td>Project Coordinator- HandiKOS</td>
</tr>
<tr>
<td>Ardian Klaqi</td>
<td>Pristina</td>
<td>Justice for Children UNICEF</td>
</tr>
<tr>
<td>Afrim Ibrahimii</td>
<td>Pristina</td>
<td>CP officer UNICEF</td>
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<tr>
<td>Ibadete Krasnici</td>
<td>Pristina</td>
<td>Director- OFAP</td>
</tr>
<tr>
<td>Burim Behluli</td>
<td>Pristina</td>
<td>Director for Project Development-SOS Children's Village</td>
</tr>
<tr>
<td>Lulavere Behluli</td>
<td>Pristina</td>
<td>MEST</td>
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<tr>
<td>Gazmend Tahiraj</td>
<td>Pristina</td>
<td>KAPIE</td>
</tr>
<tr>
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<td>Director- SOS Kopshti</td>
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<td>Member of Kosovo Parliament</td>
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<td>Liridona Preniqi</td>
<td>Pristina</td>
<td>DKA Officer</td>
</tr>
<tr>
<td>Qazim Gashi</td>
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<td>MLSW</td>
</tr>
<tr>
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</tr>
<tr>
<td>Imrane Ramadani</td>
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<tr>
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<td>Special Olympics Kosovo</td>
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<td>Mitrovica</td>
<td>UNICEF</td>
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<td>Timur Ramiqi</td>
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<td>UNICEF</td>
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<td>Sh.V.K</td>
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<td>Hajrie Xhemali</td>
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<td>Sh.V.K</td>
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<td>Feride Dashi</td>
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<td>Arijeta Sojeva</td>
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<td>Milena Ilievksa</td>
<td>Zvecan</td>
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<td>Nenad Radivojevic</td>
<td>Mitrovica</td>
<td>Caritas Kosovo</td>
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<td>Ermira Shabani</td>
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<tr>
<td>Paula Hunt</td>
<td>Portugal</td>
<td>International Consultant for UNICEF</td>
</tr>
<tr>
<td>Vjollca Caka Belegu</td>
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<td>Local consultant for UNICEF</td>
</tr>
<tr>
<td>Tamara Slavkovic</td>
<td>Mitrovica</td>
<td>UNICEF</td>
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## Annex 5 – Number of children with disabilities, per type of impairment, receiving education services in a Resource Centre

### Year 06/07
**Number of children/pupils as type of impairment**

<table>
<thead>
<tr>
<th>Type of impairment</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual</td>
<td>118</td>
<td>46</td>
<td>164</td>
</tr>
<tr>
<td>Hearing</td>
<td>65</td>
<td>33</td>
<td>98</td>
</tr>
<tr>
<td>Visual</td>
<td>36</td>
<td>33</td>
<td>69</td>
</tr>
<tr>
<td>Physical</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Multiple</td>
<td>44</td>
<td>43</td>
<td>87</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>264</td>
<td>156</td>
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</table>

### 2007/08
**Number of children/pupils as per type of impairment**

<table>
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<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual</td>
<td>78</td>
<td>36</td>
<td>114</td>
</tr>
<tr>
<td>Hearing</td>
<td>57</td>
<td>25</td>
<td>82</td>
</tr>
<tr>
<td>Visual</td>
<td>34</td>
<td>21</td>
<td>55</td>
</tr>
<tr>
<td>Physical</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Multiple</td>
<td>76</td>
<td>53</td>
<td>129</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>249</td>
<td>135</td>
<td>384</td>
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### 2008/09
**Number of children/pupils as per type of impairment**

<table>
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<tr>
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<th>Female</th>
<th>Total</th>
</tr>
</thead>
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<tr>
<td>Intellectual</td>
<td>89</td>
<td>36</td>
<td>125</td>
</tr>
<tr>
<td>Hearing</td>
<td>55</td>
<td>27</td>
<td>82</td>
</tr>
<tr>
<td>Visual</td>
<td>26</td>
<td>19</td>
<td>45</td>
</tr>
<tr>
<td>Physical</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Multiple</td>
<td>74</td>
<td>60</td>
<td>134</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>245</td>
<td>142</td>
<td>387</td>
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### 2009/10
Number of children/pupils as per type of impairment

<table>
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<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual</td>
<td>127</td>
<td>81</td>
<td>208</td>
</tr>
<tr>
<td>Hearing</td>
<td>59</td>
<td>29</td>
<td>88</td>
</tr>
<tr>
<td>Visual</td>
<td>25</td>
<td>15</td>
<td>40</td>
</tr>
<tr>
<td>Physical</td>
<td>5</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Multiple</td>
<td>52</td>
<td>24</td>
<td>76</td>
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<tr>
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<td>268</td>
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### 2010/11
Number of children/pupils as per type of impairment

<table>
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<th>Male</th>
<th>Female</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td>Intellectual</td>
<td>130</td>
<td>83</td>
<td>213</td>
</tr>
<tr>
<td>Hearing</td>
<td>58</td>
<td>31</td>
<td>89</td>
</tr>
<tr>
<td>Visual</td>
<td>25</td>
<td>27</td>
<td>52</td>
</tr>
<tr>
<td>Physical</td>
<td>3</td>
<td>2</td>
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<tr>
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<td>62</td>
<td>29</td>
<td>91</td>
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<tr>
<td>Total</td>
<td>278</td>
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### 2011/12
Number of children/pupils as per type of impairment

<table>
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<tbody>
<tr>
<td>Intellectual</td>
<td>115</td>
<td>79</td>
<td>194</td>
</tr>
<tr>
<td>Hearing</td>
<td>44</td>
<td>27</td>
<td>71</td>
</tr>
<tr>
<td>Visual</td>
<td>24</td>
<td>18</td>
<td>42</td>
</tr>
<tr>
<td>Physical</td>
<td>8</td>
<td>7</td>
<td>15</td>
</tr>
<tr>
<td>Multiple</td>
<td>90</td>
<td>42</td>
<td>132</td>
</tr>
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<td>Total</td>
<td>281</td>
<td>173</td>
<td>454</td>
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</table>
2012/13
Number of children/pupils as per type of impairment

<table>
<thead>
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<th>Type of impairment</th>
<th>Male</th>
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<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual</td>
<td>128</td>
<td>106</td>
<td>234</td>
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<tr>
<td>Hearing</td>
<td>40</td>
<td>21</td>
<td>61</td>
</tr>
<tr>
<td>Visual</td>
<td>17</td>
<td>22</td>
<td>39</td>
</tr>
<tr>
<td>Physical</td>
<td>3</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Multiple</td>
<td>69</td>
<td>42</td>
<td>111</td>
</tr>
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<td>453</td>
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</table>

2013/14
Number of children/pupils as per type of impairment

<table>
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<th>Type of impairment</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
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<tr>
<td>Intellectual</td>
<td>124</td>
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<td>Hearing</td>
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<td>17</td>
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<td>Visual</td>
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<td>23</td>
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<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Multiple</td>
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<td>41</td>
<td>109</td>
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<tr>
<td>Difficulties in speaking, communication and language</td>
<td>2</td>
<td>4</td>
<td>6</td>
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<tr>
<td>Autism</td>
<td>17</td>
<td>9</td>
<td>26</td>
</tr>
<tr>
<td>Learning difficulties/disorders</td>
<td>3</td>
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<td>6</td>
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<td>Total</td>
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<td>184</td>
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</table>

2014/15
Number of children/pupils as per type of impairment

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<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual</td>
<td>92</td>
<td>60</td>
<td>152</td>
</tr>
<tr>
<td>Hearing</td>
<td>25</td>
<td>15</td>
<td>40</td>
</tr>
<tr>
<td>Visual</td>
<td>34</td>
<td>31</td>
<td>65</td>
</tr>
<tr>
<td>Physical</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Multiple</td>
<td>77</td>
<td>63</td>
<td>140</td>
</tr>
<tr>
<td>Difficulties in speaking, communication and language</td>
<td>9</td>
<td>7</td>
<td>16</td>
</tr>
<tr>
<td>Autism</td>
<td>15</td>
<td>10</td>
<td>25</td>
</tr>
<tr>
<td>Emotional and behaviour disorders</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Learning difficulties/disorders</td>
<td>0</td>
<td>2</td>
<td>2</td>
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<tr>
<td>Total</td>
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<td>193</td>
<td>445</td>
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### 2015/16

**Number of children/pupils as per type of impairment**

<table>
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<th>Type of impairment</th>
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<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual</td>
<td>80</td>
<td>57</td>
<td>137</td>
</tr>
<tr>
<td>Hearing</td>
<td>20</td>
<td>17</td>
<td>37</td>
</tr>
<tr>
<td>Visual</td>
<td>15</td>
<td>16</td>
<td>31</td>
</tr>
<tr>
<td>Physical</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Multiple</td>
<td>54</td>
<td>39</td>
<td>93</td>
</tr>
<tr>
<td>Difficulties in speaking; communication and language</td>
<td>4</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Autism</td>
<td>11</td>
<td>13</td>
<td>24</td>
</tr>
<tr>
<td>Emotional and behaviour disorders</td>
<td>4</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Learning difficulties/disorders</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
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<td>7</td>
<td>16</td>
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<td>199</td>
<td>158</td>
<td>357</td>
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Annex 6 – Bibliography (Secondary Sources)


Twinning Programme to Support Implementation of the Kosovo Education Sector Strategic Plan 2011-2016 (Twinning No. KS 11 IB OT 02). Roadmap on Diversity and Inclusion for the Pre-University Education System in Kosovo.


Endnotes

11. IBID, pg. 12
12. IBID, pg. 20
13. IBID, pg. 24
15. Ombudsperson Institution Annual Report for 2015
19. KOMF Conference on child rights protection of children with disabilities, 3 December 2015
20. IBID, pg. 113
22. UN Convention on the Rights of Persons with Disabilities.
31. Interview, Office of Good Governance, 18 October 2016
35. Interview, Office of Good Governance, 18 October 2016
39. Personal communication with Arbena Berani, Senior Officer for the Rights of Persons with Disabilities
42. Personal communication, interview with MoE , 8 December 2016
44. IBID, pg. 17-19
52. IBID, pg.8
56. Ibid


78. Republic of Kosovo, Assembly (2012) Law N.04/L -017 on Free Legal Aid. Pristina. 2 February, 2012


90. IBID. pg. 4

91. IBID, pg. 5


101. Interview, UNICEF, 13 October 2016


108. NOTE: Article 123 of Kosovo’s Constitution reads: “Local self-government is based upon the principles of good governance, transparency, efficiency and effectiveness in providing public services having due regard for the specific needs and interests of the Communities not in the majority and their members”.


112. Note: The Child Protection Index is a pilot analysis of data included in UNICEF’s TransMonnee database, and is based on the Implementation Handbook for the Convention on the Rights of the Child. checklists for 8 countries: Albania, Armenia, Bosnia and Herzegovina, Bulgaria, Georgia, Kosovo*, Romania, and Serbia. The Index measures five dimensions (i.e. policy and law, services, capacity, coordination and accountability) of government action for each of the articles of the CRC that refer to child protection. The Index includes 626 indicators clustered in 4 measures: 1) child vulnerability, 2) governance environment, 3) efforts to end and prevent violence and care & protect children, and 4) social work capacity. Within this, the ”child vulnerability index” measures the situation of children living outside of their biological families; public sector personnel available to advocate on behalf of vulnerable children; and finally, the amount of state welfare expenditures as a percentage of GDP.

113. Note: The Child Protection Index compares data from Albania, Armenia, Bosnia and Herzegovina, Bulgaria, Georgia, Kosovo*, Moldova, Romania, and Serbia


115. IBID, www.childprotectionindex.org pg. 21


117. IBID, pg. 40

SITUATION ANALYSIS

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<td>121. IBID, pg. 8</td>
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<td>128. IBID; pg. 20</td>
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<td>129. Amici de Bambini &amp; Cooperazione Italiana allo Sviluppo (n.d.) Strengthening of Services in Favor of Minors Under the Responsibility of the Centre for Social Work Kosovo for family reasons...</td>
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<td>130. UNICEF Kosovo “Strengthening family based care, strengthening social work- A situation analysis of foster care in Kosovo (UNSCR) 2015”</td>
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<td>131. Amici de Bambini &amp; Cooperazione Italiana allo Sviluppo (n.d.) Strengthening of Services in Favor of Minors Under the Responsibility of the Centre for Social Work Kosovo for family reasons. Pg. 4</td>
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<td>132. Amici de Bambini &amp; Cooperazione Italiana allo Sviluppo (n.d.) Strengthening of Services in Favor of Minors Under the Responsibility of the Centre for Social Work Kosovo for family reasons. Pg. 5</td>
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<td>135. The title of Article 24 was changed from “Education” to “Inclusive Education” with the approval of General Comment #4 on 26 August 2016. For full text please see <a href="http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/4&amp;Lang=en">http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/4&amp;Lang=en</a></td>
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<td>140. UNICEF Reaching every child: The promise of equity, 2016</td>
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<td>143. Matero, M. (2016). Report on the Functioning of Resource Centres in Kosovo - Twinning programme to support implementation of the Kosovo Education Sector Strategic Plan 2011 - 2016 - Twinning No. KS 11 IB OT 02. Pg. 4</td>
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153. Interview, Association of Municipalities, 18 October 2016
155. Interview, Association of Municipalities, 18 October 2016
162. See, for example, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4624231/