



SITUATION ANALYSIS
ON EARLY CHILDHOOD
INTERVENTION IN KOSOVO
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ACRONYMS

AEPS	Assessment, Evaluation, and Programming System
ASQ	Ages and Stages Questionnaire
CBO	Community-Based Organization
CSO	Civil Society Organization
CRC	Convention of the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
DSPF	Department of Social Policy and Family
EASPD	European Association of Service Providers for Persons with Disabilities
EC	Early Childhood
ECD	Early Childhood Development
ECE	Early Childhood Education
ECEC	Early Childhood Education and Care
ECI	Early Childhood Intervention
EDSA	European Down Syndrome Association
EIS	Early Intervention Specialists
EMIS	Educational Management Information System
EU	European Union
EUR	Euros
FBO	Faith-Based Organization
FMC	Family Medicine Center
GDPR	General Data Protection Regulations
HMIS	Health Management Information System
IFSP	Individualized Family Service Plan
KOMF	Coalition of NGOs for Child Protection in Kosovo
MESTI	Ministry of Education, Science, Technology and Innovation
MFLT	Ministry of Finance, Labor and Transfers
MICS	Multiple Indicator Cluster Survey
MoH	Ministry of Health
NGO	Non-Governmental Organization
NICU	Neonatal Intensive Care Units
OECD	Organization for Economic Co-operation and Development
PMIS	Protection Management Information System
RAE	Roma, Ashkali and Egyptian
ToC	Theory of Change
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children’s Fund
WASH	Water, Sanitation and Hygiene
WHO	World Health Organization

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EXECUTIVE SUMMARY

Introduction

Contemporary research has revealed that by providing family-centered services for Early Childhood Intervention (ECI) from birth to five years of age, children with at-risk situations, developmental delays and/or disabilities are helped to achieve their full potential. Contemporary and supportive ECI services are provided in the child's natural environment through visits with parents and caregivers in homes and early childhood care and preschool education centers to support and assist families in maximizing the development of their child.

The establishment of a Kosovo-wide system for early childhood intervention (ECI) would complement and help to develop inclusive early childcare services and preschool education. It would help to expand preschool education and improve child development outcomes, thereby better preparing children for success in inclusive primary education. Children from birth to five would be served, enabling Kosovo's parents to improve the development of their children during their early years of rapid brain growth, thereby helping them achieve their full potential. In turn, this would help improve economic productivity and social well-being.



Goals and objectives of the study

The main goals of the Situation Analysis on Early Childhood Intervention in Kosovo were to: (a) provide an overview of the status of services for children with developmental delays and difficulties and their families; (b) identify the characteristics, strengths, challenges, needs and gaps in current services for these families and children; and (c) offer recommendations for planning an effective Kosovo-wide system of ECI services.

To achieve these goals, the main objectives of this study were to:

- » identify Kosovo's needs for child and family development.
- » analyse requirements for Kosovo-wide policies to improve, expand, and support ECI services.
- » provide an overview of public institutions and non-governmental organizations (NGOs) that offer services for families whose children have at-risk situations, developmental delays and/or disabilities – often called “developmental difficulties;”
- » identify and describe current characteristics of service-providing public institutions and NGOs that: (a) offer traditional rehabilitation services; (b) are evolving to become contemporary ECI services; or (c) have become fully contemporary ECI services.

This study sought to identify the existing strengths, capacities and needs of relevant service-providing public institutions, NGOs, and a few private entities. Issues addressed included the identification of children needing ECI services; policies and regulations for ECI services; family access to ECI services; organization of ECI services; ECI workforce; pre-and in-service training; costs and financing of ECI services; and monitoring and evaluation. The needs and requests of parents and other caregivers, service directors and personnel and leaders were addressed throughout the study. After discussing key research findings, major conclusions and recommendations were offered to establish and support the implementation of a high-quality, equitable and accountable Kosovo-wide ECI system.

Types of services

The study mainly addressed three major types of services in Kosovo for children with at-risk situations, developmental delays and/or disabilities.

1. **Traditional rehabilitation or habilitation services** are based on a medical model that serves children with disabilities, uses physicians' diagnoses of disabilities, and offers the services of specialised therapists for specific disabilities in a hospital or centre-based setting to help children function independently and participate in school and society.
2. **Evolving services** may be former rehabilitation services or new child development services that are using some or many contemporary ECI core concepts and are providing some contemporary evidence-based ECI services such as developmental screenings, team-based comprehensive developmental assessments, individualised family service plans, and family-centred services in the natural environment of the child: their homes, day-care settings, or preschool centres.

- 3. Contemporary ECI services** are based on a social and child-rights model that is family-centred, usually transdisciplinary and adheres to core concepts and methods that encourage families to provide activities and opportunities for their children to develop their abilities and learn new skills at home and in the community environments. The primary goal of contemporary ECI services is to support parents who in turn help their children achieve full participation in school and society.

Research methodology

Using the *Methodological Guide: Research for National Situation Analyses on Early Intervention*¹ that also provided generic instruments, a sequential mixed-methods research design was adopted. The research methods and instruments used in Kosovo included:

- » literature reviews of policies, public institutions, and NGOs, as well as pertinent studies on the context and status of ECI services provided by the government and civil society at all levels.
- » an initial mapping study to identify public institutions and NGOs providing services for children with developmental delays and difficulties and their families.
- » surveys of directors of public institutions and NGOs providing ECI or related services, their personnel, and the families served.

- » interviews with prominent leaders of the government and civil society, including minority groups; beneficiaries; and service personnel in ECI-like organizations as well as key health, education, and social welfare services; and
- » a cost and finance sub-study of the relevant ministries and a small sample of service providers was conducted.

The Mapping Survey identified 16 possible ECI-related public institutions, NGOs, and private entities. Some of them were not considered to be appropriate for the study, and in all a total of 8 directors of public institutions (2), NGOs (4) and private entities (2) responded to the extensive Director's Survey. Some 16 beneficiaries (mainly parents) and 20 service personnel completed shorter surveys. A total of 13 ECI-related service personnel were interviewed along with 9 beneficiaries. In addition, 6 high-level governmental leaders, and 13 health, education and social sector service personnel were interviewed. Finally, the cost and finance study reviewed financial support for ECI-related services and conducted a cost review of 3 evolving ECI organizations.

The project fully adhered to the rules of the General Data Protection Regulation (GDPR), a regional law of the European Union that requires institutions to protect personal data and the privacy of citizens of countries both inside and outside of the EU. It also followed the *UNICEF Procedures for Ethical Standards in Research, Evaluation, Data Collection and Analysis*, and the *UNICEF Strategic Guidance Note on Institutionalizing Ethical Practice for UNICEF Research*, with special attention to issues of confidentiality, consent, and research ethics.

1 Vargas-Barón, E., Diehl, K. and Kakabadze, N. (2023). *Methodological Guide: Research for National Situation Analyses on Early Childhood Intervention*. New York, NY: UNICEF. <https://www.unicef.org/eca/reports/research-national-situation-analyses-early-childhood-intervention>

Major research conclusions and recommendations

1 Conduct Initial Policy Advocacy and Social Communications

Conclusions

The study revealed that few citizens of Kosovo have a good understanding of the ECI field including its history, objectives, organization, regulatory needs, processes, methods, activities, instruments, and benefits for families, children, and communities. All ECI stakeholders, from leaders to families, communities, and relevant organizations, need to receive advocacy and information regarding ECI.

Recommendations

To build a shared understanding of the importance of ECI among all stakeholders at central and municipal levels as well as with civil society leaders and professionals, many policy advocacy, and awareness-raising activities about ECI systems and their services are urgently required. These activities will help with the organizational development of ECI, including strategic planning and service planning. Later, additional advocacy and social communications work will be needed to meet evolving requests for information and guidance.

2 Develop Initial and Longer-Term ECI Organization and Coordination

Conclusions

Kosovo currently lacks an ECI organizational framework for planning, coordinating, implementing, supervising, monitoring, and evaluating a Kosovo-wide ECI system. No ministry has been selected as a lead ministry for ECI nor does a system exist for a rotating leadership of ECI planning and development. In addition, the ministries have not developed an intersectoral steering committee or council for ECI. No mechanism for coordinating ECI multi-sectoral planning, financing, and management to develop and implement services with municipalities yet exists, and only some of the 38 municipalities in Kosovo have provided support for local evolving ECI services.

Recommendations

Kosovo leaders for ECI should discuss and decide upon two major types of options (presented in the text) for organizing the ECI system in Kosovo. Under either option, to plan and ensure the full implementation of the Kosovo ECI system, it will be essential to plan it in a fully participatory manner to enable the development of a good multisectoral and interagency structure, including rules for coordination as well as streamlined bylaws for its management. At a minimum, an intersectoral Steering and/or Coordinating Committee and/or an ECI Technical Committee, and a small central ECI central office with linkages to all municipal governments will be required.

3 Establish a Legal Basis and Planning Process for the Kosovo-wide ECI System

Conclusions

Currently, no Strategic Plan, Policy Statement or Law enables Kosovo to establish and develop Kosovo-wide ECI services. The lack of a legal basis for developing an ECI system has led to confusion and an absence of leadership for developing an ECI system and its services.

Recommendations

It is strongly recommended that an ECI Strategic Plan, including a costed ECI Action Plan, be prepared as the first organizational development activity. The preparation of an ECI Law might also be considered. To be fully implemented and effective, all stakeholders should participate actively in planning these policy documents, including families, communities, minority ethnic groups, municipalities, key members of the central government, civil society, academia, and of course, representatives of evolving ECI services. Once adopted, the ECI Strategic Plan should be monitored and evaluated annually, and annual reports should be used to prepare the ECI annual program and budget.

4 Prepare ECI Service Guidelines and Procedures and Other Regulations

Conclusions

The Situation Analysis also found that Kosovo lacks ECI regulations, usually called ECI Service Guidelines and Procedures. Also absent are ECI Service and Personnel Standards, an organizational system for licensing ECI institutions and organizations, a system for the accreditation of ECI professionals, called Early Intervention Specialists (EIS), as well as rules for the certification of other professionals in ECI services such as psychologists, special educators, therapists, nurses, and social workers.

Recommendations

Upon the adoption of the ECI Strategic Plan and/or ECI Law, detailed ECI Service Guidelines and Procedures should be prepared. This regulatory document must fit the resources and unique needs of ECI and collaborating services in Kosovo. Regular reviews will be needed to ensure that ECI Service Guidelines and Procedures fit the evolving needs of ECI services in Kosovo. Subsequently, Service and Personnel Standards can be prepared. With these essential building blocks in place, training, and licensing for ECI specialists can begin as well as pre-and in-service training. The accreditation (licensing) of ECI service organizations and Early Intervention Specialists (EIS) should be based on meeting ECI institutional and pre-and in-service training requirements. Certification to enable the participation of other specialists in ECI, such as psychologists, therapists, nurses, and social workers should also be developed.

5 Plan for ECI Financing and Costs

Conclusions

Financial support for ECI services is inadequate at both central and municipal levels. Expanded, diversified and consistent funding for ECI services is greatly needed to ensure their growth, improvement, and sustainability. Kosovo currently lacks a single budget system with a cost category for ECI that identifies and designates the funds provided by all relevant ministries for the development and implementation of ECI services. However, the prerequisites for establishing a funding system for ECI do exist, and they could be activated by establishing appropriate mechanisms for providing consistent financial support for ECI services. Some municipalities currently do not fund ECI services for their families, and those municipalities that do fund ECI services often do not provide consistent, annual support for public institutions and NGOs. No coordination for planning and managing ECI services exists between the central government and all municipal governments. No financial plan has been prepared for developing a Kosovo-wide system of community-based ECI institutions and organizations.

Recommendations

A central government **budgetary program for ECI** is greatly needed. It could either gather together all the funds allocated for planning, developing, conducting ECI services, and assessing budget implementation against achieved results OR it could provide for the coordination of different funding streams within the integrated ECI program along with the funding and budgetary activities. Funding mechanisms might include the provision of annual grants, contracts, or other funding methods to community-based ECI organizations and institutions. This ECI cost category could be “cross-walked” with a carefully developed ECI Monitoring, Evaluation and Child Tracking System. The Child Tracking mechanism would be activated as each child is enrolled in ECI services (See recommendation 9 below).

The sources of funding for the ECI system should be diversified to include central and municipal governmental budgets, foundation and corporate grants, benefactors, regional and global support, and local fundraising activities. This diversified approach is important to minimize the risk of changes in public funding and to prevent the use of (or a dramatic increase in) out-of-pocket payments by parents and other primary caregivers.

6 Conduct Community Outreach, Screening and Referrals

Conclusions

Efforts should be undertaken to ensure all children needing ECI services are identified at the earliest possible time to maximize their rapid brain development during their first months and years. However, only limited community outreach activities exist, and directors, service personnel and most especially, participating families believe that many children needing ECI services are not being identified or are being identified very late – after the age of three years.

Although a few evolving ECI programs use a developmental screening instrument, no reliable and validated screening instrument has been selected for country-wide use in Kosovo, and no system for regular and universal developmental screening yet exists for children from birth to five years of age. Finally, even for those infants and young children who currently benefit from a home health care and monitoring visit, and/or a physician's diagnosis, no consistent referral and follow-up system to ECI services currently exists in Kosovo.

Recommendations

The primary health care system, including the home visiting program that provides routine developmental monitoring virtually Kosovo-wide to identify children at risk of and with developmental difficulties, could be enhanced to conduct more community outreach, monitoring, developmental screening, and referrals to ECI services. A culturally appropriate ECD screening instrument is urgently needed, and once selected, it should be validated and applied Kosovo-wide.

In the education ministry, a major effort is underway to expand inclusive childcare and pre-school education in Kosovo. As this occurs, teachers and teachers' aides should be rapidly trained in developmental screening and serve as referral points to ECI services; however, at this time, health services provide most of the early services for infants and young children.

In addition, a comprehensive referral system for ECI services should be developed in tandem with the preparation of the ECI Service Guidelines and Procedures to ensure that effective referrals, developmental assessments, and follow-up contacts as well as the provision of regular developmental screenings because some children develop delays long after birth.

7 Promote Expanded ECI Service Development

Conclusions

No estimate of the number of children from birth to five years with at-risk situations, developmental delays and disabilities could be found in any study about Kosovo. A population study to identify the rate of young children with these conditions has not been conducted and is needed. Existing evolving ECI services are too few and are unable to serve all potentially eligible children in Kosovo, which are roughly estimated to be at least 100,000 children from birth to five years.

No fully contemporary ECI program was found in Kosovo. After extensive searches, local researchers were able to find only 12 rehabilitation public institutions, NGOs, and private entities that provide ECI-like services. Some of them continue to offer rehabilitation services and others are at different stages of evolving to become contemporary ECI services. It will be important to build on current organizational and professional strengths to improve and expand ECI services in Kosovo.

Most children receiving services were of Albanian ethnicity; however, several ECI institutions and organizations also serve Roma, Ashkali and Egyptian families. This reflects an important initial effort to develop equitable services. Nonetheless, many respondents noted that ethnic minority families and others who live in poverty and/or in rural areas usually lack access to ECI services. Most services are concentrated in the capital, Pristina.

All beneficiaries, service personnel and many high-level interviewees noted that ECI services are highly fragmented. Although a base exists for building strong ECI services, a major effort will be needed to create a coherent and unified system that will ensure all children who are eligible for and need ECI services will receive services of high quality.

Recommendations

A population study to identify the rates of infant and child developmental delays and disabilities from birth to five years is urgently needed to develop precise annual plans to meet future needs for ECI services. In addition, a Child Tracking System would enable accurate counts of children assessed to be eligible for and subsequently served by ECI services.

Given the current low coverage of early and preschool education services in Kosovo and the low level of inclusive education services for young children, it is recommended that ECI services be provided from birth to five years of age rather than the usual birth to three years period.

Because of the low program coverage of Roma, Ashkali and Egyptian families and families living in rural areas, special attention should be given to those municipalities that lack ECI services and contain many low-income and/or minority families. For rural regions, the development and use of mobile ECI teams should be given serious consideration.

8 Provide ECI Pre- and In-service Training and Pilot Demonstration and Training Sites

Conclusions

In general, Kosovo has a high level of both pre-and in-service training for professionals, and Kosovo professionals maintain good levels of certification and recertification. Most professionals working in evolving ECI services reported they annually receive between 20 to 40 hours of in-service training, mainly through conferences, online courses, and training workshops. High-quality social and health service personnel are a hallmark and strength of social services in Kosovo.

Early intervention specialists (EIS), a professional field that is present in many countries, were not found in Kosovo. However, considerable interest exists in developing a training program to prepare EIS and train other professionals to work in ECI services. Currently, no university training is offered for ECI services and no ECI pilot demonstration and training sites were found.

Recommendations

Major attention should be given to developing fully contemporary ECI services as rapidly as possible. To achieve this goal, high priority must be given to developing a phased **Pre- and In-Service Training Plan** for establishing a system to provide consistent, high-quality, and sustainable training for EIS and for certifying other professionals in fields included in ECI Transdisciplinary Teams.

In addition to developing an ECI training system, once an ECI Strategic Plan and ECI Service Guidelines and Procedures are in place, consideration should be given to designing and

developing **two or three Pilot ECI Demonstration and Training Sites** in different regions. These ECI Pilot Sites could be used for demonstrations and field practice, with coaching and mentoring for personnel from organizations in the region.

Attention should also be given to establishing certification rules, career ladders, and salary scales that are appropriate to professionals' increased levels of training and experience. Also, a streamlined and supportive system of program supervision, using methods of reflective supervision, coaching and mentoring, should be designed and provided within ECI services at municipal levels and between municipal and central levels.

9 Ensure Accountability: Monitoring, Evaluation and Child Tracking

Conclusions

Most directors of evolving ECI institutions and organizations reported that they conduct internal monitoring and evaluation processes, prepare an annual document that presents their objectives, indicators, and targets, and use a monitoring and evaluation manual. These reports reflect a positive commitment on the part of ECI directors to good program management and accountability. However, no country-wide or central system for monitoring and evaluating ECI services yet exists in Kosovo. In addition, no Child Tracking System or even a list of indicators and a database of children served by ECI institutions and organizations could be found at either central or municipal levels.

Recommendations

After the ECI Strategic Plan has been developed, an ECI Monitoring and Evaluation System including a Child Tracking System should be prepared as soon as possible. All ministries providing and/or supporting ECI services should collaborate in the development and implementation of this system. Formal agreements should be established to provide key data, create a common database, collaborate with data analyses, and prepare a annual report for purposes of annual program and budgetary planning.

In addition, a Manual for ECI Monitoring and Evaluation and instruments should be prepared for application in all ECI service programs of Kosovo.

A Child Tracking System should be carefully developed in line with Kosovo's **Strategy on the Rights of the Child 2019 – 2023** and the privacy rules of the European Union. This system would gather key information on all children with at-risk situations, developmental delays, and disabilities to ensure "no child is left behind" and, along with his or her family, each child should receive all essential ECI services and subsequently should transition well to inclusive preschool, pre-primary or primary education with the long-term goal of full social inclusion to the greatest extent possible.

10 Collaborate for Success: A Coalition of ECI Organizations of Kosovo

Conclusions

No ECI network or coalition of institutions and organizations providing ECI services yet exists. Only half of the ECI directors reported that they networked with any other organizations, and several interviewees noted that more inter-sectoral and inter-service coordination is currently needed in the entire social sector. A lack of consensus was found regarding whether to develop a coalition of organizations providing ECI services.

Recommendations

For ECI services to be fully effective, they require inter-sectoral and inter-organizational coordination. While preparing the ECI Strategic Plan, directors, and managers of evolving ECI services should begin to give serious consideration to developing a Coalition of ECI Organizations of Kosovo. It could conduct ECI advocacy, promote increased program support, build strong bonds of coordination with the central government, municipalities, and other organizations, support the good development of each ECI organization, and expand, improve, and help monitor and report on ECI services. As found in other countries, such a coalition could work closely with the central and municipal governments to enable the rapid development of a highly effective ECI system in Kosovo.

1. INTRODUCTION

Contemporary research reveals that the prenatal period and the early childhood years can lay the foundation for healthy and holistic child development. Early experiences shape the way the young brain develops and provide the basis for all future learning, behavior, and health. A child's early years have lifelong physical, social, and emotional impacts; every effort should be made to ensure that children's early experiences are positive and provide a secure foundation for future development. (Sameroff, 2009; Shonkoff, 2010; Shonkoff & Phillips, 2000; Sroufe, 2009; Worthman et al., 2010).

Furthermore, the first six years of a child's life are when the brain develops the most and there is solid evidence that children learn more during this period than they do at any other point in their life. In particular, the time between birth and age 3 is a period of rapid brain development when billions of connections among individual neurons are established. Interventions to support optimal child development must be available, beginning at birth. Children lacking appropriate health, nutrition, education, and responsive caregiving during these critical years may develop long-term delays and/or difficulties in learning and life outcomes.² A strong foundation helps children develop the skills they need to become well-functioning adults.



² Angela Demas, Mike Aliu, Sarah Coll-Black, Aglaia Zafeirakou, Aline Hankey, and Boryana Gotcheva (2021). A Situational Analysis of Early Childhood Development (ECD) Services in Kosovo. WORLD BANK GROUP

The early years are especially important for children with developmental delays or disabilities. Adequate support for children delivered during these critical years can enhance child development, improve their participation and inclusion, as well as overall quality of life. The early years are also very important for the whole family because this is when they can best learn how to support and nurture their child, meet their child's needs, and adapt positively to having a child with developmental difficulties.³

When children experience developmental delays, learning challenges or difficulties, the earlier they are identified, the easier it is to reverse delays, improve early learning, and help them to achieve their full potential in all or most developmental areas.

Early childhood intervention (ECI) services can change a child's developmental path and improve outcomes for them and their families and communities. Infants and toddlers learn best through everyday experiences and interactions with familiar people in familiar contexts. Services for young children who have or are at risk for developmental delays have been shown to positively impact outcomes across developmental domains, including health, gross and fine motor, language/communication, cognitive, and social-emotional development.

Families and caregivers play a central role in shaping high-quality outcomes for children; therefore, families benefit from ECI services by being able to better meet their children's needs from an early age and throughout their lives. With the necessary support and resources, most families can contribute to enhancing their children's learning and development. ECI services can improve the quality of life of children and their families, especially when we deal with children with developmental delays and disabilities. Benefits to society include reducing economic burdens through a decreased need for special education, special health and nutrition services, and social welfare services⁴.

Early childhood intervention is the term used to describe services and support that help young children from birth to 6 years of age with developmental delays or disabilities and their families. Intervention may include speech therapy, physical therapy, and other types of services based on the needs of the child and family and can have a significant impact on a child's ability to learn new skills and increase his or her success in school and life.

Early Childhood Intervention

ECI is defined as a "social model" composed of multisectoral and transdisciplinary services that are based on the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD). ECI services are family-centered and they support families with young children who have developmental delays and disabilities from birth to 3 or up to 5 or 6 years of age. ECI service providers include public institutions and civil society organizations that offer family-centered, coordinated, intensive, and individualized services to improve child development and resilience, and strengthen family competencies, communications, and skills to improve child development. ECI services often include advocacy for the educational and social inclusion of children and their families, and they work to prevent and mitigate child abuse, neglect, and abandonment. Contemporary ECI service providers often assist with the deinstitutionalisation of children from institutions (e.g., orphanages and transition homes) and they support family placement services and families receiving children.

3 ECIA- Best practices in Early Childhood Intervention- ECI Australia

4 NECTAC (2011). The Importance of Early Intervention for Infants and Toddlers with Disabilities and their Families the Importance of Early Intervention for Infants and Toddlers.

Early childhood intervention services seek to reduce risk factors and increase protective factors in a child's life. By focusing on supporting four key aspects of child development – their **physical, cognitive, behavioral, and social and emotional development** – ECI services have the greatest potential to provide benefits throughout the child's life. Children considered for enrolment in ECI services generally include those with **at-risk situations** (pre-term birth, low birth weight and chronic illnesses), **developmental delays** in at least one domain of development, **disabilities of all types, behavioral conditions** (i.e., autism spectrum disorders, attention deficit and hyperactivity disorders, and other behavioral disorders) and mental health needs (i.e., depression, trauma, poor coping skills). In some countries, ECI also targets children who are exposed to external 'threats' to their development which are strongly associated with adverse outcomes during adolescence and adulthood, such as child maltreatment, neglect, parental substance abuse and other environmental or contextual factors negatively impacting child development. This means that ECI services provide case management to children and parents and families in a comprehensive manner to support children who are exposed to threats that could potentially impact their development.

The emergence of family-centered ECI services is related to the growing understanding of the importance of the role of families in the development of their children; the process of deinstitutionalization and the development of alternative care for children (with special needs); decentralization, leading to the growing role of the local communities and networks of community-based services; as well as an increased understanding of the importance of the early identification of children with developmental delays and disabilities and family-centered, cross-sectoral, multidisciplinary approaches to service provision for children and their families⁵.

In countries around the world, services for children with developmental delays and disabilities are evolving in a continuum from traditional rehabilitation and habilitation center-based services to becoming contemporary ECI services. Therefore, this Situation Analysis aimed to study all services along the continuum, including: 1) contemporary ECI services, 2) legacy systems evolving toward becoming contemporary ECI services, and 3) legacy rehabilitation or habilitation systems that provide treatment services. These services are briefly outlined below:

1. **Contemporary ECI services** are based on a social and child-rights model that is family-centered, usually transdisciplinary, and adheres to core concepts and methods that encourage families to provide activities and opportunities for their children to develop their abilities and learn new skills at home and in community environments. The primary goal of contemporary ECI services is to support the society and relevant institutions to create an enabling environment for such services and support the participation of children and their parents, who in turn help children achieve full participation in life and society.
2. **Legacy systems that are evolving toward becoming contemporary ECI services** may be former rehabilitation services or new child development services that are **using some or many contemporary ECI core concepts and are providing some contemporary evidence-based ECI services** such as developmental screenings, team-based comprehensive developmental assessments, individualized family service plans, and family-centered services in the natural environment of the child: their homes, day care settings, or preschool centers.

- 3. Legacy rehabilitation or habilitation services** are based on a medical model that mainly serves children with disabilities, uses physicians' diagnoses of disabilities, and offers the services of specialised therapists for specific disabilities in a hospital, clinic or another center to help children function independently and participate in school and society.⁶

For more detailed information on ECI as a field, please see the following Annexes:

- » Annex 1: Detailed description of the attributes of traditional rehabilitation services, services evolving to include ECI concepts and methods, and contemporary ECI services.
- » Annex 2: ECI Core Concepts
- » Annex 3: ECI Theory of Change (ToC) which illustrates how and why positive child and family outcomes are achieved by using high-quality and universally available ECI services.
- » Annex 4: Contemporary ECI Service Process.

The ToC postulates the establishment of a Kosovo ECI System that would result in positive changes in children's acquisition of functional skills and in enhanced caregiver competence and confidence in supporting the development of their child. Existing services for childcare, education and child well-being in Kosovo should be designed and developed to help parents to support the healthy development of their children, reduce the risk of developmental delays, empower families with competencies to support their children in their health, development, and education, and to benefit from social services. However, the scarcity of ECI services and the perceived high costs of quality ECI, have resulted in few children and families being able to access and receive any type of ECI services.

The general unavailability of developmental monitoring and screening for developmental difficulties as well as ECI services has resulted in many children with at-risk situations, developmental delays, disabilities, behavioral conditions, and mental health needs who remain unidentified and unserved in Kosovo. Kosovo institutions and society need to foster an enabling environment, easily accessible to all, promote inclusive learning approaches, and model positive and supportive attitudes to support the inclusion and participation of all children and families. The families of these young children are not receiving the necessary support to enhance the development of their children well thereby enabling them to participate in school and society and become, to the extent possible, productive citizens. Moreover, young boys and girls from ethnic minority groups, including those with developmental challenges and disabilities, often suffer disproportionately from poverty, low access to health services and social benefits, and are negatively affected by exclusion and discrimination.⁷

Country-wide ECI Systems are guided by a ECI strategic plan and/or legislation. Countries also establish national regulations called ECI Service Guidelines and Procedures as well as ECI Service and Personnel Standards. National ECI systems seek to ensure that all families who have young children with developmental delays or disabilities will receive high-quality services in all municipalities, thereby assisting them to maximize their children's physical, language, cognitive, and social/emotional development while also respecting the diversity

⁶ The World Health Organization's definition of rehabilitation is: "a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment. (WHO website, 2022)

⁷ Social Inclusion of Roma Children and Children with Disabilities in the Western Balkans and Moldova Inception Report (2019). UNICEF ECARO to ADA.

of families and communities. Special attention is given to ensuring the rights of vulnerable young girls and boys living in poverty, rural and remote areas, and minority ethnic groups through equitably including them in culturally appropriate ECI services. National ECI systems should include a Kosovo-wide specification of roles by types and levels of organizations for implementing intersectoral coordination, planning, training, supervision, and accountability. ECI systems are developed in phases to attain nationwide coverage with equitable services that are of high quality, fully accountable and sustainable.

Chapter 2 of this Situation Analysis presents the research methodology that was used, including its purpose and scope, objectives, conceptual framework, research questions, research team, supporters and stakeholders, research design, sample contents and sizes, data management and analysis, study limitations, and research ethics. Chapter 3 presents the main research findings, while Chapter 4 presents the cost and finance study and its recommendations. Finally, Chapter 5 offers major study conclusions paired with key recommendations for establishing a well-functioning ECI system.



2. RESEARCH

2.1 Purpose and Scope of the Analysis

The ECI Situation Analysis provides an overview of the status of children with developmental delays and disabilities from birth to six years and their family, their challenges and needs, as well as the policy context, and an assessment of the human, institutional, training, and financial resources of ECI services. The Situation Analysis identified and mapped existing evolving ECI organizations and ECI-related services. Surveys and high-level interviews were conducted to provide information currently unavailable in Kosovo and in the international literature on ECI services. Finally, the study provides major conclusions and recommendations for planning a Kosovo-wide ECI system in Kosovo.

This ECI Situation Analysis is intended to serve as a foundation for building a Kosovo-wide ECI system based on the existing strengths, resources, and needs of the children, families, government and of potential ECI public institutions, organizations, services, and professionals at all levels to serve all municipalities of Kosovo.



The Situation Analysis is Kosovo-wide in scope and will require major leadership and coordination at the central level, and vertical and horizontal coordination at the municipal level. This coordination is essential to create a comprehensive and sustainable organizational framework that will ensure all potentially eligible children and their families are identified as early in life as possible and receive individualized services.

The ECI research team made every attempt to identify and survey ECI institutions and NGOs in Kosovo, including functioning services, hybrid or evolving services that are in the process of becoming comprehensive ECI services, and of course, contemporary ECI services that exhibit all critical dimensions of competency. The areas of strength of the service providers that do not yet fully provide contemporary ECI services but are evolving toward becoming contemporary services were emphasized so they can leverage their progress.

To gather helpful information on ECI for policy and program planning purposes, the ECI research team prioritized studying the characteristics, coverage, and status of current ECI services.

Notably, this study was not a “program evaluation.” It did not assess the content, methods, and processes of ECI services in detail. Instead, it addressed the general status of service providers that are evolving toward becoming contemporary services as well as some legacy organizations that serve children with at-risk situations, developmental delays, and disabilities.

2.2 Research Objectives

The methodological objectives of this research study were to:

- » **Review domestic and international literature** related to ECI and other health, education, and social work services in Kosovo with special emphases on policies, normative and regulatory documents, and studies and statistics on children with developmental delays and disabilities and their families.
- » Conduct a **Mapping Study** to (a) identify relevant service providers, with a focus on rehabilitation, evolving, and contemporary ECI services; and (b) decide on a sample of service providers that should be included in the study.
- » Apply a **sequential mixed-methods research design**, using qualitative and quantitative methods, to study service providers and services for children and families with developmental delays and disabilities.
- » Conduct a Cost and Finance Sub-Study with selected ECI organizations, using a questionnaire for case studies, and semi-structured interviews with ECI directors or financial managers to secure further information regarding their cost and finance data.
- » Conduct **data analyses, interpret findings, and offer conclusions and recommendations** for the phased development of a Kosovo-wide ECI system that would respond to key needs, challenges, and gaps in services.

2.3 Conceptual Framework

The Conceptual Framework presented in Annex 5 is based on global research of ECI policy planning and service provision in several nations (Black et al., 2017; Guralnick, 2011, 2013; Richter et al., 2019; Vargas-Barón et al., 2019; Vargas-Barón, 2009, 2013, 2015, 2016, 2019, 2020). This Conceptual Framework outlines methodological approaches used for the literature review, use of research instruments, and field research processes that were employed to gather data for this study.

The Conceptual Framework includes the following key elements:

- » Sources of Knowledge, including both external and internal sources.
- » The Policy, Social, and Resource Contexts.
- » Research Strategies, including Systemic Enquiries, Service Provider Enquiries, and Parental Enquiries, with lists of the types of instruments per type of enquiry.
- » Analytic Framework for Quantitative and Qualitative Analysis with Conclusions and Recommendations.
- » Knowledge Application for Building Kosovo-wide ECI Systems.

2.4 Research questions

Some of the major research questions for conducting research to prepare the Kosovo ECI Situation Analyses are presented in Annex 8. Research questions dealt with basic information; the enabling policy environment; child and family status; outreach, developmental screening and referrals; ECI service provision; human resources; ECI workforce development; ECI service costs; and ECI financial resources. Each research question was linked to one or more specific instruments. Please see Annex 8 for the major research questions.

2.5 Research Team, Supporters and Stakeholders

The research team was composed of four researchers from Kosovo and three international ECI researchers who are Senior Fellows of the RISE Institute. Their names and roles are presented in Annex 6: Research Team.

The UNICEF Kosovo Office selected the members of the Reference Group, which was composed of representatives of state ministries, regulatory and service providing public institutions, and non-governmental organizations. The Reference Group approved the research methodology, helped to contact service providers, facilitated data collection, assisted researchers to arrange interviews, and reviewed the first draft of the report, as well as the second draft with general findings and recommendations of the Situation Analysis.

Annex 9 presents an overview of the key stakeholders who were included in this research project and the research instruments that were used with each type of stakeholder. Given the shortage of time, local researchers decided not to conduct focus groups of ECI service personnel and ECI beneficiaries. Instead, they conducted [substituted them with] some additional in-depth interviews.

2.6 Instruments, Data Collection, and Samples of Study Participants

The research activities and instruments used to prepare this ECI Situation Analysis were based on the **Methodological Guide: Research for National Situation Analyses on Early Childhood Intervention** (Vargas-Barón et al., 2022). Similar research had been conducted previously in Croatia, Montenegro, and North Macedonia. The purpose of the **Methodological Guide** is to assist countries in analyzing the development of ECI services with the goal of providing data analyses, findings, conclusions, and recommendations for ECI strategic planning to improve and expand family-centered ECI services.

2.6.1 Instruments and Data Collection

The following methodologies and generic instruments from the **Methodological Guide** were used by the Kosovo ECI Research Team to prepare the literature review and conduct field research activities.

All instruments were translated, adapted, and field tested by the Kosovo Research Team. Initially, the surveys, and interview questions were administered to a small number of individuals to determine if the questions were well understood or if any of the questions might be intrusive or make respondents feel uncomfortable. Based on feedback received from participants in the pilot test, members of the Research Team revised the instruments before using them with study participants.

a) Literature Review

A comprehensive and thorough literature review on ECI services and related topics was conducted. Sources included government documents (policy and legal documents, strategies, guidelines), local studies, international policy documents, peer-reviewed journal articles, studies, and monitoring and evaluation documents from multilateral and bilateral agencies and organizations as well as documents and technical guidance from local ECI and related local organizations, universities and training institutes.

b) ECI Mapping Study Questionnaire

The ECI Mapping Survey was conducted at the inception of the study to identify all ECI organizations that met the criteria of providing services that aim to enhance the development of children with developmental delays and/or disabilities. A brief Mapping Survey was distributed and completed online by directors or managers of public institutions from the health, education, or social welfare sectors, non-governmental organizations (NGOs) and a few private institutions considered to be evolving toward becoming ECI service providers or rehabilitation services that included young children.

c) Survey of ECI Service Directors

The results from the Mapping Survey were used to establish the list of public institutions, NGOs and private institutions to be included in the study, using some of the criteria stated in the *Methodological Guide*. The Survey of directors of public institutions, NGOs and private institutions, aimed to secure basic information on the status of ECI services in the

Kosovo, including topics such as location, number of users, community outreach, the provision of developmental screening, comprehensive developmental assessments and family assessments, individualized family service plans (IFSPs), home visits and/or center-based activities, types of personnel and their training, service caseloads, referrals and coordination with other relevant sectors for provision of ECI services.

This survey was filled out by ECI directors identified through the Mapping Study. The questionnaire included 68 questions, and it was made available through an online survey platform with options for computer or tablet responses. Directors were also offered to fill in a hard copy of the questionnaire, if they so preferred.

d) Survey of ECI Service Directors

The Survey of Service directors of public, private and non-governmental organizations that responded to the Directors' Survey was conducted to learn about the following topics: organizational identification; work role, age, and gender of service personnel; municipalities served; numbers, gender, ages and conditions of children; socio-cultural dimensions of children/families served; professional training; types, frequency, duration, and timing of services provided; types and location of child/parent services; key challenges and needs for ECI services; and key recommendations for expanding and improving ECI services. This survey provided important quantitative information. ECI personnel included professionals of various disciplines related to ECI. The questionnaire was made available through an online survey platform with options for computer or tablet responses.

e) Survey of ECI Beneficiaries

ECI beneficiaries are the parents, other family members and caregivers of children with developmental delays or difficulties. They receive services from identified public institutions, NGOs or private organizations.

ECI beneficiaries were given the opportunity to express parental and family needs, reveal barriers to access, explain the level and type of participation they have in their ECI services, identify concerns regarding themselves and their children, and provide information on ECI services as they experience them. Their observations and opinions were of fundamental importance to addressing their needs. Beneficiaries were given access to an online survey platform or a hard copy of the survey. They were assured that the survey would give them an opportunity to represent families who greatly need ECI services and to provide their recommendations regarding ECI services.

f) Interview of ECI Service Personnel

Semi-structured interviews and discussions with ECI Service Personnel working directly with children and families were held to secure their observations regarding contemporary ECI services, community outreach, ECI service quality, pre-and in-service training, personnel retention, supervision and monitoring and evaluation, networking and inter-institutional/organizational coordination as well as their recommendations for expanding and improving ECI services.

g) Interview of ECI Beneficiaries

Semi-structured interviews were used with parents and caregivers, who benefited from the services provided by the ECI organizations (public, private and NGO sector) whose directors responded to the Directors' Survey. These interviews had a more qualitative approach and sought to identify the parents' experiences in accessing ECI services, their challenges, their preferences regarding types of services, the quality of the services obtained, and their recommendations for the future.

h) High-Level Interviews

Structured interviews lasting approximately 40 minutes were conducted with a few leaders at the central level to learn about their opinions regarding local needs for ECI services. Their recommendations for ECI services were also sought. They were asked about ways they currently support ECI services, and how they might provide more support in the future.

i) Interviews with Sectoral Specialists in Health and Education

To complement interviews conducted with service personnel and beneficiaries of pertaining to ECI-like institutions and organizations, interviews were conducted with sectoral specialists in the fields of health and early education to gain information on their home visiting services, early childhood education services, and their observations regarding ECI services.

j) Cost and Finance Sub-Study Questionnaire and Interviews

The Cost and Finance Sub-Study was conducted with three different types of ECI organizations, using a questionnaire regarding service costs and financial support. In addition, a semi-structured interview was conducted with ECI directors or financial managers to secure explanations regarding cost and finance data. The questionnaire provides charts for entering data, with discrete responses including dual and multiple-choice answers. A few open-ended questions were also asked during the follow-up interview. In addition, financial specialists at central and local levels were interviewed regarding how existing services currently funded and the presence or absence of various types of support for ECI-like services. Finally, data from the Directors' Survey were used to identify how existing services were funded.

2.6.2 Samples of Study Participants

Information regarding the types of respondents, recommended sampling methods along with their limitations, and possible incentives to encourage respondents' participation were included for each of the generic Instruments of the Methodological Guide. Given the population and organizational parameters in Kosovo, the local Research Team set the sample sizes and sampling methods for each instrument, except for the Mapping Survey and Directors' Survey, which entailed a "universal sampling" of all ECI or ECI-like service providers. To secure a universal sample of ECI or ECI-like entities, a series of activities were undertaken to identify all evolving entities that provide services to young children with developmental delays or difficulties. Local researchers asked for recommendations from the study's Reference Group, UNICEF personnel, and members of key ministries that fund such services. In addition, all identified ECI-like service providers were asked to suggest other programs they might know. The results are presented in Table 3: Final Study Sample.

Table 3 presents an overview of the samples of study participants by the types of instruments applied in relation to the types of entities included in the study. Information regarding the types of public, NGO and private sector entities are provided, along with information regarding the designation of NGOs and private entities as evolving or traditional rehabilitation services. In general, the public institutions are ECI-related rather than ECI service providers. They either complement and collaborate with ECI organizational entities, or they could do so.

Table 1: Study Samples

Type of sample	Public sector institutions			NGOs		Private entities	
	Health sector	Education sector	Social welfare sector	Evolving/ Have some ECI services	Rehabilitation centers ⁸	Evolving	Rehabilitation centers
16 entities in Mapping Survey	3	1	2	8	1	1	
8 entities in Directors' Survey	2			4		1	1
20 service personnel surveyed	2	2		13 therapists			3
16 beneficiaries surveyed				10	6		
13 service personnel interviewed	2	2	2	6	1		
9 beneficiaries interviewed	3			6			
6 high-level Interviews	1	3	1 + 1 ⁹				
13 additional health and education sector service personnel ¹⁰	11	2					
3 Cost and Finance Sub-Study Case Studies				1	2		

The **Mapping Survey** identified 16 possible ECI entities, 6 of which were ECI-related public institutions, nine were NGOs, and one was a private center. Later one education center of the public sector was recategorized as belonging to the private sector.

Subsequently, all 16 directors were invited to fill out the extensive Directors' Survey. However, only eight directors agreed to complete the survey, which constituted only a 50% response rate. Two directors led public health entities, while four led NGOs with evolving services, and two led private entities.¹¹

The **Survey for Service Personnel** was completed by 20 persons, which was only a 40% response rate. They were employed by one of the eight service entities, including four persons from the public sector, 13 from NGOs, and three from a private rehabilitation center.

8 All health services provide preventative or rehabilitative services. This distinction was not made for public institutions, the authors attempted to differentiate among the NGO and private sector who provide rehabilitative services as well
 9 This additional interviewee is from a high government level
 10 These service personnel are not from institutions included in the Survey.
 11 This is the center recategorized from the public to the private sector.

The Survey for Beneficiaries was completed by 16 parents and caregivers, with only a 40% response rate. Ten of the beneficiaries were served by NGOs with evolving services, and six were served by NGO rehabilitation centers.

Interviews were held with 13 service personnel of surveyed public institutions, including two each of health, education, and social welfare entities, and seven from NGOs providing evolving services. The goals of these interviews were to secure qualitative information regarding ECI services, gain professionals' opinions about ECI activities, and secure their recommendations for expanding and improving ECI services.

Nine Interviews were held with parents and family caregivers receiving services from three public institutions and six NGOs providing evolving services. The interviews sought to obtain qualitative information about ECI services, and information about beneficiaries' needs, challenges, and recommendations for the future. They were interviewed individually through face-to-face meetings or via telephone calls. They were parents of children with developmental delays or disabilities, and most were beneficiaries of one or more of the service providers, with two exceptions that were randomly selected by the local research team.

Structured Interviews were held with six high-level government officials to gather information on the status of children, families, ECI and ECI-related services, and the challenges that they faced. Interviewees also offered their recommendations for expanding and improving ECI programs and creating a Kosovo-wide ECI system.

As noted above, an additional set of 13 interviews were conducted with 11 specialists in public health and two in public education services to gain a greater understanding of their services. Special attention was especially given to the Home Visiting Program of the primary health sector.

Five entities from among the sample of eight NGOs were initially selected for the **Cost and Finance Sub-study; however**, only three NGOs agreed to collaborate with the study. This Sub-study sought to identify and analyze the types and levels of financial support for ECI services as well as their service costs to secure data for the future planning of ECI services in Kosovo.

2.7 Study Limitations

This study was not intended to be a program evaluation; therefore, it did not attempt to assess the quality of the services of public institutions, NGOs and private sector entities. The research team did not conduct in-depth evaluations of each service provider; this would have entailed additional instruments, lengthy on-site observations as well as wider document reviews. Instead, it addressed the existence and status of service providers at what is beginning of an ECI system in Kosovo, as well as the range of different types of institutions and organizations that serve children with at-risk situations, developmental delays, and disabilities.

The identification of service providers proved to be quite challenging. Because ECI services in Kosovo are highly fragmented, most institutions and organizations initially thought to be conducting ECI or similar services were not doing so. Also, the study identified some new initiatives beginning to provide evolving ECI services. Furthermore, the study focused on

services provided by the Kosovo system, and it did not include the possible provision of relevant services from the parallel institutions covered by the Serbian system in the Serbian majority municipalities.

After contacting all relevant stakeholders that could be found, the Research Team members felt confident that they had identified all the relevant organizations that existed in Kosovo.

In addition, survey distribution and collection proved to be exceedingly challenging. As previously noted, despite the considerable efforts made by the local members of the research team, the response rates for all surveys were very low. Regarding interviews with government officials, the response rate was 90%; however, only seven interviews were attempted.

The Research Team decided not to hold focus group sessions due to difficulties in timing and the unavailability of service personnel, as well as the stated preferences of personnel and beneficiaries for individual interviews. Research team members attempted to maximize their work by conducting individual interviews (face-to-face, via phone, and written). The data sets that were gathered were very small, but they were largely complete. Respondents noted that the survey instruments were lengthy and required time to fill out. Securing responses from busy service directors proved to be most challenging and it took more time than initially envisaged to obtain their completed questionnaires.

2.8 Data management, analytic procedures and quality control

The study presents results from the analyses of data that were gathered by the Research Team in Kosovo as well as a synthesis of findings from the literature review. The latter provided an overview of the status of children from birth to 60 months of age and their parents, the policy context, and an assessment of human, institutional, training, and financial resources.

Using the sequential mixed methods research design, all quantitative data gathered by the Research Team in Kosovo were reviewed, double-checked, and cleaned before data analyses begun. The data were analyzed in accordance with the needs of each type of data set. Data obtained using surveys that were completed online or by means of using hard copies were entered into consolidated databases and then analyzed. Because of the simple nature of the data sets and the complexity of the array of types of service providers, frequencies were mainly used to analyze collected data, yielding numerical counts and percentages. Subsequently, tables and graphics were constructed, reviewed, finalized, and interpreted for use in the report text or for presentation in annexes.

Qualitative data were collected using either structured interviews or semi-structured interview guides. Data gathered were analyzed using a matrix that listed key findings from each interview. Local researchers prepared a summary report on each of the types of interviews, and they noted salient results that could be used in the report text. The local researchers also provided general observations for all team members. Subsequently, quantitative data analyses were paired to the extent possible by topics and question areas with the general qualitative findings from the interviews that were provided in summary form by local researchers. Once this analysis was completed, the general study findings were prepared, and they are presented in Chapter 3.

2.9 Research Ethics

The research project adhered fully to the rules of the General Data Protection Regulation (GDPR) a regional law of the European Union (EU) requiring institutions to protect personal data and the privacy of EU citizens inside and outside the EU. It also followed the **UNICEF Procedures for Ethical Standards in Research, Evaluation, Data Collection and Analysis**, and the **UNICEF Strategic Guidance Note on Institutionalizing Ethical Practice for UNICEF Research** regarding confidentiality, informed consent, and research ethics. Consent forms and background documents for our research instruments were prepared and translated. These informed consent forms and instructions were provided to participants before the instruments were administered.

All participants, including representatives of service providers, were assured that their responses would remain strictly confidential and anonymous. Their rights to end or withdraw from participation, request access, and correct or delete any of the information they provided was explained. By participating in a survey, participants acknowledged and consented to filling out the questionnaire. Interviewees received instructions informing them of the purpose of the study. Their statement of consent explained that all information they shared will be strictly confidential and anonymous, and they were informed that they could also request that data be transmitted to a different study/researcher in a structured and readable format, as regulated in the GDPR.

With respect to cultural dimensions, all field instruments were originally drafted in English, translated and adapted to Albanian or Serbian, field tested, and revised again, resulting in further refinements of the translated versions. The semi-final translated versions of all ethics statements and research instruments was field tested for comprehension and cultural appropriateness with a few persons who were considered “typical” respondents in Kosovo (e.g., parents, ECI directors and ECI stakeholders).

All data gathered with the surveys were stored electronically, with password protection in place. No names or other personal identification were put in surveys or interviews. No paper copies were made. During research activities, data were not disclosed or transferred to anyone other than team members, and all data transfers from one team member to another were recorded. Data secured during interviews were accessible only to the researcher conducting the interview. Analyzed data were used in an anonymous and group-level form. Whenever possible, data for the Cost and Finance Sub-Study were collected in an anonymous form. When it proved impossible to collect anonymous data, later during data analysis, interpretation and report preparation, special attention was given to removing any reference to the identity of the persons and institutions. The raw data in the possession of Research Team members will be destroyed as stipulated by the General Data Protection Regulation (GDPR).



3. RESEARCH FINDINGS

The development of a Kosovo-wide ECI system is fundamental to improving the lives of all families of children from birth to six years of age with at-risk situations, developmental delays, disabilities, behavioral conditions, and mental health needs. Effective ECI services are family centered. Both desk research and findings from the study found that despite the recent progress achieved in expanding the legislative and policy framework for children's services in Kosovo, there is still no policy or mechanism that legally establishes or regulates public institutions or NGOs that provide evolving ECI services. The study found that there is a lack of services for children with developmental delays and difficulties, and their families in Kosovo and the existing small number of ECI services are provided in a fragmented manner. Furthermore, the cooperation and communication among different relevant sectors remain very limited with little or no coordination among the sectors. This lack of coordination could result in the further fragmentation of services, as well as gaps in their availability, accessibility, quality, and equity.

3.1 Enabling policy environment for ECI services

In Kosovo, available data reveal a worrying situation regarding early child health, development and well-being. Many children, especially those from vulnerable communities, lack adequate caregiving, development, and access to early education.

Kosovo has incorporated the Convention on the Rights of the Child into the Constitution, which constitutes the broadest point of legal reference for maintaining a commitment to

implementing the Convention. The **Strategy on the Rights of the Child 2019 – 2023** also promotes child rights and development. Strategic Objective #5 of the **Strategy** calls for improving children’s health and protection, and for helping all children achieve their full potential as well as strengthening inclusive and integrated services for children with disabilities (Specific Objective 5.2). Additionally, it calls for:

- » increased investment in children’s services;
- » expanded inclusive preschool and pre-primary education, including alternative programs;
- » strengthened comprehensive and integrated services for children with disabilities;
- » effective mechanisms for the early identification of children with disabilities through home visits for parents and caregivers with monitoring and developmental screening of children and referral to ECI services;
- » a well-developed community-based model of day-care centers for children with disabilities, including treatment and habilitation, as needed;
- » the implementation of an instrument for the comprehensive assessment of children and the identification of those with at-risk situations, developmental delays and disabilities in childhood; and
- » a system for data collection, monitoring, analysis and evaluation including a central database for children with developmental delays and disabilities.¹²

Although, during the last decade early childhood development (ECD) has become a high priority for the government of Kosovo, it still invests relatively little in expanding ECD services or improving the quality of existing services. However, under the **National Development Strategy 2030** and the **National Education Strategy 2022-2026**, the Kosovo government has committed to increasing access to and the quality of ECD services. While policies and programs targeting young children are fairly well-developed in the sectors of health, nutrition, child protection, and social protection, policies and interventions to support early childhood education (ECE) are still emerging.¹³ Despite the government’s commitment, data reveal that many children in Kosovo are deprived of their rights and are discriminated against due to gender, disability, ethnicity, socio-economic status and place of birth.¹⁴

According to the **Situational Analysis of ECD Services** in Kosovo conducted by the World Bank, a multisectoral ECD strategy and cross-sectoral coordination and collaboration are lacking, which are considered to be major weaknesses in the provision of integrated services for early childhood as well as the establishment of a solid monitoring and evaluation system to ensure data collection, analysis, and evaluation of child development indicators. This study also found that a lead institutional intersectoral organizational framework for the health, nutrition, education, and social and child protection sectors is also lacking.¹⁵

The **National Strategy on the Rights of Persons with Disabilities in Kosovo, 2013 – 2023**, states that “**accepting persons with disabilities as social value, part of human diversity and humanity, and equal opportunities, gender equality, respecting evolving abilities of children with disabilities as well as respecting rights of children with disabilities to preserve their identities, which are also the basic principles of the Con-**

12 Strategy on the Rights of the Child 2019 – 2023.

13 Perolli-Shehu, B., Musliu, A (2022). Supporting the Improvement of Quality Early Childhood Education and Care (ECEC). The World Bank Group

14 Ibid.

15 Angela Demas, Mrike Aliu, Sarah Coll-Black, Aglaia Zafeirakou, Aline Hankey, and Boryana Gotcheva (2021). A Situational Analysis of Early Childhood Development (ECD) Services in Kosovo. WORLD BANK GROUP

vention on the Rights of Persons with Disabilities.”¹⁶ Notwithstanding, for children with disabilities and their families, accessibility to ECI services, physical environments, transportation and information for children remains low.¹⁷

For far too long, the healthcare system has not mainstreamed disability within its plans of action. The **Law on Social and Family Services** contains some provisions regarding persons (of all ages) with physical or mental disabilities who are “in need of social services,” but there is no legislation or secondary legislation on the health care of children with disabilities. However, the **Law on Health** recognizes some important principles concerning the right of children with disabilities to health care. The **Law on Material Support for Families of Children with Permanent Disability** recognizes the right of families having a child with severe disabilities to receive assistance, irrespective of their economic position.¹⁸ A **Law on Persons with Disabilities** is currently being drafted, and it is expected to be relevant to the development of ECI services.

According to the **Situation Analysis of Children with Disabilities in Kosovo**, conducted by UNICEF in Kosovo, these children are at risk of abuse or neglect. In addition, it was found that most children and families do not know their rights under the law, how to protect themselves, or how or to whom to report instances of abuse or neglect. The 2019 **Law on Child Protection** includes regulations regarding child protection services. However, existing protection mechanisms do not explicitly include children with disabilities. Children with disabilities from Roma, Ashkali and Egyptian communities have been noted to be at exceedingly high risk of abuse.¹⁹ Regular monitoring and screenings of child development, early identification and intervention services for families of children at risk of delay or difficulty are underdeveloped, and the current system has promoted and maintained the medical model of disability both in policy and in practice. Additionally, children with disabilities and their families have been largely absent from discussion, and often families of children with disabilities are not informed of their rights and/or the few services that are available to them.²⁰

The draft **Law on Early Childhood Education** establishes the foundation for increased availability of institutional arrangements to provide inclusive, gender-equitable and quality ECE programs and integrated services in early childhood. It promotes the comprehensive development of all children, including through education, health care and support for well-being, and calls for a system for the identification of each child’s needs and developmental potential.²¹ The **Law** provides regulations for the provision of comprehensive quality early education in all forms of ECE services for children from birth to six years of age, as well as determines the norms for the organization, functioning, supervision, roles, and institutional and professional responsibilities of all ECE stakeholders. The **Law** acknowledges the right of children to inclusive and individualized quality education and requires the establishment of mechanisms for establishing integrated ECE services by calling for cross-sectoral cooperation and coordination among institutions at central and local levels, and with all relevant actors in the ECE field.

The **Kosovo Education Strategy 2022-2026** articulates difficulties regarding the access to and quality of early childhood education, including but not limited to the insufficient number

16 National Strategy on the Rights of Persons with Disabilities in Kosovo 2013 - 2023

17 Legal Framework for Children’s Rights in Kosovo, 2014

18 Ibid.

19 Situation Analysis: Children with Disabilities in Kosovo, 2017

20 Ibid.

21 MESTI- Law on Early Childhood Education

and inadequate distribution of preschool institutions in Kosovo. Despite substantial progress, access to early childhood education and care (ECEC) in Kosovo remains very low and participation of children in preschool education and care (ages 0-5) remains low. Only 15% of children three to four years of age in Kosovo participate in organized and licensed preschool programs. Children under five years of age in rural areas are enrolled in ECE three times less than their peers in urban areas because preschool services in rural areas are almost non-existent. In urban areas, 25% of children are included in ECE programs, whereas in rural areas only 8% have the opportunity to receive ECE services.²²

Persistent problems related to low access to ECE programs and the uneven distribution of ECE services have severely limited access to subsidized services at the municipal level for children from vulnerable groups, including children with developmental delays and difficulties. This situation also severely limits the early identification of children with developmental delays and disabilities because preschool institutions as well as health care services are usually the most appropriate public services for identifying such children.

As the data suggest, with a very low percentage of children below the age of five attending ECE programs, most early childhood experiences occur at home with parents and caregivers. Data reveal that family practices for early stimulation and learning are often inadequate, leading to low child development indices (2020 MICS Data).²³ According to the UNICEF Kosovo Office, only around two in three children aged two to four years in the general population, and one in three children in Roma, Ashkali and Egyptian communities received early stimulation activities and responsive care from adult household members. The situation is worse for the children coming from disadvantaged backgrounds since they have lower access to organized ECE opportunities. Children missing appropriate support in these critical years may not be able to achieve their full developmental potential, which can result to low school achievement and a variety of inadequate life outcomes.

For children with developmental delays and disabilities, obstacles still remain in the form of limited access to appropriate education, health care and early childhood intervention services. In addition, access to public facilities and services is often lacking.

The **Strategy and Action Plan on Children's Rights** adopted in January 2019 confirms the commitment of the Kosovo Government and relevant stakeholders to prioritizing ECD services. Policies supporting the development of young children have been mainstreamed in sectoral strategies; however, much remains to be done.

The development of a Kosovo-wide ECI system is fundamental to improving the lives of all families of children from birth to six years of age with at-risk situations, developmental delays, disabilities, behavioral conditions, and mental health needs. ECI services are family centered, and they support and assist parents and caregivers to provide care for optimal child development and for achieving their full potential, and to the extent possible, will become productive citizens.

22 MESTI- Kosovo Education Strategy 2022-2026

23 MICS Data 2020

3.2 Current status of ECI policies and regulations in Kosovo

The few rehabilitation and evolving ECI services that are currently provided in Kosovo reported that they strive to help parents and children to reduce developmental delays, empower families with competencies to support their children in inclusive education services and benefit from social services. However, given that few ECI services exist in Kosovo, few families and children are accessing and receiving them.

Currently, no policy document provides a legal basis for ECI services, and their organization and coordination. Other existing frameworks for early childhood services could help with the development and/or integration of ECI specific policies and mechanisms.- Kosovo institutions have stated their commitment to increasing access and improving the quality of ECD as stated in the new **National Education Strategy 2022-2026**, the National Development Strategy 2030, and the **Law on Early Childhood Education**. However, a specific strategic plan and/or a law for a national system of ECI services is missing.

Kosovo legislation and policy documents have recognized the importance of ECD and ECE, and they are based on the principles of the CRC. However, the current identification of children at risk of developmental delays and disabilities who require ECI service, as seen in this study, is far from sufficient to meet the needs. Both early identification services as well as early intervention services, to meet the needs of children in Kosovo, are urgently needed.

Several service providers offer some forms of support on a project-by-project basis; however, often in Kosovo they have limited sustainability and differ greatly in quality and coverage. Counselling services for parents are also scarce. Although current legislation foresees and fosters cross-sectoral collaboration, mechanisms to strengthen ECI services, that integrate the education, health, nutrition and protection sectors, are still lacking resulting in few services that target the parents, families and caregivers of children with at risk situations, developmental delays and difficulties.

In addition, the literature review conducted for this study did not find any local normative ECI Service Guidelines and Procedures for developing, implementing and regulating contemporary ECI services. No protocols or regulations are in place to address this major gap.

Legislative documents referring to children with developmental delays and disabilities also lack a clear definition of "early childhood intervention." However, the term "early childhood identification" was recently defined in the new **Law on Early Childhood Education** as the process by which developmental risks, delays or disabilities are identified. Yet, most local ECD, ECE and ECEC documents do not place an emphasis on the first three years of life, which constitute the most critically important period of brain development in children when it is most important to identify these children to ensure they will attain their full potential.

Interviews that were conducted with government officials at the policy level and leaders of sectoral institutions revealed that they believe current policies and laws addressing service provision for children from birth to five or six years of age, including ECI, consider children's social, educational, and health needs in a holistic manner and promote integrative approaches and comprehensive child evaluation and intervention. Specifically, they noted that the new **Law on Early Childhood Education** calls for the development of a framework and mechanisms for cross-sectoral coordination and the integration of services. However, cross-sectoral coordination and integration have not yet been institutionalized, implying that

new strategies or mechanisms must be developed and implemented to ensure that this occurs. To overcome the compartmentalized approach to service provision, interviewees stated that ECI in Kosovo requires a new integrative approach and ECI services need to be further developed and specialized to ensure the holistic and balanced development of children with at-risk situations, developmental delays and disabilities.

Additionally, many interviewees stated that there is a lack of Kosovo-wide data and an analysis of the number of children who require ECI services. Indeed, none of the interviewed representatives of institutions stated that they have statistics on the number of children needing ECI services in Kosovo.

Of particular concern, was the finding that all interviewed parents declared that no ECI services exist in Kosovo, either at the central or community level! They all stated that they receive bits of services from different providers and that they do not have a person (case manager) coordinating the interventions for them and their child. They observed that in all cases, it is they themselves who must try to find, contract and organize services for their child.

In summary, an urgent need exists for an integrated approach to organizing a local ECI system, the formulation of a local ECI policy, plan and/or law, and for developing comprehensive and detailed ECI regulations in the form of ECI Service Guidelines and Procedures. This work is essential for subsequently preparing service and personnel standards, pre- and in-service training, and an effective system for supervision, monitoring and evaluation.

3.3 ECI services in Kosovo

While conducting the mapping study, the research team included various services for children and families, including local NGOs, community-based centers, preschool institutions, hospitals and even private clinics. Initial data from the literature review had indicated that the system of ECI in Kosovo is quite fragmented.²⁴ In addition, the review found that few providers offer sustainable high-quality, and integrated services. As previously noted, after the Mapping Study, 16 services were selected for inclusion in the study and Directors' Surveys were sent to all 16 directors of these services. However, after many reminders, only 8 directors/managers completed the survey. This may have been due to the length of the survey, doubts regarding whether they provided ECI-like services, or other factors that were not identified. In addition, only 20 ECI service personnel, and 16 beneficiaries completed their surveys. Because of these low response rates, study findings must be interpreted as tentative. Nonetheless, they give an insight into the current status of legacy and evolving ECI services in Kosovo.

Findings from the Mapping Survey revealed that several types of rehabilitation services for children with developmental disabilities and their families exist in Kosovo. These services were found to be mainly provided by the public sector, local NGOs, and private clinics. Most current service-providing organizations for children with at-risk situations and developmental delays and disabilities had been established after the war in Kosovo and during the last two decades. The first service-providing organization was founded in 2005, and the most recent - in 2019. As anticipated, these services were found to be fragmented, offering services in

²⁴ For the purposes of this analysis, "fragmented service" means not comprehensive and is understood as a separate health, education or social protection service, or service offered for specific types of disabilities or developmental disabilities.

one specific field, such as education, health, or social and child protection. They were not integrated, and none were found to have most of the major attributes of contemporary ECI services. However, the study discovered that several of them could potentially serve as a basis for developing multisectoral and interdisciplinary contemporary ECI services. Below we present the types of services identified through the Mapping Survey.

According to interviewees (parents/caregivers and personnel), most ECI services are delivered by NGOs. They believed that services would most likely be mainly provided by existing NGOs and in the future, by even more NGOs because the establishment, development, and maintenance of ECI services by public institutions might take considerable time and be difficult to finance. Therefore, these interviewees thought that governmental contracting of NGO services and possibly other private services might be a way forward. Respondents agreed that to ensure sustainability, these services would need to be consistently contracted for longer periods of time than is currently the case.

Health Services

Health services were based on the concept of Family Medicine, with Family Medicine Centers (FMCs) that have been established across Kosovo and provide universally available services in or near all communities. These Centers are organized and managed at the municipal level, with a single main FMC in each of the municipalities, and 153 additional FMCs, and 227 Ambulatory Services distributed across all 38 municipalities.²⁵ These Centers aim to offer efficient and inclusive healthcare services to all in need, through appointing a family doctor, that serves as an entry and referral point to other services. The FMCs include services for maternal and child health and nutrition, antenatal and post-partum care, immunizations for children, breastfeeding promotion, monitoring of child development, and prenatal nutrition for pregnant women (in limited cases). They seek to maintain an overall good quality of care and provide health care and child development services.

Services of the Home Visiting Program, established in 2013 have reached Kosovo-wide coverage. FMC personnel have received training that was based on a community health model rather than a purely medical model. Moreover, the same trainings are provided to educators and social service providers aiming to ensure a better linkage and service provision in an integrated way. These HV services are focused on child development using a holistic approach including nutrition, responsive parenting, fathers' involvement, early stimulation and education, and to some extent, early identification of developmental delays. They currently provide an important entry point for essential maternal and infant care including health, nutrition and child protection services. They could be further developed to conduct developmental monitoring and screenings for the early identification of children with at-risk situations, developmental delays and disabilities. Upon identification and with written parental consent, they could provide rapid and effective referrals to local or if need be, central ECI services once they become available. Lastly, they might also participate in transdisciplinary ECI teams and thereby contribute to and enrich the services of other primary ECI service providers.

According to interviews of representatives of the health sector, including nurses, primary health care divisions, FMC directors, municipal directors, medical doctors, a psychologist and university professors, the Home Visiting Program could conduct early identification and referrals to ECI intervention services for families and children in the natural environment

25 Angela Demas, Mrike Aliu, Sarah Coll-Black, Aglaia Zafeirakou, Aline Hankey, and Boryana Gotcheva (2021). A Situational Analysis of Early Childhood Development (ECD) Services in Kosovo. WORLD BANK GROUP

of the child that in Kosovo, is usually the home or a family-based childcare arrangement. The Program strives to ensure that children are healthy, well-fed, active, and developing properly as per health parameters and psycho-motoric and cognitive milestones. The visits are obligatory and are focused on (i) examining the infant development, (ii) child nutrition, and (iii) mother's emotional state. Two prenatal visits are planned as well as a total of five visits as per the following schedule: 1st visit within the first three days after the child is discharged from the maternal hospital, 2nd visit when the child is four to six months, 3rd visit 11-12 months, 4th visit 18 months, and 5th visit at 36 months. This program is intended to give services from the conception to 36 months of age.

The HV Program as such is not an ECI service, however they have the potential to play a significant role in developmental monitoring, in transdisciplinary teams, and in some cases the nurse might become a primary service provider for some children and families. It is understood that this work would require a formal inter-institutional agreement.

According to the interviewees, nurses are generally trained to detect delays and difficulties in child development; however, at present they do not conduct a developmental screening or provide parents with referrals to ECI services. The low number of nurses' visits would not allow them to become ECI visits, which are much more intensive, frequent and individualized. According to the health sector interviewees, the public health system does not offer ECI services for children and families. They observed and confirmed that in Kosovo, these services are usually offered by NGOs and private clinics. Furthermore, the Family Medicine Centers and the Home Visiting Program do not have a team of requisite ECI professionals, including psychologists, ECI specialists, speech/language, physical and occupational therapists, or social workers that could provide ECI services.

Education Services

Education services are mainly provided by preschool institutions and a limited number of community-based centers, including public-private partnerships, which often offer a range of services beyond education, including health screenings, nutritious meals, early identification of developmental delays (not uniformly provided), center-based stimulation activities for children, and support services for parents (not uniformly provided). In public preschools, FMCs also provide routine health check-ups free of charge. However, as previously noted, participation in preschools is limited, especially for disadvantaged populations.

Although educators are generally well prepared for the early detection of developmental delays and disabilities and for making referrals to other services, the focus of preschool and pre-primary education is still mainly on providing general education services, and very few inclusive ECE services were mentioned. The educators, particularly those who graduated recently, are equipped with knowledge on early detection, but they lack the experience and tools to conduct developmental screenings and assessments, hence there is no systematic and standardized approach in place that uses on validated tools. In addition, the low level of enrollment in preschool and childcare services below five years of age suggests that the education system currently is unable to play a major role in providing universal and regular developmental screening and referrals to ECI services. However, the collaboration and coordination of preschool and childcare services should become more important as they expand over time, and they should become fully involved in the development of local ECI services from now onward.

Social Protection Services

Social and child protection services are mainly provided by Centers of Social Work, which have been established in each municipality to provide support to young children and families through social services and social assistance, including generalized support, specialized services responsive to at-risk and vulnerable family situations, including violence, child abandonment, and children with disabilities, and targeted anti-poverty initiatives, including cash and in-kind assistance, for families and children facing severe financial instability. Child protection is at the core of these services, rather than conducting early detection and early intervention for child development. Services are offered by social work professionals, who in most cases do not have additional preparation or training for ECI services. Small numbers of social workers are also trained to use the Home Visiting training package, which is the same package as for the nurses. They too might become part of specific transdisciplinary teams formed by ECI services. They could also refer children and families to ECI services whom they believe would benefit from receiving this in-depth support and they could help families to network with other service providers in the community, in accordance with their needs.

Non-Governmental Organizations

No exact statistics or lists could be found regarding the number of NGOs that provide some form of services for children from birth to six years with at-risk situations, developmental delays and disabilities. In Kosovo, numerous NGOs provide services for children with developmental delays and disabilities. However, many only serve older, school-age children and do not provide services for infants and young children. Some only provide educational support, and most tend to be project-based, lack diversified financial support, and tend to be unstable and less sustainable. Others focus on infants and young children, and they are beginning to provide elements of contemporary ECI services.

3.4 Coverage

No estimate of children with at-risk situations, developmental delays or disabilities was found in any study about children from birth to five years in Kosovo and no study of the rate of disability and other conditions in early childhood has yet been conducted in Kosovo. However, according to the UNICEF website for Kosovo (2023), 23% of children live in poverty, with 7% in extreme poverty. Developmental delays and disabilities are correlated with poverty. According to the Multiple Indicator Cluster Survey of 2019-2020, 4% of all children were stunted but 15% of children from Roma, Ashkali and Egyptian communities were stunted. Developmental delays and disabilities tend to be highly correlated with stunting. Given various socio-economic factors, such as poverty, ethnicity, lack of access to services, from 10% to 12% of children from birth to five years, are roughly estimated to need ECI services in Kosovo. One study in low and middle-income countries presented the rates of developmental delays per domain for children in Kosovo, as measured by the application of the Early Childhood Development Index (ECDI). Table X presents the findings for Kosovo:²⁶

Table 2: Proportion of children with suspected development delay in Kosovo (ECDI)

Domains	Percentages
Physical	1.5
Social-emotional	9.4
Learning	1.1
Literacy-numeracy	76.7
Early Childhood Development Index	8.7

In general, using the overall measure of the Index for Kosovo, up to 8.7% of children from birth to five years (36 to 59 months) may have a developmental delay and/or disability.

According to the birth statistics of the Kosovo Agency for Statistics for the period 2017-2021, there are 102,970 children born in Kosovo. This would yield a total of a minimum of 8,000 children who might be eligible for ECI services, and the total could be considerably more.

According to the Mapping Survey, 12 (75%) of the 16 service providers that participated serve low-income families, and 10 (63%) serve families from Roma, Ashkali and Egyptian communities. Twelve out of 16 (75%) provided services for children up to 61 months of age, whereas others (25%) provided services for older children as well. ECI services should be focused on providing services for children from birth to three years and up to five years, depending upon need. Given the low rate of participation in preschool education and the low availability of inclusive preschool education, ECI services appear to be needed from birth to five years of age.

All responding institutions and organizations considered that their services are based on the equity approach. Regarding the groups they target, they provided the following answers.

Table 3: Targeted beneficiaries

Type of beneficiaries	Responses	
Children with developmental delays (in one or more areas of development)	77%	10
Children with disabilities (all types of disabilities)	77%	10
Children with behavioral problems and emotional regulation (autism spectrum disorder, attention deficit and hyperactivity disorders...)	69%	9
Children with mental health needs (depression, anxiety, children with different traumatic experiences etc.)	46%	6
Children with at-risk conditions (pre-term, low birth weight, stunted, congenital problems)	38%	5
	Answered	13
	No response	3

Regarding the types of services offered, the 15 responses to this question in the Mapping Survey are presented below:

Table 4: Type of services

Type of services	Responses	
Early childhood intervention center-based services	73%	11
Early childhood intervention home visits	47%	7
Inclusive early childhood development services in a center, such as nurseries, childcare centers	40%	6
Inclusive pre-primary education services in a center	27%	4
Rehabilitation or habilitation therapy services in a center	20%	3
Community-based rehabilitation	13%	2
Other (describe briefly):	47%	7
	Answered	15
	Skipped	1

According to the eight directors that completed the Directors' Survey, 61% of the children receiving ECI-related services live in urban areas, while approximately 18% live in rural areas, and 14% in mixed urban/rural areas.²⁷ Directors of seven of the eight institutions and NGOs reported providing home visits, and six serve children who are enrolled in nurseries or other childcare centers. Both can be considered as natural environments of the child.

Regarding the geographical coverage of services, data from the Directors' Survey showed that five out of the eight institutions and organizations were situated in the capital of Prishtina. These included four evolving NGOs, two public health centers, one evolving private center, and one legacy rehabilitation center. All of them were serving families whose infants and young children have at-risk situations, developmental delays and disabilities. In addition, some entities were located in other municipalities, including Ferizaj, Shtime, Mitrovica, Prizren, and Fushe Kosove. A few service providers were also identified in municipalities populated by minority groups, such as Gračanica (mainly Serbian minorities) and Obiliq (a municipality with a mix of ethnic groups). Only one service provider stated that its program serves children throughout Kosovo. Interviewees observed that ECI services are mainly available in urban areas, and that few to no services are available for families living in rural areas.

Of the eight service directors who responded to the Directors' Survey, the number of children who received services varied greatly, ranging from 54 to 450 children. In 2021, most children who received services were of Albanian ethnicity. However, it is essential to note that children from other ethnic minorities also received services, namely 125 Roma children, 317 Ashkali children, and 51 Egyptian children. It is notable that approximately 25% of services were delivered to children from Roma, Ashkali and Egyptian families, and from other ethnic minorities who tend to have significant developmental needs often due to poverty and a lack of access to basic health and social welfare services. Although from a small sample, this trend toward service equity is a most positive finding.

According to the Directors' Survey, a smaller number of boys (7,931) than girls (8,138) received services, and usually boys have a slightly higher rate of disability. In the Beneficiaries' Survey, parents reported the following age ranges for their children receiving ECI-like services: percentages of children aged birth to 36 months (38%), 37 to 60 months (31%), and above 60 months (31%). Once ECI services become well established, it will be import-

27 Two programs stated they have no data.

ant to regularly review age ranges because ECI services should focus most on the birth to 36-month period, when the brain of children is most rapidly developing and neuroplasticity is high.

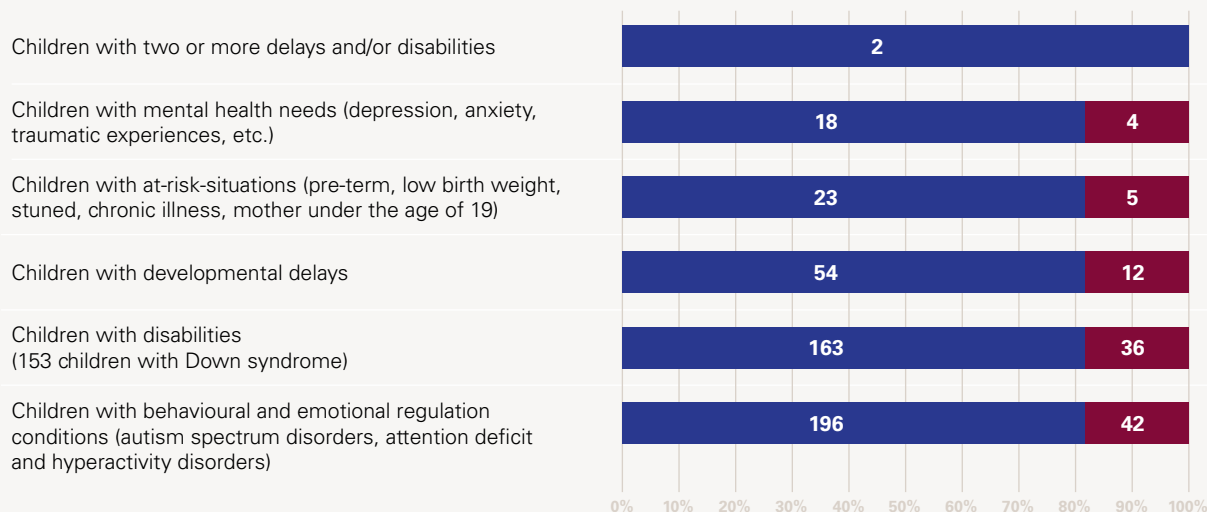
In their surveys, directors and service personnel were asked about the groups of children they served according to the types of developmental delays and disabilities they had identified. The earlier reported total children served included many who were receiving general health care services. Regarding child status, according to directors, a total of only 456 children were currently receiving services due to a disability. In contrast, personnel reported serving 312 children with disabilities (See Figure 1 and Figure 2).

Both directors and service personnel reported they provided services to approximately the same percentages of children with all types of disabilities (36%/35%), and with developmental delays (12%/14%). Directors reported that they mainly provided services for children with behavioural and emotional regulation conditions (43%); however, service personnel, who were not necessarily reporting on the same cohorts of children, reported a considerably lower percentage of only 14%.

Overall, the data reveal how very few children with developmental delays and disabilities were served at the time this study was conducted.

Figure 1: Directors' responses on child conditions

Direct response on child conditions

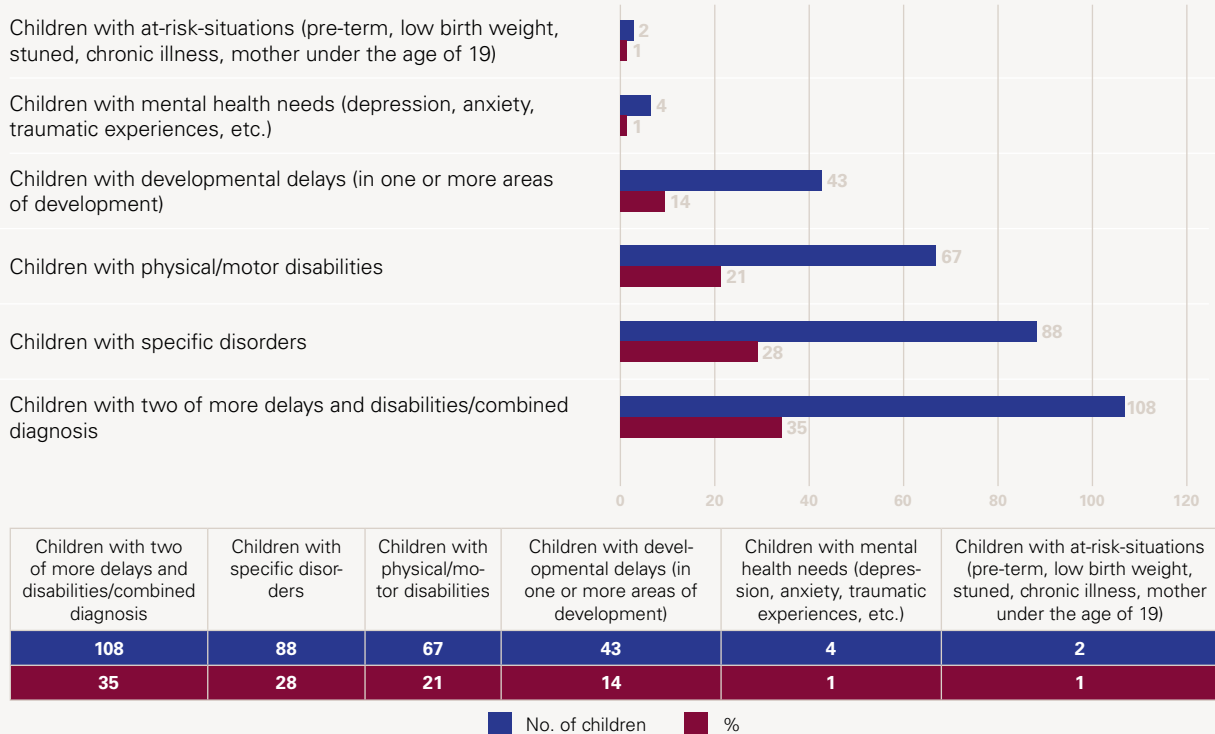


Children with behavioural and emotional regulation conditions (autism spectrum disorders, attention deficit and hyperactivity disorders)	Children with disabilities (153 children with Down syndrome)	Children with developmental delays	Children with at-risk-situations (pre-term, low birth weight, stunted, chronic illness, mother under the age of 19)	Children with mental health needs (depression, anxiety, traumatic experiences, etc.)	Children with two or more delays and/or disabilities
196	163	54	23	18	2
43	36	12	5	4	0

■ No. of children ■ %

Figure 2: Personnel’s responses on child conditions

Personnel response on child conditions



Regarding beneficiary reports on their children’s developmental status 6 out of 16 (38%) parents reported that Down Syndrome was the main reason they enrolled their child in ECI services. Others noted a speech/language delay (5, 31%), growth and development delay (5, 21%), chronic illness (3, 19%), and low birth weight, vision problems, attention deficit and hyperactivity, social and emotional problems (1, 6%).

Directors reported that only 5% of the children they serve have at-risk situations and 4% have mental health needs, while service personnel stated that only 1% of the children have at-risk situations and mental health needs, respectively. This difference in the percentage of children classified per condition by the directors and personnel might be either due to inaccurate recalling of statistics by directors, or to the difference in knowledge and capacities to recognize, follow up on assessment and support children as per their needs. However, to date, children with at-risk situations and mental health needs are especially under-served.

Regarding families’ socio-economic status, directors reported that most of the families receiving their services were at risk for poverty (11%) or lived in moderate poverty (49%) while 40% were not at risk for poverty. Service personnel reported that most families were at risk for poverty (37%) or lived in moderate poverty (25%) while (38%) were not at risk for poverty. These results are similar, and they indicate that considerable effort has been made to provide equitable services.



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Regarding employment status, the Beneficiaries' Survey found that 38% reported they were employed full-time and 6% were self-employed, while 31% were homemakers, 13% were unable to work, and 6% were unemployed and not looking for work. Thus, half of the sample were persons working at home, homemakers or unemployed and not looking for work. These findings reveal that having a child with developmental difficulties may have contributed to caregivers' ability to work outside of the home and to the challenges that families face, especially when living in poverty or near poverty.

3.5 Types of services and access

In the Directors' Survey, directors were asked to report on the types of services they currently provide to young children with developmental delays and disabilities and their families. Directors stated that they provide either a program with mixed features of the medical and social model (4, 50%) or a fully social model (4, 50%). Service delivery was reported to be center-based for two out of seven organizations, center-based with some home visits for four organizations, and one only provided home visits. Six organizations reported that they deliver multisectoral services (social support services, psychological, educational, and health services), while one of them said they offered integrated family-centered services.

As presented in Table 6, all eight institutions and organizations reported that they provided a wide range and types of services.

Table 5: Type of provided services

Type of Provided Services	No. of mentions	% of mentions
Comprehensive assessments of child development	6	8
Center-based group parenting education	6	8
Specialized assessments of child development	5	7
Psychological and/or psychiatric support and treatment	5	7
Developmental screenings of children	4	6
Speech/Language/Hearing Therapy Services	4	6
Occupational therapy services	4	6
Case management services and referrals to other services/programs	4	6
Health and nutrition education services	4	6
Assessments of parent-child interaction	3	4
Development of Individualized Family Service Plans (IFSP)	3	4
Parent education during home visits	3	4
Parent and peer support groups	3	4
Personal and household hygiene and safety education	3	4
Transition plans with parents, children and future service providers (principals and teachers in comprehensive pre-primary schools, primary schools, specialized schools, etc.	3	4
Assessments of child health, nutrition, health and hygiene	2	3
Assistance in obtaining assistive technologies (devices)	2	3
Community outreach activities to find potentially eligible children	1	1
Determining children's eligibility for ECI services	1	1
Physical therapy services	1	1
Audiology Services	1	1
Online visits	1	1
Parental care services	1	1
Vision therapy services	0	0
Other	1	1
	71	
Answered	8	
Skipped	0	

The responses reveal that several ECI service providers offer various elements of contemporary ECI services while others mainly provide health or social support services for children with developmental delays and disabilities and their families. Particularly noteworthy is the moderate level of reports regarding comprehensive developmental assessments, parent education, various therapy services and case management services. However, low reports are of concern regarding assessments of parent-child interaction, the determination of eligibility, development of IFSPs, parent education during home visits, home safety, physical therapy, and the preparation of transition plans. Overall, these data show the evolution of services from rehabilitation to contemporary ECI services is underway given the use of parent education, child developmental assessments, IFSPs and interdisciplinary services; however, considerable training, coaching, and mentoring will be needed to achieve the goal of providing fully contemporary ECI services.

Regarding service intensity, public health institutions reported that they provide various services for children with developmental delays and disabilities and their families (in 68% of the cases direct services, others are referred to specialists); however, service personnel of NGOs reported providing services for children with developmental delays and disabilities three to four times a week (19%), once to twice a week (8%), or once or twice a month (4%). Although service flexibility was found, guidelines regarding service intensity will be needed to develop an effective local ECI system.

Service personnel reported that 67% of the children they serve receive 30-minute visits, which is usually too short a time to be very effective. Some 22% of children are given one-hour visits. The remaining children receive two-hour visits (6%), and 3% receive four-hour visits. The latter usually pertain to clinic-based rehabilitation sessions. Home visits tend to range from 45 minutes to one hour, and they tend to be more effective due to providing opportunities for a high level of parental participation.

A total of 11 out of 19 service personnel (58%) reported that they meet with the child and parent together and they coached and supported the parent. However, five (26%) meet with the child alone, and three with the child with the parent present (15%), both of which are not ECI family-centered methods but rather traditional rehabilitation approaches where the focus is on the professional.

In the Directors' Survey, five out of eight directors of institutions and organizations reported that they place significant attention on family environments and support networks while three other directors expressed a growing interest in addressing family environments and building support networks.

In terms of team approaches, four organizations (57%) reported that the individualized family service plan (IFSP) was prepared by a transdisciplinary team with parents as full members. In contrast, three organizations (43%) reported they only use physicians, therapists or other professionals) to prepare the IFSP for the child and family. Again, evolving programs were identified.

In terms of types of services provided to families, two organizations (29%) mentioned that they work with the child and the parent is an observer, while five organizations (71%) work with the child and parent together and they coach and support the parent.

Eleven beneficiaries, reported their participation as presented in Table 7.

Table 6: Parent participation

Parent participation (number)	In all visits	In some visits	In few to no visits	Total
If home visits are made, how often do you participate in activities for early childhood intervention with your child?	4	1	1	6
If visits are in a center, how often do you participate in activities for early childhood intervention with your child?	7	4	0	11
Answered				11
Skipped				5

It appears that most beneficiaries felt they were welcome to participate in most visits, whether in a home visit or a center.

However, regarding the type of professional support, six out of 13 beneficiaries reported that only one person worked with their child while two reported that only one person worked with them and their child together. At the same time, three reported that a team was assigned to work with the child alone. Thus, parents may be reporting the reality of services while service personnel and directors' observations may be more aspirational.

Additionally, ten out of 14 beneficiaries reported an IFSP had been developed for their child. However, only three out of 11 of the beneficiaries noted that they participated in making decisions regarding services their child needed. Instead, six reported that the professional team decided on the types of services their child would receive, two said that only one professional made the decisions for them, and only three reported that they had made the decisions after discussing options with the team. Eleven out of 12 reported that they signed and dated their child's IFSP. Thus, the preparation of some form of an IFSP has been integrated into a small number of evolving ECI service organizations in Kosovo. However, considerable further training will be needed to establish a common IFSP format, processes, and methods as well as to guide the establishment, processes and methods for creating transdisciplinary teams and enabling family-centered decision-making.

In interviews with beneficiaries, they agreed that once children's development was assessed, the focus of the ECI work was on stimulating the development of specific functional abilities (speech, motor development, cognitive abilities, etc.). Three parents reported that they have an impression that the same model of stimulation is sometimes offered to different children, indicating a lack of an individualized approach. Based on the Beneficiaries' Survey, only three of them reported that the child had a development plan (IFSP) and that they had participated in its drafting. This confirms that IFSPs are not fully implemented in ECI services in Kosovo.

Additionally, parents stated that there are no formal or substantial programs available for the provision of systematic ECI services, specifically for children with developmental delays or disabilities. They observed that some specialized services exist for children with autism, Down syndrome, or children with physical disabilities; however, services for children with neuro-developmental delays are not available.

Barriers to access

According to findings from Directors' Surveys and Service Personnel Survey, major barriers to accessing ECI services were related to the stigma associated with disability (29%/15%), ECI services located too far from families' homes (18%/13%), the general lack of knowledge about ECI services (12%/9%), and the low family incomes that render parents unable to pay even for transportation to the location where services are offered (12%/13%).

Barriers reported by beneficiaries are presented in Table 8.

Table 7: Barriers families faced in accessing ECI Services according to beneficiaries

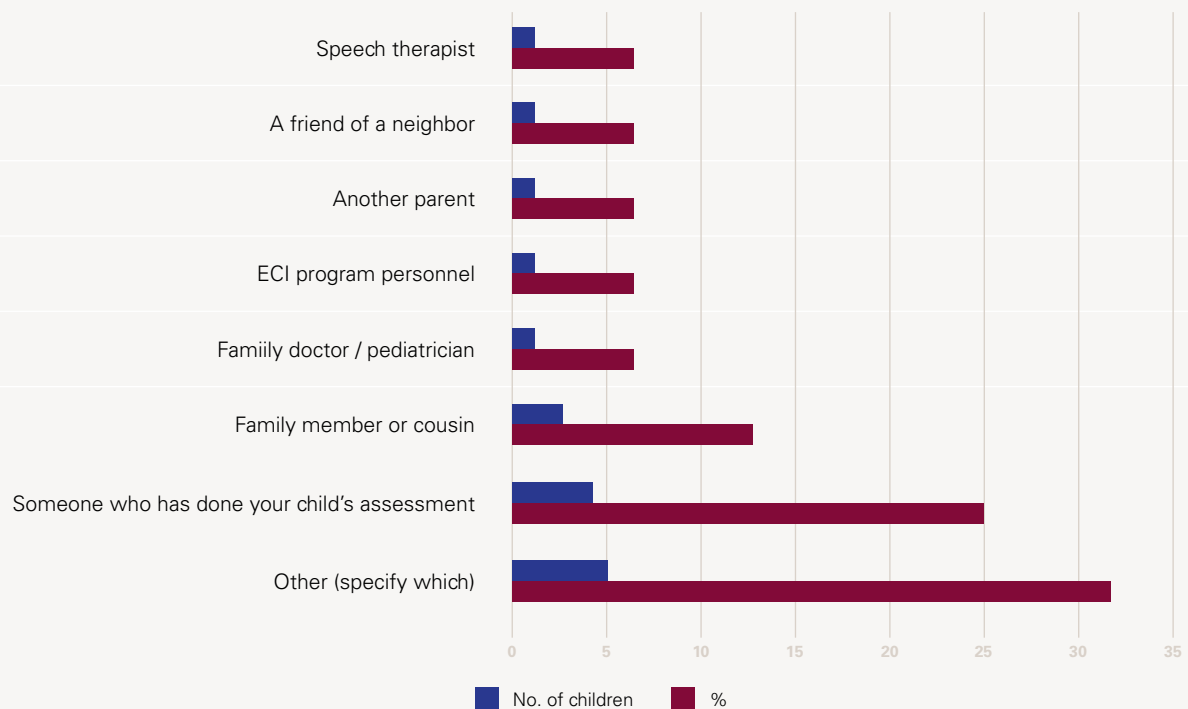
Barriers you faced	No. of mentions	% of mentions
I had no information about ECI	6	35
There are no ECI services in my community	1	6
ECI services are far from my house	1	6
It was difficult to find transport to ECI	1	6
It was difficult to find a referral for ECI services	1	6
There was a long waiting list for ECI services	1	6
The registration process was difficult	1	6
There is no specialist in the area my child needs	1	6
The costs of ECI are very high	1	6
Answered	14	
Skipped	2	

The findings from the Beneficiaries' Surveys support the findings from the Directors' and Service Personnel Surveys, showing that most beneficiaries did not know about ECI services and learned about them only through word of mouth, either from someone who had received ECI services (four out of 16, 25%) or through family members (two out of 16, 13%). Only one (6%) mentioned that they had received information from pediatric services and/or ECI program personnel or speech therapists. Five (31%) beneficiaries answered "Other" to the question: "Who told you about the center with activities for early childhood intervention where your child is enrolled?" Responses included:

- » Down Syndrome Kosovo (2)
- » I have knowledge of my own (1)
- » Various trainings and reading of psychological literature (1)
- » Community mobilizer (1)

Figure 3 provides further information.

Figure 3. Knowledge about the ECI services²⁸



Nine out of 16 (56%) of the beneficiaries reported that they were on waiting lists for receiving services. In terms of length of time on waiting lists, six out of nine beneficiaries reported they had waited less than three months, whereas two stated they waited from three to six months for services.

Five out of 15 beneficiaries reported that they inquired about services when their children were one to six months old (33%), whereas three (20%) inquired about services when their children were either seven to 12 months, and another three (20%) responded that their children were 13 to 24 months of age. Only one out of 15 beneficiaries (7%) reported that they inquired about services when their child was still a newborn (up to one month). A major need for advocacy and social communications about ECI services exists at the community, municipal and central levels, and in every relevant sector.

Parents stated in the interviews that access to information on available services and access to them is very limited. Parents reported that no effort had been made to provide information to families in need of ECI services and no coordinated effort had been undertaken to provide these services. In most cases, the identification of childhood disabilities came from the parents/families themselves or their preschool teachers. When informed that their child was not developing as expected, parents reported that they faced hardships in finding a professional to conduct a comprehensive assessment. Many reported that they didn't know where to go, so they went to the doctors. Others stated that they sought the support of psychologists. In all cases, they agreed that finding proper services was very difficult. Subsequently, they said they found it very challenging to secure a correct "diagnosis" and professionals who could conduct a comprehensive developmental assessment. Those who

28 Others include specific NGOs, or other information sources (trainings, written information)

were not from Prishtina reported that they had travelled to Prishtina because no services were available in their municipalities. Some reported that they had sought support outside of Kosovo.

Service personnel noted inequities regarding access to ECI services since no nationwide system yet exists in Kosovo that aims to identify developmental difficulties, including children at higher risk. They identified the home visiting program of the health sector as a possible major nationwide entry point for developmental monitoring, screening, and referrals to ECI services. They noted the absence of a proactive approach to early detection and intervention on the part of all sectors.

Besides services that these families receive from the organizations to which they were referred by other professionals, they needed to pay for other services. In some cases, they stated that even though the child was receiving services from an organization, the personnel requested additional assessments or analyses that needed to be done elsewhere and usually these services had to be paid by the families themselves. In the Beneficiaries' Survey, only three out of 16 stated that they pay a fee for the ECI services, and seven reported they receive some social benefits that cover the cost for ECI services for their child. However, during the interviews, parents reported that the service costs of a child with disabilities in the family are very expensive. They also said they felt that their cost was the lesser problem, whereas the lack of services and/or the fragmentation of services was their biggest challenge. According to parents, public institutions offer the bare minimum of services due to a lack of specialized human resources and infrastructural capacities, whereas services provided by private institutions are very expensive.

3.6 Screenings, assessments, eligibility

In the Directors' Survey, several developmental screening instruments were listed. They included two measures that have been validated in other countries: the Ages and Stages Questionnaire II and III (ASQ II and III) and the Denver Developmental Screening Test II. Regarding comprehensive developmental assessment instruments, directors listed the following: Assessment, Evaluation, and Programming System (AEPS); Battelle Developmental Inventory 2 (BDI 2); ABLSR, Growth and Development Standards based on the child's age; and Vineland II. Other directors mentioned some program-specific child assessment forms, without providing any details. It is evident that several instruments have been used for screening or for the comprehensive evaluation of child development. As yet, no single developmental screening instrument or comprehensive developmental assessment instrument has been selected for Kosovo-wide use by ECI services, although some programs are familiar with one or more of these instruments. It will be important to select a validated and approved developmental screening instrument and one or two comprehensive developmental assessment instruments for use in all ECI institutions and organizations of Kosovo.

According to high-level interviews, a common agreement has not been reached regarding professional profiles and the types of teams that should become responsible for the assessment of children with at-risk situations, developmental delays and disabilities. Currently, different types of professionals mainly use specialized instruments in a separate manner to evaluate the specific developmental needs of children. Less emphasis has been placed on

comprehensive developmental assessments that enable the measurement of all developmental domains. Often children have a disability in one domain and unidentified delays in others, making it essential to gain a comprehensive picture of the child's needs for purposes of planning to address and achieve well-balanced child development.

Eleven of 14 (79%) beneficiaries reported that they participated in the screening process of their children, whereas two (14%) did not participate in screening, and one (7%) only observed but did not participate in the process. Thirteen (81%) beneficiaries stated that a comprehensive developmental assessment process had been conducted with their children. Seven of 12 (58%) beneficiaries reported that a team of professionals (such as psychologists, special educators and/or therapists) conducted the assessment.

Health sector interviewees described the process of screening and assessment. The approach is individual and depends on the child's age. At birth, hospital staff conduct the first assessment with the Apgar test, and they measure the infant's height, weight, head circumference, and sensory and motor reflexes. They noted that no universal system for developmental screening exists in Kosovo. Some physical and cognitive measures are conducted during home visits, three data collection methods are used as sources of information, during each home visits. Measurements are taken of the child's weight, height, and head perimeter, and a health screening is conducted using age and milestone-based standards. Nurses fill out a form during their planned visits which includes questions focused on identifying delays or difficulties in child development. The second method is child observation, upon which a narrative statement is provided by the nurse in the report. No specific observation protocol in place; however, interviewees stated that an observation of child development is part of the training program. In the third method, an interview is conducted with the mother and/or parents that requests information on the baby's milestones (i.e. first words, first steps), diet, vaccinations and other characteristics. All developmental data are collected in the form of an anamnesis (parent's account) to determine which developmental milestones the child has attained. If there appear to be reasons for concern regarding the child's development, the child is referred to the family doctor in the respective Family Medicine Center, who then proceeds to assess the child's status. The doctor may refer the child to a pediatrician, orthopedic doctor, neurologist, psychologist, etc.

One health representative pointed out that the current law on child protection foresees that each municipality is expected to have a case management multidisciplinary roundtable (taskforce), who would also tend to for children with developmental delays and disabilities. The Law foresees a special sublegal act that will determine detailed procedures, however, according to this health representative, these multidisciplinary roundtables are to be responsible for conducting thorough assessments and preparing individual treatment plans. According to this representative, this law is still in its initial phases of implementation, and many parents and other stakeholders are unaware of its existence.²⁹

In the Directors' Survey, only five out of eight directors responded to a question on eligibility. A medical diagnosis with a comprehensive developmental assessment prior to admission is required by two directors, whereas two admit children with evidence of at-risk status, and one stated that they only require a medical diagnosis. These results are not surprising because no local guidelines and procedures for ECI eligibility yet exist in Kosovo.

29 It is important to note that this law's approach would separate child identification, assessment, and planning functions from family-centered ECI services. This situation would lead to separating comprehensive assessments from IFSP preparation, lower service quality, unnecessary duplications of services, and ultimately, much higher costs.

3.7 Referrals

Regarding referrals, three out of seven directors of institutions and organizations reported that they accept medical and community referrals, while two accept physicians' referrals; however, only one provider undertakes a proactive approach and conducts community outreach and developmental screenings in the community. Table 9 presents the full array of methods of referral.

Table 8: Method of referral

Method of referral	No. of mentions	% of mentions
Parents call or visit your program to request ECI services	5	19
Your program receives referrals from health centers and children's hospitals	4	15
Your program trains others (parents, nurses, preschool teachers, community health workers) to perform developmental screenings and make referrals to your ECI program	4	15
Your program receives referrals from Neonatal Intensive Care Units (NICUs)	3	12
Your program performs developmental screenings	3	12
Your program receives referrals from daycares, childcare centers, and preschool levels	3	12
Your program receives referrals from the social welfare programs	3	12
Your program personnel visit families in the community to find children who may need ECI services	1	4
	26	
Answered	7	
Skipped	1	

In interviews with health sector representatives, they stated that after the child is referred by the family medicine doctor to see a specialist, there is no structured referral pathway to ensure that the child is followed up and has received a developmental assessment, and if eligible for ECI services, appropriate individualized interventions. In summary, as also corroborated by parents, a structured system for community outreach, developmental screening, developmental assessment and medical diagnosis, multiple points for referrals, and consistent follow-up does not yet exist. Instead, parents have to search for and find services on their own. This leads to late identification, the loss of precious time for family support and child development, and deep frustration on the part of parents.

3.8 Home- and center-based services, transition planning and parent participation

Contemporary ECI service methods are beginning to be used in some service organizations. In the Directors' Survey, four out of seven directors stated that their program forms interdisciplinary teams for planning, and each member works separately with the child, two reported that their professionals work separately with each child, while only one stated that their program forms transdisciplinary teams for each family with one main service provider who receives professional support from the members of the team.

The following table presents the activities where the directors stated the parents participate in their programs:

Table 9: Parent participation according to directors

Parent participation in	No. of mentions
Comprehensive developmental assessments	5
Assessments of parent-child interaction	5
Specialized assessments (e.g., language, motor development, etc.)	4
Transition Plans	4
Assessments of home safety, health and hygiene	3
Developmental screenings	2
Preparation of Individualized Family Service Plans (IFSPs)	2
Total	25
Answered	6
Skipped	2

Additionally, according to the directors, only three out of eight organizations (38%) reported that they provide regular home visits for children enrolled in their program. According to the Table 11, only one organization reported that they provide regular home visits or visits to the child's other natural settings (childcare centers, preschools) to approximately 70% of the overall number of children they serve. Another organization reported that they provide regular home visits to only 10% of the children. Six directors skipped this question.

In terms of the number of visits per day, the Directors' Survey found that in two out of three organizations responding to this question, each home visitor averages three to four home visits per day, while in one organization visitors complete only one to two home visits per day. According to directors, the average number of children visited in one month by each home visitor ranged from five or fewer for two organizations, and ten to 15 children for one organization. These are low rates of home visitation unless they are also making visits which children and caregivers or parents who are in a childcare center or preschool.

According to the interviews with high level respondents, there are no family-based services except the aforementioned Home Visiting Program of the health sector that is conducted in all municipalities by trained nurses of the Family Medicine Centers, although it is not an ECI service. To the knowledge of these interviewed officials, very few services specifically target the parents or families of children who need ECI services. However, the interviewees

considered that the Home Visiting Program provided by trained nurses to newborns might be the most viable option for identifying children at risk and parental needs, and for connecting families with ECI services, including comprehensive developmental assessments, IFSPs and service provision.

Additionally, six directors out of eight reported that they provide regular services. Five of the directors reported that these services were mainly facility-based, serving approximately 70% of children at the facility, while one organization reported that they provide facility-based services for at least 10% of the children that they serve. According to two directors (66%), professionals provide an average daily number of sessions to five to six children, while one organization reported that its daily average is only one to two children. Five organizations reported that their monthly caseload is 21 children or more, whereas only one reported serving five or fewer children per month. Regarding the number of program sessions provided for each child, four out of six organizations (67%) reported that they provide seven or more sessions each month to each child. In contrast, one organization reported that their professionals provide three to four sessions per month per child, and one organization reported that they provide one to two sessions per month per child. Clearly, both guidelines and procedures as well as comprehensive ECI training are needed by all ECI service organizations and their professionals and paraprofessionals to support them well and help them to maximize the use of their resources by means of serving more children, especially given the manifest need for expanded ECI services in Kosovo.

According to the Directors' Survey, only one organization offers tele-visits, and these services are provided to from one to two families with children per day, with a caseload of five children per month. However, it is important to note that in response to another question, the directors of two centers mentioned that they use blended ("hybrid") sessions, including home visits, center-based sessions, and tele-visits. In the field of ECI, increasingly, this modality of sessions is being used, depending on child and family needs and preferences.

These findings are similar to those from the Beneficiaries' Survey. As noted in Table 12 seven (46%) of beneficiaries reported that they receive services in the ECI center, four (24%) in another center, two (12%) in their child's kindergarten, daycare center, or preschools, and two (12%) receive visits both at home and at the ECI center, while only 1 solely receives home visits.

Table 10: Places where ECI services were provided, beneficiaries' response.

Place ECI services given	No.	% of mentions
In the ECI center	7	46
In another center	4	24
In other places where my child regularly spends time (such as Kindergarten, daycare, school)	2	12
Both at home and at the ECI center	2	12
In my home	1	6
Answered	16	
Skipped	0	

Additionally, in the Directors' Survey, three directors reported that they offer parent education during home visits, while six directors stated they rely on providing parent education through center-based groups.

Moreover, in the Beneficiaries' Survey, six out of 14 beneficiaries reported that they have received family support or consultation services, six out of 14 reported they have received sessions with other parents involved in the program, and ten out of 14 reported they are provided educational sessions. Four out of 14 beneficiaries received referrals to health and education services, whereas one parent reported that they were offered support groups for siblings. According to eight out of 15 beneficiaries, they received more than three sessions per week, whereas six beneficiaries received two sessions per week. Parenting groups may be a preferred way for Kosovar parents to receive parent support; however, for individualized services, it is essential to offer parents opportunities for mentoring and coaching. Both approaches complement each other and help meet the needs for companionship, peer group support, and individualized attention to the specific goals of the family and their child.

However, when parents were asked in one-on-one interviews about services provided to families, most indicated that these services are only on paper. Two parents said that they attended support groups with other parents that were facilitated by their organization; however, they reported that they did not receive individual or family counseling and support.

Regarding the transition from ECI services to other services, in the Directors' Survey, six out of seven directors stated that they involve parents in preparing a transition plan and work with early years teachers to support the child and family's transition to an inclusive pre-primary or primary school. One director reported that their services do not prepare a transition plan, but that children are increasingly being sent to an inclusive school. This interest in transition plans seems to be quite strong.

3.9 Human resources, professional development, and quality assurance

In the Directors' Survey, information was requested about their paid staff members including supervisors, professionals, paraprofessionals and support staff. All eight directors reported having a total of 182 paid staff members, with an average of 22.7 staff members per organization, with a minimum of five and a maximum 47 staff members.

Regarding professional staff members, it was noted that the profession of "early intervention specialist (EIS)" now found in many countries, does not exist in Kosovo. The paid staff come from a wide variety of disciplines, as presented in Table 13 below:

Table 11: Paid and volunteer staff working in ECI or ECI-related service providers.

#	Professional disciplines	No of staff in 8 ECI organization
1	Psychologists	40
2	Early childhood educators	27
3	Comprehensive primary education teachers	22
4	Early childhood development specialists	20
5	Rehabilitation specialists	19
6	Speech therapist and language therapists	15
7	Public or community health workers	13
8	Social workers	10
9	Nutritionists	5
10	Law and human rights specialists	4
11	Medical personnel	4
12	Physical therapists	3
13	Managers and administrators	25
14	Paraprofessionals (caretakers/assistants who help professionals, conduct activities with mothers and children, and help with administrative work)	5
15	Volunteers	89 (from a minimum of one to a maximum of 30)

Three directors of institutions and organizations out of a total of seven, stated that they hire paraprofessionals and train them for the job. Of the 20 staff members that participated in the Service Personnel Survey, 19 (95%) are female, 13 (65%) are between 20 and 29 years old, four (20%) are between 30 and 39 years old, 3 (15%) are above 40 years of age. Thus, currently, personnel are largely young women.

In the Service Personnel Survey, they were asked about the types of services they provide to beneficiaries. Table 14 below outlines these services.

Table 12: Types of services that personnel provide

Services that personnel provide	No. of mentions	% of mentions
Psychological and/or psychiatric support and treatment	8	10
Occupational therapy services	7	9
Developmental screenings of children	6	7
Comprehensive assessments of all domains of child development	6	7
Assessments of parent-child interaction	5	6
Parent and peer support groups	5	6
Specialized assessments of child development	4	5
Parent education during home visits	4	5
Health and nutrition education services	4	5
Personal and home hygiene and safety education	4	5
Assessments of child health, nutrition, health and hygiene	3	4
Individualized Family Service Plans (IFSPs)	3	4
Physical therapy services	3	4
Speech/language/hearing therapy services	3	4
Case management services and referrals to centers	3	4
Transition plans with parents, children and next service providers (principals and teachers in inclusive pre-primary schools, primary schools, specialized schools, etc.)	3	4
Respite-care services for parents	3	4
Community outreach activities to find potentially eligible children	2	2
Establishment of eligibility of children for ECI services	2	2
Parent education in center-based groups	2	2
Help to obtain assistive technologies (equipment)	1	1
Tele-visits	1	1
Audiology services	0	0
Vision therapy services	0	0
Other (please specify)	0	0
	82	
Answered	18	
Skipped	2	

These responses generally appear to reflect the evolving status of ECI services in Kosovo, revealing that in addition to a wider range of professionals, considerable training in ECI methods and processes is needed.

In the Service Personnel Survey, nine out of 19 (47%) responding professionals working in the eight organizations, reported receiving approximately 40 hours of annual in-service professional ECI training, eight (42%) reported receiving around 20 hours, and two (11%) reported receiving less than 10 hours of training. Opportunities for in-service training were obtained through professional conferences (26%), online education courses (23%), and professional training workshops (23%). Additionally, three out of 20 (6%) reported having opportunities for inter-site exchange visits, and eight (15%) for continuous on-site in-service training. Most of them reported that they will need additional training to work effectively in contemporary ECI services.

In terms of supervision, the directors of five out of six organizations responding to this question reported that they have at least one ECI staff member who supervises other ECI staff members. The directors reported that the types of supervision most used are mentoring (six), coaching (five), review of child and family files (five), reflective supervision (four) and observation of center-based visits (four). On the other hand, in the Service Personnel Survey, personnel reported that only ten out of 20 (50%) were provided mentoring, nine (45%) with observations of their center-based visits, eight (40%) with reflective supervision, eight (40%) with coaching, and eight (40%) with reviews of child and family files. Additionally, two out of 20 (10%) of the personnel reported that they did not receive any supervision. All in all, a great deal of supervision already exists in these services. Undoubtedly, though, more training in reflective supervisory techniques could be helpful.

As noted, health sector representatives stated in personal interviews that nurses in the Home Visiting Program are specifically trained to assess child development. They attend a total of 35 hours of additional training, of which 7 hours are dedicated specifically to identifying developmental delays.

Because no early intervention specialists (EIS) are known to be available in Kosovo, specialists trained for example in clinical psychology, often work with young children with developmental delays and disabilities. Most of them are employed in NGOs or have private practices. Such specialists, who already have professional education and some field training and experience, might be invited to pursue additional training to become Kosovo's first well-trained EIS.

In interviews with service personnel, they too noted the lack of a specialized professional profile called an EIS. They also stated that there is a need for cross-sectoral coordination and for trained specialists with the capacity to do early identification and early childhood intervention services in both governmental and civil society organizations. During the last four years, early identification, and inclusive early education has been incorporated to some degree into the pre-service training curriculum for ECE educators who have been hired to work in preschool education. Joint activities have been undertaken by the Faculty of Education and UNICEF to train in-service personnel for integrated and inclusive ECE service provision, which also included early identification and some aspects of early childhood intervention through play and education activities; however, this is considered only a first step towards professionalizing the approach to ECI. Preschool educators have received training in recognizing learning delays, communicating such findings to parents, and in explaining what they might do to support and help their child. However, they lack the capacity to intervene or address more pronounced developmental challenges of the child because there is a lack of services to support both the preschools and the families in this respect. As noted, families usually must find services by themselves, in many cases by visiting private clinics or therapists.

In addition to pre-service training, service personnel expressed a need for more in-service professional training for all specialized personnel working in ECI services.

Regarding salary scales, seven out of eight directors stated that they have a salary scale in place, whereas five out of seven reported that they require their staff to have professional certificates, and four out of seven said they have a career ladder for their personnel. This advanced level of professional regulations will be helpful for establishing salary scales, certification and career ladders for early intervention specialists and other professionals working in future ECI programs.

In the Directors' Survey, four out of eight (50%) directors responded that their programs have external supervision from government or agency offices. They reported that they are subject to supervision from the Ministry of Finance, the Ministry of Health, and the Department of Social Policy and Families (DPSF). An office for ECI Kosovo-wide supervision currently does not exist.

3.10 Monitoring and evaluation

Another key feature of contemporary ECI systems is the development of a Kosovo-wide system of accountability for ECI institutions and organizations and their services. Such a system includes both internal and external monitoring and evaluation processes. On the basis of the literature review, primary research and the Cost and Finance Sub-Study, no Kosovo-wide system of accountability for ECI services was found in Kosovo.

However, of eight reporting directors of institutions and organizations, six (75%) stated that they conducted internal monitoring and evaluation. Similarly, six (75%) reported they have a document stating their annual objectives, indicators, and targets for monitoring and evaluation, and a monitoring and evaluation manual. Because it was not in the scope of this analysis to review these documents, no comment can be made regarding the quality of this work, but it is positive to find a strong commitment to accountability. In addition, six organizations reported that they had received external evaluations. These results reveal considerable interest in ensuring a high level of service accountability, which is a positive and important attribute of contemporary, evidence based ECI services.

According to interviews with high-level representatives, in terms of monitoring ECI services, no Kosovo-wide monitoring and evaluation model specifically for ECI services is currently in place, and no specific licensing process exists for the provision of ECI services.

The Service Personnel Survey confirmed that no system for monitoring and evaluating ECI services currently exists. In addition, they noted a lack of funds for ECI services in central and municipal budgets. They also stated that they all are funded by or officially registered, licensed, or certified by the central government but for other services. No certification or registration for providing ECI services yet exists.

3.11 Networking and Intersectoral coordination

ECI coalitions and networks usually include NGOs and other civil society organizations. Sometimes they include governmental ECI services or offices at the central and municipal levels. In countries such as Georgia and Moldova, ECI coalitions coordinate their work with ministries, parliament, other service organizations, parent associations and universities. ECI coalitions and networks work to 1) promote high-quality and equitable ECI services that support all parents and caregivers of ECI-eligible young children with developmental delays and disabilities, 2) expand, improve, fund and strengthen their services, and 3) provide or help to coordinate pre- and in-service training.

Based on the literature review and primary research, no coalition or network of ECI organizations was found in Kosovo. Out of eight responding service providers, only four reported

that their organization had participated in one or more networks. These four organizations reported that they network with the European Down Syndrome Association (EDSA), European Association of Service Providers for Persons with Disabilities (EASPD), and the Coalition of NGOs for Child Protection in Kosovo (KOMF). Three of these organizations conduct advocacy initiatives to improve services for and the status of adults and children with disabilities of all ages, including minority groups in rural and remote communities. KOMF is considered to be one of the local coalitions gathering all actors in the area of child protection and it also covers early childhood education and development. Although KOMF places priority on conducting advocacy for early childhood and their work on promoting integrated services is continuous, no specific activities were found to conduct ECI advocacy or to develop an ECI network or coalition.

Some high-level interviewees stated that they felt an umbrella association of organizations providing ECI services is not currently needed. Because only a handful of organizations offer such services, they believed they are already a part of all policy-making processes and consultations. However, Georgia and Moldova have found that their coalitions of ECI organizations have been very useful for advocacy, financing, and service expansion and improvement.³⁰

Intersectoral coordination and close collaboration are critical components of all successful ECI systems and their institutions and organizations. In the Directors' Survey, six (20%) directors reported that they coordinate and share referrals with Family Medicine Centers, community centers (six, 20%), social work centers (five, 17%), health centers (four, 13%), inclusive pre-primary schools (three, 10%), and inclusive primary schools (three, 10%). These findings are very positive; however, no formal intersectoral organization, strategy or activities for coordination were found for ECI, which doesn't allow ensuring continuity of support and follow-up.

During interviews with service personnel, they noted that families find it very difficult to benefit from services because they are unable to secure most services, they and their child need from the same service organization. They said that access to services is difficult, and in many cases, the service quality is questionable due to a lack of coordination, and the absence of an organizational structure, service standards, monitoring, and evaluation. They also stated that, most importantly, the lack of policies and regulations for ECI implementation and a licensing system for ECI organizations are major problems. However, they noted that there is a general lack of awareness and action to develop an early childhood intervention system. They thought that although many organizations offer services, most of them are specialized for a particular area of disability or another need, and they are not identified as ECI organizations *per se*. In addition, they felt that these organizations and their services are not complementary, and they are unable to meet all the needs for ECI services.

Linked to the previous point, personnel stated that there is no integration of these services at any level. There is no integration at the central level, and hence no integration at the local level as well. Most of the services provided in the education, health and social welfare sectors are currently isolated, compartmentalized and uncoordinated with other sectors. Although a case management process exists, it is implemented mainly in the Centers for Social Welfare. They have a referral system; however, in reality, referrals and the joint pro-

30 The Coalition of ECI Organizations of Georgia succeeded in expanding their membership from seven organizations to over 35 organizations, and they have secured strong governmental support, built confidence in the quality of their services, and attained almost full Kosovo-wide coverage.

vision of complementary services are not provided. At the municipal level, organizational structures are in place (i.e., case management roundtables), however, they mainly address child protection services and not ECI services, and they focus on high-risk cases rather than on prevention. All service personnel voiced a need for a multi-disciplinary approach, at both policy and service delivery levels.

All beneficiaries agreed on the need for integrated and community-based services located as close as possible to the children and their families. One representative recommended that coordination for preparing an ECI strategy and its services be led by the Department of Social Policy and Families because decisions regarding ECI services were usually made at the municipal level by the now outdated commissions. However, it was noted that this type of arrangement might miss many families who do not inquire about social services from public institutions.

Another representative pointed out that a thorough analysis of current laws on child protection, early childhood education, health services, and social services should be conducted to create and facilitate the conditions for establishing more coordinating mechanisms for integrated services. It was thought that this would enable the establishment of entirely contemporary ECI services. Social services are currently placed under the Ministry of Finance, Labor, and Transfers. It is planned that in 2023 social assistance component of services will remain under this Ministry, whereas social services are to be led by the Ministry of Justice. The division made might pose some challenges in the implementation of current law and further the coordination of services.

Another representative, suggested that inter-ministerial coordination and collaboration on ECI are recommended to be led from the highest level, the responsible structures at the Prime Minister's Office i.e. The Office for Good Governance.

Additionally, two representatives mentioned regarding technical support the need for technical consultants to help strategically design integrated ECI services, which would be relevant and affordable within Kosovar financial and human resource capacities.

3.12 Challenges

In the Directors' Survey, all eight service directors answered the question regarding their challenges and needs. Their answers represent a major appeal for increased support and organizational development for the provision of ECI services. The directors' top challenges included:

- » inadequate funding to meet ECI program costs and expand ECI services (6 out of 8);
- » inadequate policies, plans, laws and regulations for ECI organizations and services (5);
- » weak ECI organizational structure for intersectoral and financial planning (5); and
- » lack of awareness regarding the importance of implementing ECI services on the part of central and municipal governments to meet child and family needs (5).

Moreover, difficulties faced by families in accessing ECI services in remote areas and in communities with minority groups as well as the stigma and lack of inclusion of children

with developmental delays and disabilities in preschools and society were also mentioned. In the Survey of Service Personnel, they identified the main challenges of ECI services as:

- » stigma and lack of inclusion of children with developmental disabilities in communities (14);
- » inadequate funding to meet ECI center costs and expand ECI services (12);
- » difficulty in accessing and serving families in remote rural areas and minority ethnic groups (12); and
- » a lack of awareness of ECI services on the part of central and municipal governments (8).

In the Beneficiaries' Survey, the lack of information about ECI services was listed by six respondents, and all other options received only one response. This response demonstrates the great need for public advocacy and social communications for families and communities regarding the benefits, methods and content of ECI services, and perhaps, a lack of hope that much will be done to meet their and their children's needs.

In figures 6-8 below the main challenges are presented as reported by the different respondents including directors, service personnel and beneficiaries.

Figure 4: Directors' responses on challenges

Director responses on challenges

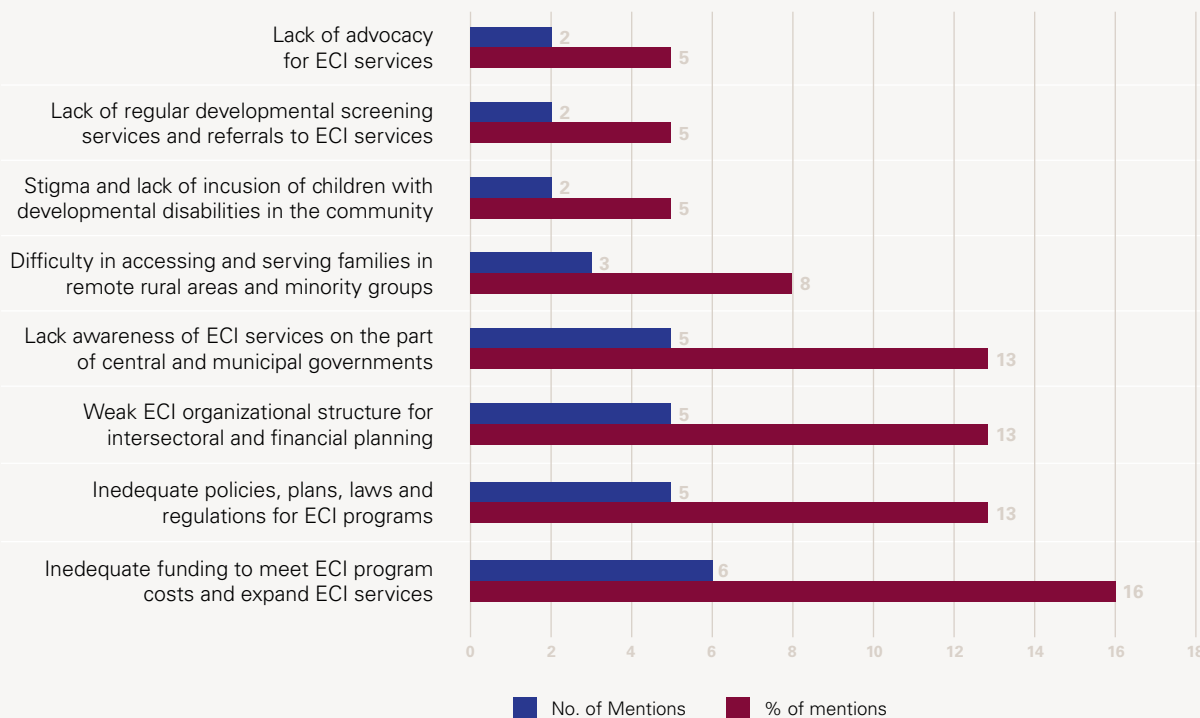


Figure 5: Service personnel responses on challenges

Personnel responses on challenges

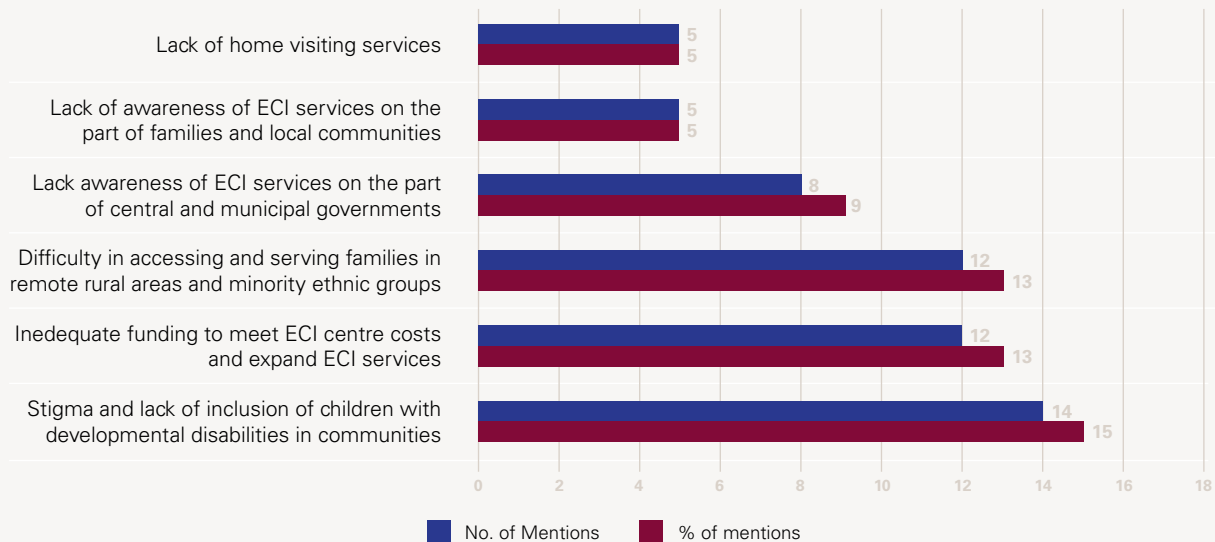
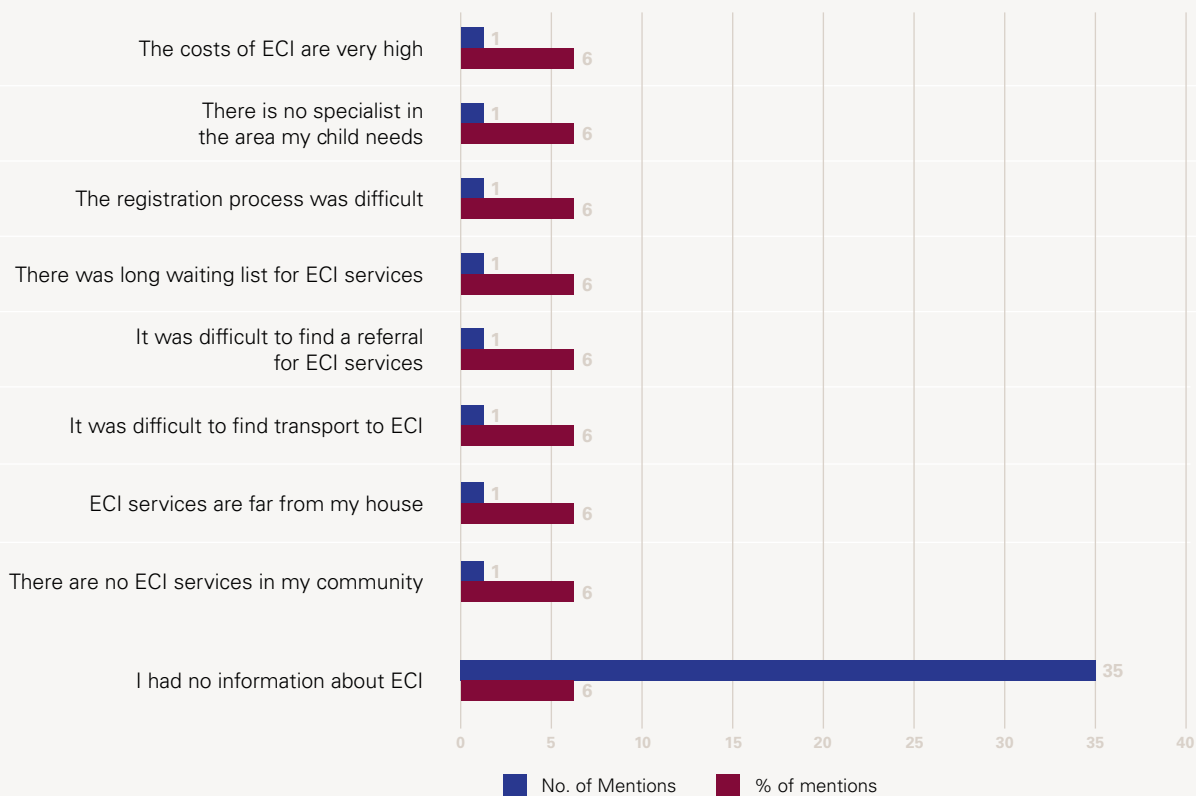


Figure 6: Beneficiaries responses on challenges

Beneficiaries responses on challenges



In the interviews, parents reported facing stigma, prejudice and judgement when looking for and accessing services. They observed a general lack of knowledge regarding factors affecting child development, a lack of awareness about services needed for children with developmental disabilities, and a lack of sensitivity and empathy on the part of professionals (especially in public institutions) in communicating and working with parents of children with developmental delays or disabilities.

Another important challenge expressed in high-level interviews was that no system of financing exists that is specifically targeted for ECI services. They believed that most of the funding of ECI services is dependent on municipal budgets which often invest very little in ECI services and are inconsistent in their funding. One interviewee recommended that specific financial support and training for the parents and caregivers of children needing complex childhood interventions be considered because currently, they are the backbone of support provided to their children. These comments reveal a deep concern regarding whether or not major change benefitting children with developmental delays and disabilities and their families can be achieved. However, many countries have developed thriving ECI systems, and with adequate political will, Kosovo could also achieve this goal for its children and families.

It is appropriate that we now turn to the Cost and Finance Sub-Study that addresses current finances for ECI services and also considers some possible ways forward to meet some of the challenges presented above.

4. COST AND FINANCE SUB-STUDY

The objectives of this sub-study are to 1) describe existing funding sources that support services for children with at-risk situations, developmental delays, disabilities, behavioral conditions and mental health needs aged 0-6 years (hereinafter referred to as “children with developmental delays and disabilities” or “the target group of children”), 2) identify the funding sources, general costs, and financial challenges of three service providers that agreed to provide information for the sub-study, and 3) provide recommendations for developing funding mechanisms to create a comprehensive ECI system as soon as possible.

As a part of this Sub-Study, representatives of the central and local governments were interviewed regarding service providers that serve the target group of children and the possible availability of a database and system to monitor funds spent. Face-to-face interviews were conducted with representatives of the Ministry of Finance, Labor and Transfers (MFLT), the Ministry of Health (MoH) and the municipalities of Lipjan and Gračanica. Representatives of the Ministry of Education, Science, Technology and Innovation (MESTI) and the Municipality of Gjilan and Gjakova responded in writing to a questionnaire on the funding of service providers for children with developmental delays and disabilities.



In addition, in the aforementioned Directors' Survey, eight organizations offering services similar to ECI services provided information regarding their sources of financial support.

With respect to the sample used in this sub-study, five of the directors or financial managers of organizations that were identified through the initial Mapping Survey were asked to complete a questionnaire on organizational costs and expenses and they were to be interviewed by telephone and email. However, only three of the selected five organizations completed the questionnaire and subsequently provided answers through telephone interviews.

Central Level

After considerable search, it was ascertained that no specific budget programs for organizations providing ECI services currently exist in the ministries' budgets; however, MFLT, MoH and MESTI allocate certain general funds for social protection, education and health for young children with developmental disabilities, among other beneficiaries. The ministries were asked if they had developed databases listing the number of children served from the target group, and whether the budget execution of organizations is assessed in relation to results achieved. The findings from interviews with ministerial representatives follow.

Ministry of Education, Science, Technology and Innovation (MESTI)

In the budget of this ministry, there is a budget line for "Arrangements, supervision of all types of education systems," which refers to children with developmental delays and disabilities in inclusive early childhood and preschool institutions. However, it was impossible to determine what proportion of the funds allocated to service-providing organizations addressed the needs of children from the target group.

While planning a specific grant for pre-university education, MESTI also planned the Early Childhood Education (ECE) budget for 2023-2025. The budget allocation for pre-primary education, which is the responsibility of municipalities, for 2023-2025 includes government grants, education grant, their own revenues and donor funding. The determination of the budget allocation is conducted on the basis of existing laws and sub-legal acts, jointly with MoF and MEST. The law on the financing of local government obliges the central government to share the budget in addition to the general grant for education and health. MESTI has issued Administrative Instruction No. 03/2022 for the inclusion of children with developmental delays and disabilities in preschool education. Based on this instruction, children from risk groups are exempt from payment, including children from families receiving social assistance, children with special educational needs, children without parental care, children of single mothers, children living with one parent, and children of war veterans. Municipalities are obliged to provide places in preschool institutions for children who apply from the groups at risk listed above.

Ministry of Finance, Labor and Transfers (MFLT)

MFLT has a budget line to monitor all types of social benefits for children with disabilities, low-income families, orphans, foster families, the elderly and others. However, it was impossible to determine what proportion of the funds allocated to each service provider addresses the needs of children in the target group. In MFLT, the Department of Social Policies and Family (DSPF) provides various services for children aged birth to five years. This department is responsible for 1. insurance for children and pregnant women; 2. social benefits to families; 3. accommodation of families in age-appropriate housing; 4. schemes for children with disabilities aged birth to 18 years; 5. child allowances; 6. the allocation and provision of financial support for foster care services for children without parental care; and 7. funding for NGOs.

By the end of 2021, 48 Non-Governmental Organizations and Private Entities Providing Social and Family Services had been licensed. Out of 48 NGOs, 44 were reported to benefit from funds for the public call announced by the ministry. The amount of funding for children from 0-5 years constituted 20% of the total funds provided by MFPT/DSPF to services delivered by licensed NGOs. This amount for all NGOs was reported to be approximately 200,000 EUR per year. Thus, the average amount per year per NGO would only be 4,546 EUR.

It was impossible to extract the number of children with developmental disabilities served from the MFPT/DSPF database, although the total number of children aged birth to five years and the amounts allocated for the implementation of various programs to support them are given in Annex 7 a and b.

Ministry of Health (MoH)

The health system in Kosovo is divided into three usual levels: Primary, Secondary and Tertiary care. Health services are organized and delivered by service providers as inpatient, outpatient, comprehensive and emergency services. Services are provided by public and private facilities.

The health sector in Kosovo is mainly financed by income taxes, other taxes and co-payments, while private out-of-pocket payments are very high and account for about 40% of expenditure on health services. Services in all public health facilities are free for all children, pregnant women, infants and vulnerable groups.

In 2023, for the first time, the Ministry of Health allocated the expanded amount of 3.4 million EUR for the Home Visiting Program. Home visiting is considered to be a cost-effective method for promoting good infant and child health, preventing maltreatment and improving family life. Home visiting program provide support to parents and expectant parents to build basic caregiving skills and to assist parents and other primary caregivers to bond well with their children to promote healthy child development and a positive home environment. This service was introduced in two municipalities in 2014 and has been gradually expanded to other municipalities, reaching a national scale in 2022. UNICEF has supported this program from the beginning. In 2021 UNICEF provided 255,015 EUR, in 2022 614,875 EUR, and in 2023 80,025 EUR for home visits (data for the first quarter of the year).

As previously noted, home visits are important activities provided by comprehensive ECI services. The Home Visiting Program might become a possible organizational approach for the provision of specific ECI services, namely for conducting developmental screening and referrals to ECI services as well as for the provision of health and nutritional support for children and families enrolled in ECI services.

Local Level – Municipalities

Kosovo has 38 municipalities, and according to the Law on Local Self-Government and Law on Municipalities in Kosovo, municipalities are responsible for primary health care service provision and education services, including ECE. While there is no specific budget line for early childhood programs, most municipalities provide the following services to children aged birth to five years of age:

- » Health services, Home Visiting Program, and immunization units as part of Family Medicine Centers,
- » Early childhood education institutions including preschools and preprimary classes.

For example, In Lipjan municipality, only the budget for early childhood education (0-5 years) is known. In 2022, the staff involved in early childhood education consisted of 38 persons. The budget included salaries (236,000 EUR); goods and services (50,000 EUR); cost of utilities (11,000 EUR), and capital investments (267,280 EUR).

The municipality of Gračanica is mainly inhabited by Serbians. As in other municipalities, the only child-related budget line is for early childhood education. It provides direct support for preschools, and it includes wages and per diems (137,473 EUR); goods and services (30,120 EUR), and utilities (10,000 EUR). The total budget is 177,593 EUR.

The Government of Kosovo has recently adopted Administrative Instruction No. 06/2022 on the Establishment and Functioning of Teams for Children's Rights. The purpose of this Administrative Instruction is to establish the rules of procedure, composition and functioning of Teams for Children's Rights for the implementation of the mandate defined in the Law on Child Protection. By the end of 2022, 11 municipalities have established Children's Rights Teams, which are to be headed by the mayors of each municipality. The tasks of the Teams include:

- a. Establishing the municipality's priorities for the promotion of the rights of the child;
- b. Coordinating and monitoring the implementation of measures for the rights of the child;
- c. Ensuring the implementation of the various recommendations, resolutions, etc.;
- d. Ensuring the compatibility of municipal policies on children's rights;
- e. Developing programs for children; and
- f. Making recommendations to the mayor for the promotion of children's rights.

Sources of current funding for evolving ECI activities

The directors of the eight organizations that participated in the Directors' Survey were asked about their sources of funding for their ECI activities, and whether these sources were their main (major) or their additional (minor) sources. The Directors' responses are presented in Table 15.

Table 13: Types of funding sources

Types of funding sources	Minor funding source	Major funding source	Total number of organizations answered the question
Governmental funding			
Ministry of Finance, Labor and Transfers	3	1	4
Municipal/city government	4	0	4
Ministry of Education	3	0	3
Ministry of Health	1	0	1
Another ministry	1	0	1
Civil society funding			
Non-governmental organizations	1	0	1
Faith-based organizations	1	0	1
Community-based organizations	2	0	2
Other national sources	1	0	1
Private funding sources			
Private benefactors/groups	3	1	4
Corporation or business donors	3	0	3
National foundations	1	0	1
Fees			
Parent payment of fees	1	3	4
Membership fees	0	0	0
Fundraising activities			
Fundraising activities conducted by your organizations	1	1	2
European regional organizations			
European Union	0	4	4
European Agency for Development/Special Needs	1	0	1
European Fund for Social Development	0	0	0
European Structural Fund	0	0	0
International organizations			
UNICEF	0	5	5
International foundations	2	1	3
Bilateral agency (USAID, DfID, etc.)	1	1	2
World Bank	1	0	1
Agency for persons with disabilities	1	0	1
Another UN organization	0	0	0
Summary			
Answered			8
Skipped			0

For four organizations, MFLT was their source of funding, but it was the main source of funding for only one of them. All other ministries were only minor sources of funding. Thus, to date, central ministries appear not be strong sources of funding for ECI institutions and organizations. For four organizations, the municipalities were only minor sources of funding. In contrast to other countries in the region, central and local governments mainly play minor roles in financing ECI services, and this finding requires serious consideration since government support usually provides about 70% of ECI service funding.

Currently, the role of UNICEF in funding organizations providing ECI or related services is important. For five organizations, UNICEF was a major source of financial support.

For four organizations, private benefactors and parental contributions were also sources of funding, with three of the organizations mainly dependent upon parental payments, which can lead to the exclusion of low-income parents.

Importantly, the EU has been the main source for four organizations.

Community organizations, businesses, corporations, benefactors, and fundraising activities are mainly minor sources of funding for several organizations. Though small, this support should become increasingly important because most ECI programs around the world require diversified funding sources to provide approximately 30% of institutional and service costs in addition to government support (approximately 70% of costs) at central and local levels.

Program costs

As noted, due to difficulties encountered in securing data from two institutions, the cost portion of this sub-study presents only 3 case studies of service-providing organizations. They are referred to as organizations A, B and C. All of the responding organizations were NGOs.

Organization A

In 2022, this organization provides mainly center-based psychological and educational services to about 300 beneficiaries, including adults and children. It also provides some home visits. However, this organization reported that only six of the 300 children were found to have developmental disabilities. The organization provides services for children with special needs, but its scope of activities also includes other areas such as psychological and educational services. The organization provides various trainings for different groups, including alternative and potential foster families and to parents and relatives of school children. They also provide training on child protection policies and on child psychology for the different stages of child development. In 2021, there were five trainings for professional staff, three for paraprofessionals, and three for parents. However, the organization did not provide any information on the cost of their training services. The organization also provides home visits and remote consultations. In 2021, caregivers provided 20 home visits, social workers provided 100 visits, and psychologists made 300 visits. In addition, 20 online counselling sessions were held with six beneficiaries.

The organization employs 15 professionals including supervisors, social workers, psychologists and educators. This organization reported that the psychologists devote 60% of their

time to the children of the target group which was also reported to be very small, and the other professionals provide 100% of their time. The total number of professionals (considering the time spent on the children of the target group) is 11.

The organization receives funding from international organizations as well as from the central and local governments (see Table 16). Funding from non-governmental sources is usually project-based and depends on the duration of the projects. The organization stated that at the time of the survey, it needed additional funding for training professionals, increasing salaries, and buying an additional transport vehicle.

Organization B

This organization has 300 beneficiaries, including 153 children with developmental delays. For these children, the organization offers center-based early care and education programs and therapeutic services such as speech and language therapy, developmental and occupational therapy, and physiotherapy. The organization provides training for professionals as well as for parents and volunteers.

The organization employs supervisors, therapists, social workers and psychologists. Three physiotherapists spent 35% of their total time serving children with developmental delays, and the other professionals spent 30% of their time serving those children. Eight professionals served children of the target group, and their total salary for these times was 191,880 EUR.

Although the organization receives funding from various sources and in-kind contributions (see Table 16), these are insufficient to ensure the long-term sustainability of therapy services.

Organization C

This organization represents and supports community-based centers that provide services to 138 beneficiaries, 8 of whom are children with developmental delays and disabilities from 0 to 6 years of age. The separate centers provide services to children whose families are unable to send them to kindergarten (public or private). They provide early childhood education services in accordance with MESTI guidelines. The organization provides training for professionals and parents. In 2021, the organization gave 29 training sessions for professionals and 21 training sessions for parents and volunteers.

The center operates in several municipalities and its activities have been funded by UNICEF and international donors (in 2021); however, the organization lacks financial sustainability, and at the time of the study, it was seeking additional funding to purchase a media server application (Quick Box), specialized equipment and a motor vehicle.

**Table 14: Sources of funds received during 2019-2021
(estimated amounts utilized for services for children
with developmental delays or disabilities in the organization), EUR**

	A	B	C
Central government	1,490	48,768	0
Local government	961	31,130	0
UNICEF	0	0	5,865
Other International donor organizations	0	0	923
International Foundation	5,594	0	0
International non-governmental or faith-based organization	0	138,778	0
European Union	0	17,773	0
Private support/donations	118	100,985	0
Parent fees	0	0	0
Ffoundations, businesses and corporations	0	0	0
Fundraising activities	100	47,825	0
Other	82	0	0
Total	8,345	385,259	6,788

The figures in Table 16 represent the amounts received by each organization over the last three years. The amounts are adjusted to reflect the proportion of children with developmental delays in the organizations. Central and local governments were the sources of funding for organizations A and B, while organization C received funding from UNICEF and other international donor organizations. Organization B has the most diversified sources of funding, including amounts from donations and fundraising activities.

Program costs and cost per child

Table 17 presents the various operating and service costs of the three organizations. Total costs are presented by cost category and the proportion of these costs related to the share of children with developmental disabilities served by each organization. Organizations A and B provide direct services to children and their families. Organization C is an NGO association that is "child-related" because it provides training and support services for centers which in turn serve a few children with children with developmental disabilities.

Table 15: Estimated cost composition by category (CDD share), EUR

Number of Children	Organizations		
	A	B	C
Total number of beneficiaries	300	300	135
Number of children with development disabilities (CDD)	6	153	8
The share of those children in total %	2%	51%	6%
In-kind support (during the last 3 years) ³¹	A	B	C
In-kind support (share of CDD in EUR)	8,580	64,199	0
Distant Consultations	A	B	C
Distant Consultations (share of CDD in EUR)	18	0	0
Transportation to professional meetings	A	B	C
Cost of transportation to professional meetings (share of CDD)	0	7,018	0
Cost of transportation for home visits	A	B	C
Cost of transportation of home visits (share of CDD in EUR)	252	0	0
Cost of Professional Trainings	A	B	C
Cost of trainings (share of CDD in EUR)	n/a	2,040	446
Cost of Utilities	A	B	C
Cost of Utilities (share of CDD in EUR)	496	22,640	n/a
Total cost (share of CDD)	9,346	95,897	446
Cost of CDD child	1,558	627	56

Tentative cost findings from the sub-study

The highest cost per child with developmental disabilities was found in Organization A because it reported a low proportion of CDD children. Organization B may present a more realistic cost per child with developmental disabilities; however, due to a lack of responses from other organizations that might be similar to organization B, the results must not be considered as “representative” of ECI organizations. Organization C had the lowest cost per child; however, these costs were related solely to the training of specialists in other centers who in turn provided services to children with developmental disabilities.

Opportunities for developing an ECI budget program

Even though no single budget program exists for ECI services, the prerequisites for establishing a comprehensive ECI budget program are in place. The sectoral ministries (MFLT, MESTI and MoH) have included service provider organizations for children with developmental delays among other beneficiaries in their budgets. MFLT has accommodated various programs where children with developmental delays and disabilities are among the bene-

31 In-kind support reflects the cost of all in-kind consumables or goods received by the organization.

ficiaries. MESTI is planning for a specific grant that includes an Early Childhood Education (ECE) budget which will be reflected in budget allocations for upcoming years. The MoH will continue to allocate funds for the Home Visiting Program from 2023 onwards, which potentially could be well coordinated with ECI services; however, no mechanisms or previous practices currently exist to enable this cross-coordination.

Child Rights Team at municipal level

Child Rights Teams constitutes a mechanism that could advocate for the needs of children with developmental delays and disabilities and their support services at the local level. The establishment of the Child Rights Teams is regulated with Administrative Instruction deriving from the Law on Child Protection. The tasks of each could team include the development of service programs for children with developmental delays and disabilities.

Lack of coordination among government structures

Ministries and local self-governments that fund services for the target group of children lack any form of coordination regarding both funding and program development, implementation and monitoring and evaluation. A strong structure and coordination system is urgently needed to make the best use of resources and well as program planning, targeting and implementation.

Need for child tracking and national monitoring and evaluation of ECI-related services

No unified database for the target group of children currently exists in any ministry or among ministries. Similarly, no system for tracking these children was found, and furthermore, a notable fragmentation of data exists causing a major barrier to conducting program planning, implementation, monitoring and evaluation.

Unstable sources of funding for ECI services

The current sources of funding for evolving ECI service organizations usually are notably limited in both time and amount. UNICEF has played an important role in supporting these services, both in terms of technical support and of financing. Some international NGOs also provide funding to organizations. However, both of these types of external funding sources are time-limited regarding project duration. Stable and sustainable governmental and other funding at both central and municipal levels will be essential for the development of a system of ECI services.

5. CONCLUSIONS AND RECOMMENDATIONS

Based on the findings presented in Chapter 4, this chapter presents the main conclusions of the study followed by specific recommendations for future strategies and activities to develop a system of effective ECI services.

If the recommendations presented below are followed, it can be anticipated that over a five-year period, country-wide coverage of families whose children have at-risk situations, developmental delays and disabilities will become a reality.

To attain this goal, strong multisectoral coordination and political will to giving a high priority to serving children with developmental difficulties and their families will be needed among relevant sectors at the central level, namely the ministries of finance, health and nutrition, education and social protection, all municipal structures, and relevant civil society organizations. The order of topics is not strictly sequential. At any one point in time, several topics could be addressed simultaneously. However, the initial topics 1 through 5 that are listed below should be developed in the order presented, to the extent possible, because each succeeding activity is based on the achievement of the prior one.



5.1 Conduct Initial Policy Advocacy and Social Communications

Conclusions

Based on interviews with high-level leaders, surveys of directors of ECI organizations, and surveys and interviews with ECI service personnel and their beneficiaries, it became clear that few persons have a good understanding of the ECI field including its history, objectives, organization, regulatory needs, processes, methods, activities, instruments, and benefits for families, children, and communities. All stakeholders from local leaders to families, communities and relevant organizations must be supported through advocacy and information.

ECI is based on evidence from extensive research as well as the careful assessment of good practices in countries around the world, yet study respondents frequently stated that little is known about this field in Kosovo and throughout the region, and about how ECI differs from other services. **A major and urgent need for advocacy and social communications about ECI services exists at community, municipal and central levels, and in every relevant sector and among all professionals in those sectors.**

Recommendations

To build a shared understanding of the importance of ECI among all stakeholders at central and municipal levels as well as with civil society leaders and professionals, it will be essential to conduct initial policy advocacy and awareness-raising activities regarding the nature of ECI systems and their services. This could include the development and wide distribution of introductory ECI briefs, easy-to-read materials, media events, and the holding of workshops and webinars introducing ECI concepts and approaches. It will be important to provide extensive social communications regarding ECI services and their benefits to communities, parents, professionals, and paraprofessionals. These advocacy and communication activities will help to facilitate all subsequent steps for ECI organizational development, strategic planning and program planning. Later, additional advocacy and social communications work will be needed to meet evolving requests for information and guidance.

In this regard, Child Rights Teams for the implementation of the mandate in the Law on Child Protection are to be developed in every municipality. These Teams might be invited to help conduct ECI advocacy and assist with prioritizing the needs of children with developmental delays and disabilities in communities as well as strengthening the role of local governments in consistently funding contemporary ECI services.

5.2 Develop Initial and Longer-Term ECI Organization and Coordination

Conclusions

Based on the literature review and interviews, it was found that a competent organizational framework for planning and subsequently implementing, supervising, monitoring and evaluating the ECI system will be essential.

Currently, the Ministry of Finance, Labor and Transfers, the Ministry of Education, Science, Technology and Innovation, and the Ministry of Health are among the principal ministries that support some ECI services. However, no ministry has yet been selected as a lead ministry for ECI nor does a system exist for rotating leadership of ECI planning and development. Furthermore, the ministries have not developed an intersectoral council or committee for ECI.

All respondents noted that ministries lack a system for the intersectoral coordination of ECI services. They also lack a way to coordinate ECI multisectoral planning, financing and management for developing and implementing services with municipalities; therefore, it is not surprising that only some of the 38 municipalities in Kosovo have provided support for local evolving ECI services. A local ECI organizational framework would help all ministries to work together, coordinate and improve their services and collaborate with municipal governments. Similarly, ECI services will need a coordinating structure to work with and secure support from international organizations, such as UNICEF, regional entities including the EU.

Recommendations

Kosovo central and municipal decision-makers and key stakeholders will soon face a major decision regarding the selection of the best way to design a strong, effective, high-quality, equitable and accountable ECI system. Two major options exist:

1. Establish a local integrated ECI system that builds on the strengths, competencies, knowledge, and resources of all relevant ministries and of all municipalities which would participate in the formulation, development, funding, coordination, implementation, monitoring and evaluation of the system. It would have a small central leadership and coordination body and a streamlined infrastructure.
2. Develop a multisectoral ECI system that seeks to establish ECI services within each relevant ministry and then coordinate those separate initiatives around a common policy/strategic plan, ECI service guidelines and procedures, and other guidance documents and shared activities.

The first option features a fully integrated system that builds on existing resources and the capacity and strengths of all participating ministries, municipalities, and professionals. It is particularly well suited to small to medium-sized countries where coordination tends to be less complex, and where leaders and professionals are accustomed to working in a streamlined manner.

The second option is sometimes necessary in a federal state where provinces have a strong history of regional leadership, sector by sector. In these countries, ministries often have well-established systems of sectoral management at each level. However, many intersec-

toral agreements, councils and coordination bodies become necessary at central, provincial, and municipal levels. This often results in higher costs for administration and management and more formal agreements become necessary to ensure good coordination, quality, equity, and accountability.

The selection of one of these two major options will be essential, and it must be a decision with the participation of all stakeholders and decision-makers.

Under either approach, to plan Kosovo's ECI system in a fully participatory manner and to enable good intersectoral and interagency coordination, it will be essential to begin by developing an initial organizational structure with bylaws. At first, the structure should be simple and unencumbered, such as creating a small but representative ECI Steering Committee with high-level representation from all relevant central ministries, selected municipal governments, key civil society organizations, and ECI civil society leaders. It is often also advisable to invite international agencies represented by UNICEF, the EU and possibly others to provide their comments and support.

The ECI Steering Committee might be complemented by an ECI technical planning group, such as an interim ECI Technical Team, that would work with an International ECI Advisor and serve the ECI Steering Committee and key ECI stakeholders. It would have the mission of conducting consultations and preparing draft documents essential to providing a legal basis, regulations and plans for the ECI system.

During the preparation of an ECI Strategic Plan and possibly an ECI Law, if necessary, as deemed essential, additional structures could be created and codified into law. As is the case in other countries, they might comprise an ECI Coordinating Committee and/or an ECI Technical Committee, and a small central ECI governmental office, each with its Terms of References including discrete roles, a membership list as well as streamlined rules, schedules and processes for inter-institutional coordination and collaboration. Care should be given to developing a system that is easy to manage and does not unnecessarily duplicate any existing entities.

5.3 Establish a Legal Basis and Planning Process for the Country-Wide ECI System

Conclusions

All countries with an ECI system need to establish a legal basis for their Kosovo-wide ECI system. The literature review and high-level interviews revealed that Kosovo lacks this essential legal basis. Currently, no Strategic Plan, Policy Statement or Law enables Kosovo to establish and develop Kosovo-wide ECI services. The lack of a legal basis for developing an ECI system has led to much of the confusion and absence of leadership that was noted by many interviewees. A legal framework is needed to develop an effective Kosovo-wide ECI system. This is usually accomplished by preparing and officially adopting an ECI Strategic Plan and/or an ECI law or both. Discussions are currently moving forward to consider Kosovo's options; however, to date, no concrete and fully participatory planning process for developing an ECI system has been initiated.

Recommendations

Because countries require a well-structured and sufficiently detailed planning document to develop an effective and efficient ECI system, it is strongly recommended that a Strategic Plan, including a costed action plan, be prepared as the first organizational activity. In addition, given the historical roles of parliamentarians and ministries in Kosovo, a focused law might be considered to ensure the establishment of an even stronger legal basis for the ECI system.

A Strategic Plan is best developed by means of securing the full participation of all types of stakeholders, e.g., families, communities, minority ethnic groups, municipalities, key members of the central government, civil society, academia and of course, representatives of evolving ECI services and all ethnic groups. The planning process is usually based in part on this Situation Analysis, and it should also include focus group discussions, consultation workshops, a continued mapping of relevant services, and the careful identification of all key options, as noted above, followed by consensus-building sessions and drafting work. It is through this consultative process that a strong and vibrant five-year ECI Strategic Plan could be prepared.

It will be important to annually monitor and evaluate the implementation of the ECI Strategic Plan and use the resulting reports for annual program and budget planning. In five years, the system will have grown and changed. After another broadly-based consultation process, it will be necessary to redraft the Strategic Plan, and undoubtedly, various sections will be added along with expanded and refined plans and activities. Essentially, it will constitute a new ECI Strategic Plan.

Finally, an ECI Strategic Plan is essential for subsequently developing detailed regulations for ECI services. These regulations are usually called ***ECI Service Guidelines and Procedures***. They, in turn, include many elements that are required to be able to prepare appropriate ***ECI Service and Personnel Standards*** for Kosovo's ECI services and professionals.

5.4 Prepare ECI Service Guidelines and Procedures and Other Regulations

Conclusions

The study found that Kosovo lacks ECI Service Guidelines and Procedures, ECI Service and Personnel Standards, an organizational system for licensing ECI institutions and organizations, and a system for the accreditation of ECI professionals, called Early Intervention Specialists.

As a result of a lack of a Strategic Plan and ECI Service Guidelines and Procedures, evolving ECI services are not provided the guidance that they require to conduct reliable and valid developmental screenings and comprehensive developmental assessments, assess whether or not children are eligible for their services, provide fully family-centered services, establish transdisciplinary teams, prepare Individualized Family Service Plans with parents, conduct effective visits with coaching and mentoring, in the daily natural environment of the home, and much more. This lack of a basic orientation has resulted in fragmented and greatly differing services as well as frustration on the part of parents, service personnel

and institutional and organizational directors of ECI services. Furthermore, these regulatory documents are essential for preparing professionals as early intervention specialists as well as other specialists who work in ECI service organizations, such as psychologists, special educators, therapists, nurses, and social workers.

Recommendations

Once the ECI Strategic Plan and/or ECI Law have been formally adopted, the next step would be to develop and adopt by consensus, the Kosovo's ECI Service Guidelines and Procedures. It should be carefully formulated to fit the resources and unique needs of ECI and other collaborating health, education, and social work services in Kosovo.

The topics of these documents are well known but their content and rules differ from country to country depending upon the status of the development of ECI services, local resources, and cultural and linguistic dimensions that are so important for achieving high-quality, well-adapted and effective ECI activities. If the rules of another country were to be copied and imposed, invariably they would be found to be inadequate for meeting Kosovo's specific needs.

Even after careful development in Kosovo, within one year, the need for both minor and major revisions will appear, and for this reason, it is recommended they be reviewed and revised annually for the first two years and then every two to three years thereafter. Situations change within countries, and it is important for newly prepared regulations to be flexible.

After the first set of ECI Service Guidelines and Procedures have been agreed upon, then the Service and Personnel Standards can be drafted and widely reviewed. Once this occurs, the need for a Coalition of ECI Organizations usually becomes more apparent.

With these essential building blocks in place, training, and licensing for ECI specialists can begin. Licensing for Early Intervention Specialists (EIS, also called Early Interventionists), should be based on meeting pre- and in-service training requirements. Further, with similar training, an ECI certification or license can be added to other specialists' professional standing (e.g., physical therapists, speech/language therapists, occupational therapists, social workers, psychologists, program directors, planners, supervisors, evaluators, and others) to enable them to work effectively in trans-disciplinary teams.

5.5 Plan for ECI Financing and Costs

Conclusions

The Situation Analysis revealed the urgent need to greatly expand financial support for ECI services and ensure consistent, diversified and sustainable financial support for ECI institutions and organizations.

Kosovo currently lacks a single budget system with a cost category for ECI that identifies and designates the funds provided by all relevant ministries for the development and implementation of ECI services. However, the prerequisites for establishing a local funding system for ECI do exist, and they could be activated by establishing appropriate mechanisms

for providing consistent financial support for ECI services. As previously noted, no entity or ministry has been selected to lead ECI services and no coordination system exists to ensure the effective financial management of monetary and in-kind resources for planning, implementing and evaluating ECI services.

Similarly, not all municipalities fund ECI services, and those that do fund them do not provide consistent support for those institutions and organizations. Furthermore, no coordination exists for planning and managing ECI services between the central government and the 38 municipal governments of Kosovo.

Most importantly, no financial plan has been prepared as yet for developing a Kosovo-wide system of community-based ECI institutions and organizations. Discussions and training regarding effective ways to develop and implement diversified financial plans for community based ECI services will also be needed.

Recommendations

Often the first step in building a strong system for financing ECI services is to create a central government **budgetary program for ECI** that could either gather all the funds allocated for planning, developing and conducting ECI services and for assessing budget implementation against achieved results OR provide for the coordination of different funding streams within the integrated ECI program. This system with its ECI cost category would enable the ECI system as a whole and each participating sector to identify the support it provides for ECI services. Similarly, municipalities might be encouraged to use the same cost category of “ECI services” to budget and expend funds for ECI institutions or organizations through one or more funding mechanisms. These mechanisms might include the provision of annual grants or contracts or other funding methods to community based ECI organizations and institutions.

This essential step would help all entities working in ECI to understand how they and other sectors are contributing to the country-wide effort to provide ECI services for families with children who have at-risk situations, developmental delays and disabilities. This would establish the basis for all future planning for funding high-quality ECI services for families and children in Kosovo.

This ECI cost category could be “cross-walked” with a carefully developed ECI Monitoring, Evaluation and Child Tracking System. The Child Tracking mechanism would be activated as each child is enrolled in ECI services. (See Recommendation No. 9). Once enrolled, each child would either use an existing unique identifying number or would be given a unique number.

This activity would reinforce the above-mentioned future ECI intersectoral steering committee or council that would lead ECI program coordination. That entity and additional leaders would consider which of at least two options might be pursued to ensure the development of an effective coordination system for funding and implementing ECI:

- » **The establishment of a small ECI office in a designated ministry or agency that works with all separate ministerial sectoral programs and all municipalities** to coordinate their efforts and ensure they jointly fund ECI programs and projects that are fully integrated, coordinated, intersectoral, interdisciplinary, equitable, high in quality, and accountable to meet the needs of children and families.

- » **The establishment of a small ECI office in a designated ministry or agency that uses a multisource funding mechanism to receive and pool funds from each sector and, in collaboration with municipalities as co-financiers of ECI using the forms of cooperation established in the Law of Self Government of Kosovo,** ensures that programs and projects are fully integrated, coordinated, intersectoral, interdisciplinary, equitable, high in quality, and accountable to meet the needs of children and families.

In addition, under the same Law, local self-governments should conclude cooperation agreements with organizations providing services as well as with parents to strengthen their right to participate in local program budget priority setting and planning.³²

The ECI Office would also assist with coordinating international and regional funding for ECI programs as well as help to channel grants from foundations and other benefactors to ECI services throughout Kosovo.

As noted in recommendation 2, to enable effective ECI service development, a cross-sectoral and cross-level coordination mechanism for the ECI system should be established to ensure close coordination between central and local governments and other stakeholders, including service directors and managers, service personnel, civil society organizations, parents and caregivers. This coordination mechanism should enable the development of a comprehensive and sustainable organizational framework and consolidate existing financial resources to provide adequate, cost-reflective and sustainable funding for an ECI system that will provide cost-effective services in the child's natural environment, whether at home or in an inclusive preschool education setting.

The sources of funding for the ECI system should be diversified to include central and local governmental budgets, foundations, corporate foundations, benefactors, other donor sources and local fundraising activities. This diversified approach is important to minimize the risk of insufficient public funding and to prevent the use of or a dramatic increase in out-of-pocket payments by parents and other primary caregivers. ECI funding usually is highly diversified, and the ECI Office should help community-based institutions and organizations to develop diversified sources of financing.

Finally, it is recommended that detailed and fully verified cost studies be conducted regularly in several ECI organizations to ascertain the range of costs per child or per cohort per year. Study results could then be used to prepare reliable projections and simulations for central and municipal planning and budgetary purposes. Cost studies, financial projections and simulations should be conducted every two or three years to maximize the use of scarce resources while maintaining high program quality.

32 In the Law of Self Government of Kosovo, Chapter IX regulates the mechanism of citizen participation.

5.6 Conduct Community Outreach, Screening and Referrals

Conclusions

The Situation Analysis identified that the potential use of the primary health care system, including the home visiting program that provides routine developmental monitoring to identify children at risk of and with developmental difficulties, has not been fully realized. Some important steps have been made to introduce developmental monitoring into the work of the Home Visiting Service; however, further steps should be given to ensure all children needing ECI services are identified at the earliest possible time.

Furthermore, every ECI system requires community outreach to inform families about ECI services and to help with the initial identification of infants and young children, especially from birth to three years of age, who may need and benefit from ECI services. The study found that only limited community outreach activities exist, and that directors, service personnel and most especially, participating families believe that many children needing ECI services are not being identified or are being identified well after the age of three years.

Although a few evolving ECI programs use a developmental screening instrument, no reliable and validated screening instrument has been selected for country-wide use in Kosovo, and no system for developmental screening exists. The home visiting program of the health sector conducts a general observation of child developmental and health status but currently lacks a standardized and validated monitoring and screening instrument. A regular and universal developmental screening system is urgently needed to complement the monitoring and surveillance methods used by some physicians. Even for the few children who currently benefit from a developmental screening and/or a physician's diagnosis, no consistent referral and follow-up system to ECI services currently exists in Kosovo.

Recommendations

Since 2013, a virtually Kosovo-wide Home Visiting Program, with a good training program, has been developed by the Ministry of Health of Kosovo. Trained nurses provide home visits: 1) within the first three days of arrival home; 2) when the child is four to six months; 3) at 11-12 months, 4) at 18 months; and 5) at 36 months. During each of these visits, an age-appropriate developmental monitoring and the application of a validated screening instrument could be conducted with the mother by a trained nurse that would take only 10 to 15 minutes. If a need appears to be identified, the nurse would be able to give the mother a referral to the nearest ECI center. If none exists nearby, then an alert could be issued that the municipality needs an ECI center and ECI mobile team services should be provided within a specified period of time.

It will be essential to place a high priority on selecting a low-cost and effective standardized and validated tool. One such tool has been translated and validated for the Croatian, Serbian and Turkish languages and cultures, but Albanian is not yet listed.

Equally important to conducting developmental monitoring and screening activities, is the establishment of an effective referral system with rules for following up on referrals to ensure each child is provided a comprehensive developmental assessment within a specified number of days after referral.

The health sector's Home Visiting Program and Family Medicine Centers are not contemporary ECI services because they lack the requisite service personnel and methods and this would go beyond their current mandate, which is very large. Therefore, close coordination will be needed to establish functional referral pathways from these health sector programs to community based ECI services. The Home Visiting Program and Family Medicine Centers could become entry gateways enabling rapid family access to inter-sectoral, transdisciplinary and integrated ECI services in Kosovo.

In some countries, early care and education services (birth to three years) and preschool education services (three to five years) are widespread and they serve virtually all young children. This is not the case in Kosovo, which is working rapidly to expand and improve the provision of early and preschool education, and only recently has begun to develop inclusive early and preschool education services. Therefore, soon, the education sector should be able to provide consistent developmental screening and referrals for children in their services. However, with the anticipated growth of inclusive early and preschool education due to decisions of the education ministry, it will be important to continue to encourage developmental screenings and referrals from teachers and teachers' aides to ECI services in collaboration with parents. Both educators and parents often spot children with late onset at-risk situations, developmental delays and disabilities, and these children should be urgently referred to ECI services.

5.7 Promote Expanded ECI Service Development

Conclusions

No estimate of the number of children from birth to five years with at-risk situations, developmental delays and disabilities could be found in any study about Kosovo. A population study to identify the rate of young children with these conditions has not been conducted.

No fully contemporary ECI program was found in Kosovo. However, based on the Mapping Study, as many as 12 of the 16 institutions or organizations that were initially identified appear to be providing services that are evolving toward becoming contemporary ECI services.

The existing services do not have the capacity to serve all potentially eligible children in Kosovo, which are roughly estimated to be at least 100,000 children from birth to five years.

Most children receiving services were of Albanian ethnicity; however, several ECI institutions and organizations also serve Roma, Ashkali and Egyptian families. This reflects an important initial effort to develop equitable services. Nonetheless, many respondents noted that ethnic minority families and others who live in poverty and/or in rural areas usually lack access to ECI services.

All evolving ECI institutions and organizations provided some family-centered services. However, no one or two approved instruments for conducting comprehensive developmental assessments have been selected yet for use throughout Kosovo.

Few ECI institutions and organizations establish ECI program eligibility for the children they serve. Worldwide, establishing ECI eligibility is an essential core role of ECI services. Eligibility is based on either a physician's diagnosis that is sent to the ECI organization and/or on

the results of a comprehensive developmental assessment of the child that is conducted by the transdisciplinary team of the ECI organization formed for the child and family and including parents and/or other family members or caregivers. Often both diagnoses and developmental assessments are used to establish eligibility. Due to the lack of ECI Service Guidelines and Procedures, no rules have been forged regarding how to establish eligibility for ECI services, and these are greatly needed.

Many ECI institutions and organizations still only (or mainly) provide center-based services, and most programs mainly offer therapy services for the child without the full participation or even the presence of a parent or caregiver. Several organizations lacked the use of parent-child interaction assessments, transdisciplinary teams, individualized family service plans, parent coaching and mentoring during visits, and the preparation of transition plans from ECI services to inclusive preschool, pre-primary or primary education. In general, the study revealed that the evolution of services from rehabilitation to contemporary ECI services is well underway, although considerable training in contemporary ECI core concepts, processes, methods and instruments is greatly needed.

The absence of ECI Service Guidelines and Procedures was notable, as reflected in responses to questions about visits and other services. While a good amount of necessary flexibility was found, guidance will be needed to ensure that the quality, intensity and duration of visits will be appropriate to ensure that Kosovo develops an effective ECI system.

Many respondents noted the absence and/or the inadequacy of case management services for ECI programs. Perhaps few realized that **case management is usually a basic service** of ECI programs for they both receive referrals, and they provide them to help ensure families receive the support, benefits and services that they and their children need.

Finally, all beneficiaries and many high-level interviewees noted that ECI services are highly fragmented. Although a base exists for building strong ECI services, a major effort will be needed to create a coherent and unified system that will ensure all children who are eligible for and need ECI services will receive services of high quality.

Recommendations

A population study to identify the rate of infant and child developmental delays and disabilities from birth to five years is urgently needed to develop plans to meet current and future needs for ECI services. In addition, a Child Tracking System, discussed in recommendation 9 below, would enable accurate counts of children assessed to be eligible and subsequently served by ECI services.

Given the low coverage of early and preschool education services in Kosovo and the low level of inclusive education services for young children, it is recommended that ECI services be provided from birth to five years of age rather than the usual birth to three years period.

Because of the low program coverage of Roma, Ashkali and Egyptian families and families living in rural areas, special attention should be given to those municipalities that lack ECI services and contain many low-income and/or minority families. For rural regions, the development and use of mobile ECI teams should be given serious consideration.

Because Kosovo's services are still in the early stages of adopting contemporary ECI processes, methods and instruments, the provision of pre-and in-service training will be very important. For example, training is needed about the role of case management in ECI ser-

vices. Case managers receive referrals from other services, and they also refer program families to social, health, nutrition and maternal and child protection assistance and follow-up to ensure the families receive the support they need. They also meet regularly with case managers in other organizations to conduct case reviews, plan together and support one another.

Major attention must be given to developing fully contemporary ECI services as rapidly as possible. They should include: community outreach; the provision of developmental screenings, especially at first until the Home Visiting Program fully adds this function; comprehensive developmental child assessments and family assessments (eco-mapping, family interaction activities/responsive caregiving, home safety and nutritional assessments); establishment of eligibility; formation of transdisciplinary teams and selection of the primary service provider; preparation individualized family service plans; provision of regular visits, with an agreed upon frequency per child and family, in the daily natural environment of the child (home visits or visits to inclusive early or preschool education where available); scheduled revisions of assessments and the IFSP; and the preparation of transition plans to inclusive pre-primary and primary education services.

Regarding comprehensive developmental assessments and family assessments, they will need to be selected. Subsequently, all personnel working in ECI services will require in-depth training, coaching, mentoring and supervision to ensure that instruments are applied appropriately and with the supportive inclusion and full participation of parents and other caregivers in these essential activities.

5.8 Provide ECI Pre- and In-service Training and Pilot Demonstration and Training Sites

Conclusions

Kosovo has a high level of both pre- and in-service training for professionals. This status was reflected in the study findings. In addition, Kosovo professionals maintain a good level of certification and recertification. Most professionals who work in evolving ECI services reported that they annually receive between 20 to 40 hours of in-service training, mainly through conferences, online courses, and training workshops. A few of them also made inter-site exchange visits and participated in continuous on-site in-service training, which usually are very effective forms of in-service training.

Early intervention specialists (EIS), a professional field present in many countries, were not yet found in Kosovo. However, considerable interest exists in developing a training program to prepare EIS. Study results also revealed that attention will need to be given to improving and expanding on-site reflective supervision, coaching and mentoring.

To provide fully contemporary ECI services, considerable further training will be needed and fortunately, it is wanted by many professionals of Kosovo. In this regard, in addition to a lack of university training for ECI services, no ECI pilot demonstration and training sites were found.

Recommendations

Pre-service training will be needed for both existing professionals to upgrade their knowledge and skills in the ECI field and to provide them with additional certification. Also, consideration should be given to developing a university program to train Early Intervention Specialists (EIS) who are thoroughly prepared in ECI concepts, methods and practices as well as in child development, disabilities, and an array of therapies. EIS can guide transdisciplinary teams, home visiting methods, assessments, IFSPs and all other essential ECI roles.

A phased **Pre- and In-Service Training Plan** should be prepared, with attention given to developing a sustainable and long-term approach for training licensed professionals, providing 1) an ECI certification for existing professionals in various fields (e.g., program leadership and planning, therapies, social work, psychology, monitoring and evaluation, etc.), 2) core training for Early Intervention Specialists, and 3) annual in-service training for all persons working in ECI services to continuously upgrade the knowledge of both professionals and paraprofessionals and maintain their licensure or certification.

In addition, once an ECI Strategic Plan and ECI Service Guidelines and Procedures are in place, consideration should be given to developing **two or three Pilot ECI Demonstration and Training Sites** in different regions. All ECI specialists would be able to visit these sites and receive not only university workshops but also immediate personal learning experiences through field training combined with coaching and mentoring. For reasons of equity and manifest need, at least one of the sites should serve Roma, Ashkali and Egyptian families.

Since ECI services work in homes with families, the cultural and linguistic dimensions of families are critically important to providing culturally and language-appropriate services. As soon as possible, a major effort should be made to recruit promising students from these ethnic groups to become professionals and paraprofessionals in ECI services. This initiative could be included in the recommended Pre- and In-Service Training Plan.

Based on progress made in pre- and in-service training, attention should be given to establishing revised certification rules, career ladders, and new salary scales that are appropriate to professionals' increased levels of training and experience.

Finally, in collaboration with the ECI Pre- and In-Service Training Plan, a streamlined and supportive system of program supervision, using especially methods of reflective supervision, coaching and mentoring, should be designed and instituted at all levels, within ECI programs at municipal levels, and between municipal and central levels.

5.9 Ensure Accountability: Monitoring, Evaluation and Child Tracking

Conclusions

Six out of eight directors of evolving ECI institutions and organizations stated that they conduct internal monitoring and evaluation processes, and they also reported that they have a document stating their annual objectives, indicators, and targets for monitoring and evaluation and they use a monitoring and evaluation manual. These reports reflect a positive commitment on the part of ECI directors to good program management and accountability.

However, no country-wide or central system for monitoring and evaluating ECI services yet exists. In addition, no Child Tracking System or even a list of indicators and a database of children served by ECI institutions and organizations could be found at either central or municipal levels.

All ECI systems require a well-designed system of accountability that features monitoring, evaluation and child tracking with reports and processes that are linked to annual program planning and budgeting.

Recommendations

After a Strategic Plan has been developed, a Plan for developing an ECI Monitoring, Evaluation and Child Tracking System should be prepared as soon as possible. All ministries providing or supporting ECI services should collaborate in the development and implementation of this system. Usually, a major ministry or agency that leads in measuring national policy indicators is selected to lead this monitoring and evaluation process. For example, this could be a finance ministry, an Educational Management Information System (EMIS), a Health Management Information System (HMIS), a national statistics bureau or another entity that manages cross-sectoral data systems and analyses. Formal agreements are established to provide key data, create a common database, collaborate with data analyses, and prepare a national annual report for purposes of annual program and budgetary planning.

A Manual for ECI Monitoring and Evaluation and instruments should be prepared for application in all ECI service programs of Kosovo. The Manual should describe how the universal and regular developmental screening and referral system would be linked to ECI services including initial intake and the comprehensive developmental assessment, establishment of eligibility and the full enrolment of the child and family in ECI services.

The Child Tracking System should be carefully developed in line with Kosovo's **Strategy on the Rights of the Child 2019 – 2023** and the privacy rules of the European Union. This system should gather key information on all children with at-risk situations, developmental delays and disabilities to ensure "no child is left behind" and, along with his or her family, each child should receive all essential ECI services and subsequently transition well to inclusive preschool, pre-primary or primary education with the long-term goal of full social inclusion to the greatest extent possible.

As noted, the ECI Monitoring, Evaluation and Child Tracking System should collect, analyze and interpret data that are essential for annual planning, budgeting and accountability. It should help with annual program and budget planning and assist planners and program directors to prepare a well-coordinated and adequately funded Kosovo-wide ECI system that is essential to providing robust, high-quality, cost-effective and sustainable ECI services.

5.10 Collaborate for Success: A Coalition of ECI Organizations of Kosovo

Conclusions

The literature review and primary research conducted in Kosovo revealed that no network or coalition of institutions and organizations providing ECI services exists yet. Only half of the ECI directors reported that they networked with any other organizations. Indeed, several interviewees noted that more inter-sectoral and inter-service coordination is currently needed in the entire social sector.

Some interviewees stated that they felt that an umbrella association of organizations providing ECI services would not be needed. They said that because only a handful of organizations offer such services, they believed representatives of these organizations are already a part of all policy-making processes and consultations.

Recommendations

Because inter-sectoral and inter-organizational coordination is essential for ECI services to be fully effective, it is recommended that during the preparation of the ECI Strategic Plan, directors and managers of evolving ECI services give serious consideration to developing a Coalition of ECI Organizations of Kosovo to conduct ECI advocacy, promote increased program support, build strong bonds of coordination with the central government and with municipalities and with other organizations, support each ECI organization, and expand, improve and monitor ECI services. As in Georgia and Moldova, a modest collaborative initiative could serve to work with the central government and with municipal governments to advance the rapid development of a highly effective Kosovo-wide ECI system in Kosovo.

ANNEXES

Annex 1:

Detailed description of the attributes of traditional rehabilitation services, services evolving to include ECI concepts and methods, and contemporary ECI services.

Continuum of Legacy, Evolving and Contemporary ECI Services			
Attribute	Legacy Services	Evolving Services	Contemporary Services
Structural Framework			
Type of model	Medical model	Evolving from Medical to Social Model	Social Model
Service approaches	Disciplinary and practice-based services	Moving toward interdisciplinary, evidence-based services	Interdisciplinary and evidence-based services
Legal basis	Medical policies and protocols	Considering the development of a Strategic Plan or Legislation	National ECI Strategic Plan and/or Legislation
Regulations	Medical protocols	Medical protocols plus beginning to develop national regulations	ECI Guidelines and Procedures
Standards	Rarely found	Some service standards	ECI service and personnel standards
Location of services	Hospital or center-based	Mainly hospital or center-based	Natural environments of child: home, preschool
Support and Coordination	Medical and rehabilitation coordination	Beginning to consider nationwide multisectoral support and coordination	ECI integrated support and coordination at national, regional and municipal levels
Personnel			
Personnel	Physicians, therapists	Physicians, therapists and a widening array of specialists	Early intervention specialists, therapists, home visitors, social workers, etc.
Professional status	Certified professionals	Certified professionals	Certified professionals and trained and supervised paraprofessionals in defined roles
Supervisors	Medical or rehabilitation supervisors	Mainly medical or rehabilitation supervisors	Interdisciplinary ECI-trained supervisors
Beneficiaries and their roles			
Types of children served	Mainly serving children with disabilities, often in the older age range from three to six years, but serving few children with delays, behavioral needs or mental health needs, and few children from birth to three years	Evolving toward serving more children with developmental delays, behavioral conditions and mental health needs, as well as children with disabilities through initiating screening from birth to three years	Developmental screening is provided, resulting in serving children with at-risk situations, developmental delays, disabilities, behavioral conditions, and mental health needs from birth to three and up to six years, as needed

Child or family focus	Entirely child-focused	Family beginning to become more involved	Entirely Family-focused
Parenting skills	Not focused on parenting skills	Evolving toward more attention to parenting skills	Major emphasis on parenting skills
Parent participation in child development	Little participation	Some participation	Parents lead, participate fully, and make decisions
ECI Services			
Early identification and eligibility	Medical diagnosis, surveillance and monitoring only	Medical diagnosis, surveillance and monitoring, some developmental screening beginning	Community outreach, developmental screening, medical diagnosis, surveillance and monitoring
Child assessment	Medical and therapist specialized assessments	Mainly specialized assessments and some comprehensive developmental assessments	Comprehensive developmental assessments plus some specialized assessments, as needed
Family environments and support	Little or no attention given to family environment and support	Growing interest in understanding family environment and support	Major attention paid to family environment and support networks (eco-mapping)
Leadership for preparing the Plan of services	Prepared by a physician or therapist	Prepared by a physician or therapist with the family	As key members of the Transdisciplinary or Interdisciplinary Team, parents fully participate in the development of the plan
Transition Plan to next services	No transition plan is prepared; service specialists sent child to a specialized school	No transition plan is prepared; service specialists send the child to an inclusive school	Parents are involved in preparing a Transition Plan and the child is usually transitioned to an inclusive pre-primary or primary school

Annex 2:

ECI Core Concepts

Core concepts of contemporary ECI services.

The following core ECI concepts guide the development of comprehensive, effective, equitable, high-quality and sustainable ECI systems and services. Together, they provide some key contemporary ECI concepts that should help ECI research teams design and conduct their research.

ECI is a social model.

ECI is an integrated social model that contains elements related to education, health, therapies, nutrition, social protection, child and parental rights, and welfare. It usually has the strong support and collaboration of ministries and agencies in the major social development sectors of education, health, nutrition, sanitation and social protection, policy and welfare. This integrated social approach differentiates ECI from diagnostic and rehabilitation services of the field of medicine that focus mainly or solely on the child's area(s) of delay or disability. Instead, **ECI focuses on the comprehensive and holistic development of the child and the family**, with special attention given to the areas of greatest need of the family and child. ECI builds on each child's strengths and then addresses emerging areas of development. Abundant research has shown that the social model is highly effective in achieving improved child development and competent functioning and participation in school and society (Kennedy et al., 2010). At no point does ECI seek to "cure the child." Rather, it helps children with differing abilities attain their full developmental potential.

In all world regions, increasingly many, but not all, rehabilitation and habilitation services are evolving to become ECI services. This change has been slow, but once it begins, experience has shown that it tends to continue and speed up over time. This evolution is composed of small and large changes over time. Ultimately, ECI's social model has been found to be eminently rewarding to personnel, highly beneficial for families and children, and helpful to nations that have the goal of building a better developed and a more competent and productive citizenry.

ECI is family-centered.

ECI services are family-centered while also focusing on the child's good and balanced development. In ECI, the important actors are the parents, close relatives and daily caregivers rather than professionals or well trained and supervised paraprofessional home visitors. ECI service personnel ask parents what they want their child to achieve and enquire about how the personnel might best be able to help parents achieve their goals for their child and their family. They suggest options and coach and mentor parents and other caregivers to assist them to achieve their goals for their child and themselves. They seek to **ensure that parents make all the key decisions regarding their child's goals and services** while also addressing the parents' voiced needs for support. Research has shown that this family-centered approach strengthens families and leads to better child development outcomes (Dunst, 2006).

ECI is early and continuous.

ECI services seek to identify and support children as infants or as early in life as possible, preferably during the first weeks or months of life, and well before 3 years of age. Thus, services are provided from the earliest identification of a child with an at-risk situation, developmental delay, disability, behavioral condition or mental health need. Depending upon national policy decisions, ECI services extend either from birth to 36 months of age or up to 6 years of age. Once a child attains typical levels of development, parents are usually offered from three to six months of occasional visits to ensure that the child's developmental gains are consolidated. For children with delays or disabilities who could benefit from additional services, depending upon policy decisions, they either remain in ECI services and/or transition to inclusive preschool services. Those remaining in ECI services transition by age 6 usually to inclusive primary education, or if parents so decide, to other available services and educational facilities. Preference is given to inclusive educational services to begin the child's full inclusion in society.

ECI is individualized.

ECI processes and contents focus on the strengths, needs and challenges of each individual child within the family context. It does not provide a common curriculum to be used with all children – irrespective of their needs. This approach enables ECI service providers to build on the strengths of each family and child while identifying their needs and addressing their emerging developmental abilities.

ECI is intensive.

According to the needs of each child and family, the designated ECI service provider (that can include an early intervention specialist (EIS), physical therapist, speech/language therapist, occupational therapist, psychologist, special educator, social worker, other professional or a paraprofessional home visitor) provides scheduled visits to families in the natural environment of the child, which is usually the child's home. The schedule of visits is established with the full participation and agreement of the parents during the preparation of an Individualized Family Service Plan (IFSP). Visit schedules can vary according to the needs of the child and the family. During the early weeks of service, visits can be quite intensive due to identified needs, varying from two to even four visits a week. Usually, after the child's situation is stabilized, visits can be reduced to once a week. After a child and family have made major progress in attaining agreed-upon goals, visits may be reduced to once every two weeks. For the final consolidation of gains achieved, visits can be reduced to once per month. These decisions are made collaboratively between the main service provider and parents or caregivers, and sometimes with the support of the supervisor. Some children who are already enrolled in daily services of inclusive childcare centers or preschools may receive some of their visits in those establishments, with the full participation of their center-based caregivers or teachers. Parents are invited to participate in these visits. However, if parents are employed full-time, they are encouraged to participate in at least one visit per month in the center. In the meantime, center-based caregivers or teachers are instructed to regularly share the activities of each center-based visit with the child's parents.

ECI services are evidence-based and outcomes-driven.

All ECI organizations and ECI components within other organizations seek to use the latest and most reliable research results that are available to help them plan, develop and provide their services with families and children. The large international literature on ECI services and their outcomes was used as the basis for listing these core ECI concepts, framing the Conceptual Framework, and applying the Theory of Change. This evidence base should guide the development of all ECI public institutions, organizations and components, including the selection and application of research instruments, and the analysis of study findings. ECI services develop a discrete list of indicators that are related to desired outcomes. These monitoring and evaluation frameworks help guide service planning and implementation, the activities of the national ECI systems, and the functioning of their monitoring and evaluation systems. Ultimately, selected outcomes drive all ECI work, and they help ECI institutions, organizations and their components to achieve high-quality services that will improve child and family development and will achieve a wide array of other short-, medium- and long-term objectives.

ECI is interdisciplinary and usually transdisciplinary, integrated and team-based.

As noted, all ECI services are interdisciplinary, including the sectors of education, health, nutrition, sanitation, child protection and child welfare, as well as several disciplines that pertain to these sectors, from social work, education and health to therapies, psychology and related social development fields. For this reason, **ECI systems and organizations are always integrated across sectors and disciplines to provide one united service to families and their children.**

Legacy systems are multidisciplinary; however, they rarely form teams. Instead, professionals from various sectors and disciplines provide separate services directly to individual children. In contrast, contemporary ECI services are always provided in teams that function in an interdisciplinary or transdisciplinary manner. ECI services are not offered by single therapists or a group of therapists in one therapeutic field. ECI teams include two or more professionals in different fields, including therapists, early intervention specialists (EIS), social workers, psychologists and others. EIS are interdisciplinary ECI specialists who are trained in skills pertaining to all disciplines, therapies, ECI guidelines and procedures, and standards used in ECI services.

In **Transdisciplinary Teams**, all or most members of the team jointly conduct comprehensive child assessments and Individualized Family Service Plans (IFSPs). They select one member of their team to become the **primary service provider** who makes most of the home visits and/or center-based visits. Other members of the Transdisciplinary Team provide technical support to the primary service provider.

In **Interdisciplinary Teams**, team members often conduct comprehensive developmental assessments together, although sometimes they conduct separate specialized assessments and then meet to discuss their findings. They also meet as a group to prepare the IFSP with the parents. Interdisciplinary team members usually do not appoint a primary service provider. Instead, they make separate individual visits with the parent. In contrast to multidisciplinary services where each specialist usually works separately, in interdisciplinary teams they regularly confer amongst themselves and support each other before and after visits. Other variants of interdisciplinary teams may be found in some countries.

Increasingly, contemporary ECI institutions, organizations and components are using Transdisciplinary Teams because they tend to be more cost-effective, permitting them to serve more families and children better, and usually at a lower overall cost per child.

All members of ECI Transdisciplinary or Interdisciplinary Teams focus on supporting, mentoring and coaching parents and family members as the best way to serve the child. Parents are always key members of both Transdisciplinary and Interdisciplinary Teams.

Every ECI organization or ECI component within another organization offers a discrete list of essential services and some optional ones.

The national selection of essential and optional services is always presented in regulatory documents usually called **“ECI Guidelines and Procedures”**, along with core ECI concepts, rules, guidance and methods.

Essential ECI services usually include:

- » Community and health outreach activities to locate, identify, screen and assess children from birth to 3 years or older, if not previously identified
- » Referrals to and from ECI services
- » Developmental monitoring and screenings for all children leading to the initial identification of children who may need ECI services
- » Initial entry procedures
- » Comprehensive developmental assessments and regular re-assessments over time
- » Specialized developmental assessments, i.e., autism, speech/ language, etc. as needed
- » Decisions regarding eligibility or parent-approved referrals to other services
- » Family and home-context assessments
- » Preparation of Individualized Family Service Plans (IFSPs) and regular revisions, as needed
- » Provision of early stimulation and development visits in the natural environment of the child (home visits or visits to inclusive childcare centres, inclusive ECE centres or other places where the child is present on a regular basis)
- » Provision of occupational therapy services, including self-help skills, sensory or physical development, and adaptive behavior and play
- » Physical therapy services to improve gross and fine motor development, develop agile movements and strength, and manage functional challenges
- » Speech therapy services to overcome speech delays, improve receptive language, communications skills, swallowing and other speech difficulties
- » Individualized and/or group parent education services to help families to parent well in developmental, health, nutritional and other areas, to understand the needs of their child, etc.
- » Case management services for parents to help them learn their rights and their children’s rights, identify their strengths and needs, and to support them by means of service management
- » Support parents in making their home environments more stimulating, safe and hygienic for their child and family
- » Translation and interpretation services for families, if needed, to ensure services are provided in the family’s home language to enhance understanding
- » Help the family and child with supportive transition and completion activities from ECI services to inclusive early childhood education or primary school services

Optional services vary by the country, the needs and requests of families and communities, and the level of development of ECI systems. They may include:

- » Nutrition services to help parents meet the nutritional needs of their children, such as: improvement of the child's daily diet, feeding skills, breastfeeding, complementary feeding, allergies, improving the nutritional status of a child with stunting or wasting
- » Psychological support services for children or parents, e.g., administering psychological tests, assessing child behavior, mental health counselling, family therapy
- » Provision of assistive technologies and adaptive equipment to help children develop, see, hear, play, eat, learn, communicate and move better Audiology services for children to identify, prevent or treat hearing loss
- » Ophthalmological and other vision services to identify children with low vision, visual disorders or delays, and support their parents
- » Parental peer groups, when requested with the goal of reducing parental isolation by helping them forge friendships with other parents facing similar challenges and needs
- » Access to a Toy and Book Library¹³ and toy-making support in ECI centres, local libraries or other community centres
- » Nursing services to support the special healthcare needs of a child and to teach parents how to administer medications, provide treatments and conduct other healthcare activities
- » Provision of respite care for parents and other primary caregivers to give them a break from constant caregiving
- » Mobility and orientation specialists for blind and low-vision children
- » Rehabilitation or habilitation services requiring specialized equipment and other technologies

ECI provides services in the natural environment of the child

ECI services are usually provided through home visits, with a focus on using the daily routines of the family and their childcare-giving activities to embed opportunities for enhancing child development. However, for children who receive daily center-based services, some or most of the visits may be provided in the child's care center, nursery, inclusive preschool, or another similar place. Parents are asked to be present for as many of the center-based visits as possible. Sometimes visits also occur in parks, markets and playgrounds. In some countries, services are provided in residential institutions for young children. However, increasingly ECI services are playing a critically important role in the deinstitutionalization of children, and in the prevention of institutionalization through supporting biological families to provide nurturing care, thereby reducing the risk of separation and institutionalization. They also assist with the placement of children in nurturing families, and they support adoptive or foster parents to develop well the children they receive in their homes.

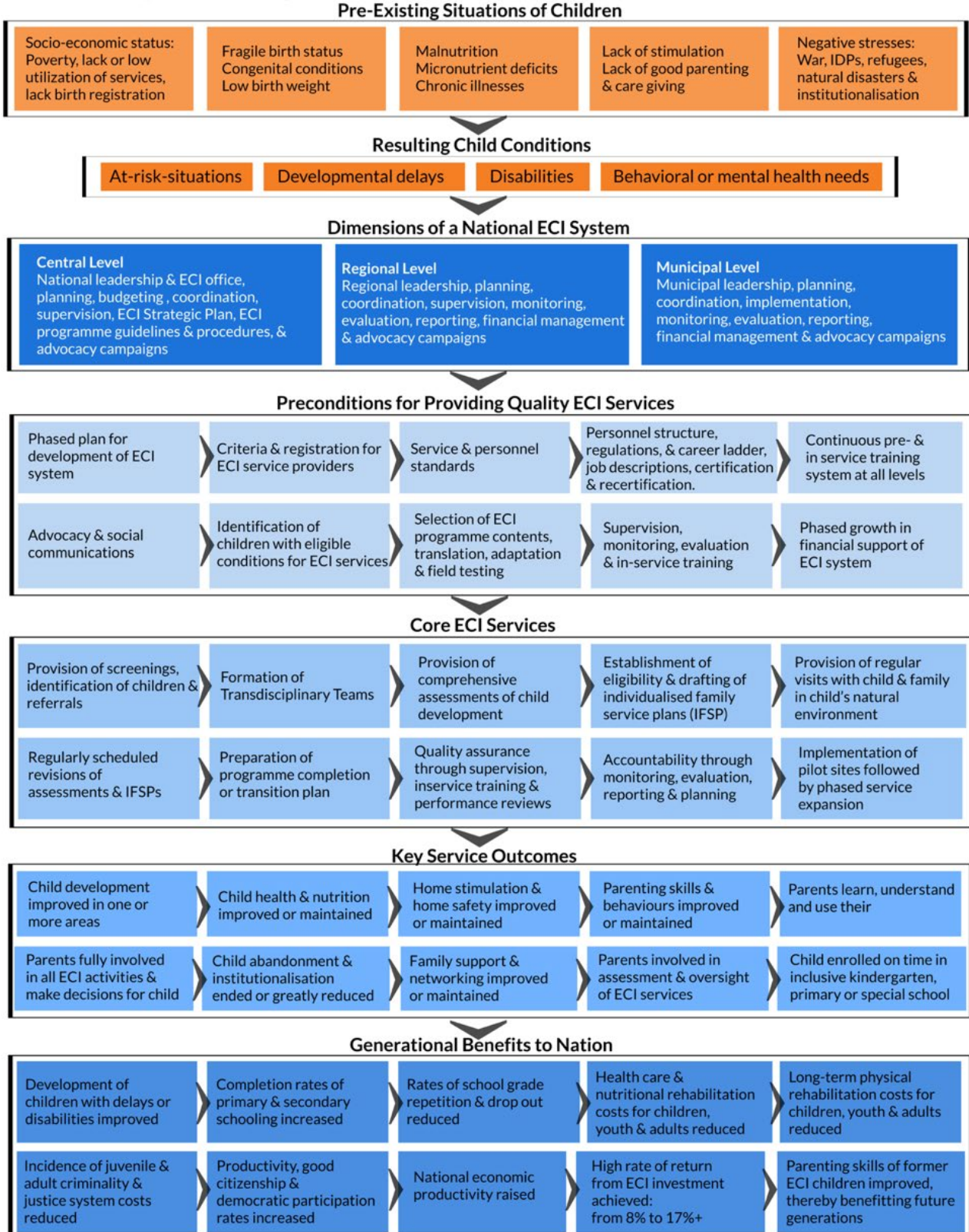
ECI is community-based and supported from the regional and central levels.

All effective ECI services are well-knit into the community. They secure local support from ECI community boards and accept community volunteers. In mature ECI systems, regional and central managers and supervisors usually support, coach, mentor, assist and monitor and evaluate community-level ECI services. Both vertical and horizontal coordination and sharing occur in large ECI systems.

Annex 3:

ECI Theory of Change (ToC)

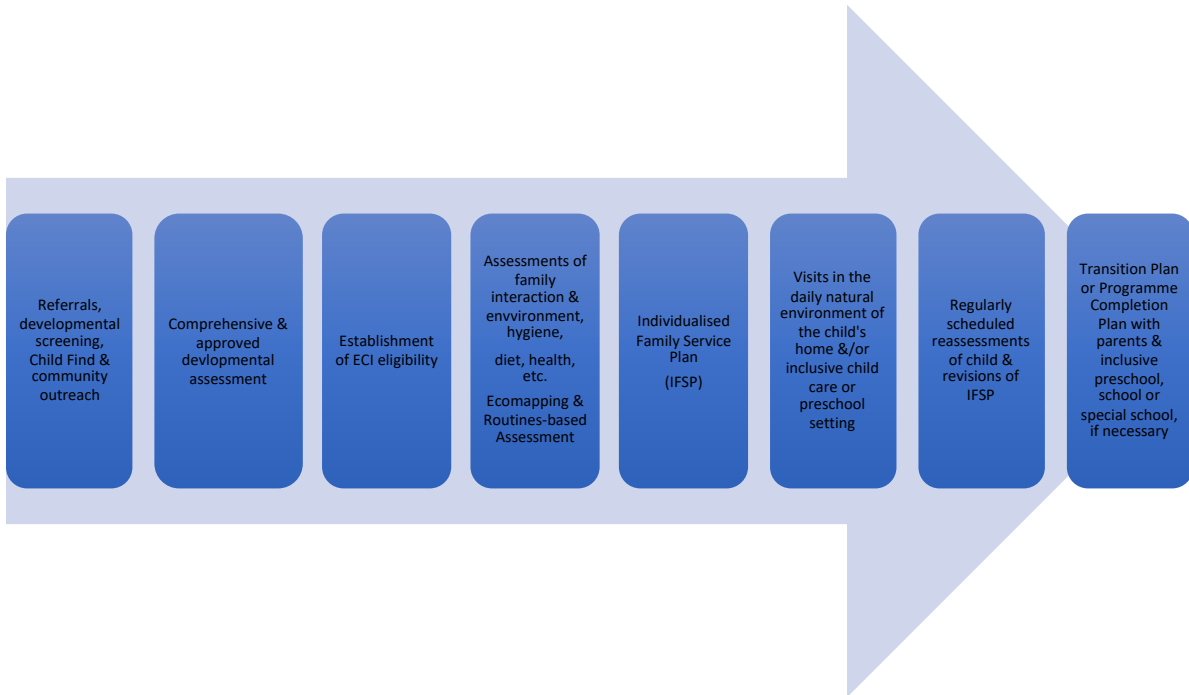
Theory of Change for Early Childhood Intervention Services



Annex 4:

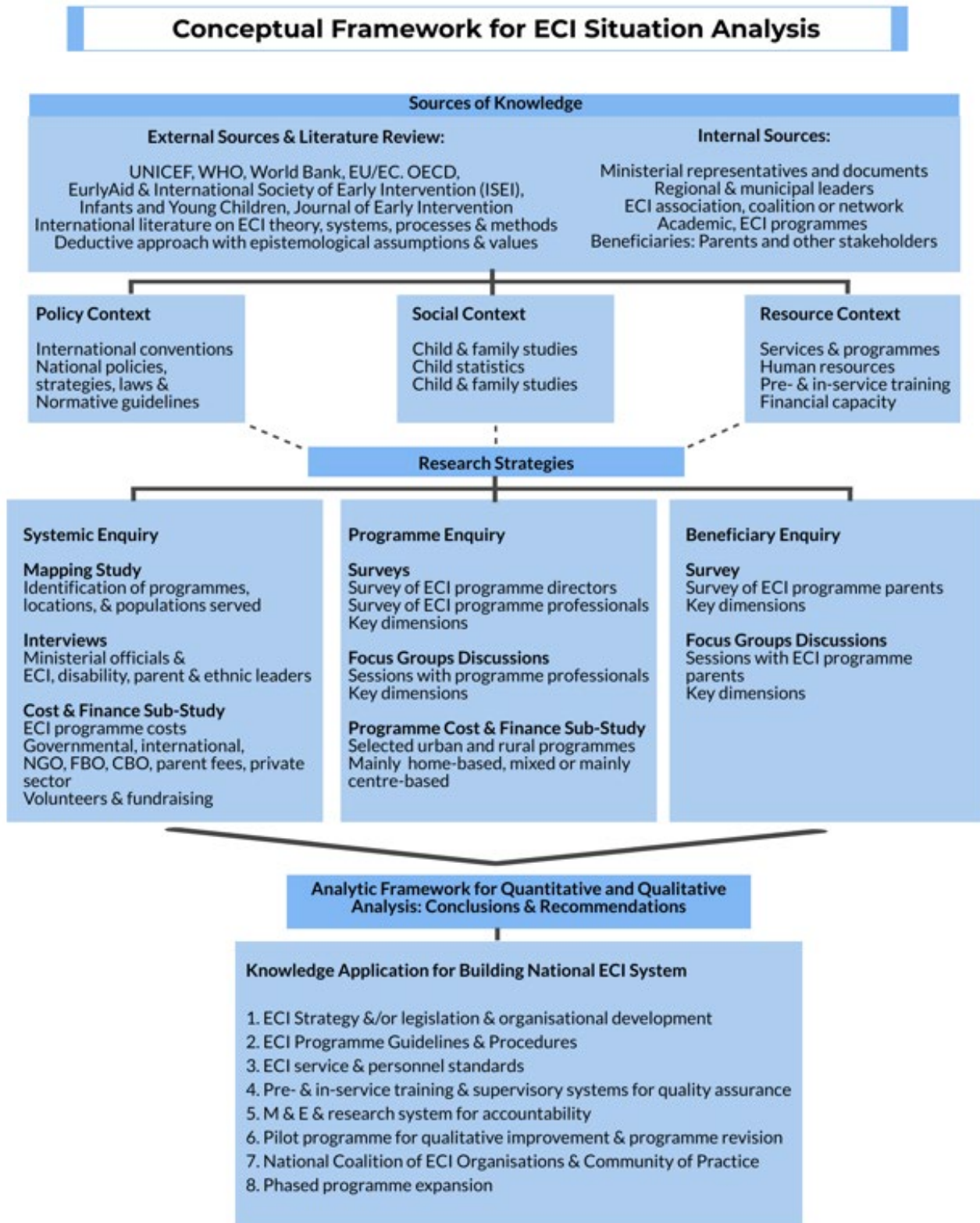
Contemporary ECI Service Process.

Contemporary ECI services follow a basic sequence of steps in usual ECI service processes. These basic steps are presented in Figure 1 and described below:



Annex 5:

Conceptual Framework



Annex 6:

Research Team

The Research Team is composed of the following specialists:

Research Team	
Name	Roles
Emily Vargas-Barón, Ph.D., Director, RISE Institute	Author of the Methodological Guide and Research Advisor
Kristel Diehl, M.A., M.S. Senior Fellow & Deputy Director, RISE Institute	Researcher. Methodological support, guidance and quality assurance. Instrument Revision, Surveys, Quantitative Data Analysis, Interpretation and Author
Blerta Perolli-Shehu, Ph.D. Vice-Dean for Academic Affairs and Master's Studies of the Faculty of Education, University of Prishtina	Local Team Leader and Researcher Coordination, Field Research Coordination, Instrument Revision, High-level Interviews, Qualitative measures and data, General Data Interpretation and Author
Aliriza Arënliu, Ph.D. Director of the Institute of Psychology and is an Associate Professor of Psychology in the Department of Psychology, in the University of Prishtina	Local Researcher Coordination, Instrument Revision, Qualitative and Quantitative data collection and analysis, General Data Interpretation and Author
Kaltrina Kelmendi, Ph. D. Assistant Professor in the Department of Psychology of the Faculty of Philosophy of the University of Prishtina	Local Researcher Coordination, Instrument Revision, Quantitative data collection and analysis, General Data Interpretation and Author
Natalia Kakabadze, Diploma, M.A. RISE Fellow and International Consultant	Cost and Finance Sub-Study, Researcher, Quantitative and Qualitative Data Analysis, Interpretation and Author

Annex 7a.

Budget allocations for pre-primary and pre-school education 2020-2022 and planning 2023-2025

Education Sector	2020	2021	2022	2023	2024	2025
	Budget allocation			Planned		
Central level	79,444,690	64,116,454	73,086,831	82,799,243	85,428,300	140,596,527
Local level	301,496,274	315,569,712	280,738,847	297,950,527	315,202,070	338,848,293
Budget for Pre-school Education	11,952,503	12,097,817	13,052,495	18,851,726	21,649,755	26,649,755
Total budget for education sector	380,940,964	379,686,166	353,825,678	380,749,770	400,630,370	479,444,820
Participation in budget allocations in education as % per preschool	3.14%	3.19%	3.69%	4.95%	5.40%	5.56%

Annex 7b

Ministry of Finance, Labor and Transfers: Activities to support children from birth to five

The number of children up to the age of five who are placed in family accommodation outside of relatives was 26 in 2021, the amount of payment for these children was 6700 EUR per month (caregivers for 24 children received payments of 250 EUR and due to limited income, the payments for two children were 350 EUR). The number of children up to the age of five placed in family accommodation with relatives was 42 for 2021, and the payments for these children were 4,200 EUR per month. Thus, the total payments for family housing (two housings) for children up to the age of five were 10,900 EUR per month and per year were 130,800 EUR.

The 44 NGOs, mentioned in the text, also benefited from funds provided through a public call announced by the Ministry at the end of 2021. Funding for children aged up to five years accounted for 20% of the total funding provided by MFPT/DFSP for services provided to licensed NGOs, totaling approximately 200,000 EUR per year. The number of children up to five years of age placed in family shelters was 26 in 2021.

Regarding the pension scheme for children from birth to five years with disabilities for the year 2021, totaled 296 children, whose caregivers were given cash support. The amount of payments for these children was 355,200 EUR per year. In 2021, the total annual expenditure for the Social Assistance Scheme for children aged birth to five years, totaling 13,630 children, was 3,271,200 EUR.

As for the allowances for children aged birth to five years, the total amount was 17,010,120 EUR for 102,471 children. Recently, the government began to offer payments for maternity leave, and it is divided into two groups. One group is for unemployed mothers and their children, and another group is for employed mothers and their children. In the first group the payment for 6 months for each month is 170 EUR, and the annual payment for 6,869 children was 7,006,380 EUR. For the second group the payment was only for 3 months (also 170 EUR), and the annual payment for 1,464 children was 746,640 EUR.

Annex 8:

Research Questions

Basic Information

Where are ECI organizations (legacy, evolving, and contemporary) located?

What regions, villages, towns or cities do they serve?

What is their coverage in terms of children served?

Enabling policy environment

What are the local policies, strategic plans, laws, regulations, guidelines, and standards in sectors, such as health, education and social protection related to ECI system and services?

What gaps exist in the policy environment to enable the establishment of a ECI system and the improvement and expansion of ECI organizations?

Child and family status

What is the status of children, parents and caregivers receiving ECI services? (By developmental status, family poverty level or income quintile, gender, geographical areas, etc.)

How many of which types of children need ECI services in Kosovo?

What can be done to improve service equity? (Rural, remote vs urban, upper vs low-income, majority vs minority groups)

What roles do parents play in ECI services and what is their level of participation?

How should ECI services ensure they become fully family-centered and enable parents to make decisions and play active roles in maximizing the development of their children?

In what ways do parents participate in ECI services?

Outreach, developmental screening and referrals

What community outreach services are provided?

Is developmental screening conducted along with referrals?

What types of developmental screening are conducted?

What are the needs for more developmental screening and improving the referral system?

ECI service provision

What is the ECI service capacity, quality, and coverage, with attention to rural and remote communities, disadvantaged ethnic minority groups and others?

What should be done to overcome barriers and expand service capacity, quality and coverage?

To what extent are ECI services contemporary, e.g.?

Community outreach

Developmental screenings

Comprehensive developmental assessments

Family assessments and eco-mapping

Individualized Family Service Plans decided by parents

Transdisciplinary or Interdisciplinary Teams

Visits in natural environment of the child

Revisions of assessments and IFSPs

Transition plans

What more needs to be done to ensure ECI organizations can adopt the core concepts and key services of contemporary ECI organizations?

Human resources

What types of professionals, paraprofessionals and volunteers work in ECI organizations, or evolving ECI services, and what roles do they play?

What are the needs for more accredited or licensed professionals, paraprofessionals and volunteers?

ECI workforce development

Is pre- and in-service training provided in the Kosovo for managers, supervisors, professionals, paraprofessionals and volunteers of ECI services?

What are the gaps in pre- and in-service training and what should be done to fill those gaps?

What ECI quality assurance measures exist and what more should be done to achieve quality assurance

ECI service costs

What are the major costs of ECI organizations in relation to the types of services they provide?

What major needs could be met through expanded financial support?

ECI financial resources

What financial resources are invested in ECI by source of funding including parent fees, and type of services (urban/rural; contemporary ECI, evolving and legacy)?

Annex 9:

Key Stakeholders and Instruments Applied

No.	Stakeholders	Instruments
1	Directors of ECI-like service institutions and organizations	Mapping Survey
2	Directors of ECI-like service institutions and organizations	Directors' Survey
3	Service personnel	Service Personnel Survey
4	Parents and other caregivers	Beneficiaries' Survey
5	Service personnel	Interview guide for service personnel
6	Parents and other caregivers	Interview guide for beneficiaries
7	High-level leaders, policy makers	Interview guide for high-level officials
8	Sectoral specialists in health and education	Interview guide for sectoral specialists
9	Directors/managers of selected ECI-like service institutions and organizations	Cost and finance questionnaire and interview guide

SITUATION ANALYSIS
ON EARLY CHILDHOOD
INTERVENTION IN KOSOVO

