SITUATION ANALYSIS

on Early Childhood Intervention in North Macedonia

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Acronyms

AEPS	Evaluation and Programming System
ASD	Autism Spectrum Disorder
CBO	Community-Based Organisations
CBR	Community-Based Rehabilitation
CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
CSO	Civil Society Organisations
ECEC	Early Childhood Education and Care
ECI	Early Childhood Intervention
EIS	Early Intervention Specialists
ESF	European Social Fund
EU	European Union
FBO	Faith-Based Organisations
GDPR	General Data Protection Regulation
HELP	Hawaiian Early Learning Profile
ICF-CY	International Classification of Functioning, Disability and Health: Children and Youth Version
IFSP	Individualised Family Service Plan
MES	Ministry of Education and Science
MoF	Ministry of Finance
MoH	Ministry of Health
MoLSP	Ministry of Labour and Social Policy
NGO	Non-Governmental Organisations
NICU	Neonatal Intensive Care Unit
PEDS	Parents Evaluation of Development Status
RBI	Routines-Based Intervention
SDG	Sustainable Development Goals
ToC	Theory of Change
ToR	Terms of Reference
UN	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNICEF	United Nations Children's Fund
WHO	World Health Organisation

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Executive Summary

The essential purpose and scope of interest of the Situation Analysis on Early Childhood Intervention (ECI) in North Macedonia was to conduct a comprehensive national-level Situation Analysis of the ECI system and its programmes and services in North Macedonia; to generate reliable evidence on existing national strengths and capacities, salient needs, and opportunities to establish and further support contemporary and sustainable programmes for ECI for children aged 0-6 years, with emphasis on the birth to three period, who are at risk of or have developmental difficulties, including disabilities; and to make recommendations regarding next steps for building, strengthening, improving, expanding, and financially supporting the national ECI system and its programmes.

Respondents for this study included the Ministry of Health (MoH), Ministry of Education and Science (MoES), Ministry of Labour and Social Policy (MLSP), the Health Insurance Fund (HIF), Office of Ombudsperson for Children, Office of Ombudsperson for Persons with Disabilities, the Parliament of North Macedonia, Governmental Body for Implementation of the Convention of the rights of persons with disabilities, Municipality leaders, Centre for assessment according the International Classification of Disabilities (ICF), ECI programmes and specialists, parents and families, relevant professional associations, academic leaders in ECI, additional ECI stakeholder groups, and the UNICEF Country Office for North Macedonia. The intended audience is expected to use this ECI Situation Analysis to prepare national, municipal plans and policies to serve Macedonian families; to be a part of the National Strategy for Disabilities; to improve the development of children with at-risk situations, developmental delays, disabilities and behavioural or mental health needs; and prepare policy briefs and advocacy materials for ECI services.

Key objectives

The key objectives of the ECI Situation Analysis were to:

- Generate data on the existing arrangements for children at risk of or with developmental difficulties aged 0-6 years by applying UNICEF ECA Regional methodology for situational analysis of ECI.

- Analyze existing ECI frameworks and references in multisectoral and sectoral policies, plans and legislation, with a particular focus on the education, health and social protection sectors, that may provide a legal basis for an ECI system as well as identify current gaps in existing strategic planning and legislation.

- Analyze the status and needs of children, parents, legal guardians, and caregivers targeted by the ECI system and its services, including low-income populations of children and their families and Roma and other minority groups, and identify gaps in data availability, children and families most in need of ECI services, barriers to accessing services, and current programme coverage in urban and rural areas and other remote areas.

- Analyze the capacities of existing sectoral funding and support services of all types as well as service arrangements for delivering integrated, multi-sectoral and interdisciplinary family-centered ECI systems, including: 1) community outreach; 2) developmental screening and hospital/physician surveillance and monitoring for the identification of children with developmental difficulties; 3) provision of family-centered, multi-sectoral ECI services in terms of types of programmes, availability, access, utilization, financing, etc.; 4) provision of developmental assessments, eligibility decisions, and individualized family service plans; 5) case management and effective referrals to other complementary services; and 6) transition planning and activities to ensure entry into inclusive early childhood and primary education services.

- Identify existing human resources for the provision of ECI services, including managers, supervisors, professionals, paraprofessionals and skilled volunteers, and analyze programme needs for additional personnel.

- Identify and assess existing resources for pre- and in-service training, personnel and performance standards, licensing/certification, career ladders or lattices, salary scales, personnel training plans, and other human resource needs.

- Analyze the current budgets and expenditures of national ministries and agencies, and regional and municipal governmental support for ECI services as well as all sources of financing for selected ECI programmes in relation to their funding needs and modalities for ensuring the sustainability of ECI services.

- Analyze and identify potentially promising programmes and practices for scale up, scope of services within those ECI programmes, their coverage in terms of child and family characteristics, human resource capacities, needs for training and support, and gaps in current services.

- Offer evidence-based recommendations regarding needs for: 1) strengthening the ECI policy environment; 2) using key entry points for the establishment or strengthening of the organization and coordination of the ECI system in relation to country context and needs; 3) improving and expanding ECI programmes; 4) allocating and expanding human resources; 5) planning for providing sufficient high-quality pre- and in-service training; and 6) expanding and diversifying financial support for managing and expanding ECI programmes.

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, Diehl, and Kakabadze, 2022). Similar research has been conducted in Croatia, Montenegro, and Kosovo. The fundamental purpose of the *Methodological Guide* is to assist countries to analyse 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 centred ECI services for child development.

A sequential mixed methods research design was used to prepare National ECI Situation Analyses in North Macedonia. This approach of using different methods of data collection and types of respondents has several strengths including the potential triangulation of results as well as the discovery and reaffirmation of major existing strengths, gaps and needs in ECI services, resources and enabling policy environments. To design and guide the implementation of this complex study, eleven major research questions with many sub-questions were posed, core ECI concepts were listed, a previously applied ECI Theory of Change was selected for use and a Conceptual Framework for Research was prepared and applied. This research project provides guiding theoretical constructs and multiple methodological approaches that may be useful for others that are seeking to conduct planning activities to expand and improve their ECI systems. This complex nationwide study met its stated goals and secured useful and valuable results. As a result, twelve major conclusions were identified and related recommendations were offered.

Methodology and analysis

A Research Team composed of eleven national ECI researchers and practitioners and three international researchers in early childhood intervention services, costs and finance conducted this study. Existing ECI and ECI-related services were identified and mapped, and surveys, focus groups and high-level interviews were conducted to provide additional information previously unavailable in existing national and international literature on Macedonian ECI programmes and their beneficiaries.

A mixed-methods approach was used to meet research objectives and answer major research question.

1. **Literature Review.** A literature review was conducted to provide a solid foundation for fieldwork and to serve as an introduction to the current ECI system in North Macedonia. It included analysis of policy instruments, qualitative and quantitative studies, technical reports, and statistics. This review helped the research team to identify new data sources, assess political and legislative provisions for ECI in North Macedonia, and gain an understanding of the background, context, and current status of ECI services.

2. **Mapping Study.** The mapping study, together with the literature review, represented a solid foundation for further and thorough analysis of the ECI services. The information gained through this survey secured the initial list of contact information and enabled the research team to strategically plan the next steps of the study. Through the mapping phase, 55 ECI centers were identified throughout the country. The research team made a decision to include public centres which were state financed ECI centers (general hospitals, clinical hospitals and medical centers), private for profit ECI centers and non-governmental organizations (NGOs/Associations of citizens) in order to have a full picture of the Early Childhood Intervention situation in the country. The results from the mapping study show that from all the 55 centers, 20 are public state centers and 35 are private centers and NGOs/Associations (more than half or 64% of the ECI services are being provided by private for-profit or non-profit centers).

3. **Survey of ECI Directors.** From the total of **55** identified **ECI centres**[1], **44 ECI Directors** (80%) responded to the surveys thereby yielding a representative sample. The Directors survey was oriented towards defining the registration of the ECI centers, characteristics of children served, types of services offered; access to services, networking, monitoring, coordination, barriers, challenges and recommendations.

4. **Survey of ECI Staff.** A total number of **76 ECI personnel** responded to the survey. More than half were special educators and rehabilitators. The respondents gave information regarding types and frequency of ECI services, ECI pre-service and in-service training, monitoring and evaluation of ECI service provision, and challenges and needs of ECI services.

5. **Survey of ECI Beneficiaries.** In total, **98 ECI beneficiaries** (parents, guardians and caregivers) responded to the survey. They gave an insight into the services the children use, barriers they face in obtaining ECI services, types of professional assessment, types of specialists, participation in in ECI services, parental fees for ECI services, recommendations for development of future ECI services.

6. **Focus groups with ECI Staff.** Six focus groups were organized within this research. Most of the focus groups were realized online through the Zoom video conferencing platform (4 focus groups), and two focus groups were held hybrid (with physical presence and online). A total number of **33 persons** participated (75%) of those invited to participate. The participants were from six cities in North Macedonia. This qualitative part of the research gave an insight into the types of contemporary services provided, community outreach, developmental screening and assessment, ECI service quality, training, ECI supervision and evaluation, networking, coordination, referrals and recommendations for ECI.

7. **Focus group with ECI Beneficiaries.** Seven focus groups with parents were conducted within this research. A total number of **36 persons** participated (72% of those invited) in the focus groups. They gave in-depth information regarding the experiences and challenges they faced in obtaining ECI services, community-based services, types of ECI services that the children receive, assessment procedures, participation in ECI services, social benefits and recommendations for improving ECI services in North Macedonia.

8. **High-level interviews with Government Officials and Representatives of Organisations.** A total number of **21** high level interview were held to gain their views regarding the status of children, families and ECI services as well as their understanding of challenges ECI programmes face and recommendations for expanding and improving ECI programmes to create a national ECI system.

[1] "ECI centres" term is used throughout the report for all providers of ECI services (private and state), from NGOs and specialised centres to those that are part of larger medical clinics.

9. **Cost and Finance Sub-Study.** This study was designed, organized and implemented to identify and analyse all types and levels of possible financial support for ECI centres with and centres with ECI elements. The sources of funding were discussed, and the participation of the central government and local self-government in ECI funding was elaborated. Additionally, case studies of five ECI programmes were conducted, yielding useful results for future programme design and systems planning. The Centres were selected according to the type of funding. There are 3 for-profit private organizations and 2 non-profit organisations (one is an NGO and another – a public clinical center). Four centres have ECI children alongside other beneficiaries, while one Centre provides comprehensive ECI services consisting of 100% ECI children.

During field research, all GDPR requirements were followed rigorously. All data was reviewed, double-checked, and cleaned before data analyses began. The data was analysed in accordance with the needs of each type of data set. Subsequently, tables and graphics were constructed, reviewed, finalised and interpreted. In addition, several maps were composed to illustrate specific information geographically. For purposes of presenting findings secured through the application of multiple research instruments, a structural outline was developed keyed to basic eleven research questions and related major study themes. Research findings are presented and interpreted in Chapter 4, and major study conclusions and recommendations are offered in Chapter 5.

Main findings

ECI programmes are located in most of the major regions of the country, however, their coverage is geographically limited. According to the 2021 Census, there are 140.436 children under the age of six in North Macedonia. The ECI directors (42 ECI directors responded to this question), in 2022 reported that they serve a total of 7.809 children, which is an average of 185 children per program. Thus, the total number of children enrolled in 55 ECI centres could be as many as high as 10.175 children.

Using the probable rate of 12,5% (world statistics show that 10-15% of children from birth to six have developmental delays) of 140.436 children from birth to six years, as many as 17.554 children may need ECI services. If this is the case, then around 58% of ECI eligible children are being served[2], and additional places are needed for approximately 7.379 children.

These findings reveal an urgent need to expand ECI programme services. Before expanding services there is also a need to regulate and further define the early intervention programmes, which should include development of evidence-based bylaws in line with the CRPD.

Before expanding programme services, it will be essential to build on the strengths of current ECI programmes and their trained and experienced personnel while also addressing areas for improvement. Such areas include:

- Planning equitable programme coverage, including rural and remote communities, poverty zones, and minority groups with a focus on communities;
- Developing initiatives for community outreach, developmental screening, and a referral and child tracking system;
- Offering opportunities for the progressive adoption of contemporary family-centred ECI processes and methods, including comprehensive developmental assessments, the formation of transdisciplinary teams, routines-based interventions, individualised family service plans, home visits and visits in other natural environments of the child, and the provision of family transition plans to inclusive Early Childhood Education (ECE) centres (kindergartens) and primary schools.
- Addressing issues of early identification from birth to three, gender and ethnic equity, and meeting adequately the needs of children with disabilities and also those with at-risk situations, developmental delays, behavioural or mental health needs.
- Overcoming a plethora of barriers found to limit access to ECI services, including the prolonged use of non-functional medical review committees and waiting lists; and
- Addressing requirements for building a comprehensive system of integrated service delivery and ensuring effective intersectoral and inter-institutional coordination.

[2] For the children that are a part of the 58% of children served, it doesn't necessarily mean that all of their needs are being met, but that they are receiving at least one service.

Major conclusions and recommendations

Based on these and other study findings, conclusions and recommendations were offered:

1. Creation of an ECI Strategy and Action Plan

Conclusions from the study: There are no laws, regulations or policies for ECI. A national strategy for ECI services as well as an elaborate action plan does not exist. There are no regulations regarding the manner and preconditions for opening an ECI centre. The type of registration of ECI centres is not yet defined. ECI services are a part of a disorganized system with no clear pathways and directions that can be followed by parents. The need for an efficient, equitable and sustainable National ECI System is in line with the requests by both the Convention on the Rights of the Persons with Disabilities as well as the Convention on the Rights on the Child. A creation of a National ECI Strategy and subsequently an Action Plan for provision of ECI services is the first step towards an organization and highly effective system for ECI.

Recommendations: The strategy (accompanied with an action plan) suggested needs to be typically for a five-year period (preferably with a two year budgeting plan) and it needs to be created with an interdisciplinary approach with the participation of all key stakeholders such as: Ministry of Health, Ministry of Education and Science and Ministry of Labour and Social Policy; representatives from the National Body for Implementation of the CRPD; representatives from the office of the Ombudsman; academic leaders in ECI; NGOs; parental organizations; private sector companies that provide ECI services and UNICEF. This needs to be a multi-sectoral ECI strategy.

2. Raising Awareness and Advocating at Municipal and National Levels

Conclusions from the study: One of the biggest barriers in obtaining ECI services was the stigma and discrimination that parents face when trying to provide services for their child. On the other hand, one of the most important recommendations by them was to expand awareness in order to reduce the stigma and discriminations. One of the other most pressing issues was to expand advocacy to increase demand for ECI services. There was a significant lack of national and municipal advocacy for expanding and improving ECI services.

Recommendations: Regarding awareness, we need to work on better informing families and communities, so that they can understand the goal and importance of ECI and be informed of the rights of the child and the family. They need to be informed regarding the difference between rehabilitation and medical approaches on one hand and interventions in early childhood on the other hand. Regarding advocacy, an advocacy paper should be developed, with a sole purpose not only to collect signatures but also to be used for lobbying to national authorities for implementation of the activities written in it. Parents need to be included in planning future ECI services. They can be the best advocates for their children.

3. Create a National ECI Organisational Framework and Effective Intersectoral Coordination for ECI Services

Conclusions from the study: There is no national ECI organisational framework or intersectoral coordination system in North Macedonia. A unified system of leadership, coordination, planning, budgeting for equity, quality assurance, accountability and sustainability is lacking. ECI programmes also require essential guidance and opportunities to influence the future development of their services. The health sector will be the most important one regarding children from birth to three (particularly because of initial screenings and referral, as well as the fact that all public ECI centres are under the Ministry of Health). Social policy and education sector should also highly engage in the ECI (or ECI-like) services, having in mind that the best manner of providing services from three-to-six years of age is within kindergartens. A particular role can be given to the Ministry of Education, through including professionals from resource centres in providing services for children at this age.

Recommendations: An organisational framework with processes for strong intersectoral coordination at all levels should be designed and described in the National ECI Strategy and Action Plan. An intersectoral group can be formed including all stakeholders. A central office (as recommended by the study participants) should be established, with representatives from all sectors (health, education and social welfare). Municipality offices need to be established as well. A system of coordination should be established among all ECI stakeholders, via memorandum of cooperation that could be established between ECI programmes and municipal representatives. To include the various sectors more, training sessions on ECI can be organized between medical professionals, kindergarten employees as well as representatives from the social centres. A National network or coalition of ECI centres was a recommendation that prevailed during the entire research.

4. Develop and Implement ECI Programme Guidelines and Procedures

Conclusions from the study: In North Macedonia there are no guidelines, procedures or any regulations regarding provision of ECI services. Different centres

provide an array of different services, that ranges from legacy (rehabilitation and habilitation services) to contemporary services. An official document regarding ECI Guidelines and Procedures should be developed and approved. This document should include ECI concepts, requirements for eligibility, child and parental statements, available ECI services and other additional procedures related to ECI. Procedures for certification and licensing should be established as well. Currently there is no licensing required for working with children with developmental delays/disabilities nor any established prerequisites for opening an ECI centre (other than a diploma in the required area). We need to establish guidelines and procedure in order to establish equal quality in all ECI services provided for all children.

Recommendations: The Guidelines and Procedures should be developed with a wide consensus of all relevant stakeholders. It cannot be a one-sided document brought by a few stakeholders. In order to establish consensus, workshops need to be organized with both ECI providers and government officials. Once this document is drafted it needs to be frequently reviewed in order to enable equitable services to urban, rural and minority populations. If an ECI centre does not meet the requirements, technical support must be given. This process of developing ECI guidelines and procedure will go parallel with the establishing of the process of registration and certification of ECI programmes.

5. Equitable ECI Services

Conclusions from the study: Large inequalities were found in the provision of services. Rural areas, minorities as well as families with a low income status were dramatically underserved. The largest number of centres were located in the capital Skopje. Many cities and municipalities do not have an ECI centre and parents travel long distances to receive ECI services. Inequality is found in the fees parents pay to receive services. Waiting lists in state centres are usually so long, that parents decide to get ECI services by private providers.

Recommendations: Because demand exceeds supply and long waiting lists exist in many ECI programmes, it will be essential to place priority on underserved populations and expand ECI services while conducting community outreach to identify the many children who require ECI services. Such programmes will also need adequate funding for transportation. One option, in order to use the experiences and developed services of already well established private ECI centres, is to create public-private partnerships. This can be done via government social packages, that will aim particularly towards these underserved groups of the population.

6. Establish and Implement ECI Service and Personnel Standards

Conclusions from the study: There are no ECI service and personnel (professionals, paraprofessionals and volunteers) standards. There are no standards regarding qualifications, certification, licensing, personnel development or other comparable requirements. Every system needs to have personnel standards in order to assure that that personnel has the qualifications needed to carry out the goals of ECI and to assure that the personnel is appropriately and adequately prepared and trained.

Recommendations: The ECI guidelines and Procedure must provide for the establishment and maintenance of qualification standards that will be consistent with a state-approved certification, licensing, registration and other requirements that apply to the profession, discipline, or area in which the personnel are providing ECI services.

7. Prepare and Implement an ECI Pre- and In-Service Training Plans

Conclusions from the study: There are no official ECI pre-service or in-service training plans. Pre-service training is developed for special educators and rehabilitators. ECI courses are offered on two different universities, in Macedonian and in Albanian as well. These courses need to be more contemporary and provide more information regarding family-centred practices. ECI professionals are generally satisfied with the knowledge for ECI gained on the undergraduate level, however they were very specific in their demands for the necessity of organizing specialist studies in ECI.

Recommendations: It is recommended that both pre- and in-service training be reviewed in light of the contents of the future National ECI Strategy and Action Plan, National ECI Programme Guidelines and Procedures, and ECI Service and Personnel Standards. The extensive evidence-based knowledge for contemporary ECI services could help inform all pre-service training programmes and help to expand the training of Early Intervention Specialists (EIS). In-Service Training Plan be prepared with the full participation ECI leaders, programmes, university professors, associations, and students. Usually, field training, coaching and mentoring for ECI professionals and paraprofessionals are emphasized.

8. Development of a National Database for Children in ECI Services and an ECI System for Monitoring, Evaluation, Reporting, Planning and Accountability

Conclusions from the study: No national framework and guidance for ECI programme indicators, monitoring, evaluation and reporting exists. While this situational

analysis is being prepared, there is no national database for children in ECI services as well as children that are in need of ECI services. However, this research showed that the Ministry of Labour and Social Policy is in the process of creating such a database. This research also points out the number of families in need for ECI services. A system of monitoring, evaluation, reporting, planning and accountability has not been developed yet. Some ECI directors claimed to have internal monitoring.

Recommendations: Considering that a national database for children in ECI services will be developed, the focus should be moved towards the creation of a framework for and guidelines for programme monitoring, evaluation and reporting. A national system of ECI monitoring and evaluation is greatly needed to assess programme inputs, outputs and outcomes.

9. Provide Supervision for the ECI System and ECI Programmes to Achieve Quality Assurance

Conclusions from the study: There is no supervision of the work of professionals that provide ECI services. Some of the centres stated that they have internal supervision and that the ECI director serves as a supervisor of the work of his employees. In a situation where we do not have supervision of the ECI system or ECI service being given, we cannot discuss quality assurance. ECI professionals stated they need supportive supervisory services, including coaching, mentoring and reflective supervision.

Recommendations: To create a system of quality assurance for ECI services, two levels of supervision are needed: A national, county and municipal unified supervisory system with all supervisors working together to support ECI services, reward achievements, and develop new competencies and systems of supervision at the local level; and ECI supervisors in programmes who will play supportive roles of coaching, mentoring, and reflective supervision with all professional and paraprofessional personnel.

10. Develop a Universal System of Developmental Screening, Assessments and Referrals

Conclusions from the study: The study showed that half of the surveyed parents received developmental screenings and comprehensive assessments. Half of the ECI centres conduct screenings and also half of them conduct assessments. A relatively large number of parents stated that they receive developmental screenings. However, the age of children first enrolled in services shows that we have a late identification of children with developmental delays/disabilities. Regarding referral, the parents were usually the ones that seek out services.

Recommendations: North Macedonia should develop a system of Universal Screening that will lead to an effective system of referrals. Family doctors, pediatricians, patronage nurses and vaccination points should be the "gate-keepers" together with the ECE professionals (working in kindergartens) or the entry points that will conduct this Universal Screening. There should be referral follow up, possibly done by the patronage nurses (envisioned in the Universal Progressive Model of Patronage). In contemporary ECI services, developmental assessments are conducted at the individual programme level and eligibility is established by the ECI service provider's transdisciplinary team on the basis of medical diagnoses, where needed, the child's developmental levels, and at-risk situations.

11. Design and Implement a Pilot Project for the Qualitative Improvement of ECI Programmes

Conclusions from the study: Many of the directors, but also many of the ECI personnel expressed their interest and eagerness in learning new principles, methods, using new instruments and learning new approaches. A large number of them were interested about being trained in the transdisciplinary approach with a primary service provider. What is encouraging is that ECI personnel from the state medical institutions were also interested in learning these new ECI approaches.

Recommendations: To field test new approaches and enable a few ECI programmes to serve as testing and demonstration sites for others, a pilot project might be considered. It is recommended that a maximum of three ECI programme sites be selected and located in: Urban; Rural; and Minority communities.

12. Develop a Phased Investment Plan with Guidelines for Regional Equity and Development, Resource Maximisation, and Cost Monitoring

Conclusions from the study: There is no specific ECI budget programme in any sectoral ministry. The costs of ECI services (salaries and utilities) in public centres are covered by the Ministry of Health through the Health Insurance Fund. Other ministries are not involved in funding ECI. In private ECI centres, parents' fees are the main source of funding, paid out of pocket. There is no insurance to cover these costs in the private and NGO sectors. There is a lack of knowledge about ECI services, how to conduct needs assessments, and tools to prepare an ECI budget at the local level. Although social, child protection and health programmes exist that are the responsibility of municipalities, there are no specific budget lines for ECI services in municipal budgets. Some of the ECI centres (mainly in the capital city) receive one-off funding from the municipalities, but this support is not yet provided on a regular basis. There is no single standard for salaries in ECI

centres. The Ministry of Health sets the salaries for professionals in the public/non-profit centres, while the private/profit centres have their own rates.

Recommendations: Reducing the financial burden on parents with children who receive and need ECI services should be the primary goal of the financial part of ECI reform in this country. This should be achieved by creating ECI programme budget for comprehensive ECI services at multiple government levels and from multiple sources. At the National Level a working group (or sub-group) should be established to design a central ECI budget programme. The budget programme should be based on the projected cost of services that in turn, will be based on ECI guidelines, procedures and standards. The ECI budget programme should be consistent with the medium-term strategic priorities of the country's budget. The working group, together with the lead ministry, should work with international donor agencies, foundations and NGOs to identify and secure additional funding sources, especially for a comprehensive training programme, pilot ECI demonstration and training services and short-term initial developmental costs of all new ECI service providers. At the Local level there should be needs assessments at the community level, including urban, rural and national minority-inhabited areas, should be conducted at the local level. Regular consultation with local stakeholders should become the basis of a strong public-private partnership. Local authorities and ECI staff members should be trained in programme budgeting. At the service provider level all levels of government should work to increase the fundraising capacity of service providers to ensure that alternative and additional sources of funding are developed alongside government funding, which typically accounts for 75% to 80% of ECI funding in countries.

I. Background and Rationale

The essential purpose and scope of interest of the Situation Analysis on Early Childhood Intervention (ECI) in North Macedonia was to conduct a comprehensive national-level Situation Analysis of the ECI system and its programmes and services in North Macedonia; to generate reliable evidence on existing national strengths and capacities, salient needs, and opportunities to establish and further support contemporary and sustainable programmes for ECI for children aged 0-6 years, with emphasis on the birth to three period, who are at risk of or have developmental difficulties, including disabilities; and to make recommendations regarding next steps for building, strengthening, improving, expanding, and financially supporting the national ECI system and its programmes.

A Research Team composed of eleven national ECI researchers and practitioners and three international researchers in early childhood intervention services, costs and finance conducted this study. Existing ECI and ECI-related services were identified and mapped, and surveys, focus groups and high-level interviews were conducted to provide additional information previously unavailable in existing national and international literature on Macedonian ECI programmes and their beneficiaries.

Respondents for this study included the Ministry of Health (MoH), Ministry of Education and Science (MoES), Ministry of Labour and Social Policy (MLSP), the Health Insurance Fund (HIF), Office of Ombudsperson for Children, Office of Ombudsperson for Persons with Disabilities, the Parliament of the North Macedonia, Governmental Body for Implementation of the Convention of the rights of persons with disabilities, Municipality leaders, Centre for assessment according the ICF (International Classification of Disabilities) , ECI programmes and specialists, parents and families, relevant professional associations, academic leaders in ECI, additional ECI stakeholder groups, and the UNICEF Country Office for North Macedonia. The intended audience is expected to use this ECI Situation Analysis to prepare national, municipal plans and programmes to serve Macedonian families; to be a part of the National Strategy for Disabilities, to improve the development of children with at-risk situations, developmental delays, disabilities and behavioural or mental health needs; and prepare policy briefs and advocacy materials for ECI services.

The scarcity and unavailability of early childhood developmental screenings and Early Childhood Intervention (ECI) services at the national level, specifically in state-funded public ECI services, results in a high proportion of children in at-risk situations, developmental delays and/or disabilities who go unrecognized and unserved in North Macedonia as well as in many other countries. This suggests that infants and toddlers with or at risk for developmental delays are not receiving the necessary support that would allow them to acquire certain functional skills and to be able to contribute to the community they live in. National ECI systems should provide high-quality services guaranteeing the fulfilment of child and parental rights, preventing and reducing developmental delays, helping parents ensure their children with disabilities will achieve their full potential, and empowering families and caregivers to become competent and confident in supporting their children as well as helping them to transition to inclusive pre-primary and primary education and other social services.

This ECI Situation Analysis is being considered as a foundation for building a national system for early childhood intervention (ECI) services that will be based on existing strengths, resources and needs of the children, families, Government and ECI institutions, centres and professionals at all levels in North Macedonia.

As listed in the Terms of Reference (See Annex 1) for this research project, the primary objectives of the ECI Situation Analysis were to:

- Generate data on the existing arrangements for children at risk of or with developmental difficulties aged 0-6 years by applying UNICEF ECA Regional Methodology for Situational Analysis of ECI.
- Analyse existing ECI frameworks and references in multisectoral and sectoral policies, plans and legislation, with a particular focus on the education, health and social protection sectors, that may provide a legal basis for an ECI system as well as identify current gaps in existing strategic planning and legislation.
- Analyse the status and needs of children, parents, legal guardians, and caregivers targeted by the ECI system and its services, including low-income populations of children and their families and Roma and other minority groups, and identify gaps in data availability, children and families most in need of ECI services, barriers

to accessing services, and current programme coverage in urban and rural areas and other remote areas.

- Analyse the capacities of existing sectoral funding and support services of all types as well as service arrangements for delivering integrated, multi-sectoral and interdisciplinary family-centred ECI systems, including: 1) community outreach; 2) developmental screening and hospital/physician surveillance and monitoring for the identification of children with developmental difficulties; 3) provision of family-centred, multi-sectoral ECI services in terms of types of programmes, availability, access, utilisation, financing, etc.; 4) provision of developmental assessments, eligibility decisions, and individualised family service plans; 5) case management and effective referrals to other complementary services; and 6) transition planning and activities to ensure entry into inclusive early childhood and primary education services.

- Identify existing human resources for the provision of ECI services, including managers, supervisors, professionals, paraprofessionals and skilled volunteers, and analyse programme needs for additional personnel.

- Identify and assess existing resources for pre- and in-service training, personnel and performance standards, licensing/certification, career ladders or lattices, salary scales, personnel training plans, and other human resource needs.

- Analyse the current budgets and expenditures of national ministries and agencies, and regional and municipal governmental support for ECI services as well as all sources of financing for selected ECI programmes in relation to their funding needs and modalities for ensuring the sustainability of ECI services.

- Analyse and identify potentially promising programmes and practices for scale up, scope of services within those ECI programmes, their coverage in terms of child and family characteristics, human resource capacities, needs for training and support, and gaps in current services.

- Offer evidence-based recommendations regarding needs for: 1) strengthening the ECI policy environment; 2) using key entry points for the establishment or strengthening of the organisation and coordination of the ECI system in relation to country context and needs; 3) improving and expanding ECI programmes; 4) allocating and expanding human resources; 5) planning for providing sufficient high-quality pre- and in-service training; and 6) expanding and diversifying financial support for managing and expanding ECI programmes.

This Situational analysis met its established goals. The mixed-methods approach and triangulation secured useful and valuable results. Further research is recommended, possibly accompanied with field visits to ECI centres and evolving programs, to receive additional data and give additional support. Future research should focus on developing policies, strategies, action plans and in the general, research should be oriented towards generation a specific outline of the National ECI system, with particular roles of each Ministry, stakeholders, ECI professionals etc.

As a result of this ECI Situation Analysis, twelve major conclusions and recommendations were identified. They are presented in Chapter V for the consideration of the relevant Ministries and all ECI stakeholders as they plan their next steps.

II. Early Childhood Intervention and Conceptual Framework

This study was based on a Methodological Guide developed by UNICEF Regional Office for Europe and Central Asia designed with the purpose to collect and analyse data required to conduct effective strategic planning for developing a national system of competent ECI services. Quantitative and qualitative methods were used for this situational analysis. Because in empirical research the problem is studied by measuring the occurrence, as is the case in this research, the quantitative research strategy is applied. However, qualitative techniques were also used – focus groups and high-level interviews, in order to obtain more valid and more reliable results with the help of multimethod triangulation. Most previous analyses on ECI programmes in different countries including North Macedonia were based solely on literature reviews. This research provides theoretical constructs and methodological approaches that enable a complete National Situational Analysis of ECI.

2.1 Research questions

To achieve research objectives, eleven major questions were posed. The full list of subordinate questions is presented in Annex 2.

Table 1: Major Research Questions

1. Where are the ECI centres located and what is their coverage in terms of children served?
2. What are the national policies, strategic plans, laws, regulations, guidelines, and standards in sectors, such as health, education and social protection related to ECI system and services and what gaps exist in policy environment?
3. What is the status of children, parents and caregivers receiving ECI services, how many children need ECI services in this country, what can be done to improve service equity and how should ECI services ensure they become fully family-centred?
4. What community outreach services are provided, how does the current screening referral system works and what are the rules for eligibility?
5. What is the current ECI service provision and to what extent is ECI contemporary?
6. What are the roles or ECI professionals, paraprofessionals, and volunteers in ECI services?
7. What is the ECI workforce development and what can be done to achieve quality assurance?
8. What are the major costs of ECI centres and what major needs could be met through expanded financial support?
9. What financial resources are invested in ECI and which financial resources should be expanded and where should these resources be invested?
10. What is the status of organizational frameworks and coalitions and what is the capacity of the ECI system for monitoring, evaluation and reporting?
11. What can be done to achieve nationwide ECI coverage What types of policy advocacy communications are needed to build more support for contemporary ECI services?

2.2 ECI Concepts

Following are essential core concepts of effective ECI systems and their services. Together, they provided a theoretical construct of contemporary ECI concepts that guided this research project.

ECI is a social model

ECI is a social model that always contains educational, medical-therapeutic and social welfare elements. It embraces the major social development sectors of education, health, nutrition, sanitation, and social protection and welfare. This distinction differentiates ECI from rehabilitation and medical diagnoses that focus mainly or solely on a child's main area or areas of delay or disability. Instead, ECI focuses on the comprehensive and holistic development of the child and the family, with special attention to the areas of greatest need. ECI bases its work on building on points of strength and moving to other areas of need. Abundant research has shown that the social model is highly effective in achieving improved child development (Kennedy et al, 2010).

In all world regions, increasingly rehabilitation and habilitation services are evolving to become ECI services. This change is slow but once it begins, it continues. It is composed of many small and large changes over time. ECI services are eminently rewarding to programme personnel, highly beneficial for families and children, and help nations to build a more competent and productive citizenry.

ECI is individualised

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

ECI is continuous

ECI services are provided from the earliest identification of an at-risk situation, a developmental delay, a disability or a behavioural or mental health need. Services continue until a child attains typical levels of development or transitions to other age and/or developmentally appropriate services.

ECI is intensive

According to needs of each child and family, ECI service coordinators, early intervention specialists or home visitors usually provide frequent visits to families in the natural environment of the child. The schedule of visits is established with the full participation and agreement of the parents during the preparation of an Individualised Family Service Plan (IFSP). Some children who are already enrolled daily in ECE centres or childcare centres receive some of their visits in those establishments, with the full participation of their caregivers and at least once a month with their parents. Child caregivers are instructed to share the activities of each centre-based visit with the parents on a regular basis.

ECI services are evidence-informed and outcomes-driven

All ECI programmes seek to use the latest and most reliable research results that are available to 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 core ECI concepts, framing the Conceptual Framework, and applying the Theory of Change. It also should guide the development of all ECI services, including the selection and application of research instruments, and the analysis of study findings. All ECI services develop a discrete list of desired outcomes that help to guide programme planning and implementation of the national ECI system, as well as its monitoring and evaluation system. Ultimately, selected outcomes drive all ECI work and help ECI programmes achieve high-quality services that improve child and family development as well as achieve a wide array of other short-, medium- and long-term objectives.

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

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

ECI services are always provided in teams that function in an interdisciplinary or transdisciplinary manner rather than by single therapists or a group of therapists in one therapeutic field. Early intervention specialists (EIS) should be trained in skills pertaining to all of the disciplines and therapies used in ECI services; therefore, they become interdisciplinary specialists. All members of ECI teams focus on supporting and coaching family members as the way to best serve the child. They create either interdisciplinary or transdisciplinary teams.

With parents as key members of transdisciplinary teams, ECI services always work directly with the family and child. Members of transdisciplinary teams conduct comprehensive child assessments and Individualised Family Service Plans. They usually select one member of their team to become the primary service provider who makes most of the home visits and/or centre-based visits. Other members of the transdisciplinary team provide technical support to the primary service provider.

ECI builds strong relationships with families

ECI services are family-focused while also being child-centred. They seek to empower parents and ensure parents make **all key decisions** regarding their child's goals and services while also addressing parental needs for support. Research has shown that this family-focussed approach leads to better child development outcomes (Dunst et al, 2006).

Every ECI programme 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 that are usually called **ECI Programme Guidelines and Procedures**, along with core ECI concepts, rules, guidance and methods.

Essential ECI services usually include:

- Referrals to and from ECI services;
- Developmental screening for initial identification of children needing ECI services;
- Initial programme reception procedures;
- Comprehensive developmental assessments and regular re-assessments over time;
- Decisions regarding programme eligibility or referral to other services;
- Preparation and regular revisions of IFSPs;
- Provision of early stimulation and intervention visits in the natural environment of the child (home, substitute family home, inclusive child care centre or inclusive ECE centre);
- Provision of occupational therapy services, including self-help skills, sensory or physical development, and adaptive behaviour 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;
- Individualised and/or group parent education services to help families parent well in all areas, understand the special needs of their child;
- Case management services for parents to help them learn their and their children's rights, identify their strengths and needs, and to support them with service management;
- Support parents to make their home environments more stimulating, safe and hygienic
- Translation and interpretation services for families, if needed, to ensure services are provided in the family's mother tongue 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, which vary by country and the level of development of the ECI system, may include:

- Nutrition services helping parents meet nutritional needs of children such as: diet improvement, feeding skills, breastfeeding, complementary feeding, allergies, etc.;
- Psychological support services for children or parents, e.g. administering psychological tests, assessing child behaviour, mental health counselling, family therapy, etc.;
- Audiology services for children in order 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 and helping them to forge friendships with other parents facing similar challenges and needs;
- Provision of access to a Toy and Book Library in ECI service centres;
- Nursing services to support special health care needs of a child and teach parents how to administer medications, provide treatments, and conduct other health care activities;
- Provision of respite care for parents and other primary caregivers to give them a break from constant care giving;
- Mobility and orientation specialists for blind and low-vision children;
- Rehabilitation services requiring specialised equipment and other technologies; and
- Provision of assistive technologies and adaptive equipment to help children develop, see, hear, play, eat, learn, communicate, and move better.

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. However, for children who receive daily centre-based services, some or most of the visits may be provided in the child's care centre, nursery, ECE centre or another similar place. Parents are asked to be present for as many of the centre-based

visits as possible. In some countries, services are also provided in residential institutions for young children. However, increasingly ECI programmes are playing a critically important role in deinstitutionalisation and the prevention of institutionalisation by helping to place children with nurturing families and assisting adoptive or foster parents with the good development of the children they receive.

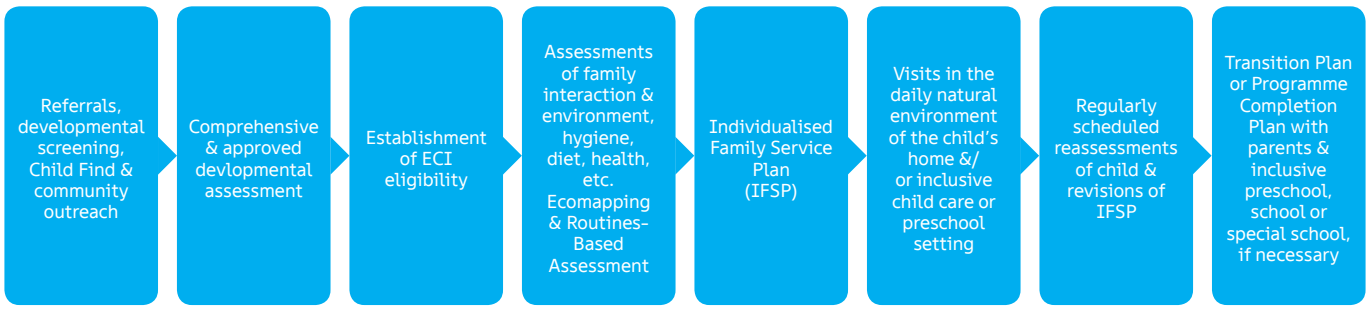
ECI Is community-based and supported from regional and central levels

All effective ECI services are well knit into the community in terms of local support, community-based boards, and community volunteers. In mature ECI systems, regional and central programme leaders and supervisors usually support, coach, mentor, assist, and monitor and evaluate community-level ECI services. Both vertical and horizontal coordination and sharing occurs in large ECI systems.

2.3 ECI Services

ECI programmes use similar basic processes for providing essential ECI services. On the basis of considerable research, ECI processes have been well outlined. In **Figure 1**, a streamlined flow chart presents main and essential sequences of activities for families and children enrolled in ECI services. Contemporary high-quality ECI services include these elements, usually in this order.

Picture 1: Sequence of Contemporary ECI Activities to Serve Children and Families



Community outreach, developmental screening and referrals

ECI services begin with community outreach and Child Find services,[3] which include outreach to hospitals, neonatal intensive care units (NICU), and physicians, such as obstetricians, neonatologists, perinatologists, paediatricians and family medicine doctors. Primary health services that offer regular child check-ups and/or immunisations are often used to also conduct developmental screenings along with physicians' surveillance and monitoring activities. Developmental surveillance and monitoring are an information gathering process that is flexible, longitudinal, continuous and cumulative that is completed by a health care professional.[4] Increasingly, physicians ask their nurses to sit with parents and conduct a rapid developmental screening using a culturally appropriate and validated instrument. In many countries, developmental screenings are conducted by childcare personnel, preschool teachers, parents themselves, community health workers, and other community service providers who can be trained in half a day to conduct reliable developmental screenings. Such personnel should be supervised and observed for the style and accuracy of their work with parents. A system of referrals to ECI services should be developed, along with procedural safeguards regarding child and parental rights. Systematic feedback from the ECI services to the point of referral is very important and must be conducted to ensure any barriers to service access are overcome and families can easily access needed services.

Comprehensive and approved developmental assessments

Comprehensive developmental assessments are then conducted by a Transdisciplinary Team or an Interdisciplinary Team. If the child is eligible for ECI services, most centres offer to conduct family assessments with full parental acceptance and participation, including parent-child interaction assessments, diet assessments, health service reviews, home safety and hygiene checklists, family eco-maps that elicit the family's existing and desired support

[3] Child Find is a continuous process of public awareness activities, community outreach, developmental screening and comprehensive developmental assessment (evaluation) of infants, toddlers and young children that is designed to locate, identify, and evaluate children with at-risk situations, developmental delays, disabilities, behavioral conditions or mental health needs who are in need of ECI programs.

[4] Developmental surveillance and monitoring often labelled "developmental monitoring," is an information gathering process that is flexible, longitudinal, continuous and cumulative.

systems and needs, and facilitate the identification of the family's daily routines.

Establishment of ECI eligibility

Based on a medical diagnosis, which may be secured at birth or any time thereafter, and/or the results of the application of a comprehensive developmental assessment instrument, eligibility is established. In some countries with legacy systems, only medical diagnoses were accepted. In contemporary ECI systems, both medical diagnoses and comprehensive developmental assessments are used to establish the eligibility of infants and young children to receive ECI services. In ECI centres, all children, including those with a medical diagnosis, receive a comprehensive developmental assessment because assessment results provide essential information for planning Individualised Family Service Plans and planning and providing of developmentally appropriate home visits and other types of visits. These elements of ECI and ECI-like services were studied during research activities for preparing the Situation Analysis.

Individualised Family Service Plan (IFSP)

IFSP is a contractual service plan that is developed with full parental involvement. It establishes the developmental goals of the child and family, identifies child and family support needs, notes the periodicity of visits, and other topics. Participants include the parents, professionals from at least two disciplines, and perhaps a paraprofessional Home Visitor. When Transdisciplinary Teams are used, the primary service provider (Early Interventionist, Therapist or paraprofessional Home Visitor) is often selected during the session. Then the IFSP is signed and dated by the parents and the other members of the Team.

Visits to the child's home or other natural environment

The visits are planned and conducted by the primary service provider with the parents or another primary caregiver in the home or another natural environment of the child. They usually cover developmental areas, child health, nutrition and safety needs, family needs and other matters of importance to the family. A report is prepared on each visit and the next home visit is usually planned at that time. At first, visits tend to be made frequently. The number of visits per week or per month are usually reduced as parents begin to feel more confident, become more adept at conducting activities with their child during regular daily routines, and the child improves in his or her development.

Regularly scheduled reassessments of the child and family

After six months, the comprehensive developmental assessment, and depending upon need, other assessments are conducted. If findings reveal that major changes are needed in the IFSP, it is also revised and updated with the participation of the full Transdisciplinary or Interdisciplinary Team.

Transition Plan after Completion

Children who attain typical levels of development (often after 9 to 18 months) simply complete the process after final assessments are conducted. Parents of children who continue to have developmental delays, disabilities or other conditions and reach an older age usually want them to transition to an inclusive pre-primary school/inclusive primary school. Between 6 to 12 months before transition, parents and their children enter a supportive process of developing and implementing a Transition Plan. This Plan should provide considerable emotional support to families and children as well as assist personnel of the receiving school or centre. Teachers and principals receive technical guidance from ECI personnel on how to build on the child's strengths and achievements, support the child's continuing development, and ensure the involvement of parents in their child's further growth and development.

2.4 ECI Theory of Change

Annex 3 presents the detailed general **ECI Theory of Change** (ToC) (Vargas-Barón, 2018). The ToC shows how children with a range of pre-existing birth outcomes, socio-economic, parenting and life situations often have developmental delays and disabilities that require ECI services. The Theory of Change (ToC) illustrates how and why positive child and family outcomes are expected to occur as a result of high-quality and universally available national ECI services. The ToC postulates that a National ECI System will result in positive changes in child acquisition of functional skills and enhanced caregiver competence and confidence in supporting the development of their children.

In order to create comprehensive, high-quality and universally available ECI services, an organizational framework of central and community level services is needed. A series of pre-conditions, policy instruments and programme initiatives are required to develop that national system of integrated, accountable and sustainable ECI services. Once the ECI organisational framework and services are well implemented nationwide, a series of key child and family outcomes can be attained that lead to major generational benefits for children, families, communities and the nation. The ECI ToC guided the development of the conceptual framework of this research as well as the development and application of field instruments.

2.5 Conceptual Framework for the Situational Analysis

The Conceptual Framework presented in Annex 4 is based on global state-of-the-art research on ECI policy planning and programme development in several nations.

The first box of the Conceptual Framework presents **External and Internal Sources of Knowledge** on ECI in North Macedonia and the region of South-eastern Europe. External sources are statistics and publications included in the baseline literature review. Internal Macedonian sources share their analyses of the current status of ECI and recommend ideas for the future.

Three Main Contexts are presented in this ECI Situation Analysis:

1. **Policy Context:** including both international and national policies, strategic plans, laws and normative guidelines;

2. **Social Context:** focussing on the child and the family; and

3. **Resource Context:** including ECI services, workforce, training capacity, and financial sources.

Research Strategies to address the three main contexts included:

1. **Systemic Enquiry:** including the mapping study, interviews, and cost and finance sub-study at the national financial support level.

2. **Programme Enquiry:** focussing on the survey of ECI programme directors, focus groups with ECI programme personnel, and the cost and finance study on ECI programmes.

3. **Beneficiary Enquiry:** featuring a survey of parents in ECI programmes and focus groups with parents enrolled in ECI programmes

Research strategies, methodologies, processes and instrument and the analytic framework for quantitative and qualitative analysis are presented in **Chapter III, Research Team, Methodology, Data Analysis and Ethics**. Major study findings in relation to initial research questions and main research topics are presented in **Chapter IV, Analysis of ECI Services in North Macedonia.** In **Chapter V, Major Conclusions and Recommendations for ECI Programmes in North Macedonia** are offered.

III. Research Team, Methodology, Data Analysis and Ethics

This chapter first describes the roles of the researchers and the responsibilities of the field staff. It reviews the roles of UNICEF and ministries. Methodologies used are briefly described as well as the limitations and challenges researchers faced along with activities conducted to mitigate them. Procedures regarding data handling, data analysis, record keeping, quality control and research ethics are reviewed.

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, Diehl, and Kakabadze, 2022). Similar research has been conducted in Croatia, Montenegro, and Kosovo. The fundamental purpose of the *Methodological Guide* is to assist countries to analyse 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 centred ECI services for child development.

The Regional Methodological Guide provided detailed information about the ECI field, explanations of all methodologies and scope of research and analysis, including suggested sampling and types of respondents, generic instruments for surveys, interviews, and focus groups, and a recommended process for implementing the Situation Analysis. It outlined potential ethical consideration and mitigation strategies. The Guide is flexible and can was adapted to the specific national context.

3.1 Research Team and Roles

The **Research Team,** presented in Table 2, was composed of eleven national and three international ECI researchers. They conducted the following roles:

Table 2: Research Team

Name	Roles
Assoc. prof. Aleksandra Karovska Ristovska, PhD, Ss. Cyril and Methodius University, Faculty of Philosophy, Institute of Special Education and Rehabilitation	Team Leader and Researcher, Field Research coordination, Instrument Revision, Mapping Study, High-Level Interviews, Qualitative Data Analysis and Interpretation, General Data Interpretation and Author
Maja Filipovska, M.Sc., Ss. Cyril and Methodius University, Faculty of Philosophy, Institute of Special Education and Rehabilitation	Instrument revision, Mapping Study, Field researcher for Cost-benefit analysis, Assessment and screening tool analysis
Prof. Goran Ajdinski, PhD, Ss. Cyril and Methodius University, Faculty of Philosophy, Institute of Special Education and Rehabilitation	Field researcher, Assessment and screening tools analysis
Prof. Natasha Chichevska-Jovanova, PhD, Ss. Cyril and Methodius University, Faculty of Philosophy, Institute of Special Education and Rehabilitation	Instrument revision, Desk-top researcher, ECI Directors Survey, ECI Beneficiaries Survey, ECI Staff Survey
Prof. Daniela Dimitrova-Radojichikj, PhD, Ss. Cyril and Methodius University, Faculty of Philosophy, Institute of Special Education and Rehabilitation	Field researcher (Focus groups), Qualitative Data analysis
Assoc. prof. Olivera Rashikj-Canevska, PhD, Ss. Cyril and Methodius University, Faculty of Philosophy, Institute of Special Education and Rehabilitation	Instrument revision, Desk-top researcher, ECI Directors Survey, ECI Beneficiaries Survey, ECI Staff Survey
Assoc. prof. Natasha Stanojkovska-Trajkovska, PhD, Ss. Cyril and Methodius University, Faculty of Philosophy, Institute of Special Education and Rehabilitation	Field researcher (High-level interviews)

Name	Roles
Assist. prof. Angelka Keskinova, PhD, Ss. Cyril and Methodius University, Faculty of Philosophy, Institute of Family Studies	Instrument revision, Mapping Study, Field researcher (Focus groups), Qualitative Data analysis
Prof. Sofija Gjeorgieva, PhD, Ss. Cyril and Methodius University, Faculty of Philosophy, Institute of Social Work and Social Policy	Quantitative Data Analysis
Valentina Dukoska, PhD, University clinic for Pediatric Diseases	Field researcher (Focus groups), Qualitative Data analysis
Elena Kostadinovska, General Hospital Veles, Development counseling with child prevention service and patronage	Field researcher (Focus groups), Qualitative Data analysis
Natalia Kakabadze, Diploma, M.A. Senior Fellow, RISE Institute	Cost and finance researcher, quantitative and qualitative data analysis
Kristel Diehl, M.A., M.S. Senior Fellow, RISE Institute	Methodological support, guidance and quality assurance.
Emily Vargas-Barón, Ph.D., Director, RISE Institute	Research Advisor

3.2 Roles of UNICEF, Ministries and Other Stakeholders

The research team of national and international consultants was supported continuously by UNICEF. UNICEF reviewed draft instruments for cultural and linguistic appropriateness, and helped contact ECI programmes and secure survey responses. In addition, UNICEF reviewed successive drafts of this study. The National consultants and the members of RISE Institute conducted internal reviews of the manuscript as well.

To answer fundamental research questions, the following key stakeholders were included in this research project. Instruments used with each type of stakeholder are noted in parentheses.

ECI Beneficiaries (Parent survey, parent focus groups)

- Parents/caregivers and families of children receiving ECI services; and
- Parent associations.

National Leaders (High-level Interviews)

- Representatives of ministries;
  - Ministry of Education and Science (MoES)
  - Ministry of Health (MoH)
  - Ministry for Labour and Social Policy (MLSP)
- Office of Ombudsperson;
- Municipal leaders in rural and urban areas;
- Academic leaders in ECI;
- Government Body for Implementation of the Convention of the Rights of Persons with Disabilities;
- Centre for functional assessment according the ICF;
- Association of Special Educators and Rehabilitators; and
- UNICEF office.

Collaborating Specialists (ECI directors survey, ECI staff surveys, focus groups with ECI professionals)

- ECI centres directors of state and private institutions; and
- ECI centres personnel of state and private institutions.

3.3 Limitations and Challenges Faced During Research

Research activities that were not incorporated into the study included: in-depth visits to each ECI programme and on-site observations of the provision of ECI services. The basic reasons for not conducting these activities, although similar activities were conducted in the neighbouring countries were the large number of centres in North Macedonia; short period of time available for field visits; potential cost of conducting so many field visits in all municipalities of North Macedonia; and notable complexity of the research methodologies stipulated *a priori* for the research. Some of these activities were not deemed possible because of the COVID 19 situation.

One of the largest challenges was the mapping study, more specifically the identification of ECI centers, public centres (state financed), private centres (for profit organizations) and NGOs/Associations of citizens. In North Macedonia there is no official registry of ECI centers, programs or ECI service providers. The state centers are part of hospitals or clinics, while the private ECI centers are registered in a variety of designations (educational centers, private companies [DOOEL], NGOs/Associations and others). In order to conduct the mapping study, which was essential for locating ECI services and the subsequent study, we conducted an extensive desk-top and literature research with the purpose to identify ECI centers in North Macedonia. All centers were identified in this manner. National researchers contacted and double-checked all of the centers and compiled them into there final lists of 1) ECI programmes (that provide family-centred services), and 2) evolving ECE centres with ECI elements (that provide child-centred services); and 3) traditional (legacy) centres (that provide rehabilitation and habilitation services). Regarding registration, ECI centres were also divided in three groups: DOOEL (private companies); NGOs/Associations; and Health Institutions (opened by the state). These break-downs of ECI centres/service providers enabled cross tabulation of results that led to in-depth discoveries regarding provision of ECI services.

Although we had no challenges in identifying and providing responses from ECI personnel (for surveys and focus groups) and ECI beneficiaries (for focus groups), some challenges arose while trying to provide surveys from ECI Directors (surveys) and ECI beneficiaries (surveys). The ECI Directors Survey was the most challenging of all surveys, but they were contacted personally and individually (and some were contacted by the UNICEF office) in order to provide a representative sample of over 80%. Securing an adequate representative sample of parents for the survey of beneficiaries was also challenging. Another, challenge was the language limitations of international researchers. The challenges were overcome with the support of the UNICEF office during meetings. They also assisted with the translation of all documents, instruments, reviews, reports by the National team of consultants.

Ultimately at the end of the field work, the research team managed to compile a list of what we believe to be all existing state and private ECI centres/ECI service providers. This list will be beneficial for all future research and policy making.

3.4 Research Methodologies

The following sub-section shows the different research methods used in this study.

3.4.1 Literature Review

A literature review was conducted to provide a solid foundation for fieldwork and to serve as an introduction to the current ECI system in North Macedonia. It included policy instruments, qualitative and quantitative studies, technical reports, and statistics. This review helped the research team to identify new data sources, assess political and legislative provisions for ECI in North Macedonia, and gain an understanding of the background, context, and current status of ECI services. Most of the documents and the experiences we draw from, were from other countries, having in mind the scarcity of legislation, policy papers, strategies and scientific papers in Macedonian language and for the Macedonian context. The literature review consisted of: government documents, peer-reviewed journals, ECI websites, studies and monitoring and evaluation documents from international organizations, internet search, child and family status documents, international policy documents pertaining to the ECI system, ECI and related services information, human resource documents, training resource documents and other.

3.4.2 Mapping study and survey of ECI directors

The mapping study, together with the literature review, represents a solid foundation for further and thorough analysis of the ECI services. The information gained through this survey secured the initial list of contact information and enabled the research team to strategically plan the next steps of the study. Through the mapping phase, 55 ECI centers were identified throughout the country. The research team made a decision to include public centres which were state financed ECI centers (general hospitals, clinical hospitals and medical centers), private for profit ECI centers and non-governmental organizations (NGOs/ Associations of citizens) in order to have the full picture of the Early Childhood Intervention situation in

the country. The results from the mapping study show that from all the 55 centers, 20 are public state centers and 35 are private (more than half or 64% of the ECI services are being given by private for profit providers or NGOs/Associations). From the public centres, 4 are general hospitals, 8 are clinical hospitals and 8 are medical centres. From the remaining 35 centres, 16 are NGOs and Associations, 10 are private for-profit companies, and one is a private medical center.

3.4.3 Survey of ECI Directors

From the total of 55 identified ECI centres, 44 ECI Directors (80%) responded to the surveys thereby yielding a representative sample. The Directors' survey was oriented towards defining the registration of the ECI centers, characteristics of children served, access to services, networking, monitoring, coordination, barriers, challenges and recommendations. This extensive survey was conducted from March to early June 2022. After mounting the survey on the *SurveyMonkey* platform, an invitation was sent to each ECI director by the research team leader and by the field researcher responsible for the ECI Directors surveys. After encountering a few technical difficulties, some of the directors were approached by the UNICEF office in order to provide feed-back. Many reminders were sent, and ultimately the sampling goal was met in June 2022. The largest number of unfilled surveys came from the public ECI centres. Some public ECI service providers organize their work within a very complicated bureaucratic system, making the surveys difficult to complete by some of the respondents. Of the 44 centres that responded to the survey – 14 (32%) provide rehabilitation and habilitation services (legacy); 25 (57%) provide services in centres for children (evolving ECI service providers); and 5 (11%) provided family-centred services (contemporary ECI service providers).

3.4.4 Survey of ECI personnel

A total number of 76 ECI personnel responded to the survey (out of the 130 surveys that were sent out to the ECI professionals). The response rate was 58%. More than half were special educators and rehabilitators. Other ECI staff took part in the ECI staff surveys including speech therapists, psychologists, medical nurses, paediatricians, administration and others. The respondents gave information regarding types and frequency of ECI services, ECI training, monitoring and evaluation of ECI service provision, and challenges and recommendations for ECI services.

3.4.5 Survey of ECI beneficiaries

In total, 98 ECI beneficiaries (parents, guardians and caregivers) responded to the survey, out of the 130 surveys that were sent out. The response rate of the ECI beneficiaries was 75%. They gave an insight into the services the children use, barriers they face in obtaining ECI services, types of professional assessment, types of specialists, participation in in ECI services, recommendations for development of future ECI services.

3.4.6 Focus groups with ECI staff

Six focus groups were organized within this research. Most of the focus groups were realized online through the Zoom video conferencing platform (4 focus groups), and two focus groups were held hybrid (with physical presence and online). A total number of 33 persons participated, which represented 75% of those invited to participate. The participants were from six cities, from all regions in North Macedonia. Out of these 33 professions, 15 worked in public ECI centres while 18 worked in the private sector. This qualitative part of the research gave an insight into the types of contemporary services provided, community outreach, developmental screening and assessment, ECI service quality, training, ECI supervision and evaluation, networking, coordination, referrals and recommendations for ECI.

3.4.7 Focus group with ECI beneficiaries

Seven focus groups with parents were conducted within this research. A total number of 36 persons from six regions participated (72% of those invited) in the focus groups. They gave in-depth information regarding the experiences and challenges they faced in obtaining ECI services, community-based services, types of ECI services that the children receive, assessment procedures, participation in ECI services, social benefits and recommendations for improving ECI services in North Macedonia.

3.4.8 High-level Interviews with Government Officials and Representatives of Organisations

A total number of **21** high-level interviews were held to gain interviewees views regarding the status of children, families and ECI services as well as their understanding of challenges ECI programmes face and recommendations for expanding and improving ECI programmes to create a national ECI system. The high-level interviews were conducted with enthusiasm on the part of all respondents (listed above in 3.2).

The insights, thoughts and suggestions of all respondents, as well as the suggestions gathered by different techniques were of substantial assistance in preparing unified conclusions and recommendations for the creation of the ECI system in a Macedonian context.

3.4.9 Cost and Finance Sub-Study

This study was designed, organized and implemented to identify and analyse all types and levels of possible financial support for ECI centres with and centres with ECI elements. The sources of funding were discussed, and the participation of the central government and local self-government in ECI funding was elaborated. Additionally, case studies of five ECI programmes were conducted, yielding useful results for future programme design and systems planning. The Centres were selected according to the type of funding. There are 3 for-profit private organizations and 2 non-profit organisations (one is an NGO and another – a public clinical center). Four centres have ECI children alongside other beneficiaries, while one Centre provides comprehensive ECI services consisting of 100% ECI children.

3.5 Data Management and Analysis

All data obtained for this report were reviewed, double-checked and cleaned before data analyses began. The questionnaires of the surveys conducted in the research were extensive and took about 30 minutes to complete (for all three target groups). The quantitative data obtained both online and through hard copies were entered into consolidated databases and then analysed using SPSS in accordance with the needs for each type of data set. The arithmetic mean, which is a set of measurement data divided by the number of measurements, was used to describe the quantitative data obtained from this research. To measure the variability of the data, the measure of variability-standard deviation was used, which is the best indicator for the scattering of scores in the sample and is the basis for assessing the variability of the occurrence in the population. Chi-square was used to determine the differences between the groups. Subsequently, tables and graphics were constructed, reviewed, finalised and interpreted. In addition, several maps were composed to illustrate specific information geographically. Finally, in Chapter 4, the main findings were presented and interpreted, and in Chapter 5 eight major conclusions made and recommendations offered.

Qualitative data were obtained through expert interviews, and the processing was performed with the help of classifying the answers into categories, ie. "closing the answers". A qualitative technique was also used as an aid - in-depth expert interviews (high-level interviews), in order to obtain more valid and more reliable results with the help of multimethod triangulation. Qualitative data were collected through the use of structured focus groups and interviews. The resulting reports were prepared, often in a matrix format, for each focus group or interview, with questions in one column and answers and comments in other column. Each national researcher prepared a report on each of the types of focus groups or interviews, and under appropriate topics, salient results are presented in this research report. In addition, a few compelling examples or comments resulting from the focus groups and interviews are provided in the text, along with some of the general observations of the national consultants.

For purposes of presenting findings secured through the application of multiple research instruments, a structural outline was developed keyed to the main themes of the study and the basic eleven questions of this research project. Using this structural outline, Chapter IV "Analysis of ECI Services in North Macedonia" provides syntheses of major research results. Some syntheses were drawn in part from the literature review but mainly they reflect findings from primary research. Conclusions judged to be the most important are presented in Chapter V, "Major Conclusions and Recommendations for ECI Programmes in North Macedonia."

3.6 Research Ethics

Regarding confidentiality, consent and research ethics, this study was conducted in full accordance with the following international and regional guidelines for research ethics and methods:

- *UNICEF Procedures for Ethical Standards in Research, Evaluation, Data Collection and Analysis*
- *UNICEF Strategic Guidance Note on Institutionalizing Ethical Practice for UNICEF Research*
- *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 of the EU.

With respect to cultural dimensions, all field instruments were originally drafted in English, translated and adapted to Macedonian, and then back translated to English, resulting in further refinements of the Macedonian versions. The semi-final Macedonian versions of all ethics statements and research instruments were field tested for comprehension and cultural appropriateness with a few persons who were considered to be typical respondents (e.g., parents, ECI directors and ECI staff). As a result, a few questions or topics were improved or revised. The ethics statements and instruments were further refined and finalised for application in surveys, focus groups and interviews.

Special attention was given to ensuring the "do no harm" principle was observed with respect to avoiding any possible risk to study participants. After all study instruments and ethics statements were prepared, they were given a final review and approved by UNICEF specialists. Experienced research team members collected all focus group and interview data in a respectful, ethical and culturally appropriate manner. No criticisms were received from any study participant.

In compliance with GDPR, when collecting information and data with surveys, questionnaires for focus groups and interviews, and instruments of the cost and finance sub-study, statements of participant consent and instructions were first provided. Prior consent was requested of all study participants before securing personal and/or institutional data. All participants, including representatives of organisations, were assured their responses would be kept strictly confidential and anonymous. Their rights to end or withdraw from participation, request access, and correct or delete any of the information they provided were explained. By participating in a survey, participants acknowledged and consented to filling out the questionnaire. Focus group participants and interviewees received instructions informing them of the purpose of the study, the focus group or the interview. Their statement of consent explained that all information they shared would be strictly confidential and anonymous, and they were informed they could also request that data be transmitted to a different study/researcher in a structured and readable format, as regulated in the GDPR.

All data gathered with the surveys were stored electronically, with password protection in place, and when in paper, placed in locked safe boxes kept under the supervision of one of the national researchers. No names or other personal identification were collected in surveys, focus groups or interview. Paper copies were secured in locked safe boxes. 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 focus groups were placed in a locked storage box accessible only to the researcher. Analysed 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. Upon the completion of the study, as stipulated in the contract with UNICEF, all raw data will be transferred to UNICEF without any identifying information on study participants. The raw data in the possession of research team members will be destroyed as stipulated by GDPR.

In this report, persons and institutions are not identified, other than ministries because it is impossible to write a useful ECI situation analysis without identifying them. Lists of responding ECI Programmes and the total corpus of identified ECI Programmes are not provided in this Report; however, maps of territory covered by ECI services are presented, without naming any institutions. A written record was maintained of all data processing activities, with an anonymous list of study participants, categories of personal data and modes of data collection. In summary, full confidentiality, fair and transparent data processing, and the protection of the legitimate interests of all study participants were fully observed at all points during research activities.

Finally, ECI services are essential for attaining the goals of the Convention on the Rights of the Child (CRC), Convention on the Rights of Persons with Disabilities (CRPD) and Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), and this study incorporated all perspectives included in these conventions regarding human rights, child rights and gender equity.

IV. Analysis of ECI Services in North Macedonia

Within this section, the analysed data from the literature review, mapping study, ECI directors, ECI personnel, ECI beneficiaries, focus groups for parents, focus groups for personnel, high-level interviews and cost-benefit analysis has been presented. A triangulation of data has been made with the purpose to give answers to the research questions posed. Although typically researchers do not give comments/suggestions/recommendations in the analysis section, small comments were given at the end of each section for better explanation of the data and the results. The main conclusions and recommendation are given in chapter V.

4.1 Early intervention services in North Macedonia – literature review

4.1.1 Concept of ECI

It is a well-known fact that every child is born as an individual with certain biological characteristics that make it unique. Sometimes these unique biological features bring developmental delays and difficulties, and sometimes carry only risks of developing developmental abnormalities in childhood. Knowledge of modern neuroscience states that human is a prosocial creature which develops under the influence of learning, whereby the extraordinary potential for learning of the child is emphasized in early childhood. It is thought that neuronal links responsible for a particular function are directly influenced by genetic predisposition and environmental influences, and the biggest plasticity human brain has in the early childhood 0-6 years. Based on this, early learning, exposure to different experiences and stimuli are basic prerequisites for maximal utilization of biological potentials (Košiček et all., 2009). Globally, an estimated 250 million children under age of 5 years (43%) are at risk of not achieving their developmental potential in the earliest years of life due to a host of nutritional, health, and psychosocial risks (Jeong et all., 2021).

The term ***early intervention*** refers to the early age process of informing, counseling, educating and supporting children with possible developmental delays and / or at high risk for further developmental delays and their parents, from an early age. This process also includes children with a risk factor for developmental delays that could later affect their further development in future schooling. An early intervention program can be provided in a variety of settings, but the emphasis is on the child's natural environment. An early intervention program is most effective if provided immediately after the detection of risk factors or developmental delays. More precisely early childhood interventions are interventions for children ages from birth to 3 or 5 who are living with disabilities or developmental delays, are malnourished, have low birth weight, or have chronic illnesses (Karovska-Ristovska, 2019).

The concept of early childhood intervention began in the United States in the 1970s. With constant tendency to reduce costs in the area of health and social care, developed countries check and improve the effectiveness of their measures in various sectors, which is followed by investment in advancing early intervention. Economic research has shown the usefulness of these programs pointing out that the benefits are not only based on the principles of humanity and social justice, but also have great economic profitability (Ljubešić, 2003). Evidence suggests that the earlier the onset of intervention, the greater likelihood of an improved developmental trajectory. It is argued that early intervention is more cost- and time efficient than a "wait and see" approach (Karovska-Ristovska, 2019).

Looking at the child as a biopsychosocial unit, in recent decades in Europe a so-called model of ecological-systemic approach to early intervention has been developed, in which the main goal is not only the child but also his family and immediate environment, in order to achieve optimal development and reduce or reverse the effect of the inhibitory factors (Barnet et all., 1997). According to the instructions of the World Health Organization (WHO) the contemporary concept of the early childhood intervention implies holistic access to the child and his development deviations, which implies joint work of different professions, interaction of different participants in the intervention, cooperation of a number of departments and direct involvement and participation of parents and other family members (Jeong et all., 2021).

The politics and programs related to the early learning and development of the children are very complex.

4.1.2 Early Childhood Education and Care (ECEC) and Early Childhood Intervention (ECI) in North Macedonia

The investment in the early childhood development in North Macedonia is still on a very low level. Establishing quality in the process of the early

childhood development and stimulation in North Macedonia is further complicated due to the division of competencies between three ministries (Ministry for Labor and Social Policy, Ministry of Education and Science and the Ministry of Health). Such division often leads to mixing competencies and transferring the responsibility of a ministry to another which, of course, results in reducing the quality of the early learning and development of children (BRO, 2018). In North Macedonia, early childhood education and care (ECEC) provision aims to provide care and education to children from birth until the age of 6 years, when they enter primary education. In practice, children usually start attending preschool when they are 8–9 months old. ECEC is not compulsory (EURYDICE, 2022). There are two types of centre-based ECEC settings. The majority of the children who participate in ECEC attend preschools (detska gradinka), which include nursery groups (jasli) for children under the age of 3 years. A small number of children aged 3–6 years attend centres for early childhood development (centar za ran detski razvoj). Centre-based provision can be public or private. Public provision predominates, with 95 % of children attending preschool being enrolled in public preschools. The enrolment rate of children aged 3–6 years in 2019 was 40 %, which is far lower than the European Union's recommended level of 95 %. Depending on where they live, the wealth of their families, their ethnicity, disability or simply because they are different, some children are more at risk of missing out on early education. Poverty facing children are particularly at high risk since only one out of 300 children visits any form of pre-school education (UNICEF, 2016). Participation in preschool is also low across minority groups. According to a United Nations Children's Fund report, over half of children of Macedonian ethnicity attend preschool education, compared with fewer than one in five children of Albanian ethnicity. Only 2.6 % of 4-year-olds from Roma communities attend preschool education. Parents or guardians pay fees only for children who attend the full preschool programme. Children with disabilities are also at greater risk of missing out on early childhood education. Less than five percent of children with disabilities were enjoying the benefits of visiting some form of pre-school since 2016 year (UNICEF, 2016 - https://www.unicef.org/northmacedonia/early-childhood-education). Only 32% of 59 kindergartens included in a research study in 2018 year provided by the Ombudsman of North Macedonia, reported that they have children with disabilities, or an average of 10.64 children per kindergarten, that means in the total of number of 34,700 children enrolled and included in kindergartens, the percentage of children with disabilities is 1.19%. According to the data from that survey, most of the children have autism (104), followed by children with intellectual disabilities (101), 70 children with combined difficulties, 42 children with hearing and speech impairments, 13 children with physical disabilities and only 7 children with impaired vision (OMBUDSMAN, 2018). According to the data, the detection and, consequently, the registration of children with disabilities in kindergartens begins after the 18th month. The largest number of children with disabilities are detected in the large group, which covers the age of five to six years, and their number is 143. No children with disabilities were detected in the nursery groups (OMBUDSMAN, 2018). Disappointing is the result that 72.2% of the kindergartens did not have a complete expert team, they did not have special educators and rehabilitators, but the current situation has not changed much.

In terms of access to ECE, the country has made significant advances in improving participation in preschool education, the number of children enrolled in all types of preschool institutions has increased by 11% between 2009 and 2019, which is a considerable accomplishment. However, despite improvements of access to ECE, the country has no system for monitoring the quality of ECE, thus facing challenges in answering the question: what is the quality of early learning in North Macedonia and how can we continuously improve it? (Naceva et all., 2022).

The key national documents that shape teaching and learning in preschools are the Early Learning and Development Standards and the Curriculum for Early Learning and Development (EURYDICE, 2022). There is also home-based ECEC provision, regulated under the conditions of the Child Protection Law. Home-based ECEC can be provided in the child's home, in the home of the individual providing care (neguvatel), in the premises of the service provider (agencija za davanje uslugi) offering home-based provision or in other premises that meet the conditions set by the law. Responsibility for home-based provision is in the hands of the Ministry of Labour and Social Policy (EURYDICE, 2022). In order to include a larger number of children with developmental disabilities in kindergardens, a Programme for Early Learning and Development for Children with Developmental Disabilities was adopted in 2015 (MINISTRY OF FOREIGN AFFAIRS of North Macedonia, 2019).

Early intervention means identifying and providing effective early support to children and young people who are at risk of poor outcomes. It also helps to foster a whole set of personal strengths and skills that prepare a child for school and adult life. Early intervention works to reduce the risk factors and increase the protective factors in a child's life. Technical-technological progress, the progress of medicine and better quality in the operation of the neonatal intensive care units are leading to an increase in the number of high-risk neonatal survivors, especially premature infants. But advances in science are not always accompanied by a reduction in the percentage of short-term and long-term neurodevelopmental disorders in children born

with a risk factor. According to some studies, 50% of premature babies have problems with attention and behavior and need professional help (Dukovska et all., 2017). The increasing number of surviving high-risk newborns automatically entails the need for an increased number and opportunities for services in the field of early childhood intervention. As in many other countries, the Government of North Macedonia has made a commitment to care and education for children with disabilities, as well as children with a high risk for a developmental delay. Article 23 of the Convention on the Rights of the Child states that state parties recognize that any mentally or physically disabled child should enjoy a full and decent life. State parties ensure that children have effective access to and receive education, training, healthcare and rehabilitation services in a manner conducive to children achieving the fullest possible social integration and individual development. Nevertheless, early intervention centres in North Macedonia cannot always meet the preconditions and ease access and care for children with developmental disabilities. The awareness of the benefits of early intervention and early inclusion for all (children with disabilities, parents, children peers, educators) is still at a very low level (Karovska-Ristovska, 2019).

4.1.3 Laws and regulations

Given that the care in terms of prevention, detection, treatment and rehabilitation, education and protection of children and persons with disabilities is divided into three sectors, and their regulation is prescribed in various documents, strategies, laws. Early childhood development and education are included in the Law on Child Protection, where through several articles are determined ways and places of care and upbringing of preschool children. (The law of Amendments to the Law on Child Protection "Official Gazette of North Macedonia "No. 275/19). While the Law on Health Care regulates the issues related to the system and the organization of health care and the performance of the health activity, among which Article 26 covers the early detection of risk factors for the occurrence of chronic diseases and their control and screening services, in accordance with the programs referred to in Article 16. of this Law, then the part for Health activity at primary level, more precisely Article 30, item 6 (implementation of preventive programs and measures for children, youth, women, employees and the elderly and other particularly vulnerable groups, ie groups that are specifically exposed to certain health risks and conduct screening programs to detect risk factors for occurrence of the disease, ie for early detection of the first signs of the disease, except for those screenings for which health facilities at other levels are designated) and item 9 (health treatment and medical rehabilitation of adults, children and young people with special needs) (Службен весник на РМ бр. 37 од 2016 година). The access to healthcare for persons with disabilities is governed by the Law on Healthcare (primary healthcare), the Law on Health Insurance (universal health insurance coverage, exemption from paying participation), Law on Patients' Rights (individual aspects of the right to health), the law on Mental Health (right to respecting the personality, dignity and privacy of every person with a mental illness) (Ministryof Foreign Affairs of North Macedonia, 2019). The analysis of the documents shows that there is no legislative regulation of the services for early childhood intervention in North Macedonia and there are only few reviews and documents related to the early childhood intervention services.

We can find strategic plan of the Ministry of Labour and Social Policy from 2020 where they plan the opening of Counseling centers for children and parents within a public kindergarten, in function of socialization of children and early detection of obstacles and problems in early childhood development as well as providing assistance to parents (Ministry of Labour and Social Policy, 2020).

Healthcare for children with developmental problems is provided at the centres for primary healthcare, secondary healthcare for children with developmental problems and special educational needs (where there are developmental pediatrics units and two specialised mental health institutions (in Skopje and in Bitola) for early detection, diagnostics, treatment and following of the functional growth and development of children born with risks, tertiary healthcare centres, concentrated in the bigger cities (Ministry of Foreign Affairs of North Macedonia, 2019).

Under the 2008–2018 National Strategy for Deinstitutionalisation, within the Social Protection System, a number of measures were taken to promote the accessibility of inclusive care to children with disabilities. In recent years, the Ministry of Labour and Social Policy has raised its commitment to improving the inclusion of children with disabilities through policy and service changes, more specifically by increasing the number of child day-care centres, introducing new legal benefits and increasing the existent benefits for children with disabilities. After establishing that the model of assessing children with developmental disabilities (categorisation based on medical assessment) is obsolete, the Ministry of Labour and Social Policy, together with UNICEF, was working on developing a new model of functional assessment of children, aimed at establishing the potential that the child can reach and identifying the obstacles in the environment that impede it (Ministry of Foreign Affairs of North Macedonia, 2019).

In cooperation with UNICEF, an assessment was made of alternative care forms and support services for the

families of children with disabilities, which resulted in an analysis and recommendations for revision of the day-care centres for children with disabilities. The goal was to move from "day care" to various types of services that do not segregate, but help the children to be involved in the everyday life in the community.

In 2017, the Ministry of Health established a Working Body for the Implementation of the Action Plan for Improving the Healthcare of Children with Disabilities. The measures and activities outlined under the Action Plan address problems faced by families of persons suffering from autism, rare diseases and other disabilities (ensuring easier access to healthcare and social services through correct diagnostics, enabling treatment with the newly introduced methods, timely provision of medication, laboratory reagents and other necessary therapy as well as maintaining continuous cooperation and training of professionals from the country together with colleagues from abroad). Since 2017, in cooperation with the Macedonian Medical Association and the Association of Nurses and Obstetricians, UNICEF has been working on developing the capacities of family medicine specialists and primary healthcare professionals for early detection of developmental disabilities in children and early intervention in cases detected.

4.1.4 New model of assessment of disability

In cooperation with the Macedonian Medical Association, the use of ICF was piloted in the beginning of 2019 in 10 primary healthcare institutions over the course of the entire year using the "follow the child" model. As set forth under the Law on Records Keeping in the Field of Healthcare, an Individual Report for Children with Developmental Disabilities (0-18 years old) was prepared together with the accompanying Report-filling Instructions. Plans are also in place to develop special software for recording persons with developmental disabilities in in-patient treatment and admitted to day hospitals as a useful tool for monitoring the health status of this category of patients (Ministry of Foreign Affairs of North Macedonia, 2019).

The new model of assessment of disability enables an analysis of each child's potential and what the child can achieve but it also locates the barriers in the child's surroundings. This new model of functional assessment for additional educational, health and social support of children and youth is now being conducted in the Centre for functional assessment according the ICF in Skopje (additional centres are being established in other cities in North Macedonia). Following world trends this model is based on the ICF will replace the medical model of work of the commissions with a social model. The assessment done in the centres will not only define the services the child needs, but it will determine the needs for his/her future development.

4.1.5 Current situation

According to the Service Capacity Assessment of health, education and social protection sectors for the inclusion of children with disabilities developed by UNICEF (2015), the prevailing opinion is that the state is still responsible for the care of children with disabilities, and it is also considered that these children mainly need medical care or protection. The main issues identified in the health sector are related to the absence of a clear process which enables professionals and services to cooperate and assign the appropriate activity at the appropriate level of services. This leads to service overload at the tertiary health level protection due to improper referrals and A problem of lack of capacity of services at the secondary level has been detected, where normally most of the interventions should be directed. The social sector carries the main responsibility for formal identification of children with disabilities, monitoring of families and ensuring they can get the services they need. However, the first contacts for families, detection and identification of the disabilities are delegated to the health sector, due to the lack of staff, resources and too many other obligations in social centers. Identification of children with disabilities often happens too late, it does not always accompany by support services and parents always avoid it when possible. This process is initiated isolated from previous services that gives the health sector, where assessment information can be widely available. Despite that, it seems, today, still most financial resources are invested in institutional protection versus forms of family support, who usually receive only a small cash disability assistance. Numerous children with developmental disabilities are often recognized during birth, but their further following up and support are unpredictable after leaving the hospital. The family doctor or pediatrician, as well as the patronage nurses, should be stronger advocates and should help families in accessing the necessary services, ensuring an early identification that will be followed by intervention. A focus on medical disorders that are immutable results in missed opportunities to create a favorable environment and provide services that focus on the family and the child (UNICEF, 2015).

According to the current practice in public centres, one of the main creators and implementers of early childhood intervention practices are the departments for developmental pediatrics, which provide protection at the secondary level and are organized in multi-professional teams including a developmental pediatrician, psychologist, therapists (special educator and rehabilitator, speech therapist, occupational therapists), patronage nurses. They receive requests through general practitioners, from families, schools and maternity hospitals, institutions for tertiary protection, and have access to tertiary level consultations. They have diagnostic and long-term capacity treatment

of habilitation / rehabilitation with low intensity (e.g. psychomotor reeducation treatment for motor delay development, speech therapy for problems in communication, ...). Departments for developmental pediatrics should provide field services through the patronage nurse. According to The National Action Plan 8 to 10 departments for developmental pediatrics were planned, but only two are functioning. Many of the professionals working in these departments are also part of the commissions for assessment (UNICEF, 2015). The findings also show that the current number of services per secondary level is far below what is provided in the National Action Plan. This results in an uneven presence of secondary protection services throughout the country. Their current concentration in larger urban areas provides optimal coverage for children who are born and living in the environments covered (for example, Skopje), but cannot provide continuity of care for many children who were born in Skopje, but live in others regions (40% of live births in Skopje live outside the city). According to the UNICEF's findings children born with a recognized risk are discharged from hospital with programs for protection and monitoring implemented by primary health care centers. However, it should always be kept in mind that the newborn should be together with mother and family. If families get proper support at this early stage, dysfunctionality or misdiagnosis can later be avoided. Pediatricians should use unified screening checklist for early identification of children with disabilities, based on ICF in order to facilitate communication between professionals and services. It is important to establish and strengthen early identification and services of intervention through patronage sisters; the triage system can improve service delivery efficiency by emphasizing access to counseling, development services or to others specialized services. Central role in the early childhood development has the development of basic abilities on which future development is built (UNICEF, 2015).

The Ministry of Health of North Macedonia in 2018 developed an Action Plan for "Improving the health care of children with disabilities and persons with disabilities", which among other things provides: Preparation of a proposal - a plan for further development of a network of Centers for Early Detection and Intervention in Children with Disabilities, and Opportunity for development of regional centers in the country and / or Skopje, Stip, Tetovo, Bitola, Strumica (Ministry of Health, 2018).

After abandoning the model of medical approach and starting with work of the functional assessment commissions according to the ICF, more attention began to be paid to the early detection of risk factors and early stimulation of children with risk factors or developmental disorders. In that direction in 2020 UNICEF in cooperation with the national partners (Ministry of Health, Ministry of Labour and Social Policy, National association of special educators and rehabilitators) promoted a new web platform "Early Intervention for parents and caregivers of children with developmental delays and children with disabilities from 0 to 6 years" to offer families an access to early intervention services and online psycho-social support. The Early Intervention Platform for Children with Disabilities is a new, innovative tool in our country that will help families of children with disabilities and the professionals who work with them to determine the best approach to provide support, according to the individual needs of the child. UNICEF office in North Macedonia also launched a mobile app named Bebbo. This is a free app developed by UNICEF and national partners and is designed to lend a helping hand to parents, with easy tips on topics like breast pumps, baby weaning, learning, toys, child protection and much more. Bebbo provides users with information based on studies and UNICEF's expertise and helpful, interactive tools to help nurture and aid their child's health and development. Bebbo is an application that supports responsive, positive parenting. Its aim is to provide comprehensive information about early childhood development and parental care in a parent-friendly format. The app is developed to support parents to engage in developmentally stimulating practices through games and activities with their children and will help them monitor child growth, development and health status.

UNICEF in cooperation with USAID and FINANCE THINK conducted a research study about the socio-economic effects of the COVID-19 pandemic on the children in North Macedonia (2021). Among other consequences, the findings indicate that Covid-19 caused a delay in access to hospital for newborns, children and mothers. Providing services through the health system decreased by 39 percent of the whole population, 33 per cent of children and 25 per cent of mothers and newborns. However, the main reason is the reduced demand for emergency services for fear of infection, not on significant redirecting anti-virus resources.

Families of a disabled child face a number of challenges that greatly change the expected course of family functioning. Depending on the functionality, a child has different needs than a typical child and the family faces a range of financial, emotional and life challenges. According to the analysis, the average salary of employed parents of children with disabilities is 18.000 denars, which is 9,206 denars (34%) lower than the average salary in the general population (27.206 denars - data refer to February 2020 when the survey was conducted) (7). We have had a similar situation 10 years ago, when the difference in monthly income was 5.217 denars (25%). In order to improve the socio-economic status of families, the state provides

social benefits. Those benefits are defined in the Law of Child Protection and Law of Social Protection. In terms of social benefits, according to the data, most families use special allowance (73%), then free public transport (19%), a small number of families use reimbursement of part-time job and specific medical interventions. High percentage of families, i.e., 79% of the sample, are not satisfied with the effects of the social benefits and think that they do not meet their daily financial challenges. About 14% of the families are partially satisfied with the social benefits, and 7% are completely satisfied with them. As we can see in the results, the most used social benefit is the special allowance provided by the Law of Child Protection. This social benefit is provided as a compensation intended for children with disabilities up to 26 years of age, and it is given on the proposal of a commission for assessment of the functional abilities of the child. The last change in relation to this allowance was made in 2018, when the special allowance of 4.202 denars per month increased to 5.096 denars. No matter what kind of disability is, no matter from which aspect we define it, it is always treated as a condition, which means that as a condition it always exists. The rehabilitation process can improve the condition, but cannot cure it. So, the child with a disability will be involved in the rehabilitation process for many years, and his/her family will have to financially support this process in all those years. Results from our research showed that 23 children (50%) receive monthly medications therapy which costs an average of 4.064 denars per month. While during the previous year (2019), 8 children from the sample needed special medical intervention with an average cost of 59.500 denars. In addition to medications therapy, a child with a disability often attends a series of rehabilitation treatments that enable improvement of his/her development or maintain the condition unchanged. These treatments according to the recommended frequency usually range from 2-3 times a week, and sometimes more often. These include the treatments of a special educator and rehabilitator, speech therapist, physiotherapist, etc. Children from the families in our sample, most often visit a speech therapist with a frequency of 2.7 times a week, and that costs them an average of 1.604 denars per week. The most expensive treatment they receive is the treatment by a psychologist with an average cost of 2.350 denars per week, with a frequency of 3 times a week. Further, we were interested whether families, for financial reasons, could not afford any treatment that they considered to be extremely important for the development of their child. According to the results, even 67% of the parents answered positively on this question, most of them or 33% thinking that they have an additional need for a speech therapist, and 22% have an additional need for a special educator and rehabilitator (Keskinova, Chichevska-Jovanova, Ajdinski, 2019). Knowing the socio-economic status of parents of children with disabilities on the one hand and the amount of costs for treatment and rehabilitation of children, in 2017 a project was started to provide financial support to economically and socially disadvantaged families, in order to provide conditions for intensive treatment of their children with autistic spectrum disorders. The project was organized and cooperated by the Ministry of Labor and Social Policy of of North Macedonia, the Association "In my world" and the Ministry of Foreign Affairs of R. Bulgaria (Gjorgjevska, Najdova, Stanojkovska-Trajkovska, 2018).

It can be concluded that in North Macedonia the field of health care, health insurance and protection of persons with disabilities is relatively well organized, but, of course, there are series of ambiguities and opportunities for advancing the rights of children with disabilities and persons with disabilities. Joint efforts of both the governmental and non-governmental sectors are necessary.

Early childhood intervention is an issue that is addressed in the ranks of the scientific field, including the Institute of Special Education and Rehabilitation through the program contents of several courses related to early intervention in various types of disabilities in the first and second cycle of studies. The professors responsible for the implementation of the programs visited the centers for early childhood intervention in several countries in Europe and the world, and took part in a number of projects.

Back in 2011, the Institute together with the Association of Special educators and rehabilitators and the Association of Pediatricians organized a conference dedicated to early childhood intervention, where as one of the main conclusions that emerged were: Introduction of development programs and early intervention in the Units for neonatal intensive care due to an increase in the number of high risky newborns, especially premature ones, in order to prevent and reduce the number of people with special needs; Expanding the network of development consultants at the local level community, coordination between all institutions working with at-risk children and children with disabilities and enabling interdisciplinary cooperation.

4.2 Coverage of ECI centers

A total of 55 ECI programmes were identified in North Macedonia, and the directors of 44 (80%) centres responded to the survey. It is important to note at the outset that some of the 44 ECI centres surveyed are governmental (public) state financed organisations (health institutions) while others are for-profit companies (known as DOOELs). The third type were NGOs/Associations of citizens. The for-profit organizations were included in this research because of their large representation in the ECI system in North Macedonia.

Early Childhood Education centres (such as kindergartens) and Day-Care centres were not included in the study. Educational services for children with developmental difficulties/disabilities are not regarded as ECI centres nor are ECI services conducted in kindergartens in North Macedonia. Although there are special educators and rehabilitators, and in some kindergartens a speech and language therapist is employed, their role is usually administrative. Screenings, assessments, individual treatments and family-centred services are rarely organized and conducted. Day-care centres do not provide ECI services, so they were also exempt from the survey.

4.2.1 Coverage of ECI centres in North Macedonia

In the mapping phase, **55 ECI** centers were located throughout the country. The research team made a decision to include public ECI centres, private ECI centers and NGOs/Associations in order to gain a complete picture of the Early Childhood Intervention situation in the country. As explained above, Kindergartens and Early Education Centers were excluded from the study. The goal was to focus on the typical Early Intervention Services for children with developmental delays/disabilities. Below the precise numbers of ECI centers and their coverage are given.

Table 3: Regions/Cities served by ECI centers/service providers

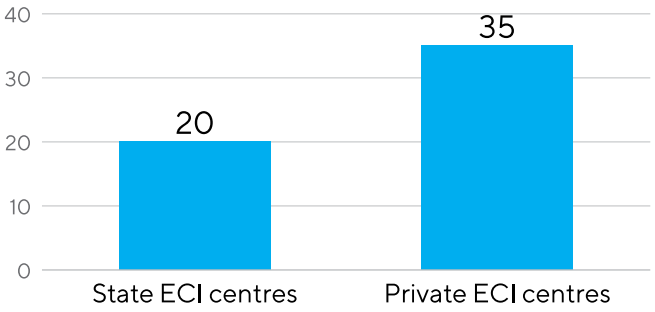
Regions/Cities	Total ECI programmes in cities	Cities where ECI beneficiaries live
Vardar region	**3**	**4**
Veles	2	4
Demir Kapija	0	0
Kavadarci	0	0
Negotino	1	0
Sveti Nikole	0	0
Istochen region	**2**	**10**
Berovo	0	0
Vinica	0	0
Delchevo	0	0
Kochani	1	0
Makedonska Kamenica	0	0
Pehchevo	0	0
Probishtip	0	1
Shtip	1	9
Jugozapaden region	**3**	**10**
Debar	0	0
Kichevo	0	0
Makedonski Brod	0	0
Ohrid	3	10
Struga	0	0
Jugoistochen region	**3**	**5**
Bogdanci	0	0
Valandovo	0	1
Gevgelija	2	3
Radovish	0	0
Strumica	1	1
Pelagoniski region	**9**	**11**
Bitola	7	11
Demir Hisar	0	0
Krushevo	0	0
Prilep	2	0
Resen	0	0
Polog region	**5**	**3**
Gostivar	1	2
Tetovo	4	1
Severoistochen region	**4**	**0**
Kratovo	0	0
Kriva Palanka	1	0
Kumanovo	3	0
Skopje region	**33**	**53**
Skopje	33	53
Totals	**62**	**96**

In terms of coverage, most of the ECI centers are located in the state capital, the city of Skopje. The total number of ECI centers established in Skopje is 33. But it should be noted that 4 of these centers have opened clones in other cities and with this, the coverage of ECI services increases. There is one contemporary Center for Early Intervention and Family Support in Skopje. This center was opened and funded by UNICEF and it is basically a non-profit NGO. Currently it is being funded by the city of Skopje. This is the only contemporary ECI center that provides family-centered home-based services. The services are for free.

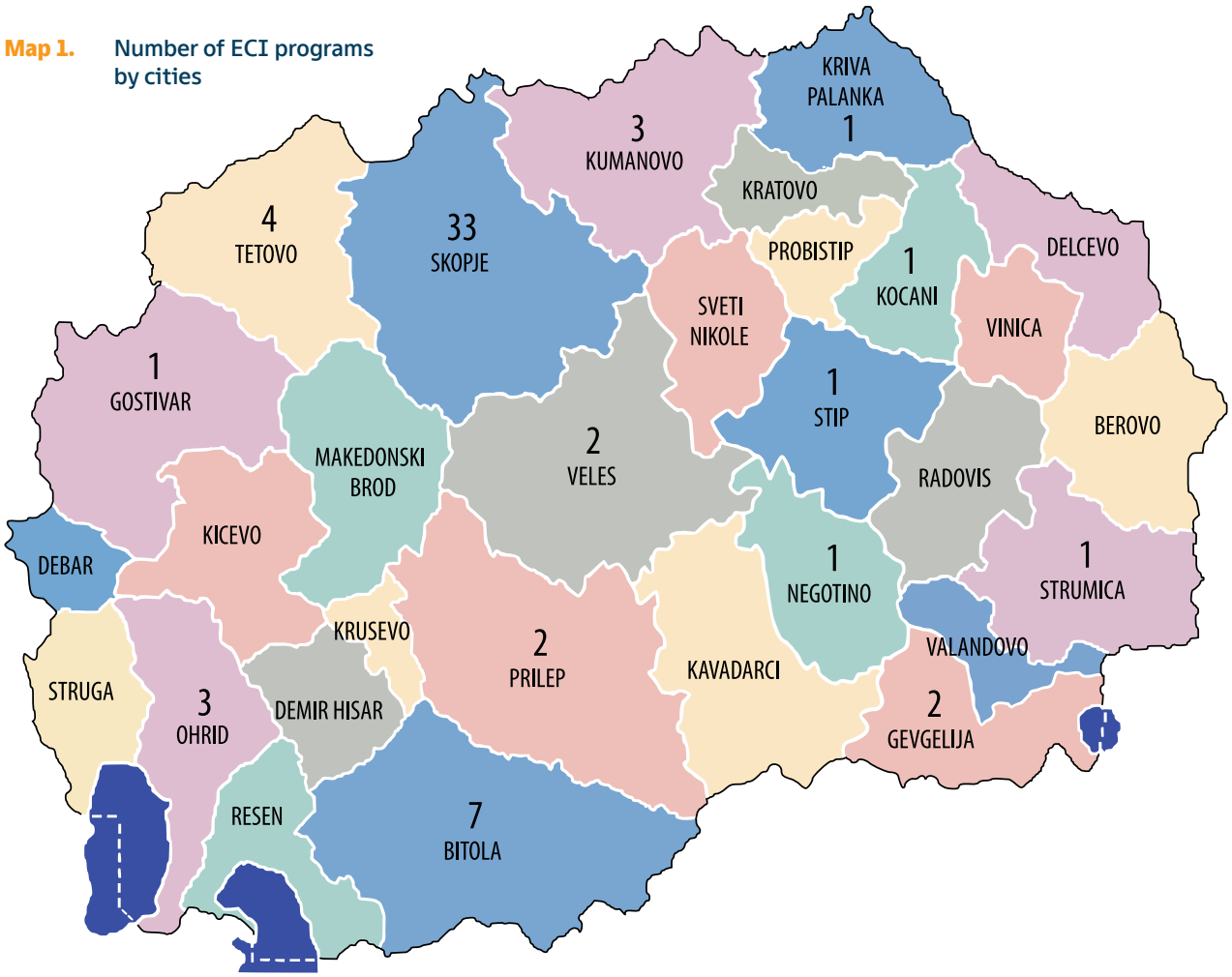
In the table above (table no.3) the numbers of ECI programs by cities are presented. Of all 34 cities in North Macedonia, ECI centers/service providers are located in 14 of them. The total number of center's amounts to 62. This is because some centers from Skopje or Veles opened clones in other cities. Officially, when it comes to ECI centres and ECI directors, the number that we operate with is 55. The map below (map 1) is given as a visual representation of the cities where the ECI centers are located. Even though there are no ECI centers in every town, the existent ones provide their services to children from all the neighboring municipalities/cities. Some of the centers give services to beneficiaries from the entire country, and sometimes the services are even given to families that live abroad when there is an online option.

The results from the mapping study show that from 55 centers, 20 are public state centers and 35 are private (figure 1). All public/government service centres are in the health field. This implies that more than half or 64% of the ECI services in North Macedonia are given by private entities. This was the main reason that private ECI centers were included in the study.

Figure 1: Types of ECI centers in North Macedonia



Map 1. Number of ECI programs by cities



The state centers are integrated into various departments within the medical hospitals (general and clinical) and some medical centers. They predominantly provide rehabilitation and habilitation services or child-centered services. Out of 20 public ECI centers:

- 8 worked within clinical hospitals;
- 8 were medical centers;
- 4 were located in general hospitals.

The private centres were various for-profit and non-profit organizations. Out of the 35 private centers:

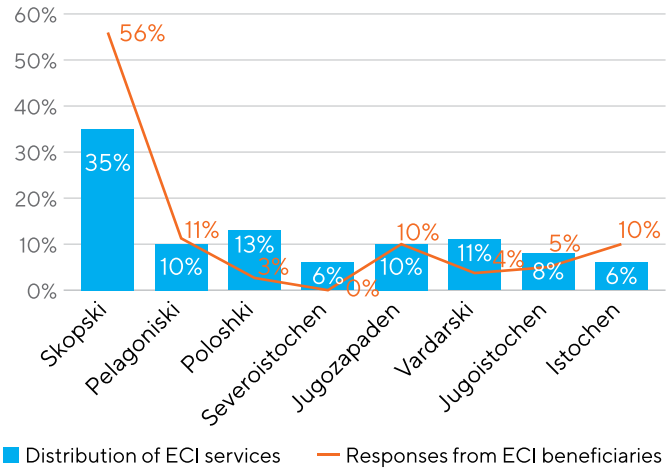
- 18 were private companies (DOOELs and DOOs);
- 16 were associations of citizens and NGOs;
- 1 was a private medical center.

Out of 44 ECI Directors that responded to the survey (80% of the centres) 41 gave an insight into the types of registration of services thus showing one of the largest problems with ECI services and centres in North Macedonia – the lack of a unified designation for registration of these type of services. Having in mind that there is a variety of registration designations for private centers, they are hard to find, and a unification is necessary and should be suggested for future reference, as it would be easier for the centers to be found by those who need their services. The registered centers were divided in three groups (for the purposes of this research):

- 14 (34%) were registered as private companies DOOEL / DOO (private companies).
- 16 (39%) of them were registered as associations of citizens and non-governmental organizations; and
- 11 (27%) were registered as public health institutions (state centers).

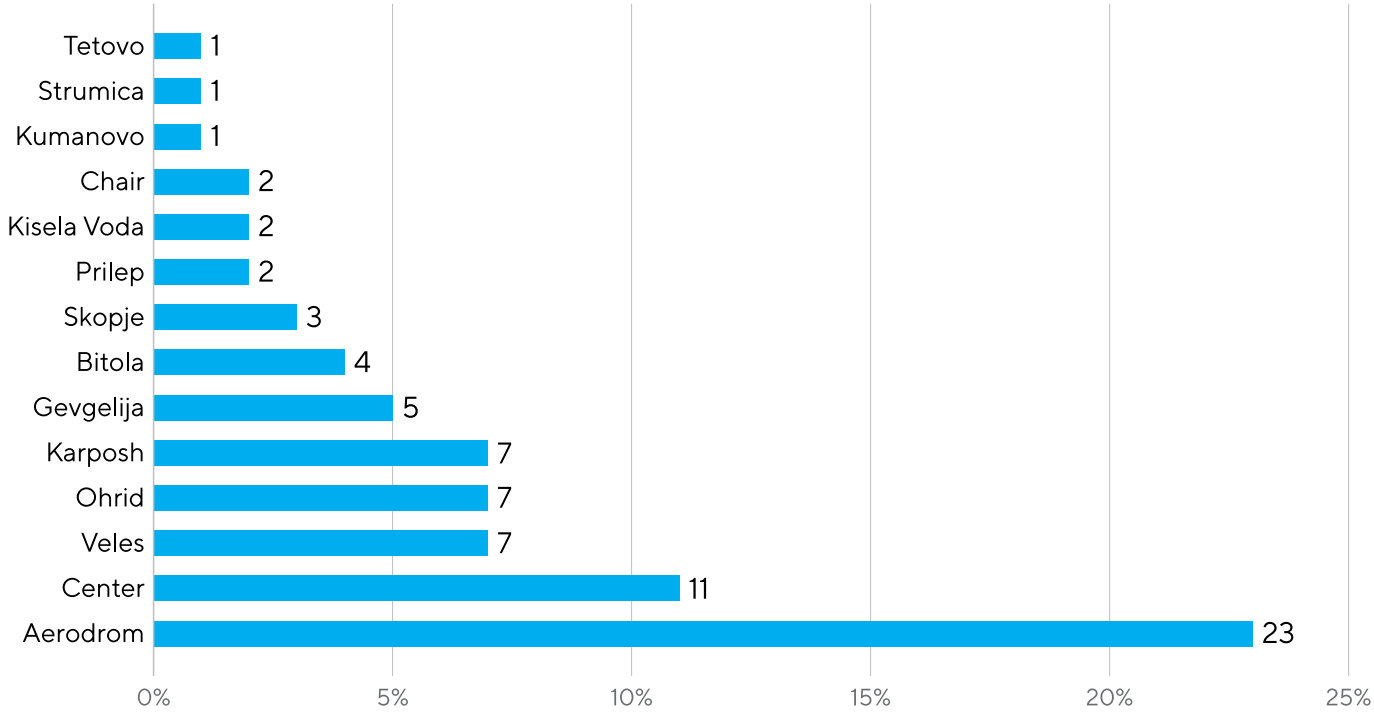
Below, on Figure 2 the percentage of ECI services given by ECI centres in different regions. Also the distribution of responses from the surveys of ECI beneficiaries in all regions of North Macedonia is given. The largest number of services are given in the Skopski region, while the smallest percentage of ECI services are given in the Severoistochen and Istochen regions.

Figure 2: Distribution of ECI services and responses from ECI beneficiaries from different regions in North Macedonia



The ECI personnel survey showed that the largest number of employees (63%) work in Skopje (together with the municipalities of Aerodrom, Centar, Karposh, Kisela Voda and Chair). The largest number of ECI personnel (survey respondents) are located in the municipality of Aerodrom – 23 respondents. This is because the largest number of centres are located in this municipality. They give ECI services to children from various municipalities, not just the municipality of Aerodrom.

Figure 3: ECI personnel distribution



4.2.2 Rural/Urban programme coverage

As presented in Table 4, the survey of ECI Directors shows that 17% of the families receiving ECI service live in rural/village areas, while 83% live in urban areas. This percentage shows large discrepancies between the coverage of ECI services in rural and urban areas and raises the issue of equity, having in mind that 38.4% of the general population live in rural and 61.6% in urban areas. Children with disabilities/developmental delays are underserved in the rural areas.

Table 4. Rural/Urban ECI coverage

Coverage	No. of families	%of families served
Rural/village	1216	17
Urban	5866	83
Total	7082	100

The ECI personnel survey showed very similar results to the ECI directors study. ECI personnel stated that they serve a total number of 2958 families (82%) in urban areas and 632 families (18%) in rural areas. The discrepancies are the same as the ones mentioned above in the ECI directors survey.

The ECI personnel focus groups showed a lack of ECI service systems and centres in small towns and rural areas. Some parents are looking for organized transport to the ECI centers for families from rural areas and small towns.

All parents that participated in the ECI beneficiaries survey agreed that there isn't enough ECI services in their community, especially the ECI services provided by the state. Most of the centres, private and public, are located in Skopje. According to the parents, there are towns in North Macedonia without any ECI services. Sometimes parents and their children have to travel 100 km and more, or move to another town just to get appropriate services.

The high-level interviews showed that there were difficulties with giving services to remote communities (rural areas) which were defined as almost non-existent.

"Children are being kept at home. Some of them later in life get services (or care) in day-care centres, or are accompanied by an educational assistant in schools. Free family-centred ECI services should be offered in all areas (particularly remote and rural areas)." – Academic leader in the area of ECI.

"Government can only suggest opening of new centres, not their location." – Government officials.

The data shows that greater attention should be given to families that live in rural areas. There should be additional funding for ECI services in rural and remote areas and more community services developed to satisfy these needs. The best option for these areas are mobile family-centred ECI teams. The existing

ECI centres/service providers can be trained in the contemporary model of ECI which is based on family-centred services provided in the natural learning environments for the child (such as their homes, play-grounds, kinder-gardens etc.). The mobile transdisciplinary teams, in this manner, can provide services to children in the remote rural areas as well.

4.3 Populations Served by ECI centers

4.3.1 ECI coverage of potentially eligible children from birth to age 6

A comprehensive survey has not been conducted in North Macedonia on the incidence of children from birth to six years of age who have been born at-risk for development of a disability, developmental delays, disabilities or behavioural or mental health needs. For children above the age of six, the Ministry of Education and Science has full information regarding the needs and the coverage. The Ministry of Labour and Social Policy is preparing a registry with the number of children and type of disability/developmental delay that need ECI services (from birth to six).

According the 2021 Census, there are 140.436 children until the age of six in North Macedonia. The 42 ECI directors that responded to this question in 2022 reported that they serve a total of 7.809 children, which is an average of 185 children per program. Thus, the total number of children enrolled in 55 ECI centres could be as many as high as 10.175 children.

Using the possible rate of 12,5% (world statistics show that 10-15% of children from birth to six have developmental delays) of 140.436 children from birth to six years, as many as 17.554 children may need ECI services. If this is the case, then around 58% of ECI eligible children are being served with at least one type of ECI service, and additional places are needed for approximately 7.379 children.

For a developing country as North Macedonia this can be considered as a high accomplishment. The statistics shows that the largest number of children are receiving ECI services in state (medical) centers – 80%, while 20% of the children are receiving services in private centers. However, the focus groups of ECI beneficiaries and ECI personnel showed that parents of children from birth to three visit public centers for assessment and for recommendation for work in home-based settings. Parents visit these centers in certain intervals (example: every three months). The center-based treatment (two or three times per week) usually starts after the third year. Because of that, parents of children from birth to three mostly take their children to private centers. Additionally, parents very often take their children to state centers and private ones, where they pay parental fees[5] for additional services.

One of the suggestions of the ECI personnel is that a precondition for planning ECI services is to define the number of children that need these services.

In order to serve all Macedonian children with at-risk situations, developmental delays and disabilities, it will be essential to expand competent ECI programmes and establish additional ones, especially in underserved areas and particularly state ones. To the extent possible the services provided should be free of charge.

To plan for the phased growth of ECI programmes in each region, a national household survey of the developmental levels and functional needs of children birth to five years is required as well as a national system of regular developmental screening and outreach combined, as possible, with the provision of regular health services.

4.3.2 Age bands

Using age bands, ECI directors reported the following ages of children served in ECI:

- 44% are children from birth to 36 months of age (birth to three);
- 24% are children from 37 to 60 months of age (three to five); and
- 31% are children from 61 to72 months (five to six year olds).

The ECI personnel survey gave us the following info: 32% of children from birth to three, 37% of children from three to five, and 31% of children from five to six. There is a difference in the number of children served from birth to five served, but this can be due to the representation of the sample.

The ECI beneficiaries survey, on the other hand showed that only 19% of the children from birth to three receive ECI services, 38% of children from the age of three to five receive services, and 43% of the children that receive services are older than 5 years. A self-selection bias could be at work here (parents participating in the programme longer might have chosen to answer the survey).

Having in mind that neuroplasticity and the reforming of neural pathways is most constant and rapid particularly during the first three years of life, we need to increase the number of services provided for children during this period which will logically lead to a decrease

[5] Parental fees are finances that parents pay for monthly and/or daily services for their children in private centers/service providers.

in the need of services at a later stage (the costs for inclusive pre-primary and primary education will be much lower). Furthermore, in order to achieve this, a seamless transition from ECI services to inclusive Early Childhood Education (ECE) services (around the age of three) needs to be made.

Parents responding to the Parents' Survey reported their children were the following ages **when they were enrolled** in ECI services:

Table 5: Age of child at time of enrolment

Children's age	No.	%
0 to 1 month	0	0
1 to 6 months	6	6
7 to 12 months	7	7
13 to 24 months	18	19
25 to 36 months	36	37
37 months or older	30	31

The ECI beneficiaries survey gave us a unique insight about the age when children are identified and first start receiving services. Only 13% of children are enrolled into service from birth to one year of age. Some 19% of the children are enrolled in services from 13-24 months of age. The largest percentage of children (37%) start with receiving services from 25-36 months.

Although it is a large success that 69% of the children start with services before the age of three, efforts should be made to start with ECI at an earlier age. Regarding children's age of entry, 0 to 12 months is best, if at all possible. The 31% of children that are enrolled in ECI services after the age of three (37 months and older) is not unexpected, because of the difficulties reaching standardized assessments, lack of screening in all municipalities, low awareness among parents particularly in rural areas and other. This large percentage is worrying and coordination of services needs to be established in order to identify children at the earliest possible times.

In the focus groups of ECI personnel, the largest problem, beside the late identification, was that parents usually are placed on waiting lists and they pay parental fees for their children's ECI services.

"The waiting lists in Skopje are long. In addition to the shock of the parent that he has a child with difficulties, he should set aside funds and pay for it privately." – ECI personnel

"Some of the families, not being able to wait for their appointment, turn to private institutions where they get services faster. But not all the private centers are easy to reach. There are private centers that serve a large number of children and often the parents wait for an available term for several months." – ECI beneficiaries

The largest success of ECI systems is to identify children as early as possible and to provide services to all eligible children. However, apart from some medical conditions not all children have typical signs for developmental delay before the age of 1 (although some predictors can be seen at very early ages). To identify children below one year of age, greater coordination is needed between ECI centres and NICUs, paediatricians and other health care workers. Advocacy is needed to inform health services, parents and community leaders about the benefits and methods of ECI services. Above all, a universal system of regular developmental screening and referrals to ECI services is urgently needed. Through greater demand for ECI services at municipal and county levels, more funding could become available to expand existing ECI programmes as well as begin new ones.

4.3.3 Gender

Regarding gender, the ECI directors survey provided information that out of 5220 children (undoubtedly fewer than the originally stated number of ECI users, probably due to the fact that some of the directors did not respond to the question related to gender), 48% were boys, while 52% were girls. This shows an even distribution of ECI services regarding gender. This incidence is close to the research made by Olusanya et al (2018) which stated that about 54% of children with any developmental disability were male, although the proportions of male and female children varied by type of impairment (the data was for children from birth to five).

The ECI personnel, stated that regarding the children they provide ECI services for, 60% are boys, while (40% are girls). The ECI beneficiaries that participated in the study, stated that 67% of their children are boys, while 32% are girls. Although the general view is that boys have a higher incidence for developmental disabilities, different meta-studies show that the discrepancy is very low. The higher percentage of boys enrolled in ECI services (according to the responses received by the ECI beneficiaries) is probably due to the sampling and should not be generalized. However, attention should be given to ensuring, to the extent possible, that girls are given the same level of attention as boys with respect to enrolment in ECI services.

Table 6: Relationship of beneficiary to the child

Relationship with the child	No.	%
Mother	87	89
Father	10	10
Guardian or close relative	1	1
Caregiver	0	0
Total	98	100%

Looking at the ECI beneficiaries survey, we can conclude that 89% were mothers, 10% were fathers, and only 1% said they were guardians, caregivers or a close relative. In general, the main conclusion is that mothers are the main family members involved in ECI services. Also, in focus groups, participants stated mothers are still the main child caregivers. They observed that single and minority mothers are in a worse situation than others because single mothers lack support and minority mothers lack information about ECI services. Most mothers in focus groups stated they need psychological help.

4.3.4 Groups of children served

On the table below, the responses of ECI directors regarding serving different groups of children are given.

Table 7: Types of children's conditions

Children's conditions	No. of children	%
Children with developmental delays	2662	42
Children with at-risk situations (pre-term, low birth weight, stunted, chronic illness, mother under the age of 19)	1059	17
Children with behavioural and emotional regulation conditions (autism spectrum disorders, attention deficit and hyperactivity disorders)	1058	17
Children with disabilities	989	15
Children with mental health needs (depression, anxiety, traumatic experiences, etc.)	303	5
Children with two or more delays and/or disabilities	334	5
Total	6405	100

The total number of children varies, yet again. This is due to the fact that 40 directors (out of 44 that participated in the study choose to give a response to this question). The largest percentage of directors gave ECI services to children with developmental delays – 42%; then children with at-risk situations and behavioural and emotional regulation conditions (17% each); children with diagnosed disabilities – 15%. The two groups that were least served by ECI centres were children with mental health needs (5%) and children with two or more disabilities (5%).

ECI beneficiaries gave similar responses:

- 33% children with developmental delays;
- 22% children with disabilities;
- 22% children with behavioural and emotional regulation conditions;
- 10% children with at-risk situations;
- 10% children with two or more delays and disabilities;
- 3% children with mental health needs.

The focus groups with ECI personnel noted described and explained why the largest percentage of children that receive ECI services have developmental delays. According the ECI personnel most infants and young children do not have a medical diagnosis or a professional assessment done because there are no free appointments for a medical examination or ICF assessment. They fall under the type – developmental delay which underlines that there is a delay in some area, but it has not been assessed yet. *„It often happens that we get a realistic picture for the child when we start working, with observation...„*). – ECI personnel.

The ECI beneficiaries survey gives us data what the main reason is for enrolment of their children in ECI services. Table 8 shows the following:

Table 8: Reason for receiving services

Type of disability/de4velopmental delay	No. of mentions	% of mentions
Developmental delays		
The child has speech / language delay	62	32
The child was not developing properly	25	13
Sub-total developmental delays	**87**	**45**
Disabilities		
The child has motor disorders	15	8
The child has combined disabilities	9	5
The child has an intellectual disability	6	3
The child has hearing impairment (deafness)	4	2
The child has epilepsy	4	2
The child has a chronic illness	3	1
The child has vision problems (blindness)	2	1
The child has a syndrome	2	1
Sub-total disabilities	**45**	**23**
At-risk situations		
The child is born prematurely with low birth weight	18	9
The child was lagging behind in growth and developing slowly	16	8
Sub-total at-risk situations	**34**	**17**
Behavioural or mental health difficulties		
The child is autistic (autistic spectrum disorder)	25	13
The child has ADHD	3	2
The child has depression or trauma	0	0
Sub-total behavioural or mental health difficulties	**28**	**15**
Total	194	100

The responses from the ECI beneficiaries gave us insight in the wide variety of children receiving ECI services. The parents responded that the children receiving services in 45% of the cases had developmental delays, while 23% had some type of disability. At-risk were 17% of the children, and 15% had some behavioural or mental health difficulties. The impression is that a larger number of children with ASD receive ECI services (this goes hand by hand with statistics of children receiving services in countries with more developed ECI systems). The low percentage given here can be due to the fact that some of the children are not yet officially assessed and identified.

ECI beneficiaries stated that the best access to ECI services is for children with at-risk situations. "*Children born with a risk factor are observed by the neonatology center and they received the first ECI services by the ECI Center at the Clinic in Skopje.*" – *ECI beneficiaries*

The ECI personnel strongly suggested the need for developmental screenings, adequate development screening instruments and comprehensive development assessments that would define the condition the child has, much earlier. ECI personnel stated that many families do not get ECI services because of the lack of information on ECI programs and services and lack of services for parents that will help them to learn their rights and their children's rights, identify their strengths and needs. ECI personnel also pointed out that the National list of risk factors needs to be updated. The last version was created 2004.

When it comes to eligibility, regardless of the predominance of children with developmental delays in the ECI system in North Macedonia as the primary cause for receiving ECI services, ECI needs to be provided for all eligible children or all children that are in need of services.

4.3.5 *Serving Roma and other minority families*

Related to serving Roma and other minority families, the ECI directors gave their responses which are shown on the table below (table 9):

Table 9: ECI services given to children from minorities (according ECI Directors)

Number of children from minorities served	No. of centres
0	13
2	6
1	4
10	3
142	2
702	1
400	1
160	1
121	1
98	1
75	1
60	1
30	1
26	1
21	1
17	1
15	1
8	1
7	1
5	1
Total: 1900	43

Forty-three directors responded to this question. The responses show that 1900 children under the age of six, are being given ECI services in their mother tongue (Albanian, Roma etc). Only thirteen centres stated that they do not provide services to children that only speak in some minority language. That leaves, 30 centres that do provide ECI services to minorities.

Table 10: Ethnic status of children in ECI (according ECI personnel)

Ethnicity of children in ECI	Number of children you serve	%
Macedonian	3091	80
Albanian	552	13
Roma	117	3
Other ethnicity	169	4
Total no. of children you serve	3857	100

The ECI personnel survey gave us more insight into the percentage of children that receive ECI services from different ethnicities. From the ECI personnel, 80% stated that they work with Macedonian children, 13% with Albanian children, 3% with Roma children and 4% with other ethnicities.

There was a consensus among participants from the ECI personnel that low-income families face various barriers to accessing ECI programs. However, some of them also mentioned "*Now more and more Roma parents bring their children to ECI services*."

The participants from the high-level interviews suggested that in order to find these children, we need to offer free services, like in the day-care centers. We should also organize and implement family-centered ECI and have bigger outreach to minority families through the centers for social work. **"***Free services. More home-based visits and community-based services. Bigger involvement of the municipalities. Distribution of their disability funds to ECI."* – Academic leader in ECI.

According to the data the Roma children are the ones that are underserved, so efforts should be made to have a bigger outreach to their communities, and enrol Roma children that are eligible for services in the ECI centres. Also, some advocacy efforts need to be made in these communities in order to raise awareness for the importance of ECI.

4.3.6 *Status of families receiving ECI services regarding poverty levels*

North Macedonia has made considerable gains in poverty reduction since the 2008 global financial crisis. The poverty rate (based on the upper middle income class poverty line of $5.5/day in 2011 PPP) has fallen steadily from 35.1 percent in 2009 to 18.2 percent in 2017 (latest available household survey data), propelled mainly by improvements in job opportunities and increases in labor earnings (World Bank, 2020). Government spending played an

important role in contributing to these improved labor market outcomes through subsidies to foreign direct investment, active labor market policies, and spending on improving infrastructure. Increases in pensions also contributed to poverty reduction, though to a lesser extent than labor market improvements, while social assistance programs played a more limited role due to their low coverage and fragmented nature. Continued improvements in employment and real wages suggest that poverty has declined further in 2017-2019.

Looking ahead, continued progress in poverty reduction will depend crucially on improved earning opportunities for the poor and on tackling the still high levels of unemployment and recent improvements. Yet, unemployment in North Macedonia remains among the highest in the Europe and Central Asia (ECA) region. According to the data available by the Statistic Bureau of North Macedonia (according the 2021 census), the at-risk-of-poverty rate in North Macedonia in 2020 was 21.8% (State Statistical Office, 2022).

The main priorities related to the possible provision of increased ECI services are:

- To continue with the development of social (and combined services) especially at the local level (It is necessary to continue the process of activation, with direct work with families- case management); and
- Strengthen health care system and introduce new programs for maintaining safe and accessible services (attention to the mental health of citizens).

The ECI directors gave the following responses regarding economic status (table 11).

Table 11: Economic status of families receiving ECI (according ECI Directors)

Economic status	No. of families	%
Low socio-economic status	672	15
Medium socio-economic status	2831	64
High socio-economic status	891	20
Total	4394	
Answered	41	
Skipped	4	

A total number of 41 directors stated that regarding the economic status of the families they serve: 15% have a low economic status, 64% are medium economic status families while 20% have a high socio-economic status.

According the ECI personnel survey, below the general economic status of the families they are currently serving is given (table 12):

Table 12: Economic status of families receiving ECI (according ECI personnel)

Economic status	No. of children	%
Low socio-economic status	437	18
Medium socio-economic status	1480	60
High socio-economic status	535	22
Total	2452	100

From the 76 persons that took part of this survey, only 70 gave responses to this question. From their answers we can conclude that 18% of the families have a low socio-economic status, and 22% have a high socio-economic status. The largest percentage – 60% have a medium socio-economic status. The triangulation of the surveys of ECI directors and ECI personnel show almost identical results. There is a high percentage of families that cannot afford private services with parental fees. The majority of families with medium and high socio-economic status usually pay for the ECI services.

Rates of children with developmental delays and stunting are always higher in regions that have higher levels of poverty (Black et al, 2016). Future national strategies and action plans need to plan ECI services on an equitable level. ECI services need to be available to all, particularly the families with low socio-economic status, children from rural areas as well as children from minorities (in general marginalized groups).

4.3.7 Barriers parents face in accessing ECI services

One of the most important issues from this research was to identify barriers parents encounter when attempting to access other social services.

Table 13: Barriers families face in accessing ECI service (according ECI directors)

Barriers families face	No. of mentions	%
They lacked knowledge about ECI eligibility criteria or ECI services in general	27	29
ECI services are located too far from their homes	20	21
They felt excluded due to costs related to services (transportation, fees or other costs)	20	21
They feared stigma related to disability	18	19
They felt excluded due to language or cultural barriers	4	4
They lacked birth registration for their child	0	0
Other (specify)	5	5
Total:	94	100

ECI directors reported that 29% of the parent lacked knowledge about ECI, ECI services and ECI eligibility; 21% of the parents couldn't manage to attain ECI services because they were located outside of the area where they live (mostly in the large cities); 21% didn't have the financial means to cover the costs for ECI (here included are transportation to the ECI services, fees that they had to pay [private centers] and other costs). Although much has been done in North Macedonia regarding raising awareness for disability, still 19% of the parents feared stigma related to disability, which is a very large percentage of parents. A very small percentage (4%) felt that they could not receive services because of some language or cultural barriers, while there was no report that they couldn't receive service because they lacked a birth certification for their child.

Some of the other answers (5 mentions/5%) included: Lack of advisory and consultative support for parents; Untimely identification of children delays their inclusion in ECI services/ inadequate developmental assessment and the fact that ECI services in Skopje are provided only to children born at risk, all other children are not systematically monitored for development. Parents seek ECI services on their own initiative or on the recommendation of a pediatrician.

Table 14: Barriers families face in accessing ECI service (according ECI beneficiaries)

Barriers families face	No. of mentions	% of mentions
I did not face a barrier	38	23
I did not have enough information about ECI services	20	12
There are no ECI centers in my municipality	17	11
ECI centers are located too far from my home	15	9
My child's development was not screened / assessed as part of regular check-ups at the pediatrician	14	9
I did not have the financial means to pay for the services with activities for ECI	11	7
ECI services are not offered when I am not at work	11	7
There was a long waiting list for these services	9	6
There are no specialists in the area my child needs	8	5
It was difficult to get a recommendation to work in an ECI activity center	7	4
It was really difficult to find transport to these centers	6	4
The enrollment process was very complicated	2	1
I needed a translator / interpreter to talk to the ECI service staff	2	1
My child is of another nationality	0	0
My child is of another nationality	0	0
Other barriers (specify which)	2	1
Total	162	100

The parent's answers differed in some segments from the answers of the directors. 23% of the parents mentioned that they never had any barriers in receiving ECI services; 12% mentioned that they do not have enough information for ECI services (oppose to 29% mentioned by the ECI directors); 11% stated that there are no ECI services in their municipality while 9% stated

that the service are located far from the home (oppose to 21% stated by the ECI directors); 9% of the parents mentioned that the child was not screened during regular medical check-ups; 7% mentioned the lack of finances to pay for services, 7% mentioned that state ECI centres only offer services during working hours; 6% mentioned the long waiting lists; 5% mentioned that there are no ECI specialists that can work with the specific needs of their child; 4% difficulty with getting a recommendation; 4% had issues with transport to get ECI services; 1% has issues with the enrolment process and 1% needed the services of an interpreter in order to talk to the ECI staff.

Other barriers that were mentioned by the ECI beneficiaries included:

- The child needs to be over 36 months of age to receive ECI services;
- Services stopped during the COVID-19 pandemic.

All of the barriers mentioned above need to be taken into consideration when creating a strategy for disability, a strategy for Early Childhood Intervention, a referral system or any policies related to ECI. Awareness for ECI is still not fairly raised, and this is an issue that should be seriously tackled. The location of ECI centres (no ECI centre in the municipality or city families live in), paying for ECI centres, and high costs for transport are also still major barriers.

The ECI focus group for beneficiaries showed that parents often take their children to private centres, due to lack of available time-slots in public centers or due to dissatisfaction with the treatment the child receives there. Usually they change several centres trying to find the most suitable for their child. This service-seeking could last from few months to 2 years. The waiting lists in public institutions are very long. Usually they wait for 2-3 months for the onset of services. Some of the parents manage to get services sooner due to personal contacts. Some families, in these cases, turn to private organization where they are provided with services sooner. But not all the private centres are easy to reach. There are private centres that serve a large number of children and often the parents wait for an available slot for several months. Also, the ECI services in some cases are very far away from the place of living. *"Sometimes we have to travel 100 km and more, or move to another town just to get appropriate services."* – ECI beneficiary.

The high-level interviews resulted with several suggestions for overcoming of some of these barriers such as:

- Some of the ECI services can be provided in kindergartens (age group 3-6 year olds);
- ECI centers should be opened/ECI services provided in every municipality (equipped with vehicles and staff);
- There should be free family-centered ECI services (which would enable access to ECI services for families in rural areas);
- Pediatricians and family nurses should be utilized in the screening process; and so on.

These findings show that barriers to accessing ECI and other essential services should be considered during the design of a referral system for ECI services.

4.4 Types of ECI Services Provided

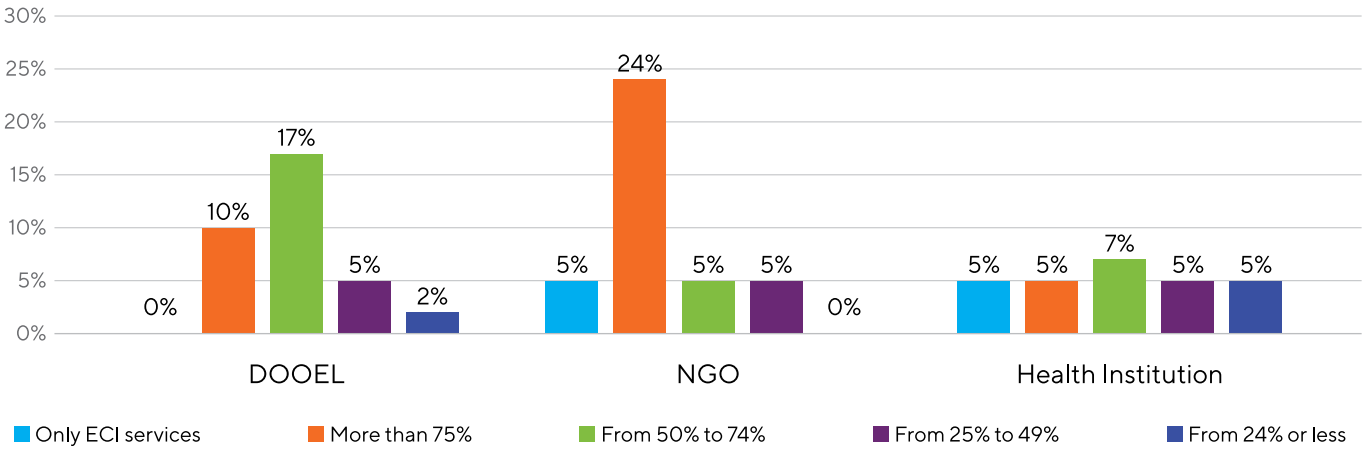
The basic info for the types of ECI services that are currently provided in ECI centers (whether the center only provides ECI services or other services as well) in North Macedonia was taken from the ECI Directors survey that showed the following (table 15):

Table 15: Percentage of services dedicated to ECI

ECI services provided by centres	No. of centers	%
We only provide ECI services	5	11
More than 75%	17	39
From 50% to 74%	13	29
From 25% to 49%	6	14
24% or fewer	3	7

The directors survey shows that the largest percentage of ECI centres (39%) provide ECI services in more than 75% of the cases. 29% of the centres provide ECI services from 50% to 74% of the time. Only 11% provide only ECI service. In order to get more compelling data, we did a cross tabulation regarding the types of centres and percentage of services dedicated to ECI. The results are shown below (figure 4).

Figure 4: Percentage of ECI services for children in the centre



From the figure above we can conclude that from the centres that are registered as DOOEL, 17% give ECI services in 50% to 75% of the time; 24% of NGOs that give ECI services, do that in more than 75% of the full load of cases. Health institutions have an even distribution and work completely differently from one another. Regarding provision only of ECI services:

- 0% of DOOEL only provides ECI services;
- 5% of NGOs only provide ECI services; and
- 5% of Health institutions only provide ECI services.

The overarching notion is that generally in North Macedonia there are very few centres (11%) that are oriented only towards the provision of ECI services. ECI services/programs are being provided within larger centres, institutions that work with children and adults on different ages, albeit they predominantly work with children until the age of six which can be seen in the tables above.

Regarding where the services are being provided we got the following responses from the ECI directors (table 16):

Table 16: Location of provision of services

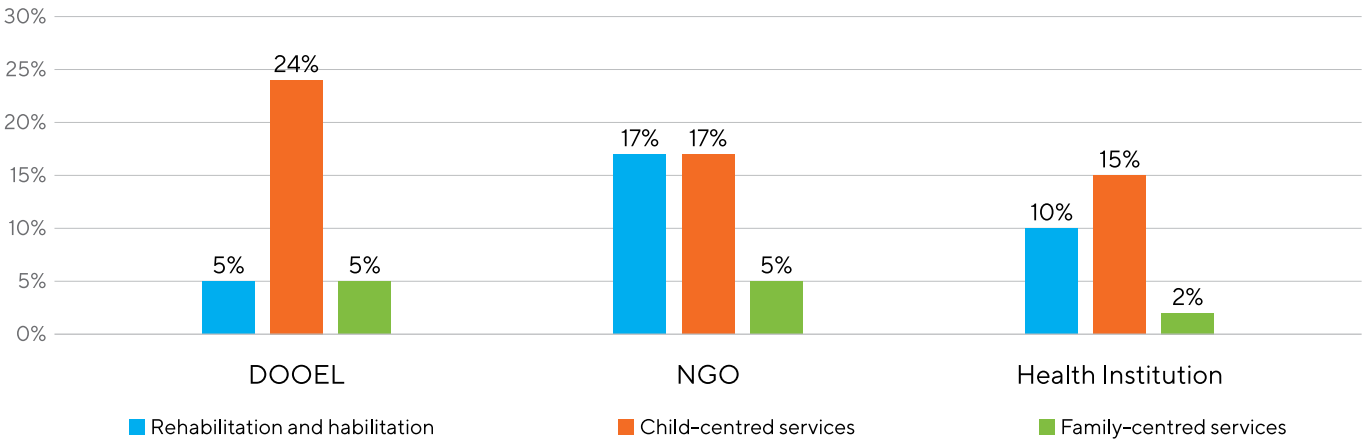
Location of provided services	No. of centers	%
a hospital or centre entirely	34	81
a centre with some home visits	8	19
mainly through home visits	0	0

The ECI Directors survey showed that from 42 centres (that answered this question), 81% provide the services in a hospital or in a centre entirely; 19% provide services in a centre with some home visits while 0% provide all services through home visits. Of course, this refers to services provided for children from birth to six.

Regarding the types of services which are mainly provided, the ECI Directors survey stated that 56% of the services/25 centres are child-centred services (evolving services), 32% (14) centres are rehabilitation or habilitation services (legacy services) and 12% (5 centres) are family-centred services.

In order to get a more in-depth info, we did a cross tabulation regarding types of services and types of institutions. The results are shown in figure 5 below.

Figure 5: Types of ECI centres and types of services they provide



The cross tabulation showed that out of all three types of center/institutions – the DOOEL (private companies) are the ones that provide the most child-centred services (24%), but basically all centers mainly provide services for the children them-selves. The health institutions are the ones that work least with the parents (provision of family-centred services). NGOs are the ones that mostly (out of all three types of institutions) provide habilitation and rehabilitation services.

The ECI directors survey gave us plentiful information regarding the types of services. Some of the services that can be noted are that 11% of all centers give comprehensive assessments of the child's development; 10% give speech and language therapy; 7% give psychological assessment and counseling; 6% give occupational services. 4% are specialized in assessments of children with specialized instruments. Only 3% work with Individualized Family Service Plans (IFSPs), only 3% work with on parent education within the center; only 2% work on parent education during home-visits. None of them provides respite care services for parents.

Table 17: Types of services currently provided in ECI programmes

Types of ECI services	No. of mentions	% of mentions
Comprehensive assessments of all domains of child development	36	11
Speech/language therapy services	32	10
Assessments of parent-child interaction	29	9
Psychological assessment and counselling	24	7
Developmental screenings of children	20	6
Occupational therapy services	20	6
Establishment of eligibility of children for ECI services	17	5
Online visits	17	5
Case management services and referrals to other services	16	5
Specialised assessments of child development, i.e., hearing, autism, or other specialised instruments	12	4
Transition plans with parents, children and next service providers (principals and teachers in inclusive pre-primary schools, primary schools, specialised schools, etc.)	12	4
Development of Individualised Family Service Plans (IFSPs)	10	3
Parent education in centre-based groups	10	3
Assessments of child health, nutrition, health and hygiene	9	3
Personal and home hygiene and safety education	9	3

Types of ECI services	No. of mentions	% of mentions
Parent education during home visits	8	2
Health and nutrition education services	8	2
Help to obtain assistive technologies (equipment)	6	2
Psychiatric support and treatment	5	2
Physical therapy services	4	1
Parent and peer support groups	4	1
Audiology services	3	1
Community outreach activities to find potentially eligible children	3	1
Vision therapy services	3	1
Respite-care services for parents	1	0
Other (please specify)	5	2
Total	323	100

Some of the ECI Directors gave additional comments for the provision of services that were not part of the table above, such as:

- A holistic approach that, in addition to individual work and developmental assessment and stimulation of children, includes family-system counseling and family systemic psychotherapy and interventions for the whole family;
- Assistive technology needs assessment service and individualized assistive technology support service;
- Working with parents to accept the deviation in their child's development, further guidance of parents to work at home with the child;
- Intensive comprehensive treatment.

The high-level interviews gave an insight in the types of services and their location in North Macedonia. According to these interviews there is one typically contemporary ECI centre in Skopje, which was funded and opened by UNICEF. During the COVID-19 pandemic it provided online services. Currently the centre is being funded by the City of Skopje. Evolving and Legacy services can be found in larger and smaller cities in the state. The legacy (medically-oriented) ECI programs are within clinics (medical institutions) or hospitals while evolving are some of the ECI programs in hospitals (members of the team go into homes-patronage nurses) and some of the private ones. Some of the NGOs/Associations provide some family-centred services that are evolving toward becoming contemporary ECI services.

The focus groups with parents showed that most families do not use any ECI services, but rather rehabilitation services. *"Children attend treatments in centers, according the recommendations, they received treatments by a speech therapist, special educator and rehabilitator and/or physiotherapist."* – ECI beneficiary. When asked what type of ECI services they would like to receive they mentioned the following: support in everyday activities; home support; family counselling; continuous treatment; child care respite and others.

Regarding what needs to be done to make ECI programmes/centres more contemporary, ECI personnel gave the following suggestions. ECI programs should provide:

- Comprehensive development assessments;
- Developmental screening;
- Adequate development screening instruments;
- Development supervision and monitoring;
- Family-centered ECI services;
- Individualized Family Service Plan (IFSP);
- Home visitors;
- Parent education services;
- Multisectoral and interdisciplinary ECI programs.

From the results, we can state that the ECI and ECI-related centres are providing a variety of services, which are mainly child-centred. The lack of IFSPs during the provision of services, lack of parent education both center and home based and the lack of transition plans with parents, children and future service providers indicates low use of contemporary ECI services. However, personnel revealed a great interest in learning more about how to conduct effective, family-centred ECI services in the natural daily environment of the child and family.

4.5 Referrals, Community Outreach, Waiting Lists and Eligibility

4.5.1 Referrals to ECI services

Regarding the referrals for ECI system, the ECI Directors survey provided the following responses (see table 18 below) – in the largest percentage (29%) parents call the centres in order to ask for ECI services; 22% of referrals come from nurseries, kindergartens and preschools; 19% of referrals come from hospitals and medical institutions; in 9% the screening is conducted within the centre. In a much smaller percentage, the referrals come from social welfare centres, NICUs, persons outside the centre but trained from the centre to do screenings and field assessments made by the centre itself. Some 4% of the referrals come from the official commission for assessment according the International Classification of Functionality (ICF).

Table 18: Method of referral

Referral method	No. of mentions	% of mentions
Parents call or visit your centre to ask for ECI services	41	29
Your centre receives referrals from nurseries, childcare centres, and/or preschools	30	22
Your centre receives referrals from child health centres and hospitals	26	19
Your centre conducts developmental screenings	16	12
Your centre receives referrals from social welfare centres	8	6
Your centre receives referrals from Neonatal Intensive Care Units (NICUs)	7	5
Your centre receives referrals from a commission (for directing children into the educational system) [or if for some other reason, please specify]	6	4
Your centre trains others (parents, nurses, physicians, preschool teachers, community health workers) to conduct developmental screenings and make referrals to your ECI centre	3	2
Your personnel visit families in the community to find children who may need ECI services	2	1

The ECI survey of beneficiaries, regarding the question who suggested the ECI center or services for their child, showed that in the largest percentage of cases – that was another parent (25%); in 18% a neighbor or friend; in14% an ECI staff member; 12% a family doctor. In a smaller percentage, parents are being told about ECI centers by: other doctors; kindergarten staff; family members, social workers, social media, nurses. What is worrying is that none of the parents responded that they were given information about an ECI center by some of the staff in the NICU or someone else from the hospital. Also, none of the parents learned about ECI centers through the media.

Table 19: Suggestion for ECI services

Recommendation for ECI services	No.	%
Another parent	24	25
Friend or neighbor	17	18
The staff in the center that offers services for early childhood intervention	13	14
Family doctor / pediatrician	11	12
Another doctor	8	8
The staff in a preschool institution	6	6
A family member or relative	5	5
Someone else who screened your child	4	4
Social worker in the center for social work	2	2
Social media or website	2	2
The nurse	1	1
Others (specify which)	3	2
Staff in the neonatal intensive care unit	0	0
Someone else in the hospital	0	0
Media	0	0

The high-level interviews showed that the ICF is not yet part of the system. It will soon be embedded into a Rulebook for additional educational, social and health support for children under 26. *"This new rule-book will replace the old ad hoc commissions for categorization."* – Government representative. It is important to separate ECI Guidelines and Procedures from general Rule Books for health and social services. The latter should refer to the ECI Guidelines and Procedures. The ECI system needs its own rules and regulations.

The ICF centre is doing some screenings, assessments and referrals for ECI services. Unfortunately, very few ECI services are free and therefore parents go to private centres. This explains the low percentage of referrals for ECI that come from the Centre for assessment according the ICF. One of the high-level interviewees suggested that the referral rate would be improved if medical students (through inserting content in a bachelor course)

are trained to do screenings or by connecting maternal hospitals to ECI centres and kindergartens.

The focus group of ECI beneficiaries stated that when it comes to seeking out ECI services in most of the cases parents noticed the first sights of development problem. After which they went to:

- Pediatricians. Some of the pediatricians conducted short autism screenings, and all of them referred the parents to state institutions, the Institute for Mental Health and the Institute for Rehabilitation of Hearing, Speech and Voice. And in some cases, parents were referred to state development counseling center "Bit Pazar", Skopje;
- Private hospital (Sistina) and ECI private centers.

Children born with a risk factor were observed by the neonatology center and they received the first ECI services by the ECI Center at the Clinic in Skopje.

Regarding what organization helped them to find their ECI services, the parents stated that they had:

- Recommendation by medical institutions (paediatricians);
- Personal contacts with the people involved in ECI services;
- Recommendation by people with similar problems;
- Recommendation of the preschool institution and
- Recommendation from the vaccination center.

4.5.2 Medical Review Committees

Currently, a Rulebook for defining the type and degree of the physical or intellectual disability of persons, is still officially in force. This rulebook is for persons under 26. The condition of the person under 26 is being determined (categorized) according to this rulebook. The detection, identification and referral is being made by a health institution, social protection institution, child protection institution, educational institution or by the parent. For each person with disability, an Opinion for the type and degree of disability is being formed. After a disability is defined, the parents have a certain compensation/allowance (financial support), which depends and varies from the type and degree of disability. These commissions for categorization are usually found in the larger cities, so one of the difficulties parents encountered was the travel distance and subsequent assessment of their children (which were usually very tired and didn't show their maximum potential).

This problem is found wherever commissions continue to be used. Moving to establishing ECI eligibility in the ECI service institution enables community-based and more sensitive support for the child and family and ends the problems of transportation, lack of knowledge of the family and their circumstances, etc. and they and their child enter ECI services in a seamless fashion.

Although the ICF centre (Center for developmental assessment according the ICF) is planned to replace the AD HOC commissions for categorization, this has yet not happened. *"We are moving from the medical to the social model. Regional ICF are opened and will be opened. They give the referrals. This was done in the Centers for Mental health in Skopje, Veles, Prilep. In the future they will work on treatment of children and diagnostics."* – Ministry representative.

Children are being send to the ICF centers where comprehensive assessment by expert teams is being made. However, as a system, the ICF assessment is more oriented towards children above the age of six. After the assessment the ICF center can refer these children to certain services, such as educational assistants in inclusive mainstream schools. Unfortunately, parents usually are not motivated to have their child assessed in the ICF center because the free ECI services are very few. Private centers also, usually (not always) prefer to do their own assessments of the development of the children in order to create working plans. Currently ECI, geographically and financially is not available for all. It is available for families that can pay for it, in the cities where such ECI services are offered. *"For now, as the system is put, who managed to enter the system and get the services, that's it – for the others that didn't manage, it is virtually impossible to enter the system."* – Representative from an Association of Special Educators and Rehabilitators.

"Currently a very small number of children birth to 6 are being assessed. The goal is to assess all children, but parents simply do not come because of the limited free services offered. We simply don't have places where we can send the child...in the other cities (other than Skopje) the situation worsens. Parents then go to private centres, pay for the services, we don't have monitoring over these centres. We cannot refer them to some private centre or give a recommendation because we do not know how that centre works-there is no program, no licensure." – ICF assessment centre.

In order to enable effective referrals of children and their families to ECI services, contemporary ECI processes of developmental screening and/or medical diagnoses with referrals directly to ECI services should be specified in ECI programme guidelines and procedures. Contemporary ECI programmes conduct comprehensive developmental assessments and specialised assessments, if needed,

to identify the child's abilities as well as his or her developmental domains requiring special attention.

As is the case in ECI programmes around the world, on the basis of the 1) bio-social risk situations of the child, (such as low-birth weight, stunting, trauma or severe poverty), 2) a comprehensive developmental assessment (such as the HELP Strands, AEPs, Bayley Scales or others), and/or 3) an immediately allowable medical diagnosis of a disability or chronic health condition (such as cerebral palsy, visual or auditory impairments or ASD), the ECI programme would establish the eligibility of the child for ECI services.

A legal framework as well as *National ECI Programme Guidelines and Procedures*, are needed to enable ECI programmes to establish eligibility for ECI services as well as provide the approval required for parents to receive financial support.

4.5.3 Community outreach

As more contemporary ECI services will be offered and provided, more community outreach activities will be needed in North Macedonia. The ECI directors survey led us to these results regarding community outreach:

- Only 3 centres conducted outreach activities;
- Only 2 centres visit families to find children who may need ECI services in order to conduct screenings;
- 4 centres mentioned that they share referrals with some community centres.

The high-level interviews showed that ECI services, [according the high-level interviews] are not recognized as community services. Municipalities are not providing community outreach services for ECI. UNICEF has worked in the past period on piloting and establishing these types of centres. They worked with different associations to give community-based services and to use already established capacities. *"During covid-19 these centres were giving online services. This is continued by [one project]. But predominantly the capital, the network needs to be widened, and we need to offer community-based services."* – International organization representative.

Given the lack of information related to community outreach activities, it can be stated that this very important aspect of ECI is not being conducted in North Macedonia. This is the reason that there are many unidentified children with developmental delays/disabilities, particularly in the rural areas. ECI personnel rarely conducts these types of activities, given the facts that they have long waiting lists already.

However, every eligible child should be served with ECI, and the most functional way to do that is by conducting community outreach activities. Community outreach is a necessary and functional part of ECI services, and it is conducted in many ways through community outreach volunteers, radio and television broadcasts, fliers and posters.

4.5.4 Waiting lists for enrolment in ECI services

The parents, within the ECI beneficiaries' surveys were asked to share information regarding the existence of waiting lists before enrolling in the centres for ECI. Out of 96 responses, 81% of the parents responded that there weren't any waiting lists, while 19% mentioned that they were put on a waiting list.

Out of these 19% of ECI parents:

- 68% waited less than 3 months;
- 11% waited from 3-6 months;
- 4% waited from 7 months to one year; and
- 8% waited for more than one year.

ECI personnel focus groups discussed that the waiting lists in state centres in Skopje are very long. Some ECI beneficiaries, within the focus groups mentioned that they have issues with timely provision of ECI services. *"Most of the parents at the very beginning start using services from private centers because the waiting list for the public institutions are very long. There is a special program for scheduling treatments in public institutions, it is called „My appointment". But the waiting list is very long. Usually there are placed 2 to 3 months on a waiting list.* – ECI parent.

Some of the parents managed to get services sooner due to personal contacts. Some of the families, not being able to wait for their appointment, turn to private institutions where they get services faster. But not all the private centers are easy to reach. There are private centers that serve a large number of children and often the parents wait for an available term for several months. *We have been waiting for a time-slot for a certain service for months. Services need to be far more accessible and diverse"* – ECI parent.

4.5.5 Eligibility for services

Some countries and states with well-developed ECI systems have eligibility criteria which is usually related to the budget one country/state has. For example, some states in the US have eligibility criteria that a child can receive ECI services if there is a 25% delay in one of the developmental areas. Other states have eligibility criteria that the child has to have a 25%

delays in at least two developmental areas (for example speech and motor area). However, the best examples of ECI systems show that we need to strive to give ECI services to all children in need for that, regardless the percentage of delay or the area in which the delay occurs (here including children with all types of at-risk situations, disabilities, delays and behavioural or mental health needs).

The ECI directors survey showed the following results:

- 8 centres (19%) required medical diagnosis only;
- 12 centres (28%) accepted a medical diagnosis but also a comprehensive developmental assessment for eligibility for services; and
- 23 centres (53%) accepted a medical diagnosis, a comprehensive developmental assessment or evidence of at-risk status.

In order to get concrete results for eligibility, we did a cross-tabulation regarding the referrals and diagnosis in regards to the different types of centres that were part of this study. On the figure below it can be seen that: all types of centers accept medical diagnosis, health referrals and community referrals (DOOEL, NGOs, health institutions) and among them the highest percentage can be seen in the NGOs (32%).

Another cross tabulation was done, regarding eligibility to receive ECI services on one hand and the types of services the centre provides on the other hand. The results are given on the figure below (figure 7). Legacy services (21%) usually require a medical diagnosis, or a comprehensive developmental assessment, or some type of confirmation [in Macedonian-Наод и мислење] to deem the child eligible for ECI services. The same applies for child-centred services that require these types of confirmation in 30% of the cases. Family-centred services accept medical diagnosis or they conduct their own comprehensive developmental assessment.

Figure 6: Eligibility and diagnosis (in different types of ECI centers)

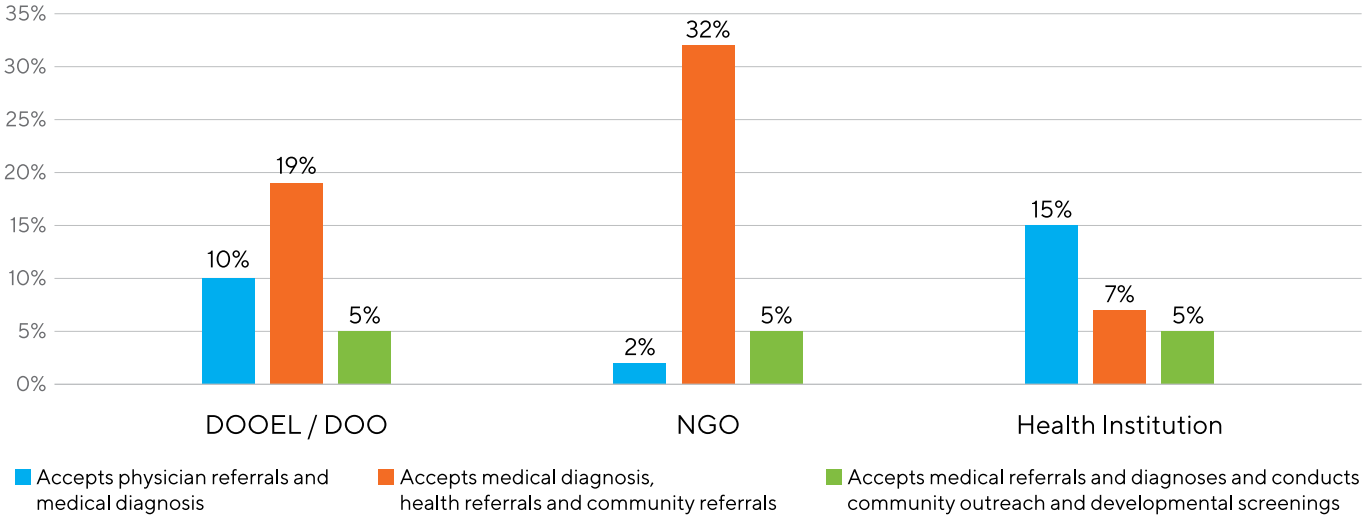
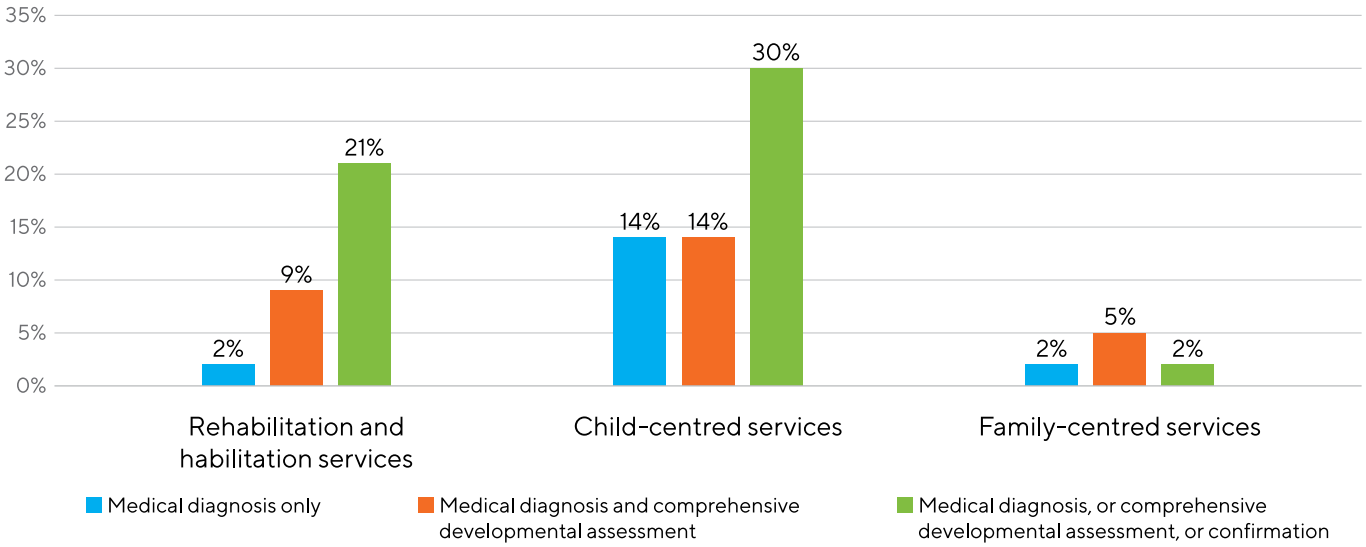


Figure 7: Eligibility to start different types of services



The research shows that ECI centres, whether public or private ones or NGOs/Associations usually need a medical diagnosis to start ECI services, or conduct their own comprehensive developmental assessment.

4.6 Developmental Screening, Comprehensive Developmental Assessments, ECI Teams and Service Eligibility

4.6.1 Developmental screenings

One of basic requirements of the study we've conducted was to define whether developmental screening is being conducted for children from birth to six, where it was conducted, by whom and did the parents participate in the screening.

The ECI beneficiaries survey showed that parents have had developmental screening for their children in 60% of the cases, 19% of them did not receive screening, and 21% were not aware whether their child has received any type of developmental screening. For the 60% of parents that got screening for their child, the following issue was to define whether they participated in the screening. Out of those parents:

- 39% participated in the screening;
- 23% observed, but did not participate in the screening; and
- 26% did not participate nor observed the screening.

This shows that, although a large number of parents participated or observed the screening of their child (which implies the use of family-friendly screening instruments such as ASQ3 and others), still a large percentage of parents were not included in the developmental screening of their child. It is very important to emphasize that parents should be informed and should participate in every aspect of the ECI services, including the screenings. Parents can provide valuable information regarding their child that could lead to a better IFSP and enhance his/her development.

Regarding the ECI directors survey, we got the following results regarding the use of screening instruments:

- 56% of the centres use screening instruments; and
- 44% do not use screening instruments.

Out of the 56% of centres that use screening instruments, NGOs use screening tools the most (22%), in comparison with health institutions (19%) and DOOEL (16%). The largest difference found in the using vs not using screening instruments can be found in health institutions where 11% do not use screenings in comparison to 19% that do use screenings for identification of developmental delays.

Another point of interest was to see whether ECI centres that provide different kind of service use screenings instruments. Figure 9 shows that the largest number of services that use screening instruments are child centred services. Some 31% of them use screenings. The rehabilitation and habilitation services use screening instruments in 21% of the cases, and family-centred services use them in 5% of the cases.

Figure 8: Use of screening tools for identification of children with delays

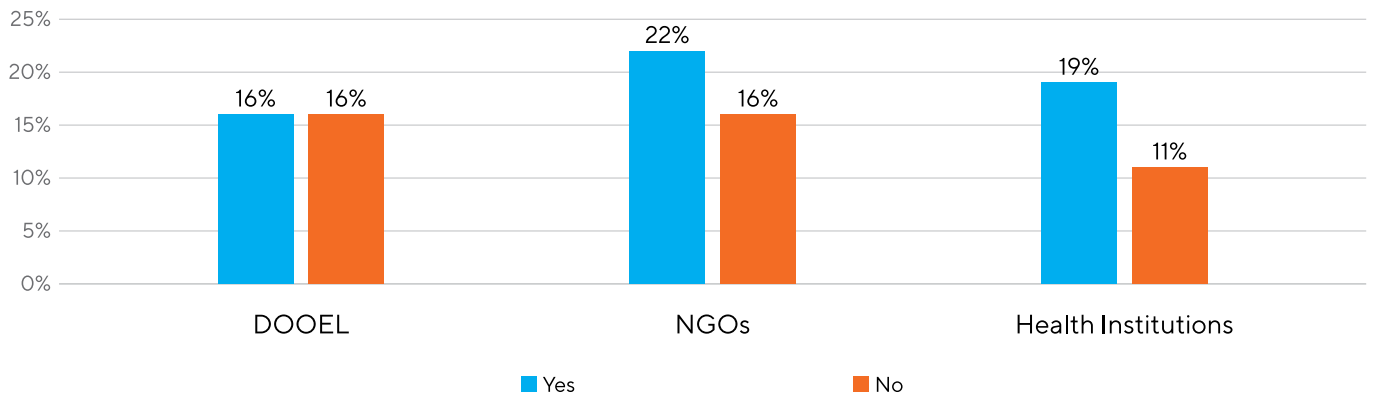
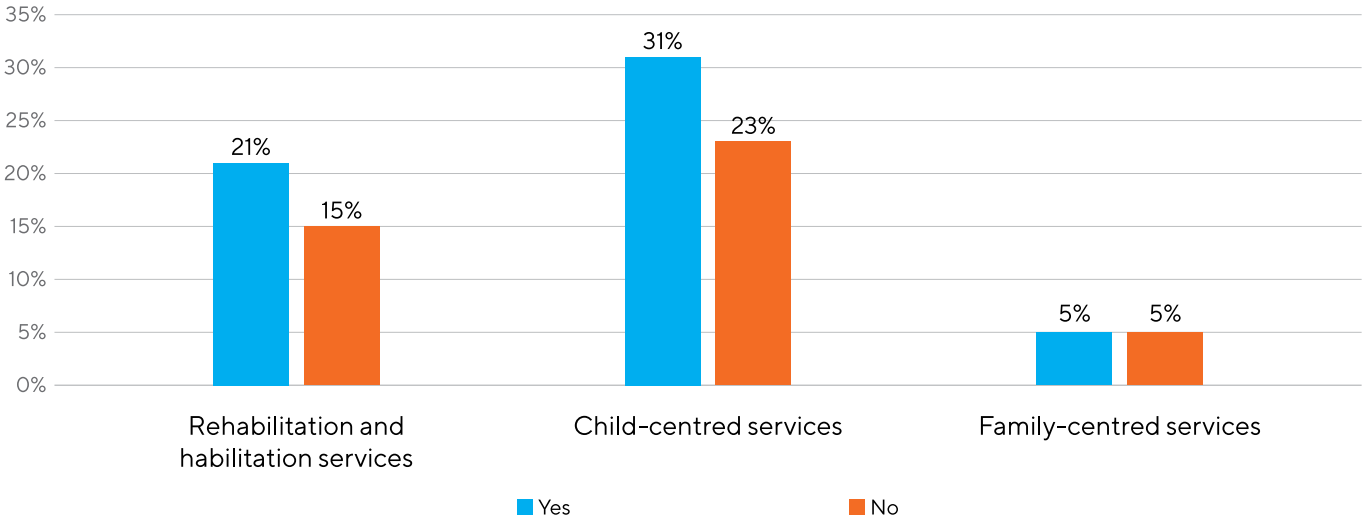


Figure 9: Use of screening instruments by ECI centers that provide different types of services



Regarding the types of screening instruments used, below there is a table with the number of mentions and their percentage. Only 21 of the ECI Directors answered this question. The largest percentage (22%) of centres used the Ages and Stages Questionnaire III (ASQ III) and a large number (11%) of them also use the ASQ Social-Emotional Scale. Some 6% use the Parents Evaluation of Development Status (PEDS) while high 17% use the Denver Developmental Screening Test II. Some 44% of the ECI directors mentioned that they use different types of tests such as:

- M- CHAT;
- ADOS II;
- Munich Development Scale;
- First Step Screening, ABLLS;
- GARS - 3 (Gilliam Autism Rating Scale);
- Autism Treatment Evaluation Checklist (ATEC);
- ADHD and ADD Detection Questionnaire;
- Tailor-made Screenings;
- Development scale from 0-6 years.

Table 20: Use of developmental screening instruments

Developmental screening instruments	No. of mentions	%
Ages and Stages Questionnaire III (ASQ III)	8	22
Denver Developmental Screening Test II	6	17
Ages and Stages Questionnaire – Social-Emotional (ASQ SE II)	4	11
Parents Evaluation of Development Status (PEDS)	2	6
Another screening instrument (specify)	16	44
Total	36	100

The high-level interviews suggested that some screening are also done in kindergartens. Professionals in kindergartens monitor the children's development from the age of 2 until the age of 6, by using the standards for early childhood development. One of the suggestions of these interviews was that patronage nurses can be trained to make these screenings when they visit the family. Of course this needs to be within a so called universal progressive model of patronage where patronage nurses make continuous visits to the families.

Regarding the thoughts of the ECI personnel (focus groups) on the implementation of developmental screening, it was clear that:

- Some of them conduct medical and therapeutic specialized assessments;

- A small number of them do not use standard procedures for developmental screenings;
- There is a lack of doctors (pediatricians, neurologists, etc.);
- All of them wanted to learn new development screening tools for infants and young children.

4.6.2 Comprehensive developmental assessments

One of the basic questions within the study was also whether the child has received a comprehensive developmental assessment, after the developmental screening that only gives a brief insight in the child's condition. The ECI beneficiaries survey showed the following responses:

- 76% of the parents received a comprehensive developmental assessment of the child;
- 24% did not receive a comprehensive developmental assessment of the child (an assessment of all areas of child development).
- From those 76% of parents that did receive a comprehensive assessment of their child:
- 27% stated that one professional conducted the assessment;
- 49% stated that more than one professional conducted the assessment, at different times; and
- 24% stated that a team of professionals conducted the assessment at the same time.

The ECI directors survey (39 directors of centres answered this question on the survey) showed that:

- 49% conduct comprehensive developmental assessments;
- 51% do not conduct comprehensive developmental assessments.

This basically implies that a large number of the parents got the comprehensive assessment in larger centers for diagnostics, such as the ICF centre, the centre for mental health, the centre for rehabilitation of hearing, speech and voice and others.

On figure 10 below it can be seen that the NGOs use their own assessments in the largest percentage of cases (22%) opposed to the 17% of health centres and 8% of DOOEL that use comprehensive assessments. From this is can be seen that DOOELs and Health institutions rely more on official diagnosis from official institutions than the NGOs. This percentage can also imply that to prepare plans (IFSPs), the NGOs needed to conduct their own comprehensive developmental assessments, especially depending upon the type of assessment used (normative or curriculum-based).

To get information whether ECI centres that provide different types of services differ in organizing comprehensive assessments. As it can be seen on the figure below, centres that give rehabilitation and habilitation services as well as the family-centred services conduct assessments in only 10% of the cases while 28% of the child-centred services use comprehensive assessments.

Figure 10: Use of comprehensive developmental assessments

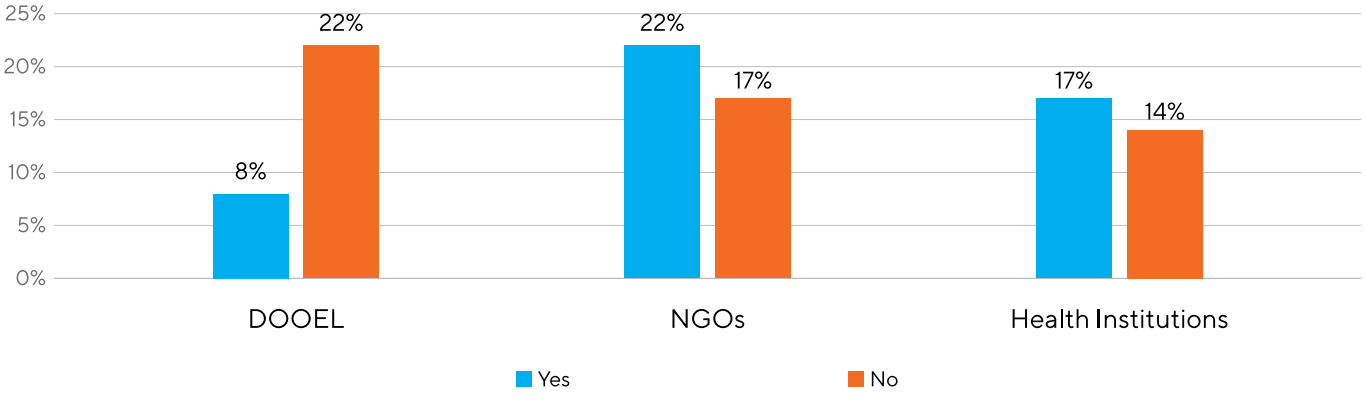
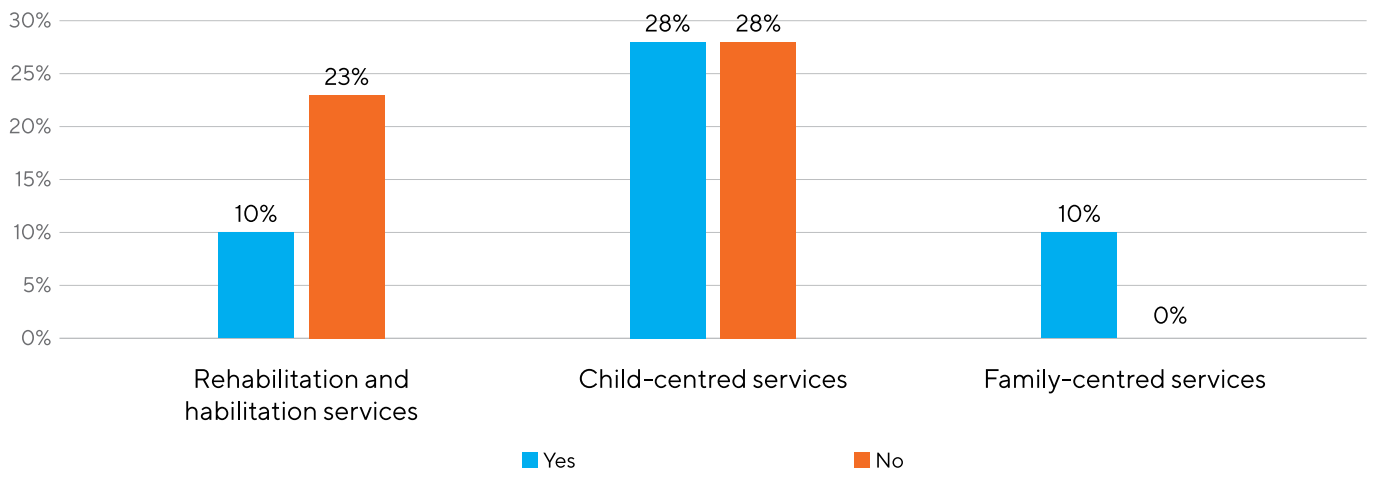


Figure 11: Use of comprehensive assessments by ECI centers that provide different types of service



Regarding the type of Assessment instrument used by the centers, the ECI directors responded (only 20 directors responded to this question) the most used one is the Munich Diagnostic Instrument (26% of the centers use it); 12% use the AEPS; 12% use HELP; 6% use the Battelle and 3% use the Brigance. 41% of the centers use other assessments such as:

- Standard special education and rehabilitation assessment;
- Griffiths Developmental Test;
- Reynell assessment;
- Wechsler scale of Intelligence;
- Vineland Adaptive Behavior Scale;
- LAP;
- Battery tests for assemsment og spoken language;
- Assessment of communication skills – Andersons, Miles, Matheney;
- Assessment scales for psycho-physiological abilities;
- Brine-Lezin, Bine-Simon, Gudinaf drawwings, Progressive matrixes;
- Self-made instruments adapted to the center's needs.

Table 21: Use of developmental assessment instruments

Developmental assessment instruments	No. of mentions	%
Munich Functional Diagnostic Instrument	9	26
Assessment, Evaluation and Programming System (AEPS)	4	12
Hawaiian Early Learning Profile (HELP)	4	12
Battelle Developmental Inventory 2 (BDI 2)	2	6
Brigance Assessment	1	3
Other (State name)	14	41

Regarding parent participation in the assessments, ECI parents, in the focus groups, stated that most of them did not participate in the assessment of the child, they do not know how it was conducted and which tests were used. Only two of the mothers stated that they attended the assessment, and every time they come for control assessment they attend/participate in it. No parent participated in the assessment or particpated in the writing of outcomes. None of the parents signed an IFSP.

The focus group of ECI personnel, regarding assessments stated that:

- Some of them conduct comprehensive developmental assessments of infants and young children;
- Most infants and young children do not have a medical diagnosis because there are no free appointments for a medical examination (and that

is why they have to do thorough assessments);

- All would like to learn how to conduct comprehensive assessments of infants and young children (new and more advanced methods of assessment).

There is a huge need for ECI service providers (transdisciplinary teams) to conduct comprehensive developmental assessments and also be given the role of establishing eligibility for ECI services. Specialized assessments should also be used, where needed, such as MCHAT, Peabody language, etc. But in all cases, a comprehensive developmental assessment is needed because ECI addresses the balanced development of the child and does not just provide services in just one area. Children's holistic development is the framework for holistic services.

4.6.3 *Formation of multidisciplinary, interdisciplinary or transdisciplinary teams*

The establishment of the type of teams that will work with the child or preferably with the family, is one of the most important issues in ECI. All ECI directors responded to this question. The ECI directors survey shows that:

- 64% (28) of the centers have professionals that work directly with each child;
- 30% (13) of centers create interdisciplinary teams that jointly plan, and each member works separately with the child; and
- 6% (3) create transdisciplinary teams with a primary service provider for each family who receives support from other team members.

With the purpose to get more in-depth information we cross tabulated the results. Regarding forming teams in different types of ECI centers, the survey and figure below (figure 12) clearly showed that the largest number of centers have professionals that only work individually with the children, and the largest percentage can be seen in the DOOEL (27% of all centers). A very small percentage of DOOELs create transdisciplinary teams (only 2%). NGOs, also in the largest percentage have individuals that work one on one with the child (20%) and have a slightly higher percentage of formation of transdisciplinary teams than DOOELs (5%). NGO also have the highest percentage when it comes to creation of interdisciplinary teams – 15%. What is worrying is that none of the health institutions have transdisciplinary teams. 14% of them have professionals that work individually with the child and 12% have interdisciplinary teams.

The analysis after the cross tabulation of methods of work with children and parents on one hand, and the types of service the centers provide on the other hand, shows the following results (presented on Figure 13). Child-centred services mostly use professionals to work with the children (39%), and so do rehabilitation and habilitation services (23%). Rehabilitation and habilitation services do not create transdisciplinary teams, at all (0%). These teams are created in 2% of the child-centred services and in 5% in the family-centred services. The largest number of interdisciplinary teams can be seen in the child-centred services (16%).

Figure 12: Methods of working with children and families in different types of ECI centres

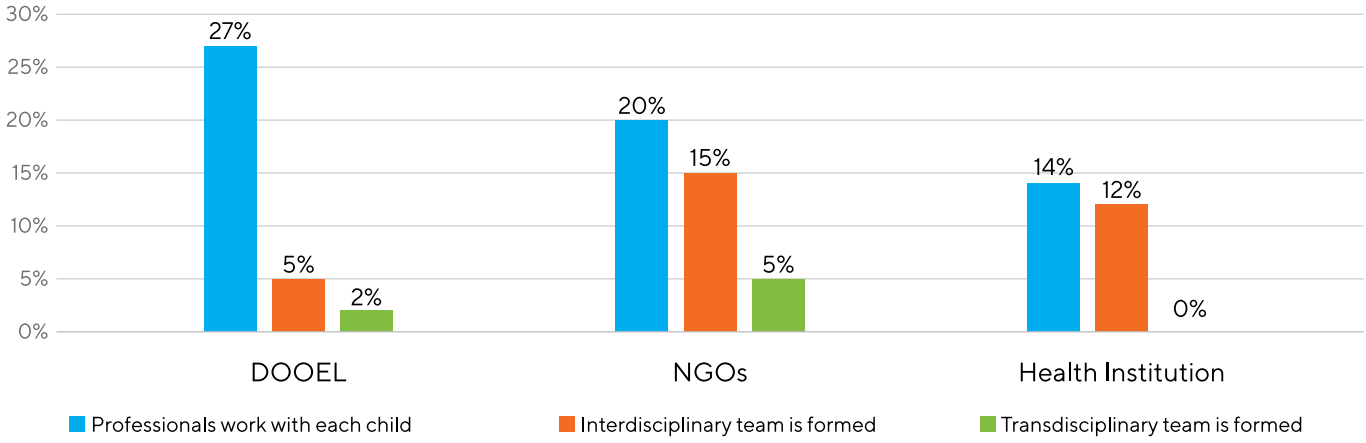
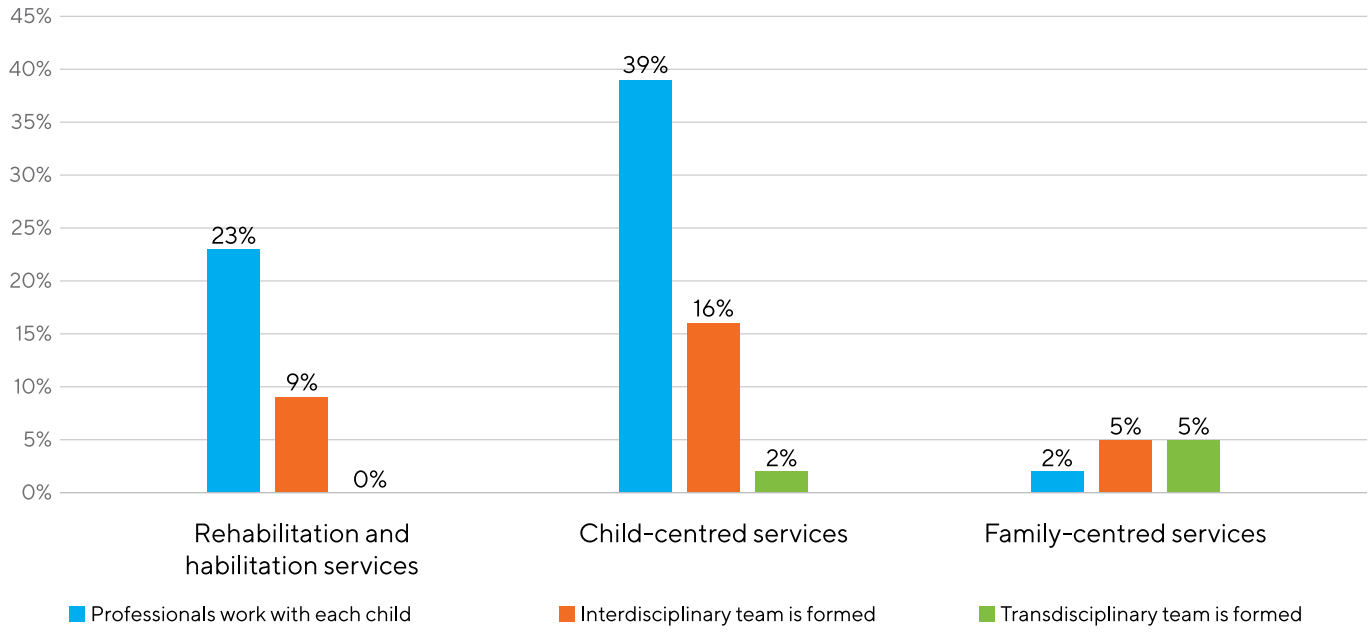


Figure 13: Methods of working with children and families in centers that provide different services



FThe ECI parents, being asked in what way they and their child receive support services and/or treatment from a team of professionals stated:

- In 77% one person works alone with the child;
- In 1% of the cases one person works with the parent and the child separately;
- In 3% one person works with the parent and the child together;
- In 12% of the team was assigned to work with the child alone;
- In 1% a team was assigned to work with the parent and child together;
- In 1% one person works with more than one child;
- In 4% one team works with more children.

The ECI personnel survey showed that professionals:

- Work with the child alone in 76% of the cases;
- Work with the parent looking on in 13% of the cases;
- Coach the parent in 7% of the cases;
- Work with a group of two or more children in 4% of the cases.

From both of these surveys we can conclude that the results are in alignment with the results from the ECI directors survey, where the largest number of centers have professionals that work one on one with the child, with no consultation with other representatives from the center. A positive aspect is that there are some forms of coaching by the ECI personnel, which is a step forward towards contemporary services.

The focus group of ECI parents stated that the children receive individual treatment with a special educator, speech therapist and physiotherapist while the professionals from the focus group of ECI personnel stated that ECI services are always provided in teams that function in an interdisciplinary manner. All participants stated that there are teams in their institution and that once a week they have the so-called main meeting. Parents are constantly informed about their child's development. *"We need to move towards an interdisciplinary and transdisciplinary teams"* – ECI personnel

We can conclude professionals in ECI centers work individually, seldom as a part of a team, and that working with the family with the creation of transdisciplinary manner is very rare. A transformation needs to be done and a movement from this individualistic manner of work towards a more interdisciplinary and even transdisciplinary manner of work.

We need more highly-trained and effective professionals in the field that will have competencies to collaborate closely within different teams. In order to do this, university curricula in ECI needs to be updated. We need to change the manner in which we train ECI

professionals. *"ECI is still focused on the child itself not the family."* – Academic leader in ECI.

"Transdisciplinarity is a challenge in our society and it needs to be developed, but it is difficult for the staff to shift." – high-level interview quote by a representative of the Association of special educators and rehabilitators.

4.7 Individualized Family Service Plans and Family Participation

Individualised Family Service Planning is a process during which parents and ECI programmes work together in describing the strengths and needs of the child and family, state their goals, and list the types, frequency and duration of ECI services to be provided. This process is marked with the signing of a document which is also called the Individualized Family Service Plan (IFSP). The idea is that parent work actively in the process of the creation of these documents, not just to be included in the last signing phase.

Always used in contemporary ECI services, IFSPs are developed jointly by parents and ECI service providers. All IFSPs are signed and dated by the parents and members of their Transdisciplinary or Interdisciplinary Team, depending upon the type of team used. Parental participation and leadership is essential in all decision making regarding their child and family, and are an essential right guaranteed under the Convention on the Rights of the Child. This is a fundamental difference between contemporary ECI services and traditional rehabilitation services.

The ECI directors survey shows that a physician or therapist creates the plan of services for the child in 32%; in 30% a physician or therapist or others in the ECI centre create the service plan for the child and family, and in 38% a transdisciplinary or interdisciplinary team creates the plan, with the parents as full team members.

The ECI beneficiaries survey (97 parents responded to this question) showed that:

- 22% of the parents have IFSPs;
- 58% do not have IFSP;
- 21% did not have information whether an IFSP has been made for their child.

The beneficiaries survey stated that in 30% a professional made the decision regarding services and in 27% a team of professionals made the decision. The positive aspect is that in 43% the parents, after discussing options with the team, made the decision about their child's ECI services. Asked whether they signed the IFSP, 43% said yes, while 58% said that they have not signed an IFSP for their child.

The ECI personnel focus groups stated that every organization makes their own service plans. *"ECI professionals make different Individualised Child Service Plan, there is no standardized template for an IFSP"* – ECI professional.

The high-level interviews gave us an insight in the link between ECI service and the ICF centre as well as the dynamics of writing IFSPs – *"When children come to the ICF centre, and have received ECI services before, they rarely bring an IFSP. For me this is not organized work by professionals. We need licenced professionals, that will give reports every 3-6 months (on the goals achieved)."* – Representative from ICF assessment commission.

"IFSPs are very rarely written, and very rarely decided by parents. Visits are still being made at homes (rarely) and in centres, not yet in natural environments of the child. No transition plans yet." – ECI academic.

These findings reveal that considerable training is needed to prepare ECI professionals in the core concepts underpinning the IFSP process as well as the methods for preparing them with the full participation and leadership of parents. A culturally appropriate IFSP format, guide and training manual must be selected or developed, field-tested and disseminated for use in North Macedonia. Considerable pre- and in-service training, mentoring, coaching and supervision will be required to teach professionals how to prepare IFSPs effectively together with parents.

4.7.2 Family participation in other ECI services

Regarding family participation in ECI services, the table below (table 22) taken out of the ECI directors survey, shows that parents participate in comprehensive developmental assessments in 24% of the cases; 22% of them participate in the assessments of the parent-child communication; 21% participate in specialized assessments; 13% in developmental screenings; 9% in transition plans, 7% in preparation of IFSPs and 4% in assessments of home safety, health and hygiene.

Table 22: Family participation in ECI services

Family involvements	No. of mentions	% of mentions
Comprehensive developmental assessments	27	24
Assessments of parent-child interaction	25	22
Specialised assessments (e.g., language, motor development, etc.)	23	21
Developmental screenings	15	13
Transition Plans	10	9
Preparation of Individualised Family Service Plans (IFSPs)	8	7
Assessments of home safety, health and hygiene	4	4
Total	112	

The high-level interviews underlined the need of a greater inclusion of the families in ECI processes. "*The family needs to become a full member of the ECI team and to get a primary authority to make decisions.*" – ECI university professor.

The focus group of ECI beneficiaries revealed that no parent participated in the assessment, goal setting, or signed the child work program. The focus groups of ECI personnel stated that some staff make a short-term (2-3 weeks) and long-term (4-6 months) plan for working with children. Others have weekly and monthly working plans. They all state that they make decisions as a team. Parents are not usually included after the assessment process. Again, although there is a shift towards contemporary family-centred services, we need far greater involvement of the parents/caregivers of the children with disabilities/developmental delays in all aspects of the ECI process.

4.8 Home and Centre-Based Services, Family Services and Transition Planning

4.8.1 Services in the child's natural environments and/or centre-based services

Contemporary ECI programmes are oriented towards providing family-centred services in the child's natural environments. A common misconception is that natural environments is the child's home alone. The contemporary services are provided in many settings such as: the child's kindergarten, playgrounds, markets and other places where the child goes about his/her daily routines, which are also family routines. The goal of the contemporary programs is to enhance the competencies of the parents/coach the parents to conduct developmental activities with their children during various family routines: bath-time, play-time, bed-time and others. This highly effective approach is called routines-based intervention (RBI) (McWilliam et all, 2020) and it is particularly beneficial for children from birth to three years of age.

ECI directors (40 directors responded to this question) stated that in 90% of the cases (36 centers) they do not provide regular home-visits for some of the children enrolled in the center. Only 10% (4 centers) provide services in home-based settings.

From these four ECI directors we got the following responses to the additional questions:

- 2 centers provide regular home visits for between 1% and 9% of the children served;
- 1 center provides regular home visits are provided for between 10% and 29% of the children serve
- 1 center provides regular home visits or visits in other natural environments of the child are provided for between 30% and 69% of the children served.

No center provides home visits or visits to other natural environments of the child (pre-primary schools) for 70% or more of the children served.

Regarding the average number of home visits made per day by each home visitor, the responses from the four ECI directors that provide such services were that make only 1-2 visits per day per visitor. This response got 100% mentions. The other responses (3-4; 5-6; 7 or more) got 0% of mentions.

The cross tabulations done for types of centres and provision of regular home visits show (as seen on the figure below) that: Health institutions do not provide home visits at all (0%); while NGOs and DOOELs provide home visits in only 5% of the cases.

Figure 14: Provision of regular home visits by different types of ECI centres

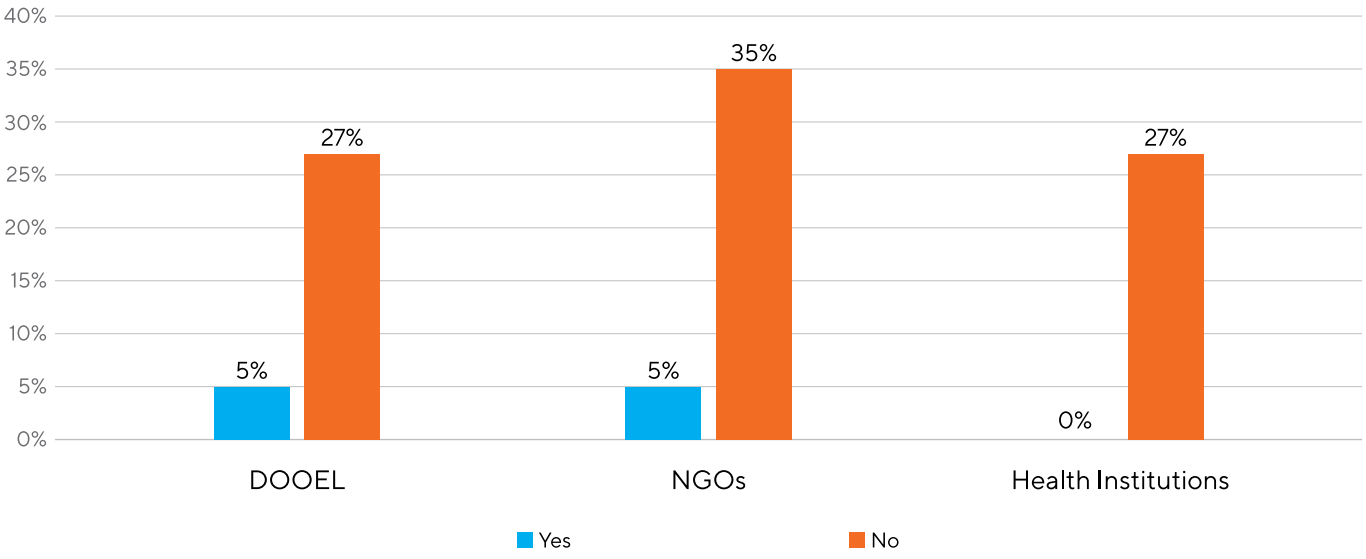
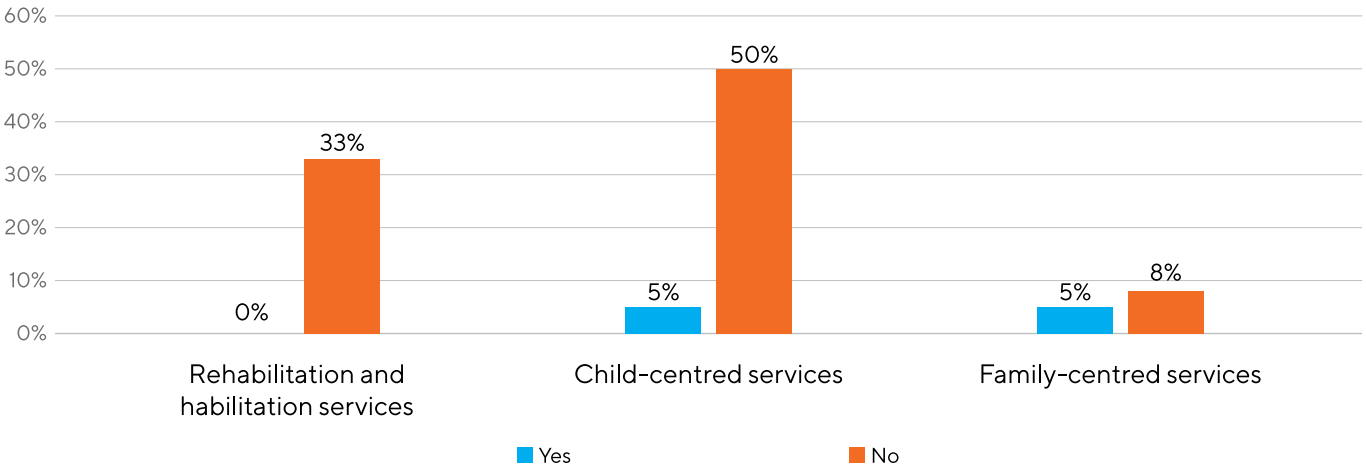


Figure 15: Provision of regular home visits by centres that provide different types of services



The analysis of home visits and types of services the centre provides show (as seen on figure 15 below) that: rehabilitation and habilitation services do not provide home services at all (0%); while family-centred services and child-centred services provide home based treatments in 5% of the cases.

The ECI beneficiaries survey gave results regarding where the parents and their children receive ECI services (according to their experiences). The largest number of beneficiaries received services in the ECI centre (56%); 7% in other places where the child regularly spends time; 7% in pre-primary school; 5% in a health centre; 5% in the home and ECI centre; only 3% in the home; and 17% of the beneficiaries gave other alternative answers (day-care centers; center for assistive technology; parents working at home with the child; private treatments with special educators and rehabilitators). The percentage of home-based services is slightly lower than the one received from the ECI directors survey, but this is probably due to the sampling.

ECI personnel, regarding the meetings with the children and parents for services, gave the following responses:

- 53% provide services in centres or hospitals;
- 46% in child-care or pre-primary school;
- 1% in community centres or other places;
- 0% in the home of the child.

Again, these differences with the surveys above are due to sampling. The large percentage of answers of ECI personnel that gives services in child-care centres or pre-primary schools is most likely due to the nature of the question in Macedonian. It does not imply that personnel from an ECI centre provides services in a child-care centre or pre-primary school. This data is verifiable through the professions of personnel given below.

The focus groups of parents stated the professional works only with the child, and gives instructions to the parents to work at home. In general, all parents received instructions for working at home. In North Macedonia, usually after each treatment/session parents are advised what to work with their children at home. This is related to the pre-service training of professionals, particularly special educators and rehabilitators.

Focus groups of ECI personnel pointed out that ECI refers more to the family and work with it, but at the same time in our country there is still no law that would allow the provision of services at home. That is why the institutions try to train the parents while taking the child for treatment. It was stressed that "*Work is needed with the parents to overcome, resolve and accept the diagnosis of the child*." – ECI personnel.

"... Then, after each completed rehabilitation treatment, even it is practically shown to parents that they have to work at home." – ECI personnel. Some of the professionals send videos that can help the parents work with their children at home.

The high-level interviews led to some conclusion such as the fact that visits are still made only at homes (rarely) and in centers, not yet in the [other] natural environments of the child, they are also not routine-based. Homes are the major natural environments of the child. In the US and other countries around 80% of visits to natural environments are to the homes, the remainder are visits to work with caregivers and teachers in childcare and preschool settings. A few are made to markets, playgrounds and other places to introduce other opportunities for the development of abilities and skills.

They also gave some suggestions regarding the services - *"We need to make ECI birth to three more family-centred. We now have children that receive services for three-four years and they block the centres. If you work with the family at the home or other natural environments of the child, then we can unblock these institutions for more children."* – Representative from an Association of special educators and rehabilitators

Given the predominance of highly structured centre-based services and child-centred services, it may take considerable time for some ECI programmes to modify their methodological approaches to include home visits and other services in the natural environment of the child. Centre-based ECI programmes that mainly provide hospital rehabilitation services may decide to remain as they are or begin to provide a blend of ECI and hospital services. More training could be given to ECI programme directors and professionals on effective methods for family-focused services, home visits, and routines-based interventions (Vargas-Barón et al, 2016).

4.8.2 Home visiting child caseloads and frequency of home visits

One of the important questions regarding home-visits was what is the average number of children (caseload) that home visitors visit during one months. The ECI directors responded:

- 75% (3 centres) visit 5 children or fewer;
- 25% (1 centre) visits 6-9 children.

We got 0% answers for the remaining answers (10-15 children visited per month; 16-20 children visited per month; 21 children or more visited per month).

Related to this question, the ECI directors were asked what is the average number of monthly visits each child receives. We got the following responses:

- 25% (one centre) of the centres visit each child 1-2 times per month;
- 25% (one centre) of the centres visit each child 3-4 times per month;
- 25% (one centre) of the centres visit each child 5-6 times per month;
- 25% (one centre) of the centres visit each child 7 or more times per month;

In programmes providing home visits, the usual caseload of children is 5 or fewer, and only one centre visits 6-9 children. Generally speaking, the norm or standard case-load for home visitations is around 15-20 children per month, so we are generally underserving children using this model. A caseload of over 25 children is difficult to manage. These low caseloads may be due to issues of transportation, distance or requests that they also perform other types of services.

A large range of numbers of home visits per child was found: from 1 to over 7 home visits per month. Some children and their parents will be completing the programme and will only need one of two visits per month, while other children and families recently enrolled with major needs may require from 5 to 8 visits or even more per month. Home visits may be exhausting, particularly in rural areas because of the time it takes to travel from one family setting to the next.

4.8.3 Centre-based services

Regarding centre-based services, the ECI directors survey provided the following responses:

- 90% (37) of the service providers provide centre-based services;
- 10% (4) of the service providers do not provide centre based services.

Out of these 37 centres (90%) that provide centre-based services:

- 68% of service providers provide centre-based services as main services for over 70% of the children they serve;
- 27% service providers provide centre-based services as main services for at least 40% of the children they serve; and
- 5% service providers provide centre-based services as main services for at least 10% of the children they serve.

The percentage clearly states that largest part of ECI centres provides centre-based services for more than 70% of the children they serve.

The average number of children served by each ECI professional each day is:

- 1-2 children in 8% of the centres;
- 3-4 children in 32% of the centres;
- 5-6 children in 30% of the cases;
- 7 or more in 30% of the cases.

The research shows that professionals that provide centre-based services to a large number of children per-day. Very rarely the number is between 1 and 2 children per day, and they usually serve more than 3 children per day.

Regarding the case-load or average number of children served by each professional per month: 3% professionals serve 3 children or less; 14% of professionals serve 6-9 children; 36% serve 10-15 children; 8% serve 16-20 children; and 39% serve 21 children or more. Again we can see that ECI professionals that provide centre-based services have a very big case-load unlike the home-based services where they serve a significantly lower number of children. This is a question of programme design. Usually home visiting programmes should have 1) higher caseloads, and 2) more visits per child in the caseloads but again, it depends upon the design of the programme.

Regarding how many centre sessions each child/family receives each month, 67% of ECI directors stated that they give 7 or more sessions to each child each month; 11% provide 5-6 sessions each month; 11% give 3-4 sessions; and also 11% give 1-2 sessions per month, per child.

Again, we did two cross tabulations in order to see the percentage of center-based services in different types of ECI centers. As seen from 16 below, all three types of organizations provide center-based services, with the NGOs being the ones that provide the most center-based service (35%). Very few of the institutions reported that they do not give center-based services. This corresponds with the data above (only 4 centers provide home-based services).

Regarding the types of services provided, we got the following responses (shown below on figure 17). What is interesting here is that even the family-centred services offer center-based services in 12% of the cases. This is probably due to the fact that they provide home-based services for children from birth to three, and center-based services for children from 3-6 years old. The largest percentage of center-based services (51%) is given by the child-centered services.

Figure 16: Provision of centre-based services by different types of ECI centres

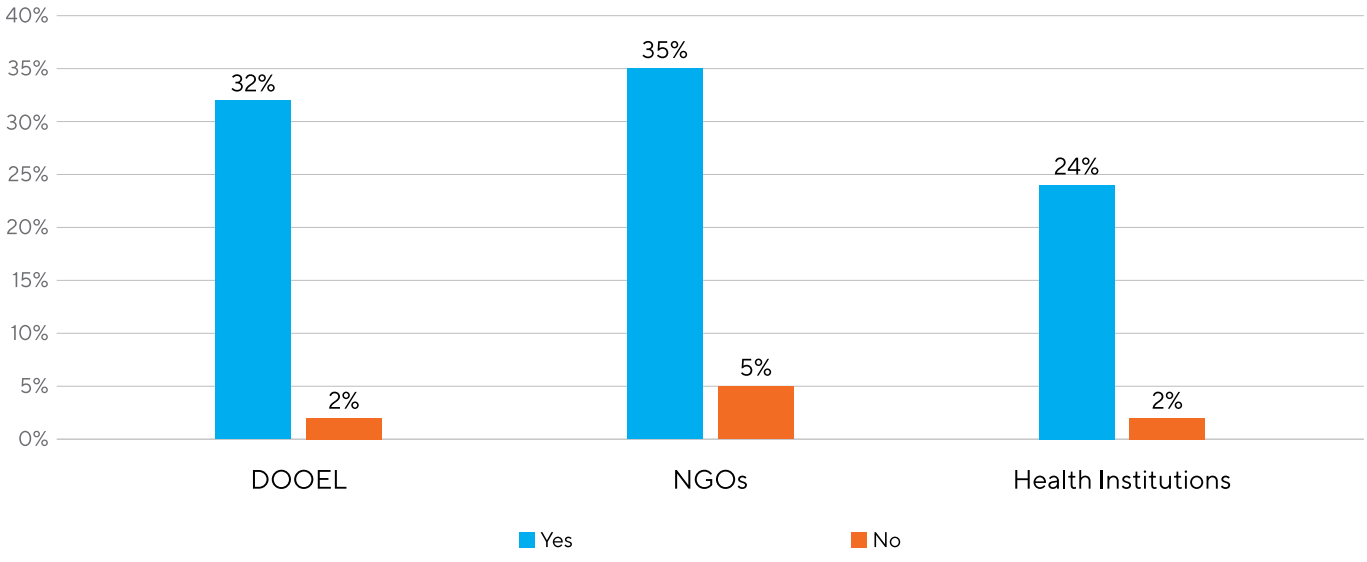
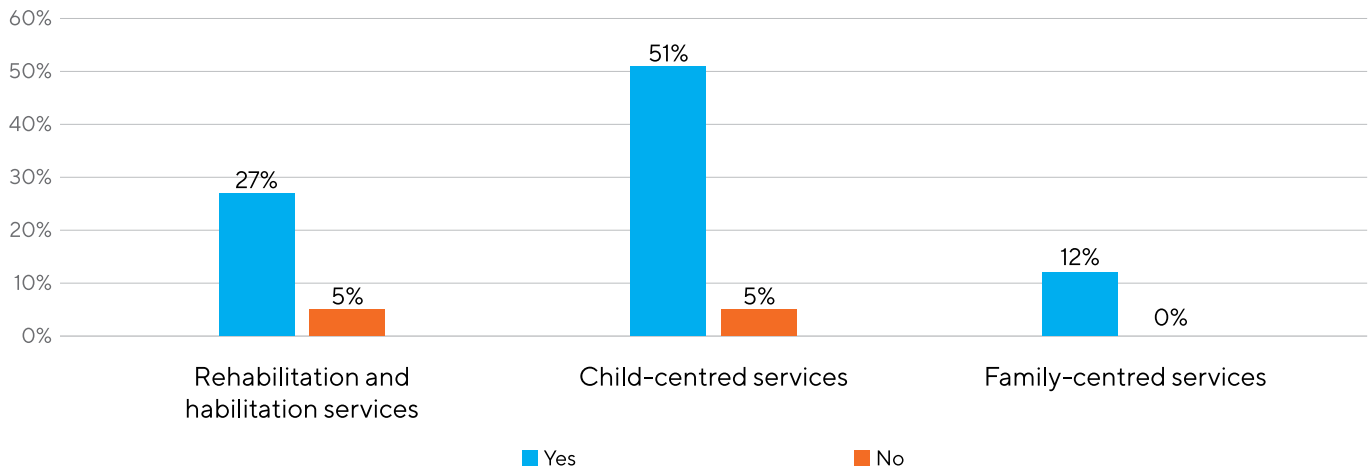


Figure 17: Provision of centre-based services by centres that provide different types of services



4.8.4 *Duration of visits of ECI personnel in home-based and centre-based settings*

ECI personnel was asked how long are the usual visits with children and families. Their responses were that they usually serve children with the following length of time:

- 31% serve children and families for 30 minutes per visit;
- 13% serve children and families 45 minutes per visit;
- 53% serve children and families more than one hour;
- 1 % serve children and families more than 2 hours;
- 1 % serve children and families more than 3 hours;
- 1 % serve children and families more than 4 hours;
- 0 % serve children and families 5 hours and more.

The statistics clearly shows that ECI professionals usually serve children and families (in home-based or center-based settings) from half an hour to one hour maximum.

The ECI parents focus group stated that ECI services are provided only at the centers. "In terms of frequency it is 2 to 5 times a week for a period of 40 minutes to 1 hour." – ECI beneficiary

ECI focus groups personnel stated similar responses - 40-45 minutes, 2-3 times per week. Of course this varies, it depends on the delays/disabilities, the financial means of the families for the private centres and the availability of the state centers for provision of services.

4.8.5 *Online services*

The COVID-19 pandemic conditioned provision of online ECI services. Some of the ECI centres quickly shifted to the new reality and started with online treatments. Of the 42 directors that responded the survey 31% said their centres provided online services (sometimes called tele-visits) while 69% did not provide such services. The average number of children served daily by a tele-visitor is given below (out of 13 ECI directors that provided this service):

- 69% (9 centres) served 1-2 children per day;
- 15% (2 centres) served 3-4 children per day;
- 8% (1 centre) served 5-6 children per day;
- 0% (0 centres) served 7-8 children per day; and
- 8% (1 centre) served 9-10 children or more per day.

The largest percentage of professionals gave online services to one or two children per day, but what is interesting is that one centre – 8% of the total number of centres (and the professionals that work there) managed to provide online service for 9-10 children and more.

69% of the ECI directors stated that the average number of children or the case-load of each tele-visitor per month was five or fewer. 23% ECI directors stated that a tele-visitor has a case-load of 6-9 children per month. One ECI director mentioned that the case-load of a tele-visitor is 26 children or more. This centre is the one mentioned above, that also serves 9-10 children or more per day.

Usually each parent and child receive 5-6 tele-visits every month (38% of ECI directors). 31% of ECI directors (4 centres) provide 1-2 tele-visits every month and also 31% of ECI directors (4 centres) provide 3-4 tele-visits every month.

The focus group of ECI beneficiaries had only one mother that received online support during the COVID-19 crisis. *"During the pandemic situations all the centers were closed for a long time. We received online support during that period."* – ECI beneficiary

After the COVID-19 pandemic, many of the centres continued to provide online service but used hybrid model, where they worked online but also on the field. 24% of the ECI directors (9 centres) stated that they have started to use this blended model while 76% (29 centres) are not using it and are not providing online services at all. Out of the nine centres that provide blended services:

- 78% provide a blend of tele-visits and centre-based visits;
- 11% provide a blend of tele-visits and home visits; and
- 11% provide a blend of tele-visits, home visits and centre-based visits.

From all of this data it can be seen that home-based services are not very common yet. This may be due to transportation issues or to a need to provide more training on home visiting methods. Considerable attention should be given to maximising the performance, productivity and impact of ECI services provided in both the natural environments of the child and in services that are partially or fully centre-based. Attention should also be given to offering training in effective methods for providing home visiting services, routines-based interventions, and online tele-visiting services as well as hybrid approaches.

4.8.6 Family participation during both home and centre-based visits

The participation of the families in the early childhood intervention of their children during provision of services is essential. All contemporary ECI programs are based on the premise that the ECI professionals should work with the child and parent/caregiver jointly. Furthermore, when it comes to children from birth to three, the ECI professionals (within the transdisciplinary model) should coach the parents on how to conduct activities that will enhance the child's development. ECI professionals work with both the parent and the child using multiple strategies.

The ECI directors stated that the service providers work directly only with the child in 34% of the cases. They work with the child while the parent observes the visit in 14% of the cases. And the ECI directors stated that the service providers work with the child and the parent together and coach and support the parents in 52% of the cases.

However, the ECI beneficiaries survey showed the following results:

- During home visits, parents participate 15% in all visits, 30% in some visits and 55% in few to no visits;
- During centre visits, parents participate 22% in all visits, 25% in some visits and 51% in few to no visits.

It can be seen here that parents are slightly more included in centre-based services than in home-based services. Nevertheless, a large percentage of parents are not included in the provision of services, regardless if they are given at home or at a centre. The goal of the home-based intervention is not only to relocate the service from the centre to the home. The entire philosophy of family-centred home-based services is to include the parent 100% in the services and to provide the service in natural environments for the child, not just the home.

Greater attention should be given to finding ways to fully include and engage parents and/or regular caregivers in all or most sessions with their children in centre-based services as well as in home visits and other natural environments of the child. To accomplish this goal, additional demonstration, practice and guided field training will be needed for all ECI personnel, complemented by coaching, mentoring and reflective supervision.

4.8.7 Frequency of services as reported by parents

In order to see the frequency of services as reported by parent we got the following answers from the ECI beneficiaries related to the question – how many times a month do they and their child receive services with activities for ECI:

- 3% of parents said that they receive services once a month;
- 2% stated that they receive services once in two weeks;
- 14% stated that they receive services once a week;
- 51% stated that they receive service twice a week; and
- 29% mentioned that they receive ECI services three or more time per week.

We can state that children predominantly receive services twice per week. A large number of parents (29%) also reported that they get ECI service three or more times per week. This is the general picture for ECI services in North Macedonia.

ECI services are usually offered and are provided with a higher frequency after the child is first assessed and deemed eligible for services. As the child's condition is improved, the frequency of services is decreased. Yet, the centre-based services lack flexibility. The home-based services and provision of services is flexible and allows for more children to be served and less frequently. This lies in the concept that highly trained professionals coach the parents on using routines-based and activity-based strategies with their children that enhance their development.

4.8.8 Services for parents and families

Case management is one of the important aspects of contemporary ECI services. In this study, only 5% of centres, mentioned that they provide case management. Only 3% of ECI personnel stated that they provide case management services. This is a devastatingly low percentage of efforts put into case management. Greater attention should be given to case coordination, along with improving inter-agency referral systems and expanding opportunities for parent support and counselling, and sessions for parents, peer groups and sibling support.

Regarding services that were offered to parents, from the ECI beneficiary survey we got the following results:

- In 37% parents were offered family support or counselling sessions;
- 31% referrals to other services;
- 9% parent education meetings;
- 6% peer group sessions with other parents in center;
- 17% were other recommendations (such as: no offer of other services [10% of the total answers]; recommendation to center for assistive technology; regular consultations with professionals regarding the realization of an IFSP).

Family activities appear to have been offered several ECI programmes. It is obvious that there is an increased awareness for the participation of parents in the ECI services. However, this participation should not be limited only to counselling sessions (which are very necessary) and parent education meetings. The parent participation is the bases of the contemporary model and more research and trainings should go into this area.

4.8.9 Programme transition or completion

Regarding the transition of the child to future services, the ECI directors stated that:

- 7% do not prepare a transition plan and the child is usually sent to a special school;
- 33% do not prepare a transition plan, but the children are increasingly sent into inclusive schools;
- 60% involve parents in the preparation of a transition plan and they work with teachers/ pedagogues to support the transition to an inclusive pre-primary or primary school.

The high-level interviews gave information that transition plans are rarely made. From the ECI personnel survey we got data that only 3% of the professionals make transition plans. But from the data given above (ECI directors), we can conclude that a certain number of centres prepare a transition plan. There is no template for how this plan should look like, nor any rule-book about the communication between the ECI centre and pre-primary or primary schools. Nevertheless, ECI professionals and centres make efforts to do a smooth transition into future services for the child. This transition and its preconditions, however, need to be more structured.

Programme transition is one of the core issues in contemporary ECI services. Some children will enhance their development and will end with the provision of services when the ECI service end. Others will have to transition to other services. In order to enable successful transition of children from ECI services to pre-primary or primary inclusive service a transition plan needs to be made. In North Macedonia usually there are individual consultations between the service providers and the kindergartens or schools. However, more serious, transition planning based on certain protocols need to be established within the ECI system in North Macedonia.

4.9 ECI Programme Personnel, Professional Development and Quality Assurance

4.9.1 Numbers of paid personnel, paraprofessionals and volunteers

ECI services are traditionally provided by certified ECI staff, that is consisted of special educators and rehabilitators, speech and language therapists, occupational therapists, physiotherapists, psychologists, social workers, family therapists and others. However, evidence-based practices from other countries such as the US, show that paraprofessionals, which are well trained and continuously supervised, monitored and guided by the ECI professionals, can be effective members of the ECI team. Trained volunteers are also a valuable asset but they rarely provide direct services.

The 41 ECI directors that responded to this question stated that the total number of paid staff in these 41 centres is 571. The average number of employees per centre is 11. The number of employees ranges from 1 employed person (only two institutions) to 268. Only one centre has that number of employees and this is a health institution. The total number is likely not all ECI staff. One centre has 87 employees, one has 62 employees, one has 39 employees. All other centres range from 2-17 employees. Three centres stated that the number of paid staff is zero. For planning purposes, using the average of 11 members per programme, for 55 ECI programmes, there may be a total of approximately 605 ECI staff members in North Macedonia.

From 40 ECI centres (that responded to this question) 90% (36 centres) do not hire any paraprofessionals, while 10% (4 centres) hire paraprofessionals. From these 4 centres, regarding the type of centre it is, 3 are NGOs, 1 is DOOEL. Health institutions do not hire paraprofessionals. Regarding the types of services that they provide, from these four ECI centre that hire paraprofessionals, 1 is a rehabilitation and habilitation centre, 3 are child-centred service. No family-centred service hires paraprofessionals. From these four centres, two centres employ 2 paraprofessionals, 1 centre employs two paraprofessionals and one centre employs one paraprofessionals. Asked whether the ECI centre trains paraprofessionals, 57% stated that they train them while 43% stated that they do not train them. The only job description for paraprofessionals is that they assist professionals in their work. They do not assist with community outreach, make home visits, do activities with mothers and children under supervision and other roles that they might have. Paraprofessionals can be a vital part of the contemporary services, but their roles need to be defined and their competencies strengthened.

Out of 40 ECI directors, 15 directors (38%) stated that they have volunteers, while 25 directors (63%) stated that they do not have volunteers assisting in the ECI center. The number of volunteers ranges from 1-10. Five centers reported that they have 1 volunteer and only one center stated that it has 10 volunteers. In one center, the volunteer is a parent, in another center 25% of the volunteers are parents. In the remaining centers none of the volunteers are parents. We can state that a very low number of the volunteers are parents. Volunteers are usually special educators and rehabilitators or SLPs that still haven't finished their education. They usually assist the professionals and naturally learn and gather experience.

4.9.2 Professional roles

In Annex 5, the roles of professional staff members listed by 44 ECI programme directors are presented. Many rehabilitation roles continue; however, some experienced specialists have begun to learn and adopt some contemporary concepts and methodologies. This situation varies from centre to centre.

The Focus groups of personnel showed that ECI professionals are eager to learn new evidence-based practices and work on their professional development.

Leading roles presented in Annex 5 included:

- SLPs (30%);
- Psychologists (16%);
- Managers (centre directors) (12%);
- Special educators and rehabilitators (9%);
- Administrator (8%);
- Occupational therapists (5%);
- Early childhood development specialist (5%);
- Early intervention specialist (5%);
- Medical or health specialist (2%);
- In service trainer (1%);
- Physical therapist (1%);
- Social worker (1%);
- Child protection/human rights or disability specialist (1%);
- Case manager or family support manager.

In the Parents' Survey, parents were asked what types of specialists worked with them and their child. As shown in Table 23, parents reported a similar array of specialists, with a major emphasis on therapists.

Table 23: Types of specialists that work in ECI (according ECI beneficiaries)

Type of specialist	No. of mentions	% of mentions
Speech and language therapist / speech therapist	63	34
Special educator and rehabilitator	59	32
Early Childhood Intervention Specialist	15	8
Physiotherapist	13	7
Psychologist	9	5
Occupational therapist	6	3
Doctor	5	3
I'm not sure	4	2
Nurse	3	2
Social worker	1	1
Orthoptic / pleoptic therapist	1	1
Audiologist	1	1
None of the above	1	1
Total	181	110

Relatively few professionals were identified as early intervention specialists. Most were still labelled as specialised therapists or other professionals. For purposes of future programme growth, the option of training more early intervention specialists should be considered. Specialist post-graduate studies on the Department of Special Education and Rehabilitation should be developed and organized with the purpose to train more ECI specialists.

4.9.3 Professional development: pre-service training

Pre-services training for ECI in North Macedonia is received at a University level. On the undergraduate level, at the Department of Special Education and Rehabilitation, Faculty of Philosophy, Ss. Cyril and Methodius University, four courses in ECI are being offered to future special educators and rehabilitators (Early intervention and education for children with impaired hearing; impaired vision; motor disabilities and intellectual disabilities.) On the postgraduate level, several courses are offered within different modules. A course for early childhood intervention is offered at the Doctoral level. The course has the title Collaborative and Consultative Approaches in Early Intervention and it is a contemporary course.

On the Faculty in Tetovo where the lectures are in Albanian language, the have the same four ECI courses mentioned above as well as one additional course on the undergraduate level – Game-based early intervention and education.

Other professionals such as psychologists, social workers, family therapists get basic and limited knowledge regarding ECI during their undergraduate education. Specialised trainings (not university-based) are offered regarding specific therapies, procedures, and assessments but only some of these programmes teach ECI family-centred approaches.

Focus groups of ECI professionals noted that greater agreement is needed regarding essential elements of ECI services as well as a more holistic approach. They did not think that specialised post-graduate training in ECI should be obliged of all ECI professionals because it is expensive and additional problems might arise. Instead, they suggested increasing quotas and opening new departments in the Faculty of Education and Rehabilitation as well as recognizing degrees from abroad. They observed that more funds and time should also be given for in-service training.

The focus groups of personnel regarding pre-service training stated that:

- Acquired basic knowledge of ECI on an undergraduate or postgraduate level;
- All attended some trainings that were not comprehensive and certified;
- A specialization in ECI should be opened at the Faculty (not a master academic-level program but practical specialist studies).

During the focus groups it was consensual that regarding pre-service education, they had acquired a very basic knowledge of ECI and they need deeper knowledge. They also believe that there should be more courses related to working with and coaching parents. "*What we lacked at the beginning was a strategy for working with parents*" – ECI personnel. The focus group largely agreed that it is necessary to have a specialization at the Department of Special Education and Rehabilitation. They underlined that, if this specialization is organized it needs to be recognized by the state system which basically implies that a specialization should be a precondition (for employment) for all professionals that work in ECI. The participants also reported that they had a lot of practice on an undergraduate level,

and that the emphasis of the pre-service training is more on the education part than on the medical part.

The high-level interviews gave a significant insight in the pre-services training for other professionals besides special educators and speech therapists. They stated that there is no pre-service training for ECI for pedagogues, social workers and psychologists. A positive aspect is that the students enrolled on the Medical faculties are being educated about ICF. This leads to an opportunity for future family doctors to be one of the professionals that will be doing the initial screening, identification and referral).

Other suggestions were that the pre-service studies should be more oriented towards contemporary approaches. – *"Update the University curricula in ECI (not just spec ed, but also speech therapists, pedagogues, psychologists, social workers, physiotherapists, family therapists).* – Academic leader in ECI.

Additionally, field training, coaching and mentoring could be done at both undergraduate and graduate levels. Also at graduate levels, ECI planners, M&E specialists, programme directors/managers can be trained and very importantly, kindly and supportive supervisors.

4.9.4 *Professional development: current and preferred in-service training*

Regarding in-service trainings for ECI personnel, 30 ECI directors (73%) stated that they offer in-service training in their centres. Regarding the types of in-service trainings, they are given on the table 24 below. The in-service training is mostly oriented towards opportunities to attend professional conferences, professional training workshops and online education or training courses.

Table 24: Types of in-service training for ECI personnel (according to ECI directors)

In-service training for ECI personnel	No. of mentions	% of mentions
Opportunities to attend professional conferences	25	17
Professional training workshops	25	17
Online education or training courses	24	17
Continuous on-site in-service training activities	21	15
Face-to-face training courses	17	12
Online and face-to-face education or training courses	9	6
On-site field training	8	6
Inter-centre exchange visits	8	6
Formal educational programmes at universities	7	5
Total:	144	100

The follow up question for the ECI directors was related to the type of training that they would most like to provide for the ECI personnel. From this data (given below on table 25) we can notice that they would like to conduct more inter-centre exchange visits but still believe that professional conferences and professional training workshops are the best manner of conducting in-service trainings. Inter-site exchanges of personnel among ECI programmes have been shown to be a highly effective way of disseminating innovations rapidly, and this approach might be given more attention in the future.

Table 24: Type of desired in-service training for ECI personnel (according to ECI directors)

Desired in-service training for ECI personnel	No. of mentions	% of mentions
Professional training workshops	33	18
Opportunities to attend professional conferences	29	16
Inter-centre exchange visits	24	13
Continuous on-site in-service training activities	22	12
Formal educational programmes at universities	20	11
Face-to-face training courses	19	10
On-site field training	18	10
Online education or training courses	14	8
Online and face-to-face education or training courses	7	4
Total:	186	100

Table 25: Types of desired in-service training by the ECI personnel

Desired in-service training by ECI personnel	No. of mentions	%
Professional training workshops	55	18
Face-to-face education or training courses	53	17
Continuous on-site in-service training activities	41	13
Opportunities to attend professional conferences	38	13
Inter-centre exchange visits	36	12
On-site field training	33	11
Online education or training courses	25	8
Formal educational centres at universities	23	8
Total	304	100

The ECI personnel (73 persons responded to this question) stated that annually they receive:

- No in-service training in 14% of the cases;
- Less than 10 hours in 19% of the cases;
- 11-20 hours in 33% of the cases;
- 21-40 hours in 12% of the cases;
- More than 4 hours in 22% of the cases.

It can be seen from the data here, that the hours of training are notably low. There should be provisions of a higher number of hours for professional development of employed ECI personnel.

ECI personnel usually attend professional conferences (24%); online education courses (23%); professional training workshops (18%); face-to-face training courses (13%); inter-centre exchange visits (9%); on site trainings (8%); continuous on-site in-service training activities (4%) and formal education at universities (2%). Being asked about the type of training they would like to receive, there was an increase on the demand of continuous on-site in-service training activities. They would also prefer professional training workshops over professional conferences. Their responses were the following:

The focus groups of ECI professionals stated they that feel the need for training, but unfortunately do not have the funds to attend them. Also, the courses that they do attend are usually introductory courses. *"It is all Introduction (i.e. Introduction to primitive reflexes, Introduction to art therapy, Introduction to music therapy, etc.). We need complete licensed trainings, and it is too expensive for us."* – ECI personnel

The high-level interviews showed that there is no in-service training for paraprofessionals (they are not yet part of the ECI potential system) and there are very few volunteers in centres. They stated that there is a very large need for training modules (theoretical and practical). One aspect of ECI mentioned in the high-level interviews was the Intervention that is provided from 3 - 6 years of age. The interviewees suggested that this age group should be separated from the birth-to-three group, and services should be provided in kindergartens. *"International organizations can provide in-service trainings in kindergartens for children on the age from 3-6."* – Government representative.

Field training should also be emphasised in formal education at universities and it generally is. The departments of special education and rehabilitation have always been one of the most outstanding departments when it comes to practical work. This is quite logical, having in mind that special education and rehabilitation is a practical discipline.

Continuous on-site in-service training combined with mentoring and coaching is one of the most highly effective forms of in-service training and should be given more consideration, along with inter-site exchange visits, which have been shown to be highly effective in improving programme quality.

4.9.5 Quality assurance of ECI programmes

With regard to quality assurance, 37 ECI directors assessed their own services according to the parameters presented in table 26.

Table 26: Activities for quality assurance in ECI centres

Quality assurance activities	No. of mentions	% of mentions
All ECI personnel meets pre-service training and certification/licensing requirements	16	30
All ECI service personnel receives some in-service training	10	19
Children's files are reviewed weekly to ensure they are complete and up to date	10	19
Service personnel meet each week to discuss their services for children they support together	6	11
All ECI services are based on research results	5	9
At least each two weeks, a supervisor supports all service staff members	2	4
All service personnel prepare visit reports on each visit	2	4
Before each home or centre-based visit, all personnel prepare visit plans for each child and family	0	0
Other	2	4
Total	53	100

Other:
All professionals are supervised monthly by the director of the center, and daily expert opinions and mutual support and cooperation between the professionals in the team are exchanged.
the staff receives on-the-job training and works under the supervision of the manager. For the work, everyone keeps records of the number and quality of the provided service and prepares monthly reports. Once a week, and if necessary more, a meeting is held with the whole team and everyone is familiar with the current situation of the users, the challenges and jointly plans the next steps. The children's files are also reviewed and revised after each session. Additionally, after each service, a form for a given service is filled out.

30% of the ECI directors stated that all ECI personnel meet pre-service training and certification requirements. However, this low percentage is due to the manner this question is posed. All ECI professionals, in order to work in ECI, must hold a University degree. However, we do not have licencing of ECI professionals (beside the medical professionals and psychologists). That is why only 30% of all ECI staff meets this requirement. Currently a law for special education and rehabilitation is being made. With it, a Chamber of Special Educators and Rehabilitators will be created. This Chamber will provide licencing and certification which will help to lead to quality assurance. Naturally, more than licencing is needed to achieve quality assurance.

Further on, 19% of the ECI personnel received some in-service training. Only 19% of the ECI directors stated that the children's files are being reviewed weekly. This is a very low percentage for an activity that is the basis of contemporary ECI programs. Contemporary ECI methods emphasise the frequent review of children's files, planning and reporting on home visits and continuous supervision. A low percentage (11%) of service personnel meets weekly to discuss services. This is due to the manner of provision of services. ECI services in North Macedonia are still being provided largely in legacy and child-centred services, and the percentage of interdisciplinary teams, or for that matter transdisciplinary teams is on a very low level. Professionals, as stated in the chapters above still provide individual services with no consultations with their peers.

In only 9% ECI centres, services are based on research results. Although there has been a call for the use of evidence-based methods in the provision of ECI services we can see that there is a considerably low percentage of ECI centers that use such methods. This is also due to the problem with provision of trainings for these methods, that seek additional funding by the ECI directors. It can also be due to the lack of action

research in the ECI facilities, as well as lack of research related to evidence-based practices on a state level.

Only two centers mentioned that they have a supervisor that supports all staff members and they prepare visit reports for each visit. Unfortunately, one of the weakest links of the Macedonian ECI system is the monitoring and evaluation of the provision of services. State institutions do not have supervision of their work, while these two private centers hired supervisors to support their staff members.

The ECI directors made two additional mentions (one each), that didn't correspond with the responses given above:

- The ECI director supervises the staff monthly;
- The staff provides monthly reports.

From focus groups held with ECI professionals, many causes were identified for the low level of quality assurance such as: lack of timely and accurate assessments of children and the unavailability of quality ECI services, appropriate specialists, working spaces, and funding. They also noted misunderstandings about ECI concepts and methods among professionals and sectors.

The high-level interviewees suggested that we need to create ECI standards, and then an ECI system can be established. "*We need to create an institution on a national level, that will operate as an umbrella organization. With this we will enable the same quality in the approach, same quality and standards. Just like the Center for ICF assessment. Centers like this can be opened in every major city*". – Government officials.

4.9.6 Salary scales, certification and career ladders

Quality is measured also by salary scales, certification and career ladders. Out of 41 ECI directors, 49% (20 centers) have a salary scale for ECI personnel, while 51% do not have a salary scale. The health institutions have the lowest percentage (10%) for the use of salary scales. A cross tabulation of salary scales and types of services revealed that: the child-centers services have the highest percentage of use of salary scales (29%) and family-centred services had the lowest use (5%). Regarding types of centers, the cross tabulation showed that NGOs (8 of them) have the highest percentage of use of salary scales (21%). DOOELS use salary scales in 15% (6 centers) and health institutions in 10% (4 centers).

Regarding certification, 68% require their ECI personnel to have professional certificates, while 32% do not. Discussing career ladders, ECI directors stated that they use career ladders in 54% of the cases (22 centers). A cross tabulation which are the types of centers that have career ladders revealed that: DOOELs and NGOs responded that they use career ladders in a larger percentage (20,5% each). Analyzing career ladder according to the type of service the centers provide we concluded that child-centred services have the largest percentage of use of career ladders (32%) opposite to 10% in family-centred services and 12% in rehabilitation and habilitation services. The focus group of ECI personnel mentioned that some of them submit their career development plans to the institution where they work, but the institution rarely allocates funds for that. This focus group made the following statements:

- No ECI certified program
- There is no career ladder
- There is no salary scale
- There is a need for national criteria for registration for ECI service providers.

So, as mentioned in the chapters above, the designation of a particular identifier will enable identical registration of ECI services. The newly-formed Chamber of Special Educators and Rehabilitators may give guidelines on licensing. The combination of these two outcomes will lead to standards in ECI that will enable the creation of career ladders and salary scales.

Another and/or complementary approach might be for the ECI system to establish these rules using the ECI Guidelines and Procedures, and furthermore, based on the guidelines, establish service and personnel standards. Career ladders could be established and then salary scales could be established and revised as the economy and the professions evolve.

4.9.7 Supervision

The ECI directors also shared information regarding supervision of provision of ECI services and the work of ECI personnel. Out of 41 directors 19 (46%) answered that they do have an ECI staff member that supervises other ECI staff members. Regarding the types of supervision, we got the following responses (shown on table 27). The largest number of mentions is related to the review of child and family files – 22% of ECI directors use that as a supervision measure; 20% use mentoring; 20% use in-service training; 17% use coaching; 14% observe provision of services; 8% give reflective supervision. There were zero mentions of supervision through observation of home visits.

Table 27: Types of supervision (according ECI Directors)

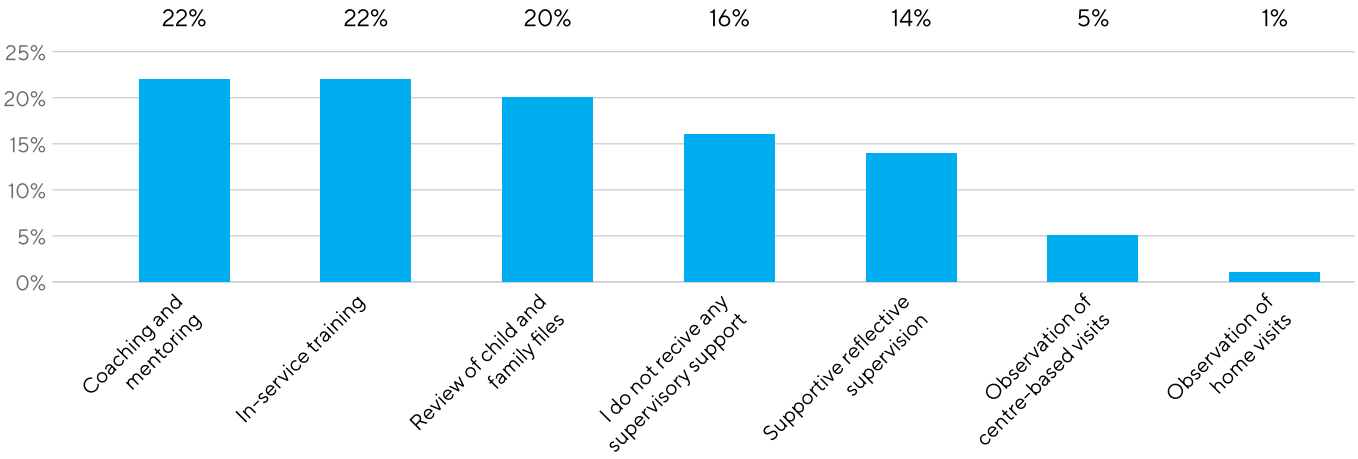
Supervision in ECI centres	No. of mentions	%
Review of child and family files	14	22
Mentoring	13	20
In-service training	13	20
Coaching	11	17
Observation of centre-based visits	9	14
Reflective supervision	5	8
Observation of home visits	0	0
Total	65	100

Another important aspect of supervision is the external supervision, such as supervision from government or other offices. Only 10% (4 centers) have external supervision. They were all NGOs. These four ECI centers stated where the external supervisors work. The following were providing external supervision:

- Health facilities;
- University of the Republic of Albania, EMI Italy;
- Anima Center for Personal Growth and Development;
- Ministry of Labor and Social Policy.

The ECI personnel was also surveyed regarding the type of supervision and professional support they receive. Figure 18 shows that they receive coaching and mentoring in the largest percentage (22%) as well as in-service training (22%). There was only one mention of observation of home visits, and only 7 mentions (5%) of observations of centre-based visits.

Figure 18: Type of supervision (according ECI personnel)



The focus groups of ECI personnel stated that:

- There is no supervision of the ECI programs;
- It is necessary to establish a national licensing body for ECI services (i.e. certification and recertification).

The representatives from the health institutions noted that the Ministry of Health, formally supervises their work. The participants from the private centers noted that no private center has any professional supervision unless they organize it themselves.

Participants pointed out that they lack external supervision of their work in the field of ECI services. One of the participants pointed out that they have a project for ECI that envisages supervision over their work, i.e. supervision by Italian experts. Some of the participants from state institutions stated that they had no official supervision of their work - *„Nobody asks us what we do*!" – ECI personnel

The essential contemporary supervisory roles of reflective supervision, visit observations, and coaching ranked low. Contemporary ECI programmes include trained and experienced supervisors at regional and central levels, and as possible, within each ECI programme. A graduate-level programme is needed to train leading early intervention specialists to become skilled supervisors.

4.10 Programme Guidelines, Procedures, Standards and Accountability

4.10.1 ECI Programme Guidelines, Procedures and Standards

To ensure high quality services are provided by all ECI programmes and that families are able to secure the same types of ECI services in all regions, national regulations in the form of ECI Programme Guidelines and Procedures and Service and Personnel Standards are required. These types of documents had not yet been prepared and officially established in North Macedonia.

The focus groups of ECI personnel and high-level interviews noted that there are some basic guidelines in the Law for health protection, under the term preventive services but in general there are no national policies, strategic plans, laws, regulations or guidelines in any sector (health, social protection, education or on a municipality level) regarding ECI services.

"We as an assembly (parliament) have never opened this subject." – Parliament members

"There is no plan, no strategy, no inter-sectorial cooperation and no established monitoring." – International organization representative.

The National body for implementation of the CRPD is preparing a disability strategy (with the participation of all Ministries) within which ECI will take an important part. The development of ECI Programme Guidelines and Procedures, and subsequently service and personnel standards based on those regulations will be essential to ensuring the good development of the National ECI System.

4.10.2 Programme accountability through monitoring and evaluation

One of the important aspects of any program, including ECI programs as well is the accountability of the program/center through monitoring and evaluation activities. The ECI directors in 61% stated that they do not have any internal monitoring and evaluation system in their centers. Out of 38 ECI directors, 15 (39%) have an internal monitoring and evaluation system. 10 (43%) of the ECI directors noted that they do have a document where they state their annual ECI objectives, indicators and targets for monitoring and evaluation. 57% (13 ECI directors) stated that they do not have such a document. Only one ECI director noted that they have a manual for ECI monitoring and evaluation. This manual has a time-table, copies of instruments used and a guide for the instruments. The manual does not have input, output and outcome indicators and indicator targets. Regarding external evaluation of the center, 3 directors (8%) stated that such evaluation has been conducted, while 35 (92%) stated that they haven't gotten an external evaluation.

At the moment, no system of accountability exists in North Macedonia. It is however surprising that 15 centres do have an internal mechanism for evaluation. The focus groups of ECI personnel stated that they would like to have technical support to develop manuals, instruments and other aspects. Government representatives also stated that they would like to have technical support for the development of indicators for monitoring, evaluation and so on. A national system of ECI monitoring and evaluation is greatly needed to assess programme inputs, outputs and outcomes. External longitudinal evaluations should be considered to study programme processes and service outcomes, for example with regard to child development, parenting skills and later inclusion in schools.

4.10.4 Administrative monitoring and evaluation

Countries with national systems of ECI services also design and implement nationwide systems of monitoring and evaluation. Unfortunately, at this point nothing can be said regarding administrative

monitoring and evaluation (both external or internal) simply because it is non-existent in North Macedonia. Municipalities have no roles in monitoring and evaluation of ECI services, private centres are not being monitored by anyone, health institution usually only have internal monitoring.

For future reference, administrative offices for ECI programmes should be set up, and they may be the ones that collect, analyse and issue statistics on ECI programme services. An inter-agency committee supporting ECI services should be set up in larger cities and/or municipalities. An effective national system of supervision, monitoring, evaluation and reporting for ECI programmes throughout North Macedonia should be set up as well.

4.11 Programme Networking and Intersectoral Coordination

4.11.1 Networking

Out of 38 ECI directors, only 3 (8%) stated that they participate in a coalition or network of ECI services. These three coalitions or networks were:

- FRI and other associations;
- EASPD – European Association (Network) of Service Providers; and
- Institute for Rehabilitation of Hearing, Speech and Voice in Skopje.

One of this networks helps the ECI centre to provide services in rural and remote communities; another helps provision of services to Roma communities and one helps with the provision of services of other communities that are underserved. Two of the networks help with serving families that request ECI services.

The number of ECI centers that participate in any types of networks is disappointing. ECI centers need to be more included in different national and international networks in order to exchange experiences, learn about evidence-based practices, learn about novelties in the ECI area. The only body that serves as some type of network is the National Body for implementation of the CRPD. ECI is briefly discussed within their meetings.

ECI professionals stated the importance of networking for ECI between national institutions starting from the gynecology clinics and finishing with the kindergartens. Currently they network (between centers) on a private basis and personal contacts.

Another issue in North Macedonia is that there is no coalition or network of ECI organizations. 80% of the ECI centers expressed their interest in joining such a coalition or network while 20% stated that they wouldn't want to be a part of a coalition/network. All participants in the high-level interviews also expressed their interest in the creation and participation in a ECI coalition/network.

4.11.2 Intersectoral Coordination

Regarding intersectoral coordination we got the following responses. Some 35 ECI directors stated that:

- 26% of the centres coordinate with health centres and hospitals;
- 24% with inclusive primary schools;
- 19% with inclusive pre-primary schools;
- 15% with nurseries/childcare centres;
- 11% with social welfare centres;
- 11% with community centres;
- 1% with neonatal intensive care units

To support children and families well, ECI programmes must coordinate closely with other social service providers in their communities and regions. The coordination with preschools and primary schools is essential so that the services are coordinated and transitions planned. There seems to be high coordination with the health centres, which is natural, having in mind that they are full partners in the provision of ECI centres.

A positive example in North Macedonia is the coordination between the health, social welfare and education sector when it comes to the creation and organization of work of the ICF centre (centres for ICF assessments). All three ministries have backed-up and supported this centre. This positive example of cooperation and coordination can be applicable in the provision of ECI services and the establishment of the ECI system in North Macedonia as well.

4.12 Sub-Study on Costs and Finance

The objectives of this Sub-Study are 1) to describe existing funding sources to support services for children with at-risk situations, developmental delays, disabilities, behavioral disorders and mental health needs aged 0-6 years of age, 2) to establish a baseline by calculating the unit costs of different types of service providers, and 3) to provide recommendations for improving and developing funding mechanisms in order to establish a comprehensive national ECI system as soon as possible. Results of the survey of directors of centres serving ECI children and of parent focus groups conducted for the Situation Analysis were used to provide important insights for specific findings of this sub-study on costs and finance. The local consultant interviewed representatives from the Ministry of Health, the Health Insurance Fund, the Ministry of Labour and Social Policy, and the Ministry of Education by telephone and email. Prior to the interviews, ECI funding questionnaires were distributed to these institutions.

Based on the results of the Mapping Survey, five ECI service providers (centres) were selected. These centres included public and private providers located in the country's capital and in other municipalities, including those where national minorities predominate in the population. The directors and financial managers of the five centres were asked to complete the questionnaire on costs and expenditures, and subsequently they were interviewed by telephone and email. Desk research was conducted on recent economic developments and reforms in North Macedonia and on local development through the website of the Association of Units of Local Self-government. Country reports from the World Bank, World Health Organisation, European Commission, OECD and European Union Commission, as well as brief information from various think tanks such as Brookings, were also examined. The international consultant on costs and financing analysed the information and data collected and provided the findings and final recommendations.

4.12.1 Sources of funding

Adequate funding for service providers is critical to ensure the quality, sustainability and affordability of services meet essential needs of ECI children. The directors' surveys and high-level interviews, among other tools, included questions on the funding sources of 44 service providers.

Table 28: Source of funding – according to ECI Directors survey

Types of funding sources	Major funding source	Minor funding source	Not a funding source	Total number of responding centres	% of responding institutions for whom it is major and/or minor source
National governmental funding					
Ministry of Health	8	1	16	25	36
National Health Insurance Fund	1	1	15	17	12
Ministry of Finance	0	1	15	16	6
Ministry of Labour and Social Policy	0	0	15	15	0
Ministry of Education	0	0	15	15	0
Local self-government funding					
Other municipal/city government	3	5	13	21	38
City of Skopje	0	1	14	15	7
Insurances, vouchers and taxes					
Vouchers for programme or for parents to give to their programme	0	0	15	15	0
Special taxes for ECI services	0	0	15	15	0

Types of funding sources	Major funding source	Minor funding source	Not a funding source	Total number of responding centres	% of responding institutions for whom it is major and/or minor source
National civil society funding					
Faith-based organisations	1	0	15	16	6
Non-governmental organisations	0	4	14	18	22
Other national sources	0	1	14	15	7
Community-based organisations	0	0	15	15	0
Private funding sources					
National foundations	0	0	15	15	0
Corporation or business donors	0	8	11	19	42
Private benefactors/groups	0	7	12	19	37
Fees					
Parent payment of fees	21	4	1	26	96
Membership fees	2	6	12	20	40
National fundraising activities					
Fundraising activities conducted by your organisation	0	5	12	17	29
European regional organisation					
European Union/Commission	1	0	15	16	6
European Agency for Development/Special Needs	0	0	15	15	0
European Fund for Social Development	0	0	15	15	0
European Structural Fund	0	0	15	15	0
International organisations					
UNICEF	1	1	14	15	13
International foundations (Pestalozzi Children's Foundation)	1	0	14	15	7
World Bank	0	0	15	15	0
Bilateral agency (USAID, DfID, etc.)	0	0	15	15	0
Agency for persons with disabilities	0	0	15	15	0
Answered				38	
Skipped				6	

According to information given by the representatives of the ministries and other relevant institutions related to ECI services, it was evident that there are two main ways of financing the provision of ECI services in North Macedonia, depending on the type of ECI centres (whether they are public state or private for profit or non-governmental centres/associations).

As shown in Table 28, parental contributions are the main source of funding for ECI services, while the Ministry of Health and local governments are the second and third largest investors. Some 96% of the directors who responded to the survey cited parental contributions as the main source of funding for their facilities. UNICEF and an international NGO, as well as faith-based organisations, were also cited as the main source of funding, but their share appears to be much smaller.

4.12.2 *Participation of the Central Government in ECI funding*

The Ministry of Labour and Social Policy does not provide funds for ECI benefits and is only involved in informing the health insurance fund of the recipients of social benefits who are exempt from paying for participation in health services, including those in the field of ECI in the public state centres. This Ministry provides a special allowance to the families of children with disabilities up to the age of 26. The amount of the special allowance for the year 2022 is MKD 5,365. The total number of recipients of such an allowance in 2020 was 6603 (State Statistics Office), and the current number of children up to the age of 6 is 550.

The Ministry of Education and Science is also not involved in ECI for children from birth to age 6, but there is a positive attitude towards future involvement. As the resource centres that provide staff to support pupils with disabilities in mainstream schools fall within their remit, the Ministry could use the same resource centres to provide ECI specialists to pre-schools and kindergartens.

The main source of funding for the public centres is the Ministry of Health, together with the Health Insurance Fund. The Ministry is responsible for making health policy, organising health services and enforcing health laws, and all policies must be coordinated with relevant ministries and agencies through regulated legal procedures. The HIF is responsible for purchasing services from public and private for profit and non-profit NGO providers on behalf of users. Relations between the HIF and the various providers at the primary, secondary and tertiary levels are governed by performance-based contracts that are negotiated and signed for a predetermined period.

The North Macedonia health system provides a relatively comprehensive basic package of services, with about 90% of the population covered by social health insurance. Public spending on health care has declined in recent years and is among the lowest in Southeastern Europe. About 88% of the HIF's revenue comes from health insurance contributions from salaries, as well as contributions from the Labour Agency for the unemployed, the Ministry of Labour and Social Policy for insured persons with social entitlements, the Pension and Disability Fund for pensioners, and the Ministry of Health for uninsured persons. Transfers from the Ministry of Labour and Social Policy for maternity leave accounted for a further 8.3% of the HIF budget in 2019 (Ministry of Health data, 2021). Compared to some other Eastern European countries (e.g., Bulgaria, Czech Republic, Poland and Romania), transfers from the state budget to social health insurance are relatively low (WHO, 2021).

The Ministry of Health and Health Insurance Fund are interconnected and allow for the provision of ECI services, even if these services are not recognised as such in the system. This makes it difficult to determine the exact budget lines for the provision of ECI services. The Ministry of Health provides salaries for staff involved in ECI, including special educators and rehabilitators, speech and language therapists and psychologists. ECI services in the public sector are provided in general hospitals and some clinical centres, and the cost of care is covered for the entire medical facility. There are no exact costs for the units that provide ECI services.

The ECI services in the public sector for children of parents insured in the Health Insurance Fund are free of charge or, in some cases, the parents contribute, but not more than 20% of the average amount of the total cost of the health service. This provision is regulated by the Law on Health Insurance. The amount of participation is determined by the HIF through a general legal act approved by the Minister of Health. After referral by the pediatrician, the child is entitled to a certain package for basic health care, according to need.

There is a heavy reliance on out-of-pocket (OOP) payments. Out-of-pocket (OOP) expenditures on health accounted for 42% of health expenditures in 2018, well above the average for SEE (33%) and EU countries (22%). This creates problems in accessing health services, especially for low-income households. Catastrophic health expenditures remain a problem, especially for poorer households, and is largely caused by out-of-pocket payments for outpatient medicines. Unmet needs for health care for financial reasons has declined over the last decade, but remains relatively high among low-income people. The financing model that exists in the country's health care system also affects ECI services, which are based on the health care delivery model.

For the private providers, parental contributions are the main source of funding. Prices vary depending on the services the centre offers and the location in the country. The private providers are for-profit ones established by a single person or multiple legal persons. Considering that 33 of the 44 centres covered by the Director's survey are private, the private sector predominates in ECI services. According to the parent survey, parents must apply to private providers because of the long waiting lists for public services. The average net salary since January 2022 was MKD 29 980 (about EUR 490). According to the parent survey, 56% of respondents paid more than EUR 500 out of their own pocket in 2021, 25% between EUR 200 and EUR 500, 18% - up to EUR 200. A total of 21% of parents surveyed did not have the financial resources to cover the costs of ECI services (including transport to ECI services, fees they had to pay to private centres, and other costs).

Due to the increase in world prices for energy and food caused by the war in Ukraine and the increase in the minimum wage from March 2022, inflation in the country is expected to increase significantly. This in turn will have a negative impact on the income and savings of families. The prevalence of private providers and the increasing financial burden of families would increase the number of children who will not be able to receive adequate and timely services.

14.12.3 Participation of local self-governments in the financing of ECI Centres

Regions in North Macedonia are not administrative divisions but rather are used for statistical and analytical purposes. There are eight statistical regions in the country. Local self-government is represented by 83 municipalities. The Law of Self-Government sets up the competences of the municipalities. In social protection sphere they have the competence to perform the activities which include child-related activities among others; however, no activities related to children with disabilities, developmental delays or at-risk situations are mentioned there. The competences in health care are also mentioned in broader sense; however, assistance to patients with special needs and the targeted group of children is not mentioned.

The municipalities have funds for programmes in the field of child protection and health care, and they are financing activities for persons with disabilities like educational inclusion, vocational training, day care centres, but most of the time those funds are not intended for ECI, or the ECI service funding is intertwined with other services. Some of the ECI centres receive one-off funding from the municipalities and donations from other sources, but these funds were not provided on a regular basis.

In 2022, the City of Skopje funded 55 projects and project activities of associations and foundations in the field of social, child and health protection in the city of Skopje, of which 6 were related to ECI services. The amount spent on ECI centres is MKD 4,950,000 out of MKD 22,607,466 allocated for this purpose (or 22%). The total budget of the City of Skopje for 2022 is MKD 6,325,268,000 and given the amount spent, the percentage for ECI services is 0.07%. The data is relevant in that most of the ECI centres are in Skopje.

Local governments are generally aware of the problems and needs of vulnerable groups, but they are not considered in the budgets. Although the Law on Social Protection has strengthened the powers of social services as part of the decentralisation process (Table 8.7 in Chapter 8), municipalities in North Macedonia still do not have sufficient capacity to provide quality social services (European Commission, 2021 [1]). In March 2021, the Ministry of Finance launched a fiscal decentralisation reform to improve fiscal capacity and increase municipal revenues, strengthen fiscal discipline, and improve transparency and accountability. Even though this reform will significantly increase the municipalities' budgets over the next three years, it does not emphasise that more will be spent on social services or child and health protection, as all municipalities may decide for themselves.

4.12.4 Sources of funding for five centres serving ECI children

In-depth cost studies were conducted for five centres. In the Sub-Study, they are referred to as Centres from 1 to 5 due to confidentiality rules. The Centres selected for the Sub-Study are located in the capital city, in a smaller town, and in a municipality inhabited by national minorities. The Centres were selected according to the type of funding. There are 3 for-profit private organizations and 2 non-profit organisations (one is an NGO and another – a public clinical center). Four centres have ECI children alongside other beneficiaries, while one Centre provides comprehensive ECI services consisting of 100% ECI children.

Centre representatives provided information on the amounts they receive from various sources, as shown in Figure 19. As some funding sources were not available in each year and/or the amount allocated was not the same in each year, the charts show the proportion of funding received and spent by the Centres on ECI children during 2019 - 2021. Figure 20 represents the share of the different sources in the total funding.

Figure 19: Sources of funding

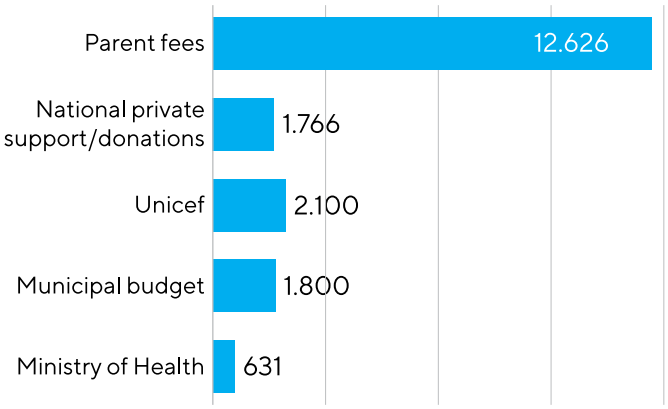
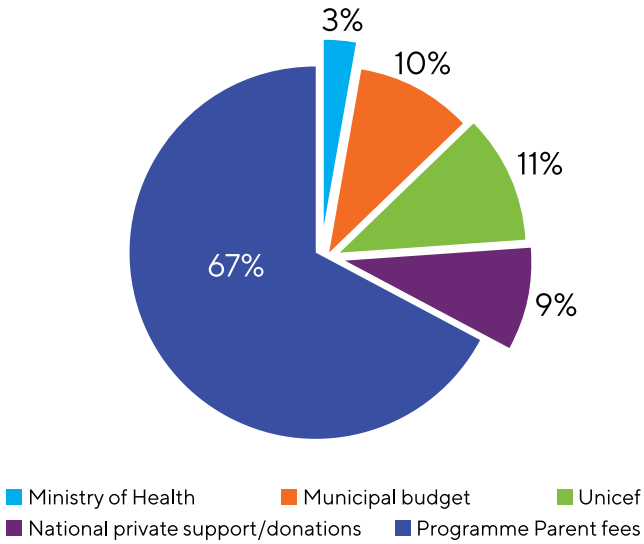


Figure 20: Share in total funding



Three centres were funded by parental contributions, their share of total funding was 67%. The Ministry of Health (HIF) funded three centres, but its share of total funding was only 10%. The amounts these centres received from the Ministry were the lowest in absolute terms. The municipal budget funded only one centre; its share was 3 %. UNICEF and private donations were the sources of funding for two centres.

Table 29: Amounts received by the Centres during 2019-2021 (MKD)

Name of the source of funding	Centre No1	Centre No 2	Centre No 3	Centre No 4	Centre No 5	Total with ECI children's share
Ministry of Health	362,637	0	0	217,131	51,459	631,227
Municipal budget	0	0	1,800,000	0	0	1,800,000
UNICEF	0	0	2,100,000	0	0	2,100,000
National private support/donations	0	1,765,633	0	0	0	1,765,633
Programme Parent fees	6,879,685	3,045,792	0	0	2,700,901	12,626,377
Total with ECI children's share	7,242,323	4,811,425	3,900,000	217,131	2,752,359	18,923,238

Short description of five ECI centres that participated in the Sub-Study

Centre No. 1

Established in 2015 in the capital, the centre provides ECI services for children up to 6 years of age, as well as for children over 6 years of age. All services provided by the centre are centre based. There are currently 91 service recipients, 55 of whom are part of the children receiving ECI services. The centre is fully financed by parental fees. Only during the COVID pandemic, the centre received funds from the Ministry of Health intended for business support. Part of these funds had to be returned. Beyond that, the centre has not received any in-kind contributions. According to the Centre director's opinion, they see the public-private partnership as a way to improve ECI services. Under this partnership, all ECI facilities should be certified and the state should provide a social package for the families of children with disabilities that can be accessed by any certified ECI facility, regardless of whether it is public or private. In this case, the financial burden on parents who now pay out of pocket for the private facilities will be reduced and the private facilities will receive a certain percentage of the funds earmarked for health insurance from the fund instead of from the parents.

Centre No. 2

This centre, established in 2019 in a smaller town in North Macedonia, also provides centre-based services only, including ECI. The total number of service recipients is 67, of which only 7 are older than 6 years. This means that staff spend 90% of their time providing ECI services. The centre employs special educators and rehabilitators, speech and language therapists, but also a nurse. This centre is a start-up company supported by the Innovation and Technological Development Fund. The grant they received was for the economic growth of the company. The support from the Fund was limited to one year, and currently the Centre is financed by parental fees. Last year, the director managed to open another branch of the Centre in the state capital. As the centre expands, more funds are needed for further development and professional equipment.

Centre No. 3

This NGO centre was established in 2019 by the UNICEF office in Skopje Municipality. It provides ECI family-centred services. Children from birth to 3 years old are visited at home and children from 4 to 6 years old visit the Centre to receive the services they need. Currently there are 15 beneficiaries. The number of beneficiaries depends on the staff currently deployed. In 2021, there were 40 children. Services are provided by special educators and rehabilitators, speech and language therapists, physiotherapists and psychologists as needed. It is expected that the number of teams will increase and with it the number of children. The children are cared for in the city of Skopje and in the surrounding villages. Initially, the funds for this centre were provided by UNICEF, but in the last two years all costs have been covered by the city of Skopje. According to Centre representatives, the Centre should secure a permanent source of funding so that better planning and more professional teams can be hired and more children can receive the services they need.

Centre No. 4

The centre has been operating for 8 years (since 2014) as a developmental counselling department within the health centre in a city other than Skopje. The team working there consists of a special educator and rehabilitator, a speech therapist and a psychologist. The services they provide are mainly in the field of ECI, as more than 80% of the children are up to 6 years old. All the funding the Centre receives is provided by the Ministry of Health and consists mainly of staff salaries. The Centre needs more funding, including additional training and working equipment. There are no parental fees at this Centre and parents do not pay for the services their children receive. They are referred to this centre by a paediatrician or a family doctor.

Centre No. 5

This centre was established in 2019 and it is in a municipality inhabited mainly by Albanians. The staff, composed of special educators and rehabilitators, speech therapists and psychologists, work 80% of their time at the ECI Centre. Services are provided exclusively at the Centre; home visits have not been carried out so far. The Centre is financed by the fees parents pay for the care of their children. No in-kind contributions or subsidies have been provided. Interview responses indicate that there is insufficient funding to improve the centre's accommodations and to renew working materials.

Composition of Cost of the Centres Participated in the Sub-Study

Table 30: The total number of beneficiaries, number of ECI children and their share

Number of Children	Center no 1	Center no 2	Center no 3	Center no 4	Center no 5
Total beneficiaries	61	67	15	61	34
Children from the target group	50	60	15	50	27
% share of total beneficiaries	60	89	100	82	79

All beneficiaries of Centre 3 are ECI children, the other four Centres include ECI children together with other beneficiaries. In these four Centres, the staff devote only part of their time to the children in the target group.

In the different Centers, the number of professionals per child varies. In the public Centers, salaries are set by the Ministry of Health, while the private Centers have professional salary scales, which can vary from Centre to Centre. The lowest salary of professionals was found in Centre 4. The Centre employs only three professionals (a speech therapist, a special needs teacher and a psychologist), each of whom devotes 80% of their time to ECI children (a total of 2,4 professionals when time spent is considered). At the same time, 3 professionals serve 50 ECI children. Thus, the number of professionals and the salary per child is lowest in Center 4

In the contemporary ECI Center there are 3 professionals. A supervisor devotes 10% of his/her time to the ECI children, a speech therapist and a special educator 100%, a physiotherapist and a psychologist 50%. The number of professionals per child is the highest. There are 4.1 professionals in total and 0.3 per child. Even though the salary per child is the highest compared to other Centers, each child in this Centre receives more professional support than in other Centers.

Table 31: Annual gross salary of professionals (MKD), Number of staff members according to their time devoted to the target group of children, number of staff per child and professionals' salaries per child

	Center 1	Center 2	Center 3	Center 4	Center 5
Salary of Professionals	4,754,400	3,110,400	2,402,400	852,480	2,073,600
Number of Professionals	5.0	8.1	4.1	2.4	5.6
Number of professionals per child	0.1	0.1	0.3	0.05	0.2
Salary of professionals per child	86,444	51,840	160,160	17,050	76,800

Table 30 shows the number of professionals considering the proportion of their time devoted to the target group of children. For example, if a professional spends 70% of her/his time with the target group of children, the proportion of time spent is 0.7. In the table, "total professionals" stands for the total amount of time spent by all professionals in a Centre.

In this Sub-Study, "professionals" are associated with those who work with children and parents of the target group to improve their conditions. As it proved difficult to obtain data on the salaries of other staff (e.g., managers, accountants, drivers), they are not included in the calculations.

In the tables and text, the term "per child" refers to each ECI child. The salary cost per child is calculated by dividing the amount of the total salary by the number of ECI children, as shown in Table 31. The number of professionals per child is calculated by dividing the number of professionals by the number of ECI children in a Centre.

Transportation costs for home visits

Table 32: Transportation costs of home visits

	Center 1	Center 2	Centre 3	Center 4	Center 5
Cost of transportation of home visits (ECI children share)	0	0	47,280	0	0
Cost of transportation of home visits per child	0	0	3,152	0	0

Only Centre 3 provides comprehensive ECI services that include home visits, while the other organisations only provide services based in the Centres. During the year, professionals visited children at home 86 times, speech therapists 5 times, physiotherapists 38 times and

psychologists 27 times. The total cost of these visits was MKD 47 280, with each visit costing MKD 156.

Cost of professional and parents' development trips

Table 33: Cost of professional development trips

	Center 1	Center 2	Centre 3	Center 4	Center 5
Cost of parents' trips (ECI children share)	151,099	0	0	0	14,294
Cost of staff trips (ECI children share)	120,879	89,552	0	0	0
Total cost of other professional development trips (ECI children share)	271,978	89,552	0	0	14,294
Total cost per child	4,945	1,493	0	0	529

Centers 1 and 5 cover the costs of parent and staff development trips, and Centers 1 and 2 cover the costs of professional meetings and training. In-service training was not observed in any of the other Centers. All Centers emphasized the importance of pre- and post-training for professionals and the need for additional funding for these activities. It is noteworthy that in Centre 3, which provides comprehensive ECI services, no training trips were observed.

Other costs

Table 34: Other costs, including utilities, meals, rent and special equipment

	Center 1	Center 2	Centre 3	Center 4	Center 5
Cost of utilities, etc (ECI children share)	1,376,245	443,284	370,400	650,000	133,278
Cost per child	25,022	7,388	24,693	13,000	4,936

The cost of utilities spent for ECI children was calculated by applying the total cost of utilities in the Center to the proportion of ECI children. The cost per child was calculated by dividing the cost of utilities (based applied to the proportion of ECI children to the number of ECI children) by the number of ECI children. The highest costs for utilities were observed in Centre 1, both in absolute numbers and as costs per child. The lowest costs per child were observed in Centre 5, both in absolute numbers and per child.

Total cost

Table 35 Total annual cost of ECI service providers and cost per child

Total	6,402,623	3,643,236	2,820,080	1,502,480	2,221,172
Cost per child	116,411	60,721	188,005	30,050	82,266

The highest total cost per child was found in Center 3. Although the total cost in absolute terms was not the highest, when combined with the relatively small number of ECI children, the cost per child was the highest. It should be noted that this is the only center with home visits, which cost was reflected in the total costs.

ECI children in this Centre also receive more professional support than in other Centres, but without the system of quality control before and during training, staffing and performance standards, licensing/certification, career ladders or lattices, salary scales, staff training plans and other human resource requirements, it is difficult to make a final judgement. Additionally, this center has just gotten new funding and is in the process of assessments and referrals. An increase of ECI services and enrolments of ECI beneficiaries is expected.

4.12.5 Findings

There is no specific ECI budget programme in any sectoral ministry. The costs of ECI services (salaries and utilities) in public centres are covered by the Ministry of Health through the Health Insurance Fund. Other ministries are not involved in funding ECI. ECI services in the public sector for children of parents insured by the Health Insurance Fund are free of charge or, in some cases, parents pay a contribution, but not more than 20% of the average total cost of health services. There is no monitoring of the existing budget of ECI service providers in terms of objectives, targets and budget disbursements. A comprehensive monitoring and evaluation component has not been identified. There is no nationwide database of children in ECI services and needing those services. The Ministry of Labour and Social Policy has the total number of beneficiaries of disability allowances and the number of children up to six years could be extracted from it. In addition, the Ministry is in the process of creating an ECI database.

In private ECI centres, parents' fees are the main source of funding, paid out of pocket. There is no insurance to cover these costs in the private and NGO sectors; therefore, they are paid out of pocket. The high level of out-of-pocket payments is common for the whole health sector, although the level of OOP has decreased in recent years. At the same time, the ECI services provided by the private and NGO centres seem to predominate. 33 of the 44 centres that participated in the survey were run by them. The parent survey showed that financial constraints are one of the biggest barriers to the timely access to ECI services.

There is a risk that commodity prices and household spending will rise and family savings will fall, further exacerbating the situation. The war in Ukraine has led to an increase in gas and energy prices and consequently in the prices of basic products. The increase in the minimum wage in the country could also trigger inflation. The financial burden could become greater, especially for poor families. As a result, fewer children will be able to secure needed service in a timely manner.

There is a lack of knowledge about ECI services, how to conduct needs assessments, and tools to prepare an ECI budget at the local level. Although social, child protection and health programmes exist that are the responsibility of municipalities, there are no specific budget lines for ECI services in municipal budgets. Some of the ECI centres (mainly in the capital city) receive one-off funding from the municipalities, but this support is not yet provided on a regular basis. The fiscal decentralisation reform was launched in the country in March 2021, but currently no emphasis could be found regarding plans to increase expenditures for child protection and health.

Local budget programmes are not based on a comprehensive and thorough analysis and needs assessment of vulnerable groups in the community, nor on a broader consultation process among local stakeholders. Consequently, the programmes are conceptually and contextually inadequate, formal, not comprehensive and usually do not reflect the real needs of the citizens. In all municipalities, the lack of financial resources is cited as a fundamental obstacle to the implementation of these programmes. Coordination between governmental structures (ministries and local self-governments) involved in funding services for ECI children does not yet exist and is urgently needed to maximise the use of available and future resources.

There is no single standard for salaries in ECI centres. The Ministry of Health sets the salaries for professionals in the public/non-profit centres, while the private/profit centres have their own rates.

While there were a few instances of support from international NGOs and private donations for ECI centres, this is not widespread. Furthermore, national NGOs working on child protection appear to have little training and experience in fundraising. The composition of costs for service providers shows that only a few organisations can afford to pay for training for their professional and paraprofessional staff as well as for parents. However, all organisations emphasized their need for in-service training, exchange between organisations, and study tours.

4.12.6 Recommendations

Reducing the financial burden on parents with children who receive and need ECI services should be the primary goal of the financial part of ECI reform in this country. This should be achieved by creating ECI programme budget for comprehensive ECI services at multiple government levels and from multiple sources. The following activities are recommended to create these forms of funding:

At the National Level.

A working group (or sub-group) should be established to design a central ECI budget programme. Representatives of sectoral ministries, national associations of municipalities and local self-governments, international and national non-governmental organisations, professional associations, and parents' associations, as well as international and regional organisations dealing with ECI and other stakeholders, such as regional banks, foundations and corporate foundations should be involved.

The budget programme should be based on the exact current number of children enrolled in ECI services and projections of the number of children who will need them. The budget programme should be based on the projected cost of services that in turn, will be based on ECI guidelines, procedures and standards. The ECI budget programme should be consistent with the medium-term strategic priorities of the country's budget. The programme budget should be accommodated in one of the sectoral ministries. ECI services should have a single administrative unit to reduce administrative costs, plan in a multisectoral manner, and provide transdisciplinary services. A system should be established to monitor the results achieved against the budget spent.

Budget planning for the coming years should be based on the monitoring of results. The development of an effective budget planning process is impossible without the provision of data on beneficiaries; therefore, the entire tracking system and database of ECI children should be created. Careful attention must be taken to avoid labelling children and families and ensuring that their right to confidentiality is fully respected.

It is important that the interests all ECI children and their parents/caregivers are taken into account, regardless of their income. Even if it is decided that parents should pay to some extent, best international practises should be applied in terms of grants and/or contracts. If necessary, different scenarios of insurance schemes (public, private and/or differentiated) might be considered, although administrative and billing costs tend to absorb a lot of the funds. The working group should guide the process of calculating the unit cost of services based on comprehensive ECI guidelines, procedures and standards yet to be established. Thereafter, existing ministerial service providers should be reviewed, with a focus on building on existing strengths and their effectiveness in using public funds in relation to the outcomes achieved for children and families.

A lead ministry should be selected to host the service provider and manage the budget in close collaboration with local self-governments. Alternatively, a multi-source funding mechanism could be established whereby the ministries would jointly fund the ECI components and local self-governments would act as co-financiers.

The ECI budget service provider should identify possible sources of funding other than government funds to ensure, insofar as possible, the continuous provision of additional funding sources (donor support, international and regional service providers, fundraising, etc.). This diversified approach is important to minimise the risk of budget cuts or insufficient public funding and to maximise the impact of Government investment in families and children. The working group, together with the lead ministry, should work with international donor agencies, foundations and NGOs to identify and secure additional funding sources, especially for a comprehensive training programme, pilot ECI demonstration and training services and short-term initial developmental costs of all new ECI service providers.

At the Local level.

Needs assessments at the community level, including urban, rural and national minority-inhabited areas, should be conducted at the local level. Regular consultation with local stakeholders should become the basis of a strong public-private partnership. Local authorities and ECI staff members should be trained in programme budgeting. Cooperation between the central government and local authorities should be based on the forms set out in the Law on Local- Self Government.

Every effort should be made to raise awareness of existing ECI services among parents and caregivers of ECI children to give them the right to participate in priority setting and local budget planning.

At the service provider level

All levels of government should work to increase the fundraising capacity of service providers to ensure that alternative and additional sources of funding are developed alongside government funding, which typically accounts for 75% to 80% of ECI funding in countries.

4.13 Challenges and Recommendations

The survey of ECI programme directors, ECI personnel and ECI beneficiaries asked them to identify the top five barriers and challenges that hindered programme development, growth and quality and to provide their recommendations for improving and expanding ECI programmes. Detailed results are presented in annexes, and the main findings are discussed below.

4.13.1 Challenges and needs of ECI services

In Annex 7, the ECI programme directors selected challenges and needs of ECI services. Their top five selections were (out of 24 picks):

1. Weak ECI organizational structure for coordination – ranking score 22 out of 24;
2. Inadequate policies, plans, laws and regulations for ECI programmes – ranking score 21 out of 24;
3. Weak ECI organizational structure for intersectoral and financial planning – ranking score 21 out of 24;
4. Lack of strong leadership for ECI services – ranking score 20 out of 24;
5. Stigma and lack of inclusion of children with developmental disabilities in communities – ranking score 20 out of 24.

Moderately mentioned selections included these additional challenges:

1. Inadequate national survey data on developmental delays and disabilities – ranking score 19 out of 24;
2. Lack of regular developmental screening services and referrals to ECI services – ranking score 19 out of 24;
3. Lack of awareness of ECI services on the part of national, regional and municipal governments – ranking score 19 out of 24;
4. Lack of awareness of ECI on the part of families and local communities – ranking score 18 out of 24; and

5. Lack of agreement regarding core ECI concepts – ranking score 17 out of 24.

The ECI staff pointed out the following challenges and needs as most important (full list is given in annex 8):

1. Weak ECI organizational structure for coordination – ranking score 21 out of 23;
2. Inadequate policies, plans, laws and regulations for ECI programmes – ranking score 21 out of 23;
3. Inadequate national survey data on developmental delays and disabilities – ranking score 20 out of 23;
4. Stigma and lack of inclusion of children with developmental disabilities in communities – ranking score 19 out of 23; and
5. Lack of regular developmental screening services and referrals to ECI services – ranking score 19 out of 23.

What can be seen here is that ECI directors and ECI personnel basically have the same opinions regarding the biggest challenges of the ECI services that are currently provided in North Macedonia. ECI directors and ECI personnel believe that these five barriers, decrease the quality of ECI services and impede their development. These barriers, particularly the first two are in line with the data given above in the previous sections and chapters. To overcome these barriers, the ECI directors call for: Enhanced coordination of ECI services; a properly organized ECI system; creation of policies, plans, laws, regulations; Larger inter-sectoral cooperation; planning for leadership in ECI; and raising awareness about the importance and need for inclusion of children with developmental delays/disabilities in society.

4.13.2 Recommendations for the future for expanding and improving ECI services: ECI programme directors

Some 41 ECI directors gave their top recommendations for expanding and improving ECI services. They gave priority to the following five choices (the full list is given in annex 9):

1. Expand advocacy to reduce stigma and discrimination – ranking score 21 out of 21;
2. Expand advocacy to increase demand for and expand services for ECI – ranking score 20 out of 21;
3. Develop national policies, plans, laws, and regulations for services for ECI – ranking score 20 out of 21;
4. Establish a nationwide system for regular developmental screening and referrals – ranking score 19 out of 21;
5. Improve the organisation and coordination of services for ECI with other services – ranking score 19 out of 21.

Moderately mentioned, but still with a very close percentage to the ones give above are:

1. Achieve greater equity through improving access to services for ECI services – ranking score 19 out of 21;
2. Provide high-quality and comprehensive child and family developmental assessments – ranking score 17 out of 21;
3. Develop a coalition or network of services for ECI – ranking score 16 out of 21;
4. Offer more parenting education and support services – ranking score 14 out of 21; and
5. Give more opportunities for parent involvement in programmes for ECI – ranking score 14 out of 21.

ECI directors recognised the need for raising awareness to reduce stigma and discriminations, expand advocacy for ECI services, to develop national plans, laws and regulations for ECI as well as to establish a nationwide system for ECI. These choices reflect the major findings of this study.

4.13.3 Recommendations for the future for expanding and improving ECI services: ECI programme personnel

The ECI personnel also gave their insight in what they believe were the top priorities for the development of ECI service in North Macedonia. The full list is given in annex 10.

1. Expand advocacy to reduce stigma and discrimination – ranking score 21 out of 21;
2. Expand advocacy to increase demand for and expand ECI services – ranking score 20 out of 21;
3. Develop national policies, plans, laws and regulations for ECI services – ranking score 19 out of 21;
4. Improve the organisation and coordination of ECI services with other services – ranking score 19 out of 21;
5. Achieve greater equity through improving access to ECI services – ranking score 18 out of 21.

Moderately mentioned, but still very important were the following recommendations:

1. Establish a nationwide system for regular developmental screening and referrals – ranking score 18 out of 21;
2. Provide high-quality and comprehensive child and family developmental assessments – ranking score 17 out of 21;
3. Develop a coalition or network of services for ECI – ranking score 15 out of 21;
4. Offer more parenting education and support services – ranking score 15 out of 21; and
5. Provide more home visiting services – ranking score 14 out of 21.

The ECI personnel recommendations leaned more towards increasing advocacy efforts in two directions: - first to raise awareness in order to reduce the stigma and discrimination, particularly towards ECI professionals that work in this field and secondly to increase lobbying efforts in order to raise more financial means and expand ECI services (enhance the outreach as well). One of the main recommendations, as given by the ECI directors as well, was to develop national policies, plans, laws, regulations which are much needed in North Macedonia. Development of coordination between services, enable greater equity in the provision of ECI services, enable comprehensive assessments were one of the main recommendation as well. One of the important recommendations, for ECI personnel as well was the establishment of a nationwide system for screenings and referral.

4.13.4 Recommendations for the future for expanding and improving ECI services: ECI beneficiaries

In Annex 11, a total of 97 parents provided the following recommendations for ECI services:

1. Expand advocacy to reduce stigma and discrimination and to increase demand for services for early childhood intervention - ranking score 20 out of 22;
2. Expand advocacy to increase demand for and expand services for early childhood intervention - ranking score 20 out of 22;
3. Develop national policies, plans, laws, and regulations for services for early childhood intervention - ranking score 20 out of 22;
4. Achieve greater equity through improving access to services for early childhood intervention - ranking score 20 out of 22;
5. Improve the organisation and coordination of services for early childhood intervention with other services - ranking score 20 out of 22;
6. Establish a nationwide system for regular developmental screening and referrals - ranking score 18 out of 22;
7. Provide high-quality and comprehensive child and family developmental assessments - ranking score 18 out of 22;
8. Develop a coalition or network of services for early childhood intervention - ranking score 16 out of 22;
9. Provide more home visiting services - ranking score 16 out of 22; and
10. Offer more parenting education and support services - ranking score 15 out of 22;

Parents focused on their main interests: advocacy to decrease the stigma which is something that unfortunately North Macedonia as a country still needs to work on; and similarly to the ECI personnel to expand advocacy to increase demand and expansion of ECI services, so more finances and resources into ECI. The third recommendation from the parents is also identical as the one given by the ECI personnel – Development of national policies, plans, laws, regulations or simply put development of an ECI system in North Macedonia. Parents also recommended the need for greater equity and improvement of coordination of services.

Of particular note, parents selected areas where this study revealed parental discontent with current services, including comprehensive developmental assessments, coalition of networks, more home visits and more parenting education and support services.

4.14 Lessons Learned from the Study

Several major lessons were learned about the ECI services in North Macedonia during the conducting of this very comprehensive and ambitious study.

1. One of the largest and most pressing issues in North Macedonia is that there is no official registry of ECI centers, programs or ECI service providers. The state centers are part of hospitals or clinics, while the private ECI centers are registered in a variety of designations (educational centers, private companies [DOOEL], NGOs and others). A unified code (or designation) needs to be created. This is closely related to licensing which is also a pressing issue.

2. There is a much larger coverage of urban than of rural areas. ECI services are not available to all. Services are very distant; travel is a heavy burden on parents. The study demonstrated that only few ECI programmes serve rural areas. Roma children and other minorities are significantly underserved. More community-based services and community outreach programs need to be developed, awareness for the ECI services needs to be raised, more funds need to be released and mobile teams for provision of services need to be organized in order to provide ECI services for these vulnerable groups. Intentional planning efforts, including training ethnic minorities as early intervention specialists, will be needed, region-by-region, to ensure the attainment of equitable service coverage.

3. Parents usually pay large fees in order to get ECI services for their children. Besides the existence of a large number of families that pay for services, and a certain number of children that use state service, there is a significant number of children that are not served. The waiting lists in the state financed centres are long. Parents sometimes wait are informed that they have to wait for months until their child is provided with ECI services. Instead, they opt for private ECI services. The statistics show that additional services are needed for over 7000 children. State ECI services with no parental fees need to be offered.

4. There is a lack of awareness in different levels of the ECI provision of services which is expected since very little ECI advocacy has been conducted. Many points arose during the research related to a need for advocacy to overcome stigma, help families to know their rights, identify children who most need ECI services, and improve access to ECI services. The lack of a national ECI system appears to be part of the reason for absence of cooperation for ECI advocacy at central, regional and community levels.

5. Full national initiatives are needed for universal developmental screenings conducted at regular intervals. The services that are mostly provided in ECI centres are comprehensive assessments of all domains of the child development. Basically, the majority of centres conduct assessments. The ICF centre, currently is assessing a very small number of children birth-to-six. The accent in on the children from 6 years and onwards. The difference in numbers is due to the fact that there are free services for children in inclusive education whilst the percentage of state ECI services (universally available) is scarce. Early enrolment in services is low. The largest number of children enrol services from 25-36 months. This points to a flaw in the child-find system and a lack of provision of free state-based ECI services. The most persistent method of referral is through parents.

6. The largest provision of services is centre-based. There isn't any centre that only provides home-visits. There are very few centers that provide family-centred services. Individual work is predominant, one third of centers use interdisciplinary teams while only 3 centers have transdisciplinary teams. A contemporary model of ECI needs to be developed with the development of core ECI services. Quality assurance is on a minimum. Supervisions are usually done only by the Director and there is no external supervision. There needs to be regulations for larger quality assurance with supervisors, licencing, in-service training, weekly revision of children's plans, use of evidence-based practices.

7. There is generally full eligibility for all children with delays/disabilities to receive ECI services. This is naturally occurring since the parents usually pay the fees. The state based centres usually request a medical diagnosis or comprehensive assessment. Again, the waiting lists are very long, usually not less than 3 months, while some parents wait for over a year.

8. Very little communication, planning and coordination exist among ECI programmes and other social services, leading to a limited amount of knowledge sharing and service coordination that would benefit ECI programme participants. ECI directors and professionals agree there should be more inter-agency communication and coordination; however, leadership has not arisen to assume these roles, and it needs to be fostered.

9. There is no network or ECI coalition in North Macedonia. Almost all participants in the study, particularly the participants in the high-level interviews expressed their interest to be a part of such a coalition/network. Hopefully, this study and the ECI Commission will help encourage the

development of new national leadership for ECI that will be focussed on consensus building and oriented towards working in the frames of a coalition.

10. North Macedonia has not formally nor informally adopted any policies and plans for development of ECI services. Municipalities are supporting some type of ECI or ECI-related services. This is a beginning effort of municipalities to fund ECI. It is suggested that municipalities become fully involved in all ECI programmes and budgeting activities. Government and Ministries rarely discuss the development of a contemporary ECI system. ECI will be a part of the new Strategy for Disability which is being developed by the National Coordinative Body for implementation of the CRPD. Additionally, a National Strategic Plan for establishing of ECI services needs to be developed in order to build a coherent national system of ECI services as well as regulations, guidelines, procedures and standards. A legal basis for ECI services needs to be concretized.

11. North Macedonia has a well-developed system of training special educators and rehabilitators with a solid base for practical trainings. However, there is no specialized in-service training for Early Childhood Intervention. Specialist ECI studies need to be developed and organized. In-service training needs to be strengthened and further planned and developed (with an emphasis on field training, on-site trainings with mentoring and coaching e.t.c.).

12. There is a lack of supervisors and contemporary supervisory systems, no administrative monitoring no system of program accountability (beside the accountability to a ECI director), no guidelines, procedures or standards. This is expected, having in mind that in North Macedonia there are no regulations for ECI services. There is usually only internal supervision conducted by the ECI director. For an ECI system to function well with full quality assurance, a comprehensive and up-to-date supervisory system is needed with well-trained and monitored supervisors.

V. Conclusions and Recommendations for ECI in North Macedonia

Although ECI services are being provided in some shape and form in North Macedonia and there has been a shift in the paradigm and a move towards family-centred contemporary services, still North Macedonia does not have an established and well organized national system for provision of ECI services that would enable large coverage and ECI services for all eligible children with at risk situations, developmental delays/disabilities, behavioral and mental needs and their families. There are no laws that regulate ECI services, the registration of ECI center, as well as all the ECI components. Financing of ECI is not regulated by law either.

The suggestions and recommendations that are given here will potentially assist more than 17.500 children and their families annually to receive ECI services, thereby helping them to achieve their full potential; indeed, most of them (approximately (70%-80%), will attain typical levels of development, as has been found in other countries.

5.1 Creation of an ECI Strategy and Action Plan

Conclusions from the study: The desk-top analysis showed that there are no laws, regulation or policies for ECI. Also, a national strategy for ECI services as well as an elaborate action plan does not exist. There are no regulations regarding the manner and preconditions for opening an ECI centre. The type of registration of ECI centres is not yet defined (centres are being opened as NGOs, DOOELs, education centres and so on). ECI services are a part of a disorganized system with no clear pathways and directions that can be followed by parents (who are usually overwhelmed and lost in the bureaucracy).

The need for an efficient, equitable and sustainable National ECI System is in line with the requests by both the Convention on the Rights of the Persons with Disabilities as well as the Convention on the Rights on the Child. A creation of a National ECI Strategy and subsequently an Action Plan for provision of ECI services is the first step towards the organization of a highly effective system for ECI.

Recommendations: The ECI strategy suggested needs to be typically for a five-year period and it needs to be created with an interdisciplinary approach with the participation of all key stakeholders such as: Ministry of Health, Ministry of Education and Science and Ministry of Labour and Social Policy; representatives from the National Body for Implementation of the CRPD; representatives from the office of the Ombudsman; academic leaders in ECI; NGOs; CBOs; parental organizations; private sector companies that provide ECI services and UNICEF. This needs to be a multi-sectoral ECI strategy.

National strategy elements represent the common elements considered by countries as they set national direction on quality and are selected based on co-development with countries and global quality experts. The prerequisite for developing a comprehensive strategy – a situation analysis - has been covered with this study. A situation analysis for ECI provides a solid foundation on which to build policy and strategy that respond to local need. The situational analysis builds understanding of the state of quality, identifies strengths of the health care system, the educational system and the social protection system to leverage for improvement, and finds challenges, priorities, contextual factors, barriers and facilitators for the policy and development process. The other key-elements of the strategy should include: vision and mission statements; goals; strategic priorities; services and activities; ECI organizational framework; an action plan with concrete phases; and a monitoring and evaluation framework with indicators.

One of the key aspects of the strategy needs to be the governance and the organization structure for ECI. The success at improving quality relies on strong structures and systems for governance and accountability. The development and implementation of the ECI system requires clear organizational structures for quality across the health system, educational system and the social protection system.

5.2 Raising Awareness and Advocating at Municipal and National Levels

Conclusions from the study: One of the biggest barriers in obtaining ECI services (as pointed out from ECI beneficiaries in particular) was the stigma and discrimination that parents face when trying to provide services for their child. On the other hand, one of the most important recommendations by them was to expand awareness in order to reduce the stigma and discriminations The recommendations of ECI directors and ECI personnel were in the same line as

the ECI beneficiaries, making this the most important recommendation given by the study participants.

One of the other most pressing issues was to expand advocacy to increase demand for ECI services. There was a significant lack of national and municipal advocacy for expanding and improving ECI services. Parents (particularly form rural areas) knew little about ECI services. It will be important for ECI programmes to work together to advocate for expanding their services to enable them to end their waiting lists, increase funding to meet urgent personnel and transportation needs, and participate in planning future ECI services. Parents also requested more parent education and support (particularly psychological support); free ECI services and increased governmental funding; greater equity; a nationwide system of regular developmental screening and more home visiting services.

Recommendations: Regarding awareness, we need to work on better informing families and communities, so that they can understand the goal and importance of ECI and be informed of the rights of the child and the family. They need to be informed regarding the difference between rehabilitation and medical approaches on one hand and interventions in early childhood on the other hand. Informing can be done via websites with video-clips related to early intervention and the importance of early identification and giving support (as the newly created app by UNICEF – BEBBO). The presence of ECI programme websites that are parent-friendly would be advisable. Printed materials for centres for ECI (for consultation, identification or interventions) with information about individuals that parents can communicate with and turn to when they encounter a problem or are worried about their child. A map of community services can be made, for different municipalities across the country which will make all ECI information available to parents and professionals for different areas. At the national level, an ECI website and radio and television education programmes could help parents secure developmental screenings and assessments for children, find registered and certified ECI programmes in their municipality, and secure up-to-date information about child development.

Regarding advocacy, an advocacy paper should be developed, with a sole purpose not only to collect signatures but also to be used for lobbying to national authorities for implementation of the activities written in it. Parents need to be included in planning future ECI services. They can be the best advocates for their children. Initiatives within and across ECI programmes are needed to address the unmet needs of parents, including their requests for counselling services, free-of-charge ECI services, peer group sessions with childcare, and greater access to information and guidance on their roles as parents. These activities could be conducted as a part of family-focussed ECI services.

5.3 Create a National ECI Organisational Framework and Effective Intersectoral Coordination for ECI Services

***Conclusions from the study*:** The high-level interviews, surveys and focus groups pointed out that there is no national ECI organisational framework or intersectoral coordination system has been developed North Macedonia. A unified system of leadership, coordination, planning, budgeting for equity, quality assurance, accountability and sustainability is lacking. ECI programmes also require essential guidance and opportunities to influence the future development of their services. The health sector will be the most important one regarding children from birth to three (particularly because of initial screenings and referral, as well as the fact that all state ECI centres are under the Ministry of Health). Social policy and education sector should also highly engage in the ECI services, having in mind that the best manner of providing services from three-to-six years of age is within kindergartens. A particular role can be given to the Ministry of Education, through including professionals from resource centres in providing services for children at this age. However, in order to achieve ECI goals, there needs to be a strong intersectoral coordination of services. Although no ECI network or coalition of ECI programmes exists as yet, universal interest was expressed in creating such an entity.

Recommendations: An organisational framework with processes for strong intersectoral coordination at all levels should be designed and described in the National ECI Strategy and Action Plan. An *intersectoral group* can be formed including stakeholders from the: Ministry of Health, Ministry of Education and Science and Ministry of Labour and Social Policy; representatives from the National Body for Implementation of the CRPD; representatives from the office of the Ombudsman; academic leaders in ECI; NGOs; CBOs; parental organizations; private sector companies that provide ECI services and UNICEF. A *central office* (as recommended by the study participants) should be established, with representatives from all sectors (health, education and social welfare). This office can plan and coordinate all ECI activities on national and municipal levels and can work closely with the *National ECI Commission*. In order to have a well-established organizational framework, *municipality offices* need to be established as well. They can assist the development of ECI services but also provide supervision to the ECI centres.

A system of coordination could be established among all ECI stakeholders, via *memorandum of cooperation* that could be established between ECI programmes and municipal representatives. To include the various sectors more, *training sessions on ECI* can be organized between medical professionals,

kindergarten employees as well as representatives from the social centres. A *National network or coalition of ECI programmes* was a recommendation that prevailed during the entire research. This coalition of ECI organizations can improve and expand ECI services for children and families.

5.4 Develop and Implement ECI Programme Guidelines and Procedures

Conclusions from the study: In North Macedonia there are no guidelines, procedures or any regulations regarding provision of ECI services. Different state and private centres provide an array of different services, that ranges from legacy (rehabilitation and habilitation services) to contemporary services. An official document regarding ECI Guidelines and Procedures should be developed and approved. This document should include ECI concepts, requirements for eligibility, child and parental statements, available ECI services and other additional procedures related to ECI. Procedures for certification and licencing should be established as well having in mind that currently there is no licencing is required for working with children with developmental delays/disabilities nor any established prerequisites to open an ECI centre (other than a diploma in the required area). We need to establish guidelines and procedure in order to establish equal quality in all ECI services provided for all children.

Recommendations: The Guidelines and Procedure should be developed with a wide consensus of all relevant factors. It cannot be a one-sided document brought by a few stakeholders. In order to establish consensus, workshops need to be organized with both ECI providers and government officials. Once this document is drafted it needs to be frequently reviewed in order to enable the provision of equitable services to urban, rural and minority populations. If an ECI centre does not meet the requirements, technical support must be given. This process of developing ECI guidelines and procedure will go parallel with the establishing of the process of registration and certification of ECI programmes.

5.5 Equitable ECI Services

Conclusions from the study: As in all neighbouring countries that conducted situational analysis such as this one, as well as other countries that still do not have an organized system of ECI, large inequalities were found in the provision of services. Rural areas, minorities as well as families with a low socio-emotional status were dramatically underserved. The largest number of centres were located in the capital Skopje. Many cities and municipalities do not have a state or private ECI centre and parents travel long distances to receive ECI services. Inequality is found in the fees parents pay to receive services. Waiting lists in state centres are usually so long, that parents decide to get ECI services by private providers. ECI should be free and accessible to all.

Recommendations: Because demand exceeds supply and long waiting lists exist in many ECI programmes, it will be essential to place priority on underserved populations and expand ECI services while conducting community outreach to identify the many children who require ECI services. Such programmes will also need adequate funding for transportation. One option, in order to use the experiences and developed services of already well established private ECI centres, is to create public-NGO/private partnerships. This can be done via government social packages, that will aim particularly towards these underserved groups of the population. Regarding minorities, it is essential to train professionals and paraprofessionals from these minorities that can give services in their mother tongue. Also, efforts should be made to increase their awareness of services such as developmental screening, assessments, and home visits, most especially given their transportation challenges.

5.6 Establish and Implement ECI Service and Personnel Standards

Conclusions from the study: The desk-top research, as well as the field research showed that there are no ECI service and personnel (professionals, paraprofessionals and volunteers) standards. There are no standards regarding qualifications, certification, licencing, personnel development or other comparable requirements. Every system needs to have personnel standards in order to assure that that personnel has the qualifications needed to carry out the purposes of ECI and to assure that the personnel is appropriately and adequately prepared and trained.

Recommendations: The ECI guidelines and Procedures provide the basis for the establishment and maintenance of qualification standards for ECI services as institutions and for ECI personnel that will be consistent with a state-approved certification, licencing, registration and other requirements that apply to service institutions and ECI personnel. Attention should be given to their ECI skills and knowledge, additional professions or disciplines for some specialists, and the areas in which they are providing ECI services (e.g., home visitors, counsellors, supervisors, managers, evaluators, etc.)

5.7 Prepare and Implement an ECI Pre- and In-Service Training Plans

Conclusions from the study: There are no official ECI pre-service or in-service training plans. Pre-service training is developed for special educators and rehabilitators. ECI courses are offered on two different universities, in Macedonian and in Albanian as well. These courses are basic courses for ECI services for children with different types of disabilities. There are some courses on post-graduate and PhD level as well. However, firstly these courses on a graduate level are academic courses that lead to a master of sciences diploma. This is more research oriented than oriented towards practice. Secondly, and this is related to both undergraduate and graduate level courses, these courses need to be more contemporary and provide more information regarding family-centred practices. ECI professionals are generally satisfied with the knowledge for ECI gained on the undergraduate level, however they were very specific in their demands for the necessity of organizing specialist studies in ECI (which will be oriented more towards practice). There are no courses for ECI offered to other ECI professionals, such as psychologists, social workers e.t.c. In-service trainings are oriented towards attendance of conferences and workshops. Continuous on-site in-service training combined with mentoring and coaching is one of the most highly effective forms of in-service training and should be given more consideration, along with inter-site exchange visits, which have been shown to be highly effective in improving ECI quality.

Recommendations: It is recommended that both pre- and in-service training be reviewed in light of the contents of the future National ECI Strategy and Action Plan, National ECI Programme Guidelines and Procedures, and ECI Service and Personnel Standards. The extensive evidence base for contemporary ECI services could help inform all pre-service training programmes and help to expand the training of Early Intervention Specialists (EIS). An In-Service Training Plan should be prepared with the full participation ECI leaders, programmes, university professors, associations, and students. Usually, field training, coaching and mentoring for ECI professionals and paraprofessionals are emphasised. To update experienced professionals, the following training topics might include:

- Contemporary ECI methods and procedures;
- Core ECI concepts;
- Child and parental rights;
- ECI teamwork methods; developmental screening;
- Comprehensive developmental assessments as well as specialised assessments;
- Family and home assessments conducted with parents, including possibly ecosystem activities;
- Preparation and implementation of Individualised Family Service Plans (IFSPs);
- Home visit planning, methods and reporting;
- Routines-based interventions;
- Methods for working with parents and other family members;
- Programme management methods;
- Supervisory methods for coaching, mentoring and reflective supervision; and
- Programme monitoring, evaluation and reporting.

It is recommended that methods for continuous and just-in-time in-service training be emphasised, along with in-service training and the supervision of paraprofessionals. A schedule of annual professional training workshops with professional credits might be provided.

5.8 Development of a National Database for Children in ECI Services and an ECI System for Monitoring, Evaluation, Reporting, Planning and Accountability

Conclusions from the study: No national framework and guidance for ECI programme indicators, monitoring, evaluation and reporting exists. While this situational analysis is being prepared, there is no national database for children in ECI services as well as children that are in need of ECI services. However, this research showed that the Ministry of Labour and Social Policy is in the process of creating such a database. This database is important for creation of plans and policies regarding ECI. An additional suggestion is that the data can be received by municipalities as well. This can be beneficial for the inclusion of municipalities in the ECI process as well.

A system of monitoring, evaluation, reporting, planning and accountability has not been developed yet. Some ECI directors claimed to have internal monitoring. However, all centres can benefit from technical support and guidance with the purpose to improve their ECI systems and us methods and instruments for effective monitoring, evaluation and reporting.

Recommendations: Considering that a national database for children in ECI services will be developed, the focus should be moved towards the creation of a framework for and guidelines for programme monitoring, evaluation and reporting. A national system of ECI monitoring and evaluation is greatly needed to assess programme inputs, outputs and outcomes. A parallel child tracking system is required to identify children and then ensure the provision of continuous services when needed along with consistent levels and qualities of services in all municipalities. of efforts. External longitudinal evaluations should be considered to study programme processes and service outcomes over time, for example with regard to child development, parenting skills and later inclusion in schools.

5.9 Provide Supervision for the ECI System and ECI Programmes to Achieve Quality Assurance

Conclusions from the study: The desk-top and particularly the field research showed that there is no supervision of the work of professionals that provide ECI services. Some of the centres stated that they have internal supervision and that the ECI director serves as a supervisor of the work of his employees. In a situation where we do not have supervision of the ECI system or ECI service being given, we cannot discuss quality assurance. ECI professionals stated they need supportive supervisory services, including coaching, mentoring and reflective supervision.

Recommendations: To create a system of quality assurance for ECI services, two levels of supervision are needed:

1. A national, county and municipal unified supervisory system with all supervisors working together to support ECI services, reward achievements, and develop new competencies and systems of supervision at the local level; and

2. ECI supervisors in programmes who will play supportive roles of coaching, mentoring, and reflective supervision with all professional and paraprofessional personnel.

5.10 Develop a Universal System of Developmental Screening, Assessments and Referrals

Conclusions from the study: The study showed that half of the parents received developmental screenings and comprehensive assessments. Half of the ECI centres conduct screenings and also half of them conduct assessments. A relatively large number of parents stated that they receive developmental screenings. However, the age of children first enrolled in services shows that we have a late identification of children with developmental delays/disabilities. Regarding referral, the parents were usually the ones that seek out services. We need a system that will detect, identify and make referrals for children during the first year of life in order to not miss out of the important periods for brain development

Recommendations: North Macedonia should develop a system of Universal Screening that will lead to an effective system of referrals. Family doctors, paediatricians, patronage nurses and vaccination points as well as child care providers and preschool teachers should be the "gate-keepers" or the entry points that will conduct this universal screening (the instrument that can be used is Ages and Stages Questionnaire III – ASQ). There should be referral follow up, possibly done by the patronage nurses (envisioned in the Universal Progressive Model of Patronage). These services should be free and accessible for all.

Comprehensive developmental assessments, according positive evidence-based practices should be done by the transdisciplinary teams of the ECI centres/ programmes/service providers. The need to do these assessments in ECI centres originates from the fact that these assessments form the basis of the child development sections of the IFSP and decision making by parents on their goals for their child's development.

5.11 Design and Implement a Pilot Project for the Qualitative Improvement of ECI Programmes

Conclusions from the study: Some of the ECI centres in North Macedonia still provide habilitation and rehabilitation services. The largest number of centres offer child-centred services while very few centres provide family-centred service and offer home-visits. Many of the directors, but also many of the ECI personnel expressed their interest and eagerness in learning new principles, methods, using new instruments and learning new approaches. A large number of them were interested about being trained in the transdisciplinary approach with a primary service provider. What is encouraging is that ECI personnel from the state medical institutions were also interested in learning these new ECI approaches. One such pilot project was funded by UNICEF and it showed promising results. It is the only family-centred ECI centre that provides home visit with the transdisciplinary approach. It is important, for the development of a contemporary ECI system in North Macedonia, to conduct an additional pilot project with such innovative ECI services. In

addition, it will be important to field test and evaluate newly developed ECI materials, instruments and processes.

Recommendations: To field test new approaches and enable a few ECI programmes to serve as testing and demonstration sites for others, pilot projects might be considered. It is recommended that a maximum of three ECI programme sites be selected and located in:

1. Urban;
2. Rural; and
3. Minority communities.

Preparatory planning, training of professionals and paraprofessionals, design of one or more mobile teams, and the selection of monitoring and evaluation instruments will be essential. Modest technical support and an external evaluation will also be needed. A final report could be used to support other ECI programmes as they modify their methods and approaches. The pilot sites could be used as a demonstration place for in-service training of nearby ECI service providers.

5.12 Develop a Phased Investment Plan with Guidelines for Regional Equity and Development, Resource Maximisation, and Cost Monitoring

Conclusions from the study: There is no specific ECI budget programme in any sectoral ministry. The costs of ECI services (salaries and utilities) in public centres are covered by the Ministry of Health through the Health Insurance Fund. Other ministries are not involved in funding ECI. ECI services in the public sector for children of parents insured by the Health Insurance Fund are free of charge or, in some cases, parents pay a contribution, but not more than 20% of the average total cost of health services. There is no monitoring of the existing budget of ECI service providers in terms of objectives, targets and budget disbursements. In private ECI centres, parents' fees are the main source of funding, paid out of pocket. There is no insurance to cover these costs in the private and NGO sectors. At the same time, the ECI services provided by the private and NGO centres seem to predominate. The parent survey showed that financial constraints are one of the biggest barriers to the timely access to ECI services.

There is a lack of knowledge about ECI services, how to conduct needs assessments, and tools to prepare an ECI budget at the local level. Although social, child protection and health programmes exist that are the responsibility of municipalities, there are no specific budget lines for ECI services in municipal budgets. Some of the ECI centres (mainly in the capital city) receive one-off funding from the municipalities, but this support is not yet provided on a regular basis. Local budget programmes are not based on a comprehensive and thorough analysis and needs assessment of vulnerable groups in the community, nor on a broader consultation process among local stakeholders. Consequently, the programmes are conceptually and contextually inadequate, formal, not comprehensive and usually do not reflect the real needs of the citizens. Coordination between governmental structures (ministries and local self-governments) involved in funding services for ECI children does not yet exist and is urgently needed to maximise the use of available and future resources. There is no single standard for salaries in ECI centres. The Ministry of Health sets the salaries for professionals in the public/non-profit centres, while the private/profit centres have their own rates.

Recommendations: Reducing the financial burden on parents with children who receive and need ECI services should be the primary goal of the financial part of ECI reform in this country. This should be achieved by creating ECI programme budget for comprehensive ECI services at multiple government levels and from multiple sources.

The following activities are recommended to create these forms of funding:

At the National Level. A working group (or sub-group) should be established to design a central ECI budget programme. Representatives of sectoral ministries, national associations of municipalities and local self-governments, international and national non-governmental organisations, professional associations, and parents' associations, as well as international and regional organisations dealing with ECI and other stakeholders, such as regional banks, foundations and corporate foundations should be involved.

The budget programme should be based on the projected cost of services that in turn, will be based on ECI guidelines, procedures and standards. The ECI budget programme should be consistent with the medium-term strategic priorities of the country's budget. The programme budget should be accommodated in one of the sectoral ministries. ECI services should have a single administrative unit to reduce administrative costs, plan in a multisectoral manner, and provide transdisciplinary services. The development of an effective budget planning process is impossible without the provision of data on beneficiaries; therefore, the entire tracking system and database of ECI children should be created. It is important that the interests all ECI children and their parents/caregivers are taken into account, regardless of their income. Even if it is decided that parents should pay to some extent,

best international practises should be applied in terms of grants and/or contracts. If necessary, different scenarios of insurance schemes (public, private and/or differentiated) might be considered.

The working group should guide the process of calculating the unit cost of services based on comprehensive ECI guidelines, procedures and standards yet to be established. Thereafter, existing ministerial service providers should be reviewed, with a focus on building on existing strengths and their effectiveness in using public funds in relation to the outcomes achieved for children and families. A lead ministry should be selected to host the service provider and manage the budget in close collaboration with local self-governments. Alternatively, a multi-source funding mechanism could be established whereby the ministries would jointly fund the ECI components and local self-governments would act as co-financiers.

The ECI budget service provider should identify possible sources of funding other than government funds to ensure, insofar as possible, the continuous provision of additional funding sources (donor support, international and regional service providers, fundraising, etc.). The working group, together with the lead ministry, should work with international donor agencies, foundations and NGOs to identify and secure additional funding sources, especially for a comprehensive training programme, pilot ECI demonstration and training services and short-term initial developmental costs of all new ECI service providers.

At the Local level. Needs assessments at the community level, including urban, rural and national minority-inhabited areas, should be conducted at the local level. Regular consultation with local stakeholders should become the basis of a strong public-private partnership. Local authorities and ECI staff members should be trained in programme budgeting. Cooperation between the central government and local authorities should be based on the forms set out in the Law on Local- Self Government.

At the service provider level. All levels of government should work to increase the fundraising capacity of service providers to ensure that alternative and additional sources of funding are developed alongside government funding, which typically accounts for 75% to 80% of ECI funding in countries.