

Building and strengthening integrated ECI systems: Balkan Report

Report by EASPD Member Forum on Early Childhood Intervention



EASPD

Lighthouse Network

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Table of contents

Table of contents.....	2
Country Report Albania.....	5
1. Legal framework and bylaws on Early Childhood Intervention (ECI) services for children with developmental difficulties.....	5
2. Description of ECI services	7
2.1 ECI services offer	7
2.2 Challenges in implementation	8
3. Funding of the services	9
4. Recommendations	10
Country Report Greece	11
1. Description of the legal framework and bylaws on Early Childhood Intervention (ECI) services for children with developmental difficulties	11
2. Description of ECI services	13
3. Funding of the services	14
4. Recommendations	14
Country Report Kosovo	16
1. Description of the legal framework and bylaws on Early Childhood Intervention (ECI) services/for children with developmental difficulties.....	16
2. Description of ECI services	17
3. Funding of the services	19
4. Recommendations	20
Country Report Montenegro	21
1. Description of the legal framework and bylaws on Early Childhood Intervention (ECI) services for children with developmental difficulties	21
2. Description of ECI services	27
3. Funding of the services	29
4. Recommendations	31
Country Report North Macedonia	32



1. Description of the legal framework and bylaws on Early Childhood Intervention (ECI) services/for children with developmental difficulties.....	32
2. Description of ECI services	34
3. Funding of the services	35
4. Recommendations	36
5. Conclusions.....	37
Legal and regulatory framework.....	37
Governance and coordination structures	37
Provision of ECI services.....	38
Funding mechanisms.....	38
Challenges	39
Overall conclusion	40



Introduction

Early Childhood Intervention (ECI) services are increasingly recognised as a crucial instrument for families with a young child with a disability or developmental difficulties, that empowers them to support the development of their child in the best possible way.

One of the eight European Association of Service providers for Persons with Disabilities (EASPD) Member Fora focuses on ECI and brings together EASPD at present 54 members and experts on ECI. The ECI Member Forum is an important space for mutual learning. Most of the members are pioneers in providing ECI services in their countries and shared the difficulties they face in their day-to day practices. Since 2021 the Lighthouse Network Project was developed within EASPD as a tool to facilitate member-led peer exchange.

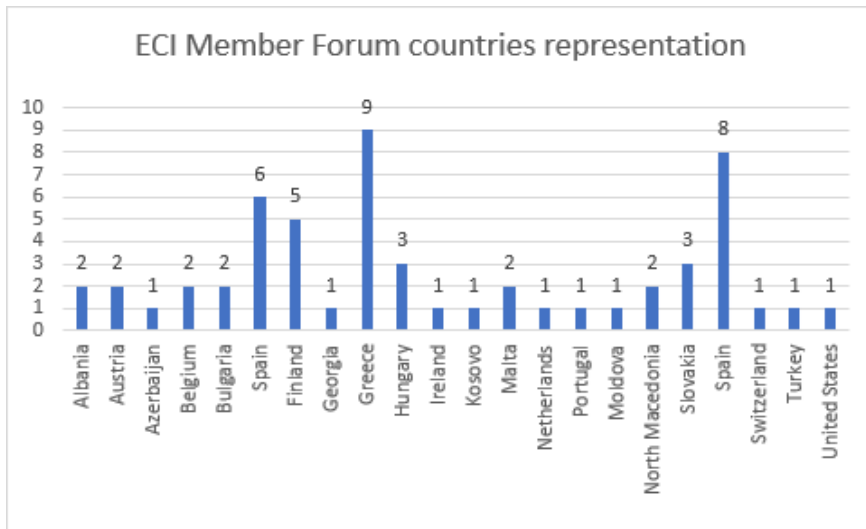


Figure 1: Bar chart showing level of representation per country in EASPD Member Forum on ECI

In the group, the Balkan region is highly represented, with members coming from Albania, Bulgaria, Greece, Kosovo, and North Macedonia. Discussion and exchange highlighted that several countries in this region faced similar problems.

The Member Forum thus decided to take the opportunity created by the Lighthouse Network Project to get a better understanding of the situation

of ECI in five Balkan countries (Albania, Greece, Kosovo, Montenegro, and North Macedonia) to compare their situation, and to propose solutions to common challenges. Five country reports were drafted with the help of national researchers, focusing on the legal framework, the type of services offered, and their funding and proposing country-specific recommendations. The results and conclusions of the study are presented in this document.



Country Report Albania

1. Legal framework and bylaws on Early Childhood Intervention (ECI) services for children with developmental difficulties

Albania has ratified the United Nation Convention on the Rights of Persons with Disabilities (UNCRPD) in 2012 and became a State Party in 2013. The policy and the legislative framework in support of the rights of persons with disabilities (PwD) is dynamic and evolving but it is facing a lot of challenges in its implementation.

In November 2016, the parliament of Albania passed the new law on “Social Care Services in the Republic of Albania 161/2016” as a new law following the objectives of the convention.

The definition of ECI in the new Law is:

“1. Early intervention is an individual social service provided in the family, social centers for the provision of services in the community or education institutions and consists of professional and incentive assistance for children up to 8 years old, counseling assistance for parents and other family members with blood ties or for the foster family, in order to reintegrate the child into society. 2. Early intervention involves referring the child's case to a social services center, education institution or medical institution, based on the characteristics of the child.”

The new Law 121/2016 “On social care services in the Republic of Albania” has identified 8 types of social care services including for the first time the Early intervention services for children up to 8 years. In practice, this service is not functional yet as lacks bylaws and funding mechanisms to build the necessary infrastructure on delivering ECI in Albania. One of the most important phases for integrated services is the building of the ECI model adapted to the needs; environment and the human resources for this service. Now, five years after the approval of the law, there is not an official model nor a study on how the early intervention child services are offered, where, how and from whom. It neither exists a professional education pathway for ECI professionals. The government also compiled a decision regarding a basket of services which, for the moment, has had no development.

The improvement and the development of the services for persons with disabilities are in synergy with Tirana Municipality’s current Social Local Plan (2021 – 2024), where children and youths with disabilities are one of the main targets to be reached by interventions. The National Action Plan for People (2021 – 2025) foresees the provision of social services for persons with disabilities, including



children and youths with disabilities, and a need to collaborate with the not for profit sector in increasing the capacities to professionals to provide those service.

By being part of the UN CRPD the state of Albania has been supervised by the Comitte on the Rights of Persons with Disabilities. This committee is the competent body that monitors the implementation of the Convention by the States Parties. In the case of Albania, the committe is concerned about the lack of services as it was published in the report on the implementation of the Convention. The following recommendations regarding services in Albania were formulated: *“The Albanian state should provide all children with disabilities, regardless of their impairment, with sufficient social and health-care services, including early intervention and development services, in cooperation with representative organizations of children with disabilities, including at the local level, and provide also a transparent road map for achieving progress;”* and *“Develop evidence-based public policies to respond to the situation of persons with disabilities, in collaboration with their representative organizations”*. Page | 6

Albania has also ratified the Universal Declaration of Human rights, which in Article 25 recalls:

“Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

Although the Laws and political documents foresaw different social services to be provided for persons with disability, the functioning of the Institutional System at Central and Local level and the way of financing new types of services, make the situation in Albania still critical, in terms of access to rehabilitation services compared to the needs, as well as their quality. One of the main challenges is lack of budget and bylaws, which are not a priority for the government.

Since 2012, Albania has officially an inclusive education Law, based also on the UNCRPD. Based on this Law, children with disability are provided with a dedicated support teacher and rehabilitation services based on their needs. At the moment, only the assistant teacher is provided and no other rehabilitation services.

Despite the system also offers assesment for the children with disabilities, the commissions of Regional Educational Directories and school commissions do the assessment just as a procedure. They do not only lack specific tests to measure what a child knows or its needs, but also they do not



interfere in adapting the curricula or ensuring learning materials (not even the ones suggested from parents). At the school level, they come up with the Individual Education Plan (IEP) which is drafted by the support teacher, sometimes in collaboration with the main teacher.

2. Description of ECI services

In practice, there are sporadic cases of functioning of this system with the support of Civil Society Organisations (CSOs), which work in cooperation with local units in Tirana, Durrës, Vlorë, and Kukës. They have undertaken actions, such as the setting up the Disability Local Network, the drafting of training Manuals for early detection and early intervention, the strengthening of professionals capacities in public early education settings, the provision of support for children with needs of the age group 3-6 years old at home or in the community-based center, and others. However, these interventions are insignificant compare to the number of the children in need of such services and these models have to be extended in other municipalities of the country.

The 6 community centers in Tirana Municipality provide currently services to only 202 PwD. The given figures from official data on beneficiaries using these community centers highlight an immediate need for increasing the number of PwD accessing social services, especially for children with disabilities aged between 0 and 8 years old. They also show the need for mobile services for PwD, especially in rural areas or in specific communities, such as the new social residences in the city. Mobile services are offered based on projects or World Vision Albania, by Non Governmental Organisations (NGOs) for years, but only in some cities. The social plan draft of Tirana Municipality identifies the need to strengthen the capacities of professionals working with PwD, the decision-makers and managerial positions at the local level, as well as the improving of the dialogue between the local level, government and NGOs that represent the rights&the needs of people with disabilities. For example, even though the main Hospital of Tirana has a physical therapy service offered by the pediatry department, it is not clear if this service is offered in hospitals of other cities.

2.1 ECI services offer

ECI services in Albania cover the following:

- assessment (cognitive development, speech & language, emotional, social, physical, self-care/personal autonomy. no diagnostic, & the team lacks a child neurologist & child psychiatrist;
- development & occupational therapy;
- physical therapy;



- group therapy;
- art & play therapy;
- speech & language therapy;
- home visits;
- after school service.

These services are delivered by professionals such as speech and language therapists, Applied Behaviour Analysis (ABA) therapists, physical therapists, psychologists, art and play therapists, academic experts etc.

2.2 Challenges in implementation

The challenges in the implementation of ECI services are the following:

- The government has not calculated and agreed yet on the cost of the services and reference service prices.
- There is only one public center in Albania for the assessment and treatment of children at an early age.
- Lack of awareness campaigns on early detection and intervention.
- Lack of information in understanding how ECI is provided, by whom and where.
- Lack of official data on the number of children 0-8 years old assessed and treated.
- Lack of models and curricula for professionals that provide ECI program.
- Stigma of the parents in accepting the disability of the child at an early age, and referring and including him/her on the support system.

Referring to all these challenges, parents have been trying to ensure the provision of services for their children with disabilities and learning difficulties, from the private sector of service providers, such as NGOs or other freelance professionals (these last ones mostly work informally/unlicensed by the State).

One of the objectives of the National Action Plan for People with Disabilities (2021-2025) focuses also on prevention and early assessment of disability. Nevertheless, as we lack the necessary instruments and expertise stands in the way of early assessments, publication of awareness-raising materials and campaigns for the prevention of disability should continue. For the moment, primary care doctors have received a protocol on how to refer children for assessment, when necessary. Also, social administrators and/or Children's Protection Units maintain regular contact with families, but they



lack capacities to refer children consistently. Finally, teacher are often requested to do an assessment when the child has reached school age and is seen to find it difficult to cope with various issues.

3. Funding of the services

Sources of funding for social care services, including ECI, and provided by public and non-public institutions, consist of:

- a) Funds delegated from the State Budget, including the Social Fund;
- b) Funds from the budgets of local government units;
- c) Income determined from assets and other activities of the municipality;
- d) Service fees for the beneficiaries of social care services.¹

The creation a “Social Fund” by the Ministry of Health and Social Protection, and transfer it to Local Government to finance Services for Persons with Disabilities has been seen as an efficient way of financing services at local level. It is supposed to be a funding instrument to support NGOs and private sector social care service providers. However, in order to benefit from this fund, the Local Government has to have a “Social Plan” where they state their priorities and their needs. So far, about 30 municipalities throughout the country (out of 61) have these Social Plans. Consequently, in practice it doesn’t work and is not a sustainable support for over 50% of the services of the country. The services most at risk are the Services provided by the Associations (Non-Public Services) which for a long time have provided services of high standards, supported by donor funds. Nevertheless, due to lack of funds from the government, these services have been closed or are in great difficulty of surviving and having an uncertain future.

Other challenges of Social Fund:

1. Small funds allocated
2. It covers different target groups not only PwD (youth, elderly, woman, etc.)
3. It is of a grant form (meaning all group categories need to apply for it when there is a call).

¹ LAW no. 121/2016 ON SOCIAL CARE SERVICES IN THE REPUBLIC OF ALBANIA



4. Recommendations

Based on this research, here a set of recommendations to improve the quality and availability of ECI services in Albania:

Page | 10

- Increase the allocated budget for social care services to support existing services in the private sector and to build/expand state's social care services.
- Design and approve service standards for each type of service and age group of beneficiaries as a tool to improve the quality of these services.
- Support the NGO sector that provides services through funds, grants, facilities, and other financial means. Adopt a new law on charity, sponsorship and philanthropy to support motivate and stimulate the business sector and individual donations.
- Ensure a caregiver's allowance financial contribution for all individuals with disabilities for as long as there are not accessible/in place quality public services, so parents can pay privately for the services.
- Develop and establish a model of early identification of intellectual disabilities (development delays and learning disabilities) as a job description for all the pediatricians and family physicians and establish a communication bridge between the primary health care system and the service providers.
- Establish an effective monitoring system for social service providers in terms of quality (private and public ones).
- Build the "Disability Service Provision Map" at national level and make it accessible to the public.
- Ensure capacity building of professionals working with children and PwD as service providers.
- Increase awareness among employees of public administration on disability and especially on intellectual disability.



Country Report Greece

1. Description of the legal framework and bylaws on Early Childhood Intervention (ECI) services for children with developmental difficulties

According to our research, the concept of early intervention was introduced for the first time in the Special Education Act (SEA) of 2008, that allowed preschool special educational units to implement early intervention programs for children until the 7th year of age (L3699/2008). In addition, according to the SEA, the institution for diagnosis and support of special education needs (KEDDY) could suggest whether the implementation of early intervention programs was needed.

According to the respective laws, Early Intervention mainly focuses on school preparation and is therefore under the responsibility of the Ministry of Education. L3699/2008 on Special Education and Education for Persons with Disabilities and Special Education Needs, that regulates the operation and services of Special Education School Units, mentions early intervention as a potential service to be offered to children within the context of special kindergarten and or Special Primary School and focuses on children up to 7 years old. It mainly focuses on supporting children to facilitate their introduction to primary school.

Recently the Ministry of Labor and Social Affairs has launched a request for technical assistance from EU Commission to form a new legislative and funding framework on ECI. In September 2021 a Technical Support Instrument (TSI) project financed by the Directorate-General for Structural Reform started early October 2021, and will be implemented by EASPD, in collaboration with the European Commission. This same Ministry has also reserved funding for piloting ECI in Greece from the Recovery Plan. Therefore, MoLSA seems to be the future coordinating Ministry for ECI.

According to the latest Commission European Country Report written in the framework of the European Semester in Greece more children have access to early childhood education and care. Between 2016 and 2018, enrolment rates in formal childcare sharply increased: from 8.9% to 40.9% for children aged 0-3². However, this progress does not affect equally the children with disabilities,

² COMMISSION STAFF WORKING DOCUMENT Country Report Greece 2020/ 2020 European Semester: Assessment of progress on structural reforms, prevention and correction of macroeconomic imbalances, and results of in-depth reviews under Regulation (EU) No 1176/2011



especially the ones aged from 0 to 3years old. Unfortunately, despite the Special Education Act legislation (L3699/2008, articles 8 & 32), ECI is not systematically applied in Greece.

According to the National Confederation of Disabled People (NCDP)³ a basic weakness of the Greek educational system is the very limited access to early intervention and pre-school services for children with disabilities, services that in fact are provided by a few non-governmental organisations (NGOs). According to the Government Gazette (2008b), the development of public early intervention structures as foreseen by the Law 3699/2008 has not been released yet.

The 2019 Committee on the Rights of Persons with Disabilities report⁴ mentions that the legislation and the existing legislative framework for disability assessment mechanism lack a harmonized human rights-based approach to disability. Public data collection on persons with disabilities still refers to the medical model of disability (Health Survey 2019) and it is fragmented, unsystematic and incomplete. The report explicitly highlights the lack of a comprehensive legislative framework guaranteeing equal treatment, protection from discrimination and individualised supports. Also, the Greek legislation has a gap related to families with children with disabilities from their birth up to 2,5 years old in terms of financial support and accessibility to ECI services. Furthermore, there is great difficulty to identify the families and children in need also due to social stigmatization, especially in rural areas, and a lack of systematic research and available data.

³ Human Rights and Persons with Disabilities/Alternative report Greece 2019, by the National Confederation of Disabled People (NCDP)

⁴ From the Committee on the Rights of Persons with Disabilities / Concluding observations on the initial report of Greece* (September 2019)



2. Description of ECI services

Although a commonly agreed definition of ECI is not established, in practice, Early Childhood Intervention services focus on providing health, social support, and education services to children with disabilities from 0 to 6 (or 7) years of age.

Such services are provided by a) public institutions for early intervention; b) private institutions; c) non-profit organizations; d) non-governmental organizations; and e) associations of parents of children with disabilities, the latter being financed through private donations and sponsorships. All these providers have their own operating rules, cater for different age ranges (usually 0-4, 2-6 or 0-6), and offer early intervention programmes on their own initiative or in collaboration with the Ministry of Education, Research and Religious Affairs. Most early intervention services are offered by private therapy centers or non-profit welfare organizations.

According to the existing legislation, Early Intervention educators should be teachers at primary schools or kindergarten with Special Education orientation. However, all private institutions and NGO's providing Early Intervention program may employ other specialisations including Special educators, Psychologists, occupational therapists, speech therapists, etc.

Medical Pedagogical Centers and Diagnostic Assessment and Support Centers offer mainly diagnostic and evaluation services and they have not yet expanded to ECI services.

In Greece at present, the following challenges are faced, particularly for family-centered, home visiting ECI services:

- Absence of official mapping at the State level of the services provided from private and public institutions (per age and type of service);
- The institutional gap for services targeting families and children with disabilities under the age of 2.5;
- Lack of information to community social care personnel on the services available and consequently limited guidance to families, especially in reference to home visiting services.

Furthermore, structural shortcomings of the welfare system relate to:

- Absence of education / training for professional employment of Early Intervention professionals;
- No funding / uncertainty for the sustainability of the services which are mostly funded by private institutions;



- Lack of objective/common system for quality assurance, control, impact measurement and evaluation of the services provided. The lack of such a system exposes family and the vulnerable child to great risk;
- The situation is particularly burdensome in the province, where the social stigma and the access to services is either limited or absent;
- Extremely limited number of home visiting, family centered ECI programs. The great majority of the available services are center based.

3. Funding of the services

There is no common funding scheme for ECI services in Greece.

Home-based ECI programs are exclusively funded by private donations. In some cases, the funding is being supported by a small contribution from the families –when this is feasible– since the service has increased operational costs due to its home visiting character. Center based programs are mainly funded from allowances related to the therapies of the child with no specified budget allocated to ECI as such.

4. Recommendations

Greece is currently facing the unique opportunity to link the deinstitutionalization strategy –under development - with the need to provide a comprehensive action plan for the design and implementation of the ECI services strategy. This will possibly lead to a well-structured and organized way to develop this service and officially acknowledge the important role of ECI for the future of the disability policies addressed to families and children with disabilities.

Such approach should be guided by the Council of Europe recommendations for:

- a national, coordinating transdisciplinary system for identifying and assessing abilities and needs;
- mutual support programmers for parents and appropriate consideration of the individual needs of children and their families; design individualized programs to ensure their social inclusion;
- promoting and supporting active involvement in, and ownership of, the situation by families;
- inclusion of organizations of parents and NGOs representing them in the development of community-based services;



- provide a strong legal basis and quality standards for service provision; the quality-of-service provision should be regularly reviewed or assessed;
- assess the existing services and the needs of all other stakeholders, such as service providers, families, etc.;
- raising public awareness on the special needs of children with disabilities with special provision to creating awareness in medical staff;
- training of the medical community to ensure their cooperation in the process of referral of the families to the appropriate ECI services;
- adequate human and financial resourcing and continuing staff training;
- sustainable funding for the service provision including high quality of training for staff and educational material and tools;
- funds should be allocated to research, monitoring and evaluation.



Country Report Kosovo

1. Description of the legal framework and bylaws on Early Childhood Intervention (ECI) services/for children with developmental difficulties

Despite improvements made on legislation regarding disability, Kosovo does not have a specific law or bylaw to regulate ECI services. The right for these services is an object of different laws in Kosovo but none of them regulates and specifies the provision, type of services and their structure. Even though there are different laws that do regulate the status of people with disability based on the type of disability, there are some types of disability, mainly intellectual disability, and autism, that are excluded from these laws and do not have any benefit.

Kosovo has shown commitment in the development of legislation and policy for disability such as the National Strategy on the Rights of Person with Disabilities 2013-2023, different laws like Preschool Education Law, Pre-University Education Law and Child's Protection Law. However, the legal framework lacks clarity because of the co-existence of laws with both a medical and a social approach to disability.

The current National Strategy on the Rights of Person with Disabilities 2013-2023 (henceforth, NSPWD) is an "important mechanism to ensure that principles that are embodied in the United Nations Convention on the Rights of People with Disabilities are incorporated in the policies and programs that impact the life quality of People with Disabilities in the Republic of Kosovo"ⁱ. Its goal is "to promote, protect and ensure the complete and equal enjoyment of all human rights and fundamental freedoms by all the persons with disabilities and to promote respect for their inherent dignity". The document aims to provide guidance to all government sectors, and calls for actions which are specific, measurable, and achievable and ruled by budgeted action plans with clearly defined timelines. It requires that all governmental institutions work in non-discriminatory ways and emphasises collaboration with Disabled Person's Organizations (DPOs) and civil society organisations (CSOs). Furthermore, the NSPWD is based upon existing regulation and determines all upcoming legislation concerning persons with disabilities in Kosovo.

Preschool education law, approved in 2006, specifies only the right that children with disability have on preschool education. Additionally, and regarding professional services for them, it specifies that when the Ministry of Education and municipalities decide to support public initiatives, must have as a criteria provision of services from that undertaken initiative. In contrast, the Pre-University



Education law, approved in 2011 by the Kosovo Assembly, ensures the right for education and specifies that municipalities are responsible to provide for schools needed staff and equipment which would facilitate the education of disability.

There is a Bylaw that regulates the Pedagogical Education of Children with Special Education Needs (SENs). Based on this bylaw, every municipality creates its Municipal Evaluation Team, which would evaluate every child that the teacher, parents, and school management considered for the evaluation. This team decides if the child needs Individualized Education Plan or not. The usage and procedures of applying Individualized Education Plan are regulated in another bylaw. Finally, there is another bylaw which regulates the professional background that every staff that work in education institutions should have. Page | 17

Child's Protection Law is another law approved in 2019 by the Assembly of Kosovo. This law describes and ensures the right of children with disability to be protected, the right to receive education and/or rehabilitation services.

Lately, with the initiative of NGOs engaged in the field of disability, it has been drafted an Inclusive Law for all disabilities. This law is in the process of approval by the assembly of the Republic of Kosovo. In this draft-law are included all the types of disability and it is regulated the evaluation, benefits, and services provision. The law has its article for ECI services, where is described how to structure, as well as the types of services and beneficiaries.

2. Description of ECI services

ECI services, even though not structured, are provided mainly from therapeutic fields, such as psychology, speech pathology, ergo therapy, physiotherapy, among others. Services are provided mostly by NGOs which represent people with disability or other specific disorder and from private clinics.

There are centers which provide services in daily basis with a specific frequency of each service during the day. There are also day care centers which provide services within their daily program, where the child stays longer in that environment. The home-based services are a model which is rarely applied in Kosovo due to its complexity and costs.



In general, in Kosovo early intervention services are intended for an early age but in the programs of NGOs and clinics there is not an exact definition of age. There are some cases of NGOs where the age for an early intervention is set from 0–3-year-old or 0–6-year-old.

Due to the lack of monitoring from state institutions, the procedures of services and its documentation are not being applied. For examples, there are cases where the child gets an evaluation, but the parents do not get any report or other document which would be as guide for the parents. Page | 18

There is no adequate preparation which consist specific preparation in the field of early intervention of the professionals. Usually, the staff that provides therapeutic services within private centers or NGOs is from social field of therapeutic field, as psychologist, physiotherapist, speech pathologist, but their academic qualification is not specifically in the field of child development or early intervention. The possibilities to increase capacities in this area are minor, usually through trainings or other short courses which are project based.

The evaluation of disability is made by the commission, which is under the Ministry of Labour and Social Welfare. Based on the Law for Material Support of families of children with permanent disability, the Ministry of Labour and Social Welfare created the medical commission which evaluate the disability. The commission report than is sent to Center for Social Work, which is part of every municipality.

Centers for Social Work (CSW) are the primary bodies of municipal authorities mandated to deliver social services like family counselling, consultation on social protection issues, and referral to other relevant services (if they exist locally). The Law on Social and Family Services provides that each municipality establishes and maintains a Centre for Social Work staffed by appropriately trained and qualified professionals and social service officers.

The Law on Social and Family Services (LSFS) mandates municipal authorities with responsibilities to provide through Centers for Social Work or other mechanisms, assistance, and day care for individuals who because of age or disability are unable to perform these functions for themselves and who have no family or assistance available to them [Article 6.7 (a) (b)].

Until 2009, the CSWs were operating under the direct management of the central level, i.e., the Ministry of Labour and Social Welfare. The delivery of social services was decentralised from the central government to the municipalities in 2009, giving them full and exclusive powers in the



provision of family and other social welfare services, such as care for the vulnerable, foster care, childcare, elderly care, registration, and licensing of the care centers, as well as recruitment, payment of salaries and training of social welfare professionals.

Although decentralisation aimed to bring services closer to the citizens by transferring them to the purview of the municipalities where they could be better prioritized and monitored, the findings of this study suggest that the decentralization process has not yet been finalized and it has not been well planned nor executed. Although the responsibilities were transferred from central to municipal authorities in 2009, the CSWs have not been fully incorporated into the municipal structures. The municipalities do not yet consider CSWs as institutions of their own, which is reflected in a lack of adequate funding, staffing, and facilities. Municipal and CSW representatives also reported that decentralization has created administrative burdens for the coordination with the Ministry of Labour and Social Welfare regarding the social assistance. Most of the respondents identified decentralization as a necessary process. However, it needs specific bylaws and budgeting to meet the intended objectives. Page | 19

3. Funding of the services

There is no specific fund from state institutions to support ECI services. Yearly, the Ministry for Social Welfare supports centres and NGOs that provide social services through project calls. Different private clinics and NGOs, specifically those who provide therapeutic services for children with autism, their sustainability is mostly from the fee for services which families are asked to do. Other ways to fund services are private donators, different campaigns that NGOs undertake.

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



4. Recommendations

Kosovo should develop law and bylaws to regulate ECI services at a national and local level. By developing these legislative documents, it will be structured the type of services, distribution of services into the regions, provision centers, frequency, and their funding. It is also needed the development of specific parameters for determining a specific financial formula on social services.

Page | 20

These documents should also regulate the education degrees which would have an impact on the field and service quality.



Country Report Montenegro

1. Description of the legal framework and bylaws on Early Childhood Intervention (ECI) services for children with developmental difficulties

Considering that the childhood is the most dynamic period of the neurological development throughout the whole life span of a human, every responsible society aims to give the best start to each child. Good quality of health and social care, as well as learning and education, contributes to the comprehensive development of socio-emotional competences, life achievements, prevention of deviant behaviours, efficacy and efficiency of the systems and improvement of demographic indicators of a nation. Also, that apart from the previous factors, the crucial role in improving the situation of the children 0-5 years belongs to the public perception of the importance of early child development and the attitudes towards children that are acceptable or not acceptable in society.

Montenegro is relatively a young state (gaining independence in 2006) and a minor regarding its population (622.393 inhabitants according to MONSTAT⁵ in 2016). Data show that in 2016 the number of children aged 0 to 17 years was 138.219 or 22,2%, the number of children under the 5 was 40,000, the birth rate was 12,2 and the mortality rate was 10,4. Mortality rate of children under five was 3,8. Unfortunately in 2020, due to the Covid 19 epidemic, for the first time in its history, Montenegro had negative ratio of born and dead.

In Montenegro there are three Ministries perceived as the key players in designing and implementing the policies relevant for the ECD. These are Ministry of Health, Ministry of Finance and Social Welfare, Ministry of Education, Science, Culture and Sport. To present the legislative framework relevant for each ministry, we will mention the most important strategic documents, laws, and bylaws in each Ministry.

⁵ MONSTAT is a national statistics institute



MINISTRY OF HEALTH			
	DOCUMENT	YEAR OF ISSUING	ARTICLES FOCUSED ON ECI
1.	Law on the health protection	2016 (with amendments in 2017 and 2018)	<ol style="list-style-type: none"> 1. Art 16 (Health education) 2. Art 17 (Promotion of the age-related topics) 3. Art 25 (Screening; protection of children and youth; reproductive health; home outreach; rehabilitation at the primary level) 4. Art 36 (Description of services available at the primary care level)
2.	Law on Health Insurance	2016, with amendments in 2017,2018 and 2019	<p>Art 6 (All persons who are users of the social protection measures are automatically considered as health insured)</p> <p>Art 12 (children are insured via insured parents and children without parents are insured per se, until the age of 26.</p> <p>Art 16 description of the specific rights)</p> <p>Art 18 and 20 (special benefits for children, persons with disabilities and pregnant women)</p>
3.	By-Law on the organization, norms, and standards of the centre for children with special needs		Regulates the work of 6 regional early intervention centres for children up to 14 years on the primary health care level
4	By-Law on medical rehabilitation in stationary health care institutions specialized for rehabilitation on tertiary level	2016, with the amendments 2017, 2018 and 2019	Regulates the indications and the mode of using stationary rehabilitation in the Rehabilitation centre “Dr S. Milosevic” Igalo



5	By-Law on the providing assistive devices	2013, with amendments in 2014	Regulate the indications for issuing assistive devices and the list of assistive devices available
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MINISTRY OF EDUCATION, SCIENCE, CULTURE AND SPORT			
	DOCUMENT	YEAR OF ISSUING	ECI related
1.	Strategy on inclusive education (2019-25)	2019	The system should provide continuous support and expert assistance, and a stimulating and non-restrictive environment for optimal development and education; it should make services accessible, cherish participation and self-reliance and create environment for full participation, the development of potentials and of personality, having in mind that early childhood development is key to a fulfilling and productive life of every child.
2.	Law on education of children with special educational needs	2004, with amendments in 2010 and 2017	<p>The term “children with special educational needs” includes children with disabilities, children with developmental physical, intellectual, sensory disabilities, children with autism-spectrum disorders, children with combined disabilities, developmental difficulties, speech/language difficulties, behavioural disorders, children with severe chronic diseases, children with long-term illnesses and other children with learning difficulties caused by emotional, social, linguistic and cultural barriers.</p> <p>Children who are issued referral decisions are admitted to preschool educational institutions free of charge.</p> <p>Individual development/education plan (IDEP) serve as the basis for working with the children with special educational needs.</p>



			The individual transition plan (ITP) serves to facilitate transition from the primary to the secondary school
3.	Strategy on the preschool education	2010-2015 2016-2020	Gives the direction for the development of early education
4.	By-Law on conditions for providing and using and minimal standards for services aimed at living in the community	2017	Regulates minimal standards and norms of personal assistance
5.	By-Law on conditions, mode, and the acting in directing children with special educational needs in the system of education	2015	Regulates the assessment of child's needs in education



MINISTRY OF FINANCE AND SOCIAL WELFARE

	DOCUMENTS	YEAR OF ISSUING	MAIN FOCUS
1.	Law on social and child protection	2013, with amendments in 2015,2015,2015,2016,20162017,2017	<p>Art 20 Focused on types of rights available for children with disabilities: BASIC CASH BENEFITS: material cash assistance for the family (MOP), personal disability allowance; human assistance and care; one-time crisis financial support</p> <p>Art 40 Child cash benefit; parents’ compensation for caring about the child with disability; fully paid salary for the parent who works half working hours if he/she cares for child with disability; special pension status for parents of children with disabilities; etc.</p> <p>Art 60 BASIC SOCIAL SERVICES. Day Care Centers, personal assistance, counselling support, home care and sign language translation, placement in foster family, placement in dormitory institution for education of children with disabilities, placement in special institution.</p>
2.	By-law on detailed conditions to use the cash benefits of social and child protection	2015	Regulating in detail the above-mentioned Law
3.	Law on the benefits for persons with disabilities during the use of public	2008, with amendments in 2015 and 2017	Focused on free of charge transportation in public means of transportation, including the costs for the personal assistant



	transportation means		
4	By-Law on the conditions, mode, and the acting in realization of the right to work half time hours with full salary	2006	Focused on the right of parents of children with disability to work half time being paid full salary
OTHER LAWS			
5	Family Law	2007, with amendments in 2016 and 2019	Art.61.a;80,81 focused on early intervention
6	Law on free of charge legal counselling		Focused on attorney’s support in the jury processes linked to disability issues

Two main international treaties ratified by Montenegro and relevant for ECI are: the United Nation Convention the Rights of Persons with Disabilities (UNCRPD) in 2009, together with the protocol and the Convention on the Rights of the child in 2006. Additionally, in the framework of the EU accession process: In negotiating chapter 23- Judiciary and fundamental rights and chapters 26 Education and culture, the principles of equity and equal opportunities are being promoted, which is provided precisely by inclusive education. Important Strategies to mention are, among others: Master plan in Health sector 2015-20, Strategy against violence in the family 2016-20; Strategy for inclusion of persons with disabilities 2016-20.



2. Description of ECI services

Here the different ECI related services present in Montenegro:

- **Day Care centres (DCCs)** for the children with moderate and severe intellectual disabilities up from 3 years of age.
Profile of employees: psychologists, physiotherapists, nurses, special teachers, teachers, speech therapists.
There are 18 DCCs, regionally equally covering the territory of the state.
This service is centre-based with few outreach programs.
Parents are members of the board.
Children are referred to the DCC by the centres for social work.
- **Local commissions for directing children with special educational needs in the system of education:** there are 17 local commissions.
Profile of experts: paediatrician, psychologist, pedagogue, social worker, special teacher, administrator. Children are assessed from age 3-15.
Parents are part of the assessment process.
The decision of the Commission is advisory.
Children are referred to the Commission by the Health centres, schools, municipal office, or by parents themselves.
- **Centres for social work:** referring children and parents through and across the system of social and child protection, providing family-centred consultancy, therapy, and psychosocial support.
There are 13 centres for social work. They employ social workers, psychologists, layers, special educators.
- **Foster care:** including children with developmental disorders, additionally trained persons under the supervision of centres for social work.
- **Home care:** additionally trained persons under the supervision of centres for social work.
- **Personal assistance:** additionally trained persons under the supervision of centres for social work.
- **Maternity wards:** in 13 cities within the general hospitals, one within the hospital Meljine in Herceg Novi (public-private partnership) and 3 within the local health centres (Ulcinj, Rozaje and Plav).
Staff: gynaecologists, midwives, nurses.
- **Local Health centres** in 17 municipalities (out of 21). Each health centre has gynecologist and paediatrician, according to the standards. In addition, all health centres have units for: patronage care, physical rehabilitation, mental health, and reproductive health. Eight health centres have the unit called Centre for children with special needs.
- **Institute for rehabilitation “Dr S. Milosevic” in Igalo.**



Profile of employees: specialists in physical rehabilitation, neurologists, psychiatrists, paediatrician, psychologist, internal medicine specialists, special educators, physiotherapists, nurses etc. paid through the public-private partnership.

Clients are referred by the Ministry of health or are self-financing clients.

- **National centre for Autism** is highly specialised, multidisciplinary, and training centre active in training, research, health care and other activities aiming at, directly or indirectly, affecting the understanding of autism and improving the psychosocial methods and acting in treating persons with autism, improving their life situation, inclusion and supporting their families.

Profile of employees: child psychiatrist, psychologists, special educators, physiotherapists, specialists for physical medicine and rehabilitation. Children are referred by the paediatricians

- **Centres for children with special needs:** there are 8 of them regionally positioned. Children are referred to these centres by maternity wards, neonatal departments, paediatricians, and centres for reproductive health or by the parents themselves.

The core team consists of paediatrician with additional training, psychologist, speech therapist and physiotherapist. Extended team could consist of the various consultants according to the needs of children.

- **Orthotic-orthopaedic Workshop "RUDO"** which is providing assistive devices.

Children are referred by the specialists of different disciplines.

Devices are paid by the Fund for Health Insurance.

- **Kindergartens and crèches.** There are about 100 public kindergartens and approximately 30 private ones.

Children are directed in the kindergartens by their parents.

Children with special needs are directed by the local commissions for directing children with special needs in the system of education.

Profile of staff: nurses, pedagogues, psychologists, speech therapists.

Children with special needs are using kindergartens free of charge.

- **Mainstream primary schools.** Seven mainstream schools have formed integrated classes, where children with special educational needs also attend some lessons with their peers from mainstream classes.

- There are three **Resource centres in Montenegro:** public Institution (PI) Resource centre for hearing and speech "Dr Peruta Ivanovic" in Kotor; PI Resource centre for children and adults with intellectual disabilities and autism "1. June" in Podgoric; Public Resource centre "Podgorica" for physical and sight impairments.

These centres support inclusive education by means of providing advice and expertise, teacher training and training of expert assistants to work with children with special needs in education, use of sign language, preparation, adaptation, and training on the use of



specialized books (in Braille and DAISY format) and other specialized teaching aids. **The Resource centres implement early intervention programmes.**

Children are referred by the Commissions for directing children with special educational needs in educational system

- **Personal assistance in education:** provided by persons additionally trained. The precondition to get the status of personal assistance in education is to have at least the secondary school education, favourably with bachelor in pedagogy, special education, or physiotherapy.
They are paid by the Ministry of Education.
They are supervised by teachers, school-based teams of professionals and school principles.
- **Mobile teams organized by The Bureau for education.** There are three teams for three regions (north, south, and central region). They consist of psychologists and special education specialists together with the rehabilitators from resource centres and from mainstream schools. The teams visit schools and assist in development of the IDEPs (Individual educational and development plan). Children are referred to mobile teams by the schools.
- **Association of parents of children with developmental disorders:** providing different types of services: rehabilitation, home care, personal assistance, peer support, socialization, advocating, legal counselling etc. They are financed by the Projects and plural sources of financing like donations, production of souvenirs, legacies etc.

3. Funding of the services

Considering the description of the services in the previous section, and following the same order, they are categorized here according to their way of funding.

Services paid by the local municipalities:

- Day Care centers (DCCs)
- Local commissions for directing children with special educational needs in the system of education.

Services paid by the Ministry of Finance and Social Welfare:

- Centres for social work
- Foster care
- Home care
- Personal assistance



Services paid by the Health Insurance Fund:

- **Maternity wards within the general hospitals**
- **Local health centers**
- **The Institute for rehabilitation “Dr S. Milosevic” in Igalo.**
- National centre for Autism
- Centres for children with special needs
- Orthotic-orthopaedic Workshop “RUDO” which is providing assistive devices.

Services paid by the Ministry of Education, Science, Culture and Sport

- Kindergartens and crèches.
- Mainstream primary schools.
- The three Resource centres in Montenegro: public Institution (PI) Resource centre for hearing and speech “Dr Peruta Ivanovic” in Kotor; PI Resource centre for children and adults with intellectual disabilities and autism “1. June” in Podgorica; Public Resource centre “Podgorica” for physical and sight impairments.
- Personal assistance in education: provided by persons additionally trained paid

Services paid by the NGO sector

- Association of parents of children with developmental disorders.



4. Recommendations

Here some recommendations for improvement of the ECI system in Montenegro:

1. Prevention of infant abandonment and boosting reintegration and adoption of young children are high priorities (de-institutionalisation). The presence of some young children in residential care is a concern that requires further strengthening. The Ministry of Finance and Social Welfare (MFSW) is enabled to support units within maternity wards. Psychologists and social workers in maternity wards should be trained to identify the first signs of infant abandonment and provide timely interventions while the mother and baby are still in maternity ward; parent-and-baby units in the municipalities to allow the mothers and the babies to stay together, if they have no alternative accommodation, (to help devote attachment and overcome psychological trauma -usually postnatal depression and other types of crisis). Centre for social work should have family support teams to create a support plan for family and community reintegration.
2. Improve the collaboration of healthcare, child and social protection and education sector with the aim of coordinating service delivery for the timely development of children with special needs in education and psycho-social-financial support to their families.
3. Improve the coordination of relevant public sectors, partners, and civil society.
4. Improve the monitoring and quality insurance mechanism in all sectors.
5. Campaign for the cultural shift towards a better recognition of the importance of early child intervention among all the society actors.
6. Ensure the participation of children with special needs in mainstream education system.
7. Revise the work of the local referral panels for the sake of maximum consistency, accountability, and uniformity.
8. Promote early intervention and involvement of children with special needs in education continuity of schooling and individual transitions across educational levels.
9. Develop a culture of inclusive approach and the active role of teachers and expert assistants.
10. Continuously work to upgrade teaching process.
11. Continuously promote the inclusive process.
12. Improve the services provided by Resource centers.
13. Work to improve accessibility of the schools and teaching materials (books, teaching materials).
14. Prevention of child neglect, abuse, and violence.
15. Prevention of discrimination of children with disabilities.

Country Report North Macedonia

1. Description of the legal framework and bylaws on Early Childhood Intervention (ECI) services/for children with developmental difficulties

The Republic of North Macedonia significantly improved over the past two and a half decades the realisation of children's rights in health, education, and social protection. The country has ratified the UN Conventions on the Rights of the Child (UN CRC) and the Rights of Persons with Disabilities (UNCRPD) and therefore, is obligated to convey to all its enshrined rights. Yet, there are many challenges present in several sectors including the service provision sector for children and persons with disabilities. One of the most challenging reforms would be to improve the fragmented system of early childhood intervention.

In the last few years, the legal framework that regulates the rights of children with disabilities was amended through:

- The latest Law on Social Protection, which provides better possibilities for creation and provision of different types of services, including ECI services for children with disabilities, by a variety of services providers.
- The new Law on Primary Education, that provides all needed legal preconditions for effective inclusive education, including the needed educational assistance to children with disabilities.

However, it is very important to note that **there is no specific reference to ECI services in the national legislation, making this an underregulated sector.**

The main legislation that regulates children's rights (including children with disabilities) is the Law on Protection of Children. Besides the financial support to disadvantaged children and/or families, this law is regulating the preschool education (the network of kindergartens) and the creation of so-called Centres for Early Childhood Development, which are basically kindergartens in rural areas. The access of children with disabilities in these services has been gradually improved in the past decade. But specific ECI services for children with disabilities have not been envisaged within the law.

Another important issue is that the needed services for children/persons with disabilities and their families are, by default, located in the social sector, but ECI services for children from 0 to 6 years are also available in the health sector (identification, assessment, basic support in medical centres).



The improvement of the fragmented early childhood intervention system has recently become a priority area for the national authorities. Supported by UNICEF, many important initiatives (located in the health sectors) have been realized: training of the health care workers, family doctors and patronage nurses, reform of the “categorization” process according to ICF of WHO, creation of several services to support children with disabilities and their families.

Unfortunately, these initiatives are insufficient to cover the gap in the service provision related to early identification, followed by service provision in early childhood intervention and support as well as counselling for parents in detecting and accepting the disability of their child. Most of the existing public services are not following the current needs nor are tailor-made so that they can respond to the actual needs of the child’s development stage, abilities etc.

Moreover, quality standards are not established nor any other mechanism for quality control when providing ECI services. This results in creating services and delivering them by private providers or freelancers. Usually, they are working at private facilities or going to children’s home to provide the service that the child needs for certain fee that parents must pay.

Another challenge is that most of the services provided for persons with disabilities, including children with disabilities, are offered in the bigger municipalities and cities. Hence, those living in rural areas have difficulties in accessing any type of social services including ECI services.

As mentioned above, the Law on Social Protection offers opportunities for provision and delivery of different types of social services, including ECI services. The lack of by-laws and regulations followed by lack of funds to provide the foreseen services hinders the process of service provision.

Furthermore, the system requires cross-sector cooperation and links among the different types of services. This is crucially important between health and social care and education since these are essential for screening, referral and offering the adequate services.



2. Description of ECI services

In the Republic of North Macedonia, the Early Childhood Intervention services are provided by different providers in deferent sectors.

In several municipalities, within the Public Health Centres, there are Centres that follow-up children born with risk (covered by the Ministry of Health), which also provide counselling services for the families. Also, the patronage nurses (trained for early detection and intervention by UNICEF) are part of the ECI Services in our country. Within the University Clinic on Paediatrics and University Clinic on Psychiatry, there are departments/specialist teams that provide early identification, treatment, and follow-up of children with disabilities, as well as support and counselling for their families.

The Ministry of Labour and Social Policy governs the network of day centres for children with intellectual and physical disabilities that are supposed to provide some forms of early intervention for children with developmental disabilities.

The municipalities, under the guidance of the Ministry of Labour and Social Policy, organize kindergartens and Centres for Early Childhood Development, where children with disabilities are enrolled as well. The inclusion of children with disabilities in these public services has been improved but is still facing many challenges.

Few NGO service providers offer different ECI services, both in-home and centre-based services. Also, different profiles of professionals (special educators, speech therapists) offer individual in-home sessions for children with disabilities. However, there is an essential need of structural development of the ECI services in the country.

Unfortunately, there is no comprehensive and reliable data on the number of children and families that use ECI services, as well for the structure, content, and costs of these services. Therefore, UNICEF is currently supporting in-depth research that would produce detailed situation analysis on ECI services (started in September 2021).

It is crucial to highlight that, with the support of UNICEF, in 2019 the Government started piloting the new assessment model based on World Health Organisation (WHO) International Classification of Functioning, Disability and Health, which should replace the old-fashioned system based on the disabilities and defects of the person. The new model emphasizes that professionals involved in the functional assessment should also provide counselling and support to the families.



3. Funding of the services

The national and local authorities are still predominant providers of public services, including the ECI services. The services that are provided within the health care sector are financed by the national budget. The services provided within the social sector (kindergartens, Centres for Early Childhood Development, public day centres for children with disabilities) are financed by the national budget. The same applies for the “educational assistance” services available for children with disabilities enrolled in inclusive education. However, there is no data on the actual costs of these services. The families are paying for the ECI services provided by private entities or individual professionals/freelancers, starting at 10 Euro per hour.

Page | 35

The latest Law on Social Protection, adopted in May 2019, and the accompanying by-laws are strongly emphasising the need for decentralisation and pluralism in the service provision sector, allowing opportunities for equal operation of public and private sector, including Non-Governmental Organisations (NGOs). There are legal possibilities that allow different types of service providers to be licensed and financed by the state. This is extremely important for the NGO service providers that are struggling to provide sustainability of the existing services.

It is also important to highlight that in the last few years the state is gradually redirecting the funds to community-based services, instead to institutional care. With the adoption of the DI strategy in 2018, the Government had allocated a specific budget line “Deinstitutionalisation and services for support” in the national budget. For 2019⁶, the Government had allocated 2.75 million Euro, demonstrating the political commitment for transformation of the institutions and a more effective service provision at the community level. ECI service providers could benefit from this budget line and develop services for children with disabilities from 0 – 6 years.

UNICEF remains the most important supporter of the child reforms in the country, technically and financially. All major initiatives have been initiated and implemented with support of UNICEF, including the development of ECI services. The Delegation of the European Commission is strongly supporting the development of social services, including services for children with disabilities and their families. Also, currently, there is an ongoing World Bank project for improvement of the social services for vulnerable groups financed with 10 million EUR allocated to support the municipalities in the process of development of a new service and improve the service delivery at the community level.

⁶ Budget of Republic Macedonia, Ministry of Finance 2018, budget line 46, page 270. Available at: <https://www.finance.gov.mk/files/u3/BUDGET%202019%20SOBRANIE.pdf>.



It is of utmost importance that the Government has taken the responsibility to provide the sustainability of the established service within the above projects, especially with the health and economic crises caused by the pandemic with COVID – 19.

4. Recommendations

Primarily, our country must provide accurate data regarding persons with disability, including children with disability, to establish adequate and quality services. Consequently, a Register for following-up children born with risk must be created as an important prerequisite for early detection and diagnosis, and referral to different services for developing the potential of every child.

- It is necessary to develop:
 - Specialized health, social and educational services, programmes and prevention services, early detection, diagnostics, early treatment and rehabilitation for children with disability
 - Counselling services to support families that have a child with disabilities.
- The ongoing reform of the assessment system of children born with risk factor should be empowered with complete implementation of the ICF model.

Accordingly, ECI services must be developed, so that will provide personalized, tailor-made support to every child with disabilities. This will lead to improvement of inclusion of the children in these services as well as equal distribution of the services throughout the country.

It is necessary to ensure continuous training of professionals working with children with disabilities. Moreover, it is crucial to provide adequate training for the staff and raise their awareness regarding the needs of children and persons with disabilities.

Within the process of deinstitutionalisation in the country, ECI services should be included in all stages. To provide ECI services is necessary to develop regulatory mechanisms, starting with mapping the needs on national and local level, developing procedures for licensing and accreditation of service providers, developing quality standards and procedures for funding services. Establishing an effective monitoring system for social service providers in terms of quality (private and public ones) is also needed.

The NGOs, which provide ECI, and other social services should be accepted as equal partners by the state, through licensing and contracting for full funding of the services provided by the NGOs.



Cross-sector cooperation must be strengthened. There is a need for genuine commitment from all stakeholders (ministries, agencies, NGOs) to work together and share information and practices. Similarly, the roles of different stakeholders must be precisely defined. This cross-sector cooperation must also provide a National Strategy on ECI service provision.

5. Conclusions

The presented conclusions are formulated on basis of five Balkan country reports compiled by members from the Member Forum on Early Childhood Intervention (MF-ECI) from the respective countries. Although each country shows its particularities in on how the ECI services are regulated, organised, financed and functioning, there are striking similarities as well. We will present our conclusions according to the categories that are used in the research.

Legal and regulatory framework

In none of the studied countries exists a functional legal framework that regulates, organises, guarantees quality or finances ECI services. In Albania and Greece exist laws on ECI, but due to the lack of bylaws and operational regulations these laws yet can be considered as non-functional. In the countries (except for Kosovo) the UNCRPD often supplemented with the UN CRC, form a basic legal reference point for the ECI sector.

All countries have laws and regulations for social and/or health services, but ECI services seldom are mentioned. It reflects the incapacity countries have in defining the nature of the ECI services; are they social services, health services, or social-health services?

In most countries, in the legislation care for the age group from zero to three years is captured in the medical sphere. As a result, there is no legal framework for family oriented ECI care.

Governance and coordination structures

The way ECI is (not) regulated is reflected in the governance and coordination in each country. There are clear differences between the countries regarding which ministry is, or should be, the leading ministry for ECI. In case there is a combined Ministry of Health and Welfare or Social Services (in Albania) the question about the social and/or medical nature of the ECI services can potentially be resolved more easily.



In most countries the Ministry of Labour and Social Policy is the leading ministry for ECI. Yet, clear regulative policies are nearly non-existent.

In none of the countries inter-sectorial coordination functions between the three for ECI key ministries of health, social affairs, and education.

The decentralisation of care services to the municipal level is taking place in all involved countries, which potentially creates chances for the recognition and financing of ECI services. Unfortunately, the lack of a functional national legal and regulatory framework for ECI and the lack of funds at the local level hamper seriously the functioning of ECI services.

In none of the countries an inter-sectorial and multi-stakeholder ECI coordination takes place. No references are made to deinstitutionalisation policies, in which the importance of ECI for the prevention of the institutionalisation of young children could be reflected.

Provision of ECI services

In all countries most services are provided by non-governmental, non-for-profit organisations (NGOs and Parents' Associations) who are not, or on an insignificant level, financed by local, regional, or national governments.

Family centered, home-/natural environment-based services are only offered by a few non-for-profit service providers. The focus of most services tends to be therapeutic. Some services combine center-based and family-based

In most centers therapists with different professions provide services. Most common are psychologists, physical therapist, occupational and speech and language therapists, and special educators. There is no mentioning of social workers. Medical staff is only available where the service is provided in the medical sector.

Funding mechanisms

The lack of clear and quality laws and regulations for ECI and the recognition of the role of the non-for-profit (NGO) services in all countries is reflected in inadequate, insecure, and insufficient financing mechanisms for these services.

Only services provided by state institutions are fully funded. The private-for-profit sector is financed with the commercial fees families pay for the services. Therefore, these services are not accessible for the poorer families.



The NGO services often depend on insecure income from donations and sponsorships and/or yearly grant competitions. As consequences the NGO service providers must dedicate a lot of institutional capacity to fundraising and face yearly.

The NGO services experience stress every year to survive financially. The lack of sufficient financing places a lot of stress on the deployment of the available staff and the management. The lack of more stable financing sometimes leads to the closure of these services.

Although the decentralisation of the social services to the municipal level provides more chances for the NGO services to become recognized and financed, in all cases the received financing is insufficient and insecure, putting at risk the quality and survival of these services.

Challenges

On top of the above-mentioned fundamental issues the following challenges need special attention:

- In none of the countries comprehensive and reliable data exist relating the number of children and families that use or need ECI services, as well for the structure, content, and costs of these services. In some countries UNICEF started to collect these data.
- A common understanding of ECI does not exist in any of the countries, resulting in a fragmented landscape of different types of services that are labelled 'ECI' and in the unequal access for families to quality services.
- In all countries among the public, professionals and policy makers doesn't exist awareness about ECI and the crucial importance of the service.
- No integrated chain of services exists between health, social and education sectors.
- In none of the countries exists a systematic pre- and in-service training service system for professionals. ECI is nonexistent in the curricula at the universities where social and health care professionals are educated. In-service trainings are organised by NGO service providers. The costs for these trainings are financed through project budgets from donors or are supported by UNICEF.
- No universal, comparable screening and assessment instruments are used. When screening or assessment is applied, they often take place at a late stage (often around the age of three) in the development of the child. There is also a need for instruments that can be used by both professionals and parents.
- Quality standards are not established, nor any mechanisms for monitoring, supervision, impact measurement, or quality control. The lack of such a quality assurance system exposes family and the vulnerable child to great risk.



- Access to the services is very unequal distributed between urban and rural areas. There is a huge need for mobile services, support on distance, and an intricate network of outreach services.

Overall conclusion

The above-described alarming situation calls for a systematic approach in developing a comprehensive and quality ECI system in each of the countries. In every country, and on the European level, good examples for developing ECI systems already exist, which should be used to support the development.

It is recommendable to formulate an *overarching regional program*, which will facilitate in each country the exchange of experiences, advocacy support, trainings, the development of the essential instruments, research, publications, curricula development, and awareness campaigns.



EASPD is the European Association of Service providers for Persons with Disabilities. We are a European not-for-profit organisation representing over 20,000 social services and disability organisations across Europe. The main objective of EASPD is to promote equal opportunities for people with disabilities through effective and high-quality service systems.