



EARLY CHILDHOOD INTERVENTION IN EUROPE

HOW CAN THE EU SUPPORT CHILDREN WITH DISABILITIES
FROM THE VERY FIRST STEP?

*2020 EASPD Report on the
European Semester*

“Early childhood development will not only benefit the children of today, but will have a direct impact on the stability and prosperity of nations in the future.”

Dr. Margaret Chan, Director-General of the UN World Health Organization¹, 2016

“Early intervention and prevention are essential for developing more effective and efficient policies, as public expenditure addressing the consequences of child poverty and social exclusion tends to be greater than that needed for intervening at an early age.”

European Commission Recommendation “Investing on children: breaking the cycle of disadvantage,”² 2013

“Infancy is a crucial developmental stage when every individual will form the core of his/her conscience, tests his confidence with his/her body, establishes intensive interpersonal bonds, develops the ability to trust and relate to others, and lays down the foundation for lifelong learning and thinking.”

EASPD Statement on Early Childhood Intervention³, 2016

¹ <https://news.un.org/en/story/2016/10/541922-investing-early-childhood-development-helps-communities-thrive-un-backed-report>

² Official Journal of the European Union, 2012/112/EU: <https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2013:059:0005:0016:EN:PDF>

³ EASPD Statement on Early Childhood Intervention, 2016

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1 FOREWORD

Early Childhood Intervention (ECI) has been at the core of EASPD's actions for many years. EASPD has set up a dedicated group of experts on the topic: the [Interest Group on Early Intervention](#) and is currently leading a major project on it: [ECI Agora](#), which has provided training on family-centred ECI services in a number of countries and has supported them to reinforce the legal framework for ECI.

On an annual basis, EASPD also organises [inclusive education programmes](#) in Europe, which build on ECI as a starting point for inclusion in schools.

This report comes at a time of health and economic crisis where everything has become a priority. Individuals, families and authorities alike are all trying to find new ways to balance family life, social life and professional life. In this regard, ECI has a crucial role to play in supporting families of children with disabilities. By providing high quality, targeted and family-centred support, ECI services empower families to:

1. Support their children in their own home;
2. develop a better work-life balance, better spread the burden of care amongst parents and go back to work earlier;
3. ensure families don't feel left alone in caring for their children with support needs.

It is crucial that the European Union supports Member States and candidate countries to develop strong and sustainable legal and financial frameworks to support ECI services, including in times of crisis.

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EASPD is thankful for the continuous support received by its members who are

delivering support services to persons with disabilities across Europe and in varying socio-cultural and economic contexts. Even in hard times and with a COVID-19 pandemic that has caused many losses and many difficulties for the provision of services to those most in need, support services have been ready to react and to adapt their support systems to ensure availability and continuity of support.

2 LIST OF ABBREVIATIONS

CR: Country Report

CSO: Civil Society Organisation

CSR: Country Specific Recommendations

DPO: Disabled Persons' Organisations

EADSNE: European Agency for Development in Special Needs Education

EASPD: European Association of Service providers for Persons with Disabilities

ECEC: Early Childhood Education and Care

ECI: Early Childhood Intervention

EPSR: European Pillar of Social Rights

ES: European Semester

ESF: European Social Fund

EU: European Union

NGOs: Non-Governmental Organisations

SDGs: Sustainable Development Goals

UNCRC: United Nations Convention of the Rights of the Child

UNCRPD: United Nations Convention of the Rights of Persons with Disabilities

Early Childhood Intervention (ECI) is intended for all children who are subject to a developmental risk or developmental disability. The aid covers the period between the prenatal diagnosis and the moment that the child reaches the age at which school is compulsory. It includes the entire process from the earliest possible identification and detection up to the moment of training and guidance. Thus, Early Childhood Intervention can be defined as all forms of child-oriented training activities and parent-oriented guidance activities implemented in direct and immediate consequence of the identification of the developmental condition. Early Intervention pertains to the child as well as to the parents, the family and the broader network of the child.

However, this definition is not used consistently. Across Europe different definitions are used, including with varying age ranges as the age of compulsory school is not unified around the EU. For example, EADSNE (European Agency for Development in Special Needs Education) defines it as 'a range of all necessary interventions – social, medical, psychological and educational – targeted towards children and their families, to meet the special needs of children who show or risk some degree of delay in development' and called it 'Early Childhood Education and Care'. This definition however is more focused on educational purposes and does not consider informal care as part of the context of ECI.

In the framework of this report, EASPD is focusing on ECI services for children from conception to 6 years old, with the aim of providing high-quality family-centred services that empower families to take control of the care and support of their children in their home.

This report is divided into 2 parts:

The first Part- Early Childhood Intervention and the UN CRPD - looks at the meaning of ECI through the legal lens offered by the United Nations and the European Union policy frameworks.

The second Part- Country-specific information and recommendations - includes an overview of ECI implementation in 7 countries - Albania, Bulgaria, Croatia, Finland, Greece, Poland and Slovakia, along with key recommendations addressed to policy makers.

Throughout the report, an assessment of ECI development and implementation is provided looking at how ECI has been addressed by the European Semester and/or how ECI issues should be strengthened in the next European Semester cycle.

EARLY CHILDHOOD INTERVENTION IN INTERNATIONAL LEGAL FRAMEWORKS

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Early Childhood Intervention (ECI) is the process of supporting families of children with disabilities through individualised, home-based interventions. At all stages, whether preschool or earlier, ECI programmes should be viewed as a two-generational approach in which professionals work with parents to help them support their infants and young children in their natural environments. Bringing the intervention into the home also provides opportunities for a whole family involvement, personalised service, individual attention, and relationship-building.¹ Building on this model, ECI is defined as a system designed to support family patterns of interaction that best promote child development, while the focus is placed upon parent-child interactions, family-orchestrated child experiences and on the help provided to parents in order to maximise their child's health and safety.²

The right for a high-quality Early Childhood Intervention is recognised by the [United Nations Convention on the Rights of Persons with Disabilities \(UNCRPD\)](#), the [United Nations Convention on the Rights of the Child \(UNCRC\)](#), the [European Pillar of Social Rights \(EPSR\)](#) and the [Sustainable Development Goals \(SDGs\)](#).

EARLY CHILDHOOD INTERVENTION & THE UNCRPD

In the last decades, the United Nations has adopted two international human rights treaties which define human rights for children and young people with disabilities at international level: the UN Convention on the Rights of the Child (2005) and the UN Convention on the Rights of Persons with Disabilities (2006).

More specifically, Article 23 of the Convention on the Rights of the Child (including General Comment 7 to the CRC Implementing Child Rights in Early Childhood), and Article 7, 23, 24 and 25 of the United Nations Convention on the Rights of Persons with Disabilities specify the standards by which all States Parties can guide the development of programmes, services, and laws necessary to comply with the Conventions.

¹ M.J. Guralnick, 2001

² Ibid.

The human rights model of the UNCRPD puts the focus on the rights and abilities of the individual, where they are empowered and receive adequate support tailored to their needs to fully enjoy their human rights and be included in society to develop “to the maximum extent possible”.

With almost universal ratification of the Convention on the Rights of the Child and the growing number of States Parties that have signed or ratified the Convention on the Rights of Persons with Disabilities, the majority of countries in the world have now committed to implementing the human rights articulated in these treaties. In addition, the European Union ratified the UNCRPD in as a regional integration organisation.

Even if Early Childhood Intervention is not explicitly defined by those conventions, the following articles of the UNCRPD are particularly important for infants and young children with disabilities and their rights to early intervention:

- **Art. 7: Children with disabilities**

The concepts of “best interests of the child,” as a primary consideration in all actions regarding children and “right to express their views” are also found in the UNCRC. In addition, the right to “full enjoyment of all human rights and fundamental freedoms” on an equal basis with other children is also restated.

- **Art. 23: Respect for family**

States Parties shall provide “early and comprehensive information, services and support” to both children with disabilities and their families so that separation from parents and/or family only occurs when necessary for the best interests of the child.”

- **Art.24: Education**

States Parties shall ensure an “inclusive education system at all levels. The article requires that States Parties provide: (1) reasonable accommodation to individual needs; (2) support to facilitate effective education within the general education system; (3) opportunities that enable individuals to learn life and social development skills that facilitate their full and equal participation in education; and (4) training for professionals and staff who work at all levels of education.”

- **Art. 25: Health**

States Parties are mandated to “provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children (...)”.

EARLY CHILDHOOD INTERVENTION & THE EUROPEAN UNION

At EU level, the European Commission built its action on ECI in the framework “Early Childhood Education and Care” (ECEC). ECEC refers to “any regulated arrangement that provides education and care for children from birth to compulsory primary school age, which may vary across the EU. It includes family-day care, privately and publicly funded provision, pre-school and pre-primary provision”³. Although it is very close to ECI, the fact that it is limited to “regulated arrangements” underlines the need for Member States to develop clear regulations for ECI services, to bridge the gap between ECEC and ECI.

The European Union uses different tools to promote high quality ECEC all around Europe.

- **European Pillar of Social Rights**

Since 2017, the [European Pillar of Social Rights](#) aims to modernise the EU legal framework to give effective social rights to EU citizens. The Pillar sets out 20 key principles to achieve fair and well-functioning labour markets and welfare systems across the EU. The principles are structured around the following three categories:

- Equal opportunities and access to the labour market.
- Fair working conditions.
- Social protection and inclusion.

Among the principles, some are directly targeting children and family policy. These include the right to quality and inclusive education (Principle 1) and the right to affordable quality early childhood education and care (Principle 11). The Pillar also recognises this in principle 11 “Childcare and support to children”, while the UN Sustainable Development Goals (SDGs) refer to this with Goal 4 on inclusive and equitable quality education. Furthermore, in order to improve social inclusion, affordable and quality ECI is essential for parental employment and female labour market participation. Therefore, this is a key measure for achieving sustainable and inclusive growth.

In 2019, the EU ministers of education adopted the [2018 proposal](#) for a Council Recommendation on quality ECEC based on the European Pillar of Social Rights. The latter proposes key actions on accessible, affordable and inclusive childcare services, staff development, monitoring and evaluation.

The need for quality ECEC has also influenced the European Semester cycle of policy coordination, which makes economic and fiscal recommendations and monitors

3 European Commission, https://ec.europa.eu/education/policies/early-childhood-education-and-care_en

the implementation of the European Pillar of Social Rights. For instance, the 2019 European Semester cycle played a critical role for programming of the EU structural funds. This year, the European Commission's country reports highlighted ECEC as a targeted investment priority for more than half of all member states in the future 2021-2027 cohesion policy funding.

- **Europe 2020 Strategy**

The European Union "[Europe 2020 Strategy](#)" aims to tackle poverty and social exclusion in Europe, acknowledging the fact that, of the 80 million people in the EU who were at risk of poverty prior to the 2008 crisis, 19 million of them were children. Thus, while reducing child poverty and social exclusion was not made a specific Europe 2020 target, it has received some increasing attention. For example, the European Semester process, which implements the Europe 2020 Strategy via Country-Specific Recommendations (CSRs), advocates Member States, amongst other issues, for the implementation of a high quality ECEC.

- **Social Investment Package**

In 2013, to maximise the impact of the Europe 2020 Strategy, the Commission adopted the [Social Investment Package](#) (SIP) calling on the Member States to:

- Ensure access to quality services by improving access to early childhood education and care including for children under 3, eliminate school segregation, enhance access to health, housing, social services
- Support children's participation in services and decisions affecting them, such as social services, education, alternative care.

WHY IS ECI IMPORTANT FOR THE EUROPEAN SEMESTER?

5

As this report shows, the availability, accessibility and affordability of quality early childhood intervention is still far from being a reality in the European Union. This can be explained by a lack a policy helping coordination between the social, health and educational sectors, tackling shortage of qualified staff, ensuring a provision of comprehensive and family-centred ECI services, as well as a lack of awareness toward ECI as a whole.

As ECI is a right recognised under the UNCRPD (art. 7, 23, 24 and 25), the European Pillar of Social Rights (Principle 11) and the United Nations Sustainable Development Goals (Goal 4), it is clear that the lack of ECI provision for millions of children and their families living in Europe is a severe violation of their human rights. It is also clear that this has a negative impact on Europe's economy and job creation because the non-access to Early Intervention leads to a poor access to quality inclusive education, which has a negative impact on future academic and labour market outcomes⁴ and could turn to *"increase of the burden on pension, insurance and healthcare systems."*⁵

The issue of Early Intervention and its positive impact are known and promoted by the European Commission because they are "essential for developing more effective and efficient policies, as public expenditure addressing the consequences of child poverty and social exclusion tends to be greater than that needed for intervening at an early age."⁶ The direct social and economic impact of ECI is also highlighted by the United Nations.⁷

The European Semester process addresses this topic by putting ECEC as an investment priority for more than half of all member states in future 2021-2027 cohesion policy funding.⁸

The lack of access to ECEC is highlighted in the Semester reports of several EU Member States.

4 Include-ed (2014): Statement on Promoting Inclusive Education Systems in Europe.

5 European Political Strategy Centre

6 European Commission Recommendation "Investing on children: breaking the cycle of disadvantage", 2013

7 "Early childhood development will not only benefit the children of today, but will have a direct impact on the stability and prosperity of nations in the future" Dr. Margaret Chan, Director-General of the UN World Health Organization, 2016

8 European Semester Country Reports, 2019: https://ec.europa.eu/info/publications/2020-european-semester-country-reports_en

For example:

- **Croatia:** *“the European Commission states that ongoing investments in Early Childhood Education and Care need to be done to increase availability and access.”*⁹
- **Finland** *“the European Commission raised its concerns about the lack of sufficient funds to implement recent educational reforms in early childhood education”*¹⁰
- **Slovakia** *“the national enrolment rate of children in early childhood education and care, in particular of children below three, is the lowest in the EU, which has a further negative impact on educational outcomes.”*¹¹

The recognition of ECI is a very positive development. However, whilst progress has been made and ECEC is more prevalent in the European Semester than before, the more general emphasis on ECEC, without referring specifically to the development of ECI (or targeted measures for children with disabilities), could be problematic and could leave many such children and their families behind and not supported in the overarching ECEC policies. Specific references to targeted ECEC measures for children with disabilities (or other excluded or disadvantaged groups), such as ECI are therefore important.

Such references are also needed to ensure that upcoming funding programmes such as the European Social Fund+, which will be increasingly linked to the European Semester, can be used for targeted funding of ECI measures at national, regional and local level.

9 EU 2020 Country report - Croatia

10 EU 2020 Country report - Finland

11 EU 2020 Country report - Slovakia

COUNTRY SPECIFIC INFORMATION AND 6 RECOMMENDATIONS

ALBANIA

ECI services for children with disabilities are not yet a government priority

Albania has ratified the UNCRPD in 2012 and became a State Party to the UNCRPD in 2013. In November 2016 the Parliament passed a new law on social care services: 'Social Care Services in the Republic of Albania 161/2016'. This law foresees the provision of all types of social care services including Early Intervention Services. The policy and the legislative framework in support of the rights of people with disabilities is dynamic and evolving but it is facing a lot of challenges in its implementation. The biggest ones are the lack of bylaws and funding.

According to a study of World Vision (WV) and Save the Children in Albania, 1 in 10 children in Albania has some degree of disability, and it is estimated that 70,000 children with disabilities between 2-17 years old (0-2 years old children are not counted in this study)¹² live in Albania. Meanwhile, other data from governmental reports state that *"according to recent statistics from the State's Social Services, in August 2018, the number of persons officially recognised and confirmed as having disabilities in Albania is 141,740 (i.e. 4.8% of the country's population)"*.¹³ It includes 73,425 people with disabilities from work-related causes (who benefit from both social insurance contribution and supplementary social insurance from the social protection scheme) and 68,315 are children and adults who receive disability allowance and other benefits from the social protection scheme. In this last category, only 19,060 persons (28%) receive an extra insurance (payment) to cover personal assistant services (previously called caregiver services).¹⁴

The ministry's statistics only count people who are registered in the State's Social Services registry to get their monthly disability allowance. In order to get the disability

12 K.Voko & F. Kulla

13 Based on a report on disability conducted by WHO 15% of the world's population lives with a form a disability https://www.who.int/disabilities/world_report/2011/report/en/ (Population of Albania is 2,846,000 people)

14 Decision Nr. 380

allowance, parents or persons with disabilities need to apply for it on their free will. Reasons why many children and people with disabilities are not registered and counted in government data are the following:

- So far, Albania is failing to provide an efficient early identification system of children with disabilities. The referral system in the primary health care and education institutions has failed both to assess children and to keep records.¹⁵
- In rural areas it is still considered shameful to have a child with disability. Thus, families do not declare them, or even hide them.
- There is still a lack of information for parents on the possibility of being eligible for disability allowances.

Besides the lack of accurate data, one of the main problems in Albania is the scarcity of social services at national level.

IMPROVEMENTS AND CHALLENGES

The purpose of the 2016 law on social care services is to determine rules on the provision and delivery of social care services which are useful for the well-being and social inclusion of individuals and families in need of social care. However, so far there have been few or little actions regarding the implementation of this law. The Albanian Government is currently years away from providing bio-psycho-social services for people with disabilities. Based on official data from the government, during 2015, only 1,647 children with disabilities have been provided with social services (residential and non-residential) in Albania. That is why in the last 7-10 years 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 (the latter mostly work informally or without license).

UNICEF Albania's report for children with disabilities stated that *"administrative data suggest (...) an increase in the number of children with disabilities accessing services, from 3% in 2015 to 8% in 2017. However, almost half of all social services are provided outside the public sector, and civil society organizations report a gradual withdrawal of external funds, a trend that is likely to continue"*.

The new Law (2016) has identified 8 types of social care services including ECI for children up to 8 years old. The lack of bylaws and funds to provide these types of services is the biggest challenge. The government has not yet calculated and agreed on their cost.

A Social Fund was created alongside the new Law and this was supposed to be a funding instrument to support NGOs/private sector of social care service providers.

¹⁵ The full scale of the need for early intervention services is unknown as there can be considerable delays in identification of developmental delays and, therefore, monitoring of the numbers of children needing support, UNICEF, We all matter report, Situation analysis of children with disabilities in Albania, Joanna Rogers and Elayn M. Sammon, November 2018, pg. 96, <https://www.unicef.org/albania/reports/we-all-matter>

However, the issues related to the Social Fund are:

- 1. Small allocation of funds**
- 2. Coverage of multiple target groups**, not only persons with disabilities (youth, older people, woman, etc.)
- 3. Grants-based and not sustainable long-term funding system** (meaning all group categories need to apply for it and share the funds when there is a call for proposals).

Therefore, the government is failing to fulfil the UNCRPD; take the reforms seriously; implement the laws (bylaws/secondary legislation are missing, making the national framework impossible to be implemented); collect (disaggregated) data and properly budget the costs in order to deliver quantitative and qualitative ECI services. The number of children with disabilities (especially intellectual disabilities) is becoming more obvious and parents are more aware than 5-6 years ago of the need for early intervention services. However, the majority of them have not access to these services, are not satisfied with public services or do not have money to pay for these services. Outside Tirana, the capital, it is hard to find private services as there is a lack of professionals.

While facing all the problems mentioned above, ECI beneficiaries have to deal with another struggle. The government of Albania was working on the reform of the assessment of disability, which consists of building a new assessment structure based on the bio-psycho-social model of ICF (International Classification of Functioning Model). This reform was supported by the NGO sector, but the new assessment divides people with disabilities in four categories (very severe, severe, mild, and light) changing the disability allowance according to the category. This has led to decreased allowance for some categories (e.g. people with Down syndrome) as they are now falling under the light and mild disability category receiving 6000-8600 Albanian LEK/month (48-70 EUR compared to 10,500 LEK/month (85 EUR) before the revision.

MAIN MESSAGES AND RECOMMENDATIONS

In light of the UNCRPD's recommendation, Albania shall *“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 organisations of children with disabilities, including at the local level, and provide also a transparent road map for achieving progress”*.¹⁶

Thus, the main needs can be summarised as:

- > **Increase the allocated budget for social care services** to support existing services, private sector organisations and to build/expand the State's social care services.
- > **Design and approve support services standards** for each type of service and age group of beneficiaries as an urgent need 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 for all individuals with disabilities when there are no accessible/available quality public services,** so parents can pay privately for the services.
- > **Develop and establish a model of early identification of intellectual 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** based on quality standards for both private and public services.
- > **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 people with disabilities as service providers.
- > **Increase awareness among public administration on disability** and especially on intellectual disability.

¹⁶ Committee on the Rights of Persons with Disabilities

BULGARIA

On the Road to Building a National ECI System

The total percentage of children in Bulgaria in the age range 0-7 years old is estimated at 42.4%, with the number of children with disabilities in 2018 being 26,422. The number of children under 16 years old who have a recognised type and degree of disability is 4,070 or 3.8 per 1000 as a share of the children population.

The situation is unclear with regard to the number of children with disabilities or developmental delays who do not have a disability registered at birth, as there is no methodology for collecting such data. A reference could be the number of premature infants who are at increased risk of developing problems. The share of premature babies in Bulgaria is high - 9.9% of all births in 2017 (a total of 5,952 children) - which means that almost one in every ten children is born premature.

General statistic indicators show an approximation of the expected number of children with developmental disabilities. According to WHO global estimates and scientific data, the estimated percentage of children with developmental disabilities in Bulgaria is 6.5% for the age group 0-5 years old. It is of crucial importance for these children and their families to receive early and timely support, and the way to this is to build a national ECI system.

ECI services have been introduced in Bulgaria in 2010 by several NGOs located in major cities in the country at a time when the process of deinstitutionalisation had started and alternative community-based services were needed. In 2010 the National Strategy "Vision for Deinstitutionalisation of Children in the Republic of Bulgaria" was adopted, with the main goals being the gradual closure of all institutions for children, the prevention of placement and raising children from 0 to 3 years old in residential care and the development of services in the family environment and in the community throughout the country.

Currently, the main providers of ECI services in Bulgaria are NGOs, the State and municipal structures under the leadership of the Ministry of Labour and Social Policy (Complexes for Integrated Social Services for Children and Families and Community Support Centres). They cooperate with other services like homes for medical and social care (under the guidance of the Ministry of Health), services connected to deinstitutionalisation, prevention of institutionalisation, foster care and adoption support (under the guidance of the Ministry of Labour and Social Policy), nurseries (under the guidance of the Ministry of Health), kindergartens and pre-school groups (under the direction of the Ministry of Education and Science). Complementary services include clinics and medical practices, hospitals, maternity hospitals and

neonatal intensive care units, home visiting community nurses supported by UNICEF, and others.

In the period 2010-2015, through the Social Inclusion Project, managed by MLSP and funded by a World Bank loan, many municipalities have launched integrated early childhood development services targeting children up to 7 years of age from vulnerable groups, including children with disabilities and their families, as well as future parents. In 2014-2015, 1400 specialists were trained, and methodological guidelines were developed for the provision of the Early Childhood Intervention services for persons with disabilities. In the period 2014-2020, services have been financed under the project 'Early Childhood Development Services' of the Human Resources Development Operational Programme. As of 2019, 62 municipalities provide integrated services, including ECI programmes.

The State has planned to ensure continuity and sustainability of the services with funding from the State budget. In 2019, a financial standard has been set for the Centre for Community Support / Community Center for Children and Families. Financial standards for the provision of the services of Day Care Centers for Children with Disabilities and the Center for Social Rehabilitation and Integration for Children with Disabilities, which include the early intervention of the disability programme, have also been approved. This financial standard is not currently applied as there is no readiness to provide such reformed and upgraded services. The entry into force of this financial standard is contingent on the introduction of the new Social Services Act and subordinate regulations governing its implementation. The new Social Services Act regulates that social support services for parents and early intervention are free of charge and it introduces for the first time a legal definition of Early Childhood Intervention of Disability. The enactment of the law, scheduled for 01.01.2020, was postponed for 6 months, but due to ambiguities, protests and political instability, its fate remains unclear.

IMPROVEMENTS AND CHALLENGES

Since 2010, thanks to State regulations, European projects and NGOs, ECI services provision, deinstitutionalisation and access to community-based support services have improved.

The number of social services for the support of children and families in the community, with consultative and day-care alternatives including foster care services, has increased threefold in this period, largely piloted thanks to the European Social Fund (ESF). There is scope in the local and national budgets to better ensure the sustainability, quality and accessibility of services for all users.

To improve participation, an ESF co-financed project 'Active inclusion in the system of pre-school education', co-financed with a budget of 41.5 million EUR provides support for more comprehensive early intervention measures and care-related kindergarten

fees.

New services and comprehensive support for children are still under consolidation after the initial deinstitutionalisation process was accomplished: all specialised institutions for children with disabilities have been closed. The number of children in specialised agencies fell from 7,587 in 2010 to 495 in 2019 (93%). Of the 137 institutions that were identified for closure (via the National Strategy 'Vision for Deinstitutionalisation of Children in Bulgaria till 2025') in 2009, only 21 are yet to be closed.

In 2019 changes in the access criteria and the 24.5% increase in allowances provided led to almost 250,000 applications being submitted by the end of October 2019, which is an 18% increase compared to 2018 .

However, several challenges still remain:

- 1. The enrolment rate in early childhood education and care in Bulgaria** (children aged less than 3 years old) **is much lower than the EU average** (16.2% vs 33.2%), particularly in rural areas. Moreover, in big cities, the lack of facilities is limiting participation: its rate for children aged 4 years to compulsory school age stands at 83.9%, significantly below the EU average of 95.4% and on a downward trend since 2014.
- 2. There is no sustainable funding secured for ECI services.** In Bulgaria, a widespread use of screening for child development by pediatricians, GPs and other professionals working with young children through which it is possible to identify and refer children to services is not applied. Key entry processes for ECI - screening, referral, diagnostics, tracking - are not widely recognised. The provision of services is in many cases linked to the diagnosis, which is very often established after 3 years of age. In this way, the most sensitive period of early childhood development is missed.
- 3. The high cost of transportation for home visits remains a challenge.** In Bulgaria, services are concentrated in cities and there is a difference in the quality of their provision between urban and rural areas. Also staffing issues are adding to the difficulties of the sector with recruitment, retention and training being problematic. The location of ECI services is usually in centres, with professionals applying an expert model without parental involvement. In extremely rare cases, services are provided in the natural environment - home, kindergartens, mainly by NGOs.
- 4. There is no services coordination unit.** Parents need to look for information on their own for diagnostics and services. The lack of support for families often requires one of the parents (usually the mother) to give up employment and to devote herself entirely to caring for a disabled child. This creates additional financial difficulties for the family. There is still a widespread social stigma in Bulgarian

society regarding children with disabilities and their families, which leads to the reluctance of parents to share their concerns and seek professional support for their children.

MAIN MESSAGES AND RECOMMENDATIONS

In the 2020 Country Recommendations, the European Commission urged Bulgaria to enhance *“provision of education and training services and a better skilled workforce would also strongly underpin the recovery and promote inclusive and sustainable growth in the medium term”*.

The main issues to address to achieve this goal are therefore the following:

- > **Provide sustainable funding for ECI services** that allows long-term planning, assessment and adaptation of support schemes as needed.
- > **Provide a legal and regulatory framework for a ECI system** through:
 - **An ECI Act and/or the preparation of a strategic plan and an action Plan** for the development and implementation of an ECI framework, national guidelines and procedures for ECI and national standards for ECI staff.
 - **A unified methodology** for the provision of ECI services.
- > **Address workforce, training and services issues:**
 - **Provide quality training for professionals, experts and other specialists to improve transdisciplinary work** and support of children and families.
 - **Employ professionals with different professional qualifications** into ECI service provision teams to enable them to share and integrate knowledge with each other.
 - **Develop a roadmap for the provision of services** to families of children with disabilities, identifying steps and developing cross-sectorial and inter-agency interaction procedures.
- > **Improve awareness raising through advocacy and data collection:**
 - **Register all children receiving ECI services in a single national register** in order to monitor the child development and collect statistics.
 - **Advocate for ECI policies at central and local level**, as well as through broad communication activities with the public, so that citizens understand the needs and benefits of ECI services.
 - Introduce and clarify, both among professionals and in the general public, **the nature and benefits of a family-centred ECI model**, including through services provided in the child's natural environment.

CROATIA

Appropriate budget allocation and use of existing resources and practices to build a systemic ECI approach at national level

There were 32,101 children with disabilities in Croatia in 2017.¹⁷ The term 'child with developmental difficulties' is used in Croatia to describe all types of disabilities children might develop over time.¹⁸ The biggest percentage of children who are registered with disabilities (46%) are between 10-14 years old which suggests issues in the detection and delayed diagnosis of disabilities.¹⁹ About 10% (or 4,800) of the total newborns in Croatia are at risk of a developmental delay. This percentage also reflects also the amount of families in need of Early Childhood Intervention services.

Early Childhood Intervention is regulated in Croatia through the Social Welfare Act (2013). It is defined as a social service encompassing a stimulating professional assistance to children and professional and counselling assistance to their parents (including other family members and foster parents) when there is an established developmental risk or a developmental difficulty for the child.

The ECI services basic legal framework consists of the definition of ECI contents, ECI service providers, ECI's age range (between 3 and 7 years old), and services' location and affordability (ECI public services are free).

Finally, the National Strategy for Rights of Children 2014-2020 established as a strategic goal support for the rights of vulnerable children, including children with disabilities.²⁰

Overall, the new legal framework, ongoing deinstitutionalisation and other societal changes led to a significant increase of ECI trained service providers, specialists, experts and researchers on ECI needs and framework.

IMPROVEMENTS AND CHALLENGES

The shift from a model based on institutional care allows the development of new and different services offered to the community. According to the Social Welfare Act, children and young people have access to day care and counselling, adoptive families can benefit from counselling and support and early intervention is foreseen

¹⁷ Croatian Institute for Public Health, 2017

¹⁸ Znaor M. et al, 2003

¹⁹ UNICEF, 2015 Croatian Register of Persons with Disabilities

²⁰ Ibid.

for children with disabilities.

Since 2010, participation in ECI as well as the provision of family and community-based services has increased. Furthermore, the Croatian authorities are drawing on EU Structural and Investment Funds (110 million EUR out of 120 million EUR total investment in ECEC) to substantially expand and modernise the network and take measures to address the shortage of pre-school teachers.²¹

Thus, in the 2020 Country Report, the European Commission acknowledged some progress for the 2019 objective as both access and quality of education and training at all levels improved. However, the report also states that ongoing investments in Early Childhood Education and Care need to be done to increase availability and access. Indeed, Croatia lags behind on participation in early childhood education and care and quality of education with rates among the lowest in the EU. In 2017 82.8% of children aged between 4 years old until compulsory school participated in ECEC, a figure well below the EU average of 95.4%. It is worth noting that for children under the age of 3, the participation rate was particularly low at 17.8% in 2018 (EU average 35.1%, Barcelona target 33%).²²

To fully implement ECI in Croatia, ECI services need to be compliant with the European Voluntary Quality Framework for Social Services (availability, accessibility, affordability, comprehensiveness, continuity, family-centred).

Challenges that need to be addressed are:

- 1. Significant lack of public funding, availability and accessibility of ECI services.** The decentralisation of ECI financing leads to significant regional disparities in terms of availability, quality and affordability of care. Children of employed parents take priority over those of unemployed and inactive ones in access to ECI services.²³ As a result, there is a discontinuity of services.
- 2. Low awareness on the importance of early identification of children at risk or with developmental delay** with really low early referral.
- 3. Lack of quality standards:** there is no mechanism for quality control on the provision of ECI services which leads to an increasing number of private suppliers providing partial and fragmented services.
- 4. The lack of coordination between sectors** (especially health and social care) and among service providers leads to a duplication of services and poor use of existing resources.

²¹ EU 2020 Country Report - Croatia

²² Ibid.

²³ Ibid.

- 5. Lack of appropriate education and standards for professionals providing services.** Existing practices are still mostly professionally-centred, and models are still dominantly based on the medical approach – expertise-based and service-based, not family centred.

These challenges were also mentioned by the UN Committee who shared its concerns about *“the high rate of child abandonment and subsequent institutionalisation of children with disabilities in the State Party, particularly owing to the lack of attention and care they receive in the areas of education (...) and the limited scope of specific measures for them in rural areas”*. More specifically, the Committee pointed out that *“many boys and girls with disabilities do not have access to early intervention services”*.

MAIN MESSAGES AND RECOMMENDATIONS

Some models of good practice in ECI already exist in Croatia (e.g. Mali dom – Zagreb and MURID in Čakovec). These models emerged from projects implemented through a multi-stakeholder approach (including representatives from government sectors and bodies). They have enough data and evidence-based practice that can be drawn upon to for scaling up at national level through national regulatory mechanisms. They use well tested methodologies, protocols and are based on referral at the earliest possible time right after birth. These services are well coordinated and integrated among different disciplines and sectors. Moreover, they are based on a transdisciplinary approach on which the system should be built upon.

Drawing on this, the main recommendations to improve ECI services are the following:

- > **Establishment of a National ECI framework** which will allow service providers to work and develop their own range of support services as relevant for each child.
- > **Development of a cross sectorial approach with a genuine commitment from Ministry-agencies to work together on the National framework.**
- > **Raise of government awareness on the need for appropriate budget allocation**, taking into account the cost-benefit analyses that have been existing for decades, to prioritise investment in well-established, timely and comprehensive ECI services, as this brings great economic benefits in the short and longer term, not to mention the quality of life of the children, families and communities involved.
- > **Establish Comprehensive Early Childhood Intervention Services as a priority at national level.**
- > **Identify Quality as an essential target for public investment in ECI programmes.**

FINLAND

The ECI sector needs more national guidance and regulation

In Finland there are no precise statistics regarding the number of children with disability. However, the figures published by the Social Insurance Institution of Finland (Kela) give a good insight. This agency is in charge of disability allowance for children under 16. Moreover, data gathering by the Finnish National Agency for Education on the number of children in need of special or intensified support at school can be a useful indicator. Thus, the number of children and young people with disabilities under the age of 18 can be estimated at around 40,000, which equals 2,200 people per age group (around 5% of each age group at national level). This estimation seems accurate as people with disabilities represent 10-15% of the total population (and disability is more common in the elderly population).

Even though there are no precise data on children with disabilities, a solid network of ECI services is established to standardise practices at national level. This network is mapping, collecting data and following the situation of ECI services in different areas of Finland.

The common view of the members of the network is that ECI quality has a fundamental impact on the wellbeing of families. This also includes the right to receive early intervention support. However, families and professionals experience it in various ways. Members of the network notice that there is some improvement in attitudes and practices regarding early intervention. Some organisations have developed their own processes and practices and there has been staff training about how to deliver early intervention support. Since that time, there has been lobby work done by the network in creating a common model in Finland.

IMPROVEMENTS AND CHALLENGES

Recently, Finland has begun to invest in education and more specifically, in Early Childhood Education and Care. Participation in ECEC has increased in recent years and is close to the EU average. By 2017 the participation rate of children under the age of 3 had increased to 33.3% (EU average: 34.2%).²⁴

However, municipalities are concerned about the lack of sufficient financial resources to implement recent educational reforms, both in early childhood education and care and in compulsory education.²⁵ Families are indeed in very different situations

²⁴ EU 2020 Country report - Finland

²⁵ Ibid.

as there is a huge variety of practices depending on municipalities and health care units. There is no national practice or principle which would guarantee sufficient and good quality early childhood intervention for all. Families with a child who has a rare diagnosis seem to be the more at risk.

Finland remains among the EU countries with the lowest participation rate of children aged between 4 and the starting age of compulsory education (87.8% – EU average 95.4% in 2017), with large regional disparities. Indeed, there is a large variety of actors providing ECI services as well as different kinds of training and coaching courses organised by the Finnish Social Insurance Institution and health care districts. In practice, ECI services are usually provided by NGOs. Hence, ECI in Finland is highly fragmented due to the lack of a common understanding, objectives and practices.

Key challenges are:

- 1. The inequal quality of ECI services depending on the geographical location of the families' residence.**
- 2. The large variety of experiences with varying degrees of quality.**
- 3. The need for training and tools for doctors, nurses and other professionals with regard to early childhood intervention.**

MAIN MESSAGES AND RECOMMENDATIONS

In the Finnish 2019 objectives assessment related to the European Semester, the European Commission raised its concerns about the lack of sufficient funds to implement recent educational reforms in early childhood education.²⁶ In fact, more than just adequate funding is needed to address the needs of ECI systems.

Key recommendations and needs are:

- > **National guidelines for ECI services.**
- > **Broader collaboration between the different partners and NGOs as part in this process.**
- > **Provision of comprehensive and family-centred ECI services: children with disabilities, families and other carers should be involved.**
- > **Adequate training for staff in child health centres and maternity hospitals.**
- > **Development of good practices in ECI services as part of a national ECI framework.**
- > **Binding regulations for the implementation of ECI.**

²⁶ Ibid.

GREECE

Early Intervention Services: the unacknowledged player of the Social Care Sector for Children with Disabilities

In Greece the concept of early intervention was introduced for the first time in the Special Education Act (SEA) in 2008 that allowed pre-school special educational units to implement early intervention programmes for children until 7 years old (L3699/2008). In addition, according to the SEA, the institution for diagnosis and support of special education needs (KEDDY) could suggest the implementation of early intervention programmes where needed. According to the latest European Semester Country Report, in Greece more children now 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 0-3. However, this progress does not affect equally children with disabilities, especially the ones aged between 0-3 years old. Unfortunately, and despite the Special Education Act legislation (L3699/2008, articles 8 & 32), ECI is not systematically applied in Greece.

Early Childhood Intervention focuses 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 organisations, d) non-governmental organisations and e) associations of parents of children with disabilities, the latter being financed through private donations and sponsorships. All of these organisations 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.^{27,28} The majority of early intervention services are offered by private therapy centred or non-profit welfare organisations.²⁹

CHALLENGES

According to NCDP, the 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 are provided in fact by few non-governmental agencies

²⁷ 27 Tavoulari, Katsoulis & Argyropoulos, 2014

²⁸ In addition, children with disabilities and special educational needs from four to seven years of age can attend the early intervention programme of the Hellenic Organisation for the Protection and Rehabilitation of Disabled Children (ELEPAP); ELEPAP attendance is equal to the attendance at any other special preschool education unit (Law 3699/2008, Art. 32).

²⁹ Greece: Fact Sheet on Social Care & Support Services Sector for Persons with Disabilities EASI, methodological guidelines are prepared as part of the EASPD "Commit" Work Programme (2018)

only.³⁰ The development of public early intervention structures as foreseen by Law 3699/2008 has not been realised yet.

According to the UNCRPD report *“the Greek State lacks of a harmonised human rights based approach to disability in the legislation and the existing legislative framework for disability assessment mechanism and that data collection on persons with disabilities in the State still associates with the medical model of disability (Health Survey 2019) thus it is fragmented, unsystematic and incomplete”*.³¹ The UNCRPD explicitly highlighted the lack of a comprehensive legislative framework guaranteeing equal treatment, protection from discrimination and individualised support.

Families of children with disabilities remain unsupported in terms of financial assistance and/or service provision by the Greek legislation. Furthermore, identifying families and children in need is still a challenge because of the social stigmatisation of disability, especially in rural areas.

Finally, the Medical Pedagogical Centred Diagnostic Assessment and Support Centred which offer diagnostic and evaluation services have not yet been expanded into ECI services.

At the present time, challenges³² (as depicted by official surveys) for family-centred and home visiting ECI services are the following:³³

- 1. Absence of official national mapping of the services** provided by private and public institutions (per age and type of service) to prevent unequal access.
2. The institutional gap for **services targeting families and children with disabilities under the age of 2.5.**
- 3. Lack of information to community social care personnel on the services available and consequently limited guidance to families,** especially with regards to home visiting services.

Furthermore, structural shortcomings of the welfare system are related to:

- 1. Absence of education/training for professional employment** of Early Intervention professionals.

30 National Confederation of Disabled People

31 UN Committee on the Rights of Persons with Disabilities

32 Limited comprehensive education and training in the field of early childhood intervention at university level, lack of coordination between all different centers and services and comprehensive State policy concerning early childhood intervention are the major shortcomings that have to be overcome in the future, if families in need are to be adequately served.

33 The specific challenges have been revealed during the 15 years of family centred ECI home visiting programme for children with visual impairments 0-6 years from Amimoni.

2. **No funding/uncertainty regarding the sustainability of the services** which are mostly funded by private institutions.
3. **Lack of objective/common system for quality assurance**, control, impact measurement and evaluation of the services provided. The lack of such a system puts families and the vulnerable child to great risk.

The situation is particularly burdensome in rural areas, where social stigma is important and access to any service is either limited or absent.

Following are two examples on the challenges faces by organisations providing ECI services for more than 15 years.

ECI SERVICES FOR VISUALLY IMPAIRED CHILDREN FROM 0 TO 6 YEARS OLD FROM AMIMONI

Since 2004, the Panhellenic Association of Parents & Friends of Visually Impaired Children with additional disabilities "AMIMONI", a non-profit organisation, has been offering services for up to 130 families in the area of Attika and 19 regions all over Greece, implementing an ECI Programme. The programme treats visually impaired infants and young children from birth up to the age of six. These children may have low vision or blindness caused by visual disorders such as retinopathy of prematurity, congenital glaucoma, cataract or Cortical Visual Impairment (CVI) and/or additional clinical conditions, such as cerebral palsy, perinatal brain damage, genetic syndromes or brain tumours that affect the visual system. A part of the home visit consists of child intervention, whereas a second part is devoted to the caregiver's counselling and support. The primary goal of the intervention is to support the development and emotional well-being of the child, as well as to support the caregiver-child interaction and to promote their social inclusion.

Recent studies highlight the importance of early support programmes for the visual functioning of infant development. Moreover, research shows that severely visually impaired children are at higher risk of poor developmental outcomes and neurodevelopmental delay and that early intervention programmes can affect positively all the aspects of development and have a preventative role for secondary disabilities.

Serious number of challenges faced during the provision of service are related to the lack of legal acknowledgement on the rights of visually impaired children and the underfunding of related programmes. Moreover, there is a lack of professional education in early intervention with visually impaired and multi-disabled children with undergraduate and postgraduate university degrees. For a home visiting programme of ECI with visually impaired and multiple disabled babies and pre-schoolers, a wide range of knowledge and skills are required, from different scientific areas such as

developmental psychology, optometry, physiotherapy, occupational therapy and counselling. Therefore, staff training depends on an ongoing education scheme delivered inside the related departments.³⁴

ECI SERVICES FOR CHILDREN FROM 2.5 YEARS OLD FROM THEOTOKOS

Theotokos Foundation is a non-profit, partially government-funded organisation, serving children and young adults with intellectual and other developmental disabilities, as well as providing support to their families. One of the Foundation's services is the Early Intervention Programme, which has been operating since 2000. The Early Childhood Intervention (ECI) Programme is a cooperation of Theotokos Foundation and the neighboring municipality childcare centred.

Theotokos Foundation's Early Childhood Intervention Programme operates on the following levels:

- **Primary Prevention level:** Raising awareness. Collaborations with neighbouring health care centres and presentations at local childcare centres
- **Secondary Prevention level:** Early identification (1,500 preschool children aged between 2-5 years were screened at municipality childcare centres) to detect developmental and/or psychosocial difficulties and provide guidance and support to the families.
- **Tertiary Prevention level:** Services for children aged 2.5 to 4.5 years. The programme supports children with intellectual developmental disorders including autism spectrum disorders. The services provided aim at strengthening the children's development, at empowering parents' skills as carers, as well as minimising developmental risks and the emerging need for health and special education services in the school years.

The Early Intervention team has an interdisciplinary approach. It assesses the developmental level of the child, in combination with family relationships, the needs and abilities of the children and their parents and intervenes individually for each child and family. In addition, it forms the connecting link for collaboration with the local health and educational organisations. A quality group programme is provided which simulates a childcare centre with a small teacher-to-child ratio and includes individual educational, speech therapy and occupational therapy sessions. Individual education and therapy plans are based on each child's profile using the International Classification of Functioning, Disability and Health – Children and Youth (ICF-CY).

34 I. Vonikaki, E. Toumazani, Amimoni

MAIN MESSAGES AND RECOMMENDATIONS

Despite the existence of some support on ECI, most constitute isolated and independent practices that are not part of a national legislative framework. What is needed to further develop ECI systems is:

- > **Strengthen its national monitoring and implementation framework**, on the basis of transparent procedures and with full participation of organisations of persons with disabilities.
- > **Ensure the provision of appropriate resources for organisations of persons with disabilities**, including support through independent and self-managed funding.

Furthermore, the European Agency for Development in Special Needs Education refers to the need of developing an action plan to ensure:³⁵

- > **The target population is reached, and support is made available as close as possible to families** to allow early identification of children with disabilities.
- > **The respect for the family's needs is at the centre of any action.**
- > **Decentralised ECI services and provisions are in place** in order to facilitate better understanding of the families' social environment, to ensure the same quality of services despite geographical differences and avoid overlaps and irrelevant pathways.
- > **The needs of families and children are met so that families are well informed.**
- > **A shared understanding of the meaning and benefit of ECI intervention with professionals**, as well as an ensured participation in the decision making and implementation of an ECI national plan.

³⁵ T. Karampalis & M. Michaelidou, 2010

POLAND

Lack of systematic disability detection and effective support for families with children with disabilities or at risk of developmental disorders

ECI as a systemic approach is not set up yet in Poland as there is no legislation concerning early intervention in the health and welfare sector. However, legislation for early childhood development support in the education sector exists (i.e. early developmental support) with the same goals and purposes as ECI. Unfortunately, the Ministry of Education did not create a proper institution to implement it, so ECI comes as an additional set of tasks for educational institutions (kindergarten, special schools, counselling centres) for which no additional resources are foreseen.

In addition, there is no collaboration and synergy between these three sectors. For example, the methodology for ECI provision is different in the education and in the social sector.³⁶ The same scenario can be seen in the health sector where there is no coordination or follow-up between the support offered by childcare and educational institutions.

Poland still has a low enrolment of children in formal childcare (for children less than 3 years old) which stands at 10.9% (EU: 35.1%). Participation in early childhood education and care for older children (from 3 years to compulsory school age) is also far below the EU average (59.4% vs. 86.8%). Finally, gaps in ECEC provision remain, in particular in rural areas, and are contributing to regional disparities.³⁷

Shortages of teachers have increased recently, and the attractiveness of the sector for professionals remains low. Teachers' salaries are below the average wages of tertiary graduates, in particular for kindergarten teachers.³⁸

One of the biggest issues is that there is no screening for young children in nursery and kindergartens (children aged 2 to 4 years old) to detect developmental delays and the professionals' shortage as well as the low percentage of children identified by the system as in need of ECI services leads to insufficient support for families and children. Indeed, access to ECI services is linked to a medical statement from a doctor which "recognises" the disability.

Finally, social services are underdeveloped. Poland fails to ensure equal access to quality, affordable and sustainable community-based social services with measurable objectives and underlying national funding. The law on Centres for Social Services adopted in 2019 aims to create integrated social services, but its impact is uncertain

³⁶ Agora Project Country Report 2019

³⁷ EU Country Report 2020 - Poland

³⁸ Ibid.

due to the lack of national financing. Moreover, no measures are planned to increase collaboration between the different actors (education, social and health services).³⁹

IMPROVEMENTS AND CHALLENGES

Data from the Report of the Ministry of Education developed by a group of experts in 2019, show that:

- 1. Only a low number of children aged 0-3 have the needed “medical statement” which is mandatory to access ECI services.** In 2017, 24,467 medical statements have been recorded, including 8,115 for 0-3 years old children, which indicates that for most children intervention is undertaken rather late.
- 2. A relatively high number of school students with additional educational needs is not diagnosed at earlier stages.**
- 3. There is a serious increase of school age children with behavioural and psychiatric issues** besides those diagnosed with an intellectual disability. In 2010, there were 114,329 students with special support needs while in 2015 143,000 students were defined as having support needs. This shows lack of family support and lack of Early Childhood Intervention before school age.
- 4. ECI services are working on a medical model focused on the child without proper family support.** Parental pressure is extremely high as families are left without any help to find out what kind of ECI services suit them the most among a large variety of methods (both in the public and private sector). This in turn results in poor public money expenditure, a drain of family pockets and often traumatic experiences for the child and his/her parents.

To cover the gap in social, health and educational services for families with disabled children, including early detection and early intervention, the Polish government dedicated 108,000,000 PLN for a 4 years National Programme 2017 – 2021 “For life”. This programme required every administration level to set up Coordination, Rehabilitation and Care Centres with different tasks including ECI services with an inter-sectorial collaboration. However, in reality, the programme does not provide a legal framework for inter-sectorial cooperation.

³⁹ EU 2020 Country Report - Poland

MAIN MESSAGES AND RECOMMENDATIONS

In conclusion, to overcome the above challenges, the following issues are to be addressed:

- > **Set up a national ECI framework with high quality standards** based on international research and evidence-based practice assuring a bio-psycho-social approach and family-centred ECI services in the local environment.
- > **Incorporate all existing services (including ECI centres run by NGOs) into a national system.**
- > **Set up a legislative framework for ECI** incorporating inter-sectorial aspects of ECI, coordination on every level and EU standards as availability, affordability, proximity, interdisciplinary working.
- > **Enhance new care and educational settings for young children and promote early inclusive education.**
- > **Increase awareness of society about the importance of ECI** in case of any child's developmental delay or disability.
- > **Promote a family-centred model of intervention** as a key element of an ECI systemic approach, quality and social inclusion of the family and the child.
- > **Increase the number of ECI professionals and encourage professional development** of ECI specialists and kindergarten teachers (pre- and in-service training) to reinforce their value on the labour market.

SLOVAKIA

The necessity to move from partial solutions to systemic changes

Slovakia is known as a country with a high degree of institutionalised citizens with disability. There is co-existence of the old system inspired by the medical institution-based approach and a new social approach partially developed in ECI services. Since January 2014, ECI services are defined by law as a set of services provided by social services (SS ECI) for children with disabilities from 0 to 7 years old and their families. Services provided by the health and the educational sector are not defined as ECI, which makes communication and coordination difficult between sectors. To solve this issue, the new government - established in March 2020 - is willing to create a coordinated framework with the involvement of the three sectors.

There is no unified methodology of data collection of new-born children with disabilities or at the risk of development delay. However, the National Association of Service Supporters and Providers (NASSP) survey among the eight self-governing regions and pediatricians between 2015 and 2017 showed that there were 8,700 to 14,000 children with disability or with developmental risks up to seven years of age in Slovakia. However, only around 10% of these children have access to ECI services due to their scarce availability.

Further sources (Ministry of Education, Ministry of Health, WHO) have claimed that the share of children with disability and with developmental risks in the population is 3.5%. Therefore, it can be estimated that Slovakia has about 14,000 children with disability up to seven years of age.

IMPROVEMENTS AND CHALLENGES

The obligatory pre-school entry age will be lowered as of 2021, which means that early childhood education and care will become more accessible.

1. However, participation in early childhood education and care is one of lowest in the EU and **the provision of childcare facilities for children under 3 is unsatisfactory** across the whole country.
2. **Gaps in the provision of early childhood education and care facilities persist**, aggravating regional and social disparities. In 2018-2019, some 12,502 child admission requests could not be met, mostly in the Bratislava region.⁴⁰

⁴⁰ 2020 EU Country Report - Slovakia

In view of the above, both the European Commission and the UN Committee on the Rights of Persons with Disabilities raised the same concerns:

“There is a significant lack of early intervention and early diagnosis services in the health, social and educational areas and that financial support for families with children with disabilities requiring early intervention is insufficient.”⁴¹

- **Limited/inexistent inclusion, limited resources, lack of professionals and public awareness about ECI are challenges that Slovakia needs to overcome.**⁴²
- **Even if ECI services provided by social services are family-centred, it is not the case for the health and the educational sector** which prevents the implementation of an individualised approach. As an example, because of the small fees reimbursed by health insurances to specialists, rehabilitation services cannot provide an individualised type of support to children with disabilities.

⁴¹ UN Committee on the Rights of Persons with Disabilities

⁴² The level of inclusion in Slovakia is currently very low. With the current system of special schools (452 special schools with 34,378 students, i.e. a 7.2% share of all children of school age) and the low number of hours per week per children/student with disability, it is actually challenging to include children with disabilities even to a special school, not mentioning the mainstream schools.

MAIN MESSAGES AND RECOMMENDATIONS

Building on the results from a survey on Early Childhood Intervention , in order to introduce a single, coordinated system of support to children with developmental risks and their families, with the aim to include them into society, the following measures are recommended:

- > **Coordinate efforts of at least three sectors (education, health care and social affairs) to develop and promote accessibility, sustainability and funding of Early Childhood Intervention services.**⁴³
- > **Improve accessibility and availability of ECI services across the country.**
- > **Provide a wider network of ECI services through the regional governments.**
- > **Improve access of services supporting children's development in the health sector** (in 2018, access to physiotherapy services reimbursed by health insurance was at 17% for small children (primarily from birth to age 3).
- > **Improve accessibility of ECI services in the Centres of Special Pedagogical Counselling (CSPC)** in the education sector (access to these service in 2018 was at 11%).
- > **Ensure a smooth transition of children with disabilities between support systems,** especially in the education sector between kindergartens and schools.

All these measures have one common denominator – they can be introduced and promoted widely only when there is a clear political will at both national and regional level.

⁴³ Survey on ECI, NASSP, 2019

CONCLUSIONS AND KEY MESSAGES 7 TO EU POLICY MAKERS

It is now well documented by studies and practical experience that Early Childhood Intervention is essential to ensure proper support in a crucial phase for the physical, and emotional wellbeing of children with disabilities or at risk of developmental delays. Across the continent Early Childhood Intervention programmes have been flourishing, though their frameworks of operation appear often fragmented and not accompanied by sustainable funding to allow for high-quality standards.

This report has documented some of the experiences available in European countries which all converge on the need to:

- **Adopt a comprehensive Early Childhood Intervention framework at national level.**
- **Provide the needed resources to ensure a smooth implementation of ECI programmes including training of professionals, widespread availability of ECI services, family-centred and affordable.**
- **Coordinate and integrate ECI services with the health and education sector.**

When possible, **ECI services should be linked to deinstitutionalisation strategies** and, overall, on any action plan concerning disability issues.

The European Union has a number of instruments that can be used to address ECI. **Through the European Semester the European Union addresses each year a number of policy issues to Member States to support them in the reform of social care systems.** If the needs of children with disabilities and their families are to be addressed correctly, offering state of the art support and promoting their wellbeing and quality of life, the crucial role of Early Childhood Intervention should be recognised as a national priority.

The upcoming Child Guarantee should act as gamechanger in the lives of children, including those with support needs.

The countries overview in the report highlight bottlenecks as well as ways out. Early Childhood Intervention is now the most powerful tool to prevent institutionalisation, to address risk-factors that could lead to poverty and social exclusion, and to allow the development of individuals to their full potential and maximum wellbeing.

We hope that this report provides for better understanding of Early Childhood Intervention and improved approaches, policies and instruments to address children and families' issues.

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CONTACT DETAILS AND CREDENTIALS

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EASPD

EASPD (European Association of Service providers for Persons with Disabilities) is a European NGO network representing over 17,000 social and health support provider organisations across Europe and across disabilities, working towards the promotion of equal opportunities for persons with disabilities through effective and high-quality service systems.

EASPD bases the development of support services on the human rights framework provided by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). EASPD is accredited to the Conference of States Parties to the CRPD and since its adoption the UNCRPD has become the core of EASPD's policy strategy.

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