

Strategies for Policy Changes in Early Childhood Intervention



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Strategies for Policy Changes in Early Childhood Intervention

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Table of contents

01	Introduction	5	5.6.1	In Castilla y Leon	14
02	Methodology	6	5.6.2	In Castilla-La Mancha	14
03	How was the process initiated?	7	5.7	In Ukraine	14
3.1	In Moldova	7	06	Ingredients of the ECI framework	15
3.2	In Portugal	7	6.1	What are the definition and the target group of ECI services?	15
3.3	In Serbia	8	6.1.1	In Moldova	15
3.4	In Slovakia	9	6.1.2	In Portugal	15
3.5	In Slovenia	9	6.1.3	In Serbia	16
3.6	In Spain	10	6.1.4	In Slovakia	16
3.6.1	In Castilla y Leon	10	6.1.5	In Slovenia	16
3.6.2	In Castilla-La Mancha	10	6.1.6	In Spain	16
3.7	In Ukraine	11	6.1.6.1	In Castilla-La Mancha	16
04	Who took part in it and realised it eventually?	12	6.1.7	In Ukraine	17
4.1	In Portugal	12	6.2	Which stakeholders and agencies did you involve?	17
4.2	In Serbia	12	6.2.1	In Portugal	17
4.3	In Slovakia	12	6.2.2	In Serbia	18
4.4	In Slovenia	13	6.2.3	In Slovakia	18
4.5	In Spain	13	6.2.4	In Slovenia	18
4.5.1	In Castilla-La Mancha	13	6.2.5	In Spain	18
4.6	In Ukraine	13	6.2.5.1	In Castilla y Leon	18
05	How long did the process last? When did it start and when did it end?	14	6.2.5.2	In Castilla-La Mancha	18
5.1	In Moldova	14	6.2.6	In Ukraine	18
5.2	In Portugal	14	6.3	Which ECI quality standards apply in your country/region	18
5.3	In Serbia	14	6.3.1	In Moldova	18
5.4	In Slovakia	14	6.3.2	In Portugal	18
5.5	In Slovenia	14	6.3.3	In Serbia	19
5.6	In Spain	14	6.3.4	In Slovakia	19
			6.3.5	In Slovenia	19

6.3.6	In Spain	19	08	Which were the main challenges faced?	25
6.3.6.1	In Castilla y Leon	19	8.1	In Portugal	25
6.3.6.2	In Castilla-La Mancha	19	8.2	In Serbia	25
6.3.7	In Ukraine	19	8.3	In Slovakia	26
6.4	Who pays what?	19	8.4	In Slovenia	26
6.4.1	In Moldova	19	8.5	In Spain	26
6.4.2	In Portugal	19	8.5.1	In Castilla y Leon	26
6.4.3	In Serbia	20	8.5.2	In Castilla-La Mancha	26
6.4.4	In Slovakia	20	8.6	In Ukraine	26
6.4.5	In Slovenia	20	09	Common recommendations to future participants in similar processes	27
6.4.6	In Spain	20	10	How was the process initiated?	28
6.4.6.1	In Castilla y Leon	20		Annex	29
6.4.6.2	In Castilla-La Mancha	20		References	31
6.4.7	In Ukraine	20			
6.5	Which professionals work in ECI services?	20			
6.5.1	In Moldova	20			
6.5.2	In Portugal	21			
6.5.3	In Serbia	21			
6.5.4	In Slovakia	21			
6.5.5	In Slovenia	21			
6.5.6	In Spain	22			
6.5.6.1	In Castilla y Leon	22			
6.5.6.2	In Castilla-La Mancha	22			
6.5.7	In Ukraine	22			
07	What was needed for the parties involved to succeed?	23			
7.1	In Moldova	23			
7.2	In Portugal	23			
7.3	In Serbia	23			
7.4	In Slovakia	24			
7.5	In Slovenia	24			
7.6	In Spain	24			
7.6.1	In Castilla-La Mancha	24			
7.7	In Ukraine	24			

Introduction

01

The present document is elaborated within the ECI Agora project: Developing ECI Services through Participation & Co-production led by the European Association of Service Providers for Persons with Disabilities (EASPD). The project aims at overcoming the challenges related to the implementation of effective early childhood intervention (ECI) services for children with disabilities in 5 Central and Eastern European countries, and namely in Bulgaria, Hungary, Poland, Romania and Slovakia. Particularly, this document will look into examples from different European countries, also such not necessarily involved as project partners, about the steps of introducing legal changes on a local, regional or national level aimed at enhancing the quality of life of children with disabilities and their families. The examples will serve as guidelines for the ECI Agora project partners from Bulgaria, Hungary, Poland, Romania and Slovakia about how to proceed with the implementation of a local, regional or national legal framework of ECI. A study about the situation of ECI in the above mentioned countries, which can be found on-line at <https://www.agora-eci.eu/wp-content/uploads/2019/12/2019-12-summary-report-A4-version.pdf>, has shown that there are specifics about ECI in each project partner country and different levels of development and cooperation exist in this field. Hence, it is evident that each partner would need to go about the process in its own way and the examples described in this paper do only give an idea about the possible steps towards achieving a legal change and introducing a normative regulation of ECI.

Apart from this strategic paper, the ECI Agora partners will be supported by an ECI network, which they will need to establish in order to get various parties involved in the process. The process of networking is expected to take place not only within the project duration but afterwards as well, whereby also ROADSHOW events will be conducted in each partner country aimed at gathering service providers, healthcare and education representatives, parents of children with disabilities, NGOs, local, regional and/or national authorities, etc. All stakeholders will get a voice and give recommendations for the production of a policy document

about setting up a legal framework of ECI, called a ROADMAP. The present strategic paper aims at facilitating the process of the ROADMAP legal adoption through the examples given below. These examples have been provided thanks to the kind collaboration of Ana Serrano and Noor van Loen, Eurllyaid; Monika Fricova and Vladislav Matej, NASSP-ECI, Slovakia; Eric Bloemkolk, SOFT tulip, and Anna Kukuruza, PhD, Charity Fund Early Intervention Institute, Ukraine; Dragana Koruga, UNICEF Serbia; Ivan Puiu, PhD, State Medical and Pharmaceutical University "N. Testemitanu", Moldova; Nevenka Zavrl, Health Centre Ljubljana, Slovenia; Reyes Pérez Rico, Director of the Department of Personal Autonomy and Care for Persons with Disabilities at the Regional Social Services Authority, Region of Castilla y Leon, Spain, and Cristina Díaz Sánchez, Asprona ECI area, Region of Castilla-La Mancha, Spain.

The good practices described are structured upon various questions aimed at illustrating the processes of establishing ECI systems in Moldova, Portugal, Serbia, Slovakia, Slovenia, Spain and Ukraine, whereby some of the processes are still ongoing. In order to be able to implement their own national ECI systems, the Agora partners can also use the manifesto on ECI services in the Annex of this document developed by Eurllyaid.

02

Methodology

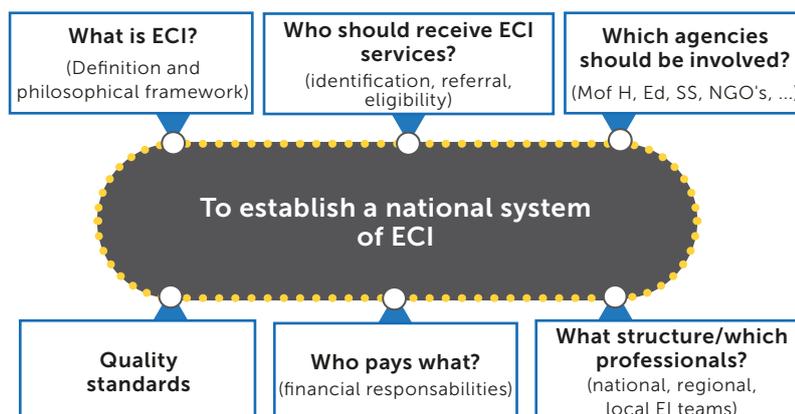
The information obtained in the present paper was gathered over a few months mainly via e-mail correspondence with the contributors mentioned above as well as by using literature sources listed under the references available at the end of the document. It is important to note that some of the responses gathered are not thorough, and thus, the paper lacks to provide information about:

- the parties involved in the process of developing an ECI system in Moldova and in the region of Castilla y Leon in Spain;
- the definition and the target group of ECI services in the region of Castilla y Leon in Spain;
- the stakeholders involved in the ECI service provision in Moldova;

- the success factors which have led to legal changes in the field of ECI in the region of Castilla y Leon in Spain;
- the challenges faced during the process of building an ECI system in Moldova.

The ECI Agora project partners approved the structure of the document based on the questions below during one of their transnational project partner meetings. They agreed that also the ingredients of the ECI framework shown under Figure 1 and promoted by the team of Eurllyaid would be included in the paper as they represent the basis of a comprehensive system of ECI.

Figure 1



Source: <https://www.agora-eci.eu/?toolbox=toolbox-number-3>

How was the process initiated?

03

3.1 | In Moldova

In 2003, the first centre, which started providing ECI services in Moldova, was the Voinicel Centre. However, it alone could not cover the needs of a few thousands (3000-4000) children aged between 0 and 3 years, and hence, a national network of ECI centres had to be developed. Thus, during 2011-2013, with the support of Soros-Moldova Foundation, 8 district teams (NGOs), some of which initiated the provision of services for little children, got trained.

Later on, other 3 centres/institutions based in Chisinau initiated the provision of ECI services – the Institute of Mother and Child of Moldova, Lumos Centre and Tony Hawks Centre. There are also some regional/rural centres ready to provide ECI services, however, they are not accredited yet. Being a resource centre in the field of ECI and a partner of the Ministry of Healthcare, Labour and Social Protection as well as of UNICEF Moldova, the aim of the State Medical and Pharmaceutical University “N. Testemitanu” is to cover all 32 districts of the country in terms of training programmes aimed at ECI specialists.

Moreover, researchers at the State Medical and Pharmaceutical University “N. Testemitanu” conducted some studies. In 2008, they came out with the PhD thesis “Elaboration of a Model of ECI Services for Children with Disabilities in Moldova”. Additionally, a team of experts at the university published 11 books, including the first Textbook on ECI (2012), the ECI Beneficiary Guide (2014), Actualities in ECI (2017), Actualities in ECI, Frequent Questions and Evidence-based Answers (2017).

Furthermore, international institutions and organisations played an important role in the promotion and development of ECI services in Moldova. Thus, the annual conference of EASPD “Growing Together: From Grassroots Initiatives to National Strategies in Early Childhood Intervention” held on 21st-22nd April 2016 was an important platform for the development of ECI in Moldova.

Eventually, the government Decision no. 816 of 30/06/2016 for the approval of the Framework Regulation on the Organisation and Operation of Early Intervention Services and Minimum Quality Standards got into force. In addition, already the Law no. 60 of 30/03/2012 on Social Inclusion of People with Disabilities included a special article (no. 44) dedicated to ECI specifically.

3.2 | In Portugal

From the late 1980's until the end of the 1990's, ECI in Portugal progressed from an emerging service provided in the context of a child-centred perspective to a rapidly changing service expansion with a totally different conceptual framework. A part of that evolution was triggered by the implementation of a community-based programme of ECI in Coimbra – the Coimbra Early Intervention Project (PIIP) – located in the central region of the country¹. The project aimed to provide individualised district-wide services to children under the age of 3 years at risk and/or with special needs and their families by using formal and informal resources already available in the community, and by creating a collaborative effort involving healthcare, education and social services. A training to all professionals involved was also provided and a wide collaboration in Portugal and abroad was promoted. The project has contributed greatly to the development of the Portuguese legislation regarding early intervention services, and it is considered the precursor of the national model created later by the legislation.

Collaboration with international experts during the 1980's encouraged the development of these then innovative ECI programmes emphasising the interaction between biological, psychological and sociocultural factors as well as the importance of working together with the families. The international partnerships were realised through:

¹ Boavida & Carvalho, 2003; Boavida, Espe-Sherwindt & Borges, 2000

- the **Portage Programme for Parents**, which offered a very relevant contribution to the paradigm shift in ECI services for children and their families. The innovative nature of that programme, at the time, was characterised by: (1) individualised planning of intervention goals and strategies; (2) a pyramid-shaped services coordination model; (3) home visiting, in-service training and supervision models that created opportunities for an interdisciplinary collaboration;
- the **Coimbra Early Intervention Integrated Project** implemented in 1989, which asserted itself as a community-based ECI programme aimed at providing individualised and comprehensive services to preschool aged children with special needs and their families, formally involving healthcare, education and social policy services. Its implementation constituted the starting point of the ECI development in Portugal. The conceptual model based on a family-centred intervention and the structure of the Coimbra project, which involved municipal ECI teams coordinated by a district team with elements from the three ministries and local institutions, initiated the paradigm shift of ECI in Portugal.

As a result, on 19th October 1999, the Joint Order 891/99 of the Ministries of Healthcare, Education and Social Policy came into force. Later on, on 6th October 2009, it was replaced by the Decree-Law 281/2009, which led to the establishment of the Portuguese National System of Early Childhood Intervention. All these internal movements were supported by international ECI organisations, such as Eurllyaid and ISEI.

Thus, ECI in Portugal progressively evolved from an emerging service offered in terms of child-centred intervention to a range of individualised family-centred services provided by community-based transdisciplinary teams. The evolution, however, was not homogeneous and was more easily undertaken in some regions of the country than in others.²

3.3 | In Serbia

Families in Serbia have access to a number of preventative and other support services during the child's early years. These include prenatal care, patronage nurse home visits and pediatric care. More specialised services for children with developmental delays and disabilities are also available.

These are offered through Developmental Counselling Units (DCUs) and secondary and tertiary healthcare services. Furthermore, UNICEF Serbia is actively working with the government of Serbia to increase the access to high-quality, inclusive preschool education by strengthening the legal and institutional frameworks and developing diversified funding systems and programmes aimed at facilitating the inclusion of Serbia's most vulnerable children. A number of pilot projects have been carried out in the country in a collaboration with non-governmental organisations and universities as well. These projects have been focused on inclusive preschool education and family separation prevention.

While not fully developed, components necessary for ECI are either in place or emerging. For example, some pediatricians implement developmental screening; a number of professionals have a significant expertise in assessment; and specialists from various disciplines have an in-depth knowledge that may serve as a solid foundation for the development of ECI services.

In 2016, a national analysis of the primary healthcare centres in Serbia was conducted. It was focused on the work of the DCUs. Thus, it was realised that there were still knowledge and human resources available that could be engaged in developing innovative services supporting children with developmental delays and difficulties and at multiple risks. Also, there were many requests and advocacy activities initiated by parental organisations as well as by professional associations and institutions to increase the availability of services for children and families.

To ensure the availability of resources for implementing a routines-based ECI model, the first step was to conduct a research, which was done by the international expert Prof. Hollie Hix Small from the USA in a collaboration with a newly established ECI National Board. The research report "Situation Analysis of Services for Infants and Young Children with Disabilities in the Republic of Serbia. Development of Early Childhood Intervention Services: Opportunities and Challenges" was presented to professionals from the sectors of healthcare, education and child protection at a conference in October 2017.

In May 2018, UNICEF Serbia decided to implement training programmes aimed at professionals providing services to children and families. During the process, Prof. Ana Maria Serrano and the team of the National Early Intervention Association (ANIP), involving colleagues from the USA, as well as national supervisors were engaged.

In the future, medical faculties and high schools, faculties of special education, psychology, pedagogy, social welfare, etc. are expected to integrate the knowledge on early childhood development and early childhood intervention

² Carvalho, L. et al. (2019). Recommended Practices in Early Childhood Intervention: A Gudebook for Professionals translated and adapted from the original *Práticas Recomendadas em Intervenção Precoce na Infância: Um Guia para Profissionais* (2016), 53-55, Eurllyaid, accessible on-line at <https://indd.adobe.com/view/ce456704-8e75-46a4-a7e6-700b024ed409>

within their Bachelor degrees as well as their Master and PhD study programmes.

3.4 | In Slovakia

The voice of those who needed ECI services in Slovakia was quiet although there were certain tries for establishing some ECI pilot centres in 1990. Eventually, such pilot centres were built up within the healthcare sector and were aimed at children with disabilities. At some of the hospitals, the services were quite successful and interested parties decided to establish that kind of pilots in all regions of the country. However, they didn't have enough resources to do it and the project collapsed after several years. Nevertheless, people knew that the approach was helpful and were convinced that it was a great idea. Certain NGOs continued working with the families who used the ECI services and they decided to re-initiate the establishment of the system. Thus, SOCIA – Social Reform Foundation, which is a Slovak organisation aimed at improving the quality of life of socially, physically and mentally disadvantaged groups of people as well as at supporting social system reforms, and some experts from the Slovak Ministry of Labour, Social and Family Affairs established a close cooperation. The partnership was also meant to change the mindset of policy makers so that they became more willing to establish a national system of ECI.

3.5 | In Slovenia

ECI starts when the need is recognised. In Slovenia, the need for ECI is rarely first recognised by the parents. Thus, in order to recognise the need early, a very good preventive care within the healthcare system and the kindergartens is required as well as a system to detect children who live "out of the system", are in home care, are not brought to vaccinations, etc.

Before passing the law on ECI in Slovenia, a very good prenatal and postnatal care in the field of healthcare existed. In all maternity hospitals, neonatologists examined the babies after birth. Systematic examinations based upon neurological check-ups took place and the Denver developmental screening test was conducted. Due to new regulations, the M-chat test and a questionnaire about the child's communication skills were introduced at 18 months. Additionally, systematic examinations by a psychologist and a speech therapist were done. The children with perinatal risk factors, showing abnormalities at neurological examinations or with an atypical development or developmental delays, were sent to developmental departments located at primary care centres and at some local hospitals.

In the field of education, there were developmental departments at the mainstream kindergartens with a special education teacher and groups of 3 to 6 children with special needs. The departments were meant for children with moderate or severe disabilities who needed a special care. Additionally, special education institutions for children with severe hearing or visual impairments or for children with a severe disability, where medical care was also provided, existed.

In the field of social care, income tax reliefs and other advantages were available. For instance:

- one of the parents could be employed for taking care of a child with a severe disability;
- having a child with a moderate disability, one of the parents could be employed ½ time and get the difference for a full social and healthcare security payment covered by the state;
- psychosocial support to parents of children with disabilities was provided;
- state-funded households to families of children with disabilities were granted, etc.

Despite all advantages provided by the sectors of healthcare, education and social services, it took over 20 years before the idea of a network of multidisciplinary teams (which was proposed in 1994) was recognised as a good one by the parents and by representatives of the Ministry of Healthcare. In 2016, the latter prepared a pilot study funded by the EU Cohesion Fund. It was completed at the end of 2019. Through the study, the standards of ECI in the healthcare system, the clinical pathways and the pathways of cooperation with the educational and social care systems were elaborated. Based on the results, the national ECI law was planned to be set up. However, the parents didn't want to wait. The NGOs had already prepared a law on ECI in the early 90's, which, however, never came to the Parliament. Hence, they picked up the idea of the pilot study and with the help of the Ministry of Education came up with a law on ECI in 2017. The other two ministries – of Healthcare and Social Policy – didn't want to hurry that much, and therefore, at a certain point, they stopped cooperating.

At that time, there were 5 parents and grandparents of children with disabilities in the Parliament representing different parties. One of them was a lady who was a lawyer and she was the most active. She got the approval of all the parties and the law was adopted without a single vote against. And still, the lack of cooperation of two of the ministries resulted in some problematic decisions. Thus, a few updates of the law on ECI need to be made and are currently being prepared.

3.6 | In Spain

3.6.1 | In Castilla y Leon

In 2000, the White Paper on Early Intervention was released in Spain, which was a turning point in the conception of ECI fostering a family- and an environment-centred approach, preventive practices and an interdisciplinary teamwork.

Thus, the Social Services Regional Managing Authority of Castilla y Leon came to a decision about designing a plan to improve ECI based on the White Paper principles. Training workshops for teams from the sectors of social services, education and healthcare in all areas (provinces) of the region with a university supervision and a national authority support were introduced.

2010 was a new turning point from a legal point of view since:

- a new Law on Social Services in Castilla y Leon was adopted: the person-centred approach was highlighted and all children with special needs and their families were entitled to early intervention;
- a Regional Rule on public coordination for delivering early intervention services came into force.

2014 was a breakthrough for the implementation of family- and environment-centred practices. A guideline was adopted in order to define the process of intervention, the roles inside early intervention teams with one professional only as a reference person for the family and other mechanisms to deliver equally distributed early intervention services throughout the whole region. However, after an in-depth evaluation of the public provision of ECI, it was concluded that the family- and environment-centred practices had to be improved.

In order to do so, the following actions were planned, carried out and monitored periodically:

- a group of professionals from different early intervention teams was made up to take an active part in the process of ECI implementation with the support of an external supervisor;
- tailored training workshops and supervisions in every ECI team on the territory of Castilla y Leon were conducted to meet the specific needs.

3.6.2 | In Castilla-La Mancha

The publication of the White Paper in the region of Castilla y Leon was an important step forward in the field of early childhood intervention in that region. Although since

2000 the White Paper took into account that ECI should be directed towards the child, the family and the environment, the professionals were still very focused on supporting the child.

Aware of that situation, in 2013, Plena Inclusión Confederation, which is a national body bringing together all associations and federations in the field of intellectual and developmental disabilities, initiated a project called "The Early Attention We Want" aimed at introducing the family-centred approach into the ECI services. In the very same year, 7 ECI centres joined the project, whereby 42 of 54 centres in the region are currently participating in it.

Thus, Plena Inclusión Confederation and Plena Inclusión Castilla-La Mancha, which is a wide regional network of associations, people with intellectual disabilities, volunteers and professionals, allied with Asprona, the biggest association of Albacete, Spain, and set up a planning and support team to design a structure assisting all organisations in the region that wanted to introduce a change in their ECI services.

Plena Inclusión Castilla-La Mancha and Asprona agreed with the Regional Ministry of Social Welfare to:

- share information about evidence-based practices in ECI;
- provide support to initiate pilot projects;
- introduce coordinated actions with all the agents involved in ECI.

As a result, in 2015, in the region of Castilla-La Mancha, the ECI centers that decided to collaborate together were introduced to:

- meetings between ECI professionals;
- data collected in a shared way related to how the number of families receiving support through a family-centred approach was increasing year after year, the number of families working with a single professional of reference, the number of families getting support in a natural context, the number of support sessions that the families were receiving;
- training actions;
- projects developed by interest groups;
- new centres initiating pilot projects in order to provide support;
- choosing a partner centre so that they improved the quality of their practices.

Plena Inclusión Castilla-La Mancha does also collaborate with CERMI Castilla-La Mancha, which is a federation representing all associations working in the disability sector in the region. As CERMI is an official partner of the Regional

Ministry of Social Welfare, all ECI-related data and information were presented to the Regional Ministry. From there on, further collaboration opportunities with the education and healthcare sectors were created.

The change of ECI services towards a family-centred approach has progressively been accompanied by legislative changes as well.

On 5th November 2017, the Decree-Law 88/2017 was published. It regulates the minimum conditions required for centres and services supporting people with disabilities in the region of Castilla-La Mancha. The normative document does also recognise that ECI services can offer support in the child's natural environment. Moreover, on 20th November 2018, the Decree-Law 85/2018 regulating the educational inclusion of students in the region of Castilla-La Mancha was published. More specifically, it is focused on the transition of the child and its family from an ECI service centre to school by implementing a family-centred approach.

3.7 | In Ukraine

The process of building an ECI system based on good grassroots practices was initiated by SOFT tulip – a Dutch NGO focusing on the improvement of healthcare services and working for the benefit of people with disabilities. In the year of 2000, Anna Kukuza, PhD and an executive director of the Charity Fund Early Intervention Institute, started the first ECI centre in the city of Kharkiv with the support of the Open Society Foundation. In 2009, two NGO-run day care centres in Lviv and Uzhgorod began providing ECI services as well. Later on, in 2011, a new ECI centre was established in Odessa.

Moreover, together with the support of the World Bank, a research in three regions of Ukraine on the situation of the care for the youngest children with disabilities or at risk by also taking into account the opinion of (young) parents was conducted.

The report of 2014 called "Early Childhood Development and Disability in Ukraine. Lessons Learned and Future Recommendations" was sequently used as the basis for the elaboration of a national plan on developing ECI in Ukraine, which was lobbied for among various stakeholders, such as UNICEF, the EU, the Commissioner on the Rights of Persons with Disabilities, the three key ministries and the Vice-Prime Minister of Ukraine.

In December 2016, the Cabinet of Ministers approved the national plan to start piloting the development of ECI, and in April 2017, a National Platform for ECI Policy Dialogue was created "to begin a dialogue and define the authority and actions of the parties in regards to the formulation and

implementation of a government policy in Ukraine that would introduce and develop a system of early intervention aimed at helping young children with developmental delays or at risk, focused on supporting the parents or the legal representatives of the children, and ensuring the best interests of the child."³ The main objective of the Policy Platform was to promote cooperation and interaction between the parties in the development of common approaches and the creation of capacity for the establishment of an early intervention system in Ukraine.

In the meantime, between 2016 and 2019, a parents' movement called "Parents for Early Intervention" was set up. Moreover, in 2019, the Cabinet of Ministers approved the extension of ECI to 6 more pilot regions and the transformation of the EI Platform into a National EI Council under the presidency of the Vice-Prime Minister and the Secretariate of the Ministry of Social Policy. Meanwhile, in the first 4 pilot regions, Regional EI Councils under the supervision of the Vice-Governor were established.

Currently, some 55 ECI teams at governmental health-care facilities (policlinics and mental health centres), in social services (rehab centres) and NGO-run day care centres are functioning, whereby the process of building a national system of ECI is still going on.

04

Who took part in it and realised it eventually?

4.1 | In Portugal

In 1994, emerging from the Coimbra ECI experience and recognising the need to create an organisational and integrated model of shared inter-service responsibilities for ECI, a task force was established. It was comprised of representatives from the Ministry of Education, the Ministry of Social Affairs and the Ministry of Healthcare, and it had the mission of developing the first ECI legislation (Joint Executive Regulation no. 891/99) aimed at establishing and organising services for young children with special needs and their families. The Joint Executive Regulation, designed by the task force, was finally enacted on 19th October 1999. The legislation allowed extending the Coimbra experience to other regions of the country, starting a pathway to building an integrated network of ECI inclusive and family-centred services. It was clearly a bottom-up process, in which the National Association of Early Intervention (ANIP) played an important role and which led to the establishment of a legislation that is unique in Europe. Additionally, universities got stimulated to introduce ECI within their curricula allowing for formal and informal international articulation, collaboration of international professionals and partnerships among services and universities. Contacts with early intervention programmes and professionals in the USA were established as well. It was the beginning of an extensive exchange of materials and ideas and a very high traffic of consultants in and out of Portugal. The collaboration with experts from the United States was absolutely crucial in areas like family participation and empowerment, development of the Individualised Family Service Plan, family-centred services, transdisciplinary teamwork, supervision, etc.⁴

4.2 | In Serbia

In 2017, UNICEF Serbia started a collaboration with Open Society Foundation UK – an organisation experienced in developing ECI systems, with other donors, international experts

as well as with Eurllyaid. Additionally, UNICEF Serbia engaged national experts from two faculties of special education at two university centres in order to supervise the practitioners in a collaboration with the international experts. On a local level, professionals from seven cities in Serbia, and particularly, from preschool institutions and social welfare centres with already recognised good practices of inclusion, got engaged in the process. All three ministries supported the process as well. They formed part of an ECI national body and were regularly informed about the results and progress achieved, also through their participation in annual ECI conferences.

4.3 | In Slovakia

The main party involved in the process was SOCIA – Social Reform Foundation, which operated in a partnership with the Social Ministry and was well aware that there were changes planned with regard to the Act on Social Services. Thanks to the close collaboration between SOCIA and the Ministry of Labour, Social Affairs and Families, the Foundation, together with another umbrella platform, and namely SocioFórum, managed to come up with law texts about ECI, which were legally adopted on 1st January 2014.

During 2014-2018, SOCIA established 7 Early Childhood Intervention Centres with the significant support provided by private donors.

Additionally, the Slovak National Programme for the Development of Living Conditions for People with Disabilities aimed at establishing a national system of ECI through a cross-sectoral group on ECI involving the National Association of Providers and Supporters of ECI, the Platform of Families of Children with Disabilities, the Ministry of Labour, Social Affairs and Families, the Ministry of Healthcare, the Ministry of Education, Science, Research and Sports, and the regional government.

One of the first activities of the workgroup mentioned above was related to amending the Act on Social Services, and namely, to involving children with disabilities and their families in the community and providing financial support to the ECI services by the regional government. The Act was amended in 2017 and the amendments came into force in 2018.

4.4 | In Slovenia

The main parties involved in the ECI law establishment were NGOs, professionals, parents of children with disabilities and the Ministry of Education.

4.5 | In Spain

4.5.1 | In Castilla-La Mancha

Different agents participated in the process, including:

- Plena Inclusión Confederation;
- Plena Inclusión Castilla-La Mancha and the working group formed by the organisation and Asprona;
- the Regional Ministry of Social Welfare;
- organisations, professionals and families that have joined "The Early Attention We Want" project.

International experts did also participate in the process. It is also important to highlight the collaboration with the Catholic University of Valencia based on the exchange of experiences and training activities. In 2019, the Regional Ministry of Education joined the process as well.

4.6 | In Ukraine

For several years, five main Ukrainian NGOs have become leaders in the development of ECI, and namely the National Assembly of People with Disabilities of Ukraine (Kyiv), the Early Intervention Institute (Kharkiv), the Training and Rehabilitation Centre "Dzherelo" (Lviv), the Health Society NGO (Odessa), and the Pass of Life NGO (Uzhgorod). The development of an ECI system was the result of a unique collaboration between the Ukrainian leading NGOs, UNICEF, SOFT tulip Foundation, the European Association on ECI (Eurlyaide), the Open Society Foundation, the UK-based charity HealthProm, etc. Hence, the network of leading NGOs and international organisations were the main parties involved in the process of paving the way towards an ECI system. The spouse of the former President of Ukraine, Mrs. Marina Poroshenko, supported the development of ECI as a prerequisite for inclusive education as well. The Commissioner on the Rights of People with Disabilities, Mr.

Valery Sushkevych, was an active supporter of the process, too. International actors, such as the Dutch, Canadian and American Embassies as well as the Council of Europe did also actively support the development of ECI in Ukraine.

Moreover, a strong ECI network of well-motivated and trained parents started operating in 2016. The combination of the strength of those parents with that of the Ukrainian ECI professionals and the international experts formed a powerful civil society to influence and co-create the system of ECI in Ukraine.

05

How long did the process last? When did it start and when did it end?

5.1 | In Moldova

The process began in 2003 and the ECI national system is still under development.

5.2 | In Portugal

The first ECI programmes emerged in Portugal in the middle of the 1980's, however, the national system of ECI was legally introduced in 2009. Hence, the whole process lasted about 30 years.⁵

5.3 | In Serbia

The process started in 2017 and it is to be completed at the end of 2020, however, the implementation will continue until the practice is extended to as many regions as possible.

5.4 | In Slovakia

The process dates back from 1990, and in 2014 the law on ECI was adopted by the Ministry of Labour, Social Affairs and Families. However, it is now still going on and the aim is to establish partnerships in different forms, e.g. among NGOs, the ministries in the different sectors, families, umbrella organisations of service providers, representatives of the healthcare and the education sectors, municipalities, funding structures, methodology authorities, international partners, etc. Moreover, the goal is to coordinate the process at both national and regional levels so that everybody involved agrees on building up a common ECI system that would be implemented all over the country and would have all three ministries – of healthcare, social policy and education – “on board”. In addition, a lot of work is still to be done as only 8,6% of all potential families in need have an access to ECI services.

5.5 | In Slovenia

The process took more than 20 years to come to a realisation – from the early 90's until 2017, however, the existing system of ECI still needs some improvements.

5.6 | In Spain

5.6.1 | In Castilla y Leon

The process was initiated in 2000 with the adoption of the National White Paper on Early Intervention, however, improvements have been made since then, particularly from 2014 onwards, and are currently still going on.

5.6.2 | In Castilla-La Mancha

The actual process began in 2013 and it is still in progress.

5.7 | In Ukraine

The process started in 2000 and it is still going on.

Ingredients of the ECI framework

06

6.1 | What are the definition and the target group of ECI services?

6.1.1 | In Moldova

According to Art. 44 of the Law no. 60 of 30/03/2012 on the Social Inclusion of People with Disabilities:

- early intervention services are medical-social services provided to children with physical, cognitive, communication, social, psycho-emotional and adaptive development-related disabilities;
- early intervention services are provided by healthcare institutions and specialised organisations in the field of medical-social services;
- early intervention services shall be provided by qualified staff, adapted to the needs of the child and delivered in a natural family- and community-based environment;
- the funding of early intervention services shall be provided by the means of the mandatory health insurance funds or, as the case may be, by grants, donations and other sources according to the legislation in force;
- the activity framework regulation and the minimum quality standards of the early intervention services are approved by the government.

The ECI services aim at an optimal adaptation of the child's environment, improving the parent-child interactions, and they are focused on children between 0-3 years with physical, cognitive, communication, social, psycho-emotional and adaptive development-related disabilities.

6.1.2 | In Portugal

In accordance with the Decree-Law 281/2009, ECI is considered to be a set of integrated support measures aimed at families and children aged between 0 and 6 years, including actions of a preventive and rehabilitation nature within the scope of education, healthcare and social services.

The ECI legislation in Portugal outlines the following aspects in particular:

- ECI services are aimed at children aged between 0 and 6 years at risk or with special needs and their families;
- ECI services are community-based public services involving healthcare, education and social policy professionals as well as private institutions and informal resources;
- ECI services are provided by a transdisciplinary team and are inter-institutional, i.e. they involve representatives of the healthcare, education and social policy sectors;
- An Individualised Family Service Plan must be developed and implemented according to a family-centred philosophy, whereby the law does also require the development of a transition plan whenever there are transitions of the child to different programmes and service delivery systems;
- Families are an integral part of the planning and provision of ECI services;
- There is a national structure that is based on a co-operation of the three ministries – of healthcare, education and social policy –, each having their financial as well as political responsibilities.⁶

⁶ Ibid., 57-58

Initially, children aged between 0 and 3 years who had some kind of a disability were the target group of ECI services. However, currently, the target of ECI services are children aged between 0 and 6 years with developmental disorders and/or at risk and their families.⁷

More specifically, as described in the law and based on definitions from the International Classification of Functioning, Disability and Health, two groups of children are eligible for ECI in Portugal:

- Group 1 - children who present changes in body function or structure that limit their normal development and participation in typical activities by taking into account developmental milestones for their age and the social context;
- Group 2 - children who are exposed to biological or environmental conditions which imply a high probability of significant delays in their development.

All children aged between 0 and 6 years and their families who present conditions included the 1st group are eligible for ECI. Eligibility for children and families from Group 2 requires the identification of four or more risk factors (biological/environmental).

6.1.3 | In Serbia

ECI is an inter-sectoral, interdisciplinary, and integrated system of professional services aimed at young children aged between 0 and 3 years (and sometimes up to 5 years or up to the age when the child enters formal education). The children targeted are those with developmental delays, disabilities, behavioural difficulties, social and emotional challenges, or young children experiencing problems in their development due to malnutrition, chronic illnesses or other biological or environmental factors.

Prof. Hollie Hix Small was the main expert at the beginning of the process in 2017 supported by a team from Open Society Foundation. She presented to our experts and a wide audience a routines-based model of ECI developed by Prof. Robin McWilliam⁸ as one of the most implemented models in the West. The routines-based interview is one of the tools used in Portugal as well. It was recognised as compatible to the Serbian system and a decision was made to go for its implementation in the country. Thus, in March 2018, the process of developing an adapted to the situation in Serbia routines-based ECI model at two pilot localities began.

6.1.4 | In Slovakia

According to the Act on Social Services, children with disabilities or at risk of a developmental delay aged between 0 and 7 years as well as their families have the right to receive ECI services. The latter have to take place at home or in nurseries, i.e. in the natural surroundings of the children with disabilities. Furthermore, there is an emphasis on what the ECI activities should be about. According to the Act on Social Services, the professionals should not only work with children with special needs to develop their cognitive skills, but also provide a complex developmental stimulation based on a bio-psycho-social model of needs in order that the family members' skills in taking care of a child with a disability are improved and a certain level of independence of the child and the family is achieved. ECI services should also provide social counselling, i.e. children with disabilities should have the right to get a wheelchair, for instance, as well as preventive activities.

6.1.5 | In Slovenia

According to the law, ECI in Slovenia is aimed at pre-school children with special needs and at risk. The ECI services include interventions for the children and their families in order to stimulate the children's development, enhance the capacities of the families and improve the social inclusion of the children and the families.

6.1.6 | In Spain

6.1.6.1 | In Castilla-La Mancha

The State Federation of Associations of Early Care Professionals developed the official definition of early intervention in 2000 and it was published in the White Paper on Early Intervention. According to this definition, "ECI is a set of interventions aimed at children aged 0-6 years, the family and the environment, which should respond as soon as possible to the temporary or permanent needs of children with disorders in their development or who are at risk. These interventions should be planned by interdisciplinary or transdisciplinary teams of professionals".⁹

The definition of the European Agency for Special Educational Needs and Educational Inclusion was also taken as a reference. Both definitions are related to offering support to the child, the family and the community.

⁷ Ibid., 57-58

⁸ <https://inclusioninstitute.fpg.unc.edu/presenters/mcwilliam-robin>

⁹ White Paper on Early Intervention, 2000

Additionally, Plena Inclusión distinguished seven crucial aspects of early intervention:

- Knowledge about human development and its alterations;
- Use of evidence-based and ethical practices;
- Implementation of family-centred approaches;
- Achievement of a greater family welfare;
- Accomplishment of a greater well-being and personal development;
- Provision of intervention services in a natural environment;
- Contribution to the generation of protective and inclusive contexts.

The target group of ECI services in Castilla-La Mancha are children aged between 0 and 6 years who have a disability and/or are at risk as well as their families. Preschool children and their families are the priority target group of the ECI centres. However, the ECI centres could exceptionally provide support to older children, too, in case of out-of-school children or when required according to the individual programmes of the children elaborated by Early Attention Teams of the Provincial Social Welfare Directorates.¹⁰

6.1.7 | In Ukraine

The ECI services in Ukraine are defined as long-term services including social, medical, psychological and pedagogical elements. They are provided by inter- and/or transdisciplinary teams supporting families of children aged between 0 and 4 years with developmental delays, disabilities and/or at risk of delays. The ECI services are aimed at improving the quality of life of the families, the development of the children as well as at supporting the parents / caretakers in their daily routines. In addition, the ECI professionals' task is to empower parents to work together with them, to defend the rights of their children, and to lobby and advocate for the best possible services and support for their children.

6.2 | Which stakeholders and agencies did you involve?

6.2.1 | In Portugal

The national ECI system of Portugal consists of two levels – one of inter-sectoral coordination represented

by the National Coordinating Committee and 5 Regional Subcommittees and one of community-based intervention constituted by Local Early Intervention Teams. The Local Early Intervention Teams are located in local healthcare centres. They include professionals from different services, such as nurses, teachers, social workers, psychologists and therapists, hired by private institutions through financial agreements with the Ministry of Social Policy.

There is also a network of Technical Supervision Teams with a district-wide scope, which are the bridge between the coordinating level and the Local Early Intervention Teams.

Healthcare, education and social policy elements should form part of the Local Early Intervention Teams with a transdisciplinary perspective in order to assist in obtaining strategies that will help approaching the problems, needs and priorities formulated by the families.

Nevertheless, each ministry has its own responsibilities as well, and namely:

- The Ministry of Social Policy is in charge of the active cooperation with private institutions for contracting social service professionals, therapists and psychologists. The ministry is also responsible for chairing and coordinating the system;
- The Ministry of Healthcare is in charge of the screening, detection and referral of children who are eligible for receiving ECI services. Thus, healthcare is the "gateway" to the system and the healthcare professionals are responsible for introducing the children who cover the eligibility criteria to the national system of ECI. The participation of the Ministry of Healthcare and its professionals, from coordination to intervention, is a very important aspect of the Portuguese legislation that is not present in most countries where the Ministry of Healthcare does only have collaboration and data exchange functions with healthcare providers when needed;
- The Ministry of Education is responsible for organising a network of reference school clusters for ECI and for involving education professionals in the Local Early Intervention Teams.¹¹

The ECI services aim at an optimal adaptation of the child's environment, improving the parent-child interactions, and they are focused on children between 0-3 years with

¹⁰ Law 7/2014 for the Guarantee of the Rights of Persons with Disabilities in Castilla-La Mancha

¹¹ Carvalho, L. et al. (2019). Recommended Practices in Early Childhood Intervention: A Gudebook for Professionals translated and adapted from the original Práticas Recomendadas em Intervenção Precoce na Infância: Um Guia para Profissionais (2016), 58-61, Eurlayid, accessible on-line at <https://indd.adobe.com/view/ce456704-8e75-46a4-a7e6-700b024ed409>

physical, cognitive, communication, social, psycho-emotional and adaptive development-related disabilities.

6.2.2 | In Serbia

The ECI system in Serbia is in a piloting phase. Professionals from three systems are involved in providing ECI services, and namely from the healthcare, the social and the education sectors. A Primary Healthcare Centre/ Pediatric Department with a Developmental Counselling Unit has a coordination role, while the preschools and the social welfare centres are equal partners together with the families. The ECI services are based on the existing service provision including a cross-sectoral collaboration at a local level and a transdisciplinary knowledge management with a focus on family-centred practices and home visits.

6.2.3 | In Slovakia

ECI in the social care system is provided by registered providers of ECI (public and NGOs) funded by the regional governments of 8 regions.

6.2.4 | In Slovenia

An interministerial commission has been established, which is supposed to coordinate the sectors of healthcare, education and social care and prepare regulations according to the law. Members of the commission are representatives of the ministries only. However, the practitioners insist that there is at least one representative from each of the three sectors of healthcare, education and social care working at grassroots level. Not much has been done at this level and there is still a lack of regulations.

6.2.5 | In Spain

6.2.5.1 | In Castilla y Leon

The main stakeholders and agencies involved in the process of establishing a system of ECI are the Regional Authority of Castilla y Leon as well as some local authorities and non-profit organisations profiled as service providers for people with disabilities.

6.2.5.2 | In Castilla-La Mancha

The White Paper on Early Intervention states that ECI services are provided by the healthcare sector, the Ministry of

Social Welfare and the sector of education. Nevertheless, the document fails to clearly define what each party specifically has to do, particularly in the field of coordination between the three ministries. This issue is currently being addressed through a "coordination table" involving the three regional structures. Organisations supporting people with disabilities and their families are represented in the so called "coordination table" as well.

6.2.6 | In Ukraine

The National Assembly of People with Disabilities, the Ukrainian network of four ECI providers in Lviv, Odessa, Kharkiv and Uzhgorod as well as SOFT Tulip Foundation operate as an informal consortium from where the dialogue with all major stakeholders takes place. The consortium collaborates closely with the EU-funded Twinning Programme, which supports the Ministry of Social Policy to develop national regulations and standards for ECI, the Open Society Foundation, which supports the development of a train-the-trainer programme, the HealthProm Foundation (GB) supporting the development of a parents' movement for ECI as well as with Eurllyaid. The new situation of establishing a national system of ECI will require a formal structure of parents and professionals representing the ECI sector in the country. The next step would be the creation of a National Association on ECI so that the system of ECI develops outside the four pilot regions. In addition, in 2019, the government of Ukraine adopted a decision to establish a National Council for Early Intervention, which was created as a temporary advisory body under the Cabinet of Ministers of Ukraine to prepare suggestions on how to develop and implement a public policy aimed at introducing and developing an early childhood intervention system.

6.3 | Which ECI quality standards apply in your country/region?

6.3.1 | In Moldova

The minimum standards of quality and regulation have been prepared by a workgroup of experts and they form part of the government Decision No. 816 of 30/06/2016 for the approval of the Framework Regulation on the Organisation and Operation of Early Intervention Services and Minimum Quality Standards.

6.3.2 | In Portugal

Quality standards are elaborated by the National System of Early Childhood Intervention (SNPI) and are disseminated

through regulations that the system has developed throughout the years since the legislation was enacted.

6.3.3 | In Serbia

Considering the fact that the ECI service provision is in a piloting phase, covering only 5-7 municipalities (out of 170), quality standards are not yet developed and officially established. The piloting ECI model in Serbia is relying on standards developed and recommended by Prof. Robin McWilliam's family-centred and routines-based ECI model and the cross-sectoral and transdisciplinary work among professionals/institutions established in Portugal within the ECI service provision.

6.3.4 | In Slovakia

The Act on Social Services includes quality standards for all types of social services. These are implemented according to the UN Convention on the Rights of Persons with Disabilities, however, not all of them are applicable for ECI, e.g. room size as, in the best case scenario, the service is provided at the homes of the families.

The National Association of Providers and Supporters of ECI had a strong influence on the methodology and standards elaboration of ECI, which were developed together with all providers in 2017 to serve as a basis for the implementation of ECI. Nevertheless, they should be revised and optimised once all providers start applying the ECI approach as according to a comprehensive national system which does not exist yet.

6.3.5 | In Slovenia

ECI quality standards have not been elaborated in Slovenia yet.

6.3.6 | In Spain

6.3.6.1 | In Castilla-La Mancha

The Ministry of Social Welfare in Castilla-La Mancha took as a reference the work carried out by professionals as well as scientific evidences and it published a Decree on the Minimum Characteristics (Decree 88/2017) which the services aimed at people with disabilities in the region should meet. The characteristics do also refer to the ECI centres, which are considered to need to apply a family-centred approach and to offer support in the child's natural environment. The Decree, however, does not oblige all services to use

a family-centred and natural context approach. And still, it allows and regulates it at least.

Additionally, the following documents have been published:

- Guide to Quality Standards in Early Intervention, Ministry of Labour and Social Affairs, 2004, available at https://www.sindromedown.net/wp-content/uploads/2014/09/21L_guiaestandaresat.pdf;
- Early Intervention. Quality Guidelines, Plena Inclusión, available at https://www.plenainclusion.org/sites/default/files/mbp_atencia3n_temprana.pdf.

The existing ECI quality standards have been developed in a collaboration with the EU-funded Twinning Programme, which has supported the Ministry of Social Policy to develop national regulations and standards for ECI. The standards are still a draft version though.

6.3.7 | In Ukraine

The ECI services in Ukraine are defined as long-term services including social, medical, psychological and pedagogical elements. They are provided by inter- and/or transdisciplinary teams supporting families of children aged between 0 and 4 years with developmental delays, disabilities and/or at risk of delays. The ECI services are aimed at improving the quality of life of the families, the development of the children as well as at supporting the parents / caretakers in their daily routines. In addition, the ECI professionals' task is to empower parents to work together with them, to defend the rights of their children, and to lobby and advocate for the best possible services and support for their children.

6.4 | Who pays what?

6.4.1 | In Moldova

The institutions accredited in ECI provision are financially supported by the National Medical Insurance Company (CNAM) as well as by grants, donations and other funding mechanisms according to the legislation in force.

6.4.2 | In Portugal

Considering the funding of the Portuguese national system of ECI within the scope of competencies legally attributed to the Ministry of Social Services, one of the main instruments of action is constituted by the cooperation agreements of

ECI with Private Institutions of Social Solidarity for hiring social workers, therapists and psychologists, who form part of the Local Early Intervention Teams. The funding of the cooperation agreements is based on validated references by the National Coordination Commission of the national ECI system and there is an established value per child according to the different typologies, which depends on the number of children and professionals involved in each Local Early Intervention Team. The other two ministries – of healthcare and education – provide human resources (doctors, nurses, early childhood special educators, etc.). Additionally, projects' funding is used for the provision of in-service trainings to the professionals of the Local Early Intervention Teams.¹²

6.4.3 | In Serbia

A system with minimal additional costs based on the existing resources coming from regular funds from the sectors of healthcare, education and social policy has been developed. At the end of the piloting process in 2020, a cost analysis will be conducted, which will be taken into consideration on a political level.

6.4.4 | In Slovakia

The corresponding regional government is responsible for covering the costs of the ECI services in the social sector, including for covering the staff costs, travel costs, education and supervision of the employees. As to the public providers, they pay all the working hours of their staff themselves. However, it has been estimated that the ECI financial support is insufficient, and hence, extra sources are still needed, e.g. grants, donations, mostly with regard to the NGOs providing ECI services.

6.4.5 | In Slovenia

ECI in the healthcare sector is funded through health insurance payments. The local communities pay for the ECI services provided in regular groups at the kindergartens. The Ministry of Education covers the costs of the developmental units at the kindergartens. The Ministry of Social Care provides financial security for the social care centres. The NGOs' sector is also funded by the Ministry of Social Care as well as through other sources, such as private donors, projects, etc.

6.4.6 | In Spain

6.4.6.1 | In Castilla y Leon

The Regional Authority of Castilla y Leon pays for the ECI services through public funds so they are free of charge for the children and their families.

6.4.6.2 | In Castilla-La Mancha

The Regional Authority of Castilla-La Mancha pays for the ECI services through public funds so they are free of charge for the children and their families.

6.4.7 | In Ukraine

The ECI services are financed by regional or local budgets from the sectors of healthcare, education and social policy. The services provided by NGOs are generally not funded through the national budget, however, they do receive – full or partial – funding from regional or municipal budgets.

Due to political and economic problems, investments to improve the healthcare, education and social sectors are scarce, which results in an insufficient quality of the service provision. The new decentralisation policies have generated new funding opportunities for the ECI service providers, however, these will only become available as a result of a strong lobby and advocacy for ECI by NGOs and active parents.

6.5 | Which professionals work in ECI services?

6.5.1 | In Moldova

Moldova has made a choice between different ECI models, selecting a heterogeneous model with inter- and transdisciplinary teams involving specialists from different fields – medical, social and educational. Thus, for example, the Voinicel team consists of 16 specialists – an executive director, a fundraiser, 2 pediatricians, a pediatric neurologist, 3 specialists in kinetotherapy, an assistant in kinetotherapy, a specialist in early development of child communication, an occupational therapy specialist / a psycho-pedagogue, a psychologist, a specialist in computer science, a chief accountant, a room manager and a receptionist. However, generally speaking, the lack of staff is a pressing problem due to the high rate of emigration.

¹² Serrano, A. M. (2018), Early Intervention in Portugal and Europe: Paradigmatic Shifts Needed for Quality Early Childhood Intervention, University of Minho, Portugal, & Eurlayid - Report for Erasmus Slovakia

6.5.2 | In Portugal

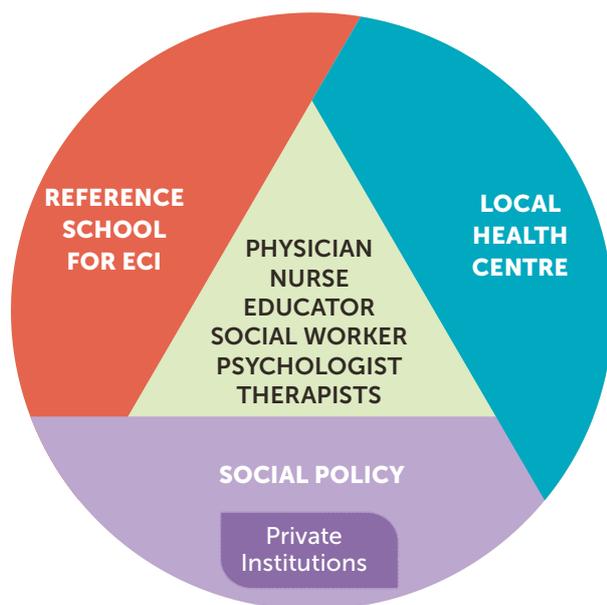
The Portuguese national ECI system is developed through the coordinated actions of the ministries of social policy, healthcare and education as well as with the involvement of the families and the community.

Transdisciplinary teams consisting of professionals with different backgrounds have been established in order that the participation of families as active elements in the ECI service provision is ensured. An important factor introduced by the transdisciplinary team is the information sharing allowing the intervention to be implemented by one professional only supported by the remaining members of the team. Additionally, the family unit has started being considered very important as well as stress factors affecting it – either social, financial or psychological – and the family’s ability to deal with them.¹³

The figure below gives a clearer overview of the structure of the ECI teams in Portugal.

Figure 2

Interdepartmental and transdisciplinary teams



Source: Source: Carvalho, L. et al. (2019). Recommended Practices in Early Childhood Intervention: A Gudebook for Professionals, 61

6.5.3 | In Serbia

The model of ECI involves pediatricians, who are responsible for the screening and counselling within the transdisciplinary teams, speech therapists, special educators, psychologists, pedagogues, etc. The ECI professionals work in natural environments, inclusive childcare and educational centres, preschools, kindergartens, community centres, nurseries and playgroups, or at other settings where children without disabilities go to as well. When the services cannot

be delivered in natural surroundings, the professionals still work to apply the same principles and practices.

Trainings for professionals, such as pediatricians, visiting nurses and pediatrician nurses, from selected institutions are provided, whereby 96 specialists are currently being engaged, however, their number is constantly increasing. The trainings are mainly provided by ANIP, which is a national association based in Portugal involving both national and international experts.

At a local level, wider bodies supporting the local processes and the collaboration with institutions and structures providing services to children and families have been established.

6.5.4 | In Slovakia

ECI services in Slovakia are provided by professionals holding a Master’s degree in the fields of social work, psychology, special education, medical education, physiotherapy or in other fields of study focused on the individual needs of a child with a disability. This has been a requirement grounded in the Act on Social Services since 2014.

6.5.5 | In Slovenia

In 1994, a group of professionals working with children with disabilities established standards for multidisciplinary developmental teams in the healthcare sector. These standards were politically accepted, but because of changes in the political system, they never got implemented. A small step forward was made in 2003, when the teams were standardised. Each included 1 pediatrician, 1 nurse, 2 neurophysical therapists, 0,5 occupational therapist and 0,5 speech therapist, however, the teams were very much medically oriented. Therefore, several attempts were made to get a team with more therapists and with a social worker, a psychologist and a special education teacher, but those were blocked for different (also personal) reasons on different levels.

Eventually, through the 2017 law on ECI, the multidisciplinary teams became a fact. Thus, according to the law, each ECI team/developmental department in the healthcare sector includes the following professionals:

- pediatricians;
- physiotherapists;
- psychologists;
- social workers;
- special education teachers;
- speech therapists;

- occupational therapists.

At the kindergartens, there are special education teachers, psychologists, social pedagogues and speech therapists. In the social care centres, social workers, psychologists and lawyers are involved in the ECI teams of professionals.

6.5.6 | In Spain

6.5.6.1 | In Castilla y Leon

The multidisciplinary early intervention teams report about their work to the Social Services Regional Managing Authority of Castilla y Leon. There is a team in each and every one of the capitals of the provinces in the region as well as mobile teams in the rural areas. The mobile teams operate thanks to agreements with non-profit organisations profiled as service providers for people with disabilities.

6.5.6.2 | In Castilla-La Mancha

The multidisciplinary ECI teams in the region of Castilla-La Mancha are composed of:

- an early intervention specialist (a special education teacher, a psychologist or a pedagogue);
- a speech therapist;
- a physiotherapist;
- a specialist in families (a psychologist or a pedagogue) who usually is the service coordinator.

Each family has an ECI provider who can receive support by other professionals of the team, whereby the family is considered a member of the team, too.

6.4.7 | In Ukraine

Teams of psychologists, speech therapists, doctors, physical therapists, social workers provide ECI services in Ukraine.

What was needed for the parties involved to succeed?

07

7.1 | In Moldova

The successful development of ECI services in a country requires many conditions, such as:

- a political will;
- a legal framework development;
- initiatives and dedication by NGOs in a collaboration with state institutions;
- persistence and many years of efforts;
- conditions for a life-long learning by developing study programmes, textbooks, etc.

7.2 | In Portugal

It has been realised that professional services should be organised and coordinated from the family perspective as the family is a constant in the child's life, and hence, it should be the priority when it comes to ECI. Thus, professionals have started considering families as an integral part of the ECI team, dropping the traditional clinic models. The collaboration and partnership between families and professionals as well as the organisation of a collaborative system between different sectors (healthcare, education and social policy) at all levels of the ECI process have turned out to be the key to a successful implementation of family-centred early intervention services.¹⁴ The interrelation and coordination of healthcare, education and social policy institutions in a partnership with private institutions have been crucial for the provision of integrated services responding comprehensively to the needs of children and families and involving the community.¹⁵

The strength of early intervention in Portugal has rested on three key features:

- The family is at the centre of the provision of early intervention services;

- There is a community-based nature of the early intervention system, including, but not limited to, the use of informal community resources for supporting children and families;
- Support and resources from multiple private and government-funded programmes and organisations are available.¹⁶

7.3 | In Serbia

The early intervention services in Serbia have been brought to the agenda thanks to the:

- continuous support provided by the institutional management in order to achieve structural and organisational changes;
- assistance provided to parents to become the main supporters of the children through routines-based services at the family's home and using the family's resources, motivation and skills;
- strong collaboration with the ministries of healthcare, education and social protection;
- collaboration with parental civil society organisations;
- cross-sectoral collaboration within transdisciplinary ECI teams;
- international and national continuous supervision and institutional mentoring;
- strong commitment of the academic and professional community.

¹⁶ Serrano, A. M. (2018). Early Intervention in Portugal and Europe: Paradigmatic Shifts Needed for Quality Early Childhood Intervention, University of Minho, Portugal, & Eurlaid - Report for Erasmus Slovakia

7.4 | In Slovakia

The following main success factors could be emphasised:

- Conduction of initiatives, which have led to the establishment of ECI pilot centres;
- Implementation of an evidence-based approach;
- Strong collaboration with the Ministry of Labour, Social Affairs and Families;
- Active involvement of the NGOs' sector;
- Provision of support by parents, families and other interested parties;
- Cooperation on a cross-sectoral level through a cross-sectoral workgroup;
- Establishment of a national umbrella association representing almost all providers and supporters.

7.5 | In Slovenia

Among the main success factors, which have led to legal changes in the field of ECI in Slovenia, are:

- the preexisting network of developmental departments;
- the preexisting system of special care for children with special needs at the kindergartens;
- the good practices of coordination and cooperation between developmental departments, kindergartens and NGO's;
- the efforts of developmental pediatricians to pass on the idea of multidisciplinary teams for children with special needs to decision-makers within the healthcare system;
- the support of representatives of the Ministries of Healthcare and Education;
- the support of some parents;
- the support of NGO's.

7.6 | In Spain

7.6.1 | In Castilla-La Mancha

The following points could be regarded as a few pre-conditions for success when it comes to the establishment of an ECI system:

- It is necessary that the public administration, the professionals working in ECI centres and the universities

have an updated knowledge about recommended ECI practices;

- A commitment to change is required by the public agencies.

7.7 | In Ukraine

As success factors in the process of building a system of early intervention in Ukraine, the following could be listed:

- Establishment of a network of stakeholders (government, international partners, NGOs, parents, etc.);
- Conduction of a study by Harvard University about the malnutrition of children in institutions;
- Involvement of international experts who have strengthened the lobby of the local partners;
- Creation of a group of motivated and dedicated professionals;
- Setting up of pilot centres and coming up with promising practices;
- Provision of long-term financial mechanisms;
- Involvement of high-level public servants;
- Building of trust between all levels;
- Having partners from different sectors (healthcare, social policy, education and finances);
- Elaboration of an ECI strategy focused on a trans-disciplinary approach;
- Establishment of a clear ECI model including quality standards;
- Implementation of an evidence-based approach;
- Training of ECI trainers;
- Elaboration of a national plan for the development of ECI services.

To sum up, the factors for success could be put together in three main categories:

- Existence of promising practices;
- Bringing the promising practices together and building up a network of stakeholders;
- Lobbying on different levels – local, regional, national.

Which were the main challenges faced?

08

8.1 | In Portugal

Among the main challenges faced when establishing the Portuguese national system of ECI are the:

- inability to implement ECI services throughout the entire country in the beginning since the Joint Executive Regulations issued by the government were not as strong as the Parliament approved public laws;
- difficulties in bringing together various stakeholders, such as parents, professionals, academics and international experts in order to put through a strong message on a political level;
- slow advancing of the process which needed nearly 30 years to get established;
- need for improving some aspects of screening and assessment;
- need for in-service trainings and supervision of professionals;
- insignificant level of collaboration among the different specialists;
- lack of parents' participation in the different levels within the ECI system;
- need for improving the adoption and adherence to family-centred capacity-building principles and practices;
- high rate of staff turnover within the Local Early Intervention Teams;
- lack of an adequate financial support to fund ECI due to the economic crisis experienced in Portugal.¹⁷

8.2 | In Serbia

The challenges faced could be summarised within two main categories, and namely:

- Changing the working methodology of the professionals involved and the attitudes of the families as well as building up new relationships between the professionals, the child and the parents/caregivers;
- Undertaking structural and organisational changes within relevant institutions aimed at changing the law and the regulations at national and local levels.

Within the first category, the following obstacles could be listed:

- Orientation from the child to the family, i.e. from one-to-one work with the child to work with the entire family;
- Moving away from working in an artificial environment at a centre to providing services in a natural environment, such as the child's home, kindergarten, etc.;
- Moving away from the support provided by different professionals to having one professional who provides support to the parents by seeking the support of other professionals if needed;
- Creating a unified plan for the child and his/her family as well as mutually informed actions directed through a "key worker" of the primary support provider;
- Following common goals that are jointly defined by the parent and the expert;
- Turning the ECI service provision into a community service that responds weekly or as often as possible to the needs of the family and the child.

¹⁷ Ibid.

With regard to the second category identified above, in the coming years, with national and professional support, the goal is to enable every child and his/her family who need ECI services to have an access to them. Hence, it is important to support and promote the work in the 5 pilot locations, which are pioneers in adapting the system to meet the needs of the children and their parents and in applying new service delivery concepts, in order to improve the services throughout the entire country and to introduce legal changes.

8.3 | In Slovakia

Among the main challenges faced during the process of setting up an ECI system are:

- providing sufficient funds by the regional governments to support ECI and relevant community-based services;
- establishing a common legal framework on ECI defining the responsibilities of all three ministries – of social policy, healthcare and education. The law on ECI put through by the Ministry of Labour, Social Affairs and Families does not specify how the three sectors should cooperate in order to provide a holistic ECI services' approach. During the law-making process, there was no time to establish a cooperation with the sectors of healthcare and education. Therefore, at the moment, ECI services are being delivered by three different systems, and hence, there are also three different types of support (with a very limited accessibility in the education and healthcare sectors), which prevents all families from getting a comprehensive assistance in all sectors;
- getting rid of the old therapy-based approach and implementing a new model of ECI, especially in the private social service sector;
- changing the mindset of service providers and families in order that the new ECI system based on a family-centred and routines-based approach in natural surroundings gets implemented successfully;
- providing ECI services within marginalised communities due to socio-economic reasons.

8.4 | In Slovenia

The main challenge in view of establishing an ECI system was (and still is) getting a consensus and making all three ministries cooperate. In addition, some other difficulties have been faced. For example:

- there are not enough professionals to enable the implementation of all tasks embodied by the law;

- the financial provision of the ECI services is partially ensured only;
- not all institutions, which are involved in ECI, are taken into account by the law;
- the voices of the professionals and these of the parents are not heard often enough.

8.5 | In Spain

8.5.1 | In Castilla y Leon

The main challenges faced are related to a resistance by the professionals themselves as well as by the representatives of non-profit organisations providing social services and support to families who don't want to detach themselves from the medical model. Additionally, there are conflicts of interest among different stakeholders.

8.5.2 | In Castilla-La Mancha

The greatest challenges are about introducing a legislation change and a change into the organisations, which the ECI centres form a part of. In addition, having a clear position by the managing authorities on what type of intervention and support should be offered in early childhood care is often a challenge as well.

8.6 | In Ukraine

The following main challenges could be identified during the process of building an ECI system:

- Lack of a shared vision on ECI;
- Difficulties in the provision of a new service and in determining where it fits – in the social, healthcare or education sector;
- Challenges in presenting the NGOs' sector, the social service providers and the parents as equal partners to the government;
- Obstacles for the government itself related to the practical implementation of the ECI model.

Common recommendations to future participants in similar processes

09

The ECI model development should be based on the conditions provided by the corresponding national system, on the existing resources and evidence-based processes, and be supported through international expertise. We all need to be patient, have faith in new practices, our capacities and be willing to take part in intensive international collaborations and exchanges of experience.

As the introduction of an ECI system requires a values-driven change, it is necessary to design rules, procedures and training on techniques, but also to pay attention to aspects aimed at changing our behaviours individually and collectively as well as within the different organisational levels and in view of the different stakeholders involved, such as politicians, managers, professionals, families, etc.

Here are a few tips:

- Try to get the consensus of the different parties involved even if that is not always easy!
- Use tools and techniques to deal with conflicts of interest!
- Build bridges, don't destroy them!
- Don't make enemies!
- Try to involve stakeholders who could support and empower you!
- Get the support of the parents (and the grandparents) and listen to them!
- Get the support and cooperation of the professionals and listen to them!
- Try to introduce both top-down and bottom-up practices!
- If possible, start the process of change together with ECI centres which have previously initiated the process!
- Try to generate a collective impact by bringing together practices of different ECI centres!

- Plan, monitor and evaluate the whole process!
- Use different strategies to bring the idea to the ears of politicians and other decision-makers!
- Even though you may face many obstacles, NEVER GIVE UP!

10

Conclusion

Since the beginning of the new millennium, services, professionals and families have become fully aware of the paradigm shift that took place towards an inclusive, family-centred and comprehensive intervention. The following list could serve as an example of the key elements of a successful ECI model:

- Availability: all eligible children and families have an access;
- Outreach: services are decentralised and the resources are made available in the community;
- Financial viability: ECI is free of charge;
- Transdisciplinary teams: ECI services are provided by professionals from different fields;
- Diversity of services: the ECI professionals do also provide different types of community services.

Nevertheless, the social and legislative changes of the past few years clearly led to new challenges for families, professionals and decision-makers. Hence, it is very important to have an efficient coordination at all levels with a clear definition of roles and responsibilities. National ECI policies should be jointly developed by the three sectors of social policy, healthcare and education. The training and qualification of professionals should be improved. ECI services should reach the whole target population without regional asymmetries. They should also promote family involvement and recognise families as allies with potential to develop the abilities and skills of their children as well as their own. Quality standards should be guaranteed. Among others, funding models, professionals' trainings, a screening and referral system and a comprehensive legal framework should all support and empower community-based services with a focus on working with families and children within their natural environments.

It is the responsibility of all of us – professionals, trainers, coordinators, policy makers – to play a relevant role in making ECI an area of excellence for all children with developmental

problems or at risk and their families. Therefore, Europe needs significant reforms of ECI if we want to transform it into a free and universal system approach of high-quality connected services for all children and families.

Annex



Manifesto on ECI Services by Eurllyaid

Early Childhood Intervention in Europe: The First Step Towards Inclusion

There are important reasons concerning the provision of early childhood intervention services for young children with special needs: ethical, developmental, economic, and empirical.

The past several decades have shown, based on scientific evidences and a strong empirical base, that the modifying capacity of the brain through experience varies throughout life but it is stronger in the first years of life. The early years constitute a “window of opportunity” for a developmental change and repairing trajectories of the brain architecture that may be ruptured due to children’s genetic predispositions and developmental problems.

This scientific evidence comes from the fields of neurodevelopmental science, psychological/developmental science and economic perspectives (Nelson, 2000; National Research Council and Institute of Medicine, 2000, Cunha et al., 2010; Heckman, 2000; Kershaw et al., 2009; Perez-Johnson & Maynard, 2007; Schonkoff & Phillips, 2000; Schweinhart, 2004).

It became clear that the continuous interaction of genetic, organismic, and environmental factors played a key role, and adults, particularly family members and caregivers close to the child, had a crucial role in the child’s development. Children’s main learning environment is the family, with early childhood programmes and community settings playing an increasingly important role as the children grow older.

The **ethical** rationale for early childhood intervention is concerned with societal and community responsibilities to meet and protect the children’s and families’ rights to using ECI services and practices.

The **developmental** rationale for ECI is based on the research evidence concerned with how young children develop, including early brain development (and its vulnerability to neglect), and young children’s receptivity to learning. The research has confirmed that the earlier children and families get support, the easier it will be for them to adapt to the challenges they face.

As far as the **economic** rationale is concerned, the research is conclusive that investments made in the early years of life are cost-effective as they save the need for more costly expenditures on remediation or other interventions in the child’s life course later on.

The **empirical** rationale supports the importance and advantages of ECI for children with a disability or a developmental delay through the research evidence in the field of early intervention. This evidence indicates that evidence-based best practices in early childhood intervention have short- and long-term positive effects on the children’s and families’ functioning and adaptation.

All these reasons form a strong foundation for policy and funding provisions.

Additionally, specific guidelines concerning how services and support should be provided in order to effectively generate benefits for the children and the families are needed. Research and empirical data have led to the following conclusions with regard to the practical implementation of ECI:

1) Adopting a family-centred approach to ECI

The aim of ECI services is to support families and caregivers as mediators throughout the children's acquisition of competencies within their natural environments, enabling the children and the families to meaningfully participate in the daily routines and build relationships with key people in their lives. Family-centred is defined as a particular type of a help-giving practice that involves adherence to principles and values, which include treating families and family members with dignity and respect; information sharing so that families can make informed decisions; acknowledging and building on the family members' strengths; active family members' participation in early childhood intervention; and provision or mobilisation of support and resources in response to the family's concerns and priorities.

2) Articulation of services

The fragmentation of services undermines the capacity of the service system to support children and families effectively. The cross-sectoral cooperation between the ministries of healthcare, education and social affairs is essential. The complexity of problems encountered by children with disabilities and their families cannot be solved by one discipline or a specific service only. It needs coordination and an interdisciplinary approach. Any system that offers a myriad of different services and professionals is likely to cause more stress to the family.

3) Inclusion and natural environments

In order to promote child and family inclusion, autonomy and sustainability of the intervention process, support services should be provided in the children's natural environments. Natural learning environments offer a set of multiple learning experiences and include the family and community surroundings, the childcare or the kindergarten. ECI should be provided within the children's routine and daily activities to promote the full participation of the children in learning experiences.

The above-mentioned leads to the following description of ECI:

- provided by early childhood practitioners and other social network members . . .
- who equipt the parents with time, energy, knowledge and skills . . .
- to engage their children in everyday learning opportunities . . .
- that promote and enhance both the children's and the parents' confidence and competences (Dunst, 2000, 2007a, 2017; Dunst & Espe-Sherwindt, 2017).

Further information on ECI:

- <https://www.eurlyaid.eu/eurlyaid-publications>
- Recommended Practices in Early Childhood Intervention: A Guidebook for Professionals
<https://indd.adobe.com/view/ce456704-8e75-46a4-a7e6-700b024ed409>
- Early Childhood Intervention in Bulgaria, Hungary, Poland, Romania and Slovakia: A Situation Analysis based on the Developmental Systems Model
<https://www.agora-eci.eu/wp-content/uploads/2019/12/2019-12-summary-report-A4-version.pdf>

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Development of the Medical-Social Service of Early Childhood Intervention in the Republic of Moldova – Presentation by Ivan Puiu, PhD, Associate Professor at the State Medical and Pharmaceutical University “N. Testemitanu”, Moldova

UNICEF Belgrade (2018). *Situation Analysis of Services for Infants and Young Children with Disabilities in Republic of Serbia; Development of Early Childhood Intervention Services: Opportunities and Challenges – Report*, available in Serbian language at https://childhub.org/en/system/tdf/library/attachments/sitan_usluga_za_bebe_i_malu_decu_sa_smetnjama_u_razvoju.pdf?file=1&type=node&id=35320

Early Intervention in Slovenia – Presentation by Nevenka Zavrl, Community Health Centre Ljubljana, and Jasna Murgel, Deputy of the National Assembly of the Republic of Slovenia

La Experiencia de Transformación Colectiva en Castilla La Mancha – Presentation by Plena inclusión Castilla-La Mancha

NGOs Building a System of Early Intervention in Ukraine 2006 - 2019 – Presentation by Eric Bloemkolk, Director of SOFT tulip Foundation, the Netherlands

Civil Society Working Towards the Co-creation of a National System of Early Childhood Intervention; Piloting in Four Regions in Ukraine 2019 - 2020 – Project Summary Report by SOFT tulip Foundation, the Netherlands

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Project partners



EASPD, Eurllyaid and partners from Central and Eastern European countries: Hungary, Slovakia, Bulgaria, Poland, Romania. The ECI Agora project, supported by The Velux Foundations, aims to support the development of adequate ECI systems at a local and national level.



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