Early Childhood Intervention in Bulgaria, Hungary, Poland, Romania and Slovakia

A situation analysis based on the Developmental Systems Model

SUMMARY REPORT
DECEMBER 2019

www.agora-eci.eu

Title:
Early Childhood Intervention in Bulgaria, Hungary, Poland, Romania and Slovakia:
A situation analysis based on the Developmental Systems Model

Eurlyaid developmental editors: Natasha Dobrova-Krol, Ana Serrano, Noor van Loen, Marilyn Espe-Sherwindt, Carolyn Blackburn

Authors:
Eurlyaid author: Natasha Dobrova-Krol
Bulgarian authors, on behalf of project partner NASO: Svetla Grigorova, Ekaterina Kostova, Nedka Vasileva-Petrova
Hungarian authors, on behalf of project partner Gezenguz: Judit Schultheisz, Bernadett Kereskényi, Judit Szalai
Polish authors, on behalf of project partner Ezra: Małgorzata Dońska-Olszko, Elżbieta Sobolewska
Romanian authors, on behalf of project partner Dizabnet: Andreia Moraru, Szász Tünde - Csilla, Júlia Gál
Slovakian authors, on behalf of project partner NASSP-ECI: Vladislav Matej, Erika Tichá, Monika Fričová

© 2019, Eurlyaid — The European Association on Early Childhood Intervention (EAECI)

Graphic editing project: BIDL Unipessoal, Lda (BID-lab)
Cover design: BID-lab
Tel.: +351 963 010 262 | Website: www.bid-lab.com | E-mail: geral@bid-lab.com
© of graphic editing project BID-lab
ISBN: 978-2-9199584-9-8

EURLYAID — E.A.E.C.I.
22, Boulevard Joseph II
1840 Luxembourg (LU)
Website: www.eurlyaid.eu I **E-mail:** guidebook@eurlyaid.eu

Disclaimer:

Any form of reproduction, distribution, public communication or transformation of this work or part of it can only be made with the express authorization of the publisher, except when otherwise legislated.

We are not responsible for outdated hyperlinks in this work, which were verified at the time of its publishing.

This summary report was written after the project partners had finalized their country reports.

Suggested citation :

Dobrova-Krol, N., Serrano, A.M., Van Loen, N., Espe-Sherwindt, M., Blackburn, C., Grigorova S., Kostova, E., Vasileva-Petrova, N., Schultheisz, J., Kereskényi, B., Szalai, J., Dońska-Olszko, M., Sobolewska, E., Moraru, A., Tünde - Csilla, S., Gál, G., Matej, V., Tichá, E., Fričová, M. (2019). Early Childhood Intervention in Bulgaria, Hungary, Poland, Romania and Slovakia: A situation analysis based on the Developmental Systems Model. Luxembourg: Eurlyaid.

Table of Contents

Executive Summary 5

Introduction 5

General overview of the ECI in the target countries: Development and implementation of the ECI services 6

Brief description of the Developmental Systems Model 7

Methods 10

Procedure 10

Participants 11

Analysis of the DSM-ECI components in Bulgaria, Hungary, Poland, Romania, and Slovakia: Main findings 12

Screening and referral 13

Monitoring 16

Point of Access 18

Comprehensive Interdisciplinary Assessment 20

Eligibility for the ECI system 22

Evaluation of potential stress factors for families 24

Development and implementation of an Individualized Family Service Plan 27

Monitoring and outcome evaluation 30

Transition planning 32

Policy and legislation 34

Funding and financial resources 36

Personnel development 39

Conclusions 41

Limitations 43

Recommendations 44

Literature 47

Appendix 48

Appendix 1 48

Appendix 2 50

Appendix 3 53

Appendix 4 56

Abreviations list

DSM	Developmental Systems Model
DSM-ECI	Developmental Systems Model for Early Childhood Intervention
EASPD	European Association of Service Providers for Persons with Disabilities
ECI	Early Childhood Intervention
Ed	Education
EU	European Union
Eurlyaid	European Association on Early Childhood Intervention
HC	Healthcare
IFSP	Individualized Family Service Plan
NGO	Non-governmental organization
PA	Point of access
PAs	Points of Access
SP	Social Policy

Executive Summary

Introduction

This report was produced within the framework of the "Agora Project on Early Childhood Intervention and Development of Early Intervention Services through Participation and Cooperation", supported by Velux Foundations. The project involved the partners from the following countries: Poland, Hungary, Slovakia, Romania and Bulgaria. In addition two European NGO's have been involved:

Bulgaria: National Alliance for Social Responsibility (NASO)

Hungary: Gezenguz Foundation

Poland: Ezra Uniwersytetu Kardynała Stefana Wyszyńskiego [Cardinal Stefan Wyszyński University in Warsaw] (UKSW)

Romania: Dizabnet Federation – The Network of Service providers for Persons with disabilities

Slovakia: National Association of Supporters and Service Providers of Early Childhood Intervention (NASSP)

European Association on Early Childhood Intervention (Eurlyaid)

European Association of Service Providers for Persons with Disabilities (EASPD)

The main **objective of the project** was to facilitate the implementation of strategies ensuring the development of an appropriate Early Childhood Intervention (ECI) system at both local and national levels. It was expected that as a result of the "Agora — Early Childhood Intervention" project, practical guidelines and tools would be developed to stimulate systemic and legislative changes in the area of early childhood development and intervention in the partner countries.

The project was expected to identify and describe quality, evidence-based practices that may be disseminated in other European countries and serve as a model for implementing support for other groups of children with special needs or children at risk of social exclusion (e.g. Roma children or children from migrant families).

The first phase of the project was aimed at the examination of the current situation in the area of ECI in the partner countries.

The **main goal of this report** was to analyze the situation regarding ECI services in Bulgaria, Hungary, Poland, Romania, and Slovakia using an overarching framework of the Developmental Systems Model for Early Childhood Intervention (DSM-ECI) as an analytic tool.

Research questions:

The following research questions were addressed in this study:

1. What are the main developments and concerns associated with each component of the DSM-ECI in the participating countries?
2. What is the degree of the implementation of the components of the DSM-ECI in the target countries from an organizational and practice perspective?

General overview of the ECI in the target countries: Development and implementation of the ECI services

The development of the current system of ECI services for young children with special needs and their families has been unfolding in the countries under consideration for several decades. In **Poland** this process was initiated in 1978 when, thanks to the efforts of a number of parents of children with special needs who were the members of the Polish Association for People with Intellectual Disability, the first centre of ECI was established in Warsaw.

In **Hungary** two years later in 1980 the Special Educational Needs Psychological Institute of Bárczi Gusztáv College for Special Educational Needs Teachers started a program for pre-kindergarten children, which laid the foundation for family-centered family education and subsequently the development of ECI programs. In **Slovakia** the development of ECI goes back to 1986 when Prof. Karol Matulay established an out-patient department for children with developmental difficulties at the Clinic of Child Psychiatry. **Romania** joined this process beginning in 1990 by setting up ECI services that were provided by NGOs, but it was not until 2003 that these services were recognized officially. **Bulgaria** introduced ECI in 1999 when the Law on Health Care Institutions supporting ECI in the health care sector was issued (see Table 2).

The emergence of the ECI in these countries and in the region in general can be related to the growing understanding and appreciation of the role of families in the development of young children; a process of deinstitutionalization and the development of alternative care for children (with special needs); decentralization, leading to the growing role of the local communities and nets of community-based services; as well as an increased understanding of the importance of early identification and diagnosis of children with special needs and family-centered, cross-sectoral, multidisciplinary approach in service provision for the children and their families.

Although having different entry points (NGO sector in Romania, NGO sector and parental movement in Poland, special education sector in Hungary, healthcare sector in Slovakia and Bulgaria), in the past decades ECI services in all five countries have been spreading to other relevant fields and involve now Healthcare (HC), Education (Ed.), Social Policy (SP) and NGO sectors. However, the cooperation and communication among these sectors until now remain very limited with little (and in such countries as Poland and Romania even no) coordination among the sectors. This lack of coordination can result in fragmentation of services, as well as gaps in availability, accessibility, quality and equity that are based on disability, family income, and location.

In order (1) to enhance the understanding of how ECI works at different levels within the countries, (2) to analyze various aspects of the ECI services and systems in a more comprehensive way, and (3) to identify existing strengths, service gaps, and follow up goals and strategies in the ECI system development and implementation, the Developmental Systems Model (DSM) has been employed. The DSM is briefly described in the following section.

Brief description of the Developmental Systems Model

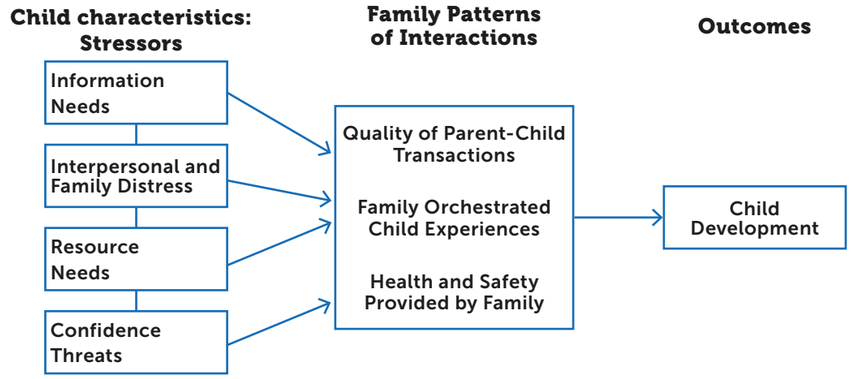
The DSM-ECI introduced by M. Guralnick (2001, 2005, 2011) encompasses and connects the wide range of strategies offered to young children with disabilities or at risk of developmental delays or disabilities and to their families and offers a framework for the development of more effective policies and strategies in the field of ECI.

DSM-ECI provides an integrated perspective on the needs of children who have or are at risk of developmental delays or disabilities which is organized around three fundamental principles. The **first core principal** or organizing feature of the DSM-ECI is its focus on the **developmental framework** which informs all components of the ECI system and *centres on families*. It views child developmental outcomes in relation to the family patterns of interaction.

The family's ability to provide the needed interactions is, in turn, affected by various resources, such as the parents' personal characteristics, financial resources, social support as well as child characteristics. If any of these resources are insufficient or lacking, family patterns of interaction and, as a consequence, the development of the child will be affected (see Figure 1 and 2).

The **second core principal** of the DSM-ECI has to do with the **integration** of different services and administrative structures and agencies involved in the service provision at all levels into a comprehensive and well-coordinated system collaborating with and involving the families. Such a system is fundamental for early identification, screening, comprehensive interdisciplinary assessment and diagnostics of the child's development and family stressors, and the development of a comprehensive intervention plan and program planning. Integration is of vital importance during the implementation of the intervention plan and helps to avoid service gaps and inefficient, duplicative service provision.

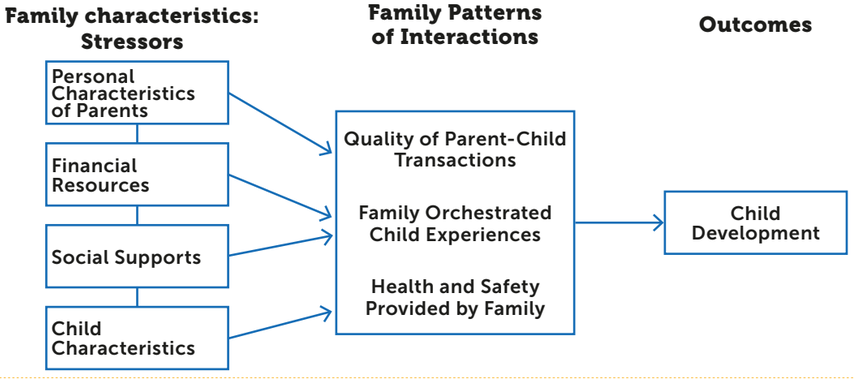
Figure 1 **The relationship among potential stressors due to child characteristics, family patterns of interaction, and child development outcomes for children at environmental risk**



Source: Guralnick, M.J. (2001). A developmental systems model for early intervention. *Infants and Young Children*, 14, 1-18.

The **third core principal** is that of **inclusion**, which, being closely related to the principal of integration, relates to the provision of services in natural environments and maximization of the participation of children and families in typical community activities.

Figure 2 **The relationship among potential stressors due to family characteristics, family patterns of interaction, and child development outcomes for children at environmental risk**



Source: Guralnick, M.J. (2001). A developmental systems model for early intervention. *Infants and Young Children*, 14, 1-18.

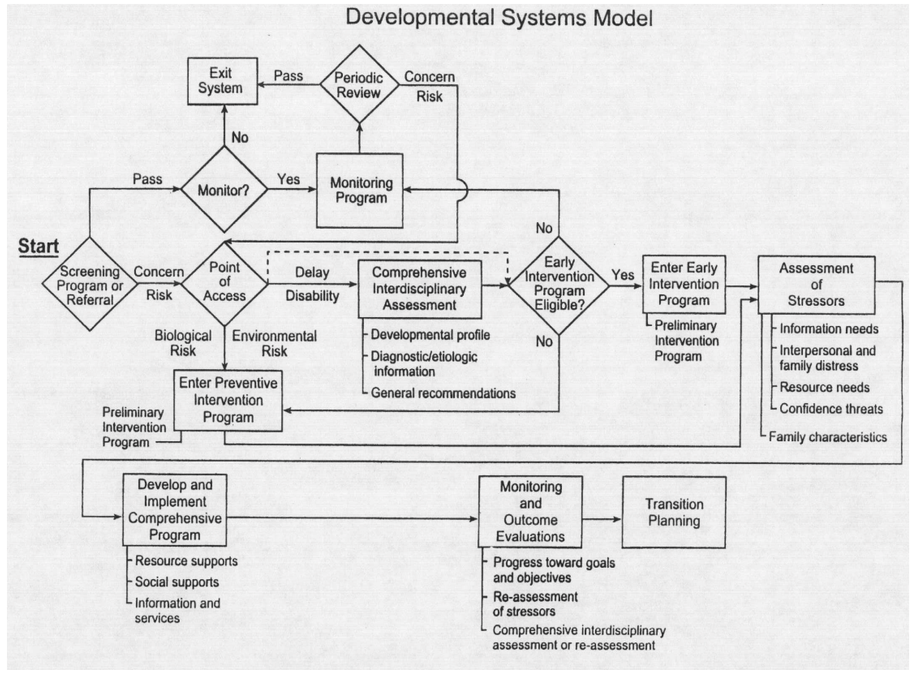
Other key principles of ECI relevant to the DSM-ECI emphasize the importance of:

- Early detection and identification procedures;
- Surveillance and monitoring;
- Individualized approach in all parts of the system;
- Strong evaluation and feedback process;

- Sensitivity to cultural differences and their developmental implications;
- Strong evidence-based foundation for programs and services.

The DSM-ECI includes the following main structural components related to the decision points and activities: (1) screening and referral, (2) eligibility for the ECI system, (3) follow-up/monitoring, (4) a point of access to the service system, (5) interdisciplinary assessment, (6) evaluation of potential stress factors for families, (7) development and implementation of an individualized service plan, (8) monitoring and evaluation of the results of the implementation of the plan, and (9) transition to new settings (see Figure 3).

Figure 3 **A Developmental Systems Model for ECI for vulnerable children and their families.**
Diamonds represent decision points, and rectangles represent activities



Source: Guralnick, M.J. (2001). A developmental systems model for early intervention. *Infants and Young Children*, 14, 1-18.

Policy, legislation and financial resources, as well as personnel development are other integral components of the ECI systems and services development and implementation.

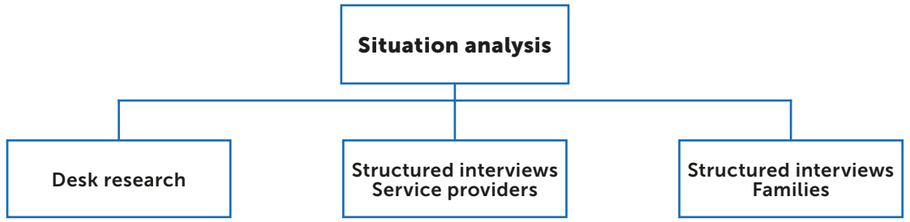
In this report each of the above mentioned major components that represents a complex system in itself will be discussed. Each component involves different protocols, services, and sectors and, ideally, should be compatible with other components and, to a certain degree, represent the overarching developmental framework as well as the core and related principles described above.

Methods

The current report represents the result of the analysis and synthesis of the data presented in the country reports based on the situation analyses around ECI systems and services in Bulgaria, Hungary, Poland, Romania, and Slovakia from the perspective of the DSM-ECI.

A variety of methods and sources of data collection were used in the country reports: desk research, structured interviews with the parents of children with special needs, and with the service providers from different sectors (see Figure 4).

Figure 4 Research design



The desk research as well as structured interviews were informed by the DSM-ECI. For the purposes of the project two questionnaires, one for families (26 items) and one for service providers (22 items) were developed by the partners of the project using a participatory approach involving researchers, service providers, and parents of children with special needs (see Appendix 1 and 2).

Procedure

Desk research (31 items) was conducted by the project partners and was based on official reports and statistical data on the ECI services and legislation in the target countries (see Appendix 3). The description of the search strategies and the scope of relevant resources for each country presented in the country reports are available on www.agora-eci.eu .

The families and service providers were recruited by the project partners. The structured interviews with service providers and families were conducted by the staff of the ECI services who are partners of the project.

The participation in the structured interviews was voluntary. All participants received detailed information about the goals and objectives of the research and provided written

informed consent. Confidentiality and anonymity were guaranteed to those participants who chose not to disclose their identity (see Appendix 4).

Upon completion of the country reports, each country team was asked to fill in the DSM-ECI checklists, which reflected different relevant aspects of the DSM-ECI components based on the results of the situation analysis in their countries and to the best of their knowledge. The checklists were designed for the purpose of this study.

Participants

In this study in each country the information was obtained from the service providers and families who have or had experience with ECI services (see Table 1).

Table 1 The number of participants interviewed in each country

Country	Representatives of service providers from different sectors			Families
	Healthcare	Education	Social Policy	
Bulgaria	3	4	3	3
Hungary	5	5	5	3
Poland	4	4	4	12
Romania	3	3	3	3
Slovakia	2	3	3	4

Participants representing ECI service providers from health, education and social policy sectors (+3 in each sector) were interviewed (see details in the country reports).

The following inclusion criteria were applied:

- Coordinator of the ECI service, and
- EC Interventionist with at least 1 year of practical experience in the field.

In each country at least 3 families/parents of children from 0 to 6 years of age with special needs were interviewed. The following **inclusion criterion** was applied:

- Experience of ECI services now or in the past in the target country.

Analysis of the DSM-ECI components in Bulgaria, Hungary, Poland, Romania, and Slovakia: Main findings

As described in the general overview of the ECI in the target countries, the development of the current systems of ECI for young children with special needs and their families has been unfolding in the countries under consideration for several decades. However, up to date comprehensive statistical data on the number of children in need of ECI and the actual number of children receiving ECI services is either lacking or inconsistent (see Table 2), which, on one hand, may conceal the urgency of the need in ECI services and, on the other hand, hamper appropriate policy and service development and budgeting.

At the same time, available statistical data from Bulgaria, Hungary, and Slovakia demonstrates that a substantial number of children in need of ECI services do not have access to ECI services which means that early identification and diagnosis is problematic. If special needs and/or disability is diagnosed too late, then important opportunities for children to achieve their full potential for health and development can be missed as a result.

In the following sections, the specific components of the ECI systems in the five countries will be explained and analyzed according to the framework of the DSM-ECI and based on the data provided in the country reports. For more detailed information and situation analysis in each country the individual country reports must be visited: www.agora-eci.eu

Table 2 General overview of the ECI system of services development in Bulgaria, Hungary, Poland, Romania and Slovakia

Country	First ECI services introduced	Sectors involved in the ECI	Cross-sectoral coordination of ECI services	Number of children (potentially) in need of ECI services	Number of children receiving ECI services
Bulgaria	1999	HC Ed. SP NGO	Insufficient	50,246[1]	HC 90%; Ed. 50%; SP 20%[2]
Hungary	1980	HC Ed. SP NGO	Insufficient	9,000 – – 15,000	2,500 – – 6,000
Poland	1978	HC Ed. SP NGO	No	190,710[3]	56,958
Romania	After 1990	HC Ed. SP NGO	No	17,000 – – 19,000[4]	N/A*
Slovakia	1986	HC Ed. SP NGO	Insufficient	8,700 – – 28,000	HC 17% Ed 11% SP 4%[5]

Note. *N/A information was not presented in the country report or not available
HC: Healthcare; Ed.: Education; SP: Social Policy; NGO: Non-governmental organization

Screening and referral

The main goal of the screening program and referral is early detection and identification of children that have developmental difficulties. It is an entrance point for children and families that can be initiated by parents and professionals in response to their concerns about the child's development.

The screening process may include the following:

- Identification of existing community screening programs and high-risk registries;

1 The number represents 10% of the total number of children aged between 0 and 7 years.

2 Official statistical data does not exist and the information both under [1] and [2] is based on experts' estimations.

3 The number represents 10% of the total number of children aged between 0 and 4 years; for the age group from 0 to 9 years old the estimate number of children in need of ECI services is 394,252.

4 The figures represent 7% - 9% of the total number of children aged between 0-6 years, according to the statistical data from the National Institute of Statistics.

5 Majority of children can receive ECI from different sectors at the same time.

- Selection of culturally relevant and appropriate screening tools, instruments and related protocols;
- Engaging developmental surveillance in health settings that includes multiple sources of information;
- Determining criteria and risk indices for identifying children for further in-depth evaluation; and
- Establishment of algorithms to guide decisions for referral.

Primary care physicians and other health professionals are central to this effort. Making decisions about universal vs. targeted screening, timing, risk criteria, and further referral requires appropriate knowledge and skills. At the same time, other aspects involve a great deal of cross-discipline and cross-sectoral cooperation as well: information campaigns to enhance public knowledge about the developmental milestones and causes for concern (especially concerns of parents and day care providers), systematizing the screening procedures, and cost-effectiveness considerations.

Therefore, the creation of an effective and efficient community-based screening program and referral component requires a high level of cooperation among relevant parties to reach decisions and implement evidence-based effective practices.

As Table 3 demonstrates, the development of the screening and referral component in all five countries is currently in progress. Bulgaria, Hungary and Poland have national screening programs in place. In Slovakia the screening program has been developed and is waiting to be implemented. In Romania, a national screening program exists only in health care system. In some communities community screening programs also exist in social policy and NGO sector. In all five countries the Healthcare sector plays the leading role in the screening process. Education and Social Policy sectors are also involved in this process. In case of Bulgaria, Hungary and Romania, NGOs are integrated into the existing screening and referral system. However, despite the participation of all sectors, cross-sectoral coordination and cooperation around the screening and referral procedures has not yet been established in all five countries.

Existing community screening programs and high-risk registries have already been identified in Hungary, Poland and Romania[6]. Screening, instruments and related protocols are in place in Bulgaria and Hungary (see country reports for more details as well as the lists of the screening tools); however, in Hungary the instruments are not used systematically. This work is in progress in Romania and Poland, whereas Slovakia has still to identify and develop the screening tools and protocols that relate to all children, especially for children at risk (e.g., Roma population).

Both Bulgaria and Hungary have managed to engage in developmental surveillance in health settings. In Hungary when children reach the age of three, the responsibility for developmental surveillance is transferred to education. In other countries this work is still in progress or has to be initiated (Romania). As country reports reveal, the medical professionals play a key role in this component. Yet the medical professionals are not always well informed or receptive to the process involved in addressing the needs of young children with or at risk

6 Only for the Healthcare sector.

of developmental delays and difficulties. Consequently, there is a risk of failure to recognize the connection between routine health screening and referral to ECI services.

Only Hungary has developed the criteria and risk indices for identifying children for further in-depth evaluation. However, according to the Hungarian neurologists, this system appears to be leading to unnecessary referrals of children with normal development for neurological assessment.

The algorithms guiding decisions for referral appear to be well developed in Bulgaria, which has formulated clear criteria and sources for referral to ECI services and serves as a good example for other countries. In Bulgaria it is not necessary for the child to be diagnosed or officially referred in order to be able to use ECI services. Consequently, parents are given the opportunity to seek help promptly without waiting for the exact diagnosis or worrying that their child would be diagnosed or labeled at such an early age. Perhaps even more importantly, families in Bulgaria have the right and the opportunity for self-referral. This system of self-referral was introduced in 2014 when the first Centers for Social and Healthcare Services were established in the framework of externally funded projects. However, social services financed by the state do not provide an opportunity for self-referral.

⚠ Main challenges:

As mentioned above, effective and efficient Screening and Referral programs require a high level of cooperation among the sectors and parties involved. However, despite some positive developments, all countries report that there are no clearly regulated pathways in the screening and referral process. The cross-sectoral coordination is either in the process of being established, or, as is the case in Romania and Slovakia, is still absent and the screening procedures are organized by sector. This situation is exacerbated by the shortage of medical personnel as well as lack of information and public awareness about ECI. As a result, not all children may be included in screening, especially children at risk. Parents are not always aware which organization they should contact for screening or self-referral. Finally, there are no comprehensive statistics as to how many children need support and do not receive it.

Table 3 Implementation of the Screening and Referral component of the DSM-ECI in the target countries

Screening and Referral components of the DSM-ECI	Bulgaria	Hungary	Poland	Romania	Slovakia
Sectors involved	HC Ed. SP NGO	HC Ed. SP NGO	HC Ed. SP	HC Ed. SP NGO	HC Ed. SP
Cross-sectoral coordination of screening and referral is in place	In progress	In progress	In progress	To do	To do
Existing community screening programs and high-risk registers are identified	To do	Done	Done	HC – done SP – in progress	To do
Screening tools, instruments and related protocols are in place	Done	Formally done; in practice not applied systematically	To do	In progress	To do
Developmental surveillance in health settings is engaged	Done	Done under the age of 3, above this age by educational settings	In progress	To do	In progress
Criteria and risk indices for identifying children for further in-depth evaluation are determined	To do	Done	In progress	To do	In progress
Algorithms to guide decisions for referral are established	To do	To do	In progress	To do	In progress

Note. *N/A information was not presented in the country report or not available
HC: Healthcare; Ed.: Education; SP: Social Policy; NGO: Non-governmental organization

Monitoring

According to the DSM-ECI, for children who do not meet screening criteria for referral, monitoring remains of great importance, especially if the children maintain a risk status (e.g., premature children) or their parents have any concerns with regard to their development.

The primary functions of monitoring that are highly cost effective and non-intrusive are:

- To minimize the risk that a child is not identified and does not receive appropriate services; and
- To maintain contact with children at risk for developmental difficulties.

Monitoring programs have to be developed individually and require:

- Monitoring protocol identifying the tools, frequency, and form, and costs; and
- Clear exit criteria.

If a concern is identified, a child re-enters the system via the point of access (see Figure 3), or otherwise exits the program.

Currently among the five countries only Hungry has a national monitoring program in place, with the Healthcare sector being responsible for this component. Hungary has identified and developed monitoring tools and protocols as well as clear exit criteria.

Although there is no national monitoring program in Bulgaria, the development of the monitoring component appears to be relatively advanced: all sectors are involved in the monitoring process, individualized monitoring protocols are in place, and the development of the cross-sectoral cooperation and monitoring tools and protocols are in progress.

Poland is in the process of the development of its national monitoring system, identifying standardized and individualized monitoring tools and protocols as well as exit criteria. Currently Healthcare and Education sectors are involved in this component. Importantly, in Poland for children who were not diagnosed and treated during the first year of life, there is no clear or consistent monitoring path within the system. However, the monitoring component in Poland is expected to be developed further thanks to the introduction of the comprehensive support programme for families that aims to establish Coordination and Rehabilitation and Care Centers in every county. Poland has developed a monitoring program for children living in foster care which can serve as an example for other children at risk that require monitoring.

According to the country reports from both Romania and Slovakia, all elements of the monitoring component have yet to be developed.

⚠ Main challenges:

In Bulgaria currently the monitoring component exists only in the Social Policy sector, whereas in Hungary and Poland monitoring is limited to the Healthcare and Education sectors, which may leave psychosocial problems and risk factors unnoticed. Cross-sectoral coordination of monitoring is still lacking, and individualized monitoring protocols are yet to be developed in Hungary, Poland, Romania and Slovakia. Lack of qualified specialists who are trained to perform the monitoring presents another challenge. Moreover, according to the country reports, families are often poorly informed about the monitoring procedures in different sectors, and are not aware in which cases and under what conditions they can apply for monitoring. Slovakia points out that one of the main challenges in the development of this process is to introduce monitoring into the quality standards of the Healthcare sector and start implementing it.

Table 4 Implementation of the Monitoring component of the DSM-ECI

Monitoring component of the DSM-ECI	Bulgaria	Hungary	Poland	Romania	Slovakia
National monitoring program is in place	Does not exist	Done	In progress	To do	To do
Sectors involved	HC Ed. SP NGO	HC	HC Ed.	In progress	N/A*
Cross-sectoral coordination of monitoring is in place	In progress	To do	To do	To do	To do
Monitoring tools and protocols are identified	In progress	Done	In progress	In progress	To do
Individualized monitoring protocols are in place	Done	To do	In progress	In progress	To do
Clear exit criteria are identified	To do	Done until school ages (7 years)	In progress	In progress	To do

Note. *N/A information was not presented in the country report or not available
HC: Healthcare; Ed.: Education; SP: Social Policy; NGO: Non-governmental organization

Point of Access

Point of access (PA) to ECI system comes into play when a concern about development reaches certain criteria (including parental concerns resulting in self-referral) or risks to development are sufficiently high. PA represents a location or setting where the process of gathering, integrating, and coordinating information occurs, and families are introduced to the possible services and forms of support that the system can provide. The way communities address PA serves as an important index of the overall level of integration and coordination of the system of services.

In larger communities there should be multiple Points of Access (PAs) to ensure the availability and proximity of services.

The primary tasks of the PAs are:

- Gathering of the information and creation of a record for the child and family;
- Differentiation of children and families into biological or environmental risk groups and children with probable delays or disabilities;
- Assistance in the organization of a comprehensive interdisciplinary assessment for the child and family to evaluate possible delay or disability or referral to the appropriate preventive intervention program for children at risk due to biological or environmental factors.

To function effectively the PAs have to be:

- Well known to local communities and community professionals;
- Easily accessible to families;
- Equipped with unified record-keeping systems and a centralized database;
- Highly familiar with and connected to other PAs;
- Well connected with the interdisciplinary assessment groups, including the groups specialized in certain disorders or disabilities, and preventive intervention programs and ECI services.

The analysis of the country reports reveals that the PA component is most developed in Hungary, where the role of PA to the ECI service system is fulfilled by the regional Expert Committees, or in special cases on a national level, by the Visual/Hearing/Speech/Motion Examining Expert Committees within the Education sector. These PAs are well known to local communities and have unified record-keeping systems and a centralized database. However, cross-sectoral coordination remains insufficient especially for those children who are older than 18 months. Hungary continues to work on the proximity and accessibility of the PAs, which are at the moment concentrated in the big cities and are not easily accessible in rural areas. The PAs are not yet well connected with each other and with the interdisciplinary assessment groups, preventive intervention programs, and ECI services.

In Poland there are no special facilities within the ECI support system that can be identified as the PA. Parents concerned with the development of their children typically seek help of their physician or within the Educational sector. However, efforts are made towards cross-sectoral cooperation in this area and establishment of the PA on the basis of the Coordination and Rehabilitation and Care Centres at the county level.

In Slovakia the function of PA is fulfilled by the Healthcare facilities functioning on request of the families, and the country makes efforts to make the PA accessible.

In Bulgaria and Romania no PAs for ECI exist at the moment. Instead, general practitioners and non-governmental organisations working in the field of ECI fulfill their role.

⚠ Main challenges:

With the exception of Hungary, this component is one of the least developed in the five countries and requires special attention. Lack of trained personnel, resources and cross-sectoral cooperation are among the main challenges. If PAs exist, they are not evenly distributed and are lacking in rural areas. According to the country reports, the unified record-keeping system and database are yet to be created in all five countries, except for Hungary. Furthermore, families usually lack the information about the PAs or their equivalents.

Table 5 Implementation of the Points of Access component of the DSM-ECI

PA component of the DSM-ECI	Bulgaria	Hungary	Poland	Romania	Slovakia
Sectors involved	Does not exist	Educational system	HC Ed.	Does not exist	HC
Cross-sectoral coordination of PAs is in place	To do	To do	In progress	To do	To do
Proximity and accessibility is in place	To do	In progress	N/A*	To do	In progress
Well known to local communi-ties and community professionals	To do	Done	N/A*	To do	To do
Unified record-keeping systems and centralized database is in place	To do	Done	N/A*	To do	To do
Well familiar and con-nected with other PAS	To do	To do	N/A*	To do	To do
Well connected with the interdisciplinary assess-ment groups, preventive intervention programs, and ECI services	To do	To do	N/A*	To do	To do

Note. *N/A information was not presented in the country report or not available
HC: Healthcare; Ed.: Education

Comprehensive Interdisciplinary Assessment

This approach to assessment is the essential part of the DSM-ECI that facilitates a subsequent intervention plan. The main goals of the Comprehensive Inter-disciplinary Assessment are:

- To obtain a general developmental profile for the child;
- To evaluate family functioning at home, neighborhood, and larger community;
- To gather information for diagnostic/etiologic purposes; and
- To make general recommendations.

This complex assessment requires:

- Time to properly organize;
- A selection of disciplines to be involved;
- Clear relationships to points of access;
- The capability of addressing a wide range of possible problems (limited number of specialty interdisciplinary teams can also be established, e. g. with a focus on autism, abuse and neglect, phenylketonuria, etc.).

As families should not have to wait to receive at least preliminary support, and since often considerable information is available from screening or monitoring components, this component at time may be bypassed in order to move forward quickly to service provision and entrance to ECI.

Interdisciplinary assessment exists in all countries under consideration and can be provided in Healthcare, Education and Social Policy sectors, with the exception of Bulgaria where Healthcare settings do not conduct interdisciplinary assessments but rather refer families to educational or social services where such assessment is done. In all countries interdisciplinary teams within the healthcare sector appear to be more inclined towards a medical model, and in Poland such assessment is provided by the Healthcare settings only during the child's first year of life. In Romania interdisciplinary assessment is still being developed.

Only Bulgaria reports having a well-functioning comprehensive interdisciplinary assessment component represented by interdisciplinary teams that assess the child's health as well as developmental profile and family functioning and can address a wide range of possible problems. In Bulgaria, according to the country report, specialized interdisciplinary team that can focus on specific problems are also available. As there are no PAs, the link between the interdisciplinary assessment teams and PA does not exist.

The other countries have also made certain progress in the development of the interdisciplinary component by involving different disciplines in the assessment, addressing not only child's health but also the developmental profile and family functioning and a wide range of possible problems (see Table 6).

⚠ Main challenges:

According to the country reports, interdisciplinary teams within different sectors focus on different aspects of the assessment: either health (traditionally by the Healthcare sector), or developmental profile of the child, or family functioning. The latter is usually done within Social Policy sector in case of families with psychosocial problems, which can hamper comprehensive assessment and the subsequent stages in service provision. In addition, lack of cooperation between the sectors can lead to the unnecessary duplication of assessment procedures performed within each sector, which in turn creates unnecessary confusion and loss of valuable time and resources for the child and family. Furthermore, Hungary as well as Poland report that parents are insufficiently involved and informed about the assessment.

Table 6 **Implementation of the Comprehensive Inter-disciplinary Assessment component of the DSM-ECI**

Comprehensive Inter-disciplinary Assessment component of the DSM-ECI	Bulgaria	Hungary	Poland	Romania	Slovakia
Sectors involved	Ed. SP	HC Ed. SP	HC Ed. SP	HC Ed. SP	HC Ed. SP
Different disciplines are involved	Yes	Yes	Yes	In progress	In social and education system – certain providers
Assessment of child's health as well as developmental profile and family functioning is in place	Done	Different aspects assessed in different sectors	In progress	Different aspects assessed in different sectors	Different aspects assessed in different sectors
Direct link to points of access are established	To do	Done	In progress	To do	To do
Address a wide range of possible problems	Done	In progress	In progress	In progress	Social care system – certain providers
Speciality interdisciplinary teams with a focus on specific problem are available	Done	To do	To do	To do	Very rarely

Note. HC: Healthcare; Ed.: Education

Eligibility for the ECI system

Eligibility decisions are usually based on pre-determined criteria that facilitate referrals of children to early intervention program (children with delays or disabilities) or to preventive intervention program (based on biological and environmental risk factors).

Importantly, the DSM-ECI suggests that children who do not meet eligibility criteria should remain in the system through the Monitoring and Surveillance, especially if the parents are concerned about their development. Eligibility criteria should be consistent across different organizations, sectors and counties.

Effective functioning of the Eligibility component requires:

- Established eligibility criteria for entry into ECI programs;
- Established eligibility criteria for entry into monitoring and preventive intervention options.

Among the five countries Bulgaria and Poland report having clearly defined eligibility criteria for entry into ECI programs.

In Bulgaria the following eligibility criteria are applied:

- Age of the child: 0-3 years or 3-6 years;
- Disability or risk of developing a disability;
- Risk of abandonment and placement in an institution;
- Delay in one or several areas of development – cognitive, motor, speech, social, emotional;
- Place of residence – the family should live within the municipality where the service is provided.

The following criteria are used to distinguish "children at risk" and "children with disabilities":

Children at *risk* of a developmental delay are:

- Children with an identified delay in one or more areas of development;
- Children at risk of delays, including premature babies, low birth weight babies and those with complications around birth;
- Children at risk due to biological or genetic factors;
- Children at risk of development delays due to environmental factors: socially disadvantaged families, low formal education, domestic violence, etc.

Children *with* disabilities are those who have a diagnosed condition or disorder that, limits their functioning in one or more areas of their development.

The following criteria are applied around the decisions for family support:

- The parent has a chronic, mental or intellectual disability;
- The parent has an alcohol and/or a drug addiction;
- The parent has a chronic illness or has experienced a family crisis;
- The child has been separated from the parent;
- The mother is very young;
- The parent is socially excluded and lacks social support;
- The family resides in is unsafe housing or dangerous living conditions;
- There are severe complications before or after birth;
- The child has a very low birth weight.

Poland also reports having established eligibility criteria for children with delays or disabilities; however, the criteria seem to be less elaborate and clear-cut.

Except for Bulgaria, in all countries the eligibility criteria for children at risk have not been established yet. In Slovakia it is expected that such criteria will be introduced in 2019, and in Poland the work is in progress.

⚠ Main challenges:

The fact that eligibility criteria for children at risk have not been established yet means that many young children and their families may not receive the necessary support on time, important preventive opportunities may be lost or with time become less effective, and, as a result, children may not receive vital chances for the best start in their lives.

Furthermore, at the moment in all countries each sector applies its own eligibility criteria and the criteria are not consistent across the organizations and sectors. As a result, parents report not being informed or being confused about the criteria and the necessary steps to be admitted to the ECI. They are often overwhelmed with the bureaucratic and sometimes redundant or confusing rules and requirements from the different sectors and organizations.

Table 7 Implementation of the Eligibility component of the DSM-ECI

Eligibility component of the DSM-ECI	Bulgaria	Hungary	Poland	Romania	Slovakia
Eligibility criteria for entry into ECI program for children with delays or disabilities established	Done	To do	Done	To do	Will be introduced in 2019[7]
Eligibility criteria for entry into monitoring and preventive intervention program for children at risk established	Done	In progress	In progress	To do Present in HC sector	Will be introduced in 2019
Consistency of criteria across the organizations and sectors is in place	To do	To do	To do	To do	To do

Note. HC: Healthcare

Evaluation of potential stress factors for families

Assessment of stressors is a central component of the DSM-ECI that helps to modify and refine the intervention program after the entry of families to the (preliminary) ECI program.

7 Will be introduced in Healthcare through screening of psycho-motoric development of young children by a general practitioner

This component is voluntary in nature and reflects the overarching developmental framework, namely:

- The focus on families;
- The highly individualized nature of the Comprehensive Intervention Program;
- Sensitivity to cultural differences in the formation of parent—professional partnerships.

Family characteristics interact with genetic and biological risk and play a role in assessment. Such characteristics include parents' personal characteristics, their mental health, intellectual capacity, child rearing attitudes and practices, financial resources, marital relationship and family networks. For families raising children with identified disabilities or those at significant biological risk four categories of stressors must be assessed as shown below (see also Fig. 1 and 2):

1. Information needs;
2. Interpersonal and family distress;
3. Resource needs;
4. Confidence threats, as to their role as parents.

Such assessment requires a combination of interviews and discussions as well as surveys or questionnaires that can be completed with the families.

Effective implementation of this component requires the following:

- Processes and protocols that guide professionals in their interactions with families and ensuring sensitivity and professionalism;
- Protocols, surveys and questionnaires that help to identify possible stressors affecting the family patterns of interaction;
- Qualified personnel who are trained to make such assessments; and
- Separate protocols when issues of abuse or neglect, illegal drug use, or other special considerations arise.

Bulgaria reports having all aspects of this component in place. According to the country report, case-managers or other team members evaluate the family situations in terms of existing concerns, priorities and resources as well as the stress factors to which they are exposed. The main goal is to plan appropriate interventions and support programs. Different tools such as questionnaires, interviews and surveys are used.

In the other four countries the work on different aspects of this component either has to be done or is in progress. In Slovakia, ECI centers operating within the Social Policy sectors already have the relevant assessment tools at their disposal and apply them in practice. As assessment of stressors is the key to optimal family support and the facilitation of optimal family patterns of interaction, the implementation of this component remains an essential task for these countries.

⚠ Main challenges:

Although there is a growing realization of the importance of this component, according to the country reports, the assessment of stressors is often focused on the stressors associated with the child and not with the family. In addition, if the assessment of stressors is undertaken, it does not happen in a systematic way, and is usually based on clinical judgment of experienced professionals in different sectors and not on relevant interdisciplinary protocols and assessment tools. Furthermore, the latter are often not readily available.

Although in Slovakia ECI centers functioning within the Social Policy sectors have such tools at their disposal and apply them in practice, in the Healthcare and Educational sectors this component remains neglected.

Table 7 Implementation of Assessment of Stressors component of the DSM-ECI

Assessment of Stressors component of the DSM-ECI	Bulgaria	Hungary	Poland	Romania	Slovakia
Processes and protocols guiding professionals in their interactions with families established	Done	To do	To do	In progress (mainly in HC, not in SP)	In progress in SP
Protocols, surveys and questionnaires that help to identify possible stressors are in place	Done	N/A	To do	To do	In progress
Qualified personnel that is trained to make such assessments is available	Done	N/A	To do	To do	To do
Separate protocols when issues of abuse or neglect, or other special considerations arise are in place	Done	N/A	To do	In progress (in SP, but not in HC)	To do

Note. *N/A information was not presented in the country report or not available
HC: Healthcare; SP: Social Policy

Development and implementation of an Individualized Family Service Plan (IFSP)

The IFSP, according to McGonigel, Kaufmann & Johnson (1991):

The IFSP is the interaction, collaboration and partnership between parents and professionals, resulting in a written plan that lists outcomes for individual families and their infants and toddlers, and describes resources/services and their coordination that will support those outcomes.

The IFSP is a promise to the children and families that their strengths will be recognized and built on, that their beliefs and values will be respected, that their choices will be honored, and that their hopes and aspirations will be encouraged and enabled.

The core principles of developmental framework, inclusion, and integration and coordination are of vital importance for this component.

For this component to be successful it is required to:

- Regulatory obligation for the development of a service plan established;
- Guideline for the development of a service plan established;
- Individualized plan is developed together with families in response to the identified stressors;
- Service plans clearly identify responsibilities of all involved parties;
- Family-friendly information packets with various conditions and listing of community programs, specialists, and parent groups are available;
- Families receive assistance with the information review;
- Cross-sectoral cooperation in the realization of the service plan is in place.

According to the country reports, regulatory obligation for the development of individualized service plan have been established in all countries, but not across all sectors within countries.

In Hungary this obligation exists only in the Educational sector, and in Slovakia in Social Policy and Educational sectors (nursery schools). Bulgaria and Poland have established the guideline for the development of service plan. In Romania the requirement for a plan is applied in Social Policy sector, and it is recommended to be used in the Educational system in the case of children with special needs and in nursery schools.

As to the other aspects of this component, in the countries under consideration (with the exception of Bulgaria) the work on them is in progress or has to be started (see Table 9).

In Bulgaria, according to the country report the families' worries and priorities are the starting points in the process that includes:

- Collecting and structuring the necessary information from different sources:
  - Medical documentation;
  - Assessment of the child's development;
  - Assessment of the family needs.
- Identification of the family priorities and resources;
- Planning of long-term and short-term goals for the child and the family.

In Hungary, professionals in some cases also develop a family service plan with the involvement of the family members; for instance, they take into consideration the wishes of the family as to the choice of the ECI service provider. The service plan contains the description of the baseline situation together with the targets, tasks and services, which will help the child/family during the process. Intervention is provided on the basis of this individualized service plan. In theory, the early intervention specialists of all three sectors should follow the service plan which in Hungary is developed by the Expert Committee, but in practice it is implemented only in Educational sector.

Hungary includes the following aspects in the plan:

- How to achieve developmental goals aimed at improving the child's functioning, strengthening his participation in social life, preparing for school education, eliminating barriers and limitations in the environment that impede the child's functioning, promoting the child's activity and participation in social life;
- How to support the child's family in the implementation of the programme;
- Depending on the needs – the scope of cooperation with:
  - Pre-school settings as well as other institutions where the child receives therapeutic interventions, to ensure consistency of all interactions supporting the child's development;
  - Healthcare providers in order to diagnose the child's needs resulting from his /her disability, provide him/her with medical and rehabilitation support and recommended medical devices, as well as advice and consultations on supporting the child's development;
  - Social assistance centre to support the child and his family according to their needs.
- The method of assessing the child's progress.

⚠ Main challenges:

The lack of well-established assessment procedures, and the lack of cross-sectoral cooperation and information for the parents, who, as country reports reveal, are often unaware about the existence of the individualized service plan, impede the realization of this component in all five countries.

Table 9 Checklist for the development and implementation of IFSP component of DSM-ECI

Development and implementation of IFSP	Bulgaria	Hungary	Poland	Romania	Slovakia
Regulatory obligation for the development of a service plan established	Done	Done in Ed.	Done	In SP In Ed. for children with special needs In nursery schools	In SP In Ed. – only in nursery school, if needed
Guideline for the development of a service plan established	Done	N/A	Done	In SP	In SP
Individualized plan is developed together with families in response to the identified stressors	Done	To do	In progress	To do	In progress in SP
Service plans clearly identify responsibilities of all involved parties	Done	To do	In progress	To do	In progress in SP
Family-friendly information packets with various conditions and listing of community programs, specialists, and parent groups are available	To do	To do	To do	To do	In progress in SP
Families receive assistance with the information review	To do	Accidentally	To do	To do	In progress in Ed. and SP
Cross-sectoral cooperation in the realization of the service plan is in place	In progress	To do	To do	To do	To do, now only rarely with certain SP ECI providers

Note. *N/A information was not presented in the country report or not available
HC: Healthcare; Ed.: Education; SP: Social Policy

Monitoring and outcome evaluation

Monitoring and evaluation procedures help to ensure the quality of ECI services and must occur at multiple levels:

- Evaluation of progress toward the plan's goals and objectives;
- Reassessment of stressors;
- Decisions as to when comprehensive interdisciplinary assessments or reassessments are needed;
- Assessment of the functioning of the system and integration of different components;
- Evaluation of the quality of implementation of the core and related principles for each of the systems components.

Parent reports, self- evaluation protocols for administrators and early intervention professionals, or external evaluations are relevant strategies for this component of the DSM-ECI.

For this component to be effective it is required to have:

- Established common assessment and intervention program development process and protocols;
- Central database for information exchange with different agencies;
- Communication of the core information to a central database (with appropriate protection for confidentiality);
- Measures of child and family outcomes;
- Measures of parent and professional satisfaction, and efficiency of the system;
- Sampling procedures involving independent evaluations.

This component is one of the least developed in the countries under consideration. In relation to specific aspects of this component (see Table 10), the measures of child outcome and parent and professional satisfaction have been identified and are in place in Bulgaria where large scale services separate monitoring and evaluation teams are formed. Within smaller services, it is done by one or two specialists. A particularly effective strategy, according to the country report from Bulgaria, are the so-called "laboratories of change," where the evaluation results are presented to the service team in special sessions and the evaluator and the service team work together to plan forthcoming activities or to introduce new working procedures.

In Slovakia for ECI services working in the Social Policy sector, the evaluation of satisfaction is obligatory, and families are involved in this process in some services. However, since this component is officially controlled by the authorities, many service providers have postponed the implementation of this component until September 2019, when it will become obligatory and will fall under the oversight of the government.

In Slovakia the measures of parent and professional satisfaction and common assessment and intervention programs are being developed by several care providers in the Social protection sector. Such measures have yet to be identified and introduced in the other four countries.

In Romania the evaluation of satisfaction of the clients is also obligatory in the Social Policy sector; however, because ECI is not defined as a distinctive service within the Social Policy sector, no specific standards or quality measures exist.

Although in Hungary the measures of child outcomes and of parent and professional satisfaction have not been developed yet, the monitoring and outcome evaluation is nevertheless performed by the Pedagogical Special Services, which review the outcomes and the service plan and, if necessary, make proposal for its modification. The Expert and Rehabilitation Committee makes an assessment of a child at the age of 18 months; thereafter it is repeated annually or on request of the parents or ECI service provider

A similar situation exists in Poland, where a team of ECI specialists working with the child systematically evaluates his or her progress on an on-going basis and discusses the outcomes with the parents. The program is gradually modified as progress is made. In the Education sector the monitoring relies mainly on observations and involves a team of specialists and parents. The entire ECI service plan is considered and different aspects of child development are evaluated.

⚠ Main challenges:

According to the country reports, there is an urgent need for ECI standards of services, quality measures and regular monitoring and outcome evaluations. Currently, a central database and the communication of core information with the central database is lacking in all five countries. Also, the sampling procedures involving independent evaluations are still to be developed and introduced in the countries under consideration. Although some countries manage to perform monitoring and outcome evaluation, it appears to be mainly focused on the child, with less or no attention paid to either parent and professional satisfaction or efficiency of the provided interventions and services and system in general.

Table 10 Implementation the Monitoring and outcome evaluation component

Monitoring and outcome evaluation component	Bulgaria	Hungary	Poland	Romania	Slovakia
Common assessment and intervention program development process established	To do	To do	To do	To do	In SP obligatory
Central data base in place	Does not exist	In progress	To do	To do	To do
Communication of the core information to a central data-base (with appropriate protection for confidentiality) in place	To do	To do	To do	To do	To do
Measures of child outcome are in place	Done	Done in clinical assessment but not by objective tools (scales, etc.)	In progress	To do	To do
Measures of parent and professional satisfaction, and efficiency of the system are in place	Done	To do	To do	To do	In progress in certain SP services
Sampling procedures involving independent evaluations are in place	To do	N/A	To do	To do	To do

Note. *N/A information was not presented in the country report or not available
SP: Social Policy

Transition planning

As the final component of the DSM-ECI model, transition planning helps to ensure continuity and creates as smooth a transition as possible. Transition can take place at many points and have various forms, e.g. from hospital to home, from infant-toddler to preschool programs, or when the transition is made from preschool to kindergarten. For children with special needs and their parents, transition can be very challenging and stressful. In order to minimize the disruption stress, effective transition planning:

- Incorporation of the transition activities into comprehensive program component;
- A well-developed planning process and transition plans;
- Good communication between programs or agencies involved in transition.

Country reports reveal that transition planning in Bulgaria, Poland and Romania is functioning in the Education and Social Policy sectors. In Hungary it is applied only in the Educational sector, and in Slovakia only in the Social Policy sector. In all five countries the Healthcare sector is not involved in this component. It is inevitable that many children with special needs have to go through transition between medical settings and their home or other services. Naturally, this component requires good cross-sectoral cooperation that includes the Healthcare sector.

Unlike other countries that participated in this study, Bulgaria reports that incorporation of transition activities into the individualized plan component, as well as the development of the planning process and transition plans, are already in place To complete the implementation of this component, Bulgaria needs to include the Healthcare sector and establish good communication between programs or agencies involved in transition.

In Hungary transition activities are usually limited to (a) evaluation of the condition of the child upon the completion of the program, (b) recommendations as to whether the child can participate in kindergarten education or special care, and (c) sharing the expert opinion, individual service plan and the assessment outcomes with the receiving institution. Transition to a new service in Hungary is usually a lengthy procedure.

Similarly, in Poland there is no legal obligation to create and implement a transition plan when a child is transferred between the services and institutions. Transition planning is usually limited to advice about the appropriate kindergarten or school. This does not mean, however, that the institution recommended to the parents is obliged to accept the child.

In Slovakia development of the transition planning component is in progress. Some service providers and hospitals have initiated pilot projects addressing transition process from hospital to ECI services, and some service providers are working on transition scheme from ECI services to a different environment (mostly to pre-primary education).

Information about the transition planning component in Romania was not presented in the country report.

⚠ Main challenges:

Despite existing efforts around transition planning, both in Hungary and Poland parents are often left to their own devices when it comes to transition planning and the choice of institution to which they apply for support. Slovakia reports that even when transition planning is undertaken, children with disabilities have very limited choices. The main challenge for all five countries is cross-sectoral cooperation and involvement of the private service providers in all DSM-ECI components, including transition planning, to ensure the quality and equity of ECI services.

Table 11 Implementation of the Transition Planning component

Transition planning	Bulgaria	Hungary	Poland	Romania	Slovakia
Transition planning is in place and applied in the following sectors	Ed. SP	Ed.	Ed. SP	Ed. SP	SP
Transition activities incorporated into individualized plan component	Done	To do	To do	To do	To do
Planning process and transition plans are developed	Done	To do	To do	To do	To do
Good communication between programs or agencies involved in transition is established	To do	To do	To do	To do	To do

Note. Ed.: Education; SP: Social Policy

Policy and legislation

By ratifying the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities, all five countries have established the legal foundation for the development of ECI services and systems and introduction of the DSM-ECI model components in line with the principles and provisions of these international treaties. The implementation and enforcement of these principles at national, regional and local levels is now in progress and requires the development of:

- National standards for ECI service provision;
- Regulatory mechanisms at national (cross-sectoral) level;
- Relevant sectoral (ministerial) laws, regulations and protocols; and
- Regulatory mechanisms at local/regional levels.

The country reports reveal that the work on the standards of the ECI service provision have yet to be started in Bulgaria, Poland and Romania (see Table 12). The development of the national ECI standards is already in progress in Hungary. In Slovakia ECI standards already exist and are applied in the Social Policy sector.

At the moment, none of the five countries have established the regulatory mechanisms for ECI services at the national (cross-sectoral) level. In Poland the governmental program "For Life" (2017-2021) may be viewed as a first step towards building the legal basis for the comprehensive ECI system at national level. "For Life" is a pilot project for future legislative solutions.

In Bulgaria the development and implementation of sectoral or ministerial laws on ECI have already been completed for all three sectors (Healthcare, Education, Social Policy). Additionally, in Bulgaria a draft Regulation on Integrated Health Care and Social Services is being prepared. The main task in this process is to enable medical specialists and specialists in the field of social services to provide integrated health care and social support to children, pregnant women, people with disabilities and chronic diseases.

For the other four countries, ministerial laws in both Education and Social Policy sectors have already been developed or the work is in progress. Thus, in Hungary ECI service provision is regulated by a number of ministerial laws and executive orders. The synergy of these documents is partly ensured by a special Decree of the Ministry of Education and Culture, which contains common regulations concerning the institutional system of ECI.

With regard to local or regional levels, again only Bulgaria has developed the relevant regulatory mechanisms guiding ECI services. In Slovakia it is the regional authorities that have the primary responsibility for developing ECI services. They have the obligation to plan, coordinate, provide accessibility, scale up existing network of service providers and ensure funding through taxes.

⚠ Main challenges:

Although formally Bulgaria appears to be rather advanced in the implementation of the regulatory basis for ECI, as a result of the country's current unfavorable economic situation, the number of ECI services is not sufficient despite the strong motivation of various institutions, civil society organizations, and individuals. In most cases, ECI services are provided within projects, which does not guarantee their sustainability and, according to the country report, parents are often uncertain about services that they receive and their children's development. In Slovakia the majority of the ECI service providers belong to the private sector where quality standards are not implemented, and the same situation applies to the services within Health and Educational sector. Finally, the Healthcare sector in Hungary, Poland, Romania, and Slovakia remains uninvolved in the development of legislation and regulatory mechanisms of the ECI service provision, which, in turn, hinders the development of the comprehensive cross-sectoral ECI system (see Table 12).

Table 12 Development of regulatory mechanisms of the provision of ECI services

Legislation and regulatory mechanisms		Bulgaria	Hungary	Poland	Romania	Slovakia
UN Convention on the Rights of the Child is ratified		Done	Done	Done	Done	Done
UN Convention on the Rights of Persons with Disabilities is ratified		Done	Done	Done	Done	Done
National Standards for ECI service provision are developed		To do	In progress	To do	To do	SP - In progress HC and Ed. - To do
Regulatory mechanisms at national (cross-sectoral) level are in place		To do	To do	To do	To do	To do
Sectoral (ministerial) laws are in place	Helthcare	Done	To do	To do	To do	To do
	Education	Done	Done	Done	In progress	In progress
	Social Policy	Done	In progress	In progress	Done	Done
Regulatory mechanisms at local/regional level are in place		Done	N/A	In progress	In progress	To do

Note. *N/A information was not presented in the country report or not available
HC: Healthcare; Ed.: Education; SP: Social Policy

Funding and financial resources

One of the basic principles of ECI is access to affordable quality services. Access allows children with disabilities and their families to overcome financial barriers that can prevent them from getting timely necessary support. Adequate financing of ECI services is essential for the implementation of the legal obligations discussed earlier as well as for sustainability of existing ECI services. In order to continue to create a network of accessible and affordable ECI services, a well developed mechanism of ECI funding should be in place.

Table 13 details the main areas of focus in the development of financial mechanisms ensuring the development and functioning of ECI systems and services in the five countries. In Slovakia both the estimation of costs of the ECI services and the development of financing mechanisms and protocols for the allocation of funds are in progress. Although cost estimation is an outstanding task in the other four countries, Bulgaria and Hungary report having financial mechanisms and protocols for the allocation of funds in place, and in Romania this work is in progress.

Current funding resources are very similar in all five countries, coming from multiple resources both domestic and international:

- National healthcare insurance;
- State budgets;
- Regional and municipal budgets;
- Donations; and
- Domestic and international grants and tenders.

In Hungary ECI is mainly provided by the regional and county Pedagogical Special Services, and services are free of charge for the families. The services provided by the private practices/ institutions are covered financially by the families.

There are noteworthy developments in Poland where the government has allocated 70 million Euro for the mentioned above "For Life" governmental pilot program (2017-2021), making provisions for integrated support of development of young children with disabilities or at risk of developmental delays or disabilities and their families.

In Romania, ECI services in the Social Policy sector are not officially recognized as a distinctive type of services; therefore ECI is partially funded, covering only the services for children with a disability status. State and local budgets fully cover the expenses of public social services, but only 20% of expenses of NGO social services. In the field of social protection, the financing of ECI services is conjunctural rather than systematical. In the Health sector, ECI services are free of charge, covered by the national healthcare insurance, and can be provided to all children with developmental delays or at risk of developmental delays; however, only medical components of services are covered.

In Slovakia where the system of services is undergoing the process of reform, the so called "old system" based on a tradition of residential services continues to attract and exhaust the public funds. In the social sector the regional resources cover 100% of the costs of the public service providers, and 57% of the costs of the non-public service providers. ECI in the health care system is free of charge for the families, but free access into ECI services in health care is limited by the capacities of the service providers. ECI within the Educational sector is financed only partially by municipalities' providers. The rest of the funding comes from the state budget in case of the public service providers, or paid by the families receiving the services in case of the private service providers.

⚠ Main challenges:

Country reports demonstrate that ECI remains an under-appreciated and underfunded area. Apart from financial and economic hardships, decentralization and other reforms, the Polish report suggests an important reason for reduced funding of ECI stems from the lack of research data and a lack of knowledge and awareness on the part of policy and decision makers of the fact that investing in the earliest years leads to some of the highest rates of return to families, societies and countries.

While services in the five countries functioning within the Healthcare, Educational and Social Policy sectors are in most cases financed by the governments, for NGOs providing ECI, the lack of financial mechanisms and allocation of funds inevitably leads to the lack of stability and sustainability of their services. The NGOs often have to charge families for their services, which in turn makes the less affordable, and sometimes even burdensome for the family budgets. At the same time, it is the NGO service providers who are usually more flexible in following the needs of the child and families and quick and proactive when it comes down to the introduction of new innovative programs and practices.

Table 13 **Checklist on the financial mechanisms**

Financial mechanisms	Bulgaria	Hungary	Poland	Romania	Slovakia
Estimation of costs of the ECI services is conducted	To do	N/A	To do	To do	SP - In progress HC and Ed. - To do
Financing mechanisms/ allocation of funds are in place	Done	Done	To do	In progress	In progress, not sufficient
Current funding resources for ECI					
National healthcare insurance	Yes	Yes	Yes	Yes	Three private insurance companies
State budget	Yes	Yes	Yes	Yes	For Ed.
Regional and municipal budget	Yes	Yes	Yes	Yes	For SP
Tenders	Yes	Yes	Yes	Yes	—
Donations	Yes	Yes	No	Yes	Yes
EU grants	Yes	Yes	Yes	Yes	Yes
Contributions of families	No	No	No	Yes	Yes

Note. *N/A information was not presented in the country report or not available
HC: Healthcare; Ed.: Education; SP: Social Policy

Personnel development

A comprehensive system of ECI personnel development is an important and integral quality indicator of an ECI service system. Children with disabilities and their families make optimal progress when services are delivered consistently and at a high-quality level across different sectors, service providers, teams and professional disciplines. To ensure high quality personnel, necessary resources and opportunities should be developed and provided through coordinated pre-service and in-service training programs, supervision, and certification/ licensure of the ECI specialists, as well as through train-the-trainer programs.

As Table 14 shows, both Bulgaria and Poland are rather advanced with regard to ECI personnel development. In Bulgaria pre- and in-service training are to be further developed, whereas train-the-trainer programs, supervision and certification/licensing of the specialists are already in place.

Training of specialists working in the field of ECI in Bulgaria is provided by (a) the University of Medicine in the city of Varna, which offers a postgraduate training on ECI; (b) NGOs; and (c) a joint postgraduate training program on ECI provided by the University of Medicine and NGOs. The training programs are usually intended for different disciplines (e.g., nurses, midwives, speech therapists, psychologists, social workers, etc.) as well as specialists in public health and health management. In addition, all community-based services are required to conduct at least one group supervision per month as well as regular individual supervision of their employees.

Poland has pre- and in-service training in place and is developing train-the-trainer and supervision programs. Higher education institutions offer full-time undergraduate and post-graduate courses for ECI professionals. Postgraduate courses on ECI target professionals with an earlier degree in education and/or special education. ECI professionals in the Educational sector provide supervision and intervision for each other, although it is not the case in all facilities, as there are no specific requirements related to supervision in ECI. According to the country report, the development of ECI services in Poland is compromised by a substantial shortage of professionals in many disciplines.

Hungary and Slovakia are at the initial stage of the personnel development. In Hungary various accredited post-graduate trainings are available for ECI specialists. These training courses are partially licensed by the Ministry of Human Capacities and are accredited by the Educational Office. In Slovakia a training course *Counsellor in Early Childhood Intervention* was introduced in 2015 and since then has been offered annually. This course is not obligatory for ECI professionals.

In Romania efforts to develop the training program for personnel have not been started since this field of professional expertise and practice has not yet been clearly defined and recognized.

Table 14 Personnel development in the area of ECI

Items	Bulgaria	Hungary	Poland	Romania	Slovakia
Pre-service training programmes are in place	Done, however, they are insufficient	To do	Done	To do	To do
In-service training programmes are in place	Done, however, they are insufficient	Partly done	Done	To do	Only for SP
Train-the-trainer programmes are in place	Done	To do	In progress	To do	To do
Supervision of ECI specialists and teams is in place	Done	To do	In progress	To do	In progress in SP
Certification/licensing of ECI specialists is in place	Done	To do	Done	To do	To do

Note. SP: Social Policy

Conclusions

This report presents the analysis of the current situation with regard to the ECI systems and services in Bulgaria, Hungary, Poland, Romania, and Slovakia, using a framework based on the Developmental Systems Approach to Early Childhood Intervention (Guralnick, 2001, 2005, 2011). Analysis of the data presented in the country reports suggests the following conclusions:

- In all five countries the services in different sectors continue to be mainly focused on the child rather than families and their resources and stressors, as the DSM-ECI emphasizes. Therefore, the first core principle, i.e., developmental framework, is only partially realized in the existing systems of services. However, country reports also demonstrate an emerging understanding and appreciation of the role of families in the development of young children, as well as the efforts to address the needs of the families and involve them at different stages of ECI service delivery.
- With regard to the second core principle, the integration of different services and administrative structures and institutions that are involved in the service provision at different levels remains likewise rather problematic in all five countries. The lack of cross-sectoral cooperation and coordination, different ministerial laws and normative regulations within Healthcare, Education and Social Policy sectors, and lack of communication between the sectors and agencies negatively affect the implementation of all components of the DSM-ECI.
- Despite some positive developments, the realization of the third core principle of inclusion and provision of services in natural environments as well as maximization of the participation of children and families in typical community activities, also remains a challenge for all five countries, at least partially due to the co-existence of the "inherited from the old" systems and the medical model institution-based approach. Other challenges are limited resources; gaps in service availability, accessibility, quality, and equity based on family income, disability and location; and the previously mentioned lack of information and coordination between the agencies that limit the possibilities and hamper the inclusion of young children with special needs and their families.
- As far as the specific components of the DSM-ECI are concerned, according to the country reports, such components as screening and referral and interdisciplinary assessment appear to be most advanced, which may be related to a certain overlap between the traditional medical approach and the DSM-ECI approach with regard to these activities.
- The least developed components of the DSM-ECI are the points of access, assessment of stressors (implemented only in Bulgaria), monitoring and outcome evaluation, and transition planning.

- The development of different aspects of the DSM-ECI components and their implementation varies substantially within the countries, and since the components are closely interrelated, the variation affects the implementation and functioning of the ECI system as a whole.
- Among the main challenges in the implementation of the DSM-ECI identified by the countries, the following factors are mentioned:
    - The lack of comprehensive overarching regulatory framework;
    - Limited financial resources, especially what concerns NGO service providers;
    - Limited opportunities for personnel development;
    - Limited or absent cross-sectoral cooperation;
    - Lack of data and information; and
    - Lack of professional and public awareness about ECI.
- A serious concern is that children at risk of developmental delays or disabilities and their families are poorly supported by the existing services, which means that many young children and their families may not get the necessary and timely support, and important preventive opportunities may be lost or with time become less effective.
- Each country offers some positive examples and solutions that are described in the report and can be seen and disseminated as good ECI practices. Information from Romania that would allow the analysis to identify good examples and practices was not available.

Limitations

The situation analysis presented in this report is exploratory in its nature; it was not intended to offer final and conclusive solutions to existing problems in the field of ECI in the five countries. The main limitations of this study include the selection of the participants in the qualitative component of the research conducted by each country, as well as insufficient data on some aspects of the DSM-ECI components. Therefore, further research is needed with more rigorous design, instruments, sampling methodology and data collection methods.

Recommendations

Basing on the information presented in the country reports and the summary report, each of the project partners has formulated recommendations for policy makers, service providers, and parents and families of children with special needs. Below general recommendations applicable across the five countries are presented. The country-specific recommendations are presented in the country reports available at www.agora-eci.eu

Recommendations for policy makers:

- Initiate and encourage efforts raising awareness and recognition of
  - The importance of the early years and its impact on positive or negative outcomes on the development of the child;
  - ECI as a unique profession and field of expertise;
  - ECI philosophy and practices as a distinctive family-centred, multi-/transdisciplinary, cross-sectoral system of services.
- Promote the development and implementation of the ECI systems and services in the target countries and other EU member states through such instruments/activities as:
  - Evaluation of the implementation of Disability Strategy 2010-2020;
  - Implementation of the UNCRPD and UNCRC at EU level;
  - High level working groups on disability - annual meetings & annual reports;
  - Development of the new Disability Strategy 2020-2030.
- Work to make Early Childhood Development and Intervention policies an EU and national priority that will ensure accessibility, equity and quality of ECI services across and within the countries;
- Cooperate with the international experts, service providers and parents' organizations to create relevant working groups to ensure the development of policies and regulatory framework for the ECI system based on the Developmental Systems Model and its core principles;
- Provide dedicated leadership for ECI programmes and coordinate efforts more effectively across sectors (Healthcare, Education, and Social Policy as well as the private sector);

Recommendations for policy makers (cont.):

- Promote the exchange, dissemination of good practices and expertise and knowledge transfer in the field of ECI between the (EU) countries and professional communities with regard to the development of
  - Consistent cross-sectoral regulatory framework and policies;
  - Quality standards;
  - Capacity building of ECI specialists.
- Promote and support the development of national programs for the professional development of the ECI specialists, pre- and in-services trainings and life-long educational opportunities in the field of ECI;
- Promote and support research and data collection on the development and implementation of ECI services as well as essential indicators of early childhood development;
- Track the progress in reaching young children in need of ECI services and meeting their developmental needs;
- Ensure the affordability of ECI services for young children with special needs and their families;
- Allocate structural funds and ensure financial investment in ECI, including budgeting and ensuring of financial support of ECI service providers in the private sector.

Recommendations for parents of children with special needs:

- Involve existing or establish new organizations of parents of children with special needs at local and national levels
  - To provide information, peer training programs, and support to the families raising children with special needs, including the information on the philosophy, practice and benefits of ECI as an evidence-based approach;
  - To ensure that the voices, experiences and needs of parents of children with special needs are well represented at different levels of ECI system and service development;
  - To lobby for quality, equity, and accessibility of ECI services.
- Engage in cooperation with the international parent organisations/networks, international experts, relevant national and international organizations, policy makers, and service providers to ensure the development of quality ECI system based on the Developmental Systems Model and its core principles.

Recommendations for service providers:

- Promote the recognition of ECI as a unique profession and field of expertise by policy makers and relevant professional groups;
- Cooperate with the international experts, policy makers, and parents' organizations to ensure the development of policies and regulatory framework for the ECI system based on the Developmental Systems Model and its core principles;
- Actively engage in cooperation, exchange, dissemination of good practices, and expertise and knowledge transfer between professional communities and sectors in order to develop
  - Consistent cross-sectoral regulatory framework and policies;
  - Quality standards and common terminology consistent across different sectors;
  - Professional education for ECI specialists, pre- and in-services trainings and life-long educational opportunities in the field of ECI.
- Cooperate with the national umbrella organizations of ECI or other relevant service providers, national and international experts, policy makers and parents organizations to establish appropriate working groups and ensure the development and implementation of the structural elements of the DSM-ECI, namely: (1) screening and referral, (2) eligibility for the ECI system, (3) follow-up/monitoring, (4) access point to the service system, (5) interdisciplinary assessment, (6) evaluation of potential stress factors for families, (7) development and implementation of individualized service plan, (8) monitoring and evaluation of the results of the implementation of the plan, (9) transition to new settings;
- Contribute in the development of comprehensive transdisciplinary ECI programmes and coordination of efforts across organizations, institutions, and sectors, including the private sector;
- Implement the quality standards and ECI evidence-based practices;
- Initiate and participate in research and data collection on the development and implementation of ECI services as well as essential indicators of early childhood development and track progress in reaching young children in need of ECI services and meeting their developmental needs and the needs of their families;
- Develop and maintain national databases and up-to-date information about the children in need of ECI services;
- Develop a system of certification and monitoring of ECI services, including ECI services provided in the private sector.

Literature

Barrett, S.W. (2000). Economics of early childhood intervention. In Shonkoff, J.P. & Meisels, S.J., Editors, *Handbook of Early Childhood Intervention*, Second Edition, Cambridge, United Kingdom: Cambridge University Press.

Braithwaite, J. and Mont, D. (2009). Disability and Poverty: A Survey of World BankPoverty Assessments and Implications, *Alter: The European Journal of Disability Research*, 3(3):219-232.

Dunst, C. J. (2004). An integrated framework for practicing early childhood intervention and family support. *Perspectives in Education*, 22(2), 1-16.

EADSNE (2010), Early Childhood Intervention – Progress and Developments, 2005– 2010.

European Agency (2005). Early Childhood Intervention: Analysis of Situations in Europe - Key Aspects and Recommendations. Available on the http://www.european-agency.org/publications/ereports/early-childhood-intervention/early-childhood-intervention-analysis-of-situations-in-europe-key-aspects-and-recommendations website (retrieved 20.12.2018).

Guralnick, M. J. (2001). A developmental systems model for early intervention. Infants and Young Children, 14(2), 1–18.

Guralnick, M. J. (2005).An overview of the developmental systems model for early intervention. In M. J. Guralnick (Ed.), *The developmental systems approach to early intervention* (pp. 3-28). Baltimore: Brookes.

Guralnick, M.J. (2011) Why early intervention works: A systems perspective. *Infants and Young Children. 24*, 6–28.

McGonigel, M.J,. Kaufmann,R.K. and Johnson,B.H. (1991). - *Guidelines and recommended Practices for the Individualized Family Service plan*. Maryland, Bethesda: Association for the Care of Children's Health

Pinto, A. I., Grande, C., Aguiar, C., de Almeida, I. C., Felgueiras, I., Pimentel, J. S., Serrano, A. M., Carvalho, L., Brandão, M. T., Boavida, T., Santos, P., & Lopesdos-Santos, P. (2012). Early childhood intervention in Portugal: An overview based on the Developmental Systems Model. *Infants and Young Children, 25*(4), 310-322.

Appendix

Appendix 1 — Structured interview for families

1) Screening and referral.

1. You had questions or worries about your child. Where did you go to to talk about it or get help? Did you need an official referral and if yes from whom? (for instance your family doctor or someone else?)
2. Does your country have an official system for early support for child and parents that parents can access or turn to when they have these kind of worries or questions? Did you know beforehand of the existence of this system?
3. Did you have to pay or meet up with specific criteria before you could be referred?
4. Did the person/professional you went to do any diagnostic tests with your child? You can think of : muscles, vision, hearing, play skills, language skills, behavior- and social skills.
5. Did they explain what would or could be the follow up after this first consultation?

2) Eligibility for the system

6. Based on your experience: what are the criteria and how is determined if you are allowed to make use of early support for your child?
7. What services (health, education or social services) are involved in defining and managing your access to early support?

3) follow-up/monitoring of the system

8. in case your child did not fit the necessary criteria to enter this early support system now but your concerns were acknowledged: do you have a clear idea at what future moments or under what circumstances you can apply again or get other support?
9. are there criteria and an official monitoring system for those children in your country?

4) access point

10. were you aware of a national bureau or office you could approach to get information about early support for your child/family? What bureau or office would that be in your country?

5) interdisciplinary assessment.

11. Was the assessment beforehand planned and prepared with you? Were you given information about this procedure and the tests they were going to perform so you knew what to expect?
12. Can you describe how your child was tested? Were tests that were used shown and explained to you?
13. Were you present during testing?
14. Was there 1 professional testing your child or more?
15. Did they ask information about you as parent/family and about your needs?

6) Evaluation of potential stress factors.

16. Following the previous question: was information gathered or discussed about your specific situation, the resources you as a family have, the possible stress you experience?
17. In case yes: was this discussed with you alone or also with your spouse, other children, grandparents, other relevant family members or important people to you, in your network?

7) Development and implementation of the individualized plan.

18. After your child was accepted into (any or the ECI) program: was there drawn up a plan of services that will be delivered? Is such a plan legally required in your country?
19. How was the plan developed and implemented?
20. Who participated in developing this plan? Could you contribute as parents together with the professionals involved? How many and which professionals? Who coordinated this process of writing?

8) Monitoring and evaluation of the results of the implementation of the plan

21. In this plan outcomes/results or goals will have been described. Are all or only some of those outcomes monitored? Did you experience these outcomes and results are being evaluated?
22. Were you or other people (who) involved in this process?

9) Planning of transitions to new settings.

23. When your child enters a new kindergarten, school or other service: what support or planning is available for you?
24. Who will be involved in this support: your family, professionals, others?

10) Policy, legislation and financial resources.

25. Does your country have a policy plan for this early support? Is this plan officially supported and realized by legislation and regulatory measures?
26. Does your country provide financial support, for instance to you as family and to service providers and professionals that contribute to the plan, to realize all that's needed and described in the plan? If not – what is the sum that your family pays for early intervention? (% of family monthly budget or sum).

Glossary

Screening - *screening* takes a closer look at how your child is developing. Your child will get a (brief) test, or you will complete a questionnaire about your child. Developmental screening can be done by a doctor or nurse, but also by other professionals in healthcare, community, or school settings.
Referral - an act of referring a child/family for services.
Interdisciplinary assessment- Assessment procedure that involves professionals from different disciplines (medical, psychology, social work, therapy, etc.) .
Access point to the service system – Service that establish first contacts with the child/family (ex. Health center, ONGs, etc.) for early Intervention support.
Individualized plan – An ECI plan that is developed containing the assessment, service goals, strategies, resources, professionals who will be involved and timelines of services provided.
Transition Plan - the process of moving from the ECI service/ organization to another one.
Eligibility for ECI - The state of having the right to obtain ECI services because the child meets the criteria.

Appendix 2 — Structured interview for service providers

QUESTIONNAIRE FOR **QUALITATIVE DATA** REPORT

Contextualization: the following questions are organized according to the different stages of the Systemic Development Model of Guralnick (2005) of an Early Intervention System (https://depts.washington.edu/chdd/guralnick/pdfs/overview_dev_systems.pdf).

1) Screening and Referral

1. What are the procedures for screening of children in your organization?
2. What screening approaches and instruments are used in your organization and by which professionals?
3. What kind of criteria and protocols that allow access to ECI do you use in your organization?
4. What kind of areas of child development (biopsychosocial) does your organization take into account in the process of screening and referral?
5. Who can do the referral for ECI services in your organization? Can families self-refer to the ECI services in your organization? How does it work in practice?

2) Eligibility for the system

6. Do you have the authority to define eligibility for ECI in your country system? Are you actually involved in this process?

3) Follow-up / monitoring system

7. How are the children who do not meet the criteria defined for the eligibility of the ECI services in the previous section, but who raise some doubts regarding possible risk factors that can undermine their development, taken into account?
8. How is the follow-up / monitoring system in your organization defined? What are the criteria for children to be followed-up / monitored?

4) Access point to the service system

9. What is the access point in the service system?

5) Interdisciplinary assessment

10. How is the assessment carried out? What instruments are used in the assessment? Concerning the use of standardized instruments are they adapted to your country population?
11. Who participates in the assessment (eg. parents, different professionals etc.)?
12. Is there any previous planning together with family to prepare the assessment moment? Is the family aware of the use of these instruments?

6) Evaluation of potential stress factors

13. How do you identify potential stress factors for families, family support networks and family resources? Do you use instruments in the assessment of stress factors? If so, what instruments are used? Do you use instruments to assess family support networks and family resources?

7) Development and implementation of the Individualized plan

14. Is there a plan of services? Is it legally required in your country?
15. How is the plan of services developed and implemented? Who participates in the development and implementation of the plan of services (eg. families, different professionals etc.)? (please indicate who is active participant in writing the plan). Is there any coordination in this process?

8) Monitoring and evaluation of the results of the implementation of the plan

16. How is monitoring performed? How do you evaluate the outcomes/results? Which outcomes are monitored? Who participates in the monitoring and evaluation of results (eg. families, different professionals, etc.)?

9) Planning of transition to new settings

17. How do you plan the transition in your organization? Who participates in transition planning process (eg. families, different professionals, etc.)?

10) Policy, Legislation and financial resources

18. Which legislation and regulatory measures do you use in your organization in providing ECI services?
19. What is the system of funding of ECI services in your organization? How do austerity measures impact the financial support for ECI in your organization?

11) Personnel preparation

20. Is there any specific training requirements/certification for professionals working in Early Intervention? If so, which are the requirements? Is this training at a postgraduate level?
21 Do you have *in-service* training provided to professionals?

22. Is there supervision of the work done by professionals to assure professional development and quality practices? Who does this in your organization (what professionals do it and what is the criteria for being supervisor).

12) Bibliography, reports and references used in your organization.

GLOSSARY

Biopsychosocial model of disability is a model that integrates different perspectives of health: biological, individual and social to understand disability and functioning.

Referral - an act of referring a child/family for services.

Interdisciplinary assessment- Assessment procedure that involves professionals from different disciplines (medical, psychology, social work, therapy, etc.).

Access point to the service system – Service that establish first contacts with the child/family (ex. Health center, ONGs, etc.) for early Intervention support.

Individualized plan – An ECI plan that is developed containing the assessment, service goals, strategies, resources, professionals who will be involved and timelines of services provided.

Transition Plan - the process of moving from the ECI service/ organization to another one.

In-service Training – training that is given to professionals during the course of employment

Eligibility for ECI - The state of having the right to obtain ECI services because meets the criteria.

Appendix 3 — Desk research

QUESTIONNAIRE FOR **DESK RESEARCH**

Contextualization: the following questions are organized according to the different stages of the Systemic Development Model of Guralnick (2005) of an Early Intervention System

Screening and Referral

1. Is there a screening system organized in your country? If yes, how does it work? What instruments are used?

2. Which are the institutions in charge for this? If not, what screening approaches and instruments are used in your country and by whom?

3. Are there criteria and protocols that allow fair access to this program?

4. What kind of areas of child development (bio-psycho-social) does your country take into account in the process of screening and referral?

5. Who can do the referral for ECI services in your country? Can families self-refer to the ECI services in your country? How does it work in practice?

Eligibility for the system

6. How is eligibility defined and assessed for ECI in your country?

7. Who defines and governs eligibility for ECI? What services (health, education, social services) are involved?

Follow-up / monitoring system

8. How are the children who do not meet the criteria defined for the eligibility of the ECI services in the previous section, but who raise some doubts regarding possible risk factors that can undermine their development, taken into account?

9. How is the follow-up / monitoring system in your country defined? What are the criteria for children to be followed-up / monitored?

Access point to the service system

11. Is there an ECI service access point defined in your country? If so, which one?

Interdisciplinary assessment

12. How is the assessment carried out? What instruments are used in the assessment?

13. Who participates in the assessment (eg. parents, different professionals, etc.)?

14. Does the family participate in the assessment? If yes, which members of the family participate and how do they participate? When do they participate?

15. What instruments are used in the assessment? Is the family aware of the use of these instruments?

16. Is there any previous planning together with family to prepare the assessment moment? Is the family aware of the use of these instruments?

Evaluation of potential stress factors

17. Are there any tools to assess family stress factors and family resources and networks? Which ones?

Development and implementation of the Individualized services plan

18. Is there a plan of services? Is it legally required in your country?

19. Who participates in the development and implementation of the plan of services (eg. families, service providers from different areas - Health, Education and social services)? Is there any coordination of this process?

Monitoring and evaluation of the results of the implementation of the plan

20. How is the monitoring of the Individualized plan? How do evaluate the outcomes/results? Which outcomes are monitored (child and family)?

21. Who participates in the monitoring and evaluation of results (eg. families, service providers from different areas - Health, Education and Social services)?

Planning of transition to new settings

22. How is the transition to new settings planned in your country?

23. Who participates in transition planning process (eg. families, different professionals, etc.)?

Policy, Legislation and financial resources

24. Does the country have a policy plan for early intervention and will it put it into effect by means of legislative and regulatory measures?

25. Does the country provide the financial means required to carry out this policy plan?

26. How does austerity measures impact the financial support for ECI in your country?

27. Are ECI services (Education, Health and Social Care) provided in a coordinated way? If not, describe how are they provided and who provides which aspects?

28. Who is responsible for financing ECI services in each sector?

30. Are services affordable, available and proximal for children and families?

Personnel preparation

28. Which professionals work in early intervention in your country? Is there any coordination of their work? Do they work in teams? If so, do they have any training concerning how to work in teams?

29. Is there any specific training requirements/certification for staff working in Early Intervention? If so, which are the requirements? Is this training at a postgraduate level?

29. Are there certified programs for Early Intervention professionals? 3Who offers those programs (Universities other institutions)?

30. Does your country/organization provides *in-service* training to ECI professionals?

31. Is there supervision of the work done by professionals to assure quality practices? Who does this in your organization (what professionals do it and what is the criteria for being a supervisor)

Appendix 4 — Accompanying letter survey

AGORA project by VELUX: country surveys on Early Childhood Intervention in Slovakia, Romania, Bulgaria, Poland and Hungary.

Dear Colleague, dear parent or caregiver,

Thank you for agreeing to be a respondent for this important survey.

Developmental risks and difficulties are the most common chronic conditions that affect children worldwide. Many children with such difficulties are not benefitting from Early Childhood Intervention Services to support them and their families to achieve their potential.

The AGORA project consists of an innovative pilot initiative developed in 5 Central and Eastern (CEE) countries (Hungary, Slovakia, Poland, Romania and Bulgaria) addressed to overcome the challenges in the implementation of strategies to develop adequate Early Childhood Intervention (ECI) systems for children with disabilities.

1. *The objectives of the project are:*
    1. *to create an all-embracing learning and convening space to bring together essential actors to co-produce high quality ECI services*
    2. *to produce practical guidance and tools to provoke a systemic change on the social welfare system by improving the legal and policy frameworks at European, national and/or regional levels*
    3. *to develop examples that can serve as inspiring guidelines for other countries in Europe and other groups of children with special needs or at risk of exclusion (such as children with Roma or migrant background).*

About this survey:

- The survey consists of structured and open-ended questions and will take approximately 1-2 hours of your time.
- In situations where there is no official information available and/or there may be marked variability in resources available in various parts of the same country, please provide your best estimate for the question.
- The data will be analysed and reported per country and analysed and summarized for all 5 countries involved.
- If you prefer, your name can be kept confidential. If you would like to be listed as a contributor in the final report, please indicate this at the end of the survey.

We thank you in advance for your time and all your efforts, and hope that the results of this survey and the final report will help ensure a better future for children in general and, in case you are a parent or caregiver, your child in particular.

This page is intentionally left blank.

Agora

Project partners

ASOCIÁCIA POSKYTOVATEĽOV A PODPOROVATEĽOV VČASNEJ INTERVENCIE

dizabnet

EASPD
IMPROVING SERVICES IMPROVING LIVES

NATIONAL ALLIANCE FOR SOCIAL RESPONSIBILITY
NAS
BULGARIA

Eurlyaid
THE EUROPEAN ASSOCIATION ON EARLY CHILDHOOD INTERVENTION

gézengúz
ALAPÍTVÁNY

ezra

EASPD, Eurlyaid 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.

Agora
Eurlyaid THE EUROPEAN ASSOCIATION ON EARLY CHILDHOOD INTERVENTION
EASPD IMPROVING SERVICES IMPROVING LIVES
THE VELUX FOUNDATIONS
VILLUM FONDEN VELUX FONDEN
ISBN 978-2-9199584-9-8

www.agora-eci.eu
www.eurlyaid.eu
info@eurlyaid.eu
Eurlyaid EAECI