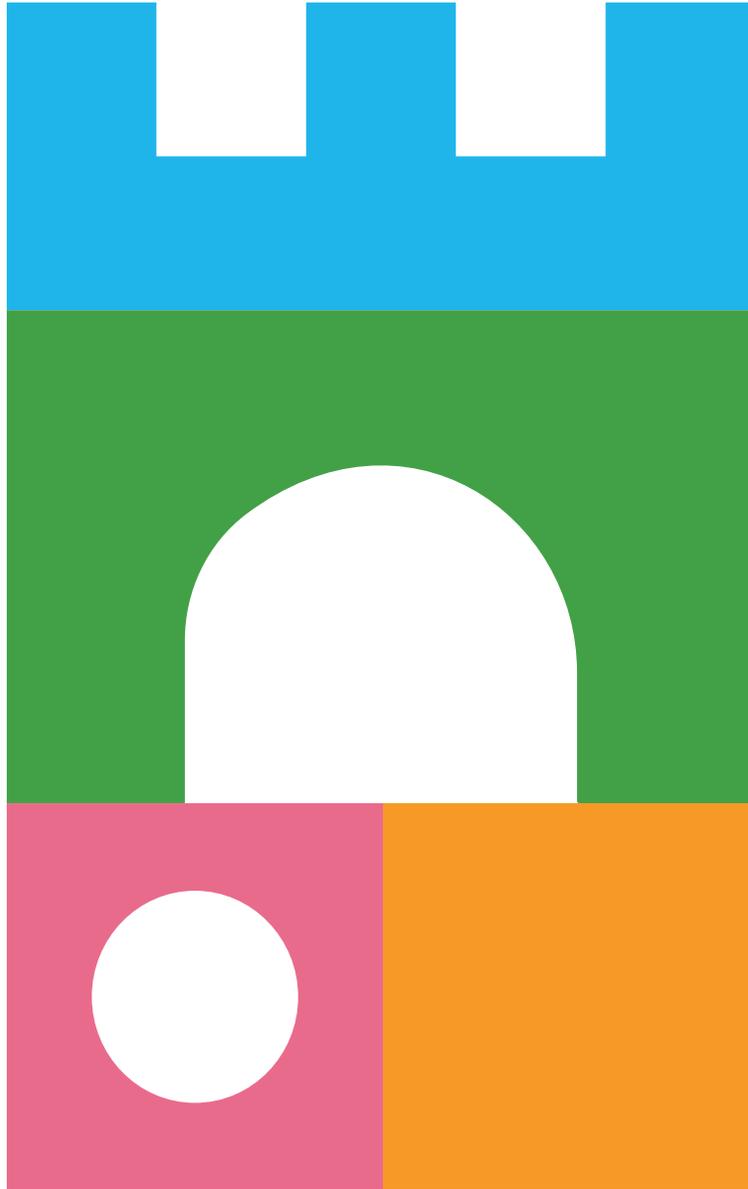


Country Report on ECI in Greece



**Technical Support to implement reforms to support the development of
family centred early childhood intervention services in Greece**

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List of abbreviations

DG REFORM: Directorate-General for Structural Reform Support, European Commission

EC: European Commission

ECEC: Early Childhood Education and Care

ECI: Early Childhood Intervention

EASPD: European Association of Service providers for Persons with Disabilities

EU: European Union

FG: Focus Group

IFSP: Individualised Family Services Plan

KDAPMEA: Children with Disabilities' Centres for Creative Activities

KEDASY: Centres for Educational Support and Counselling

MoLSA: Ministry of Labour and Social Affairs

MoSCF: Ministry of Social Cohesion and Family

NGO: Non-governmental Organisation

PWD: Persons with Disabilities

OECD: Organisation for Economic Co-operation and Development

UN: United Nations

UNCRC: United Nations Convention on the Rights of the Child

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

UNICEF: United Nations Children's Fund

UNESCO: United Nations Educational, Scientific and Cultural Organization

Executive Summary

This country report has been designed as a part of the "Technical Support to implement reforms to support the development of family-centred early childhood intervention services in Greece" project – (otherwise known as ECI Greece) that runs from September 2021 to September 2023. The project is funded by the European Union via the Technical Support Instrument and is implemented by the European Association of Service providers for Persons with Disabilities (EASPD) in cooperation with the Directorate-General for Structural Reform Support (DG REFORM) of the European Commission, with the cooperation and support of national and international stakeholders. The ECI Greece project aims at supporting the Greek government in developing a modern, evidence-based legislative and financial framework for early childhood intervention services as a crucial step towards deinstitutionalisation, and the effective inclusion of children with disabilities in society and their families through quality and adapted care and support.

This report is intended as a tool for policymakers, managers and practitioners involved in the early years and particularly those working for or with families of children between 0 and 6 years of age with developmental delays or disabilities. It provides an overview of the state of play of Early Childhood Intervention (ECI) in Greece, aiming a) to serve as the framework for a better understanding of the current response of the system to the needs of families and young children with support needs and b) to identify proposals that increase the system's efficiency and ensure sustainability and quality of the services provided. The report will accompany the other actions of the ECI Greece project to support the Ministry of Social Cohesion and Family (former Ministry of Labour and Social Affairs) in developing a legislative and financial framework for ECI services, including the piloting of family-centred methodologies in selected service providers, and the development of awareness-raising materials and activities.

The development of a national ECI system is part of the Ministry's¹ long track record of reform implementation as described in the National Strategy and Action Plan for Deinstitutionalisation that were developed with the support of the EASPD and other non- state actors, in the framework of a technical support project funded via the Structural Reform Support Programme of the European Union, as well as the National Action Plan for People with Disabilities that the Greek Government developed with the support of the National Confederation of People with Disabilities.

The main findings of the present report are the following:

- ▶ There is a lack of clarity over the definition of ECI both at the policymaking and practitioners' level.
- ▶ Apart from therapeutic interventions and special educational provisions for students with disabilities, Greece has not yet developed an integrated ECI system. However, fragmented ECI services are delivered by -mostly- private providers (including parents' associations and NGOs). Service providers can be self-funded or partially or fully funded by the Ministry of Health. Still, few of these providers deliver services in children's natural environments and family involvement varies significantly between different providers.
- ▶ ECI in Greece is still primarily based on the medical model focusing on providing services of therapeutic nature to children with an established and certified[1] disability. Such services are usually provided in specialised settings and rarely include families and caregivers as critical partners of a transdisciplinary team.
- ▶ There are currently limited resources available to support infrastructure development and ensure the sustainability of the national ECI system, but the EU offers valuable funding opportunities that, if properly

¹ The project beneficiary from the beginning of the project in September 2021 until July 2023 was the Ministry of Labour and Social Affairs (MoLSA), that after the elections of June 2023 was divided into the Ministry of Labour and Social Insurance (MoLSI) and the Ministry of Social Cohesion and Family (MoSCF). Since then, the project beneficiary is the MoSCF. Therefore, all references inside the report have been updated to reflect the current authority.

allocated, can lead to a significant change in ECI provision in Greece.

▶ There is a need to streamline the existing complex array of fragmented programmes and services supervised by different Ministries and replace them with a national well-designed family-centred national ECI system properly managed and monitored.

▶ There is an underdeveloped screening and referral system with multiple and non-coordinated entry points. Consequently, families find it challenging to identify and access comprehensive ECI services.

▶ There is a delayed response to children and families in need of support, with significant gaps in service provisions for children under the age of 3.

▶ From the age of 3 onwards, the formal education system offers a wide range of provisions that target the needs of children with additional educational needs, but these services are often inadequately implemented and monitored.

▶ There is an absence of uniform quality standards and regulations for ECI providers.

The materials in this report include:

▶ Summaries of the critical issues involved in the scope and definition of ECI, mapping of services, funding of services and ECI service provider needs.

▶ Suggestions and guidance to improve the legal and policy framework for ECI at a national level, including EU funding opportunities.

▶ Indications of further resources: footnotes are included that provide links to other valuable resources or research evidence underpinning each aspect of the ECI.

Due to the scale of this subject and the scarcity of materials available, the scope of this study does not cover in detail the wide range of issues arising from and relating to the situation of young children with disabilities and their families. It does not aim to provide an in-depth analysis but rather an overview of the situation of family-centred intervention for children with disabilities (aged 0 to 6) in Greece.

¹ *The project beneficiary from the beginning of the project in September 2021 until July 2023 was the Ministry of Labour and Social Affairs (MoLSA), that after the elections of June 2023 was divided into the Ministry of Labour and Social Insurance (MoLSI) and the Ministry of Social Cohesion and Family (MoSCF). Since then, the project beneficiary is the MoSCF. Therefore, all references inside the report have been updated to reflect the current authority.*

Introduction

Dunst defined ECI as **"The everyday experiences and opportunities afforded infants, toddlers, and young children by the children's parents and other primary caregivers in the context of naturally occurring everyday learning activities that are intended to promote children's acquisition and use of behavioural competencies shaping and influencing prosocial interactions with people and materials²".**

Even though some of the components of ECI systems as defined by Dunst are, up to a point, present in Greece, for the time being, ECI is mainly referred to as therapeutic intervention provided by different services and organisations. Moreover, the social aspects of these services are often overlooked.

This does not diminish the role of existing services operating in the context of the social, health or educational sectors. Still, both professionals and families involved with ECI in the country stress that the most prominent challenges arise from (a) the fragmentation of services targeted to children with disabilities, (b) the lack of coordination and clarification of roles and responsibilities among the agents and services that comprise an ECI system, and (c) the overall lack of a national policy for the Early Years (mainly under 4 years old) of children with disabilities.

The present country report aims to analyse the functionality and dynamics of the current ECI system in Greece and its capacity to identify and respond to the needs of young children and their families. The study examines the main components of the existing system, that is, legislation, policies, capacities and resources, and the coherence among these components.

More specifically, the goals of this country report are:

► changing the conceptual references and the existing legal framework of ECI in Greece to include children with disabilities aged 0 to 6 as parts of family systems

and stimulate a coherent, inclusion orientated and family-centred national response;

► introducing the determinant role that learning in natural environments, based on daily routines, at home, and in the community has in promoting child development and family strengthening;

► informing ECI planning to include guiding references towards greater collaboration and consensus among professionals, and between professionals and families for more effective and evidence-based, participatory practices in daily ECI work.

Methodology

To gain as much insight as possible into ECI scope, priorities, structure, and function in Greece and given the recourse restrictions due to the underdevelopment of an ECI system in our country, various research methodologies and tools had to be applied in this report. The research team conducted a desk study, semi-structured interviews, roundtable sessions, questionnaires' development and analysis, Focus Group (FG) discussions and qualitative case studies with families currently using ECI services, involving critical informants from different fields including policymakers, professionals working in the field of the early years in various sectors such as health, education and the social sector including NGOs working directly with or for children with disabilities.

Desk study

The desk study included a review of the Greek system to provide an overview of the main components of the ECI provisions on a national and regional (wherever possible) level and of their connections. The focus was on support provided in three sectors supervised by respective Ministries: Health, Education, and La-

bour and Social Affairs (former beneficiary authority of the project). The aim of this data collection was the comprehensive presentation of the basic information regarding Greek legislation and the main elements of the formal and informal services for children with disabilities, the focus being on the type and nature of services provided to children with disabilities under 6, the professionals involved in ECI and their roles, as well as the interaction among different sectors and professionals in the ECI System, the gaps often created and the responsiveness of the system to the actual needs of children with disabilities aged from 0 to 6 and their families.

The legal framework review was based on the central issues affecting the lives of children with disabilities aged 0 to 6 and their families in Greece. In this context, the search focused on the following sources:

- ▶ National Printing House: based on Law, Decrees or Ministerial Decisions³,
- ▶ NOMOS – Legal database⁴,
- ▶ Greek Parliament – search for bills⁵,
- ▶ Academic publications and webpages: looking mainly into international literature
- ▶ Information was also gathered through the competent agencies' websites and legislation provisioning the agencies' responsibilities. Data was subsequently summarised and synthesised.

Semi-structured interviews

A total of 15 Semi-structured interviews were conducted with professionals from various agencies and organisations, and families. They were based on the knowledge and experience of participants, the main components of ECI systems and the assessment of the system's functionality – that is, how the different members interact and function in practice. Depending on the complexity of each research question, they lasted from 30 to 90 minutes and were mainly conducted in person and only in a few cases by telephone or zoom. The tools used during the interviews were a) a template for collecting basic background information and b) a semi-structured interview guide comprised of questions concerning the pathway of each case, the families' experiences, the procedures followed,

the needs of service providers, the satisfaction rate of professionals and their views on case outcomes and ways to increase the efficiency of early intervention in Greece. Preparation of the research questions and tools took place during the inception phase, and these were modified and finalised with the contribution of the key Stakeholders of the Project. Key Stakeholders include the Ministry of Health, the Ministry of Education, the Greek Deputy Ombudsperson for children's rights, UNICEF, the Network of Service Providers for Persons with Disabilities (The Net), representatives of the Academic Community and the National Federation of parents and guardians of persons with disabilities. Apart from the roundtables, the collection of key stakeholders' views, concerns and needs was ensured throughout the entire length of the project. During roundtable sessions, the methodology and timeline of scheduled activities and preliminary findings regarding this report and overall project were presented. The feedback helped us develop chapter content suitable and operative in the Greek context and reflect on the practical implementation of family-centred interventions during the 1-year pilot process with seven selected ECI service providers.

Questionnaires

Questionnaires were developed based on the different stages of the Systemic Developmental Model of M. Guralnick of the Early Intervention System (Guralnick, 2005), tailored to the Greek context addressing professionals in ECI services, and parents/caregivers.

The team was supported by seven ECI service providers involved in the ECI Greece project to pilot family-centred ECI methodologies, policymakers and practitioners in early childhood education and care (ECEC), healthcare and social services. Eighty-eight (88) parents and caregivers responded by addressing questions on access points and follow-up, their involvement in developing and implementing their child's intervention, the type of services offered, their frequency and geographical range, and more. Eighteen (18) service providers gave feedback on the Greek legal framework and funding opportunities, eligibility criteria, transdisciplinary teams, assessments, and development of Individualised Family Service Plans.

³ <http://www.et.gr>

⁴ <https://lawdb.intrasoftnet.com>

⁵ <https://www.hellenicparliament.gr/>

Focus group discussions

Focus groups with professionals and policymakers informed the second, third and fourth chapters of this report. Professionals came from different fields (senior state officers, social workers, special education teachers, psychologists, legal experts, and doctors) from governmental and non-governmental organisations. Participants were identified by convenience sampling, taking into consideration the eligibility criteria set by

EASPD during the inception phase of the project. More specifically, eligible participants were health, education and child protection policymakers, European Community officials, specialists on ECI from various sectors (public entities, NGOs, parents' associations), field workers in municipal social services, legal experts and, generally, Early Years professionals working in governmental and non-governmental organisations.

Methodology of FG Discussions and Semi-Structured Interviews with professionals

| METHODOLOGY | | |
|---------------------------------|---|---|
| | Focus Group Discussion | Semi-Structured Interviews |
| Method | Focus Group Discussions with qualitative open-ended and multiple choice questions. Use of interactive presentation software. Interpretation from Greek to English and vice versa provided | Face-to-face interviews/ phone/online interviews |
| Group size | 10–15 participants per group + 3 coordinators | 1 participant and 1 interviewer |
| Duration | 120–140 mins | 30–120 mins |
| Time period | May 2022 | February–July 2022 |
| Participants recruitment | Invitations via e-mail and additional phone communication | Invitations via e-mail and additional phone communication |
| Participants preparation | Short description of the Focus Group with detailed agenda sent in advance | Short description of the Interview Agenda of the interview sent in advance |
| Co-coordinators | Coordinators: Discussion coordination Assistant coordinator: Administrative tasks, including notes, sound files, consent forms | Interviewer coordinating the discussion |
| Data | Qualitative data | Qualitative data |
| Data collection | Sound files and written notes | Sound files and written notes |
| Data analysis | Descriptive analysis of recurring answers, comments, and suggestions. Presentation of selected quotations (words, phrases, expressions) | Descriptive analysis of recurring answers, comments, and suggestions. Presentation of selected quotations (words, phrases, expressions) |



Methodology issues and limitations

Although researchers used a comprehensive methodology to gather a maximum of information, it is important to mention some limitations that might affect the quality of results:

- ▶ fragmented legislation: all legal provisions concerning children with disabilities under the age of 6 are scattered in various diverse pieces of legislation or other regulative administrative acts;
- ▶ outdated information presented on governmental organisations' websites;
- ▶ there is scarce literature relevant to ECI in Greece;
- ▶ FG had limited time and covered a wide range of issues resulting in limited possibilities for discussion and analysis;
- ▶ difficulties in reaching policymakers and senior policy officers from Ministries other than the Ministry of Social Cohesion and Family (former Ministry of Labour and Social Affairs).

Chapter 1: Definition of ECI

1.1 Introduction

Early childhood intervention has become a high priority for the Greek Government in the last few years. The government increasingly recognises the importance of a strong ECI system for children with developmental delays or disabilities and their families to enhance their development, and fully include all future citizens. This chapter aims to provide a working definition for family-centred Early Childhood Intervention (ECI) for the creation of a national legislative and funding framework for ECI in Greece. To do so it investigates the existing evidence on the benefits of ECI and the national and international legal basis and framework for ECI in Greece, and carries out an analysis of the main structural components and operational principles of existing ECI systems in Greece.

The objectives of the present chapter are to:

- 1 Summarise the existing evidence on ECI in Greece including the legal base: scientific articles, reports, and national policies.
- 2 Lay the foundations for further discussions among stakeholders on the issue of ECI in Greece. Assist MoSCF to raise awareness on the importance of ECI to all relevant stakeholders in Greece (i.e. early years experts and professionals, NGOs, public authorities, and services -at both national and local level-, social workforce).
- 3 Provide background information and support the evidence to set the basis for the design, development, and implementation of future legislation on ECI for children with disabilities in Greece as part of the country's commitments in the National Strategy and Action Plan for Deinstitutionalisation (DI). This chapter helps provide a better understanding about the scope of the research, family-centred ECI and of the Greek legal context, as a first step to better position the

mapping of the current services for children with developmental delays or disabilities in Greece's health, educational, and social sectors. This mapping will also include a critical review of scientific studies, official organisations' reports and national policies and data collection from updated and trustworthy sources. It does so comparatively by presenting how different ECI services and provisions are organised in various European countries and emerging challenges relating to their main characteristics.

1.2 The evidence base and wide-ranging benefits from ECI

Science shows that, from a neurobiological point of view, children's experiences from conception through their first six years shape their health, development, and quality of life (Law et al 2006, De Moore 2012, Cozolino, 2006), and whatever happens during the early years can have lifelong effects (Shonkoff, 2012).

Additionally, the way we raise children today will reflect the type of world we will live in tomorrow. Therefore, investing in the start of life is not an indulgence, but economically and socially critical to a prosperous society. What is critical for non-disabled children is vital for children with disabilities. Family-centred early intervention does not only enhance the skills and abilities of the child and the family but can also be a real game-changer for the child's development and social inclusion. Early identification and coordination of family and community resources that respond to the needs of children increase the potential of the environment to produce change (Eurlayid, 2019). Access to ECI, support, and education during early years can reduce disabling conditions and significantly increase the capabilities of children with disabilities (UNICEF, 2012). Creating learning opportunities in relationships

and experiences for children and families in the natural contexts of their lives will substantially influence their prospects, preventing the institutionalisation of children when families are at risk of unnecessary separation. Strengthening the parents' and caregivers' competencies promotes their confidence and nourishes the positive interaction and emotional connection between the child and the parents. Children flourish in relational environments (Richter, 2012) where parents' attunement, engagement and responsiveness are encouraged and supported by ECI professionals. This is the heart of ECI, and it is a significant shift from the way early intervention is understood. This is no longer about professionals focusing solely on the child. It is about professionals, families and communities co-creating and optimising contexts that allow families' significant participation in their child's development. Parents are afforded their rightful role, which is being the experts in their child's life, and the family's formal and informal social support networks also become change agents (De Moore, 2012).

ECI also provides a significant contribution to the child's schooling. The World Report on Disability (WHO and World Bank, 2011) highlights that early intervention can reduce the level of educational support children with disabilities may require throughout their education and ensure they reach their full potential. Furthermore, access to universally available, high-quality, and inclusive ECI services is the first step of a long-term process towards inclusive education and equal opportunities for all in an inclusive society (European Agency, 2010, p.37). ECI can reduce or even eliminate the delay of children and infants, the need for special education at school age and increase autonomy.

The World Bank (2011, 2013) has also stressed the significant social and economic return level when investing in early childhood development since it establishes 'enabling environments' that prevent future problems (Baily and Wolery, 1992). Other studies underline that high-quality ECI programmes can contain more complex interventions later in the life of the child (Eurlayd,

2019). A plethora of scientific evidence proves that early damage can seriously compromise children's life prospects and that compensating for missed opportunities often requires extensive, costly intervention later in life. Professionals working in the continuously evolving field of ECI will develop the skills needed to join efforts with professionals from the different areas involved and facilitate different intervening actors in drafting and implementing individualised, inclusive, and transdisciplinary family-centred practices based on the available research. Moreover, the interagency nature of ECI practices can increase staff competencies in the coordination and integration of services and resources.

1.3 The legal and policy base for early childhood in Greece

In Greece the current legal framework concerning Early Childhood (and not ECI explicitly) consists of provisions of national, EU and international law and covers the social welfare, education, and health sectors. The country has adopted a series of legislative measures regarding the rights of the child in general, and in particular for the protection of children belonging to vulnerable groups such as children with disabilities.

Some of the most important landmarks in the Greek legislation are presented in this review starting from 1992, when the UN Convention for the Rights of the Child (UNCRC) was ratified. Laws, presidential decrees, and decisions included were selected due to their focus on the rights of the child and their specific provisions related to various aspects of Early Childhood. Many of the laws and measures for promoting and advancing the rights of children were enacted due to international obligations and ratifications of agreements on the rights of the child. Therefore, initially the general legal framework for child's rights is outlined as this is developed following the signing and ratification of international conventions and protocols. It is worth noting that according to the Greek Constitution, ratified international conventions are integral

parts of Greek law and prevail over domestic legislation⁶.

Next, an overview of the legal framework related to early childhood and ECI in Greece is presented. Reference is also made to legislation for other aspects of wellbeing for children living in residential care as there are currently children with disabilities aged from 0 to 6 years old in Greece whose 'natural environments' are unfortunately institutions for disabled children.

1.3.1 International Conventions, protocols and policy papers

The European Convention for the Protection of Human Rights and Fundamental Freedoms (1950) (child-related Articles 3–6, 8, 14), the first Additional Protocol to the Convention, and the Charter of Fundamental Rights of the European Union (2000), Article 24 "Children Rights", were ratified in Greece firstly with the Law 2329/1953, and following with the Presidential Decree 53/1974 and in its amendments. Moreover, Greece signed the UNCRC in January 1990 and ratified it by Law 2101/1992. Greece has also ratified by Law 4074/2012 the Convention on the Rights of Persons with Disabilities (UNCPRD) and its optional protocol. The UNCRC is the world primary legal document for child's rights and the most accepted human rights-related Convention currently ratified by practically all countries globally⁷. The critical issue regarding the Conventions is ensuring that all children's rights are understood. The following list summarises the key provisions that can underpin the need for ECI in the UNCRC and the UNCPRD.

UN Convention on the Rights of the Child:

► States Parties recognise the child's right to education, and with a view to achieving this right progressively and based on equal opportunity (Article 28). Al-

though the UNCRC does not refer to ECI per se, Article 6 states that "States Parties shall ensure to the maximum extent possible the survival and development of the child".

► States Parties are to respect the local care and protection practices of parents or extended family, or community members as provided for by local custom and in a manner consistent with the evolving capacity of the child (Article 5).

► The child has a right, where possible, to know and be cared for by his or her parents (Article 7).

► The primary responsibility for the upbringing and development of children lies with parents or legal guardians.

► States are to render appropriate assistance to parents and guardians in the performance of child-rearing responsibilities (Article 18).

► Every child has the right to a standard of living that is good enough to meet their physical, social, and mental needs. Governments must help families who cannot afford to provide this (Article 27).

UN Convention on the Rights of Persons with Disabilities:

► All persons with disabilities (including children) have a right to live in the community. For children, this is interpreted as meaning the right to live with their families, included in the community and to be supported to become independent adults as far as possible (Article 19).

► State Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realising these rights, and to prevent concealment, abandonment, neglect, and segregation of

⁶ *The Constitution of Greece, Art. 28, par. 1 "1. The generally recognised rules of international law, as well as international conventions as of the time they are ratified by statute and become operative according to their respective conditions, shall be an integral part of domestic Greek law and shall prevail over any contrary provision of the law. The rules of international law and of international conventions shall be applicable to aliens only under the condition of reciprocity."*

⁷ *Except of Somalia and United States*

children with disabilities, States Parties shall undertake to provide early and comprehensive information, services, and support to children with disabilities and their families (Article 23).

State Parties shall:

- ▶ Provide persons with disabilities with the same range, quality, and standard of free or affordable health care and programmes as provided to other persons, including in sexual and reproductive health and population-based public health programmes.
- ▶ Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons.
- ▶ Provide these health services as close as possible to people's own communities, including in rural areas (Article 25).

Even though there are very few provisions protecting specifically the rights of children with disabilities, still most of the fundamental UNCRC and UNCRPD principles have been incorporated in the Greek legal order through instruments protecting the rights either of children or of persons with disabilities. However, although the provisions of the UNCRC and UNCRPD cover all aspects of the needs and rights of the children, their practical implementation is often difficult and cannot be considered adequate. Apart from Conventions, many international organisations acknowledge the value and wideranging benefits of early intervention in children's lives. To name only a few, the World Health Organisation (WHO), the European Commission, the European Agency for Development in Special Needs Education, UNESCO, UNICEF, the OECD, and the World Bank, have all stressed the crucial role of early learning for all children through publications and initiatives that underpin ECI. Only a brief reference to some of these is made here. The general comment on "Implementing Child Rights in Early Childhood"⁶ un-

derlines that the right to optimum development entails the right to education during early childhood and includes quality family involvement. It also emphasises the need for States Parties to develop a comprehensive framework for early childhood services based on the best interest of the child. The UN Committee on the Rights of the Child calls on States Parties to ensure that the services in early childhood include children with disabilities. The document highlights the importance of early screening and intervention for children with disabilities. The Committee clearly states that young children with disabilities 'should never be institutionalised solely on the grounds of disability and that "it is a priority to ensure that they have equal opportunities to participate fully in education and community life" (UN, 2006, p. 17).

Since early 1996, the OECD has developed a network on ECEC that produced valuable publications to help countries develop effective and efficient education and learning policies during the Early Years. The Starting Strong I, II, III and IV (OECD, 2001; 2006; 2012a; 2015a) reports have critically contributed to the field of ECI. The reports have underlined how ECEC services can benefit at-risk children and their families, allowing for early screening and assessment of special educational needs. They suggest that further attention should be given to children with physical, intellectual, or sensory disabilities, or children from socio-economically disadvantaged environments. The reports underline they have 'learning rights' and are entitled to inclusive universal programmes in the early educational stage. They have also highlighted that engaging families and communities in the early years will ensure positive outcomes on children's physical, cognitive, and social development before they enter primary school. The Starting Strong toolkit mentioned above has helped countries develop national early childhood policies to promote young children's holistic development. In the framework of the European Union, the Council Recommendation on high-quality ECEC systems (2021) also aimed to support EU Member States to improve access to and quality of their early childhood education and care systems. To further analyse policy options and support the Commission and Member States in

⁸ *United Nations, 2006. General Comment No. 7 (2005): Implementing Child Rights in Early Childhood. Committee on the Rights of the Child, Fortieth Session, Geneva, 12-30 September 2005. United Nations: Geneva. Available at: <https://digitallibrary.un.org/record/570528?ln=en>*

the implementation of the actions set out in the Council Conclusions, the European Commission's Directorate-General for Education, Youth, Sport and Culture (DG EAC) set up a group of experts called the European Commission Education and Training Working Group on Early Childhood Education and Care (ECEC). This allowed the Commission to engage with Member States to exchange experiences and good practices and develop targeted policy guidance. Their work refers extensively to the strong links between ECI and ECEC. Among other things, the Working Group developed a Toolkit for Inclusive Childhood Education and Care and a Report on Early childhood education and care on how to recruit, train and motivate well-qualified staff.

1.3.2 National legal and institutional framework

In the Greek Constitution, the highest source of binding law in Greece, children are acknowledged as rights holders, entitled to special care by the State. However, despite the relevant legislative framework for an increased protection to children, including children with disabilities, there are still significant problems with its implementation. Legal provisions are scattered in multiple pieces of legislation or other regulative administrative acts, each time regulating specific issues and amending or even abolishing previous ones.

Few provisions explicitly protecting the rights of children with disabilities have been identified in the national legal framework and even less for children with disabilities under the age of 4. The Greek legislation mostly refers either to children or persons with disabilities. The Greek Constitution explicitly protects the right of all children with or without disabilities to education; Article 16(4) reads, "all Greeks are entitled to free education on all levels at State educational institutions". Although the Greek Constitution does not specifically refer to the rights of children with disabilities in other fields, this does not mean that it does not protect such rights. Under the current legal frame-

work, the most important law for children with disabilities is Law 3699/2008 on the special education of students with disabilities and special educational needs. Although this Law mentions the term ECI 12 times it doesn't provide an accurate and realistic framework for implementing ECI programmes. Furthermore, there seems to be a lack of clarity and understanding concerning the age of children that qualify for ECI services and the key principles of ECI. ECI is depicted as a programme designed in the Centres for Educational Support and Counselling (KEDASY)⁹ and provided merely in Special Needs Schools for children 4 to 7 years old¹⁰.

Although no legislation was identified concerning the provision of comprehensive information to parents at an early stage of their child's disability, it is noted that the KEDASY and the Children with Disabilities Centres for Creative Activities (KDAPMEA)¹¹ are competent to provide continuous support to parents of children with disabilities¹². However, stakeholders meetings and interviews highlighted that in practice the parents of children with disabilities receive scarce information and support at the early stage of their child's disability.

There are various provisions in the Law aimed at assisting working parents with the upbringing of children with disabilities¹³. The provision of social care is the responsibility of the State and the support of the institution of family is one of its primary objectives¹⁴. Furthermore, two-year pre-school education are mandatory¹⁵ and families get financial support for access to nurseries for children from 2 months to 4 years old¹⁶. Mandatory school education starts at the age of four, although availability in daycare centres and kindergartens is limited; hence the needs of the families are not always met. Also, the Criminal Code sentences punishment to anyone who has the custody of a minor and fails to register them or supervise their attendance to school¹⁷. This includes residential institutions for children with disabilities that fail to reply to the educational needs of the children they protect.

With respect to early identification of special educational needs in daycare centres, Law 4837/2021 intro-

9 KEDASY, *The Diagnostic Centers for Assessment, Counselling and Support of people with special educational needs are decentralized public services of the Ministry of Education that provide services to people from 4 to 22 years old who attend or not in a school unit (primary or secondary education) and have special educational needs.*
 10 Ministerial Decree 211076/ΓΔ4/13-12-2018 (Art. 14, 16, 17).
 11 KDAPAMEA services can include after school clubs for recreational activities for children and adults with disabilities. Children with

mild disabilities are by law eligible to attend KDAP together with non-disabled children.
 12 Law 3600/2008 Art.4(1) and Art. 2 of the Ministerial Decree 14957/2001
 13 L. 1846/1951, L. 2527/1997, L. 3528/2007
 14 L. 2646/1998
 15 L. 4704/2020, Art. 34
 16 L. 4704/2020, Art. 35
 17 Criminal Code, Article 458

duced "Beehive": a programme to upgrade the quality of services provided to infants and toddlers in daycare centres followed by a pilot programme. Beehive is a positive step that can be further developed in future legislation for ECI in Greece. The Law introduces early identification tools and consequent training for the professionals in the early years. This aims to equip early years professionals to observe better, test and describe all aspects of the child's development and discuss the assessment results with parents. In case of significant developmental delays, parents and their children can be referred to the Centres of Educational Support and Counselling that will describe the child's needs and determine the scope of additional support that might be needed. The Law also establishes the National Council for Early Years Education (Art. 17), which could potentially contribute to the design of family-centred interventions in daycare centres.

Numerous laws aim to relieve, partially, families from disability-related expenses¹⁸. Children's access to health services is free in Greece¹⁹ and specialised therapies for the child -when deemed needed- are reimbursed by the parents' insurance fund²⁰.

As seen above, the key bodies responsible for the drafting and implementing legislation relating to the rights of children with disabilities at the governmental level are the Ministry of Social Cohesion and Family (former Ministry of Labour and Social Affairs), the Ministry of Health, the Ministry of Education. At regional level, local authorities implement law provisions regarding children with disabilities. More specifically, local authorities are entrusted with implementing policies or participating in actions to support and protect infants and children²¹. In addition, local authorities support and protect socially vulnerable groups by providing social services and promoting psychological health²² and authorise the establishment of private daycare centres and private child protection units. Furthermore, the Deputy Ombudsperson for Chil-

dren's Rights, the National Observatory on the Rights of Children²³, the National Observatory on the Rights of Persons with Disabilities²⁴, and the National Commission for Human Rights²⁵ have the responsibility to monitor and promote children's rights.

1.4 ECI guiding principles to inform the future national framework

The following section will provide an overview of the existing International ECI definitions and guiding principles to suggest a working definition of ECI in Greece and recommend the main operational principles of a National ECI System to develop future legislation.

1.4.1 International ECI definitions that build on family-centred approaches

Early Childhood Intervention has been a key area for analysis at International and EU level for the last 40 to 50 years. Various studies, reports, guidelines, and documents have been published on concepts, principles, and methods of ECI, which show the evolution of ideas and theories that have informed ECI practice (European Agency, 2005, p.13). Emphasis has been placed upon the role played by the family and caregivers, the importance of social interactions of both the child and the family and the impact of the child's and family's interaction with the environment in the child's development. These contributions have helped shift away from the medical model of intervention that is therapies to deal with the child's impairments and that focus on how the child should be to enhance chances of social integration, to an ecological-systemic model. This model provides a systematic way of analysing, understanding, and recording what is happening to children and young people within their families and the wider context in which they live (Horwath, 2000). In ECI practice this translates into services where the

18 *An exhaustive examination and analysis of these provisions exceeds the scope of this report. More detailed information on the social security and the health and social care legislation for persons with disabilities may be found in the National Confederation for Persons with Disabilities website: <https://www.esamea.gr/publications/books-studies>*

19 L. 1397/1983

20 Ministerial Decree 801557/1-1-2018

21 L. 3463/2006 as amended by L. 3852/2010

22 L. 3463/2006

23 L. 2909/2001

24 L. 3895/2010

25 L. 2667/1998

health, social, and educational sectors are inter-related and equally involved in the child's and family's life and prevention is an integral part of the intervention. Focus is no longer placed solely on the child but on the family and the community and this has influenced the conceptual framework of ECI, that is, definitions and guidelines that provide the basis for reflection and informed practices.

The future legal framework for ECI in Greece should build on definitions and guiding principles of ECI. Here will be presented some well acknowledged ECI definitions developed by three prominent special education and intervention agencies in the USA, Europe, and Australia, namely the American Speech Hearing Association (ASHA), the European Agency for Development in Special Needs Education, and the Early Childhood Intervention Australia (ECIA).

According to the American Speech Hearing Association, "ECI describes services provided to children from birth to three years old who are at risk or demonstrate developmental difficulties or delays. Such an intervention differs from the intervention in older children as a) it focuses on the activities and routines of the family, b) includes many specialities like speech therapists, physiotherapists, occupational therapists, social workers, psychologists who provide their services outside the traditional educational context and in a non- traditional educational way²⁶."

For the European Agency for Development in Special Needs Education, "ECI is a composite of services/provision for very young children and their families, provided at their request at a certain time in a child's life, covering any action undertaken when a child needs special support to: ensure and enhance their personal development, strengthen the family's competencies, and promote the social inclusion of the family and the child. These actions should be provided in the child's natural setting, preferably at a local level, with a family- oriented and multidimensional teamwork

approach²⁷."In the definition of the Early Childhood Intervention Australia "Early Childhood Intervention (ECI) is the process of providing specialised support and services for infants and young children who have developmental delays or disabilities, their families and communities, in order to promote development, well-being and community participation. All services are provided using a family-centred approach, recognising the importance of working in partnership with the family. Services are tailored to meet the individual needs of the child and focus on supporting the child in their natural environments and in their everyday experiences and activities²⁸."

1.4.2 ECI guiding principles

Some cross-cutting guidelines and principles should be considered at every stage of planning and implementing ECI programmes. Basic concepts reflected on the ECI Key principles developed by the community of practice of the office of special education programs in the USA²⁹ are briefly presented. This national workgroup produced several documents on principles and practices validated through research, model demonstration and outreach projects. Here are the seven key principles developed by the workgroup:

- 1 Infants and toddlers learn best through everyday experiences and interactions with familiar people in familiar contexts;
- 2 All families, with the necessary supports and resources, can enhance their children's learning and development;
- 3 The primary role of the service provider in early intervention is to work with and support the family members and caregivers in a child's life;
- 4 The early intervention process, from initial contacts through transition, must be dynamic and individualised to reflect the child's and family members' preferences, learning styles and cultural beliefs;

26 American Speech-Language-Hearing Association Website. Retrieved from: <https://www.asha.org/>

27 European Agency for Development in Special Needs Education. Early Childhood Intervention. Analysis of Situations in Europe. Key Aspects and Recommendations Summary Report. P.17 Retrieved from: <https://www.european-agency.org/resources/publications/early-childhood-intervention-analysis-situations-europe-key-aspects-and>

28 Early Childhood Intervention Australia website. Retrieved from: <https://www.transitiontoschoolresource.org.au/abouteci/what-is-early-childhood-intervention/>

29 Workgroup on Principles and Practices in Natural Environments, OSEP TA Community of Practice: Part C Settings. (2008, March). Seven key principles: Looks like / doesn't look like. Retrieved from: http://www.ectacenter.org/~pdfs/topics/families/Principles_LooksLike_DoesntLookLike3_11_08.pdf

- 5 IFSP³⁰ outcomes must be functional and based on children's and family needs and priorities;
- 6 The family's priorities, needs and interests are addressed most appropriately by a primary provider who represents and receives team and community support;
- 7 Interventions with young children and family members must be based on explicit principles, validated practices, best available research and relevant laws and regulations.

This list of principles emphasises family dynamics aiming to inspire systems of services that respond to the child's and families' needs.

1.4.3 Provisions for the future national legal framework

A new legislation on ECI in Greece should primarily define the targeted population in terms of their age group and needs, based on which they can qualify for ECI services. ECI itself should be appropriately defined based on international research, as a community based public service involving services and health, education and social policies professionals, private institutions, and informal resources. Furthermore, new legislation should establish that the scope of action of ECI is multidisciplinary and inter-institutional, identify the family as a relevant element for the planning and provision of ECI services and defines a national structure based on the coordination and interrelation of the three ministries' resources and in responsibility-sharing (Eurlayid, 2019).

Already through this project, the Greek Ministry of Social Cohesion and Family (former Ministry of Labour and Social Affairs) has set the ambitious goal of tackling the complexity and establishing a mechanism that ensures:

- ▶ a legal obligation on the part of the State to provide ECI services for children and families who need it;
- ▶ legislative provisions that add clarity over the defi-

nition of ECI, making sure it is understood and valued among service providers and families, and establish the rights that arise from it for children and their families;

- ▶ legislative provisions for the training and reskilling of professionals working with children and families with support needs, unified protocols, and a comprehensive management structure;
- ▶ existing legislation is sufficiently implemented by State actors / sufficient inter- agency working among different Ministries and services (services prepared to identify the need and refer to other services) / co-ordination across sectors and preventing overlaps between various services;
- ▶ policy measures that clearly define quality standards that apply to both public and private ECI services;
- ▶ sufficient flexible financing mechanisms for the new services.

1.4.5 Working ECI definition for future Greek legislation

Based on the above-mentioned definition and guiding principles, a definition is proposed, which describes the services as *family-centred* and *individualised*, targeting children *from 0* (so that the intervention can start as early as possible) to *6 years old* (as this is the moment when the child enters into primary education, and where other kind of support could be provided). ECI services are about *identifying, preventing, or minimising* the child limitations related to developmental delay or disabilities. Finally, as mentioned in several analysis the final aim of ECI is about promoting the *child potential* and *family well-being*.

Here the definition: **“Early childhood intervention is a field of family-centred, individualised services for infants and young children aged from 0 to 6, intended to identify, prevent, or minimise limitations for children related to developmental delay or disabilities and promote the child's potential and general family well-being”.**

30 Individualized Family Service Plan (IFSP) is a plan to obtain ECI services for young children with a meaningful involvement of families

1.5 ECI key elements and national standards for private and public providers

The organisation of ECI varies from country to country. Nevertheless, all countries that have set up ECI systems have ensured that these include early identification and multidisciplinary services. Early identification starts from birth or pre-natal care when possible. Children and their families are then provided with various services, provisions, and support. It is difficult, if not impossible, to summarise the complexity of the organisation of services and provision in the different countries without omitting relevant information³¹. For example, in some countries (i.e. Denmark and the UK), interdisciplinary mobile units visit all newborns at home regularly for a maximum of one year (which will be extended when they identify delays, disorders, and family risks), advising and supporting parents on their new tasks. In other countries, home-based visits are also available, but only at a secondary level once risk has been detected in a child. Some countries provide ECI at both the child's home and hospitals and private/NGO run centres by specialised teams, with the active involvement of social and educational services. Other countries (i.e. Germany and France) have invested in integrating ECI services in regular daycare centres and developing accessible and effective digital platforms for online intervention for children and families in rural areas.

All countries use more than one way of providing ECI services, and the diversity of provisions grows as the field of ECI expands. However, despite the heterogeneity of services, involving various levels of intensity and delivery modes, there are some relevant standard organisational and functional features among them that build on the ECI key elements³²:

1 Availability: A shared aim of ECI is to reach all children and families in need of support as early as possible,

including those living in isolated rural areas. ECI systems must guarantee that children and families applying for support can benefit from the same quality of services regardless of where they reside.

2 Proximity: Proximity describes both geographical availability and attunement with the family's needs through family-focused services. Clear understanding and respect for the family's needs are at the centre of any action. Support services should reach all members of the target population and be as close as possible to families, both at local and community levels. For this reason, many countries have invested in the decentralisation of services. Provisions such as mobile units for home visits and online ECI platforms should be in place to avoid long-distance travelling for families.

3 Affordability: Services are offered free or at minimal cost to families in all countries. Services are provided through public funds from health, social or education authorities or by insurance companies and NGOs. These options can co-exist, or indeed other options are possible. Additionally, in a small number of countries, private services – not supported by any public funding and fully paid for by families – are also available as an option.

4 Interdisciplinary work: Professionals in charge of direct support to young children and their families belong to different disciplines (professions) and consequently have diverse backgrounds according to the service they are related to.

5 Diversity of services: This feature is closely connected to the diversity of disciplines involved in ECI. The involvement of health, social, and education services, is common in various countries. Primary prevention embraces actions aimed at reducing disorders or problems in the population. Secondary prevention aims to diminish the number of existing cases of an identified problem. Tertiary prevention focuses on reducing the complications arising from an identified situation or a disorder. Primary prevention is ensured by health services and social and educational services in all countries. In some cases, this is implement-

³¹ For more information in European country situations, see the ECI web area on the European Agency website:

<https://www.european-agency.org/resources/publications/early-childhood-intervention-analysis-situations-europe-key-aspects-and>

³² Extract from the European Agency for Development in Special Needs Education:

https://www.european-agency.org/sites/default/files/early-childhood-intervention-analysis-of-situations-in-europe-key-aspects-and-recommendations_eci_en.pdf

ed through regular medical and social monitoring of pregnant women or developmental screening of very young children at hospitals or local health and education centres. All these services ensure the first general screening, followed by assessing needs mainly addressed to a population with biological risk factors or presenting social risk factors. This is the first step to further referral to other services or health professionals in case of an identified need.

1.6 National Standards for ECI providers

For Greece to develop and implement a state-wide, comprehensive, coordinated, multidisciplinary, inter-agency system that provides quality early intervention services for infants and toddlers with disabilities and their families, the legislative framework needs to introduce a set of minimum quality standards for both public and private providers.

Before introducing national quality standards for ECI providers, Greece needs to ensure financial sustainability of the system, develop standardised eligibility tools as well as unified protocols for professionals, and establish a Central directory of public and private ECI services that ensures local interagency (i.e. through regional directories), system coordination and a comprehensive child find and referral system. Moreover, a single line of authority in a lead agency should be designated or established by the State for carrying out: identification and coordination of all available resources, assignment of financial responsibility to the appropriate agencies, development of procedures to ensure that services are provided promptly pending resolution of any disputes, resolution of intra- and interagency disputes, development of formal interagency agreements³³.

Public and private providers should:

- ▶ **build interdisciplinary teams of professionals** coming from various fields, sectors and disciplines and ensure that all eligible children and families in their respective geographical areas are supported with timely access to: family counselling, social services and psychosocial support, health, medical and nursing services, physical, occupational, speech and language therapies, special education interventions, training in assistive technology, sign language, mobility (as per the child's needs) training in building accessible home environments;
- ▶ **ensure that all staff members are licensed, certified, or credentialed** by state laws and regulations and are provided with additional adequate and continuous training and supervision to ensure compliance and workforce quality.
- ▶ **develop, monitor, and ensure the implementation of Individualised Family Services Plan (IFSPs)** based on the assessment of the child and family's strengths and needs, develop strategies to incorporate them in families' daily activities and routines, and transition planning involving new service providers (i.e. kindergartens or primary schools) and agents to help the child and family transition to services beyond ECI;
- ▶ **establish safeguarding policies** as per L. 4837/2021;
- ▶ **include policies and procedures to ensure that services are provided in settings where children live, learn, and play:** ECI services should be provided -to the maximum extent appropriate- in natural environments and in settings other than the natural environment that are most appropriate, as determined by the parent and the IFSP team, only when early intervention services cannot be achieved satisfactorily in a natural setting;
- ▶ **establish Evaluation and Monitoring mechanisms** that refer to both how children's development is monitored using specific indicators and to evaluate the ECI provision's effectiveness in meeting established qual-

³³ *Minimum component required under Part C of IDEA: a United States' federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers ages birth-2 with disabilities, and their families.*

ity standards using structural indicators based on the resources available in the ECI system such as access and governance, financing, workforce development and parental engagement;

▶ **establish mechanisms to managing funding resources** and ensure public funding and leadership models are used accountably to make quality ECI services available to all eligible children and families;

▶ **develop systems for compiling data on the early intervention system to inform evidence-based policies;**

▶ **develop public awareness and advocacy programmes** focusing on early identification of infants and toddlers with disabilities and providing information to parents of infants and toddlers

1.7 Professionals needed in family-based programmes.

ECI transforms services, shifting their delivery from a child and deficit-based approach to a family-based one. With that guiding baseline in mind, before looking at the disciplinary backgrounds and credentials that professionals involved in ECI programmes should have, it is paramount to make sure that all parties involved (including parents and caregivers) share this epistemological approach: family participation and the child's natural environments are ECI's critical elements (Dunst & Paget, 1991; Jung & McWilliam, 2010). Practices will change only after the conception of early intervention does.

Since Greece is still in the process of building a shared vision of ECI, the understanding of family participation varies (and is sometimes disputed) between different professionals and service providers. Therefore, to identify the kind of professionals needed in ECI programmes, quality standards should clearly determine what a family-centred approach looks like in practice. They should clarify that family involvement in the early

years is not about offering guidelines and recommendations to parents and caregivers sporadically. Nor is it about telling parents or caregivers how to work with their child to achieve goals that have been set for them by the experts. It is about family members being equal partners in the ECI transdisciplinary team, empowered to co-create services around their family's and child's needs. Time allocated to working with families should be equally significant to that spent in professional-child interventions.

In that sense, ECI programmes are provided primarily by family members working with their child alongside professionals from the health, education, and psychosocial fields.

The most frequent disciplines involved in ECI services are psychology followed by speech therapy, physical and occupational therapy, special education, and social work (Garcia – Grau et al., 2020). Interdisciplinary teams do not involve less than three from the above-mentioned disciplines. However, professionals' discipline backgrounds are not necessarily a predictor of family-centred practices. What determines recommended practices in ECI are professionals' views and beliefs about the family-centred approach and this is where training and accreditation need to focus (Soriano & Kyriazopoulou, 2010).

The type and number of professionals that collaborate with families and caregivers in transdisciplinary teams depend on the type of disabilities and the number of families ECI providers serve. Often ECI providers have liaised with a pool of experts to ensure supervision for their staff and access to the best international experience on a range of subjects. To facilitate the family's involvement and support parents and caregivers, all ECI programmes normally involve psychologists and social workers.

| Type of disability | Type of personnel |
|--|--|
| Children with developmental delays, children in the autistic spectrum disorder | Child psychiatrists, Psychologists, Social workers, Special Education Teachers, Occupational Therapists |
| Deaf and hard of hearing children | Psychologists, social workers, speech and language therapists, speech and language pathologists, Special Education Teachers |
| Blind and visually impaired children | Psychologists, social workers, special education teachers, occupational therapists, mobility trainers |
| Children with mobility disabilities | Psychologists, social workers, occupational therapists, physiotherapists, rehabilitation nurses |
| Multiple/complex disabilities | Paediatricians, Child Psychiatrists Nurses, psychologists, social workers, speech and language therapists, speech pathologists, physiotherapists, occupational therapists, mobility trainers |

Auxiliary staff members also have a key role to play in ECI services and increasingly ECI providers use their services. Auxiliary staff could include professionals such as play therapists, drama therapists, music therapists, sports coaches, personal trainers, caretakers, personal assistants, and trainers in assisted technology.

The existing evidence base, in terms of both peer-reviewed research and policy research focused on ECI practices, does not provide a singular map of the provision of ECI professionals. Studies and evaluations of ECI services tend to be relatively small in scale, looking at individual services, or sometimes a pilot of a new ECI service model across several providers, rather than exploring the ECI as a system (Pleace, 2013). Control or comparison groups are also not often included in evaluations and research, making clear identification of the specific outcomes of ECI services harder to assess (Kruger and Dunning, 1999).

The ECI sector is diverse, working with a wide range of families and disabilities in a variety of ways. Provisions for professionals in ECI providers cannot be easily standardised by the type of disabilities served. Firstly, even for one type of disability, there are various, broad models of ECI that follow differing core assumptions regarding assessment and intervention; and secondly, the operational details of ECI services of the same broad type of intervention may differ considerably between different providers depending on how they are staffed and resourced. Moreover, some

assumptions and operating principles of ECI services are inconsistently evidenced, or not fully understood. This suggests that the review of curricula in academic departments and the development of training may need to be confined to areas which are relatively well evidenced, allowing trainers to present a clear case as to why a particular approach is being advocated.

It is not an easy task to identify training models in the field of ECI for managers, practitioners and front-line staff working in ECI and/or for those interested in pursuing or developing a career in this area. The Greek Authorities will determine the range and nature of education and training focused on the guiding principles in ECI incorporating also multifaceted ECI service designs and careful consideration for specific groups of disabilities.

1.8 Eligibility criteria for children from 0 to 6 years old

As for the organisation of ECI services, different countries designate differently how children qualify for ECI services. Eligibility criteria may differ by country, but they are mostly consistent with the country's legislative framework and assessment procedures. Therefore, here a non-exhaustive list of eligibility conditions is suggested based on the working ECI definition for future Greek legislation.

All eligible children aged 0 to 6 who need ECI services must be served regardless of their nationality, ethnic-

ity, and families' insurance status. Eligibility must be determined by interdisciplinary teams of professionals using well-designed standardised assessment tools³⁴, protocols and procedures.

Children may be eligible for ECI services if they meet at least one of the following criteria:

► **developmental delays** and difficulties compared to children of the same age group in one or more of the following developmental areas: motor/physical (fine and gross motor skills), cognitive, communication and speech, sensory (hearing/visual impairments), social/emotional (curiosity, enjoyment of playtime, interactions);

► **established risk conditions** in the case of known etiology that has a high probability of resulting in developmental delay or conditions with established harmful developmental consequences (i.e. syndromes that affect one or more developmental areas) or a low incidence disability (e.g., chronic illness, vision impairment, hearing impairment, severe orthopaedical impairment)

► **high risk for developmental disabilities** for children identified with factors such as prenatal substance exposure, positive infant neonatal toxicology screen or symptomatic neonatal toxicity or withdrawal, severe prematurity and low birth weight, neonatal central nervous system infections, congenital abnormalities or genetic disorders, risk factors in the child's environment (i.e. parental developmental disability, parental psychiatric conditions, extreme poverty, and malnutrition etc)

1.9 Conclusions

Although Greece has a relatively well-established legal framework for children, it needs to adopt a series of legislative measures specific to ECI. The country lacks a multisectoral strategy on ECI and coordination mechanisms to provide integrated services and ensure efficient use of resources. Policies and programmes targeting young children with disabilities

exist and some are well-developed, but in a context of scattered policies and interventions. Greece provides several essential services for maternal and child health, and there are some provisions for early education, including for children with disabilities. However, there is room for improvement in coverage of services especially for children aged from 0 to 3. Merging existing services into a comprehensive national system is key and this starts with introducing legislation that defines ECI and regulates implementing bodies and providers to monitor and assure quality of services.

Most of the fundamental UNCRC and UNCRPD rights and principles are introduced in the Greek legal order through legal instruments protecting the rights of either children or persons with disabilities. Nonetheless, the fragmentation and complexity of the legal framework and service provisions for children 0 to 6 negatively impact the implementation of their standards hindering disabled children's right to develop their potential fully.

Several guidelines, principles, and recommended practices govern service delivery to this group, the most prominent being family-centred care, inter-agency work and team process, and natural and inclusive environments. Careful legislation development is critical to prevent challenges arising from the increasing complexity and variability of service systems, the growing heterogeneity of children's and families' needs and limited resources available to support infrastructure development hence sustainability of the system. Therefore, Greece needs to invest in designing and delivering integrated health, social and educational services introducing national standards for ECI providers and clear eligibility criteria to address the future of early childhood intervention. This process also includes adopting a culture of accountability across all dimensions of service provision, developing and instituting evidence-based practice, implementing comprehensive professional protocols.

34 *Keeping in mind that even though some assessment tools are more reliable than others, there is no assessment tool that provides complete information on the child.*



Chapter 2: Mapping of services

2.1 Introduction

This chapter aims to provide an overview of the existing ECI system in Greece, resulting from a variety of research methodologies including desk research, questionnaires, Focus Groups, and semi-structured interviews. This contributed to identify and evaluate the available resources for families of children with disabilities under the age of six. The rationale behind the composition of this mapping exercise is to depict the current situation of ECI services in Greece and gain as much insight into the system's structure, functions, and dynamics.

This chapter focuses on the existing Early Childhood Intervention (ECI) system in Greece, which is analysed with the aim to:

- ▶ **evaluate its capacity to identify and respond to the needs of disabled children 0-6** (including their family needs), ensuring services are delivered timely to those children and families with the greatest need;
- ▶ **assess the congruence of the system and the level of interagency work** that has been established to connect different services as well as children and families to local services and support networks;
- ▶ **examine the degree to which the current ECI system strengthens a family's capacity to access universal services and build networks of support;**
- ▶ **study the development and implementation of individualised service plans** as well as the monitoring and evaluation of the results of the implementation of those plans (including planning for the transition to new settings) to identify best practices and inform legislation;
- ▶ help **identify eligibility criteria** for providers that would ensure quality ECI services;

- ▶ identify **entry points for strengthening the immediate and mid-term functionality** of the system;

- ▶ identify **enabling factors and bottlenecks to implement practices and standards** across all ECI services in Greece.

2.2 Type of services

This section investigates the type of ECI services present in Greece: in which settings they are provided, if from public or private suppliers, and how formal and structured the service provision is.

2.2.1 ECI Settings

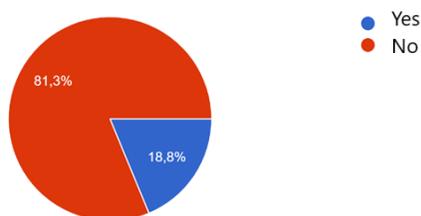
In Greece, ECI services are provided by a few centre-based public ECI settings and by public early childhood education and care (ECEC) settings. The most common and acknowledged providers, though, are private practitioners that provide therapies and special education interventions in their cabinets to children with a wide range of disabilities and age. Services at these therapy centres are provided by various professionals, most commonly speech therapists, occupational therapists, special education teachers, and psychologists. Although these settings offer services to young children as well, they usually do not operate holistic ECI programmes per se involving transdisciplinary teams.

The settings where ECI programmes are delivered in Greece most typically are centre-based ECI, educational settings (special kindergartens or preschools). Nevertheless, the common perception of what constitutes ECI in Greece is these private settings that provide special therapies to children with diagnosed disabilities, therefore, they are included in this study under the category of therapy centres.

Centre-based ECI

In Greece, ECI services are mostly delivered in formalised ECI centres and do not include home-based interventions in a regular and consistent way, as is confirmed in Figure 1, derived from the analysis of the responses to the questionnaires delivered to families receiving ECI services.

Figure 1: Does the ECI support you receive includes home visiting? (83 responses)



These settings are usually funded by the Greek health system, and they typically are age-integrated, centre-based ECI settings for children, usually from three to six years old or up to the beginning of primary school (often up to eight years old). Their programmes are mostly provided in (non-profit and for-profit) day-care and therapy centres, state welfare agencies, such as Centres of Social Welfare and the National Institute for the Deaf, and University programmes delivered on regular campuses. These programmes offer a holistic provision of special education and therapies. These settings may have an educational function but are typically attached to the health, social or welfare sectors and associated with an emphasis on therapeutic interventions and care, yet they do not always actively include families. Typically, the child will be in one room with the therapists/educators (and possibly other children), and parents/caregivers will be in the waiting room. Full-day ECI programmes often offer transportation, so families may rarely be in the centre whilst the child is receiving ECI services. In almost all cases, ECI programmes will hold consultations with parents on planned dates to discuss parents' needs and concerns and the child's progress, but it is less consistent that parents are trained by professionals to support

their child at home. ECI programmes offered by the Centres of Social Welfare to children with disabilities living in institutions rarely include the child's caregivers in transdisciplinary teams. However, to an increasing degree, ECI programmes in Greece state that they are moving away from a child/deficit approach to a family-centred philosophy, and there are some good practices to back this up. Since quality standards and protocols are lacking, the quality of services varies across different providers, as does the staff/child ratio (there are programmes where one practitioner has to work with more than one child at the same time or programmes where two or more children will share the same 'therapy room'), the credentials of the staff that these programmes include and the level of families' involvement.

ECI in educational settings

These can be regular or special kindergartens or pre-schools, often (yet not always) involving the Centres for Educational Support and Counselling (KEDASY) to develop Individualised Service Plans. Practically KEDASY refer children to special kindergartens, typical kindergartens that have provisions for inclusive classrooms, typical kindergartens where disabled children are included with parallel support and advice on further intervention for the child or the family in specialised therapy centres. These settings tend to be more formalised and linked to the education and welfare system. Most of the ECI programmes provided in educational settings are part-time, and they can be delivered either by an external ECI provider or school staff in the case of special schools. Typically, services are also provided in designated ECI centres. The time ECI programmes invest in the child's educational setting will be significantly less than the time allocated in the designated ECI centre. As Greece has only recently introduced home-based ECEC programmes (Neighbourhood nannies, L.4837/2021), it remains to be seen whether ECI programmes will also be delivered in the homes of registered home-based providers accredited to take care of children (2 months – 2, ½ years old).

Home-based ECI

Very few ECI programmes in Greece provide their services in a home setting rather than a designated centre. Practically the therapist will visit the child's home and try to adapt the intervention programme to the family's available resources (home setting, the child's toys etc.), guiding the parents on how to support the child and help her learn during activities such as family mealtimes, child bath times, child dressing/undressing etc. Interventionists in home-based ECI will not only visit the child's home but will also support the child and the family in everyday community activities such as going on walks, shopping, eating out, and going to the playground.

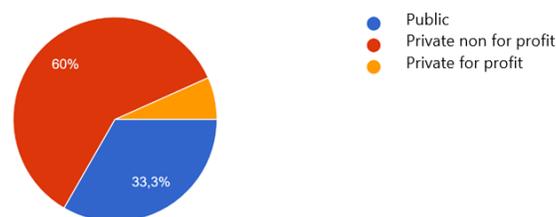
Therapy centres

In Greece, most ECI programmes are provided by private therapy centres. ECI intervention might not be the centre's main objective although working with young children is part of the staff's everyday tasks. Staff usually include speech therapists, occupational therapists, special education teachers and psychologists, not necessarily trained on working with children under the age of six. Different professionals usually work on a one-on-one basis with the child, adolescents or adults clients and families' involvement is usually limited to the initial assessment and interim consultations to mark progress and discuss questions and concerns. Quality of intervention varies across different therapy centres in terms of both structural characteristics and process quality. Only a handful of therapy centres will enrich the child's learning experience by fostering and supporting real-life interactions with the outside world (e.g. the child's home or school, parks, after-school clubs, greeting in the neighbourhood etc.). These settings are supervised by the regional authorities only regarding their premises' characteristics and status.

2.2.2 Private / Public services

Private and public ECI programmes exist in Greece, which both operate in absence of quality standards and unified protocols. Most early intervention services are offered by private for-profit or non-profit welfare organisations and NGOs. See Figure 2 below from the analysis of the questionnaires delivered to ECI service providers

Figure 2: How would you describe your ECI service?
(15 responses)



Private services

These settings are owned or administered directly or indirectly by a non-governmental for profit or non-for-profit organisation, or association of parents of children with disabilities. For-profit organisations are publicly subsidised. They offer services at a cost that is covered by parents/caregivers and is, at a large percentage, reimbursed by the Ministry of Health through the National Organisation of Health Services (EOPYY). Non-profit organisations are mostly financed through private donations and sponsorships, yet it is not uncommon that parents and caregivers still contribute financially to their child's programme. Parents' financial contributions vary across different non-profit providers. Private non-publicly subsidised settings receive no funding from the public authorities and are independent in their finances and governance. Private publicly-subsidised settings operate completely privately, and they usually only need to submit paperwork to government agencies in a timely manner. Therefore, even though they receive some or all their funding from public authorities, they are not managed nor supervised by public entities.

Public services

In Greece, there are no public ECI centres per se. There are public settings as in public institutions for ECEC or public rehabilitation centres for children with disabilities managed by public education or welfare government agencies. These typically include special kindergartens that cater for disabled children's needs (4–6 or up to the beginning of primary school) through interdisciplinary teams. Apart from early years teachers, these teams include professionals such as special education teachers, speech therapists, occupational therapists, psychologists, and social workers. Although the operation of ECI programmes for children with disabilities is laid down by Law (mainly L. 3699/2008 and the subsequent complementary laws), inclusive education policies are not always promoted for students with special education needs. For example, publicly subsidised parallel support is not available for typical kindergartens nor are integration classes. Typical kindergartens and nurseries do not have interdisciplinary teams, and although they often include students with diagnosed disabilities, they cannot offer them holistic ECI programmes unless the child's support is privately-subsidised. Some Centres of Social Welfare provide ECI services mainly to institutionalised children with disabilities, a handful of disabled children in foster care and even less eligible disabled children from the community upon their parent's socioeconomic status. With the Centres of Social Welfare being heavily understaffed and overloaded, the intensity in which ECI services are offered, the number of professionals working in ECI programmes, their credentials and working status (permanent staff vs short-term contract-based employees) vary. The National Institute for the Deaf (EIK) also provides ECI services to deaf and hard of hearing children from 0 to 6, regardless of their parent's socioeconomic status. Limitations about available resources are the same with the Centres of Social Welfare. The Educational Centre for the Blind (KEAT) provides ECI services to visually impaired children from 4 to 6 years old, operating a

special kindergarten for the blind; however, it cannot support children under the age of 4.

2.3 Formal and informal care and services

Informal (or family) care refers to care for people with care and support needs carried out by relatives, friends, generally without a contractual agreement or formal payment. Informal carers are mostly women and, although official data about informal care in Greece is scarce, the number of informal carers as estimated by Eurofound (EQLS, 2016) is 34% of the Greek population (more than 3,600,000 people). This figure includes both those who support adult and elderly persons, and children with a disability. This high figure can be correlated with the absence, or insufficiency of formal care and support provision, linked to the model present in Greece, (as in most Southern and Eastern European countries) where the key welfare provider is the family. Intensive caregiving is associated with a reduction in labour force attachment for caregivers of working age, higher poverty rates, and a higher prevalence of mental health problems (OECD, 2017).

Greece continues to suffer from a lack a clearly formulated strategy and policies regarding the regulation of informal care and the support of informal carers. Indeed, there are currently no provisions concerning in-kind benefits and in-cash support for carers. There are no benefits such as cash, pension credits/rights or allowances to compensate informal carers for the care services they provide. By and large, family carers in Greece are primarily viewed by the state as a resource and their own needs are hardly considered. The Law 4808/2021, which is the transposition of the EU Directive on Work-Life Balance defines for the first time the concept of informal carer as "an employee who provides personal care or support to a relative or person who resides in the same household as the employee and who is in need of significant care or

support for a serious medical reason." The law provides for an unpaid leave to take care of an ill child or other dependent of up to 6 working days per year. This can be increased to 8 working days if the beneficiary is providing care to two care recipients and to 14 working days for more than two care recipients, other leaves, and flexible working arrangements for carers (e.g. teleworking, flexible working hours, part-time work) if the worker has completed at least 6 months of employment with the employer (Eurocarers, 2022).

There are many differences among ECI programmes, including organisational, financial, and administrative differences, as well as in terms of governance and implementation strategies. Dunst et al. (2007, 2012) described formal early intervention as therapeutic or educational services that are defined in a child's Individualised Family Service Plan and are designed to meet children's developmental needs. Formal ECI services are commonly centre-based or provided in educational settings; they are led by practitioners and should actively involve parents and caregivers. Informal early intervention is about using everyday family and community activities as sources of interest-based everyday learning that enhance children's learning opportunities. These are mostly parents and caregivers-led naturalistic practices that, with the participation or guidance of ECI professionals, support and strengthen children's competence and confidence which, in turn, strengthens parents' and caregivers' competence and confidence. Informal ECI services may also include activities led by the child's teachers and trainers in their after-school programmes with the involvement of the child's parents and caregivers (i.e. therapeutic swimming, therapeutic horse riding, inclusive sports clubs, and centres for creational activities the child might be involved in). Whereas children in Greece (especially children 4 to 6 years old) have free access to formal ECI services or they participate in programmes that are -at least partly- reimbursed by the family's insurance, informal ECI services rarely re-

ceive public funding, and it is usually donors and foundations that substitute ECI costs.

2.4 Structure of services

This section will describe the main elements and characteristics of the ECI service provision: the screening and referral, the eligibility criteria, the follow-up and monitoring, the stress factors, the geographical range, the developing and monitoring of the IFPS, and the role and involvement of families.

2.4.1 Screening and referral

Although screening for disabilities in Greece exists as part of the established free access to the Public Health System for all citizens (even those who do not have insurance are entitled to hospitalisation, medical care in public hospitals and prescribed medication), disability identification (or risk of it) is usually not followed by referral. In practice, free access to prenatal care can flag out or identify a baby's established or potential risks for disability. Nonetheless, parents generally will not be referred to specialised services that will support, inform, and prepare them to welcome their child and care for her at home. New parents have also access to new-borns screening services in both public and private maternity clinics (the latter might charge parents for more elaborate test). However, parents of children with after-birth diagnosed disabilities are not offered specialised support nor are they referred to any services before leaving the maternity clinic.

The main access point for diagnosis is the healthcare system. Generally, the family's paediatrician will flag out the child's atypical development and will advise parents to consult with a developmental specialist or a child psychiatrist that will identify the areas in which their child might need to be tested. Parents will then receive a diagnosis followed by recommendations on the areas where the child needs intervention, the num-

ber of special therapies the child is entitled to and the professionals that should provide them (commonly speech therapists, psychologists, occupational therapists, physiotherapists). Paediatricians might also advise parents to visit a Medical and Pedagogical Centre or a Mental Health Centre. These are public agencies supervised by the Ministry of Health which provide services of early diagnosis, treatment, counselling and psychotherapeutic interventions, and psychosocial support for children, adolescents, and their families. These centres are often understaffed and overloaded and do not offer holistic ECI programmes. Less often, experienced early years teachers will detect signs of atypical development, developmental delay, or autism in children in their class and they will flag this out to their parents and caregivers. However, it is only recently that the former Ministry of Labour and Social Affairs (now Ministry of Social Cohesion and Family) introduced the legislative framework that allows early years teachers to receive training, support, methodological tools, and supervision in early identification and sharing concerns with parents and caregivers³⁵. In practise, therapies' prescriptions normally summarise the screening and referral process, and after that, parents are usually left alone to navigate the system and identify access points. Although public community centres are by Law (1344/2019) the 'local focal points for citizens' reception, service and interconnection with all social programmes and services and are entitled to 'inform and/or refer citizens to welfare programmes' they commonly fail to guide parents that have obtained therapies' prescription for their child. Community centres do not refer parents to ECI service providers, regardless of the latter's governance and funding status.

Families of children over the age of three years old will be advised to visit a Centre for Educational Support and Counselling (KEDASY) to identify possible special educational needs and support. KEDASY will not refer families to ECI programmes other than the ones oper-

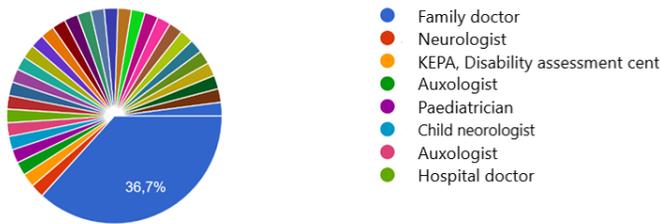
ated by public entities that are supervised by the Ministry of Education. Furthermore, there are not enough KEDASYs to cover the needs. In addition, existent KEDASYs are understaffed and overloaded entities. As a result, there are long waiting lists for assessment requests.

Sometimes parents themselves will detect developmental delays or atypical development in their child. All children born after 2016 receive a child health booklet, developed by the Institute of Child Health. The booklet is very resourceful and supports parents and paediatricians in early identification of disabilities or developmental delays but does not include access points to the system of services, nor does it provide a list of the available ECI programmes (not even public providers) to inform parents on how to obtain an official diagnosis and what to do after that. Disability or delay in children living in public institutions in Attica (institutions for neurotypical children) will be detected by the institution's psychologist or doctor (provided that the institution has one) and will be most commonly referred to Michalinio Centre. The Child Development Centre known as Michalinio Centre is a department of the Centre of Social Welfare of Attica that serves children from 0 to 18 years old. It offers both diagnosis and specialised intervention by an interdisciplinary team, however due to staff shortages Michalinio can only serve children living in institutions and mostly at the diagnosis level, children in foster care and children whose families face socio-economic problems.

The existing fragmentation of the Greek referral system is clearly depicted in Figure 3, based on the analysis of the questionnaires delivered to families receiving ECI services.

35 *Kypseli program for early identification in nursery schools (<http://www.opengov.gr/minlab/?p=5378>)*

Figure 3: Who made the initial referral of your child?
(51 responses)



2.4.2 Eligibility of the system

In lack of specific eligibility criteria, children in Greece are eligible for ECI services if they have a diagnosed disability or a medically diagnosed condition that has a high probability of contributing to a developmental delay.

Identified disabilities include one of the following: autism spectrum disorder, cerebral palsy, down syndrome or other chromosome abnormality, hearing impairment, vision impairment, developmental delay. Those at risk of a developmental delay will be eligible if they demonstrate delays in at least two developmental areas: cognition, communication, physical, social, emotional, or adaptive development. There are test protocols used to establish developmental delays. Infants and babies with atypical development, whose differences in development are to a marked degree, with significant deviations in the typical sequence of development, are also eligible for ECI services. However, there are very few providers that offer ECI programmes for children under the age of three years old with developmental delay but not an identified and diagnosed disability. Eligibility is determined in consultation with the family and other relevant practitioners, which may include a paediatrician, general practitioner, psychologist, or early years teacher. If existing information or medical records are adequate to determine eligibility, no additional assessment may be necessary to ensure eligibility. A doctor's statement/assessment, hospital discharge summary, or other

medical record that verifies the medical diagnosis that is made are usually enough. This eligibility remains as long as the diagnosis is present and there is a continuing need for the service. Disability Assessment Centres (KEPA) are responsible for ensuring uniform health assessment in terms of determining the degree of disability, and usually, children with medically diagnosed disabilities will undergo such assessment. The Ministry of Health, through the National Organisation of Health Services (EOPYY), reimburses a percentage of specialised interventions if the child's parents are insured.

Further, eligibility may be determined by ECI providers using informed opinion and judgement when standardised assessment is not appropriate or not available. This will be substantiated with direct observation data and rationale to support the need for ECI. Not all children referred to ECI programmes will meet the eligibility criteria. Children with a single area of concern, such as speech or language development, or behavioural concerns only will not receive ECI services if other developmental areas are within normal limits. Families who are not eligible will be referred to other services and professionals within their community.

Not all children are provided services in the community, for children with disabilities living in institutions, most ECI programmes are undertaken by the permanent staff. Their biological parents, legal guardians, and caregivers have little to no control or choice about the therapy sessions. As a result, children with different disabilities will be all served by the same team of professionals who might not be specialised on their disabilities nor trained on supporting children under the age of six. In addition, institutionalised children do not benefit from the social contacts they could make through similar services in the community unless the institution has established cooperation with private (non-profit or for-profit) organisations and/or practitioners. Migrant children with disabilities whose parents or legal guardians are not insured (e.g. asy-

lum seekers) are denied the right to receive a personal registration number (AMKA) even when they are cared for by a public institution.

2.4.3 Follow-up and monitoring systems

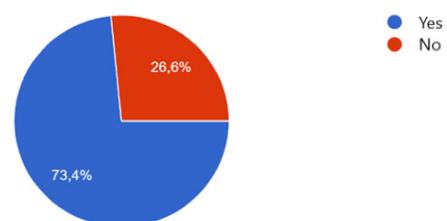
Doctors and healthcare professionals conduct children follow-up and monitoring in hospitals and outpatient clinics. Parents will usually advise the doctors involved in the initial assessment of the child to mark the child's progress and determine the next steps. Generally, follow-up and monitoring do not involve any communication between the child's doctor(s) and the ECI professionals that work with children and their families. Recommendations have been made (including in our FG and semi-structured interviews) on how to best manage and monitor the child's process with e-tools such as an individual e- assessment and service plan to be regularly updated and informed by different professionals, integrated into the existing Greek government e-platform(s) (managed by the e-government agency HDIKA). Nevertheless, there are still no official provisions and systems in place for consistent follow up and monitoring. Both for-profit and non for profit ECI providers and therapy centres have developed some monitoring and follow-up systems. However, these are not consistent and do not follow unified quality protocols.

2.4.4 Stress factors

Over the past 20 years, research increasingly calls for personalised services to be provided to children and adults with disabilities. It emphasises that the experience of disability results from the child's type of disability, severity of symptoms, neurological impairment (or lack of it), related chronic conditions, personality, physical health, family resources, and available informal and formal support services in the area where the child lives. Building from this and anecdotal evidence,

researchers and practitioners advocate for introducing and maintaining an inclusion-focused, strength-centred rather than disability-centred approach in developing assessment tools. In turn, the unique factors, complex issues, and multiple stressors that different children with disabilities face are highlighted. Drawing from a variety of perspectives and methodologies, these needs assessment tools investigate the impact of psychosocial factors on the children's condition and thus how they make meaning of and cope with their impairment(s). Although healthcare professionals who will conduct the initial assessment for disability (or risk of it) may only use tools to assess the child's type of disability, the severity of symptoms and the intensity of intervention needed, ECI professionals will use holistic approaches also to assess the child's and family's multiple stress factors. Families' will be assessed to enrich the knowledge on the child's needs; however, less attention seems to be given to parents' and caregivers' experiences per se and the effectiveness of their stress coping models. In the case of increased stress factors in the family, parents are usually advised to seek (free) psychological support, usually at Mental Health Care Centre. Although Greece lacks family support centres that would benefit so many children and families with different backgrounds and needs, there is a plethora of good initiatives both at a governmental and non-governmental level. Most of the parents were addressed through questionnaires felt that their families' stress factors (such as family's available resources or lack of them, parental stress etc.) were discussed and considered. See Figure 4, from the analysis of the questionnaires delivered to families receiving ECI services.

Figure 4: Was information gathered or discussed about your specific situation, the resources you as a family have, and the possible stress you experience? (82 responses)



However, there is still no comprehensive plan in place to integrate different social and mental health services, promote inter-agency work and support families' psychosocial needs holistically.

2.4.5 Individualised Family Services Plan: development, implementation, monitoring, evaluation, and planning of transition to new settings

The goals, services, and how progress is measured in ECI programmes are set in a document called an Individualised Family Service Plan (IFSP). The IFSP is written by the interdisciplinary team that will work with the child and parents or caregivers, and it should reflect empowered families' active role in supporting their child's progress towards meeting milestones. It should also include the child's initial level of performance in different learning fields, the type of intervention she or he will need as well as their location (including homes, daycare centres, kindergartens) frequency and duration. A service coordinator (or supervisor) is responsible for walking parents through the document and ensure that they are aware that it will be regularly reviewed and is bound to be modified upon any changes in the child's needs.

ECI programmes in Greece have enhanced their capacities to develop IFSPs that respond to the child's needs, help interventionists/therapists to measure progress and improve the effectiveness of their intervention, although the development of IFSPs is not stipulated by Law as was confirmed by ECI providers participating in the FG and answering the relevant questionnaires. See Figure 5 and 6, based on the analysis of the questionnaires delivered to service providers and families respectively.

Figure 5: Was an individual plan created for your child when he or she was admitted to the early intervention service? (78 responses)

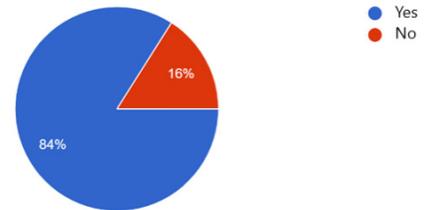
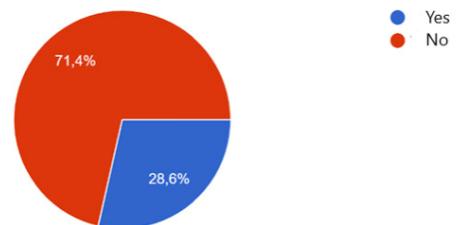


Figure 6: Is the development of individualised plans stipulated by Law in your country? (71 responses)



Currently, there are not unified protocols on how to develop IFSPs in Greece. Therefore, each ECI programme uses its own methodologies and empirical evidence to write these documents. There is a great variation in IFSPs styles and, consequently, delivery methods. In the lack of coordination between different structures created to provide ECI and the separate sectors involved in the family's life, such as the healthcare, welfare, and educational systems, IFSPs do not always follow children when they transition to their activities outside the ECI programme. Thus, the child's medical team, schoolteachers, trainers in after-school activities (etc.) do not have any access to the child's IFSP and it is usually parents (and not coordinators or supervisors) that inform them about their child present level of performance and the goals they are working on.

Transitioning planning from home or centre-based services to the public school system is more regulated. Law 3699/2008 and Ministerial Decree 211076/ΓΔ4/13-12-2018 stipulate the development of Individualised Educational Plans for children with disabilities or de-

velopmental delays. Practically, these are action plans for students with special educational needs who cannot follow general education's analytical programme. All KEDASYS across Greece use a unified protocol to develop Individualised Educational Plans. Special kindergartens and typical kindergartens are responsible for the implementation of the Individualised Educational Plans and KEDASY will monitor them and evaluate progress. Please note that KEDASY will work directly with special and typical kindergartens which are supervised by the Ministry of Education but not with Nurseries and daycare centres which are supervised by the Ministry of Social Cohesion and Family (former Ministry of Labour and Social Affairs).

KEDASYS also support students who transition from one educational stage to another over time, that is, in vertical transitions. These involve transitions between different educational settings, such as between kindergarten and primary school or from the home-learning environment and the Early Childhood Education and Care setting (kindergarten or nursery) to kindergarten. KEDASYS are less actively involved in horizontal transitions, which involve children's transitions during their everyday lives between, for instance, a kindergarten and an after-school club.

2.4.6 Geographical range

Providing ECI services is a complex task even in the most favourable geographical circumstances. For families to access specialised support for infants and young children with a disability or developmental delay in non-urban areas is often truly challenging. International research suggests that geographical proximity is very likely to be a potential barrier to early intervention access in children with disabilities in various countries (Rise Institute, 2019). Greece is not an exception to these findings. Children with a disability or developmental delay growing up in rural and remote areas in Greece face barriers that impede them

from accessing the same services available to their urban peers.

Our mapping exercise has identified two main areas in which gaps and barriers in the provision of ECI services outside the major cities occur:

- 1 Barriers to obtaining a diagnosis and an initial assessment of child and family needs
- 2 Barriers to accessing family-centred public or private ECI services.

According to our research and the findings of the Focus Groups, children with a disability living in rural and remote areas in Greece are less likely to have an early diagnosis and assessment of their needs. Even if they manage to have one, they face serious barriers in accessing evidence-based services that address everyday situations that children with a disability or developmental delay need to master. This is mainly due to a serious shortage of allied health and social professionals outside urban centres, including a lack of access to paediatricians, psychologists, special educators, occupational therapists etc. These limitations lead to restricted choices and high travel costs. Existing funding options do not include travel allowances aimed at facilitating access to ECI services. Furthermore, limited networking opportunities with other families with children with disabilities were mentioned by families living in rural areas as an additional barrier.

An additional element identified by the focus groups participants and interviews was the absence of provision of health, social and educational services through information and communication technology. These e-services could be an important tool to facilitate access to assessment and support for children with disabilities living in rural and remote locations.

2.4.7 Role and involvement of families

ECI should provide family support and specialised services to strengthen families' ability to access resources and improve their child's development through daily activities. Although parents of children using ECI programmes feel that ECI services offer interdisciplinary support, they don't necessarily understand or value their role in their child's development as illustrated in Figures 7 and 8, based on the questionnaire distributed to families receiving ECI services.

Figure 7: Is your child assessed and supported by an interdisciplinary team? (83 responses)

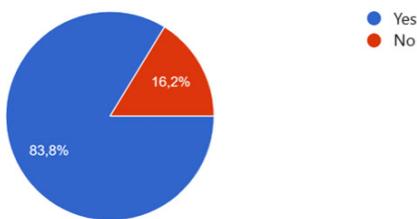
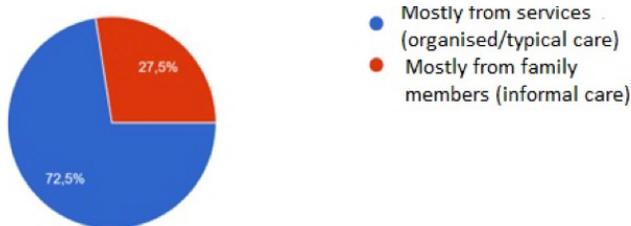


Figure 8: The support your child receive comes mostly from: (84 responses)



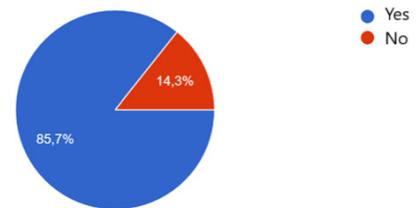
Home visiting element

Over the last years, international ECI best practices have shifted from child-focused and deficit-focused "treatment" to supporting families through collaboration and consultation. The intervention aims to promote a child's development by using evidence-based and home-based strategies during everyday routines and activities. Early interventionists support families in their own homes to use these routines as rich learn-

ing opportunities for promoting child development. They do so by embedding intervention strategies to the unique characteristics and resources of the child and the family.

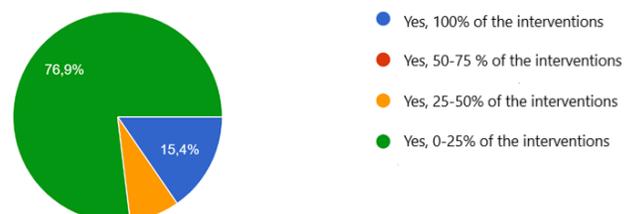
According to our research findings, early intervention providers in Greece often include home visits in their repertoire of services. This is confirmed in Figure 9, which depicts the results of the questionnaires distributed to early intervention services from different sectors.

Figure 9: Does the support ever take place in the home of the child that you support? (14 responses)



However, visits to the family home are rarely the core of the intervention and are not a requirement of operation imposed by the legal framework. They usually take place as a supportive measure during the initial diagnosis of the family's needs and subsequent information and follow-up of the intervention. ECI professionals lack specific knowledge of home-based intervention principles and methods as they have usually been trained to be more hands-on and directed toward the child rather than the caregiver and child. As reflected in Figure 10, derived from the questionnaires distributed, only a small percentage of service providers deliver most of their interventions in the family home.

Figure 10: If the intervention takes place in the family's home, how often does this happen? (13 responses)



Testimonies and case studies about families

You can find below three testimonies, from the mother of two twins in the autistic spectrum, from a psychologist in a public child protection institution, and from an ECI professional.

Expecting twins was already stressful enough for me and my husband as we already had a quite active 7 year old son and thought that we were done with having any more children plus our financial situation was not at its best. During the first two years of their lives, I was both exhausted with their everyday care and very worried about the things I would notice in their behaviour, especially Luca's behaviour. It was so difficult to comfort those children... With George, I had to drive around the neighbourhood for hours and hours. With Lucas, I had found out by accident that he would calm down if I would cover his face with a wet towel. I felt that there was something wrong with him liking this so much and I felt guilty for reinforcing this odd thing, but I desperately needed for him to stop the constant screaming and crying. I avoided discussing my concerns with my husband and he would never bring up his to me. What 'helped us' start having those difficult discussions as a couple and eventually reach out to our paediatrician was the fact that they were already 3 years old, and they would not utter one single word. Our paediatrician told us that we worried too much and that not all children follow the same line of development, but he referred us to a child- development paediatrician in a public hospital. They were almost 4 years old by then. She had to assess Lucas in the waiting room as he refused to enter her cabinet and she later took in George and my husband. It all lasted about 20 minutes but felt like forever. We were sitting in the waiting room when she finally came out with my husband and Nickolas. My husband would not look at me, he seemed crashed. I knew then. I still gave it one last shot 'could it be that they were both very tired when we came here today, we had to take the bus, and this always upsets both

of them? They are both in the autistic spectrum, for Lucas it is a bit more complicated because he also has developmental delays. The doctor told us that she would 'prescribe therapies' for both and that she wanted to see them again in six months. I left the hospital feeling both devastated and relieved. We found this ECI programme by internet search. I googled 'best therapies for autism Athens' and this therapy centre came up. We first went there with my husband without the children, we filled out a questionnaire and then discussed about what we observed in our children's behaviour and their communication. We also talked about our situation as a family, our financial situation included; we talked for almost an hour. The second time we went there we were asked to bring the boys including our first born who was 11 by that time. The therapists saw all three of them. The head of the therapy centre then asked us whether it would be possible for us to bring the twins to the centre every day and bring our oldest son once per week as he showed signs of dyslexia. She explained that the therapists involved in our twins' programme would come from a different field, but would all use the same method, the same approach to treat autism. We have been coming here for 8 months, every day from 09h30 to 12h30 for the twins and every Friday afternoon for Ioannis. In the beginning, I was so worried about coming here as we would have to use the metro and a bus to get here from where we live. Now I cannot believe I was getting so stressed about something as trivial as that. I have seen massive development in both of my boys. They now say so many words I cannot believe it. I would have never imagined that this method works, and it does so fast. I don't know what these girls are doing in that room with them, but it must be magic, and it works!'

Marina – Lucas', George's, and Ioannis' mother.

When Anthi came to the institution, she was about two weeks old. She was not premature, and her delivery took a normal course; however, we were not sure whether her pregnancy was normal as well. We already knew her biological mother quite well as her firstborn child, a very sweet, kind boy, was brought to our institution two years ago due to parental substance abuse. He was already placed in a foster home. Our initial plan for Anthi would be to try family reunification, as the mother had been consistent in following a rehabilitation programme. So Anthi would stay with us for some time with regular visitation from her mother. Anthi was an easy-going yet quite odd baby. She would not make eye contact and did not like to be held or have people around her, which made it even more difficult for us to help her mother connect to her through positive interactions. She seemed calm and content just being by herself in her crib. She walked at the age of 14 months, but still, it would take her hours (sometimes up to three hours!) to fall asleep and her sleep would be severely interrupted. She would not stand water on her head and at 18 months she would refuse to try to eat from a spoon. By the age of two she had already missed a lot of milestones and we knew that this would mean that not only would it be difficult to reunite her with her mother but also finding a foster home for her would be a challenge. The doctor of our institution referred her to Michalinio Centre for further interdisciplinary assessment. Michalinio diagnosed generalised developmental delay and psychosocial immaturity and prescribed Anthi speech and language therapies as well as occupational therapies. Our institution had a permanent occupational therapist and a contract-based speech therapist, so we were able to provide Anthi ECI services in the institution. She would have speech therapy once per week and occupational therapy twice per week. Anthi was not cooperative during therapies and both therapists reported difficulties connecting with her. After six months of therapies, Anthi was not making much progress. In her scheduled follow-up meeting

at Michalinio, they suggested we would intensify her therapy programme. However, our institution's scientific personnel were overloaded and did not have the capacity to schedule more intervention time with Anthi. What seemed to be a breakthrough in Anthi's development was our decision to enrol her at our institution's nursery. Being with neurotypical peers in a typical classroom following a regulated programme helped her cope with her behavioural problems and soon started learning at a faster pace. She would also be more attentive during her therapies and started to reach out to her caregivers for hugs. She now engages in free play with her peers and spends more time in our nursery. We no longer have a speech therapist in our institution, but Anthi continues with her occupational therapies and hopefully a new speech therapist will be employed soon. Unfortunately, our efforts to reunite her with her mother failed. After informing her about Anthi's diagnosis she would be less consistent with her visitation schedule, and she finally told us that she wanted to quit her parental rights. Although we know she would develop much faster if she was placed in a family environment, we are doing the best we can under these circumstances.

Margarita – Psychologist in a public child protection institution

A 5 1/2-year-old boy belonging to a rural family of lower socioeconomic status was brought to our Centre by his mother with complaints about repetition of acts, poor attention, irritability, low mood, and interrupted sleep since a year. He was born out of a non-consanguineous marriage, uneventful birth, and pregnancy. He was fourth in birth order and the mother states that he had achieved most of his developmental milestones at an appropriate age, except for speech which was delayed to the age of three years old. The mother reports that from his early childhood, her son was exposed to aggressive behaviour from his father, who often attempted to discipline him and in this pursuit at times was abusive toward him. Marital



problems and domestic violence since marriage lead to divorce of parents when the child attained age of 4 years old, and the boy has not seen his father ever since. The boy started pre-school education at the same time and his schoolteachers observed generalised immaturity, stereotyped behaviours (especially toe walking) and poor social skills as he was biting and spitting on his peers. Mother confirmed that since a year, she also observed her son to repeat certain acts such as pacing in the room from one end to another, continuously for up to 1-2 h, with intermittent stops. He would accept his meals only from her and would want to eat the same tastes and textures for days. He repeatedly sought assurance of his mother if he had spoken everything right. He also washed his hands repeatedly, up to 10-20 times at one time, and was unable to elaborate reason for that. When the boy turned 5 his family sought a mental state examination, and the boy was diagnosed with autistic spectrum disorder and obsessive-compulsive disorder. The mother was -and still is-in disbelief about her son's diagnosis regarding autism. The family tried faith healing. Within the next three months, his condition worsened as he showed interrupted sleep, speech decline, irritable behaviour, laughing out of context and refusal to eat food. The family sought ECI services as initially prescribed by the boy's psychiatrist. Mother and older siblings were educated about the child's condition and the need for continuous support was emphasized. The mother still denies that her son is autistic (although she seems more comfortable with OCD diagnosis) and she refers to her son's condition as 'psychological problems' or 'hyper-sensitivity' and insists that therapists use the same terminology about her son. The boy started behavioural therapy as well as speech and occupational therapy. At follow-ups, he started participating in farm work of the family, took care of himself, with some repetition of acts such as washing of hands, and it was decided that it would be best for him to maintain at the same school level (kindergarten) for one more year before he starts primary.

Michaela – ECI professional

2.5 Existing good practices

As it is already reflected in this mapping exercise, there is no robust sector of ECI services for the full age range of children with disabilities in Greece. However, several organisations have demonstrated interesting approaches and good practices that address the needs of the children and families they support in a holistic way. Two such examples are detailed below.

Amimoni's Early Childhood Intervention Program for Visually Impaired children.

Amimoni is the Panhellenic Association of Parents and Friends of the Visually Impaired People with Additional Special Needs (i.e. autism, learning disabilities, motor and sensory impairments confounded to blindness). It is a private, non-profit organization founded in Athens in 1993. The Early Child Intervention program of Amimoni has been offering services since 2004 to more than 200 families. It is a family-centred, educational, home visiting programme that supports visually impaired children from birth up to the age of six with or without additional disabilities and their families. Today the program caters for the needs of approximately 40 families in the region of Attica with systematic weekly home visits by specially trained professionals.

The primary goal of the intervention is to support the development and emotional wellbeing of the child, the caregiver-child interaction, and the family and its social inclusion. The programme follows a family-centred approach that consists of developing a family-centred intervention plan, focusing, and designing the intervention based on the daily routines of the family, encouraging the active and ongoing participation of the family during the weekly interventions, providing consulting support, and informing them on community available resources and services. Its major aim is to promote the family empowerment, aiming at its substantial participation in the development of their child and in the family's wellbeing. The interven-

tion approaches holistically the child. The promotion of functional residual vision skills in the child's natural environment, along with body awareness, tactual and auditory perception and support of orientation and mobility, gross and fine movement, as well as self-care daily activities, are possible target domains of the intervention.

The programme also has a distant support service for families in remote regions of Greece. More than 25 children and families have been served throughout the Greece since 2017, and numerous professionals who work with visually impaired children are implementing a program of early support via telecommunication.

The Early Intervention program currently employs a transdisciplinary team of nine persons with various specialisations (occupational therapists, psychologists, special educators, social workers, mobility, and orientation expert), which is the core structure of the program. The team receives constant training and supervision from experts all over the world in topics related to vision therapy, physiotherapy, family coaching etc. Amimoni's ECI program aims at promoting the child's developmental potential and skills, encouraging his self-reliance, and closely supporting the family, caregivers, and the child's supporting network (other therapists, teachers etc.).

Theotokos Foundation: ECI in the Community for Pre-school Children and their Families

Theotokos Foundation is a non-profit welfare organisation (private law entity) established in 1954. 'ECI in the Community' is a programme operating across 20 nursery daycare centres targeted at children between 1,5–4 years old and their families. Organised in cooperation with the Theotokos Foundation and the neighbouring municipalities, its principal aim is the early identification and intervention of children at risk of developmental delays or emotional difficulties.

The practice is a synergy and collaboration between the interdisciplinary team of Theotokos, the staff of daycare centres and the parents. These ECI services are made available as geographically close as possible to the families and are cost-free. The service has further provided the necessary screening and assessment tools to help specialists, healthcare support teams, staff of nursery day centres and parents identify difficulties as early as possible and seek access to ECI services.

The methodology employed is composed of six phases:

- 1 Raising awareness on the importance of prevention and the usefulness of the programme.
- 2 Conducting screenings at nursery day centres.
- 3 Performing assessments of children that have been identified as being at risk of developmental delay or emotional difficulties.
- 4 Consultation with parents.
- 5 Referral for further assessment/diagnosis of children that have been identified as having difficulties in more than one developmental area or present signs of emotional difficulties.
- 6 Providing individualised intervention for children and their families through the help of an interdisciplinary team.

Within the past six years, the Theotokos Foundation has assessed over 1600 children, of which 15% showed difficulties. Theotokos has built a strong, collaborative relationship between parents, teachers and children based on trust and the empowerment of families and educational staff. Improving the abilities of all stakeholders will allow for more timely intervention and, as a result, more sustainable social inclusion of children.

Over time, the programme can be scaled up by creating a guide on the prevention and early identification for professional health care and support staff. The guide will be used by any professional that supports educational staff and/ or is responsible for the supervision of children in daycare nurseries, broadening the number of children that can undergo screening and assessment.

2.6 Conclusions

Although integrated approaches to promoting ECI are becoming more common, effective coordination within and across sectors remains a challenge and this has an impact on the way Greece provides ECI services to children and families.

The primary issues of ECI, highlighted already through desk study, and which were reiterated and elaborated during the semi-structured interviews and the focus groups were the following:

- ▶ **lack of an integrated ECI system.** Responsibilities that may stretch from programmes and protocols development to standard-setting, monitoring, or financing are not under one leading authority in Greece;
- ▶ **underdeveloped screening and referral system** (multiple yet non-coordinated entry points);
- ▶ **lack of standardised procedures for involving families** in the initial assessment and the development and monitoring of individualised therapeutical programmes;
- ▶ **delayed response to children** – significant gaps in service provisions for children under the age of 3, strategies and investments that are adapted to developing a robust system of specialised services for children under three;

► **lack of consideration of the families' needs, priorities, and resources – therapeutical approach;**

► **lack of uniform quality standards and regulations for ECI providers;**

► **unequally distributed ECI programmes at a national, municipal, and regional level;**

► **lack of coordination among the different access points to the service system, the involved agents, services and ECI professionals.**

Efforts are needed to improve the integration of social care services vertically within the social sector (i.e. services that help identify children eligible for ECI and a robust access point to the system of services), and of different sectors, primarily the health and education sectors, horizontally (i.e. setting up mechanisms so that screening is followed by referral to specific services, coordination between health, education and ECI providers to develop and monitor children's IFSPs etc). When planning for the new comprehensive ECI system in Greece, special attention should also be given to the fact that social, education and health services are managed at different levels of governance.

Despite difficulties and shortcomings, there are Early Intervention programmes in Greece that can be examples of good practices with their own characteristics that allow the creation of a network of integrated and comprehensive responses to the needs of children with disabilities and their families.

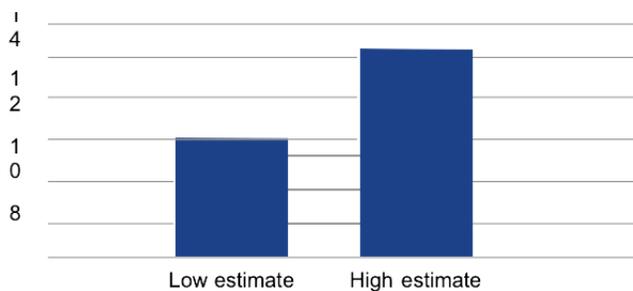


Chapter 3: Funding of services

3.1 Introduction

The research community strongly affirms that improved policy measures and investments in high-quality early childhood programs are long-term investments which benefits children, society, and the economy (Karoly, Lynn A., 2012). A significant study conducted in Michigan in the 1960s showed that a high-quality program for children of 3 to 5 years old estimated a return to society of between \$7 and \$12 for each \$1 invested (Heckman et al, 2009).

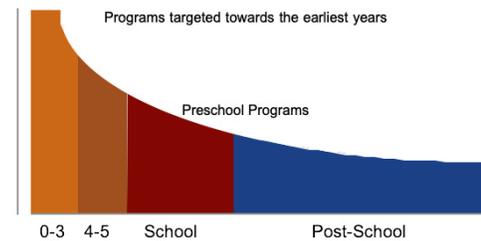
Figure 11: Perry Preschool Program: Return per \$1 invested



Source: Heckman et al 2009

Nobel Prize-winning economist James Heckman who has extensively studied the financial benefits of ECI programs, argues that returns are higher the earliest the intervention is provided in a child's life (see Figure 12).

Figure 12: Returns to a Unit Dollar Invested are Highest in Earliest Years



Source: Heckman and LaFontaine (2007)

In this part of the ECI Country report, the focus is on the funding aspect of the ECI provision with the aim to include and the level of families' involvement.

- clarify the current state of play regarding funding for ECI in Greece,
- identify threats to and opportunities for the transformation of the existing system towards a holistic model that is inclusive to all children with support needs and places particular emphasis on the active engagement of the family as a key agent for achieving social inclusion.

Affordability is one of the elements needed for ECI provision, which also include: availability (to reach out to all families and children in need of support as early as possible), proximity (to provide services as close as possible to the families), interdisciplinary work (to involve professionals from different disciplines), and diversity of services (to achieve effective cooperation between the health, social and educational sector).

3.2 Strengths of the ECI funding system

From our research and the focus group it emerged that funding is ensured for part of the activities of the early intervention system including screening, provision of individual therapies, day centres and educational support, which are largely free of charge for parents. You can find more details about the strengths of the funding system in the list below which summarises our findings:

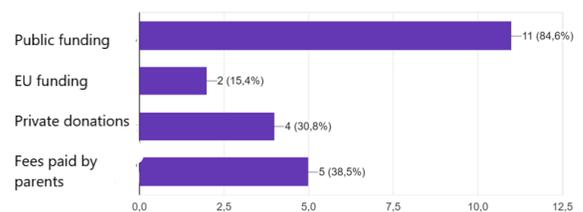
- ▶ Free access to prenatal and postnatal care and screening for disabilities is available for all children in Greece through the National Health System. (L. 4368/2016).
- ▶ According to Law 4898/2018, children with diagnosed developmental difficulties provision of specific individual therapies including occupational therapies, speech therapies, physical therapies, special education therapies, etc. The National Organisation of Health Services (EOPYY) covers those financially to a significant extent³⁶. Law 5571 issue b of 2018 also provides for the prescription by child psychiatrists, developmental pediatricians, or child neurologists of early intervention therapies, albeit only from a purely therapeutic perspective and for up to eight therapeutic sessions within six months for every eligible child.
- ▶ The network of Day Centres and Creative Activity Centres (KDAPMEA) provides intervention and support services for many young children in need of specialised support and is adequately funded by national and EU resources.

Once the children are integrated into the formal education system, all the services of identification, assessment, and educational support provided to them are free of charge (accessible educational material, differentiated teaching, special education staff and auxiliary educational staff).

3.3 Weaknesses of the ECI funding system

Services in Greece can be funded by public funding, EU funding, private donations and parents' fees as reflected in Figure 13, based on the questionnaires for ECI service providers.

Figure 13: How are your ECI services funded?
(14 answers – ECI services)



From focus groups discussions and interviews with various stakeholders, it clearly emerged that the Greek ECI system is not adequately funded, and thus families have to compensate for this gap. Also, some of the fundamental elements of a high-quality ECI system (i.e. home visits, training, music/art therapy, transition to education) are not covered by public funding. The list below summarises the most important weaknesses of the ECI funding system according to the research:

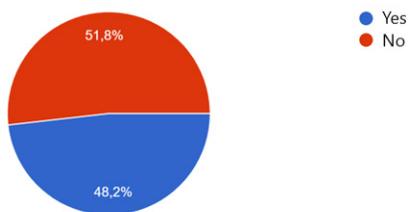
- ▶ **ECI services are often not adequately funded:** the allowances that EOPYY offers for therapies to children with neurodevelopmental delays and/or diagnosed disabilities are insufficient to cover their actual costs, resulting in families being forced to make additional financial contributions, as reflected by the responses to the questionnaires. The number of therapies justified by the EOPYY is determined solely by the type of disability without considering individual differences and the heterogeneity that similar diagnostic clusters have, and without assessing the needs of the families.

36 The State provides funding for specific therapies, the number and frequency of which depends on different categorisations of disabilities, and the outcomes of the assessment procedure. The providers can ask for additional money.

Figure 14: Is public funding enough to cover the needs of your service? (14 answers – ECI services)



Figure 15: Do you need to pay for the services you receive? (83 answers – families)



► The Greek educational system is still unable to address its students' increased needs as it relies largely on limited European Operational Programmes and not the State budget to fund parallel support for students with diagnosed disabilities. As a result, not all students with disabilities have access to educational support in mainstream schools (parallel support) and parents are often called to either cover this cost themselves or enroll their child to a special school. Moreover, funding gaps can result to students not having their parallel support teachers from the beginning of the school year. Funding gaps between different regions of Greece vary significantly.

► Accompanying services and provisions such as music therapy, art therapy, therapeutic riding, or assistive technology are not covered by public funding. Family home visits, central for a modern and holistic early intervention system, are not defined in any relevant legal framework and are not funded. Thus, costs necessary to carry out home visits, such as travel costs or the purchase of required vehicles, are not foreseen and are not eligible for funding. Early intervention service providers must cover at their own expense the

continuing education and training needs of their staff. There is a lack of training programmes which promote a new model of early intervention away from the existing deficit-centred approach, which reduces the child's potential to a diagnostic assessment.

► ECI providers are not financially supported to provide services outside of the city in which they are located. Thus, families living far from urban centres face higher

travel costs to receive diagnostic or support services. ► Public funding does not cover the transition from early intervention services to subsequent support or educational settings, which includes the development of a transition plan and good communication between families and the various professionals involved.

► There is no provision for funding therapeutic protocols and early intervention services for children with hearing and vision disabilities under the age of 4 years old since these are not included in the legal framework. Only medical interventions are funded.

3.4 Opportunities of the ECI funding system

Recently, the Greek State has made early intervention one of its key priorities for preventing institutionalisation and developing an integrated protection system for children with support needs and their families. At the same time, the field of ECI providers has progressed towards a modern, research-based practice that has moved away from the traditional model that limited early intervention to a therapeutic approach provided by experts and excluded the family. When combined with the availability of significant European funding, these advancements can create a positive context for achieving high-quality early intervention policies in Greece.

The list below indicates key opportunities related to funding for early intervention in Greece as they emerged from the consultations with the various

stakeholders and from the focus group on the Funding of ECI services:

► The former Ministry of Labour and Social Affairs³⁷ has included in the **EU Recovery and Resilience Fund (RRF)**³⁸ a programme to support actions related to Early Intervention. This programme will be implemented from 2023 to 2025 and is expected to cover 1450 beneficiaries with a total budget of approximately 32 million euros. Furthermore, there is a provision to support the ECI services after the end of 2025 by including them in the funding stream of the National Strategic Reference Framework (NSRF). The current context creates favourable funding conditions for strengthening existing early intervention services and developing new ones that will contribute to creating a holistic and effective system that can support all children in need and their families.

► **Greek Local Development and Local Government Company (EETAA)**³⁹, which manages European funds and finances the operation of private nurseries, could broaden its funding schemes in financing early identification and early intervention services that are currently absent from nurseries.

► **The continuation and expansion of the existing early identification programme "Kypseli" in nursery schools** could contribute to the creation of an effective protective network for children with support needs and their families.

► The **European Social Fund Plus** can support the development of tools and interventions for early childhood; and according to its regulation its 5% should be directed to actions toward children experiencing poverty or social exclusion.

► The **Child Guarantee Action Plan** for Greece can include actions for the establishment of an ECI system, by addressing existing gaps.

► The **PEP programme** (European Regional and Operational Program)⁴⁰, which covers provisions concerning children with support needs in pre-school and school-integration programmes can fund ECI-related actions.

► ECI funding should be considered as a supporting tool to rationalize the spending on therapies, through

prevention, empowerment of the family support and facilitation of the transition from a purely medical approach to a more holistic intervention for the child with disability and the family.

3.5 Threats to the ECI funding system

Presently, Greece is in a transitional stage regarding the provision of early intervention services. The aim is to progress from a model that is insufficient in covering the overall needs of children and their families to a more integrated and holistic system that focuses on the role of the family and social inclusion. While assessing the threats of funding this new model, it becomes clear that most of them are related to ensuring that the funding system is sustainable and addresses the current needs of children and families.

The following list summarises some crucial threats to the planning of a quality system of ECI services in Greece, as they arose from the Focus Group discussion and the consultation with various stakeholders:

► Systemic change takes years. Transitioning from the existing therapeutic model to a holistic family-centred ECI can create severe gaps in service provision, leaving some children with inadequate support.

► As there are currently no quality standards for the operation of ECI services, there is a risk that some of the newly funded ECI providers may not offer high-quality services that are responsive to the needs of children and their families.

► Cross-sectorial and multidisciplinary coordination and collaboration is challenging but necessary in developing an integrated ECI system.

► Today some families and children are excluded from ECI funding and support, in particular in the sensitive 0–3 age. Screening and referral processes must be carefully designed to ensure that all families and children with disabilities, even the ones that are at risk, will be provided with appropriate funding and support in receiving ECI services in a timely manner.

► Without funding for training and transportation



it is not possible to move towards a family-centred ECI system. ECI funding should include provisions for training of staff and transport costs for home visiting intervention.

► If not correctly planned and monitored ECI funding risks to be used as a complementary source of income to fund therapies. Funding must guarantee that the family centered character of this specific service is safeguarded and implemented appropriately.

3.6 Conclusions

The current funding system for early intervention services in Greece has significant gaps both regarding its capacity to respond to the existing support needs of children and in relation to quality.

The main findings of research were the following:

► There is a need to guarantee unhindered access to holistic ECI services for all infants and children in need – together with adequate support for their families.

► There is a need for a broad and holistic funding strategy that avoids piecemeal policies and develops an integrated, multidisciplinary approach that addresses the needs of children and families in an effective and comprehensive way.

► To ensure quality services, funding policies should invest adequate resources in strengthening the capacity of the ECI providers across different sectors and in enhancing the professional development of ECI staff to respond to the needs of the families with an accurate and up-to-date approach.

A more favourable financing framework has emerged as some important European funding instruments and policies have been committed to improving funding opportunities for early intervention in Greece. These resources, if properly allocated, can lead to a significant change in ECI provision in Greece.

It is possible to establish a new framework of ECI in Greece, that will respond to the current needs of the families, in line with recent research advancements and that views ECI not as therapy but as a family-centred intervention happening in the child's natural environment, by a well-trained multidisciplinary team, and that truly aims at building social inclusion and community change.

36 *The State provides funding for specific therapies, the number and frequency of which depends on different categorisations of disabilities, and the outcomes of the assessment procedure. The providers can ask for additional money.*

37 <https://ypergasias.gov.gr/k-chatzidakis-programma-gia-tous-pollous-me-porous-26-dis-evro-apo-to-tameio-anakampsis/>

38 https://ec.europa.eu/info/business-economy-euro/recovery-coronavirus/recovery-and-resilience-facility/greeces-recovery-and-resilience-plan_en

39 <https://www.eetaa.gr>

40 <https://www.espa.gr/el/pages/default.aspx>

Chapter 4: ECI service providers' needs

4.1 Introduction

The role of ECI providers is constantly changing as social conditions, research and empirical evidence evolve over time. In the past, ECI providers operated based on a rigid model to which service users had to adapt. In view of the international proceedings in the field of psychosocial support and social inclusion, it has become clear that ECI services can be effective only if they provide flexible and personalised support and, at the same time, respect the needs, resources, and individual characteristics of the children and of their families as well as the context of the community in which they operate⁴⁴.

To meet the current challenge of the overall transformation of services, ECI providers should:

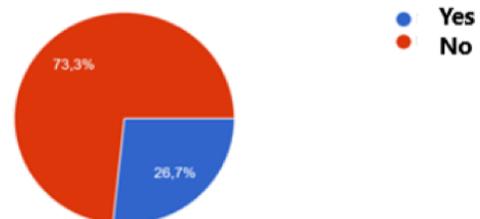
- ▶ produce optimal results in maximising the child's physical, cognitive, and social/emotional development;
- ▶ respect the diversity of families and communities;
- ▶ recognise the central role of the family and the importance of working in partnership with it: ECI providers should encourage all families to contribute to the intervention and be part of the developmental process of the child;
- ▶ be inclusion focused: their practice should promote the engagement of children, regardless of their needs, in all aspects of life by fostering learning in natural environments, daily routines, at home and in the community;
- ▶ adopt evidence and outcome-based approaches grounded in research and clinical reasoning;
- ▶ work with well-trained professionals from various disciplines to meet the diverse needs of the children and families and to ensure a qualitative and interdisciplinary approach.

Meeting all the above results in quality of ECI services. However, before getting there, several conditions have to be explored in more depth.

4.2 Legal framework

As illustrated in Figure 16 based on the responses to the questionnaire distributed to ECI providers, and as also emerged through our desk research a legal framework that sets out the basic principles of ECI provision is absent for several services, especially those operating in the social sector.

Figure 16: Is there a legal framework under which your ECI services operate? (15 answers)



Participants in the Focus Group and stakeholders' meetings raised the need for a comprehensive legal framework that would:

- 1 define the basic principles of operation of early intervention services,
- 2 emphasise the central role of families,
- 3 refer to the importance of providing services in the child's natural environment, at home and be based on the child's daily routines,
- 4 define the standards for the composition of the ECI interdisciplinary team (i.e.background training, experience, credentials etc.),
- 5 underline the importance of the development of an Individual Family Service Plan(IFSP), and
- 6 promote the value of social inclusion.

According to project meetings with high level policy makers, the development of such a legislative framework for ECI services seems to be among the immediate priorities of the Ministry of Social Cohesion and Family (former Ministry of Labour and Social Affairs).

4.3 Early identification

Another clear outcome of research is that **early intervention does not always take place sufficiently early in Greece as the early identification mechanism does not work effectively, especially for the children at risk of developmental delays who have no apparent disability**. Early diagnostic mechanisms, especially in the health sector, need to be supported so that no child is left without the necessary support net. As an ECI professional mentioned during the focus group discussion, maternity hospitals and their staff need to be properly trained both in recognising potential developmental difficulties based on defined developmental protocols and in knowing how to initially support children and families (i.e. inform on the issue, make initial referrals to appropriate and inclusive ECI services).

Family paediatricians also play a key role as most families refer to their private practice rather than hospitals. **Paediatricians, thus, must be trained on the development of children according to specific developmental milestones, which are included in health booklet⁴² published in 2017 by the Institute of Child Health.**

Another point that emerged through our desk research⁴³ and interviews with various stakeholders was that **there is a need to increase the staff capacity of social services of municipalities both in terms of the number of professionals and in terms of the training in ECI principles to be able to make appropriate referrals and initial screening at the local level**. Social workers currently serving in public sector entities are not enough to cover the increasing needs of children and families. Moreover, public sector entities are frag-

mented and scattered among different sectors (welfare organisations, municipalities, health and mental health services, prosecutors' offices and so forth). Greece, unlike many other European countries, did not develop a comprehensive welfare system with a robust social or child protection mechanism. As a result, after the ninetens, Greece has seen a massive set up of numerous -usually state-funded- NGOs, which provide an alternative to filling the gaps of the state's inefficiency but often work without coordination and without clear operational standards.

Moreover, the Social Welfare Centres that exist in every region of the country don't have mobile early intervention units with adequate staff. To move towards a quality and family-centred provision they should create interdisciplinary teams of professionals that are adequately trained to work with families in the children's homes, schools, after-school activities, and communities. The development of these flexible ECI services should be a priority for the Social Welfare Centres as they gradually change their role from institutional care providers to community-based service providers.

4.4 Assessment process

In both the health and education sectors, the assessment tools used by early intervention services are scientifically tested with high validity and reliability measures. However, this is not the case for early intervention services operating in the social sector, where there is a great deal of heterogeneity, such that different providers follow different assessment procedures. This was confirmed by the responses of the participants of the focus group organised to identify the needs of the ECI providers that stressed the lack of standardised guidelines and the need to develop a consistent assessment process at national level. It was also pointed out that families often receive services from more than one provider following different ap-

42 https://ygeiapaidiou-ich.gr/web/viewer.html?file=/sites/default/files/Vivliario_Ygeias_paidiou.pdf

43 <https://old.sunigoros.gr/?i=childrens-rights.el.dpeidikesecktheseis>

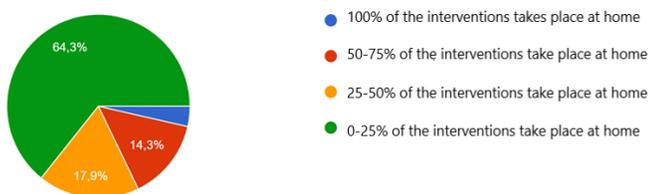
proaches, something that can be very frustrating for them.

ECI professionals participating in the focus group on the needs of services, pointed out that it is essential to create a toolbox of reliable assessment methods and train ECI professionals to use, while recognising that assessment tools need to be flexible to adapt to the various needs of different children. Additionally, they highlighted the need for an updated epistemological framework that will move away from an assessment process that is limited to identifying the deficits to an approach that focuses on the strengths and capacities of the child on the one hand and the resources of the families and the communities on the other.

4.5 Connection with families and the community

As it emerged through the FG and the interviews with stakeholders, in Greece, ECI services often follow a service provision model which is not grounded in an inclusive approach given that the provision of the service is limited to the space of a room in a therapy centre. Moreover, staff do not communicate effectively with the family and the community, nor explore together different support options. As illustrated in Figure 17, based on the responses of families whose children receive ECI services to the relevant questionnaire, support is rarely provided in the family home.

Figure 17: Does the ECI intervention take place at your home? (78 answers)

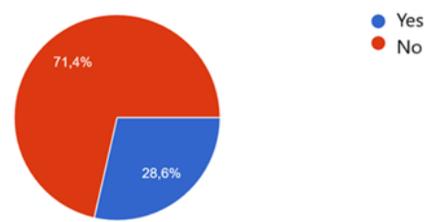


The findings of the FG and the semi-structured interviews indicated that most professionals and providers showed a great understanding of the importance of intervention in the family's natural environment. Responding to the question, "Would you consider a home visiting approach as a potential solution to incorporating families in a more constructive way in ECI services?" a participant quoted: "We understand that even if the Holy Spirit comes down just one or twice a week, nothing will change unless the family is included. Family involvement is a sine qua non." Replying to the same question another participant commented: "The intervention at home is very positive to smoothen out problems, to support good communication and to help the family to help their child". Respondents further highlighted several practical and organisational problems for not implementing home interventions. The need for developing ECI in the child's natural environment was clearly demonstrated. Achieving this requires legislative provisions, training of professionals, raising awareness activities and additional funding.

4.6 Individual Family Service Plan (IFSP)

The Individual Family Service Plan (IFSP) describes the child's current situation and suggests the interventions needed to support both the child's development and the family's efforts to help her or his development. The creation and implementation of an IFSP is not a legally regulated standardised practice in ECI service delivery in Greece, as it emerged from our desk research⁴⁴ and the response of the questionnaires to service providers.

Figure 18: Is an individual plan legally required in your country for the children you support? (14 answers)



44 De Moor, J.M.H., Tzouriadou, M., Van Waesberghe, B.T.M. & Kontopoulou, M. (1998). *Early intervention for children with developmental disabilities: manifesto of the Eurlayid working party*

This also emerged in our FG, where one professional working in a big hospital, pointed out that there is no available tool that could be used broadly especially in regard of how the family operates: "We do not have any specific tool to guide us through on how to include families".

In the educational context, Law 3699/2008 stipulates the development of ECI departments in Special Needs Schools and requires from the Centres for Educational Counselling Support to propose and implement ECI programmes, for children aged from 4 to 7 years old⁴⁵. There are also legal provisions⁴⁶ for the development of Early Educational Intervention Programs by Educational and Counselling Support, the public service that also has the responsibility to monitor and support their implementation of such plans in students' school settings. However, there are no legal framework and standardised protocols for professionals supporting children and families 0 to 6 in non-educational settings (such as the child's home, ECI centres, therapeutic centres etc).

More specifically in the educational context, by Law⁴⁷ KEDASY Centres for Educational and Counselling Support are responsible to prepare Early Educational Intervention Programs (EEIP) and have the responsibility to monitor and support their implementation (Art: 14,16,17) for children who are identified as having additional educational needs. There are guidelines for its development which involve the families although not intensively. However, semi structured interviews with policy officers, professionals and mainly families revealed that this is rarely put into practice in the way described in legislation. Centres for Educational and Counselling Support are understaffed and overloaded services. After long waiting lists for assessment and EEIP development, follow-up is rarely done in a timely manner. According to the responses collected through semi-structured interviews with professionals serving in KEDASY what is also missing in these services is the

training of professionals and monitoring of the plan's implementation.

4.7 Training standards for ECI professionals

Professionals working in ECI services in Greece (occupational therapists, speech and language therapists, psychologists) are often very competent in their field of expertise as confirmed from the responses to the Focus Group on the needs of ECI Services you can see in Figure 19.

Figure 19: Evaluate the level of training of ECI professionals



However, they are rarely adequately trained in the principles of a comprehensive family-centred ECI model as also evidenced by the responses of the participants in the focus group for the needs of ECI Services. Replying to the question "What do professionals lack training wise to best fulfil their role" several aspects were highlighted such as the lack of ongoing training and supervision, the lack of coaching skills to support professionals to interact effectively with parents and involve them in their child's learning process and the need to promote ecological, interdisciplinary models of collaboration. Currently, according to our research, there are no training or continuing education programmes focusing on family-centred ECI, and no accredited certification process exists for the professional development of ECI providers. Focus group participants highlighted the need for training pro-

45 Greek Ministry of Education: Rules of Procedure of Diagnosis, Evaluation and Support (K.D.A.Y.) of Persons with Disabilities and define the duties and responsibilities of such staff (C6 / 4494 / 1.11.2001)
 46 M.D.211076/ΓΔ4/13-12-2018
 47 *ibid.*

grams that will be developed as the capacity building of professionals is a key component about the quality of ECI services provided.

4.8 Quality standards for the operation of ECI services

The quality of the ECI services is not sufficiently monitored by the state mechanisms as clear quality standards of operation do not exist as confirmed by Figure 20, from the answers of the participants in the Focus group.

Figure 20: Are there quality standards applied to ECI service providers in Greece?



This gap creates a great deal of ambiguity as the quality of the services provided is hard to assess and the outcomes even harder to define.

As a president of public Social Care service mentioned in our FG "the same child, the same families are usually using services from both the public and private sector, and they might be given different instructions from different professionals. To ensure quality services we should be complementing the work of each other. Maybe it would be meaningful to appoint a coordinator that will be overseeing this process and the quality of services provided to the family". Therefore, there is a need to develop operational standards that will:

- 1 define the expected outcomes
- 2 link those to specific protocols developed for each scientific discipline involved and
- 3 will have to be underpinned by the key principle of family-centred practices.

All ECI service providers should be required to meet the standards to be part of a group of certified ECI organisations. Furthermore, a mechanism of ongoing evaluation of the compliance of providers with the defined criteria and indicators should be developed.

During our FG, one ECI professional proposed one single developmental profile that every child in need of ECI services could have right from birth or diagnosis and would accompany her until her school integration. 'We could use this as a tool and then a specialist from any area could feed information into the file of the child and the family should be responsible and the family could make sure that the personal profile file is constantly updated with input from various specialists.'

4.9 Awareness-raising activities

In Greece, the importance and benefits of early intervention are not widely known to professionals, families, stakeholders, and policymakers. Tavoulari et al.⁴⁸ also mention the need for awareness-raising activities at community level to promote the necessity for the early identification of developmental delays and for quality of ECI provision. These are important to emphasise the irreplaceable role of the families and of implementing ECI in the natural environment of the child. It is also crucial to design the awareness-raising activities using a participatory approach that aims to engage the community to achieve societal change. Diverse groups of professionals, cross-sector agencies and stakeholders should be invited to co-produce those activities.

48 Tavoulari et al (2014), *Early intervention in Greece: Present situation and proposal for the future*, The 8th International Scientific Conference at: Belgrade, Serbia

4.10 Conclusions

Based on the needs analysis conducted in this chapter, to establish a network of quality services at a national level that covers all those who need it the following elements need to be addressed:

- ▶ A **legislative framework** that clearly defines the main characteristics of the services.
- ▶ **Building the capacity** of providers and **upscale** the existing services to cover the area of early identification where there are currently significant gaps.
- ▶ **Developing standardised assessment procedures** that will be applied by different ECI providers. The assessment should not be limited to the children's difficulties but focus on their strengths and capacities and on the resources of the family and the community.
- ▶ Establishing **outreach programs and networking services** that will link ECI services with the families in need and the community services. In this area, it is vital to include home visits as an integral part of service delivery and to link ECI providers with agencies from different sectors, which will facilitate information sharing, collaboration, and a smooth transition from one service to another.
- ▶ **Education and ongoing training of ECI professionals** to ensure that they are aware of the principles of an evidence-based ECI approach.

To achieve these, different measures should be envisaged, including legislative interventions, training activities for professionals, awareness-raising activities targeting the wider public, families, professionals and policymakers and coordination of actions between stakeholders from different sectors, with the overarching goal of transforming the existing services towards an integrated family-centred ECI model should.

Conclusions and way forward

The major purpose of this report was to examine the state of play of Early Childhood Intervention in Greece and suggest ways that public policy can improve the quality of ECI services for children with disabilities or developmental delays between 0 and 6 years of age. At the beginning a clear definition of ECI was provided and thus it was highlighted that integrated ECI programs have the best chance of yielding quality in the range of natural environments and settings serving young children. The quality of ECI provision can be defined by such structural features as group composition, practitioners' qualifications, ongoing training and by process indicators of children's learning experiences and increased social interactions and efficient parental involvement and empowerment. Then the existing ECI system in Greece was studied, assessing its congruence and evaluating its capacity to identify and respond to the needs of disabled children 0–6 (including their families' needs). The third chapter of this report focuses on funding needs and opportunities that could ensure sustainability and scaling up of the ECI reform. At the fourth chapter the service providers's needs were examined to support the Greek Authorities in developing appropriate capacity building interventions for them. As it emerged through the research, currently there is not a comprehensive system of ECI services in Greece, but instead, a decentralised set of actors and activities with multiple goals, funding sources, and venues. Many experts and stakeholders included in this report agreed on the fact that quality in all ECI programs can be enhanced by integrating child health care and early education provisions for children with disabilities into a comprehensive National ECI system. It also became evident that regulations and standards can affect quality largely by dictating the basic structural features for the provision of services.

Looking to the future, **developing the capacity for coordinated and integrated administration of ECI programmes is of key importance to improving the quality and outreach of services.**

The first step would be to **define a common entry point and delivery chain for ECI services** in view of systematically and gradually merging the administration of services provided to children with disabilities and at risk of developmental delays and their families.

Although existing programmes and services may differ, they usually follow common procedures along the delivery chain. These include conducting outreach to potential beneficiaries and service providers, managing the application process, assessing families' needs and circumstances to determine their eligibility, awarding vouchers/benefits to cover the service package that has been determined for them, providing services, and conducting case management.

The governance aspects of this process in regard to a National ECI System include monitoring, oversight, and management of the process. Current empowerment and capacity building in the MoSCF to administer the ECI pilot program provides a good basis for developing the capacity to administer the National ECI System on an operational level. But this will require adjustment of legal acts and amendment of current regulations that define a strong mandate of the MoSCF to consolidate and optimise the delivery chains of many programmes targeted at young children with disabilities and their families and to overall manage this inter-ministerial reform. This will be inevitably a gradual process as it takes time to change the mentality, to set up common systems and to integrate several programmes one by one into the new National ECI System.

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