

Family-centred Early Childhood Intervention: The best start in life.

Position paper



European Association of
Service providers for
Persons with Disabilities

The “Family-centred Early Childhood Intervention: the best start in life” Position Paper was coordinated by **EASPD**.



It was endorsed by the following organisations:



Joint Position Paper

The European Association of Service providers for Persons with Disabilities (EASPD) promotes the views of over 20,000 social services and their umbrella associations, and opportunities for persons with disabilities through effective and high-quality service systems.

This position paper was drafted by the EASPD Member Forum on Early childhood Intervention (ECI MF) and finalised in consultation with several networks and organisations active in the fields of child and family rights, and disabilities, whom we thank for their meaningful contributions.

The aim of this paper is to raise awareness on what family-centred Early Childhood Intervention is, on why it is needed and to highlight key challenges and, finally to formulate recommendations for the European Union (EU) and its Member States (and also other national governments) to establish quality ECI systems. Our aim is to advocate together for the right to early childhood intervention for children and families. This document is thus open to endorsement of European and International networks and organisations.

ECI?



1

What is family-centred Early Childhood Intervention

Neuroscience research proves that the child's early experiences provide a strong foundation for future learning, behaviour, and physical and mental health. The early development of cognitive, emotional, and social skills are important prerequisites for the child's future development. Early Childhood Intervention or ECI is a field of family-centred, individualised services for infants and young children (generally 0-3 or 0-6) and their families. They help to identify, prevent, overcome, or minimise at-risk situations. They promote achieving the child's potential, and family strengthening and wellbeing. These services are particularly critical for children with developmental delays, physical, intellectual or sensory impairments, or conditions such as autism, and mental health issues.

Their activities are based on families' and child needs and should be provided in the natural environment of the child with active participation of parents and caregivers following a two(multi) generation approach, simultaneously working with children and the adults in their lives. They must include the assessment of child and family's members needs, the creation of individualised family service plans, the provision of regular services according to need, including speech, physical, and occupational therapies, communication and socialisation programmes, infant-parent psychotherapy, counselling to parents, and more.

Family-centred ECI services are a key element in the deinstitutionalisation process as they empower families, contribute to prevent the placement of children in institutions and foster their inclusion in education. They are integrated and interdisciplinary services, with the full participation of the health, social, and educational sectors and all relevant disciplines in supporting each family and child.



Family-centred Early Childhood Intervention is...

- **Early and continuous.** It seeks to start working with children shortly after birth or as early as possible. Early assessment is important to ensure the child and family receive the needed support with the maximum positive impact.
- **Family-centred.** Families are equal partners in the planning and implementation of ECI and the intervention should be coproduced around their needs and priorities. The relationship with families is thus key for achieving successful results. ECI supports families and helps them focus on their child's development, know and exercise their rights, and make all decisions for their child's wellbeing.
- **Based on a social model of disability.** Rather than addressing solely a child's areas of need, ECI also focuses on assessing the family's strengths and wellbeing, the child's next developmental steps, and the wider context and support network in which the family lives.
- **Intensive.** Support actions can be frequent, depending on the needs of the child and family, and should happen in the home and other natural daily environments of the child.
- **Accessible.** ECI services must be easily accessible to all, affordable for all families and the service should be based as close as possible to families' homes.
- **Transdisciplinary, integrated and team based.** Families are supported by professionals from different sectors and disciplines that work in teams to provide one integrated service of assessment, individualised family service plans and visits, with one contact point or case manager for each family and child.
- **Individualised and evidenced based.** ECI programme activities are built on child and family strengths needs, and priorities, and they are based on research findings on development, learning, communication, and effective intervention for specific disabilities and conditions with continuous monitoring and evaluation.
- **Based on the best interest and participation of the child.** Professionals need to be trained on child-friendly methods of interventions and ensure child's cooperation, taking into account children's views including emotional reactions and non-verbal cues of resistance need. The best interests need to be assessed based on child's quality of life, in agreement with parents, and not merely focused on the elimination or reduction of impairment effects.

2

Why is ECI important?

Children with disabilities are disproportionately more likely to be placed in institutional care than their non-disabled peers. Institutionalisation segregates the child from its community and is detrimental to children's health and development, as rotating staff cannot provide the stability, security, and sense of love a child can receive from a long-term bond that comes with having a family. Some parents place their child in an institution because they are uncertain how to address their child's disability or meet their needs. Family-centred ECI addresses this by empowering parents and supporting them in fulfilling their role.

Disability increases the risk of poverty and social exclusion, exacerbated by the unequal access to key services. ECI can play a major role in shaping young children's lives, including mental health and wellbeing, and livelihoods. By tackling challenges as early as possible, ECI can have a significant impact on a child's ability to learn new skills and improve her or his success in school and life. In this way, ECI is beneficial for the child, for the family and for the community all together.

The benefits for the child:

Early detection of risk of developmental delays or disabilities: Children have rapid brain development and neuroplasticity in their early years. During this period ECI services can achieve the maximum impact in addressing risks, developmental delays and impairments. ECI services have lifelong effects, and help achieve the child's full potential.

ECI promotes child wellbeing. This can include good health, nutrition, and hygiene as well as mental health, and perceptual, cognitive, language, motor, socio-emotional, and adaptive skills.

Better school readiness. ECI facilitates inclusion in general pre-primary education, adaptation in inclusive educational settings, with less school dropout and grade repetition, and better future educational outcomes.

- **Better opportunities later in life:** Inclusion in ECI services and inclusive education can lead to higher chances of participation in society and employment.

The benefits for the family:

Prevention of abandonment and institutionalisation, by supporting the creation of sustainable and secure child-parent relationships and affordable and accessible support services with solutions adapted to the family needs.

Parents positive impact their child's development through an empowering approach based on their knowledge and skills about child development and care, which are strengthened during the intervention;

Increased confidence and a sense of control over their lives. Parents learn how to be active partners and advocate to ensure their child's needs are met;

Improved mental health. Less stress and anxiety for the parents and better relationships, within the family unit by engaging and supporting the whole family, less feelings of isolation and strengthen social support networks;

The benefits for the public:

Return on investment. High quality birth-to-five programs for disadvantaged children can deliver an overall rate of return of 13% per year (Heckman, 2016).

Preventative approach. ECI services can reduce the future need for support and expensive rehabilitation services, and thus the pressure on public healthcare, education, and social protection services.

Resilient communities. Communities that prioritise ECI are more future-oriented and provide supportive environments for children and young people as they grow up.

Less social exclusion. ECI helps reduce risks for children to attend special education, have grade repetition, early parenthood, and long term dependency on social protection programmes, adult institutionalisation and incarceration.

Positive contribution to society. ECI opens up opportunities for children and help them develop their personality and achieve potential full and independent adult life. Parents are more skilful and resourceful.

Equity and poverty reduction. ECI helps to create a more equal, mature, and harmonious society.

What happens without ECI?

In most of the countries there is not a system of family-centred ECI, affordable and available for all families and children and this may help explain the high percentage of children and adults living in institutions (over 1 million in the EU).

Without quality support families are at higher risk of social exclusion and have to fill in the gap of service provision, with their financial resources, energies and time. This makes societies more unequal with a higher risk for the children to be placed in institutions. The consequences for those children can vary but have to do with higher risks of a lower development of cognitive and social skills, poor health and nutrition, educational exclusion, adult institutionalisation, fewer opportunities for inclusion in community activities and of reaching their full potential.



3

ECI national systems: challenges and solutions

In this section you can find some of the most common challenges in the creation of functional Early Childhood Intervention systems, and what it is needed at national and EU level for this to happen.

Definition and objectives

■ Main challenge:

Policy makers and professionals often lack a shared understanding of quality ECI and what it entails.

■ National solutions and recommendations:

- **Develop** through consensus building, clear ECI **guidelines** and **procedures** for ECI programmes covering topics such as access to services, identification, assessment, eligibility, service quality, family/child progress tracking and monitoring, and a shared vision and understanding among decision makers on ECI and its benefits.
- **Create platforms and campaigns** to inform national policy makers and professionals about quality family-centred ECI.

■ EU solutions and recommendations:

- Develop **EU Guidelines on ECI systems** for member states and accession countries to consider and mainstream them in relevant initiatives in the fields of child rights, family rights, disability rights and deinstitutionalisation.

State of play

■ Main challenge:

Poor or no data in most countries on the availability and quality of existing ECI services.

■ National solutions and recommendations:

- Conduct an **ECI situation analysis**, mapping existing ECI programmes contents, methods, and good practices.
- Encourage all ECI programmes to include internal **monitoring and evaluation procedures** and produce annual programmes and financial reports.

■ EU solutions and recommendations:

Compile and review existing definitions, frameworks, systems and good practices for ECI in a **EU-wide study on ECI policies and practices**. This would include monitoring and evaluation, the status of implementation of developmental screening, developmental and family assessments, and service procedures in family-centred ECI.



Legal framework and funding

■ Main challenges:

- **Lack of legislative frameworks and strategic plans** to regulate, organise, and guarantee high-quality and sustainable ECI services.
- Inadequate stable and sustainable governmental and decentralised **funding** for ECI services, especially for NGOs providing ECI.
- Ministries and different organisations involved in ECI lack **ECI coordination systems** that will enable the development of integrated ECI organisations and services. Legislation for 0-3 age group often falls solely under the medical or public health sector;
- Variable levels of access to, availability, and affordability of ECI services in different geographical and income areas, and especially in low-income, remote, rural and island areas.
- Lack of **ECI developmental monitoring, screening and assessment instruments** that have been culturally and linguistically adapted and have psychometric validity and reliability.
- Lack of **quality services and personnel standards**, related with the lack of adequate training for some specific support needs, such as autism.
- Lack of mechanisms for service supervision, **monitoring, evaluation, impact measurement, and quality control**.
- **Bureaucracy** that makes it difficult for families to access ECI services or financial support.

■ National solutions and recommendations:

- Create a multi-sectoral ECI **coordinating department** and technical committee and a high-level advisory body **for the design and implementation of a coherent national ECI system**, including pre- and in-service training that involves all relevant stakeholders, including families, child-rights organisations, service providers, and other civil society organisations.
- Prepare a **national strategic plan for family-centred and integrated ECI services**, to achieve a common vision, mission, and objectives, and built in co-production with stakeholders, including service providers, family and child-rights organisation, that:
 - **ensures availability of services and accessibility of services and procedures**
 - includes national governmental, EU **funding frameworks**, and a diversification of funding sources
 - provides **guidelines** on how to develop ECI services and ensure coordination
 - Includes clear, early, and simple **information about eligibility developmental screening and referral processes for all children and families, including those with children with complex support needs**
 - Includes a **quality assurance framework**
 - Provides a **system for monitoring, evaluation, data collection, analysis, and reporting** of ECI services.

■ EU solutions and recommendations:

- **Encourage Member States to make use of the Technical Support Instrument to implement reforms on ECI** through the Commission Directorate-General for Structural Reform Support.
- Foster the **exchange of information and experience on ECI** among national Ministries and relevant stakeholders.
- Include recommendations for creating **ECI strategic plans** as part of **EU initiatives on children, disability, and care** (in the framework of the European Semester, Strategy on the Rights of Persons with Disabilities, Child Guarantee and EU Care Strategy).
- Include **monitoring and evaluation of ECI** as a part of the European Monitoring Framework of the European Child Guarantee, and European Semester.

Training and working conditions

■ Main challenges:

- Many countries lack a public training service system for professionals and university programmes for professionals working in the ECI sector.
- Poor working conditions are often found in ECI field, and they can undermine the continuity and quality of services provided.

■ National solutions and recommendations:

- Develop a comprehensive and continuous pre- and in-services **training system**, including the creation of Vocational Education and Training (VET) and university courses, and in-job training for all professionals involved in the ECI sector, with planning and funding for implementation.
- Make **mandatory** a periodical in-job training and re-training for professionals working with children and families, with supervision, mentoring and support mechanisms, and encourage exchanges and peer support groups.
- Ensure good **working conditions**, the availability of reflective supervision and support, assistance for developing interdisciplinary teams, and the enhancement of transdisciplinary and appropriate levels of recognition for ECI personnel.

■ EU solutions and recommendations:

- Create a **platform for ECI training**, with MOOCs, presentations, and online training available in all EU languages.
- Support the development and implementation of **national ECI training plans** for systems of continuous ECI pre- and in-service training.
- Provide **funding for the sharing of good practices**, through inter-ECI organisation exchange, visits, conferences, international study tours to highly functional ECI organisations, and the funding of scientific research on ECI, at national level and EU level, through programmes such as Erasmus+ and Horizon Europe.





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