

# Young children with disabilities who require learning support, and their families

When you pay attention to the beginning of the story, you can change the whole story<sup>1</sup>

According to recent data from UNICEF,<sup>2</sup> nearly 240 million children aged 0–17 have disabilities – 1 in 10 of all children worldwide. It is estimated that 10.8 million of those children live in Europe and Central Asia. Children with disabilities are a highly diverse population. They include children born with a genetic condition affecting their physical, mental, or social development; those who have sustained a serious injury, have been subject to nutritional deficiency or infections contributing to long-term functional difficulties; or those exposed to environmental toxins resulting in developmental delays. Children with disabilities also include those who have developed anxiety or depression because of stressful life events.<sup>3</sup> Children with disabilities have been historically underrepresented in data and statistics, making them invisible to policymakers. A complete statistical assessment of disability in the EU does not yet exist.<sup>4</sup> However, despite the lack of population-level data, there is evidence that in most EU countries young children with disabilities have a greater chance of being institutionalised, segregated in special schools,

<sup>1</sup> Raffi Cavoukian, Canadian singer-songwriter and author of Armenian descent born in Egypt, best known for his children's music.

<sup>2</sup> United Nations Children's Fund, "Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities", UNICEF, New York, 2021. Available at: <https://data.unicef.org/resources/children-with-disabilities-report-2021/>

<sup>3</sup> <https://data.unicef.org/topic/child-disability/overview/>

<sup>4</sup> Briefing: "Understanding EU policies for people with disabilities." (Dec. 2022). Available at: [https://www.europarl.europa.eu/RegData/etudes/BRIE/2021/698811/EPRS\\_BRI\(2021\)698811\\_EN.pdf](https://www.europarl.europa.eu/RegData/etudes/BRIE/2021/698811/EPRS_BRI(2021)698811_EN.pdf)

and face greater risks of violence and abuse, in and out of their family setting.<sup>5</sup>

The early years of childhood represent a ‘critical window of opportunity’ for the development and well-being of young children at risk of developmental delays and disabilities. Their positive experiences in early childhood are fundamental for healthy development, which is influenced by their genes, how they interact with their surroundings, and the relationships they have with their primary caregivers.<sup>6</sup> When a child’s brain does not receive the necessary stimuli during their early years, rectifying the consequences later in life requires significant effort. Attaining optimal outcomes then becomes more difficult. In comparison with their peers, those children will be more likely to experience adverse socioeconomic outcomes, poor health conditions, exclusion from or poor education, poverty, and lack of employment in later life.<sup>7</sup> This depends also on the existing barriers in accessing different mainstream services due to lack of appropriate infrastructure, training, reasonable accommodation, or insufficient specialised support.

Thus, it is crucial for families of children with disabilities to have access to family-centred early childhood intervention (ECI) services. ECI aims to meet the needs of the child while strengthening family competencies and support networks. Family-centred ECI are evidence-based, integrated, interdisciplinary and individualised services that support children within the context of the family while promoting their optimal development and inclusion. ECI services empower parents to enhance child development in their home and in their existing family routines.<sup>8</sup> At the same time, ECI services are a key element in the deinstitutionalisation process, as they empower families, help prevent the placement of children in institutions, and foster their inclusion in education.<sup>9</sup>

Family-centred ECI requires a shift from a medical to a social model, with leadership and decision-making shared between professionals and families.<sup>10</sup> In many countries this shift has yet to happen at a systemic level, and early intervention generally happens with a medical, therapy-centred approach, with gaps in early identification and access to support, particularly for those children under 3 years of age and living in less-advantaged communities. A comprehensive approach to the healthy development of children with disabilities is required, including early identification and access to quality family centred ECI services, including assessment planning, provision, monitoring and evaluation. A life-cycle approach to programming provides a helpful framework to identify priority and sustainable interventions during the early childhood stage and to ensure a continuum of quality care, health services, protection, and education as the child transitions from birth into and through the first grades of primary school.<sup>11</sup>

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5 Crowther, N. (2019). “The right to live independently and to be included in the community in European States.” The European Network of Academic Experts in the Field of Disability (ANED) Synthesis Report. Available at: <https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fwww.disability-europe.net%2Fdownloads%2F1040-task-year-4-2018-19-policy-theme-il-synthesis-report&wdOrigin=BROWSELINK>

6 [https://easpd.eu/fileadmin/user\\_upload/ECI\\_HowToMakeItWork\\_ConferenceConclusions.pdf](https://easpd.eu/fileadmin/user_upload/ECI_HowToMakeItWork_ConferenceConclusions.pdf)

7 World report on disability: Main report (English). Washington, D.C.: World Bank Group. <http://documents.worldbank.org/curated/en/665131468331271288/Main-report>

8 “Early childhood intervention in Europe: How can the EU support children with disabilities from the very first step?” The European Association of Service providers for Persons with Disabilities (EASPD) 2020 Report on the European Semester. Available at: [https://www.easpd.eu/fileadmin/user\\_upload/Publications/easpd\\_2020\\_es\\_report.pdf](https://www.easpd.eu/fileadmin/user_upload/Publications/easpd_2020_es_report.pdf); ‘Family-centred Early Childhood Intervention: The best start in life’, EASPD, 2022, available at: [https://easpd.eu/fileadmin/user\\_upload/Publications/Family-Centred\\_ECI\\_PP\\_EASPD\\_The\\_best\\_start\\_in\\_life.pdf](https://easpd.eu/fileadmin/user_upload/Publications/Family-Centred_ECI_PP_EASPD_The_best_start_in_life.pdf)

9 Available at: [https://easpd.eu/fileadmin/user\\_upload/Publications/Family-Centred\\_ECI\\_PP\\_EASPD\\_The\\_best\\_start\\_in\\_life.pdf](https://easpd.eu/fileadmin/user_upload/Publications/Family-Centred_ECI_PP_EASPD_The_best_start_in_life.pdf)

10 “Family-centred Early Childhood Intervention: How to make it work.” EASPD and UNICEF Conference Conclusions and Recommendations, UNICEF & EASPD, 2023

11 WHO&UNICEF.(2012).Earlychildhooddevelopmentanddisability:discussionpaper.WHOLibraryCataloguing-in-PublicationData.Availableat:[https://apps.who.int/iris/bitstream/handle/10665/75355/9789241504065\\_eng.pdf;jsessionid=9B9574BBF12B0016A014CE1706DAB1B3?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/75355/9789241504065_eng.pdf;jsessionid=9B9574BBF12B0016A014CE1706DAB1B3?sequence=1)

## KEY RECOMMENDATIONS TO EU COUNTRIES AND MEMBER STATES<sup>12</sup>

### ▶ FAMILY- AND CHILD-CENTRED EARLY CHILDHOOD INTERVENTION (ECI) SERVICES AS PART OF NATIONAL EARLY CHILDHOOD SYSTEMS

Set up national policy frameworks, promoting a paradigm shift in ECI towards an integrated (health, education and social) model, with leadership and decision-making shared between professionals and families, and with a coherent and coordinated approach across sectors and professionals from relevant disciplines. Develop national roadmaps for ECI system-building, reflecting the specific challenges and opportunities, culture, resources, political realities, and economic conditions of their countries. Roles and responsibilities across key sectors (health, education, social welfare), eligibility criteria and service quality standards, sustainable financing, continuous training and supervision for professionals, and accountability mechanisms based on effective data collection and management systems should be clearly defined.

### ▶ EARLY IDENTIFICATION AND SUPPORT

Introduce systematic developmental monitoring and screening of all children in primary healthcare, giving priority access to children with disabilities. Secure *multidisciplinary health services* and quality integrated health, social and educational services for children with disabilities and their families.

### ▶ ACCESS TO MAINSTREAM SERVICES

Promote equal access for young children with disabilities to mainstream services within and across health, education and social protection sectors. Ensure disability-targeted interventions to address specific barriers and to prevent placing

young children in special schools for children with disabilities.

Implement measures in line with the European Child Guarantee and revised Barcelona targets and monitor the progress of access to integrated early childhood services (health, education, social protection), as well as the participation inclusion of children with disabilities in these services.

Invest in strengthening the capacity of early childhood professionals to move towards a family-centred approach and foster holistic development of children with disabilities, and their inclusion in mainstream early childhood education services.

### ▶ DATA SYSTEMS

Develop national and cross-national statistical information systems with disaggregated data on young children by disability, gender, and age.

### ▶ INVESTMENT IN AND COORDINATION ACROSS SERVICES

Increase investments in disability-inclusive infrastructure in both universal and targeted support services and programmes for young children at risk of/with developmental delays or disabilities, and their families.

Prioritise coordination among sectors and professionals to address the specific needs of children with developmental delays or disabilities and their families. Primary caregivers need to receive emotional, material, and informational support, and be empowered to co-design services. They should be involved in all the phases of ECI system-building and should receive quality support services to prevent placing children in residential settings (i.e., separating them from their biological families).

<sup>12</sup> The key recommendations were developed based on the analysis of the most recent data, studies and policies regarding Roma young children and their families, and on consultations with all partners and civil society organisations involved in the First Years First Priority campaign active at the European and country level.

## SNAPSHOT OF EU POLICIES TARGETING CHILDREN WITH DISABILITIES

Both the European Union (EU) and its Member States have signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD),<sup>13</sup> and use its definition of disability as a common reference at the EU level. The definition states that “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (Article 1). Article 7 of the UNCRPD mandates that States “shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children,” and adds “in all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.”

The UN Convention on the Rights of the Child (UNCRC) – which all EU Member States are signatories of – prohibits discrimination of any kind on the basis of disability or other status and recognises the rights of all disabled children to special care and support, and to measures that promote and enable them to live with dignity, self-reliance and to be active participants in the community.<sup>14</sup>

The EU is committed to promoting and protecting the rights of children, including those with disabilities. The EU has undertaken two major pieces of work to contribute to making this commitment a reality.

### ► The EU Strategy on the Rights of the Child<sup>15</sup>

This strategy proposes concrete actions to protect, promote, and fulfil children’s rights, giving priority to vulnerable children such as those with disabilities. The proposed actions encompass (i) strengthening EU cooperation on vaccine-preventable diseases; (ii) exchanging best practices to address children’s mental health; (iii) building up networks with families, schools, and other stakeholders and institutions involved in children’s mental health; (iv) promoting the toolkit for inclusion in early childhood education and care (ECEC); (v) continuing to implement fully, in close cooperation with the European Commission, all relevant actions recommended in the Action Plan on Integration and Inclusion 2021–2027 in the area of education and training; (vi) promoting national strategies and programmes to speed up deinstitutionalisation and the transition towards quality, family- and community-based care services; (vii) promoting the development and use of accessible information and communication technologies (ICT) and assistive technologies for children with disabilities such as speech recognition, closed captioning and others; (viii) ensuring the full implementation of the European Accessibility Act.

### ► The Strategy for the Rights of Persons with Disabilities 2021–2030<sup>16</sup>

This strategy guides the action of Member States as well as EU institutions, building on the achievements of the previous ten years and offering solutions to the challenges ahead. Through the Strategy, the Commission calls on Member States to implement good practices of deinstitutionalisation in the area of mental health and in respect to all persons with disabilities, including children, to strengthen the transition from institutional care to services providing support in the community. Moreover, inclusive education has been put high on the education agenda (European Education Area), starting with ECEC for young children with disabilities. The Commission issued the Toolkit for inclusive early childhood education and care: Providing high quality education and care to all young children,<sup>17</sup> which includes a specific chapter on children with disabilities. It remains the primary responsibility of Member States to design their national disability policies in line with their obligations to implement the UNCRPD and in line with applicable EU rules. Among persons with disabilities, women, children, older persons, homeless persons, refugees,

13 Available at: [https://www.un.org/disabilities/documents/convention/convention\\_accessible\\_pdf.pdf](https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf)

14 Articles 2 and 23 of the UN Convention on the Rights of the Child: <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>

15 Available at: [https://commission.europa.eu/strategy-and-policy/policies/justice-and-fundamental-rights/rights-child/eu-strategy-rights-child-and-european-child-guarantee\\_en#the-eu-strategy-on-the-rights-of-the-child](https://commission.europa.eu/strategy-and-policy/policies/justice-and-fundamental-rights/rights-child/eu-strategy-rights-child-and-european-child-guarantee_en#the-eu-strategy-on-the-rights-of-the-child)

16 Available at: <https://www.socialeconomy.eu.org/2020/11/18/strategy-on-the-rights-of-persons-with-disabilities-2021-2030/>

17 European Commission, Directorate-General for Education, Youth, Sport and Culture, “Toolkit for inclusive early childhood education and care – Providing high quality education and care to all young children”, Publications Office, available at: <https://data.europa.eu/doi/10.2766/399018>

migrants, Roma and other ethnic minorities should receive particular attention.

**Other European policy initiatives with recommendations to EU Member States to uphold the rights of children with special needs or disabilities, are as follows.**

► **Council Recommendation on the Revision of the Barcelona Targets on Early Childhood Education and Care<sup>18</sup>**

The Council Recommendation focuses on ECEC and encourages Member States to increase the participation of children in ECEC services. It reviews the original Barcelona targets (European Council, 2002) and recommends that: (i) at least 45% of children below the age of 3 participate in ECEC (specific targets apply to member states that have yet to reach the 2002 goals), and (ii) at least 96% of children between the age of 3 and the starting age for compulsory primary education should participate in ECEC. The Recommendation makes specific reference to taking measures to increase the participation of children with special needs or with disabilities in ECEC.

*“Half of children with disabilities are cared for only by their parents. It is therefore important to ensure that ECEC is accessible, inclusive, and combined with targeted measures that help address specific needs, including through measures tackling barriers and segregation, equipping staff with the necessary competencies or hiring dedicated staff to address individual needs and individualised curricula where needed.” (p.19)*

*“Accessibility includes the professionalisation of staff and specialists to adequately support children with disabilities or with special needs, in mainstream non-segregated facilities.” (p.19)*

► **European Child Guarantee<sup>19</sup>**

The European Child Guarantee (ECG) aims to ensure every child at risk of poverty in Europe has access to essential services such as free healthcare and ECEC, healthy nutrition, and adequate housing, especially for those who experience social exclusion due to poverty or other forms of disadvantage including disability.

*“Member States are recommended to identify children in need and within this group take into account, wherever appropriate in designing their national integrated measures, specific disadvantages experienced, in particular, by: (a) homeless children or children experiencing severe housing deprivation; (b) children with disabilities; (c) children with mental health issues; (d) children with a migrant background or minority ethnic origin, particularly Roma; (e) children in alternative, especially institutional, care; (f) children in precarious family situations.” (p.19)*

*“Member States are recommended to: adapt facilities and educational materials of early childhood education and care and of educational establishments and provide the most appropriate response to the specific needs of children with special educational needs and of children with disabilities, using inclusive teaching and learning methods; for this purpose ensure that qualified teachers and other professionals are available, such as psychologists, speech therapists, rehabilitators, social workers or teaching assistants (p.20); facilitate early detection and treatment of diseases and developmental problems, including those related to mental health, ensure access to periodic medical, including dental and ophthalmology, examinations and screening programmes; ensure timely curative and rehabilitative follow-up, including access to medicines, treatments and supports, and access to vaccination programmes; (b) provide targeted rehabilitation and habilitation services for children with disabilities.” (p.21)*

An overview of the National Action Plans (NAPs) of ECG including intended measures for ECEC is available at the link: <https://www.eurochild.org/resource/child-guarantee-national-action-plans-at-a-glance/>. Moreover, most NAPs provide national data on children with disabilities.

18 Available at: <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=COM:2022:442:FIN>

19 Available at: [https://commission.europa.eu/strategy-and-policy/policies/justice-and-fundamental-rights/rights-child/eu-strategy-rights-child-and-european-child-guarantee\\_en#european-child-guarantee](https://commission.europa.eu/strategy-and-policy/policies/justice-and-fundamental-rights/rights-child/eu-strategy-rights-child-and-european-child-guarantee_en#european-child-guarantee)

► **Council Recommendation on High Quality Early Childhood Education and Care Systems (22 May 2019)<sup>20</sup>**

This recommendation urges Member States to provide inclusive ECEC services for all children (including children with special educational needs or disabilities and from diverse backgrounds), to avoid segregation, and incentivise their participation regardless of the labour market status of their parents or carers.

The Council Recommendation urges Members States to:

- *analyse and address the barriers that families might encounter when accessing and using early childhood education and care services, such as costs, poverty-related barriers, geographical location, inflexible opening hours, barriers related to inadequate provisions for children with special needs, cultural and linguistic barriers, discrimination as well as a lack of information. (p.8)*
- *strengthen preventive actions, early identification of difficulties and adequate provisions for children with special needs and their families, involving all relevant actors, e.g., educational, social or health services as well as parents. (p.8)*
- *equip staff with the competences to respond to the individual needs of children from different backgrounds and with special educational needs, including disabilities. (p.8)*

## NATIONAL POLICIES AND PROGRAMMES SUPPORTING THE EARLY DEVELOPMENT OF CHILDREN WITH DISABILITIES

### PORTUGAL

Portugal has had a [National System of Early Childhood Intervention \(Sistema Nacional de Intervenção Precoce - SNIPI\)](#) for more than 13 years (Decree / Law no. 281/2009). Early childhood intervention encompasses a set of measures of integrated support focusing on children and families, including preventive and rehabilitation services in health, education, and social development.

The National System is available to all children aged 0–6 with disabilities or those who have developmental delays or are at risk of developing them. The System is implemented through local intervention multidisciplinary teams and aims to give social, educational, and/or health support to children, their families, and other caregivers (e.g., ECEC professionals). Services are tailored according to the needs assessed by the families, caregivers, and professionals, in a cooperative approach. The National System has a multi-sector coordinating body at the national level (with representatives of the Ministries of Labour, Solidarity and Social Security, Health, and Education) as well as representatives at regional and local levels. It directly serves communities and families.

### SPAIN

The [Spanish Strategy on Disability 2022–2030](#) emphasises that children and young people with disabilities can enjoy culture, tourism, leisure, sport, a life outside institutionalisation, full training, preserving their identity and guaranteeing the right to early care. The [National Plan for the Healthy Well-being of Persons with Disabilities 2022–2026](#) advocates for improving the development and the autonomy of children with disabilities.

The [State Action Plan for the Implementation of the European Child Guarantee \(2022–2030\)](#) has a cross-cutting focus on early childhood care and protection. Specific challenges include providing sufficient free places in nursery schools, increasing investment in child protection and support services, addressing regional disparities in the availability and quality of educational services, and ensuring coordination between early childhood education services, and the care system, among others. One of the concrete objectives is to ensure access to early care for all children: accessible, free, and fast. The Action Plan includes the adaptation of educational centres to advance inclusive education.

<sup>20</sup> Available at: [https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32019H0605\(01\)](https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32019H0605(01))

## FRANCE

In France, the national government has made commitments in four main areas to enhance inclusive education and support services for children with disabilities.

**Financial Assistance:** The disability inclusion bonus (*bonus inclusion handicap*) has been extended to day-care centres, providing financial support for the care of children with disabilities.

Day-care centres that welcome children with disabilities receive a bonus of €500–1,300 per place per year. Additionally, parents of children under 3 years old benefit from a disability-parental compensation benefit, which is increased by 50% if the parent lives alone.

**Early Intervention Services:** Families do not have to pay anything for the services provided by PCOs (*plateformes de coordination et d'orientation opérationnelle*), saving them an average of €1,500 per year. A guide for doctors helps to improve the identification of developmental differences in children aged 0–6.

**Inclusive Education:** A guide for early childhood professionals and parents has been developed, providing recommendations for the early detection of disabilities in children. Specific forms of schooling have been established for children with Autism Spectrum Disorder (ASD). The *CAP École Inclusive* platform of the French National Education system offers access to educational resources for students with disabilities, ensuring pedagogical continuity.

**Support Services:** The ‘parenthood’ PCH (Prestation de Compensation du Handicap) enables nearly 1,000 families to receive human and technical aids for better support of their children with disabilities up to the age of 7. The ‘Act Early’ communication campaign aims to educate over 1.5 million parents about the warning signs of neurodevelopmental disorders in young children.

## GREECE

The components of an ECI system are present in the country but are not structured as an integrated ECI system. Public and private services are available for children with disabilities and their families in the areas of health, social welfare, and education. However, the lack of any framework, coordination or quality standards generates confusion about what ECI entails. Furthermore, the dominant approach is limited to a medical perspective, focusing on children’s weaknesses rather than building on their strengths and supporting the family through community resources.

To address this issue, within the framework of the Greek National Action Plan for the Rights of Persons with Disabilities and the National Strategy on Deinstitutionalisation, the Greek government requested EU support for the development of a family-centred ECI system.

The “Technical Support to Implement Reforms to Support the Development of Family-Centered Early Childhood Intervention Services in Greece”, also known as the [ECI Greece project](#), is funded by 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. Running from September 2021 until January 2024, the project assessed the state of ECI, developed a training programme and piloted family-centred ECI methodologies in selected service providers, developed awareness-raising activities and materials, and established an action plan to create a legislative and financial framework for family-centred ECI in Greece, in consultation with key stakeholders.

In parallel, until 2025, a Resilience and Recovery Fund (RRF)-funded pilot program for ECI will be developed, offering vouchers for ECI services to 1,635 children aged 0–6, along with training for the selected service providers offering ECI services.

## UKRAINE

### Early Childhood Intervention services in Ukraine before and during the war<sup>21</sup>

**SOFT Tulip**, a network organisation of Dutch NGO service providers supports the long-term growth and development of ECI in Central and Eastern European countries, especially Ukraine. Since 2006, they have worked in close collaboration with a network of Ukrainian NGO service providers to establish an ECI system. At the national level they stimulated the creation of the National Council on ECI to develop national policies, regulations, and financing mechanisms. The Council plays a coordination role in lobby and advocacy activities, taking input from NGO ECI service providers and parents' organisations in 4 pilot regions.

In the initial pilot areas, ECI concepts were implemented within 4 NGO ECI service providers, acknowledged as 'methodological centers.' ECI policy platforms were subsequently developed at various administrative levels within these regions. The government later approved an expansion into 6 additional pilot regions, leading to the incorporation of ECI concepts by various governmental and non-governmental institutions. By 2020, 38 ECI teams were in operation across 10 regions.

The onset of the war brought about drastic changes. ECI professionals who remained in Ukraine worked intensively to support families and Internally Displaced Persons (IDPs). Professionals from heavily impacted regions had to flee to safer regions, and some even to other countries. Despite their own refugee status, they continued to provide online ECI support to families both inside and outside of Ukraine, leveraging their previous experience of online work during the pandemic. They also supervised new ECI teams while dealing with the war's mental health impact.

*"I think this is an unbelievable sign of resilience!"* concludes Eric Bloemkolk, director of SOFT Tulip.



Photo © J McConnico

<sup>21</sup> Read the complete interview at: <https://www.easpd.eu/news-detail/what-does-advocacy-do-for-eci-how-do-eci-services-in-ukraine-support-families-during-the-war-eric-bloemkolk-dives-deep-into-his-eci-journey/>



## INTERNATIONAL INITIATIVES ADDRESSING THE LACK OF DATA

### UNICEF'S REGIONAL TRANSMONEE INITIATIVE FOR EUROPE AND CENTRAL ASIA<sup>22</sup>

The Transformative Monitoring for Enhanced Equity (TransMonEE) is a three-decade-old regional partnership initiative among the National Statistics Offices (NSOs) that aims to strengthen the coverage, quality, disaggregation, accessibility and use of data on children across a breadth of areas relevant to children's rights and well-being, aligned with the Convention on the Rights of the Child and the 2030 Agenda for Sustainable Development. It brings together data on key indicators across all domains and sub-domains of child rights and well-being, while embodying a partnership with 29 countries across the region to improve data comparability and statistics on the most vulnerable groups of children, such as those with disabilities, those experiencing or witnessing violence, and comparability in alternative care.

### MEASURING DISABILITY IN CHILDREN: A NEW METHODOLOGY<sup>23</sup>

To address the paucity of data on the situation of children with disabilities, UNICEF and the Washington Group on Disability Statistics have developed the Child Functioning Module (CFM) for use in censuses and surveys. The module is intended to provide a population-level estimate of the number and proportion of children with functional difficulties. The CFM is comprised of two questionnaires, one with 16 questions for children aged 2-4 and another with 24 questions for children aged 5-17. The questions are to be addressed to the mother or primary caregiver of the child in question. They are designed to identify difficulties according to severity. To better reflect the degree of functional difficulty, each area is assessed against a rating scale. The CFM is included in the UNICEF Multiple Indicator Cluster Surveys (MICS).

### MONITORING AND EVALUATION FRAMEWORK OF THE EUROPEAN CHILD GUARANTEE

The European Commission, in cooperation with the Social Protection Committee, has been developing an EU framework for monitoring and evaluating the Child Guarantee. A set of new indicators has been discussed, including an indicator on the share of children with disabilities. The framework is to be introduced by the end of 2023.

*“It is crucial for families of children with disabilities to have access to family-centred early childhood intervention services”*

<sup>22</sup> <https://www.transmonee.org/>

<sup>23</sup> Washington Group on Disability Statistics; WG/UNICEF Child Functioning Module. Available at: <https://www.washingtongroup-disability.com/question-sets/wg-unicef-child-functioning-module-cfm/>

## KEY PRIORITIES FOR THE INCLUSION AND DEVELOPMENT OF YOUNG CHILDREN WITH DISABILITIES

### Early Childhood Intervention (ECI) policies and services

There is an urgent need to set up a coherent legislative framework that includes the development of a *national system for family-centred early childhood intervention*, including high quality and financial standards, personnel standards, a mechanism for cross-sectoral coordination, and monitoring and evaluation procedures. ECI services cover the period between the prenatal diagnosis and the moment that the child reaches the age at which school is compulsory. It includes the entire process, from the earliest possible identification and detection of a developmental problem, up to the moment of sustained assistance.

Three parallel lines of work are crucial to ECI: creating family-centred practices; building networks of experts and policymakers; and formulating national regulations for quality integrated ECI services.

### A child- and family-centred model of early intervention

*Quality social inclusion of the family and the child* are key elements of an early childhood intervention systemic approach. Responding to the specific needs of each family and child while ensuring their easy access to services, in their proximity, is essential.

### Early childhood education and care

*ECEC services* need to become more available, accessible, affordable, and inclusive. Quality can be ensured through enhanced qualifications of teachers, individualised development plans for the children with disabilities who require learning support, and accessible infrastructure, among other things.

### Social protection

Children with disabilities who are separated from their families at an early age should be provided with quality *family-based alternative care*.

### Primary healthcare

*Regular monitoring of child development and screening* can help identify and support children with developmental delays and disabilities at an early stage. *Early identification* can be organised in different ways, with routine primary healthcare services playing a unique and irreplaceable role. Healthcare professionals should have knowledge of Early Childhood Development (ECD), developmental difficulties, and the skills to build quality relationships with the family.

## Data systems

Major efforts are needed to further *improve data at both national and cross-national levels*. There is not yet a single Eurostat database, domain, or web portal dedicated specifically to statistics on children.<sup>24</sup> Age-disaggregated demographic statistics and projections disseminated by Eurostat are important for many areas of EU child-related policy.



<sup>24</sup> United Nations; Economic Commission for Europe, Conference of European Statisticians. (2022). "Guidance on statistics on children: Spotlight on children exposed to violence, in alternative care, and with a disability" (Prepared by the Task Force on statistics on children, adolescents and youth). Available at: <https://unece.org/statistics/documents/2022/05/working-documents/guidance-statistics-children-spotlight-children>



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## THE CAMPAIGN

The **First Years First Priority** Campaign focuses on prioritising children from birth to six years, with special attention to the first 1,000 days, and is rooted in an understanding that, from the first day they are born, all children are rights holders – despite their dependency status. The Campaign advocates for more political visibility and resource allocation to early childhood, focusing especially on the most vulnerable children – such as Roma and Traveller children, children with disabilities, migrant and refugee children, children in or at risk of entering alternative care, and those living in extreme poverty. With these aims in mind, the campaign works to ensure that early childhood development (ECD) remains high on the political agenda, by building a strong community of advocates at the EU and national level.

## NATIONAL COORDINATORS OF THE CAMPAIGN:

- Bulgaria – [For Our Children Foundation and Trust for Social Achievement](#)
- Finland – [Central Union for Child Welfare](#)
- France – [Ensemble pour l'Éducation de la Petite Enfance](#)
- Hungary – [Family, Child, Youth Association](#)
- Ireland – [Child Rights Alliance](#)
- Italy – [Centro per la Salute del Bambino \(Centre for Child Health and Development\)](#)
- Portugal – [Fundação Nossa Senhora do Bom Sucesso](#)
- Romania – [Step by Step Center for Education and Professional Development](#)
- Serbia – [Pomoc Deci](#)
- Slovakia – [Open Society Foundation Slovakia](#)
- Spain – [Plataforma de Infancia](#)



## STAY UP TO DATE

[Subscribe to the newsletter](#) to stay updated about the campaign

## THE PARTNERSHIP

First Years First Priority is a joint initiative of **Eurochild** and the **International Step by Step Association** (ISSA). We are the leading European networks representing the children's rights and the early childhood sectors. Our partnership pools our respective strengths to campaign for the prioritisation of early childhood development in public policies across Europe. The [European Public Health Alliance](#) and [Roma Education Fund](#) are associate partners.

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