About the case studies: To document UNICEF’s work on disability and inclusion in the Europe and Central Asia region, we have developed a set of case studies that can be read together or stand alone. UNICEF takes a comprehensive approach to inclusion, working to ensure that all children have access to vital services and opportunities. When UNICEF speaks about “inclusion” this encompasses children with and without disabilities, marginalized and vulnerable children, and children from minority and hard-to-reach groups. The case studies have a specific focus on children with disabilities and their families. However, many of the highlighted initiatives are designed for broad inclusion and benefit all children.

Contemporary ECI services: Support for children when they need it most

In Europe and Central Asia, young children with or at risk of developmental delays or disabilities constitute one of the most vulnerable and stigmatized groups. A recent UNICEF report estimated that 10.8 million of the region’s children are living with disabilities. Over 3 million of them belong to the youngest age group that would benefit from services for early childhood intervention (ECI). Longitudinal studies and research from the 1970s and 1980s have formed the foundation for understanding the core concepts that characterize contemporary ECI services.

“To ensure a good start in life, especially for new-borns, babies and young children with developmental disabilities, families should be recognized as key actors who provide the essential conditions for nurturing and stimulating care, good health and timely interventions that facilitate their child’s inclusion and protection. Families are the constant factor in their children’s lives, and thus require systematic guidance and family support services to enable them to promote and accompany the child’s development, especially during the early years.”

Garren Lumpkin and Chantal Pallais, ‘Essential Component Framework for Child Care and Family Support’, UNICEF Latin America and Caribbean Regional Office, 2018
quality and effective contemporary ECI services, including the following elements:

- **ECI is a social model** that integrates elements related to education, health, therapies, nutrition, social protection, child and parental rights and welfare, and requires coordinated support from these major social sectors.

- **ECI is strengths-based**, focusing on the comprehensive and holistic development of the child and the family. It does not seek to “cure the child” but helps children with differing abilities fulfil their potential.

- **ECI is family-centred and child-focused.** Parents are key actors, deciding on the goals for their child, participating in the development of individualized plans and delivering ECI services in home settings, supported and coached by professionals in responding to their child’s and their own needs.

- **ECI is individualized** and focuses on the strengths, needs and challenges of each individual child within the family context.

- **ECI is continuous and aims to ensure the child’s transition into inclusive education**, starting from the earliest detection and providing support until he or she attains typical levels of development and/or can be supported to participate in inclusive, mainstream education settings.

- **ECI is interdisciplinary, integrated and team-based**, bringing together professionals from all relevant disciplines and sectors to provide one united service to families and their children, with a focus on supporting, mentoring and coaching parents and family members as the best way to serve the child.

The right to this type of support is established in the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities. The science and evidence from practice strongly support the effectiveness of early intervention because these services capitalize on the child’s brain plasticity in the early years, mitigate the consequences of delays and disabilities, and prevent the higher costs of later remediation and rehabilitation.

ECI services provide support for families with children from birth up to age of 6 who are at risk of or have developmental delays, disabilities and/or behavioural or mental health needs. To ensure that children attain their full developmental potential, those requiring support should be identified as early as possible, ideally through neonatal screening or later through developmental screening, monitoring and medical diagnosis. As a follow-up, ECI services should be based on family leadership, participation and needs in planning of services and provision of all or most of the services in the natural environment of the child as part of daily family routines.

“[Research] shows that proper prevention and intervention strategies during early childhood have the potential to impact positively on young children’s current well-being and future prospects. Implementing child rights in early childhood is thus an effective way to help prevent personal, social and educational difficulties during middle childhood and adolescence."

Committee on the Rights of the Child, General Comment No. 7 (2005) Implementing child rights in early childhood, CRC/C/GC/7 United Nations, Geneva, 1 November 2005, para. 8

In reality, many children with developmental difficulties in Europe and Central Asia are not identified until they enter school, when families often become more aware of concerns regarding their child’s development. In addition, there is a lack of quality ECI services in the region for children in need and their families while countries are making efforts to build new ECI systems and transition from the legacy of the past models.

In most cases, the old models of support for children with developmental delays and disabilities was provided through ‘defectology’ centres, or rehabilitation hospitals and centres in which children are served individually and intensively with a focus on their disabilities, usually without the presence or the participation of the parents, based on medical protocols and mainly delivered by medical staff. Despite their shortcomings, these programmes represent a starting point for change, and their personnel are increasingly interested in receiving training on contemporary ECI concepts and methods.

The transition to the model that focuses on each child’s abilities requires building new ECI systems – with coherent, multisectoral child- and family-centred elements throughout the system – and UNICEF supports countries in this effort through a series of systematic interventions. This case study describes the challenges and solutions for ECI systems that are being established, expanded or strengthened in Europe and Central Asia and highlights the example of ongoing developments in Croatia and Serbia.
What is unique about UNICEF’s approach?

UNICEF is a key partner working to promote ECI services globally and support a new approach in existing services to ensure that they are grounded in the social model of disability. UNICEF’s evidence-based approach to early childhood intervention aims to help build national systems to ensure that all families with young children who are at risk or have developmental delays or disabilities can access the same quality and types of resources and support in all regions of the country.

ECI systems need to be supported by coherent policies, strategic plans and/or legislation, including the development of guidelines and procedures, service and personnel standards, and performance standards.

The end goal is to deliver the specific services needed by each child and family to maximize their child’s physical, language, cognitive and social-emotional development, while respecting the diverse contexts of families and communities. This is fostered through the development and maintenance of a country-wide organizational structure for programme coordination, planning and accountability. In addition, UNICEF recognizes that ECI programmes can be developed in phases, including pilot projects, until they achieve nationwide coverage of good-quality services that are equitable, accountable and sustainable.⁴

Building contemporary and sustainable ECI systems: From situation analysis to enabling legislation and pilot models, and on to professional capacity development

Situation analysis as a starting point: The status of ECI services differs from country to country, and services are provided by a range of ministries, municipalities, NGOs and organizations of people with disabilities. When designing the ECI system, it is important for decision makers to have a good understanding of the current status of ECI provisioning in each country – and situation analysis is the first crucial step towards achieving this.

Croatia conducted a situation analysis, in 2019, to identify strengths and weaknesses of existing ECI services, and map the resources at all levels and regions of the country, including professional and institutional capacities, training and financing. Along with providing a baseline of data and knowledge, the situation analysis aimed to establish a policy analysis regarding early childhood intervention.

UNICEF estimates that among the Croatia’s 230,188 children aged 0–5, a minimum of 24,169 (10.5%) have developmental delays or disabilities and are potentially eligible for ECI services. As of 2019, however, the country had just 47 ECI programmes, serving approximately 2,900 children, and only 1 in 8 children who could potentially benefit from early childhood intervention were participating in these services.⁵

Going forward, the situation analysis is being used to support the phased development, improvement and expansion of the national ECI system – aiming to meet the prevailing needs of families with children in at-risk situations, including children who have developmental delays, disabilities, and behavioural or mental health needs.
Serbia has conducted a series of studies to identify the conditions for developing a phased process towards building a national ECI system.

A situation analysis conducted in 2017 found that policies and services, which require multiple sectors to respond to the complex needs of young children with developmental difficulties and their families, were not integrated and coordinated. It also revealed that ECI services were scarce and that professionals lacked the capacity to provide these services based on new evidence and innovative approaches that place families at the centre of interventions. The medical approach aiming to correct ‘defects’ and ‘cure’ the child based on medical protocols or treatment/rehabilitation prevailed. The wider environment was characterized by persisting prejudice, stigma and discrimination, child abandonment and institutionalization due to disability.

A further in-depth analysis of practices in support services for young children and their families, also conducted in 2017, established a baseline in two pilot locations, identified strengths and challenges, and was used to guide development of the ECI road map for models that are feasible in Serbia.

According to research by the Paediatric Association of Serbia and the Institute of Psychology, with support from the Open Society Foundations, 60,000 of Serbia’s children aged 0–5 (12%–18%) had developmental delays or disabilities as of 2019. Among the children in this age group with developmental delays, 8%–13% required continuous monitoring and an additional 4%–5% required more intensive support.

Establishing the legal basis and piloting new models for ECI provision: Reforms in policy and legislation are key to creating an enabling environment for new models, as demonstrated in Croatia’s and Serbia’s initiatives in building sustainable ECI systems.

Croatia has been working to develop an interdisciplinary approach to ECI services, in recognition of the need for a comprehensive solution to closing the gaps in access to services. The Government of the Republic of Croatia established the Commission for Early Childhood Intervention and the Executive Working Group for drafting the National Strategic Plan for ECI for a period of five years. The Commission coordinates multiple partners and stakeholders in drafting the plan and strategies and will monitor implementation. The ECI Strategic Plan will be the basis for developing professional guidelines, standards and procedures for early intervention programmes.

Croatia is also using the unique opportunity of being a pilot country for the European Child Guarantee to model a package of ECI services that will inform the national ECI Strategic Plan. The models being piloted aim to:

- Provide evidence and lessons learned for the qualitative improvement of ECI programmes;
- Offer guidance on defining ECI eligibility criteria and protocols, with clear roles in delivering ECI services in an integrated and coordinated manner;
- Set up outreach mechanisms and community-based services in excluded communities; and
- Replicate the new models to support further ECI service expansion.
The development of a phased ECI Investment Plan should ensure equal access to services and increase in allocation of resources across the regions of Croatia.

Serbia has made significant achievements in positioning early childhood intervention higher on the national agenda during the past five years. In 2016, the National Programme for Early Childhood Development (ECD) was adopted – recognizing the need to strengthen the health system’s inclusiveness and the significance of cooperation with other sectors in supporting children with developmental risks, delays and disabilities and their families. In 2018, the Ministries of Health, Education and Social Affairs and the President of the National Child Rights Council signed a Call for Action for Early Childhood Development, in which high-quality and accessible early childhood intervention services are recognized as a priority.

To demonstrate the importance of the family-centred ECI model, a pilot was jointly conceptualized and introduced in 2018 by UNICEF Serbia, the Open Society Foundations’ Early Childhood Programme and the Open Society Foundation Serbia in partnership with the Belgrade Psychological Centre, and national and local representatives from health, education and social welfare institutions. The model aims to demonstrate how the provision of quality, contemporary and evidence-based ECI services can be institutionalized, further embedding best practices into policy and legislation. It also focuses on empowering parents and other caregivers to mitigate risk factors and support early childhood development.

A national-level intersectoral advisory board was established with the participation of Serbia’s key ministries and technical experts to:

- Accompany the piloting of the model;
- Monitor and assess its impact;
- Identify what legal changes are needed to sustain it; and
- Ensure coordination among three key sectors (health, education and social welfare).

Similar advisory bodies were established in each pilot location and were a crucial element of success.

Based on the experience in implementing the new ECI model, the Ministry of Health established an intersectoral working group in 2021 to propose legislative changes and to support the establishment of a network of quality ECI services, as defined in the National Programme for ECD. Furthermore, the Government passed a decision to establish a National Centre for ECD and Inclusion by 2024, to serve as a hub for supporting the network of both available and new early childhood intervention services and professionals across Serbia and other countries in the Western Balkan region.

**Strengthening ECI professional capacities:** As underscored below, both Serbia and Croatia are making professional development a priority, and with UNICEF support, are finding new ways to promote capacity-building.

In Serbia, the implementation of family-centred ECI services required a complete change of the paradigm in service provision and, therefore, building professional capacities to lead the process. UNICEF and partners developed a capacity-building package relying on expertise from Eurylaed (the European Association on Early Childhood Intervention) and ECI professionals from the United States and Portugal. With support from UNICEF, national capacities for training and supervision were also enhanced by pairing relevant university special education professors with international experts. Professionals from the local ECI teams coming from health, education and social welfare sectors benefited from training and ongoing mentoring on all key components of the ECI model. The capacity-building included instruction on:

- Using the Ages & Stages Questionnaire (ASQ-3) to improve screening practices, routine-based interviews and functional assessment;
- Setting up functional goals and developing an individual family support plan;
- Introducing intervention strategies, home visit protocols and goals for monitoring; and
- Teamwork and partnering with parents.

This process was coupled with ongoing support for cross-sectoral, integrated management of professionals and institutional capacities in the participating health, early childhood education and social welfare institutions. Piloting in five locations engaged 80 professionals, including 29 ECI practitioners who provided services to nearly a thousand children and their families. A comprehensive training package is currently under development and will include resources to support online working modes. With a strong interest from Serbia’s Ministry of Health to replicate this model throughout the country, further capacity-building has been provided to new districts, engaging another 200 professionals.
Developmental risks (biological and environmental) and their families. Ultimately, the objective is to empower early childhood professionals in Međimurje County and nationally to introduce contemporary and integrated early intervention services for all children in need, no matter their location, social status, gender or nationality. The online training consists of seven interactive self-paced modules on ECI principles, service delivery components, coordination and integration of services and resources, advancing early childhood development, the role of the family in early intervention, teamwork, and the transition process.

The long-term aim is to integrate this resource as an in-service mandatory training for all practitioners in Croatia who are engaged in early intervention services or who work with young children and their families – including paediatricians, general practitioners, patronage nurses, speech-language pathologists, educational rehabilitators, psychologists, social workers and occupational therapists.

Delivering ECI services: From early identification to community outreach and support for families

As shown in the graphic below, the delivery of contemporary ECI services follows a basic sequence of steps:

LearnECD: The UNICEF Europe and Central Asia Regional Office is working with partners to support sustainable capacity development for professionals through the establishment of a learning platform designed to host multi-language professional training resources for continuous professional development in the ECI sphere, as well as broader early childhood development information and services. The LearnECD Platform (available at https://learnecd.unicef.org) allows countries to access, adapt and use world-class training resources free of charge.

In Croatia, UNICEF research on available services revealed that ECI providers and representatives of leading funding institutions used different definitions of ‘early childhood intervention’. Approximately half of the country’s ECI programmes continue to provide mainly traditional rehabilitation services. Although contemporary elements are increasingly being used, especially in ECI programmes implemented by NGOs, they are still not prevalent.

In collaboration with Croatian experts, the Croatian Association on Early Childhood Intervention has developed online training on Fundamentals of Early Childhood Intervention to generate a joint vision that transcends a single profession, institution or sector. The goal is to offer optimum services in response to the complex needs of children with disabilities or developmental risks (biological and environmental) and their families.

Case study: Family-centred services for early childhood intervention: Highlighting initiatives in Croatia and Serbia
The process starts with early identification, followed by in-depth developmental assessment, determination of eligibility, and provision of family-centred support in the child’s natural environment with activities integrated into her or his daily routines. **Establishment of the national ECI system is the key prerequisite for ensuring delivery of this continuum of support to all children and families in need.** An effective system includes:

- A well-developed legal foundation;
- Effective management and coordination mechanisms;
- Well-coordinated services, including planning, budgeting, supervision, normative programme guidelines and procedures;
- Ongoing capacity-building for professionals; and
- Advocacy and outreach services that are led from the central level.

**Strengthening early identification practices:** Identifying children who have or are at risk of having developmental and behavioural delays is an essential first step to providing effective and equitable ECI services. Promoting the use of standardized assessment tools at an early age is a crucial element of the system-building work in both Serbia and Croatia.

In **Serbia**, the situation analysis found that the majority of developmental delays are recognized too late, partly because paediatricians do not use standardized tools to monitor and assess child development. Challenges to timely detection were also found to arise from delays or inconsistent use of screening tools. Without accurate and effective developmental screening, up to 60% of children with developmental delays and up to 80% of toddlers with social and emotional difficulties are at risk of not being identified.9

With support from UNICEF, 90 paediatricians in Serbia have started to use ASQ-3 to identify developmental delays. The Ages & Stages Questionnaire has been validated, standardized and translated for Serbia through research guided by the publisher (Paul H. Brookes Publishing Co.), with a sample of 1,380 children. Some counselling services also use the ‘Guide for Monitoring Child Development’ to provide parents with recommendations and identify difficulties children may be facing, including depression. These two tools have been found to be very effective for identifying children who need extra care and for facilitating their participation in vital ECI services.10

In **Croatia**, UNICEF research indicates that more than half of the children served in ECI programmes are 3–6 years old. Health-care providers – including paediatricians, general practitioners and patronage nurses – have a critical role in identifying children who would benefit from early childhood intervention. However, standardized screening instruments are currently not used across Croatia’s health and social care systems, which makes it difficult to systematically identify children at risk of developmental delay.

Within the European Union-funded project Phase III: Testing the Child Guarantee in Međimurje County, UNICEF and the Croatian Academy for Developmental Habilitation partnered to develop an online learning platform to improve the skills and knowledge among health-care professionals for early detection of developmental difficulties and support for young children. The platform offers a resource package of six interactive self-paced modules, accompanied by online mentoring, and will be available to facilitate in-service training for health-care practitioners across Croatia. In addition, ASQ-3 is being applied within the Child Guarantee pilot, and data have been collected to inform advocacy for introducing the questionnaire nationally.

**Croatia’s community outreach initiative to address children’s complex vulnerabilities due to disability and poverty:** Researchers have explored the effectiveness of early intervention for vulnerable
children and have highlighted that children with disabilities are often ‘doubly vulnerable’ given their disability status and their exposure to environmental stressors related to poverty. Access to and participation in ECI services are affected by income – the families most likely to underutilize ECI services are those from low-income households. In addition, the effects of childhood adversity, such as experience of abuse or neglect, poverty, prenatal exposure to alcohol and drugs, having a parent with a mental health condition, or maternal age below 18 years, can significantly influence child health and overall development.

According to UNICEF research, 2.5 families out of 10 who receive ECI services in Croatia live in poverty. Only a few ECI programmes serve remote rural areas, island populations and Roma communities – and 8.5 out of 10 families said ECI services are located too far from their homes. The research revealed that community outreach is urgently needed, along with universal developmental screening and rapid referrals to ECI services, especially for the excluded and children at risk.

The early intervention system can have positive effects for vulnerable families if ECI services are designed to mitigate the stressors. Strengthening community outreach for ECI is one of the elements of the model being piloted as part of the European Child Guarantee initiative in Croatia. With a focus on low-income and hard-to-reach communities, UNICEF’s partner Médecins du Monde (Doctors of the World) identifies children in communities by going house to house, engaging with families, and using the Ages & Stages Questionnaire to provide initial screening for children.

Identified children are referred to the Međimurje Association for Early Childhood Intervention (MURID), where they are provided with ECI services such as:

- Comprehensive child and family assessments;
- Individualized family and child plans that encompass options for home-, community- and centre-based services; and
- Support in the child’s transition to early childhood education and care.

Médecins du Monde then continues to provide support to families in the community and implements programmes with children who have mild developmental delays on the recommendations of MURID.

The two-year pilot (2021–2022) expects to reach 270 children aged 0–7 who have or are at risk for developmental delays or disabilities and 400 parents and other caregivers directly, along with an additional 500 children and 600 parents/caregivers as indirect beneficiaries. The results from this piloted outreach and community-based model of ECI services will inform the development of an ECI Action Plan for Međimurje County and the national strategy for building an ECI system through a cross-sectoral committee under the auspices of Croatia’s Ministry of Health.

**Supporting parents and working with families:**
ECI providers need to be supported to work closely with families in the home setting, taking an approach that is tailored to the unique family needs and contexts. This section summarizes examples of such work in Serbia and Croatia.

**Introducing assistive technologies in ECI provision:** UNICEF Europe and Central Asia has been working with five countries across the region, including Serbia and Croatia, to develop customized affordable assistive technology for augmentative and alternative communication (AAC) with a focus on reaching young children with complex communication needs.

With UNICEF support, the AAC technology solution Cboard was customized and a range of professionals working with children – including ECI professionals, speech and language experts, and teachers – participated in training to provide interdisciplinary support to children with complex communication needs and their families through the new technology. The programme aims to ensure that children who need this technology can access it as early as possible to help them develop communication and enable them to participate in family, school and community life.

In Serbia, the first phase of the ECI pilot focused on replacing the traditional, medically oriented practices with the family-centred model that engages parents as equal partners in planning and delivering early...
childhood interventions. This phase also accentuated interventions provided in the natural, home environment as the best setting for a child to learn, develop and grow, supported by parents who are empowered to use everyday routines for stimulating the development of functional skills.

To address the inefficient practice in which parents were going from one professional to another without receiving dedicated and complementary guidance and support, the integrated model for teamwork was introduced. This model includes one primary service provider who works with the family and is supported by an interdisciplinary team of professionals. Initially, it was difficult for professionals to go beyond their narrow professional roles to rely on and learn from other practitioners’ expertise, but it soon became an enriching experience for all practitioners and very empowering for parents.

Teamwork and a cross-sectoral partnership were reinforced to achieve the best results, and an ongoing capacity-development programme was offered to selected professionals from the five pilot locations in Serbia, with new pilot locations gradually added to the two original sites.

Partnership between parents and professionals proved to be one of the most significant gains from Serbia’s new ECI model. The participants emphasized that the model engages parents more than in the traditional medical model, so parents are able to support their child’s development more successfully. Parents reported that they:

- Highly valued the availability of the ECI teams;
- Found the programme to be effective in providing information regarding their rights and support when they have questions or concerns; and
- Felt more competent and empowered to support their child’s development.11

In Croatia – in addition to the family-centred, child-focused approach to assessments, home visits and the development of individual family support plans – a set of parenting workshops ‘Growing Up Together’ was offered to parents raising children in difficult and resource-constrained circumstances and additionally adapted for families of children with disabilities or developmental delays, as well as for Roma national minority families who have unique challenges. The workshops consist of three parts: a session for parents, one for children, and one for parents to play together with their children. Overall, the programme significantly improved outcomes for participating families, enabling parents to gain a better understanding of their child’s strengths, abilities and needs. The experience also helped increase families’ access to desired services, programmes and activities in their community.12

Concluding reflections

Partnerships and the active involvement of many stakeholders – from children and their families to the professionals who support them, as well as national through local-level government, civil society organizations, intergovernmental organizations such as the European Union, and multiple United Nations agencies – are vital to the advancement of effective and sustainable programmes for early childhood intervention.

During the phased roll-out of ECI services, it is fundamental that they embrace the following key activities:

- Systematic monitoring of child development as a part of routine health-care services;
- Outreach, screening and referral;
- Early and comprehensive assessment;
- Individualized planning;
- Service delivery;
- Transition planning to support entry into inclusive education; and
- Continuous monitoring and evaluation of the interventions.

Links for further reading

- AAC case study from this package “A voice for every child for open-source solutions and resources”
Continuous assessment and analysis of programme results will ensure that there is a knowledge base for gradually expanding the number of contemporary ECI services that are delivered. In addition, efforts to improve the collection of accurate data on children with disabilities and developmental delays will provide crucial support for reaching the children most in need, early in life when they most need ECI services.

By thoughtfully applying these measures and maintaining a central focus on the needs of children and their families, successful interventions can be used as models to build sustainable, up-to-date ECI systems that ensure more children are supported to fulfill their developmental potential and meaningfully participate in their communities, education and society.

Endnotes


10 Ibid.


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