

TOOLKIT FOR PARENTS PROFESSIONALS AND DECISION-MAKERS

"Early identification and intervention for children with disabilities lays the strongest foundation in the possibility of a child with disability to survive and thrive"

*Yetneberesh Nigussie Molla
Right Livelihood Award 2017*



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TOOLKIT FOR PARENTS, PROFESSIONALS, AND DECISION-MAKERS – SUPPORT FROM THE VERY BEGINNING



“
Every child deserves timely support
and opportunities for growth,
learning, and the development of
their full potential
”

This toolkit was developed within the framework of the Global Campus Alumni 2024-25 Projects scheme, in partnership with Right Livelihood. Focused on Bosnia and Herzegovina and Serbia, the project “*Right from the Start: Early Intervention and Educational Rights for Children*”—of which this toolkit is the main output—addresses the urgent need for stronger systems of early identification and support for children with developmental delays and disabilities. While grounded in the specific experiences of these two countries, the toolkit draws on international best practices and was peer-reviewed by Yetnebersh Nigussie Molla, globally respected disability rights advocate and 2017 Right Livelihood Laureate. Her contribution ensures that the toolkit reflects inclusive, rights-based approaches that are relevant and adaptable across diverse global contexts.

This toolkit is intended for parents, professionals, and policymakers to help improve the system of support for children with developmental delays. Through collaboration and understanding, we can build a more inclusive society from the earliest years.

OUR GOAL

To ensure every child receives timely, appropriate, and high-quality support from the earliest stages of life

Why is this Toolkit Important?

Parents often face a lack of accessible information about available services

Professionals may work in resource-limited environments, and systemic solutions for early intervention and inclusion are still evolving



This **TOOLKIT** offers practical information on:

- Recognizing signs of developmental delay
- Steps to take after initial concerns
- Support institutions and services
- Practical strategies parents can use at home
- Strengthening early intervention systems, including clear referral pathways to ensure timely and appropriate support

Toolkit Title: *Toolkit for Parents, Professionals, and Decision-Makers – Support from the Very Beginning*

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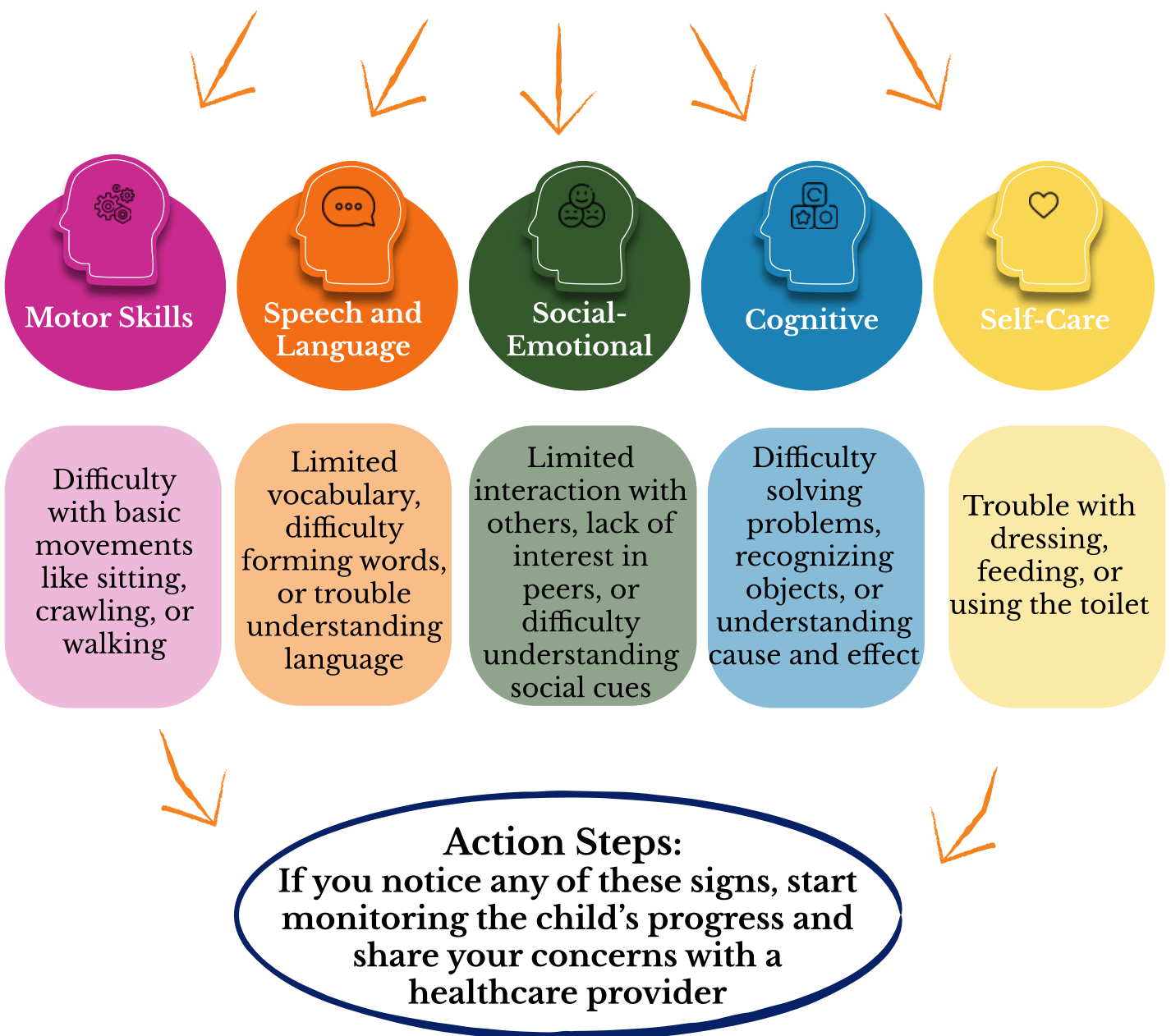
List of Acronyms

AAP	American Academy of Paediatrics
ASD	Autism Spectrum Disorder
ASQ-3	Ages and Stages Questionnaire, 3rd Edition
CRPD	Convention on the Rights of Persons with Disabilities
EDUS	Education for All - Sarajevo
GMCD	Guide for Monitoring Child Development
IEP	Individualised Education Plan
M-CHAT	Modified Checklist for Autism in Toddlers
NGO	Non-Governmental Organization
PEDS	Parents' Evaluation of Developmental Status
UNICEF	United Nations International Children's Emergency Fund

1. Recognising Signs of Developmental Delay

Early identification of developmental delays is critical for timely intervention

Look for the following signs



2. Steps to Take After Initial Concerns



Early action helps identify the cause and secure necessary interventions

Follow these steps



Observe and Document

Track the child's behavior and progress. Keep a record of any developmental concerns

Consult with a Pediatrician

Share your observations and seek professional evaluation

Screenings and Assessments

Your doctor may recommend developmental screenings or specialized tests

Engage Early Intervention Services

If a delay is suspected, connect with early intervention programs offering speech or physical therapy

Referral to Specialists

Depending on the needs, a paediatrician can assess general health, conduct developmental screenings, and refer the child to other specialists if needed

3. Support Institutions and Services

Many organizations provide support for children with developmental delays

Early Intervention Programs: Local programs providing therapies (e.g., speech therapy, physical therapy, special education).
– EDUS – Education for All - Sarajevo

Education: Schools: support learners with developmental delays through inclusive practices, ensuring access to quality education alongside their peers. This includes tailored learning strategies, individual education plans (IEPs), assistive technologies, classroom accommodations, and collaboration with specialists such as speech therapists or educational psychologists—all within mainstream educational settings, in line with the principles of the CRPD.

Healthcare Providers: Pediatricians, neurologists, psychologists, and therapists who can offer diagnosis and treatment.

Community-Based Programs: Non-profits or local government programs offering childcare, therapy, and educational services.
- Association for the Support of Children with Autism "Step by Step" Belgrade

Support Groups: Parent groups and networks providing emotional support and advice.

Action Steps:

Research and ask healthcare providers for guidance on services available in your community.

4. Practical Strategies Families Can Use at Home

Families play a key role in supporting a child's development. Parents, grandparents, siblings, and other caregivers can all contribute by creating a nurturing and supportive environment. The following strategies can be incorporated into everyday routines to encourage progress in communication, behavior, and learning

HELPFUL STRATEGIES:

Establish a Consistent Routine:

Predictable daily routines help children feel secure and understand what to expect

Encourage Communication:

Use clear, simple language, gestures, pictures, or visual aids to support understanding and expression

Create Sensory-Friendly Activities:

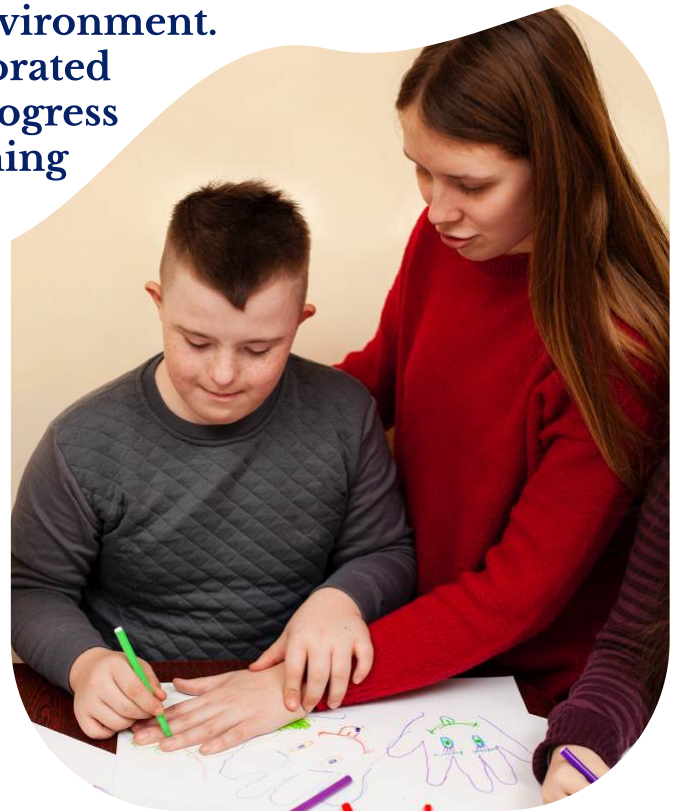
Activities like playdough, water play, music, or movement games can help engage and regulate children

Adapt the Environment:

Make spaces at home safe, calm, and responsive to the child's sensory or physical needs (e.g., quiet corners, soft lighting, or organizing materials).

Action Steps:

Regularly practice these strategies in daily routines and create a nurturing environment that encourages growth.



Model Desired Behaviors:

Show how to take turns, express emotions, or complete tasks—children often learn by watching

Inclusive Family Approach:

In many households, caregiving is shared among extended family members. Involving grandparents or other close relatives in daily developmental activities ensures consistency and strengthens the child's support network.

Use Visual Schedules and Prompts:

Breaking tasks into steps with pictures or symbols supports understanding and independence

5. Strengthening Early Intervention Systems

Timely and effective early intervention depends on strong collaboration between families, professionals, and support systems. Strengthening these systems ensures that children with developmental delays are identified early and receive appropriate, coordinated support

KEY ACTION:

Raise Community Awareness: Promote understanding of developmental milestones, the importance of early screening, and available support services.

Train Frontline Providers: Equip healthcare workers, educators, and community professionals to recognize early signs of developmental delays and take appropriate next steps.

Establish Clear Referral Pathways: Develop streamlined, well-communicated referral mechanisms so that children are promptly connected to evaluation and intervention services once concerns are raised.

Promote Multi-Disciplinary Collaboration: Bring together pediatricians, therapists, educators, and social workers to create coordinated, individualized support plans.

Ensure Equitable Access: Remove barriers—such as cost, distance, or lack of information—that prevent families from accessing services.

Monitor Progress and Adjust Services: Implement systems to track children's development over time and adapt support as needed.

Support and Educate Families: Provide parents and caregivers with accessible information, guidance, and tools to support their child's development at home and advocate for their needs.

Action Steps:

Advocate for robust early intervention systems that include clear referral pathways, cross-sector collaboration, and inclusive, accessible services. Early, coordinated action can significantly improve outcomes for children and families.

Prevalence and Diagnosis of Developmental Delays in Serbia and Bosnia and Herzegovina

Serbia

Prevalence of Developmental Delays: According to estimates by UNICEF and the Serbian Ministry of Health, approximately 60,000 children under the age of six in Serbia require early intervention services. Early detection and intervention can lead to significant improvements, with studies indicating that up to 70% of developmental difficulties can be overcome before school entry if addressed promptly.

Disability Statistics: Data from the Statistical Office of the Republic of Serbia (2023) indicates that 5.46% of the population aged two and over are persons with disabilities. Among these individuals, 12.8% experience communication-related difficulties, highlighting the need for targeted support in this area.

Early Identification Practices: A study utilizing the Parents' Evaluation of Developmental Status (PEDS) test found that 27.7% of children aged 3–7 years in Serbia required referral for detailed diagnostic procedures, and 1.7% needed inclusion in treatment or special education support.

Screening Tools Implementation: To enhance early detection, Serbia has implemented standardized screening tools such as the Ages and Stages Questionnaire (ASQ-3) and the Guide for Monitoring Child Development (GMCD). These tools are used by pediatricians and counseling services to identify developmental delays and provide appropriate recommendations to parents.

Bosnia and Herzegovina



A 2021 preliminary study by Pistoljevic et al. examined diagnostic practices and barriers to identifying autism spectrum disorder (ASD) in Bosnia and Herzegovina. The study focused on a sample of 126 children aged 23 to 94 months who were referred to treatment centers due to developmental concerns. Although parents first noticed signs of developmental delay around 17 months of age, the average time to receive any formal diagnosis was 16.8 months later, indicating a significant delay between initial concern and professional recognition. During this time, families visited more than six professionals per child, suggesting inefficiencies and fragmentation within the diagnostic pathway.

At the point of initial assessment, only 8 children (6.3%) were diagnosed with autism. However, when 110 of these children were re-assessed using more standardized and comprehensive tools, 90 children (71%) were identified as having autism spectrum disorder. This dramatic increase underscores two critical issues: underdiagnosis and lack of standardized diagnostic procedures in the country's healthcare and early intervention systems.

Bosnia and Herzegovina



The findings point to systemic barriers such as:

- Inadequate training of frontline professionals in recognizing early signs of autism
- Lack of standardized screening and diagnostic tools
- Fragmented referral pathways and inconsistent follow-up
- Limited access to multidisciplinary teams for comprehensive evaluation

These issues contribute to missed opportunities for early intervention, which is crucial for improving developmental outcomes. The study highlights an urgent need to strengthen early detection systems, develop coordinated referral pathways, and train professionals to improve the timely and accurate diagnosis of autism in Bosnia and Herzegovina.

Guidance for Parents

How can I help my child at home?

What services or programs are available?

Where can I seek support for my child?



Available Services

Primary health care centers
including developmental and
mental health support units



Preschool institutions
some offer inclusive
programs, though access
varies

Non-governmental organizations (NGOs)
often provide specialized
services and parent support

Guidance for Parents

How parents can support development at home

- **Play-based communication** – use songs, mimic sounds, and facial expressions
- **Reading aloud** – even if the child doesn't understand everything, exposure to language matters
- **Gestures and visual supports** – enhance understanding
- **Encourage exploration** – activities like crawling, stacking blocks, and drawing strengthen fine motor and cognitive skills



Examples of Specialized Support

Therapeutic centers
speech therapy, physical therapy,
developmental support



Parent counseling and workshops
emotional and practical support
for families

**Inclusive preschools and
education programs**



**NGOs focusing on
inclusion, disability rights,
and mental health**

Guidance for Professional

Professionals are crucial in providing support, yet may face systemic and resource challenges



These practices can strengthen their work:

- Use standardized screening tools and monitor developmental progress
- Observe the child during daily routines and natural settings
- Collaborate with parents – their insights are essential
- Tailor approaches to each child’s individual needs
- Promote multidisciplinary collaboration – across speech therapy, special education, psychology
- Empower families through education and training
- Explore sensory integration techniques – to support emotional regulation and skill-building through play

Guidance for Policymakers

Policy plays a pivotal role in establishing inclusive systems that support the holistic development and well-being of all children

To advance this objective, the following strategic recommendations should be prioritized:

- **Enhance Early Detection and Intervention Frameworks:** Implement universal developmental screenings in early childhood settings to ensure the early identification of developmental delays, followed by timely, evidence-based interventions.
- **Ensure Access to Inclusive Education:** Guarantee that educational institutions at all levels, including preschools and schools, are equipped with appropriately trained staff and adaptable environments to accommodate the diverse needs of all learners.
- **Foster Cross-Sectoral Collaboration:** Promote greater integration between the health, education, and social welfare sectors to ensure the provision of holistic, coordinated services for children and families.
- **Secure Sustainable Funding for Early Intervention Programs:** Advocate for consistent and long-term funding to ensure the accessibility and scalability of early intervention services, particularly for underserved and marginalized communities.
- **Develop Robust National Data Systems:** Establish comprehensive data collection and monitoring systems to track child development progress, service accessibility, and the overall effectiveness of early intervention programs, enabling data-driven policy decisions.
- **Incorporate Stakeholder Input in Policy Development:** Engage parents, caregivers, and professionals in the policy development process to ensure that policies reflect the practical needs of families and are informed by the expertise of those directly involved in early childhood development.
- **Formulate and Monitor Family-Centered Policies:** Design and implement family-friendly policies that provide parents and caregivers with the support, resources, and flexibility necessary to effectively contribute to their children's developmental and educational progress. Regularly monitor these policies to ensure they meet evolving needs.

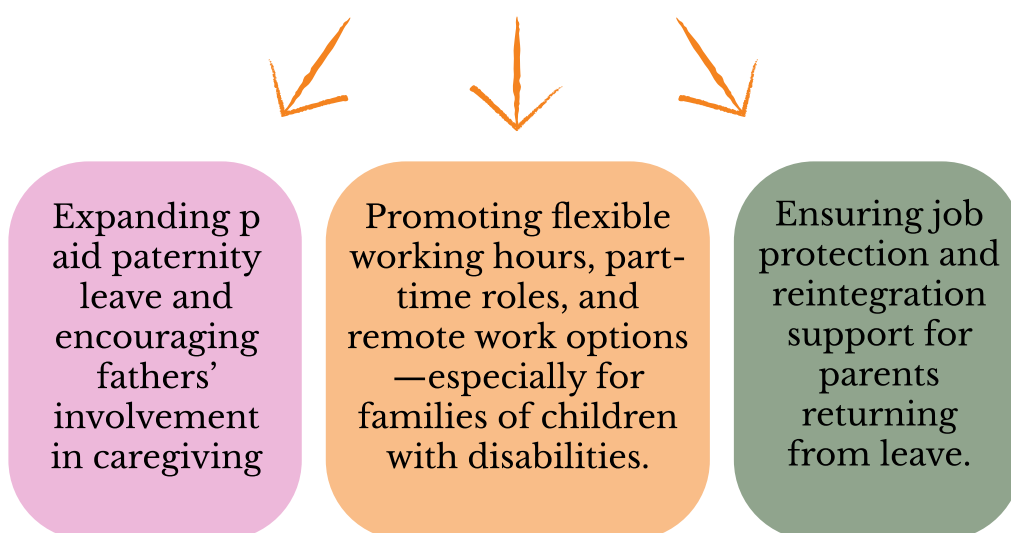
Family-Friendly Policies in the Balkans: Aligning with Global Trends

In Bosnia and Herzegovina and Serbia, families of children with developmental delays often face complex challenges—ranging from fragmented systems and delayed diagnoses to limited financial and emotional support. As awareness of early childhood development grows, so too does the opportunity to strengthen national policies that recognize families as essential partners in a child’s growth

1. Strengthening Parental Leave and Flexible Work Arrangements

Both countries provide paid maternity leave, but paternity leave and flexible employment options remain underdeveloped. A regional shift toward more gender-equitable caregiving is needed

Global alignment strategies include



Why it matters?

Flexible work and inclusive leave policies reduce caregiver stress and improve early bonding, especially when developmental challenges are present

Family-Friendly Policies in the Balkans: Aligning with Global Trends

2. Ensuring Access to Inclusive Early Childhood Education

Access to early childhood education is growing in both countries, but inclusive preschool options for children with developmental delays remain inconsistent and limited—particularly outside major urban areas.

Policy opportunities include



Why it matters?

Inclusive early education promotes learning, social development, and reduces long-term segregation of children with disabilities.

Family-Friendly Policies in the Balkans: Aligning with Global Trends

3. Advancing Early Screening and Referral Systems

Bosnia and Herzegovina and Serbia have begun using screening tools such as the ASQ-3 and GMCD, but coverage is not universal and diagnostic delays persist—with families often visiting multiple professionals before receiving a formal diagnosis.

Recommendations to strengthen systems:

- Mandate routine developmental screening in primary care centers using validated tools (e.g., ASQ-3, PEDS, M-CHAT-R).
- Train pediatricians and frontline providers to recognize early signs and refer promptly.
- Establish clear referral pathways and reduce bottlenecks in accessing specialists.

Why it matters?

Early detection leads to earlier intervention and better developmental outcomes, especially for children on the autism spectrum or with other delays.

4. Expanding Financial and Social Protection for Families

Economic stress is a major barrier for families seeking care. While both countries offer limited child disability allowances, supports often fall short of covering therapy, transport, or time away from work.

Strategic improvements include:

- Increasing disability benefits and service subsidies, particularly for low-income families.
- Providing direct support for therapy, assistive devices, and specialized childcare.
- Developing community-based family resource centers offering guidance, legal aid, and respite services.

Why it matters?

Economic security allows families to focus on caregiving without facing financial hardship or social exclusion.

Family-Friendly Policies in the Balkans: Aligning with Global Trends

5. Prioritizing Mental Health and Peer Support for Caregivers

Caregiver burnout, emotional strain, and stigma remain under-addressed in the region. Few formal support systems exist for mental health or peer connection.

Global-aligned strategies include:

- Integrating mental health services into pediatric and family support settings.
- Creating peer-led parent networks to offer emotional and practical support.
- Launching anti-stigma campaigns to normalize developmental differences and promote acceptance.

Why it matters?

Empowered, emotionally supported caregivers are more resilient and effective in advocating for their children's needs.

6. Inclusive, Evidence-Based Policy Making

Both Serbia and Bosnia and Herzegovina face challenges with data collection, cross-sector coordination, and inclusive policy design. Services are often siloed, and family voices are underrepresented in policy processes.

Steps toward more inclusive systems:

- Develop national data systems to track early development and service access.
- Institutionalize cross-ministerial collaboration across health, education, and social welfare.
- Engage parents, professionals, and NGOs in shaping family-centered policy frameworks.

Why it matters?

Inclusive, data-informed policymaking ensures that systems evolve in response to the real needs of children and families.

Action Steps for the Region

To build on these principles, stakeholders in Bosnia and Herzegovina and Serbia can:



- Expand screening and early intervention within primary healthcare services.
- Standardize inclusive education practices and build capacity at the municipal level.
- Increase funding and accessibility of services for children with developmental delays.
- Promote public awareness and caregiver engagement through education campaigns.
- Create feedback loops between families and policy bodies to ensure continuous improvement.



Conclusion

The path toward inclusive, family-friendly systems in the Balkans is already underway—but progress requires coordinated effort and commitment to global standards of equity and care. By aligning national policies with proven international approaches, Serbia and Bosnia and Herzegovina can ensure that every child, regardless of ability, has the opportunity to thrive in a supportive, inclusive society.



Families are not just recipients of support; they are partners in shaping systems that work. Strengthening family-friendly policies is not only a moral imperative—it is a smart investment in the future of the region.



Global Trends in Early Childhood Development and Inclusion

1. Enhanced Developmental Screening Practices

The AAP has observed a significant increase in paediatricians' use of standardized developmental screening tools, rising from 21% in 2002 to 63% in 2016. This trend underscores the growing emphasis on early identification of developmental delays to facilitate timely interventions.

2. Addressing Barriers in Early Childhood Screening

Despite advancements, challenges persist in the implementation of comprehensive screening practices. A recent AAP survey highlighted barriers such as time constraints, insufficient reimbursement, and lack of training, which can impede effective screening for developmental delays, maternal depression, and social determinants of health.

3. Integration of Relational Health in Early Development

The AAP emphasizes the critical role of relational health—nurturing, responsive relationships—in early brain development and overall well-being. Strengthening these relationships is pivotal in promoting healthy development and mitigating the impact of adverse childhood experiences.

4. Focus on High-Quality, Affordable Childcare

Research supported by the AAP indicates that access to high-quality, affordable childcare positively influences children's cognitive, language, and social-emotional development. Such childcare settings provide structured environments that support early learning and development.

5. Efforts to Reduce Early Childhood Expulsions

The AAP addresses the concerning trend of expulsions in early education settings, noting that children expelled from preschool or childcare are significantly more likely to face academic challenges later. The organization advocates for policies and practices that support inclusion and address behavioral issues constructively.

6. Understanding Sleep Patterns in Early Childhood

Studies published by the AAP reveal distinct patterns in sleep duration during early childhood, emphasizing the importance of adequate sleep for cognitive and behavioral development. Recognizing and addressing sleep issues early can contribute to better developmental outcomes.

Conclusion: Moving Forward Together

Children with developmental delays deserve timely, coordinated, and compassionate support. This toolkit has been developed to empower parents, inform professionals, and guide decision-makers in creating responsive, inclusive systems that put children and families at the center.

Across the globe—and in our region—awareness of early childhood development and the importance of early intervention is steadily growing. More countries are introducing universal developmental screenings, integrating inclusive education practices, and investing in parent training and community-based supports. However, challenges remain. Parents often wait months or even years for a diagnosis. Professionals face limited training or access to up-to-date tools. Systems frequently lack the coordination needed to deliver holistic care.

To close these gaps, multi-sectoral collaboration is essential. Health, education, and social protection systems must work hand-in-hand, ensuring that no child falls through the cracks. This includes:

- Strengthening primary care services to include routine developmental screenings using validated tools (e.g. ASQ-3, GMCD, M-CHAT-R).
- Training professionals in inclusive practices, trauma-informed care, and family engagement.
- Empowering families through access to practical, evidence-based strategies, emotional support, and peer networks.
- Investing in inclusive preschool settings that are equipped and staffed to support children with a range of developmental needs.
- Ensuring equity by addressing geographic, financial, and social barriers to services.

Importantly, the COVID-19 pandemic has highlighted both vulnerabilities and resilience in early childhood systems. It underscored the need for digital solutions, remote support models, and greater flexibility in service delivery—lessons that can guide us in building more adaptive and inclusive systems in the years ahead. This toolkit should be seen as a living resource—one that grows alongside the evolving needs of children, families, and professionals. The path to better outcomes is not linear, but through continuous learning, policy advocacy, and community engagement, we can ensure that children with developmental delays receive the support they need from the very beginning.

We invite all readers—whether parents, educators, therapists, or government officials—to take active steps in applying the knowledge from this toolkit and to join broader efforts for system change. Small, consistent actions—guided by empathy and evidence—can lead to transformative impact.

Together, we can create a future where every child is included, supported, and celebrated.