

UNIVERSITY OF BELGRADE - FACULTY OF SPECIAL
EDUCATION AND REHABILITATION

THE EUROPEAN ASSOCIATION ON EARLY
CHILDHOOD INTERVENTION

EUROPEAN ASSOCIATION OF SERVICE PROVIDERS
FOR PERSONS WITH DISABILITIES

Eurlyaid Conference 2017

**Early Childhood Intervention:
For meeting sustainable
development goals of the
new millennium**

PROCEEDINGS

*Belgrade, Serbia
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Situation Analysis of Early Intervention in Republic of Serbia¹

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Early Childhood Intervention (ECI) services help ensure fulfilment of internationally mandated rights, strengthen inclusive societies, and support children and families. This situation analysis, jointly supported by the Early Childhood Program of Open Society Foundations and UNICEF Serbia, examined the status of ECI services in Serbia. The analysis was part of a project to identify opportunities for the development of ECI in the country. A primarily quantitative, mixed-method approach documented existing ECI infrastructure and service provision. Data were collected from a focus group with parents, field observations, and interviews with key stakeholders belonging to Health, Education, and Social Welfare sectors, advisory board meetings, and a survey completed by professionals serving children with disabilities (e.g., teachers, medical professionals, therapists) and a survey completed by parents of children with disabilities. 184 parents and 416 professionals participated. Professionals and parents agreed parents are often the first to suspect the child has developmental needs. Over half of parents and professionals indicated pediatricians should screen children for delays. There was less agreement on who should assess and serve children. Systemic barriers include lack of time, high caseloads, insufficient human resources, cost, and attitudes toward children with disabilities. Existing infrastructure and disciplines, university programs and emerging training on ECI, patronage nursing, pediatric, and developmental counseling unit services, preschool institutions, and amenable policies and legislation may facilitate the development of ECI services. A shift from a medical to a social and interdisciplinary or transdisciplinary service delivery approach through the Routines-Based Intervention (RBI) model; cross-sector alignment and agreements with program standards and quality indicators; and clear protocols and standardized practices will improve existing services. Piloting ECI services delivered through home visits, at centers, and within inclusive preschools will guide subsequent service development. A financial and efficiency analysis will inform caseloads and service intensity and duration.

1 The opinions expressed in this Situation Analysis are those of the authors and do not necessarily reflect the policies or views of the Open Society Foundations or UNICEF.

Parents and professionals need opportunities to learn about contemporary, evidence-based ECI practices.

Key words: *early intervention, situation analysis, children with disability*

Although Serbia has made gains over the last decade for children with developmental delays and disabilities and their families, there is a growing need within the country to develop an equitable system of Early Childhood Intervention (ECI) services. With support from UNICEF Serbia and Open Society Foundations (OSF), this situation analysis explored key areas of relevancy for the development of a national ECI system. Areas explored included policy, program regulations, personnel preparation, accessibility and service reach, standards, financial support, and accountability mechanisms.

Families in Serbia have access to a number of preventative and support services during a child's early years including prenatal care, patronage nurse home visits, well-child pediatric care, nurseries, and preschool education. Specialized services for children with delays and disabilities are also available through Developmental Counseling Units (DCU) and secondary and tertiary health care. Education services include developmental groups within preschools. Inclusive preschool services continue to develop. Additionally, Roma health mediators provide support for Romani communities. UNICEF Serbia is actively working with the Government to increase access to high quality, inclusive preschool education by strengthening legal and institutional frameworks and develop diversified funding streams and programs to facilitate inclusion of Serbia's most vulnerable children.

Country pilot projects, in collaboration with nongovernmental organizations and university partners, have focused on inclusive preschool education and preventing family separation. While not fully developed, components necessary for ECI are in place or emerging. For example, some pediatricians are implementing standardized developmental screening; a number of professionals have significant expertise in assessment; and existing professionals from various disciplines have a wealth of knowledge that may serve as a solid foundation to develop ECI services. Demand and access, quality, and parent and provider attitude towards services and children with disabilities, however, needs documented.

Since there is no ECI system in place within Serbia, the analysis focused on opportunities and barriers to implementation and sought to identify and analyze pockets of emerging best practice within the country. An international and national consultant planned and carried out the analysis and Open Society Foundations Early Childhood Program and UNICEF Serbia provided guidance.

METHOD

Data included qualitative field-based observations and interviews with key stakeholders including ministry officials, health, education, and social welfare professionals, and university faculty. Six parents of children with disabilities provided information during a two-hour semi-structured interview. A brief document review was completed. A multidisciplinary advisory board representing the fields of pediatrics, psychology, pedagogy, rehabilitation, neuropsychology, special education, and public health along with a parent association representative provided guidance on the methodology as well as insight on the situation of children with disabilities in the country.

Professionals from a range of disciplines as well as parents of children with disabilities completed an online survey in Serbian. Recruitment included invitations sent through existing parent and professional associations through social media and individual emails. Professionals belonging to different sectors were included if they provided services to children with disabilities below the age of six years. A professional translated the original English surveys into Serbian. The second author and multiple Serbian early childhood, education, and health experts familiar with Serbia and highly proficient in Serbian and English reviewed and approved the translation.

Survey respondents included 184 parents and 416 professionals. Forty-three percent of the professionals were medical providers with pediatricians making up 10.6%. Thirty-one percent were defectologists, 14.9% speech therapists, and 12.7% psychologists. Preschool teachers made up 7.9% and pedagogues 6.0%. Forty-four percent of professional respondents had more than 15 years of experience working with young children with disabilities. Half of parents reported living jointly in a relationship (53.8%) and 38% reported no financial problems. Most respondents were from urban communities (86.5% professionals, 68.8% parents).

RESULTS

Many parents reported they or a relative were first to suspect their child's delays (46%) and 36% of professional respondents agreed. This was followed by preschool teacher (14.7%) and pediatrician (13.5%) as first detectors according to professional respondents. Medical respondents were more likely to endorse pediatricians and non-medical respondents were more likely to endorse preschool teacher.

Early identification and referral barriers included pediatric caseloads and the need for mandated, clearly documented referral pathways and follow-up requirements. Parents lack awareness of system navigation and their rights. Case coordination across primary, secondary, and tertiary institutions is lacking. Parents and professionals agreed pediatricians should implement developmental screening. There was less agreement around assessment. Most parents agreed their child's

pediatrician is within walking distance and time spent in the waiting room is reasonable; more than half (52.4%) said the hours of operation are difficult.

Overall, professionals identified the defectologist to carry out the assessment following a positive screen (55.8%). Medical professionals were more likely to select pediatrician or psychologist; whereas 62.2% of non-medical professionals indicated defectologist followed by psychologist and speech therapist.

The attitude towards services differed between medical and non-medical respondents. Medical professionals were more likely to indicate routine screening is important (80.6% vs. 59.9% non-medical) even though there was near universal endorsement of the effectiveness of ECI services. Non-medical professionals indicated less knowledge on how to screen (66.5% vs 80.8% medical) and a desire to receive training (92.1% vs 87.6% medical). Failure to screen universally will result in under-detection of up to 60% of children with developmental delays and as many as 80% of children with social emotional challenges (Lavigne, Binns, Christoffel, Rosenbaum, Arend, Smith, et al., 1993; Sheldrick, Merchant & Perrin, 2011; Squires, Nickel & Eisert, 1996; Sturner, 1991). Although parents suspected the delay before the first year (73.2%) and a high percentage of professionals also noticed their child's delay (63.2%), only 43.4% had a diagnosis within this period. Forty-five percent of children received a diagnosis between 12-36 months. Thirty-two percent of parents reported their child's disability established at the secondary or tertiary level (32.1% and 12.4%). Medical providers were more likely to report the tertiary (33.1%), secondary (22.8%) or DCU (21.3%) established the disability.

In general, medical professionals noted a need for professional development. The survey included a series of questions for medical professionals to report the proportion of pediatricians at their Primary Health Care Center who can carry out specific tasks (e.g., identify suspected child abuse or neglect (15.4), provide anticipatory guidance (14.6%); or use a validated screening tool (5.7%). Response options included most (100-75%), many (74-50%) and so forth. Very few respondents reported most of their colleagues as proficient (100-75%). The most highly endorsed area was the identification of biological risk such as low birth weight. Only 9% endorsed use of interview and observational skills to assess aspects of a child's development, and 5.7% use of a valid screening tool. Surprisingly, 14.6% indicated 100-75% of their colleagues could counsel parents how to enhance their child's development; 17.6% indicated their colleagues know how to access ECI or rehabilitation services; and 18% reported 100-75% of their colleagues could manage special health care needs of children with developmental difficulties.

Over half of parents reported receiving Republic or municipal intervention services for less than 30 minutes per session (55%) with 41% of parents receiving services less than once per week. Twenty-two percent of parents use private services more than twice per week. The majority of Republic and municipal services are center-based (94.3) or clinic-based (83.3%) although 60.9% of parents indicated preschool-based services. Parent preferred service location was

the home (38.6%) followed by rehabilitation center (32.6%) for children birth to three. Professionals preferred the home (51.4%) followed by inclusive classroom (46.2%). Parents of children 3-6 years preferred the rehabilitation center followed by home-based services. Professionals preferred inclusive classrooms followed by developmental groups for children 3-6 years. Although professionals prefer home-based services, only 6% indicated this is a current service delivery option.

Parents indicated their role in service provision as being in the room watching the specialist (33.3%) whereas medical professionals expect them to be in the room and trying the techniques they observe (45.5%). Non-medical professionals prefer to have the parent in and out of the room depending on what the specialist advises (56.5%).

Overall, parents and professionals most frequently endorsed a lack of knowledge about available services as a barrier for children 0-6 years. Limited or no financing and a lack of trained providers followed according to parents. Professionals agreed financing was a barrier (45.2%) and coordination among sectors (43%). A small percentage of parents knew what services were available for their child (42.4%) and how to access them (39.7%).

The role of professional and parent associations can be instrumental in knowledge building. Fifty-eight percent of non-medical professionals belong to a professional association and 50% of medical professionals claimed membership. Forty-seven percent of parents belong to an association; however, this was significantly lower for rural respondents (14%).

Educators need training and support according to parents. Thirty-percent indicated inadequate training for preschool teachers and 35.9% said there are not enough specialists to support teachers and too many children in the preschool group (28.3%). Physical access may remain a barrier at many preschools. Twenty-two percent of parents endorsed this area as a barrier.

Finally, although three-fourths of parents and professionals agreed every child has the right to mainstream education and over 80% said preschool should be universally accessible, there is a lack of consensus on which ministry should lead. This is perhaps due to the recognition that ECI crosses sectors. The overwhelming majority (90% of parents and 91% of professionals) indicated access to education for children with disabilities is the responsibility of education, health, and social welfare.

DISCUSSION

Serbia has many of the necessary components needed for the development of a national ECI system. However, no specific legislation regulates existing components, including financing. A financial assessment is needed to determine adequate caseloads and service intensity and duration. A shift from a medical to a social and interdisciplinary or transdisciplinary delivery approach through

the Routines-Based Intervention (RBI) model is recommended. The RBI model, based on understanding family ecology and a functional, family-centered needs assessment; functional goal development and integrated service delivery; and service delivery through a consultative approach, is rooted in the child's daily routine interactions with the environment and individuals. Cross-sector alignment and agreements with program standards and quality indicators as well as clear protocols and standardized practices will improve existing services. ECI program standards and quality indicators need to be developed, agreed, and monitored at the national level. Piloting ECI services delivered through home visits, at centers, and within inclusive preschools will guide subsequent service development. There are few opportunities for professional development and parent and professional awareness raising. Available opportunities are not accessible to all due to cost and free time. Although some data is recorded on the types of disability, data systems need improved. Evidence-based, contemporary pilot services need developed and trialed.

While this situation analysis informs future ECI developments, interpretive caution is warranted. Although 63.6% of the population has a personal computer and completion of the survey with a smartphone was possible, a limitation of the situation analysis is the generalizability to the wider population. Underrepresentation from rural areas and families facing financial difficulties further limit the generalizability of the findings.

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