DOI: 10.59519/mper6207

Family-Centered Early Childhood Intervention in Kosovo: Perceptions of Parents

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Abstract
This study investigates the Early Childhood Intervention (ECI) support system in Kosovo, emphasizing the perspectives of families with children experiencing developmental delays and disabilities. Drawing upon the evolution of ECI frameworks since the 1970s, the research highlights the significance of family-centered practices as a primary approach in ECI, as endorsed by the Division for Early Childhood (DEC). Utilizing a descriptive methodology, the study surveyed 89 parents of children aged 0 to 6 who accessed ECI services, focusing on their experiences, barriers encountered, and the effectiveness of current support systems. Results reveal that pediatricians are the most commonly recommended sources for ECI services, with a substantial percentage of families facing waiting lists. The findings underscore the necessity of enhancing advocacy efforts, developing comprehensive national policies, and improving access and coordination of ECI services.

Article history
Received: 14.10.2024.
Accepted: 28.10.2024.

Keywords:
Family-centered practices,
Early Childhood Intervention,
Developmental delays,
Disabilities,
Parent perceptions

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DOI: 10.59519/mper6207

Introduction

In the realm of Early Childhood Intervention (ECI), dating back to the initiation of the first programs in the USA during the 1970s, various conceptualizations and models have been adopted as benchmarks for intervention practices. These frameworks have evolved in tandem with the changing landscape of research and scientific knowledge at different junctures.

Understanding the fundamental aspects of psychomotor development is essential for delivering effective early education and rehabilitation, as well as optimizing the child's physiological potential (Rashikj-Canevska, Karovska-Ristovska & Bojadzhi, 2019).

Advancements in comprehending the learning processes of children and recognizing the pivotal role of families in child development, coupled with extensive research on the efficacy of diverse ECI programs, have played a crucial role. This collective body of knowledge has led to the acknowledgment of family-centered practices as the most congruent with the needs of both children and families. Consequently, family-centered practices have become the recommended approach for ECI. In fact, the Division for Early Childhood (DEC) has officially recognized family-centered practice as the most recommended approach in the field of ECI since 1993. This recognition is underscored by sustained positive effects observed over the medium and long term, as highlighted in the works of McWilliam and Strain (1993), Odom and McLean (1993), and Vincent and Beckett (1993), as cited in Epley, Summers, and Turnbull (2010).

An essential aspect of early intervention is its family-centered approach, where the family plays an equal role as part of the team and is actively involved in all phases of planning, evaluation, and intervention (Karovska Ristovska, A., 2021).

Historically, the endeavors of Early Childhood Intervention (ECI) were primarily centered around the child, with professionals taking on the responsibility of identifying risk factors. Their role extended to designing and executing interventions intended to mitigate the impact of these factors on both the present and future development of the child. In this traditional paradigm, ECI professionals were perceived as experts tasked with identifying the needs of the child and formulating intervention strategies. Concurrently, parents were often positioned as recipients of "training" and typically followed the guidance provided by professionals during the implementation of these interventions (McWilliam, 2003).

Professionals must always bear in mind that the family bears the primary responsibility for the child and will be the enduring presence throughout the child's journey from infancy to adulthood. When offering support services to children, any conscientious professional should recognize that, unlike professionals and service systems that may change over time, the family remains a constant in the child's life (Shelton & Stepanek, 1994).

Early intervention, effective home visits, and appropriate educational support can empower parents to create more enriching environments for their young children—environments that are crucial for healthy development across all domains. To prevent future generations of children from becoming adults who struggle to foster their own children's growth and well-being, we must increase efforts to support and educate parents (Karovska Ristovska, 2019).

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In any intervention with children, parents should be regarded as the linchpin, recognizing that this approach is pivotal for achieving outcomes that endure over the medium and long term. It is through empowering and involving parents that interventions can have a lasting impact, persisting even after the conclusion of professional support. Guralnick (2008) emphasizes a pivotal objective within Early Childhood Intervention (ECI): the enhancement of family strength to optimize patterns of interaction. This marks a significant evolution in both the philosophy and practice of ECI, prompting a profound shift in the mindset of professionals operating in this field. This transformative change extends beyond being direct intervention agents with the child, necessitating the recognition of a new role that involves promoting the contexts in which the child is involved and actively participates. These professionals are envisioned as catalysts for positive change within the broader family and community settings.

Family life holds a wealth of potential to offer diverse experiences and learning opportunities to children as part of their daily routine. The quality of experiences provided by parents significantly influences a child's development, surpassing the impact of the quantity and quality of toys, materials at home, or educational and therapeutic services they may attend (Mahoney & MacDonald, 2007).

As highlighted by Dunst (2010), early childhood intervention delivered solely by professionals, without the active involvement of parents, in an artificial setting—such as one hour, twice a week, for 50 weeks—only represents a mere 3% to 4% of the time that a two-year-old child is awake. In essence, interventions conducted by professionals in isolation from the child's primary caregivers contribute so minimally to the child's learning experiences that the likelihood of making a substantial difference in their development is minimal.

The manner in which intervention is provided plays a pivotal role in achieving intervention goals, including engagement, the sense of competency, capacity-building, and the empowerment of the family. Consequently, family-centered intervention goes beyond determining if the family's needs are being met; it extends to understanding how those needs are fulfilled (Dunst, Trivette, & Deal, 1994).

Active inclusion of parents in their child's early care and education is rooted in the dual principles of parents' rights to be involved and the benefits for children stemming from the continuity between their home and care or educational environments (Powell, 1994). This collaborative approach recognizes the integral role of parents in shaping a supportive and consistent environment for the child's overall development.

Recognizing the uniqueness of each family is paramount, necessitating the individual identification of their concerns, values, and beliefs. Gathering information that families are willing to share and understanding how they express their interests, resources, and priorities allows us to discern which details are relevant (McWilliam, Winton, & Crais, 2003).

Selecting a method, tool, or strategy to collect this information requires a thoughtful approach, taking into account the preferences, lifestyle, and cultural values of the family. The most effective way to discern the family's preferences is through active listening and direct communication. The manner in which this information is gathered holds significance; it should not adopt an "assessing"

DOI: 10.59519/mper6207

form but rather be a natural, collaborative process that supports the family, fostering a strong working relationship between the family and professionals (McGonigel, Kaufman, & Johnson, 1991).

In Kosovo is a pressing need for the development of an integrated approach to establish a local Early Childhood Intervention (ECI) system. This includes the formulation of a dedicated local ECI policy, plan, and possibly legislation, along with the creation of comprehensive and detailed ECI regulations in the form of Service Guidelines and Procedures. These foundational steps are crucial for the subsequent establishment of service and personnel standards, the design of pre- and in-service training programs, and the implementation of an effective system for supervision, monitoring, and evaluation within the ECI framework. Addressing these aspects is paramount to ensuring the success and sustainability of a robust Early Childhood Intervention system in Kosovo (Nations Children’s Fund (UNICEF), 2023). This research examines the Early Childhood Intervention (ECI) support system Kosovo, as viewed by families with children experiencing developmental delays and disabilities.

Methods

A descriptive approach was employed for this study. Descriptive studies aim to observe and characterize individuals, events, or situations by examining them in their natural state. The investigator does not alter or influence any variables but simply records and explains the characteristics of the sample or the variables involved (Siedlecki, 2020). The descriptive approach aligns with the issue explored in this study, as it involves detailing the process of accessing ECI services.

The survey instrument for parents was developed based on and adapted from the questionnaire templates provided in the Methodological Guide: Research for National Situation Analyses on Early Childhood Intervention by Vargas-Barón, E., Diehl, K., & Kakabadze, N. (2022), published by the United Nations Children’s Fund (UNICEF).

This study's sample is composed of 89 parents of children aged 0 to 6 with developmental delays or disabilities (58.4% boys and 41.6% girls). The majority of the children in the sample were between 37 and 60 months old (32.6%), followed closely by those over 61 months (30.3%). Children aged 25 to 36 months accounted for 24.7% of the sample, while smaller percentages were observed for younger age groups: 13 to 24 months (7.9%) and 7 to 12 months (4.5%). The participants include families who had accessed ECI services, treatment, or other professional support for their child's condition. The majority of responses were provided by the children's mothers (64.0%), with the remaining surveys completed by the fathers (33.7%) and guardians or close relatives (2.2%). The largest proportion of parents had completed secondary school (34.8%), followed by those with a bachelor’s degree (23.6%). A smaller percentage had completed a

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master's degree or higher (15.7%), while 13.5% had finished only primary school, and 12.4% were vocational school graduates.

Results

The most commonly recommended source for Early Childhood Intervention (ECI) services was the child's paediatrician or physician, suggested by 16.9% of participants. This was followed by personnel at nurseries or preschools (12.4%) and hospital staff, with 9% suggesting someone else at a hospital and 7.9% recommending personnel from a Neonatal Intensive Care Unit. Similar percentages (7.9%) recommended social workers at social welfare centers, family members or relatives, or friends and neighbors. Another type of physician and social media or websites were each suggested by 5.6%, while 4.5% recommended personnel from an organization providing ECI services. Recommendations from non-hospital nurses (2.2%), mass media (3.4%), and other sources (1.1%) were less frequent.

Out of the total respondents, 46.1% reported being on a waiting list, while 53.9% stated they were not.

Among those who were on the waiting list, 33.7% had been on the list for less than 3 months. Only 3.4% had been on the list for 3 to 6 months, and 4.5% had been waiting for 7 months to 1 year. Another 4.5% had been on the list for more than 1 year.

The table 1 presents the age distribution of children at the time of their initial enrollment in Early Childhood Intervention (ECI) services:

Table 1

Age of child when first enrolled in services for ECI

Child age at the time of enrollment in activities for ECI	N	%
1-6 months	7	7.9
7-12 months	21	23.6
13-24 months	22	24.7
25-36 months	23	25.8
37 months or older	16	18.0

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The table 2 outlines the various reasons parents enrolled their children in Early Childhood Intervention (ECI) services:

Table 2

Reason you enrolled your child

Reason you enrolled your child in ECI services	N	%
Child was born pre-term or with low birth weight	17	19.1
Child had a chronic condition (micronutrient disorder, chronic illness, etc.)	2	2.2
Child was not growing well	4	4.5
Child had a delay and was slow to develop	37	41.6
Child had a motor/muscular disability	12	13.5
Child had a speech/language delay	41	46.1
Child had low vision or was blind	2	2.2
Child had a hearing loss or was deaf	1	1.1
Child had a cognitive disability	7	7.9
Child had several disabilities	2	2.2
Child was on the autism spectrum	16	18.0
Child had attention deficit and hyperactivity disorder	9	10.1

The various services that children are currently utilizing. A total of 2.2%, are using services from a primary healthcare center. Accounting for 19.1%, are enrolled in a center for autism services. There are 2.2%, attending a day-care center designed for children with disabilities. The largest group, comprising 43.8%, are receiving services from private providers specializing in disabilities. A significant representing 36%, benefit from services provided by non-governmental organizations (NGOs). 3.4%, access services from a center for social services. A total of 30.3%, attend an inclusive crèche or nursery. Lastly, 6.7%, are enrolled in an inclusive preschool.

In table 3 the data illustrates the various barriers encountered by families seeking Early Childhood Intervention (ECI) services:

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Table 3

Barriers you faced in obtaining services for ECI

Barriers you faced	N	%
I lacked information about services for early childhood intervention	46	51.7
My child has a different nationality	1	1.1
Services for early childhood intervention do not exist in my community	11	12.4
Services for early childhood intervention are located too far away from my home	1	1.1
It was hard to get transportation to these services	17	19.1
It was hard to get a referral to an organization with activities for early childhood intervention	8	9.0
There were long waiting lists for these services	4	4.5
The enrolment process was very complicated	1	1.1
My child's development was not screened/assessed during routine visits to primary healthcare services	5	5.6
There are no specialists in my child's area of need	3	3.4
I did not have the financial means to pay for services for early childhood intervention	29	32.6
Services for early childhood intervention are not offered during my non-working hours	24	27.0
I needed an interpreter to speak with the personnel of services for early childhood intervention	3	3.4

The data on quick checklist screening reveals the following: A majority of respondents (59.6%) reported that they received a quick checklist screening, conversely, 18.0% indicated that they did not receive the screening, additionally, 22.5% of respondents were unsure whether they had received the screening, as indicated by their response of "Don't know."

For those who answered "yes" to receiving a checklist screening, the following insights were gathered regarding their participation in the screening process, among those who received the screening, 46.1% actively participated by providing answers for the screening, a smaller group

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(9.0%) observed the screening without participating, additionally, 4.5% reported that they neither participated in nor observed the screening, a significant portion (40.4%) of respondents didn't answer in this question which means is the category of parents which didn't received quick screening.

Table 4 presents data on the types of professional support services utilized by families:

Table 4

Ways you and your child receive support services

Type of professional support	N	%
One person works alone with my child	54	60.7
One person works with me and my child separately	7	7.9
One person works with me and my child together	3	3.4
One person works with me, my child and two or more children together	1	1.1
A team was formed to work with my child alone	13	14.6
A team was formed to work with me and my child separately	7	7.9
A team was formed to work with me and my child together	3	3.4
A team was formed to work with me, my child and two or more children together	1	1.1

Specialized Assessments for Different Areas indicates a strong prevalence of such evaluations among respondents, a significant majority (88.8%) reported that specialized assessments were conducted, while only 9.0% indicated that they did not receive such assessments, additionally, 2.2% didn't response.

For those who affirmed that specialized assessments were conducted, the following details regarding the assessment process were collected, among the respondents, 19.1% indicated that the assessment was conducted by one professional, A larger group (44.9%) reported that the assessment involved more than one professional at different times, suggesting a phased approach to evaluation, additionally, 24.7% of families indicated that a team of professionals conducted the assessment at the same time, highlighting a collaborative effort in the evaluation process.11.2% didn't response.

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The data on specialized assessments for all areas shows similar trends, an even higher percentage of respondents (89.9%) confirmed that assessments were conducted across all areas, while 10.1% indicated that they did not receive such assessments.

For respondents who answered "yes" regarding assessments for all areas, the following insights were gathered about the assessment process, as with the previous assessments, 19.1% indicated that the assessment was conducted by one professional. A substantial portion (46.1%) reported that the assessment was carried out by more than one professional at different times. Additionally, 24.7% indicated that a team of professionals conducted the assessment at the same time, promoting a comprehensive approach. 10.1% didn't response.

The data regarding the preparation of Individualized Family Service Plans (IFSPs) reveals the following insights, a majority of respondents (61.8%) confirmed that an IFSP was prepared for their family, conversely, 24.7% indicated that no IFSP was prepared. 13.5% of respondents were unsure whether an IFSP had been prepared, responding with "Don't know."

For those who affirmed that an IFSP was prepared, insights regarding the decision-making process were collected, among the respondents, 13.5% reported that decisions regarding services were made by one professional, a larger portion, 36.0%, indicated that a team of professionals made the decisions regarding the IFSP. Furthermore, 11.2% stated that they made decisions after discussing options with the team. A significant percentage (39.3%) didn't answer.

For respondents who confirmed that an IFSP was prepared, the following information was gathered about whether they signed and dated the plan. Of those who prepared an IFSP, 38.2% confirmed that they signed and dated the IFSP. In contrast, 30.3% indicated that they did not sign and date the IFSP. 31.5% of respondent didn't response.

Services offered as part of the IFSP preparation, Family Support or Counselling Sessions were reported by 54% of respondents, indicating a significant focus on family well-being. Peer-Group Sessions with Other Parents in ECI Services were indicated by 68% of respondents, reflecting a strong community support aspect. Parent Education Meetings were attended by 75% of families, demonstrating a commitment to informed parenting. Support Groups for Siblings were reported by 81%, highlighting efforts to involve all family members in the support process. Finally, Referrals to Other Services (e.g., health, education, etc.) were provided to 80% of respondents, indicating a comprehensive approach to addressing families' diverse needs.

The table 5 presents the distribution of responses regarding the locations where Early Childhood Intervention (ECI) services are delivered:

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Table 5

Place were ECI services are given

Place where ECI services are given	N	%
In my home	3	3.4
Both in my home and in a centre for early childhood intervention	4	4.5
Only in an institution or organization for early childhood intervention	81	91.0
In a health centre	4	4.5
In a nursery or inclusive preschool	14	15.7
In a centre for social work	2	2.2

The participation of respondents in home visits for Early Childhood Intervention (ECI) services. A total of (9.0%) reported participating in all home visits, while (10.1%) participated in some visits. Conversely, (4.5%) indicated they participated in few to no visits. A significant portion of respondents (76.4%) didn't take service in home.

Participation in center visits for ECI services. Among respondents, (24.7%) reported attending all center visits, whereas a larger proportion, 57 respondents (64.0%), participated in some visits. Only 10 respondents (11.2%) indicated participation in few to no center visits. This data indicates a generally higher engagement in center visits compared to home visits.

The frequency of visits for ECI services among respondents. The majority, (51.7%), reported visiting three or more times a week. Additionally, (36.0%) attended twice a week, (9.0%) visited every two weeks, and only (3.4%) reported visiting once a month. This frequency distribution highlights a strong commitment among many respondents to engage regularly with ECI services.

Table 6 details the various types of specialists involved in Early Childhood Intervention (ECI) services as reported by the respondents:

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Table 6

Type(s) of specialist(s) work with ECI

Type of specialist	N	%
I am not sure	1	1,1
Case manager, service coordinator or family support manager	2	2.2
Early childhood intervention specialist	4	4.5
Nurse	1	1.1
Occupational therapist	25	28.1
Physician	8	9.0
Physiotherapist	14	15.7
Psychologist	35	39.3
Social pedagogue	1	1.1
Social worker/social welfare specialist	3	3.4
Speech and language therapist	37	41.6
Child psychologist	33	37.1
Child neurologist	8	9.0

The top five recommendations for improving and expanding ECI services, based on the number and percentage of respondents, are as follows:

Offer more parenting education and support services – With 38 respondents (42.7%), this suggestion emphasizes the importance of empowering parents through education and support in the early stages of their child's development. *Expand advocacy to reduce stigma and discrimination and to increase demand for ECI services* -This recommendation was supported by 36 respondents (40.4%), highlighting the need to address social stigma and boost awareness of early intervention services. *Achieve greater equity through improving access to services for early childhood intervention* – 33 respondents (37.1%) advocated for ensuring equitable access to ECI services, particularly for underserved populations. *Provide high-quality and comprehensive child and family developmental assessments* – This was emphasized by 31 respondents (34.8%), reflecting the need for thorough assessments in early childhood development programs. *Develop national policies, plans, laws, and regulations for ECI services* – 30 respondents (33.7%) stressed the importance of creating a robust legal and policy framework to support the expansion and standardization of ECI services. The others are notable in table 7:

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Table 7

Recommendations for improving and expanding ECI services

	N	%
Expand advocacy to increase demand for and expand services for early childhood intervention	23	25.8
Improve the organization and coordination of services for early childhood intervention with other services	22	24.7
Establish a nationwide system for regular developmental monitoring, screening and referrals	26	29.2
Develop a coalition or network of services for early childhood intervention	25	28.1
Provide more ECI home-visiting services.	27	30.3
Give more opportunities for parent involvement in organizations for early childhood intervention	28	31.5
Improve and expand pre-service training for professionals who provide services for early childhood intervention	15	16.9
Provide in-service training on contemporary services for personnel who deliver early childhood intervention services	6	6.7
Improve and expand systems for supervision, coaching and mentoring of professionals and paraprofessionals who provide services for early childhood intervention	12	13.5
Expand services to rural regions, remote areas and minority ethnic groups	20	22.5
Develop a national monitoring and evaluation system for organizations providing services for early childhood intervention	8	9,0
Expand government/ministerial funding for early childhood intervention services at the central, (regional), and municipal levels	8	9,0
Provide computers, tablets and other technologies requested by organizations delivering services for early childhood intervention	14	15,7
Conduct national surveys to gather data on developmental delays and disabilities	10	11.2

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Discussion

Data indicates that pediatricians are the most commonly recommended source for ECI services, which aligns with findings from various other studies that highlight healthcare professionals as primary sources of referral for early intervention services. For instance, a study by Rosenberg et al. (2013) emphasizes the critical role pediatricians play in identifying and referring children to early intervention services. However, study also highlights a notable role played by personnel from nurseries or preschools, hospital staff, and social workers, which corresponds with other studies showing that early education professionals are key in recognizing developmental delays (Guralnick, 2011). Hagan et al. (2008) discussed pediatricians' influence in child development monitoring and the importance of early referrals.

The fact that 46.1% of respondents were on a waiting list for ECI services is consistent with reports from similar studies. The present study corroborates the findings of Karovska and Naumovska (2024), which indicate a significant delay from referral to the commencement of intervention services. This gap highlights systemic barriers that families encounter when seeking timely support for their children. Research by Boyle et al. (2011) McGowan et al. (2016) found that access to ECI services is often delayed due to long waiting lists, especially in underserved areas. The data showing that most families waited less than 3 months is encouraging, though the percentage waiting over a year is concerning and reflects broader systemic challenges reported in similar studies across various countries. McGowan et al. found that families in lower socioeconomic brackets were often disproportionately affected by service delays. Cottrell & Shillinglaw (2016) examined service delivery inefficiencies and found similar trends of long waiting periods, particularly in regions with less comprehensive early childhood support programs. Dunst & Dempsey (2007) emphasized that delayed intervention, particularly for children on long waiting lists, can have negative impacts on developmental outcomes.

The barriers identified in study (e.g., lack of information, long waiting lists, transportation difficulties) mirror findings from research in different contexts. Studies from developing countries, in particular, have highlighted similar challenges, such as lack of awareness and logistical difficulties Zeedyk et al. (2006). Findings on financial barriers align with research that emphasizes socioeconomic factors as significant in limiting access to these services Macy et al. (2016). Pruett (2009) suggested that addressing these barriers requires policy reforms and more equitable distribution of services,

Data on the types of professional support received—whether by individuals or teams—adds to the growing literature on the importance of multidisciplinary approaches in ECI. For example, a study by Bailey et al. (2006) supports the notion that multidisciplinary teams provide more holistic assessments and interventions. The high percentage of families receiving assessments from more than one professional at different times suggests a flexible, but potentially fragmented, system.

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Research by McWilliam (2010) and Bruder (2010) underscores the importance of multidisciplinary assessments. These studies found that collaborative assessments yield more comprehensive diagnoses and tailored interventions. The fact that 61.8% of respondents had an IFSP is consistent with expectations for early intervention services, where IFSPs are a critical component of personalized care. However, the discrepancy between those who signed the IFSP and those who didn't suggests potential gaps in communication or understanding, a finding also noted in studies like Bruder (2010), which emphasizes the importance of family involvement in the IFSP process.

The high participation rates in center-based ECI services compared to home visits reflects trends seen in other countries, where institutional care is often more accessible than home-based interventions. However, some studies suggest that home-based services can be more effective in promoting parent-child interactions and implementing interventions within the child's natural environment (Dunst, 2007). Respondents' emphasis on reducing stigma, improving access, and expanding services is echoed in global literature. One of their key recommendations was to raise awareness in order to minimize stigma and discrimination (United Nations Children's Fund [UNICEF], Skopje, 2023). A systematic review by Britto et al. (2017) highlights the need for public awareness campaigns to reduce stigma and increase the demand for services. Additionally, recommendations to improve coordination between services align with the findings of studies from the U.S. and Europe, which highlight the need for integrated service delivery models to improve outcomes for children and families (Odom et al., 2010).

Conclusion

This study highlights key challenges in Kosovo for Early Childhood Intervention (ECI) system, including long waiting lists, limited access to information, and logistical barriers. While many families benefit from multidisciplinary assessments, gaps remain in family involvement in service planning, such as the signing of Individualized Family Service Plans (IFSPs). The findings suggest a need for improved advocacy, better coordination of services, and expanded access to reduce stigma and ensure equitable service delivery. Overall, there is progress, but more comprehensive policies and support are needed to enhance the ECI system.

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