

Early Childhood Intervention in North Macedonia – Parents’ Perspective

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Abstract

Early childhood intervention (ECI) should focus on building strong relationships with families, as this family-centered approach leads to improved developmental outcomes for children. This study examines ECI and support systems in the Republic of North Macedonia from the perspective of families of children with developmental delays or disabilities. A descriptive method was used, suitable for describing individuals, processes or situations as they unfold in nature, with no manipulation of variables. The research included a sample of 78 parents of children with developmental delays or disabilities.

The findings indicate that when at-risk factors or disabilities are identified shortly after birth, ECI tends to be quick and efficient. Most services (71.4%) are provided in ECI centers, while 28.6% of families receive services at home. Some 53.8% of families reported covering the costs of all ECI services. By the age of three, 43.7% of children had been detected, diagnosed, and received some form of stimulation services or early rehabilitation treatment. The insights gained from this study may also be applicable in other countries with similar ECI systems.

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Introduction

The field of Early Childhood Intervention (ECI) has a rich evidence-based history that provides a foundation for research and development of interventions aimed at minimizing the effects of developmental delays and/or disabilities in children (Bruder, 2010). Decades of research, program development, professional training, and legislative and policy initiatives have contributed to the establishment of support systems in many countries around the world (Bruder & Guralnick, 2019). ECI can be defined as “a coordinated system of policies, programs, services and resources to support families, infants and young children who are at risk, have developmental delays or disabilities” (Guralnick, 2007). This support system should enable families to increase their capacity to adequately respond to their child's needs, encourage the child's development from an early age and thereby minimize the effects of disability and the need for special education (Dunst, 2007).

Families, as key stakeholders in the ECI process, can provide us with important information about delivery of ECI services, point out the barriers in accessing these services and suggest useful solutions (Epley, 2011; Bailey, 2001; Lanners, Romain & Mombaerts, 2000), which can help professionals revise existing delivery of services for family support (Guralnick, 2001).

The basic principle of ECI emphasizes the importance of early detection and referral for intervention (Guralnick, 2008). The earlier developmental delays or disabilities are identified and the referral is confirmed, the more likely the child will benefit from intervention strategies (Guralnick, 2005). Families benefit from the support provided through the intervention process (Dunst, 2007) but also communities benefit from reduced special education costs (Carta & Kong, 2007; Karoly et al., 2001).

The principle of family-centred practices is also becoming central to many ECI systems (Bruder, 2000; Dunst et al., 2001; Karovska Ristovska, 2021) and should be represented in each structural component and corresponding practice of each system (Guralnick, 2001; Sameroff & Fiese, 2000). Research confirms that young children with developmental delays and disabilities benefit and thrive better if they receive support in natural environments that are typical of children without disabilities (Zwaigenbaum et al., 2015; Campbell, Sawyer, & Muhlenhaupt, 2009; Karovska & Jachova, 2006; Guralnick, 2001; Bruder, 2001; Bruder & Staff, 1998). Incorporating intervention and support strategies in natural environments facilitates children's access to more learning opportunities throughout the day, interacting with their peers (Sheldon & Rush, 2013; Swanson, Raab, & Dunst, 2011; Bruder, 2010; Dunst, Hamby & Brookfield, 2007).

The transdisciplinary approach is recognized as best practice for ECI (Bruder, 2000; Berman, Miller, Rosen, & Bicchieri, 2000; Guralnick, 2001; Karovska Ristovska, A., 2021). Unlike other approaches to service delivery, this approach is thought to reduce fragmentation in services, reduce the likelihood of receiving different information and guidance from multiple service providers, and improve coordination of services (Carpenter, 2005).

Many countries, North Macedonia included, which are in the early stages of developing ECI programs and need to make important decisions regarding the design or strengthening of their early intervention systems, can be guided by these principles to develop their own early childhood systems guided by principles and implementation strategies that will respond to the specific culture, values, policies and available resources in their communities (Guralnick, 2019). This study focuses on the ECI support system in the Republic of North Macedonia from the perspective of families of children who have developmental delays and/or disabilities.

Methods

For the purposes of this research a descriptive method was used. This type of research design is suitable for describing individuals, processes or situations as they unfold in nature, with no manipulation of variables (Creswell, 2018). Descriptive studies provide information on the characteristics of the population, identify problems that exist within a unit, organization or population; or variations in characteristics or practices that are explored (Creswell, 2015). The descriptive method corresponds to the problem investigated in the paper, the nature of which requires describing the process of access to ECI services. This research method is not used to test hypotheses, so quantitative research of this type has research questions, rather than hypotheses (Creswell, 2018). This paper aims to answer the following major research questions:

1. How are ECI screenings and comprehensive developmental assessments conducted?
2. What types of ECI services and support do families receive?
3. Is ECI in North Macedonia contemporary and family-centered?

This type of research design uses multiple data collection techniques, including the survey technique that was used in this study. This technique was used because it allows a quantitative description of the characteristics, processes and perceptions of the selected sample, as well as a fast, functional and economical way of data collection (Creswell, 2014; Fowler & Cosenza, 2020). The survey questionnaire, which was used as a measuring instrument to obtain answers to the research questions defined in this paper, was composed of 32 questions. For the purposes of this research, two different procedures CAWI (Computer-assisted Web Interviewing) and PAPI (Pen-and-Paper Personal Interviewing) were used to collect data. The first procedure included families who answered the online version of the questionnaire, which was published on social networks. Parents of children with developmental delays/disabilities, served in four different ECI programs, located in Skopje, were presented with the questionnaire in paper form (second procedure). The survey questionnaire in both procedures was conducted simultaneously and was available for a duration of two months (October-November, 2023). The reasons behind using two different approaches in data collection comes down to easier access to respondents, as well as time management.

The sample of this research consists of 78 parents of children with a developmental delay or disability, age 3 to 10 years (71.7% boys; 28.3% girls). The sample includes families who used ECI services, treatment or other type of professional support due to their child's condition, in a period of at least 6 months until the time of the research. The largest number of respondents were the children's biological mothers (82.6%), the rest of the answers to the surveys were received from the biological fathers.

Results

The demographic analysis showed that the largest percentage of families (70.5%) at the time of the research have a permanent residence in Skopje. The remaining families (25.6%) are from 13 other cities in Macedonia. Only 3.9% of the families included in the research lived in rural areas which shows that children with developmental delays and/or disabilities are underserved. All 22 families living in other cities or rural areas outside Skopje received ECI services in Skopje. Some 74.1% of the children had difficulties in communication and delayed speech development, 67.6% had behavioral problems, 25.6% have intellectual disabilities, 24.7% had visual impairments, 14.3% had hearing impairments. Some 9.1% were diagnosed with epilepsy and 6.5% had physical disabilities. Developmental delay was confirmed in 6.5% of children.

At the time of the research, 70.5% of families were beneficiaries of financial assistance provided through the Ministry of Labor and Social Policy. More than half of the families (52.5%) used compensation due to disability, 28.2% of families received minimum financial assistance, 25.6% social health insurance, 23.0% compensation for part-time work due to care of a child with a disability and the severe chronic diseases and 8.9% of families used a housing allowance.

1. ECI screenings and comprehensive developmental assessments

When there are biological risks (at-risk pregnancy and premature birth, complications during childbirth, low birth weight) or disabilities that can be diagnosed shortly after birth, early intervention is a relatively quick and efficient process (11.5% of families). Parents connect with professionals through neonatology departments and start using early treatment services in the first three months after birth. In the largest percentage (80.8%) families initially show concern about the child's development - 78.2%. In 2.6% it is another member of the family. Developmental delays are detected by professionals in 19.3% of cases: 11.5% by pediatricians, 5.2% by neurologists and 2.6% by neonatologists (as shown in Table 1).

Table 1

Detection of developmental delays/disabilities

	N	%
Parents	61	78.2%
Other family member	2	2.6%
Pediatrician	9	11.5%
Neurologist	4	5.2%
Neonatologist	2	2.6%

For a formal assessment of their child's development, families visit private centers, public health institutions and clinics that offer assessment services. Some 14.1% of the families used services outside the country due to the lack of specific tests, assessments and specialists in the area.

For the assessment, families listed a total of 15 different profiles of professionals who performed an assessment of the development and health status of their child: special educator and rehabilitator, neurologist, psychologist, pediatrician, child psychiatrist, speech therapist, audiologist, ophthalmologist, physical therapist, orthopedist, physiatrist, ENT specialist, social worker, endocrinologist and geneticist (see Table 2).

Table 2

Professionals who participated in the assessment

	N	%
Special Educator and Rehabilitator	45	58.4%
Neurologist	45	58.4%
Psychologist	42	54.5%
Pediatrician	37	48.1%
Child psychiatrist	23	29.9%
Speech therapist	20	26.0%
Audiologist	17	22.1%
Ophthalmologist	15	19.5%
Physical therapist	8	10.4%
Physiatrist	4	5.2%
Orthopedist	4	5.2%
ORL specialist	3	3.9%
Social worker	2	2.6%
Geneticist	1	1.3%
Endocrinologist	1	1.3%

Families (80.8%), that is, parents in the largest percentage (78.2%) are those who first show concern about the child's development and recognize the potential need for support. The average age at which developmental concerns are expressed in our sample is 8 months, the average age of referral for ECI services is 18 months (Median=18.00) and initiation of early intervention services at 32 months of age (Median=32.00). This means that 43.7% of families are successfully involved in early intervention programs and receive support services before the child's third birthday.

2. ECI services and support of families

The largest percentage of families (60.3%) stated that they used special education and rehabilitation services for stimulation and early rehabilitation treatment, 55.6% used services for speech-language therapy and 33.8% used services for physical therapy, Some 7.7% used services for auditory training and hearing rehabilitation and 6.5% of families use psychological support services. The frequency of the intervention was measured by the total number of therapeutic visits in one week. The average number of therapeutic visits per week is three visits (Mean=3.00). The largest percentage of families, 25.6%, visit a therapist once a week. A same percentage of parents (25.6%) visit a therapist four times a week, 21.8% twice a week, 10.3% three times a week, 6.4% five times a week.

Services are usually (71.4%) conducted in ECI centers. Home services are received by

28.6% of the families, of which 10.3% receive support only in the home, while 18.3% receive combined support in the home and in ECI centers (see Table 3). Families receive support services in the home from a special educator and rehabilitators (10.4%), physical therapists (10.4%) and speech therapists (7.8%).

Table 3

ECI service delivery and support for families

	N	%
ECI center	55	71.4 %
ECI center and home-based services	14	18.3 %
Home-based services	8	10.3 %

Half of the families (53.8%) stated that they cover the costs of all intervention services - Parental fees, the remaining 46.2% of the families received certain services for free: services from a speech therapist 23.7%, services from a physical therapist 21.1% and services from a specialist - a special educator and a rehabilitator were received by 19.7% of families. A total of 21.7% of families use free orthopedic, hearing or other medical aids (see Table 4).

Table 4

Free of charge ECI services

	N	%
Parental fees	42	53.8%
Free of charge services:	36	46.2%
Speech and language therapy	19	23.7%
Physical therapy	17	21.1%
Early stimulation and early treatment	16	19.7%
Medical aids	21	21.7%

Some 61.6% of developmental delays are noticed before the child's first birthday; the highest percentage (21.8%) in the first 30 days after birth, a total of 36% in the first three months, 43.7% up to the sixth month, up to nine months of age a total of 57.8% of children (Table 16). The average age at which concern about children's development is first shown is 8 months (Median = 8.00).

The percentage of families who received an assessment for the need of additional support for the development of their child up to 35 months of age is 69.4%. The average age at which the need for additional support for the child's development is confirmed is 18 months (Median = 18.00), that is, approximately 50% of children are diagnosed up to 18 months of age and the same percentage from 18 to 48 months of age.

According to the received data, a total of 43.7% of children have been detected, diagnosed and covered by a certain type of stimulation services or early rehabilitation treatment, up to the age of three. The largest percentage of families (24.4%) start intervention services from 48 to 52 months of age; 21.8% from 36 - 47 months, 16.7% from 24 to 35 months, 15.4% between 12 and 23 months. In the first 11 months of the child's development, 11.6% of the families report that they used early intervention services; the remaining 10.1% start services after 60 months of age.

The data show that the average age at which developmental delays are first noticed in children is 8 months, the average age of developmental assessment and diagnosis of disabilities is 18 months, while the age at which ECI services begin is 32 months (shown in Table 5).

Table 5

Average age for detection, developmental assessment and onset of ECI services

	Detection	Assessment	ECI services
Median	8.00 months	18.00 months	32.00 months
Minimum	After birth	After birth	First three months
Maximum	42 months	48 months	84 months

The average time that passes from the moment when concern about the child's development has risen, to the moment of diagnosis and referral for services is 10 months (Table 6). Responses to the time frame varied, from immediately after detection of the disability to 38 months, which would mean that some families had a formal assessment done 38 months after the onset of the first concern regarding the development.

Table 6

Time frame from detection to assessment and onset of ECI services

	From detection to assessment	From assessment to services
Median	10.00 months	14.00 months
Minimum	Assessment done immediately	Immediately after assessment
Maximum	38 months	42 months

Regarding the percentage of families receiving services and support in the family's home, data showed that only 28.6% of families receive support outside ECI centers (10.3% receive services only in the family's home, 18.3% simultaneously receive services in the home and in an ECI center), while the remaining 71.4% of families receive support exclusively in ECI centers.

3. Including families as active ECI partners

Regarding the involvement of families in service planning, parents state that 37.7% of

professionals take into account their goals and priorities regarding their child's development, the family's resources - 24.1%, the family's opinion regarding the frequency of support and the services they need - 18.2% and the routine of the family, activities and organization in time during the day - 10.4%.

Regarding the involvement of families in the implementation of the intervention, the largest percentage of families (64.3%) stated that they are not present during the intervention, the professionals work individually with the child and then inform them about what was done during the treatment. Some 29.2% of the families answered that although they are not present at the treatments, they receive instructions, exercises and activities from the experts that they can apply at home. Only 6.4% of the families were present during the intervention: - 3.8% were present during the intervention and observed what was being done with the child, 2.6% answered that during the intervention the professionals demonstrated to them how they should carry out the exercises with their child. This is shown on Table 7 below.

Table 7

Including parents in the intervention

	N	%
Not present during intervention	50	64.3%
Not present during treatments, but get directions and exercises	23	29.2%
Attend and observe during sessions	3	3.9%
Attend and are included in the intervention	2	2.6%

The data from this research show that service providers in a small percentage take into account the family's concerns and priorities regarding the development of their child (37%), the family's resources (24.1%), the family's opinion regarding the frequency of support and the services they need (18.2%), and the routines of the family and the organization of time during the day (10.4%).

Only 6.4% of families are present during the therapeutic visits (3.8% were present and observed what was being done with the child, 2.6% answered that during the therapeutic visits, the therapists demonstrate to them how to implement exercises and strategies with their child); 29.2% of the families, although they were not present during the therapeutic visits, were in communication with the therapists and received instructions, exercises and strategies that they can apply in the daily routines of the family. The remaining 64.3% of the families are not involved in the intervention of their child and the communication with the therapists is reduced to brief information about what was done during the visit.

Discussion

As in other studies (Bailey et al., 2004; Sapiets et al., 2021; Friedman, Woods, Salisbury, 2012) parents in the largest percentage (78.2%) are those who first show concern about the child's development and recognize the potential need for support. Compared to other research (Bailey et al., 2004; Guralnick, 2007; Hebbeler et al., 2007; Tomris, 2022) the data from this research show that, although the average age at which families first show concern

about the child's development is 8 months, there is a delay in the process from the referral to the start of intervention services. Once the family or another person shows concern about the child's development, the next step is a formal developmental assessment to identify specific developmental disorders or disabilities (Bricker et al., 2013) which was shown with this research as well.

This research showed that the most common frequency for delivery of services is three times per week, typically with different professionals. However, some research (Dunst, Hamby & Brookfield, 2007; Dunst, Brookfield, & Epstein 1998; Shonkoff et al., 1992) shows that greater frequency of early intervention services per week is actually negatively correlated with family well-being, due to factors such as are difficulties in coordinating services, interruption of the family's daily routines, obtaining different information and directions from multiple service providers; factors identified by families as contributing to higher levels of stress. Learning opportunities during the day and activities that take place between therapeutic visits should also have a certain frequency, focus and intensity, in order to reduce the frequency of therapeutic visits, by taking advantage of learning experiences during the day, which can to demonstrate measurable functional progress in the child and benefits to families (Dunst, 2012).

More than 30 years of research work shows that young children with developmental delays and disabilities do benefit and do better if they receive support in natural environments that are typical of children without disabilities (Zwaigenbaum et al., 2015; Campbell, Sawyer, & Muhlenhaupt, 2009; Guralnick, 2001; Bruder, 2001; Bruder & Staff, 1998). To take advantage of all available learning opportunities throughout the day that have the potential to improve a child's behavior and development, therapists working with families need to plan strategies that can be implemented in all environments in which the child spends time throughout the day (Swanson, Raab, & Dunst, 2011; Campbell, 2004, Dunst et al., 2001). Learning opportunities that have the potential to enhance a child's development can be in many different contexts and environments, including family routines and everyday family activities, such as playing with water at bath time, during family meals, listening to a story or greeting relatives during family gatherings. These same learning opportunities exist in community contexts: a neighborhood walk, a children's playground, a city park, children's events, or public swimming pools (Campbell, Sawyer & Muhlenhaupt, 2004; Dunst, 2000). Including intervention and support strategies in all these environments or contexts facilitates children's access to more learning opportunities throughout the day, interacting with their peers without disabilities (Shelden & Rush, 2013; Swanson, Raab & Dunst, 2011; Bruder, 2010; Dunst, Hamby, & Brookfield, 2007).

Regarding the involvement of families in the planning and implementation of intervention services, there are at least three aspects on which there is general consensus (Sapiets, Totsika, & Hastings, 2021; Bailey, 2021; Bailey et al., 1999). First, the planning of services and support should be individualized for each family and based on the family's concerns and priorities, formal and informal resources and routines. Second, parents should be given every opportunity to participate as active partners in the planning of services for their child and themselves, as well as in the implementation of the intervention itself, requiring professionals to apply practices that recognize, value and support this type of relationships. Third, because families are the ultimate decision-makers and providers of long-term care for their children, services should be organized in ways that enable families to feel and be competent in advocating their rights and providing services for their children's needs. The data from this research show that service providers in a small percentage take into account the family's concerns and priorities regarding the development of their child (37.%), the family's resources (24.1%), the family's opinion regarding the frequency of support and the services

they need (18.2%), and the routines of the family and the organization of time during the day (10.4%).

Historically, the field of ECI advocates the use of family-centered practices and promotes the active participation of families in setting goals and making decisions related to services and supports for their child (Friedman, Woods, & Salisbury, 2012; Bruder, 2000). Families have a major impact on child developmental progress (Dunst, Trivette, & Hamby, 2006; Hanson & Lynch, 2004; Dunst, 2000; Shonkoff & Phillips, 2000), especially if they are involved in interventions for children under three years of age (Bailey et al., 2004; Blauw-Hospers & Algra-Hadders, 2005), so emphasis is being placed on the role of therapists in building the capacity of families to encourage the development of their children in the context of their daily routines and activities (Campbell & Sawyer, 2007; Dunst, Hamby, Trivette, Raab, & Bruder, 2000). Research shows that building the capacity of families is possible when therapists offer support for: strengthening the parent-child relationship and interaction, support for building the confidence and capacity of families to encourage their child's development, and support for achieving goals that families themselves identified them (Guralnick, 2011). To be able to offer this support, therapists need to strengthen and expand their specific knowledge and acquire skills in coaching parents during therapeutic visits. Some research shows that using family training during intervention can be challenging for therapists (Fleming, Sawyer, & Campbell, 2011; Campbell & Sawyer, 2007; Peterson, Luze, Eshbaugh, Jeon, & Kantz, 2007; Salisbury, Woods, & Copeland, 2010), for a number of reasons. One reason is the gap between theory and practice (Bruder, 2000; McWilliam, 1999). On one hand, researchers often describe variables and outcomes rather than specific strategies that practitioners can use in their work with families; on the other hand, practitioners may not have the time or interest in reading research (Bruder, 2000; McWilliam, 1999). McWilliam (1999) states that perhaps "professionals who have the time and inclination to keep up with published research often tend to believe only research that supports their values". Another reason may be the lack of effective education and training for family-centered practices, as practitioner training focuses on developing specific skills and knowledge for working with children and involves very little direct contact with families (Bruder, 2000; Bailey et al., 1999).

In summary, in this study we tried to describe the framework of access to ECIs and the key components of the process we gave an overview on several aspects of services. Many studies well as the data shown in this study point to the fact that ECI services in North Macedonia should transit towards the contemporary ECI practices where ECI is conducted in natural environments rather than in traditional rehabilitation centers.

ECI should be based on the social model and it should be individualized, continuous and intensive. All ECI services should be evidence-informed, outcome driven and based on the transdisciplinary model. First and foremost, ECI must be family-centered. All key decisions should be made by the parents and they should be empowered to do so. Most importantly, ECI should build strong relationships with families. The family-focused approach leads to better child development outcomes.

The data obtained from this research can be a useful starting point for further research. The enlargement of the sample as well as the adjustment of the research design, can provide missing knowledge about the Macedonian context of delivery of services for ECI and family support. The knowledge gained from this study can also be applicable in other countries with similar ECI systems.

Conflict of interests

The authors declare no conflict of interest.

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