RESEARCH ARTICLE / ARAŞTIRMA MAKALESİ

DOI: 10.4274/atfm.galenos.2025.14892
J Ankara Univ Fac Med 2025;78(1):33-41

MEDICAL SCIENCES / DAHİLİ TIP BİLİMLERİ

Family-Centeredness of Special Education and Rehabilitation Services for Young Children with Special Needs in Türkiye

Türkiye'de Özel Gereksinimleri Olan Çocuklara Erken Çocukluk Döneminde Verilen Özel Eğitim ve Rehabilitasyon Hizmetlerinin Aile Merkezliliğinin Değerlendirilmesi

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Abstract

Objectives: This study aims to evaluate the family-centeredness of early childhood special education and rehabilitation services and assess families' satisfaction with these services.

Materials and Methods: This cross-sectional study included 3-36 months-old children with special needs and their families who have been followed up at Ankara University Faculty of Medicine, Department of Pediatrics, Division of Developmental Pediatrics between 2014-2017 and receiving early intervention services for at least 3 months. The "Early Childhood Development Support Services Evaluation Scale" assessed the family-centeredness of these services.

Results: A hundred and one children were included in the study. The median age of the children was 33 months, and 51.5% were male. Neurological disorders were present in 45.5%, and genetic disorders in 35.6%. Developmental evaluations showed 68.3% of children had special needs in expressive language, 64.4% in gross motor skills, and 62.4% in receptive language. At least half of the families rated the centers as "inadequate" on at least half of the scale. However, despite this, more than half of the families reported high satisfaction in terms of "completely finding what they were looking for", "choosing the institution again", and "recommending it to others.

Conclusion: This study showed that, despite finding the early intervention services for young children with special needs in Türkiye to be inadequate regarding family-centeredness, the families remain generally satisfied. This study is significant in guiding efforts to develop family-centered early intervention services and enhancing families' awareness and demands in this area, particularly in Türkiye and other similar low- and middle-income countries.

Keywords: Family-centered care, early intervention services, children, special needs, disability

Öz

Amaç: Aile merkezli yaklaşım, erken çocukluk döneminde özel gereksinimleri olan çocukların tedavisi niteliğinde olan özel eğitim ve rehabilitasyon hizmetlerinin temel taşıdır. Bu araştırmanın amacı, erken çocukluk döneminde özel gereksinimleri olan çocukların almakta olduğu özel eğitim ve rehabilitasyon hizmetlerinin aile merkezliliğinin ve ailenin kurum hakkındaki memnuniyetlerinin değerlendirilmesidir.

Gereç ve Yöntem: Kesitsel desendeki bu araştırmaya 2014-2017 yılları arasında Ankara Üniversitesi Tıp Fakültesi, Çocuk Sağlığı ve Hastalıkları Anabilim Dalı, Gelişimsel Pediatri Bilim Dalı'nda izlenen 3-36 aylık, özel gereksinimi olan ve en az 3 aydır erken destek hizmetleri almakta olan çocukları ve ailelerini kapsamaktadır. Hizmetlerin aile merkezli olma özelliğini değerlendirmek için "Erken Çocukluk Döneminde Gelişimi Destekleme Hizmetlerini Değerlendirme Ölçeği" kullanılmıştır.

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Received/Geliş Tarihi: 20.08.2024 **Accepted/Kabul Tarihi:** 27.01.2025 **Publication Date/Yayınlanma Tarihi:** 21.03.2025

Cite this article as/Atıf: Koç Yekedüz M, Özalp Akın E, Bingöler Pekcici EB, et al. Family-centeredness of special education and rehabilitation services for young children with special needs in Türkiye. J Ankara Univ Fac Med. 2025;78(1):33-41

Bulgular: Araştırmanın örneklemini oluşturan 101 çocuğun %51,5'i erkek olup ortanca yaşı 33 ay (25,5-43,0) saptanmıştır. Örneklemdeki çocukların %45,5'inde nörolojik, %35,6'sında genetik hastalığı mevcuttur. Ayrıntılı gelişimsel değerlendirmede çocukların %68,3'ünde anlatım dili alanında, %64,4 kaba hareket alanında, %62,4'ünde alıcı dil alanında özel gereksinimi saptanmıştır. Ailelerin en az yarısı, ölçeğin en az yarısında kurumları "yetersiz" olarak değerlendirmiştir. Ancak, buna rağmen ailelerin yarısından fazlası "aradıklarını tamamen bulma", "kurumu tekrar seçme" ve "başkalarına önerme" konularında yüksek memnuniyet bildirmiştir.

Sonuç: Bulgularımız, çocuklarının hizmet aldıkları kurumları aile merkezli hizmet açısından yetersiz olarak bildirmelerine karşılık ailelerin çoğunun kurumlarından memnun olduklarını göstermektedir. Bu araştırma, aile merkezli erken destek hizmetlerinin geliştirilmesi yanında, ailelerin bu konuda taleplerinin olgunlaştırılması konusunda Türkiye'de ve benzeri düşük-orta gelirli ülkelerde yapılacak çalışmalara ışık tutması açısından önem taşımaktadır.

Anahtar Kelimeler: Aile merkezli hizmet, erken destek hizmetleri, çocuk, özel gereksinim, engellilik

Introduction

The family-centered approach is recognized as a cornerstone in early support, rehabilitation, health, and educational services for children at high risk due to chronic physical, developmental, behavioral, or emotional conditions or those with special needs (1). This approach, widely applied in services for children with special needs over the past thirty years, has been extensively researched in high-income countries (2-4). However, it has yet to be well-known how family-centered these early support services are for young children with special needs in low- and middle-income countries.

Children with special needs are defined as those who have chronic physical illnesses, developmental, behavioral, or emotional difficulties or risks and who require more than their peers. Children with special needs include those with chronic physical illnesses, such as cerebral palsy, epilepsy, or congenital heart disease, which require ongoing medical care and rehabilitation. They may also experience developmental difficulties, including delays in speech, motor skills, or cognitive abilities. Additionally, behavioral challenges, such as difficulty following routines, regulating emotions, or interacting with peers, as well as emotional difficulties, such as trouble adapting to changes in their environment, may also be present (5). According to data from the Centers for Disease Control and Prevention (CDC), a study conducted between 2014 and 2018 found that 17% of children aged 3-17 had special needs (6). According to the 2020 Health Survey data from the Turkish Statistical Institute, the prevalence of children aged 2-14 with special needs in vision, hearing, learning, or motor skills in Türkiye was 8.2% (7). The fundamental approach for children with special needs is early intervention programs. Key components of early support programs include preventing developmental difficulties when possible, integrating prevention with early intervention, reducing risk factors, and integrating early supports with the family.

A review of 55 articles from ten high-income countries found that most families of children with special needs reported that their health and rehabilitation services were planned in collaboration with families and essentially exhibited a family-centered feature (4). Other studies conducted in high-income countries have reported that adherence to family-centered service approaches increased, improved quality of life, and positively affected parents' self-efficacy, motivation, and functionality (2,3).

Family-centered studies in low- and middle-income countries typically evaluate neonatal and pediatric intensive care units or children's hospitals. These studies have shown that health services do not adequately meet family-centered characteristics (8-11). A recent study in Türkiye assessed the family-centeredness of special education and rehabilitation services for children diagnosed with Down syndrome during early childhood. The study found high scores in "respectful and supportive care" and low scores in "provision of specific information", emphasizing the urgent need to address service deficiencies, especially among mothers with lower educational levels (12). In Türkiye, thesis research conducted in 2005 at (Ankara University Faculty of Medicine, Department of Pediatrics, Division of Developmental Pediatrics) investigated the suitability of family-centered early support services in early intervention services where children receiving special education or rehabilitation services attended. The study involved home visits with the families of 54 children aged between 10 months and ten years. According to this study, families reported inadequacies, particularly in "guidance on how to raise the child", "considering the family's opinions on what would benefit the child while preparing the educational program", and "asking the family about their feelings" (13). The extent to which the services provided to children with developmental issues are family-centered remains to be discovered, and there is no recent study to clarify whether progress has been made in this area in the last decade.

Among the early intervention programs in Türkiye, the Mother Child Education Program *[Anne Çocuk Eğitim Programı* (AÇEP)], the Portage Project, and the Small Steps Early Education Project stand out. AÇEP, although a program focused on empowering families, does not adequately cover the needs of children under the age of three or those with developmental delays (14). The Portage Project, recognized for its applicability in home settings, has shown that families struggle to sustain the recommended practices without guidance The Small Steps Project has been evaluated as an effective program for children with developmental risks; however, it does not fully meet family-centered criteria. There is a significant need for new interventions in Türkiye to address the needs of children with developmental delays and studies to bring these issues to the forefront (15-18).

This study aims to evaluate the family-centeredness of special education and rehabilitation services received by children with special needs during early childhood and assess the family's satisfaction with the early intervention service. This study will contribute to the perspective of low- and middle-income countries, which are underrepresented in the literature, through the context of Türkiye and the population it represent.

Materials and Methods

This cross-sectional, observational study included children who admitted to Ankara University Faculty of Medicine, Department of Pediatrics, Division of Developmental Pediatrics between October 2014 and September 2017. The sample consisted of children aged 0-36 months diagnosed with special needs in at least one area and referred for special education and/or physiotherapy and rehabilitation services. The children and their families who consented to participate in the study received at least one of these services for at least three months.

Families who agreed to participate in the study underwent comprehensive, family-centered developmental assessments. This evaluation lasted approximately 1.5 hours and included a detailed history, physical examination, developmental assessment using the standard "The Expanded *Guide for Monitoring Child Development*" (19), and observational methods. The "Early Childhood Development Support Services Evaluation" Scale was used to assess the family-centeredness of the services (13). All other evaluations were conducted within routine clinical services.

Tools

The Expanded Guide for Monitoring Child Development

The Guide for Monitoring Child Development (GMCD), developed by Ertem et al. (20) and Ertem (21), addresses the lack of a standardized child development assessment tool suitable for health services (20). International validation studies, supported by the NIH, were conducted between 2010 and 2015 in Argentina, South Africa, India, and Türkiye with 12,000 children (21). The GMCD, the only internationally standardized tool of its kind, has trained experts in over 30 countries. Its extended version, the Expanded GMCD (E-GMCD), incorporates the World Health Organization (WHO), International Classification of Functioning, Disability and Health (ICF) framework and was developed in 2010 at Ankara University Faculty of Medicine, Department of Pediatrics, Division of Developmental Pediatrics. E-GMCD uses open-ended, parent-answered questions to provide detailed information on the child, family, and environment, enabling pediatricians to assess 95% of ICF domains (19). In our study, E-GMCD was used for comprehensive developmental assessment and to collect environmental data.

The ICF framework, developed by the WHO, provides a standardized approach to understanding and documenting health and disability. It emphasizes the interplay between an individual's physical and mental functions, activities, participation in daily life, and environmental and personal factors, offering a holistic perspective on health and well-being.

Early Childhood Development Support Services Evaluation Scale

In Türkiye, due to the lack of tools to evaluate the quality and quantity of services provided to children aged 0-3 with developmental issues, the "Early Childhood Development Support Services Evaluation Scale" was developed in 2005 at Ankara University Faculty of Medicine, Department of Pediatrics, Division of Developmental Pediatrics. During the development of the scale, the National Early Intervention Longitudinal Study (NEILS) (22), The Children with Special Health Care Needs (CSHCN) Screener (23), Measurement of Client Satisfaction (24), Consumer Evaluation of Child Health Services in the Non-government Sector in Hong Kong (25), and early support services evaluation scales used by Yale University (22-25) were utilized. In addition to questions derived from the global literature, open-ended questions were added by the researchers to align with our country's socio-cultural and educational system. After the draft form of the scale was created, feedback was collected from experienced experts working in the field nationally and internationally regarding how well the scale's questions and areas assessed family-centeredness. After two years of work, expert opinions, group meetings, and feedback from pilot studies led to a final version of the scale. The scale consists of 22 items under the subheadings of "family information", "sharing and supporting family feelings and thoughts", and "assessment and support of the family's socio-economic situation."

The parameters emphasized for determining satisfaction include communication and information sharing between the service provider and family, emotional support for the family, and addressing socio-economic challenges that may impact access to services.

The scales and data were completed step by step by the child's guardian under the supervision of the researchers to ensure no details were missed. All open-ended questions were thoroughly discussed, and responses were recorded based on a mutual agreement to achieve the most accurate results. For multiple-choice questions, the most appropriate option was selected.

General Satisfaction Questionnaire

To determine the general level of satisfaction with the early intervention services, questions such as "I found what I was looking for at the early intervention services", "If I had to choose again, I would select this early intervention services", "I would sincerely recommend it to other families with similar issues", and "If I had the opportunity to go to another early intervention services, I would immediately switch" were evaluated with "yes" or "no" responses.

Statistical Analysis

Descriptive statistics were given with percentages for categorical variables and mean ± standard or median (minimum-maximum) for numerical variables. The normality of numerical data was assessed using histograms, coefficient of variation, kurtosis-skewness, Detrended plot distribution, Kolmogorov-Smirnov, or Shapiro-Wilk tests. A chi-square test was used to evaluate the associations between categorical parameters. A p-value of less than 0.05 was considered statistically significant.

Statistical analyses were performed using the SPSS 20.0 software package. The research has received approval from the Ethics Committee of Ankara University Faculty of Medicine (decision number: I2-701-17, date: 24.07.2017). All participants have signed the informed consent form and approved the study.

Results

During this study, 2,158 children applied to (Ankara University Faculty of Medicine, Department of Pediatrics, Division of Developmental Pediatrics). Of these, 122 children met the sample entry criteria, and three were excluded. Of the 119 children constituting the sample, 101 (85%) were reached and included in the study. A total of 18 children were excluded from the study: six could not be reached by phone, seven had families who did not consent to participate, and five could not attend the hospital on the appointment date.

Among the children in the sample, 51.5% were male, and the median age was found to be 33 months (25-75 percentile: 25.5-43.0). More than half of the children (58.4%) have at least one sibling. Most mothers (68.3%) and fathers (76.2%) have a high school education or higher. Consanguinity between spouses was reported in 15.8% of the families. Other sociodemographic characteristics of the sample are detailed in Table 1.

Table 1: Sociodemographic characteristics of children and their families

Sociodemographic characteristics	**n (%)**
Child's gender	
Male	52 (51.5)
Female	49 (48.5)
Child's age (months)	
11-24	22 (21.8)
25-36	37 (36.6)
37-48	24 (23.8)
49-60	18 (17.8)
Gestational age	
Term birth	69 (68.3)
Preterm birth	32 (31.7)
Mother's education level	
Primary school graduate	12 (11.9)
Secondary school graduate	20 (19.8)
High school graduate	42 (41.6)
College graduate and above	27 (26.7)
Father's education level	
Primary school graduate	5 (5.0)
Secondary school graduate	19 (18.8)
High school	44 (43.6)
College graduate and above	33 (32.7)
Number of siblings	
0	42 (41.6)
1	33 (32.7)
2	19 (18.8)
3 or more	7 (6.9)
Consanguineous marriage	
No	84 (83.2)
Yes	16 (15.8)
Unknown	1 (1.0)
Condition of the residence	
Apartment	89 (88.1)
Rented	49 (48.5)
Homeowner	41 (40.6)
Living in a relative's home without paying rent	11 (10.9)
Shanty house	7 (6.9)
Detached house	5 (5.0)
Presence of computer at home	
Yes	41 (40.6)
No	42 (41.6)
Presence of internet at home	
Yes	35 (34.7)
No	51 (50.5)
Presence of car	
Yes	50 (49.5)
No	51 (50.5)
Monthly income (Turkish Lira)	
Minimum wage and below	51 (50.5)
Above minimum wage	50 (49.5)

Neurological disorders were present in 45.5% of the children, and genetic disorders were present in 35.6%. Detailed developmental assessments revealed special needs in 68.3% of the children in expressive language, 64.4% in gross motor skills, and 62.4% in receptive language. When evaluating activities and participation in life as per the ICF framework in E-GMCD, it was found that more than two-thirds of the children did not participate in family visits, and more than three-quarters did not engage in activities such as visiting parks, nature, or playing with other children. Approximately one-third of the families reported that their environment is prejudiced (Table 2).

The most frequently received services from the early intervention services were individual special education (82.2%) and physiotherapy (67.3%). 101 children attended 57 different early intervention services, evaluated with this scale. Responses coded as "never/not at all" and "rarely/seldom" were considered indicative of "insufficient" service, and the deficiencies of the early intervention services in relevant areas are presented in Table 3.

In the area of "informing families", approximately half of the families reported the early intervention services as insufficient in providing "home services when the family cannot attend due to health issues", "organizing the educational program to assist with daily activities such as eating and dressing", and "guidance on how the family should raise their child."

In the area of "sharing and supporting the family's feelings and thoughts", about half of the families found the early intervention services inadequate in providing "support for parents to share tensions or issues with their spouses", "support for parents to share new changes or difficulties affecting their lives at home", and "support for parents to share feelings of sadness, exhaustion, or helplessness."

In the area of "evaluating and supporting the family's socioeconomic status", more than half of the families considered the early intervention services inadequate in "inquiring about the family's financial difficulties", "informing about other assistance organizations the family can benefit from", "gathering information about the family's work conditions", and "creating opportunities for the family to interact with other families to share information and feelings" (Table 3).

When overall satisfaction with the early intervention service was assessed, more than half of the families (63.4%) reported that they found what they were looking for, 78.2% indicated they would choose the early intervention service again if needed, and 81.2% stated they would sincerely recommend it to other families with similar issues. However, 28.7% of the families mentioned changing early intervention services immediately if given the opportunity.

Twenty-nine families (28.7%) had previously changed early intervention services. Among those who changed early intervention services, 68.9% did so due to dissatisfaction. Reasons for changing early intervention services included address changes (10.3%), changes in specialists/educators (6.8%), the required service not being provided at the early intervention service (6.8%), and additional charges during the educational process (6.8%).

The frequency of changing early intervention services was examined based on the mother's education level (below high school vs. high school or higher; n=8, 25% vs. n=21, 30.4%, respectively), and no significant difference was observed (p=0.574). Similarly, when evaluating income groups presented in Table 1, no difference was found regarding the frequency of changing early intervention services (p=0.791). The mother's and father's education levels and the family's income levels were compared across all parameters of the Early Childhood Development Support Services Evaluation Scale, and no significant differences were found between groups (p>0.005). An interesting shared comment from two families who had changed centers emerged from the open-ended questions: "We hadn't fully evaluated how sufficient our previous center was, but we decided to change institutions, wondering if there could be a better option. If the progress or challenges in our child had been more clearly communicated to us, and if better communication had been established, we would have been able to more clearly understand how satisfied we were and how much our child benefited from that institution".

Discussion

This study has showed that at least half of the families of young children with special needs rated family centeredness of special education and rehabilitation services as inadequate in Türkiye. This study is significant in reflecting recent developments in family-centered practices in our country.

Numerous studies have been conducted in high-income countries in this area. One of the most comprehensive studies was conducted by Bailey et al. (22) in the United States in 2004, where 81% of families reported that decisions regarding the educational program were made in conjunction with them. In contrast, our study found this proportion to be 68%. The earlier initiation and progress of family-centered early intervention programs in the U.S. compared to the practices in our country may account for this difference. Research from various countries has indicated a need for more family information. For instance, in Hong Kong in 2003, Chan and Twinn (25) used a scale to assess the family-centeredness of early intervention programs for 246 children. They reported dissatisfaction with the lack of time and attention given by professionals and insufficient listening to their concerns. While only 29% of families in that study found the information provided about their child's developmental status sufficient, our study found this proportion to be approximately 50%. The discrepancy might be attributed to including younger children, better-educated mothers, and families with higher income levels in their data, which contrasts with the sociodemographic characteristics in our study.

Table 2: ICD diagnoses, areas of special needs, participation in daily life, and environmental stressors of children

Category	Subcategory	n (%)
ICD diagnosis groups of children	Neurological disorders	46 (45.5)
	Genetic disorders	36 (35.6)
	Cardiovascular disorders	19 (18.8)
	Nephrological disorders	14 (13.9)
	Orthopedic disorders	14 (13.9)
	Respiratory system disorders	9 (8.9)
	Endocrinological disorders	6 (5.9)
	Allergic disorders	4 (4.0)
	Gastrointestinal disorders	3 (3.0)
	Immunological disorders	2 (2.0)
	Hematological disorders	2 (2.0)
	Oncological disorders	1 (1.0)
Areas of special needs	Expressive language	69 (68.3)
	Gross motor skills	65 (64.4)
	Receptive language	63 (62.4)
	Attention	53 (52.4)
	Feeding issues	44 (43.5)
	Psychological/behavioral issues affecting learning	33 (32.7)
	Sleep problems	32 (31.6)
	Fine motor skills	30 (29.7)
	Play	22 (21.8)
	Social interaction	20 (19.8)
	Self-care	19 (18.8)
Participation in daily life	Participation in visits to relatives	
	Never	68 (67.3)
	Once a week	24 (23.8)
	Twice a week	5 (5.0)
	Three times or more a week	4 (4.0)
	Participation in playgrounds and parks	
	Never	87 (86.1)
	Once a week	8 (7.9)
	Twice a week	2 (2.0)
	Three times or more a week	4 (4.0)
	Participation in nature or play with animals	
	Never	87 (86.1)
	Once a week	9 (8.9)
	Twice a week	3 (3.0)
	Three times or more a week	2 (2.0)
	Participation in play with other children	
	Never	89 (88.1)
	Once a week	7 (6.9)
	Twice a week	1 (1.0)
	Three times or more a week	4 (4.0)
Environmental and family stressors	Community prejudice	30 (29.7)
	Unemployment	17 (16.8)
	Maternal depression	17 (16.8)
	Siblings' issues	13 (12.9)
	Paternal depression	11 (10.9)
	Lack of support from relatives/friends	9 (8.9)
	Sick family member	6 (5.9)
	Family conflict	4 (4.0)
	Job/city change	4 (4.0)
	Domestic violence	1 (1.0)

ICD: International classification of diseases

Table 3: Evaluation of family-centered approaches in early intervention services attended by children

Category	Subcategory	Inadequate
1. Family information		
1j	Provision of home services when the early intervention services cannot be visited due to health issues	88 (87.1)
1g	Adjustment of the educational program to assist with daily activities such as eating and dressing	53 (52.5)
1e	Guidance for the family on how to raise their child	51 (50.5)
1d	Information for the family on daily care of the child	45 (44.6)
1c	Informing the family about the child's activities through an activity log	42 (41.6)
1f	Provision of useful homework to encourage family time with the child	37 (36.6)
1h	Addressing the child's health issues	35 (34.7)
1k	Consulting the family on what would benefit the child when preparing the educational program	32 (31.7)
1a	Helping the family understand the child's behavior	26 (25.7)
1l	Providing adequate answers to the family's questions at all times	23 (22.8)
1ı	Making educational sessions fun to increase child participation	17 (16.8)
1b	Informing the family about topics they need assistance with	13 (12.9)
2. Sharing and supporting family feelings and thoughts		
2f	Allowing parents to share and receive support for tensions or issues with their spouses	66 (65.3)
2e	Allowing parents to share and receive support for new changes or difficulties affecting their home life	51 (50.5)
2d	Allowing parents to share their feelings of sadness, exhaustion, or helplessness	50 (49.5)
2a	Asking parents how they feel	42 (41.6)
2b	Supporting parents' self-confidence	35 (34.7)
2c	Creating a warm environment where parents can easily share their emotions	31 (30.7)
3. Assessing and supporting family socioeconomic status		
3b	Inquiring about the family's financial difficulties	73 (72.3)
3c	Informing the family about other aid organizations they can benefit from	65 (64.4)
3a	Gathering information on the family's work conditions	61 (60.4)
3d	Creating opportunities for the family to meet with other families and share information and feelings	60 (59.4)

In a 2016 study in the United States involving 60 children with special needs, families rated early intervention services with "information about the condition" and "partnership with professionals" receiving the lowest scores (3). A 2015 study in Canada evaluated family-centeredness in early intervention services serving 143 children aged 2-18 years with special needs. Families rated the early intervention services' performance in "providing information on child-rearing" and "educating on child training" at 40% and "support in family difficulties" at 60% as inadequate (4). Similarly, our study found that at least half of the families rated these aspects as inadequate. In Italy in 2017, a study involving 382 families of children diagnosed with cerebral palsy and another study in the Netherlands in the same year involving 175 families of children with special needs highlighted "family information" as a crucial centres feature (5,6). Like many international studies, our research identified inadequacies in "information provision." A 2012 study in France with 212 children and their families identified "effective communication between professionals and families" as one of the critical components determining family satisfaction with early intervention services (7). Our study also found that the significant dissatisfaction reported in open-ended questions was due to "insufficient information and communication issues."

Comparing our results with Özdemir İncesoy and Ertem. (13) study, the first study in our country with similar objectives could provide insights into the development of family-centered services over the past 12 years. However, there are methodological differences. Özdemir İncesoy and Ertem (13) study included 54 children and 36 different early intervention services, whereas ours involved 101 children and 57 different early intervention services. The age range of the children included in Özdemir İncesoy and Ertem (13) study was ten months to 10 years and older. The information reflected by families of older children may differ from that of families with younger children. Analysis explaining the scoring differences is presented in Table 4. To compare our study's data with Özdemir İncesoy and Ertem (13), we included data where frequently applied center features were also considered inadequate. This comparison shows that both studies yielded similar results, indicating a high level of inadequacy in the family-centered features of the early intervention services where the children in the sample received services.

Table 4: Comparison of the Early Childhood Development Support Services Evaluation Scale results with the 2005 research results by Özdemir İncesoy and Ertem (13)

Category	Inadequate (%)*	Inadequate (%)	Inadequate Özdemir İncesoy and Ertem (13) (%)
1. Family information			
1j. Provision of home services when the early intervention services cannot be visited due to health issues	88	92	96
1g. Adjustment of the educational program to assist with the child's daily activities such as eating and dressing	53	75	83
1e. Guidance for the family on how to raise their child	51	83	85
1d. Information for the family about the child's daily care	47	75	73
1c. Informing the family about the child's activities through an activity log	42	64	58
1f. Providing useful assignments to help the family spend time with the child at home	37	63	65
1h. Addressing the child's health issues	35	60	67
1k. Considering the family's opinions on what would benefit the child while preparing the educational program	32	62	85
1a. Helping the family understand the child's behavior	26	67	67
1l. Always providing sufficient answers to the family's questions	23	51	29
1ı. Making educational sessions enjoyable to increase the child's participation	17	47	40
1b. Providing information on topics the family needs	13	45	38
2. Sharing and supporting family's feelings and thoughts			
2f. Allowing parents to share and receive support for tensions or issues with their partners	66	83	92
2e. Allowing parents to share and receive support for new changes or difficulties affecting their lives	51	72	85
2d. Allowing parents to share feelings of sadness, exhaustion, or helplessness with the early intervention services	50	73	77
2a. Asking parents about their feelings	42	72	81
2b. Supporting parents' self-confidence	35	61	81
2c. Creating a warm environment where parents can easily share their feelings	31	61	62
3. Assessment and support of family's socioeconomic situation			
3b. Asking about the family's financial difficulties	72	87	88
3c. Providing information about other aid organizations the family can benefit from	64	81	98
3d. Creating an environment for families to meet, share information, and emotions with others	59	79	77

In our study population, families reported high levels of dissatisfaction regarding the information provided, particularly in the area of "guidance on how to raise their child", where half of the families expressed dissatisfaction. This clearly indicates the need to improve the curricula and family consultations within early intervention programs. However, it is equally important to ensure that families are empowered to demand these services from early intervention programs and to introduce them to the scope of services they are entitled to receive. Both monitoring the quality of these programs and educating families about what constitutes quality service content are essential.

Study Limitations

The strengths of our study include its design, the requirement of a minimum of 3 months of service for inclusion in the sample, and the use of a tool specifically developed for our country. However, the study's generalizability is limited due to the families' educational backgrounds. Our study includes 101 children and their families. To address the generalizability of the findings on a national level, future studies with similar designs conducted in other regions could provide valuable contributions to the literature. In our study, there were children and families who represented the population but were excluded from the sample. Including these excluded groups in the population could have provided a more comprehensive and generalizable perspective. Therefore, the generalizability of our findings is limited by the current sample.

Conclusion

This study showed that, despite finding the early intervention services for young children with special needs in

Türkiye to be inadequate regarding family-centeredness, the families remain generally satisfied. Healthcare providers, other health professionals, advocates, and health policymakers should raise awareness among families of children with special needs about family-centered service practices and requirements. This will ensure that families' service demands are appropriately met and that satisfaction scores reflect the actual quality of services. In our country and likely in other low- and middle-income countries, it is crucial to rapidly improve the awareness of families and service providers and increase the quality of family-centered practices.

Ethics

Ethics Committee Approval: The research has received approval from the Ethics Committee of Ankara University Faculty of Medicine (decision number: I2-701-17, date: 24.07.2017).

Informed Consent: All participants have signed the informed consent form and approved the study.

Footnotes

Authorship Contributions

Concept: M.K.Y., İ.E., Design: M.K.Y., E.Ö.A., E.B.B.P., İ.E., Data Collection and/or Processing: M.K.Y., İ.E., Analysis and/or Interpretation: M.K.Y., E.Ö.A., E.B.B.P., İ.E., Literature Search: M.K.Y., E.Ö.A., E.B.B.P., İ.E., Writing: M.K.Y., E.Ö.A., E.B.B.P., İ.E.

Conflict of Interest: The authors have no conflicts of interest to declare.

Financial Disclosure: The authors declared that this study has received no financial support.

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