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# Views of Parents of Children With Down Syndrome on Early Intervention Services in Turkey

## Problems, Expectations, and Suggestions

***Gozde Tomris, PhD; Secil Celik, PhD; Ibrahim Halil Diken, PhD; Yusuf Akemoğlu, PhD***

Perceptions of parents of young children receiving early intervention are important to understand. Parents have valuable opinions on the delivery of early interventions services and can provide critical feedback that can help professionals revise their existing early intervention delivery modalities. In the current study, we examined the perceptions of parents of young children with Down syndrome on early intervention services in Turkey. Specifically, we aimed to understand the parents' views on medical and educational evaluation and diagnosis processes. The study was conducted using a cross-sectional research design, which is one of the survey design methods. Data were collected from a total of 893 parents via an online survey. The results demonstrated that children with Down syndrome were diagnosed within an average of 2.3 months from birth, but the average age for starting education was 10.5 months. The majority of the parents evaluated the process until their children were diagnosed and accessed education services as a rather slow process that proceeded with their own means and efforts. Furthermore, the parents reported that during the diagnosis processes the type of materials, equipment, toys, and settings used were not relevant and time provided was insufficient. Moreover, the majority of the parents reported that the education services presented to them and their children were not sufficient and early intervention services were not provided within a system. As a result, although the legal regulations in Turkey are parallel to those in developed countries and studies in the field have been increasingly gaining momentum, issues such as the absence of an early intervention system model, insufficient cooperation between experts and institutions, and the shortage of expert staff in the field are still present and awaiting a solution. **Key words:** *Down syndrome, early childhood intervention, early intervention, online survey, parents*

***Author Affiliations:*** *Department of Special Education, Faculty of Education, Eskisehir Osmangazi University, Eskisehir, Turkey (Dr Tomris); Department of Special Education, Faculty of Education, Anadolu University, Eskisehir, Turkey (Dr Celik); Department of Special Education, Faculty of Education, Anadolu University Research Institute for Individuals With Disabilities, Eskisehir, Turkey (Dr Diken); and Department of Special Education, Faculty of Education, Düzce University, Düzce, Turkey (Dr Akemoğlu).*

*The authors declare no conflict of interest.*

***Correspondence:*** *Ibrahim Halil Diken, PhD, Department of Special Education, Faculty of Education, Anadolu University Research Institute for Individuals with Disabilities, Eskisehir, Turkey (ihdiken@anadolu.edu.tr).*

EARLY INTERVENTION (EI) refers to a system of services designed to promote the overall development of young children birth to 5 years of age who have or are at risk for disabilities and/or developmental delays, and provide support to their families. The EI system consists of the child find, diagnosis, evaluation, referral, and service delivery stages and processes. It is a field of study that makes significant contributions to young children with developmental disabilities or

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delays and their families. Although becoming widely popular and available globally, EI varies across countries due to cultural, political, economic, and social differences (Guralnick, 2019; Meisels & Shonkoff, 2000; Odom & Wolery, 2003; Spiker, 2011). When presented within a system model, EI can yield more effective and successful results (Guralnick, 2005).

The primary goal of EI is to provide families with the information, support, and services to enhance their children's development from the earliest years and thus minimize and prevent the likelihood of later impacts of the disability or delay. A high-quality EI system should be based on a family-centered approach that includes evidence-based practices by meeting the priorities and needs of both the child and the family and includes family decisions and active involvement (Bruder, 2010; Dunst, 2007; Kellar-Guenther, Rosenberg, Block, & Robinson, 2014). Thus, the main purposes of a family-centered EI system are to: (a) facilitate the child's participation in family and community activities, (b) encourage active family participation in the intervention process, (c) promote parent competence and confidence in enhancing their child's learning, and (d) deliver services within natural environments (i.e., home and childcare settings) (Dunst, 2007).

However, some findings of relevant literature reveal that the services provided do not fully meet the needs of the child and the family (Carlhed, Björck-Åkesson, & Granlund, 2003; Sarimski, Hintermair, & Lang, 2013; Ziviani, Feeney, & Khan, 2011). Therefore, studies that evaluate the quality of the EI services in line with the perspectives and opinions of different stakeholders involved in this process represent an important agenda topic (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004). Such studies play an important role in comparing the aims and effects of the services provided, identifying the existing problems, evaluating the quality of the provided services or programs, and developing better services (Bailey et al., 2004; Dunst, Hamby, & Brookfield, 2007; Epley, Summers, & Turnbull, 2011; McManus et al., 2020). Parents are one of the key stakeholders that can provide critical input about the existing barriers, and suggest useful solutions (Epley et al., 2011; Lanners & Mombaerts, 2000).

Various studies have been conducted for different disability groups in different countries that evaluate the views, expectations, and problems of parents with regard to EI services (Bailey et al., 2004; Carlhed et al., 2003; Dromi & Ingber, 1999; Gascon-Ramos, Campbell, Bamford, & Young, 2010; Konstantina et al., 2014; Sarimski et al., 2013; Ziviani et al., 2011). Findings from these studies reveal that delays at the stage of screening and diagnosis and access to EI services are the most commonly encountered barriers (Bailey, 2021). Bailey et al. (2004) reported that there was an average of 5.2-month delay between early diagnosis and referral to EI services in the United States. It is important to note that these delays may vary according to the types of disability. For example, although children with Down syndrome (DS) can be diagnosed even before birth, and can access EI services earlier, children with autism spectrum disorder can go through these processes much later (Bailey et al., 2004; Van Riper & Choi, 2011).

There is a need for the development of more effective models, especially in terms of including pediatric health services in EI services, development of a more proactive developmental screening model, and faster referral system to services (Bailey, 2021; Bailey et al., 2004). Parents might go through various emotions and feelings when they find out about their child's diagnosis (Atienza-Carrasco, Linares-Abad, Padilla-Ruiz, & Morales-Gil, 2018; Piepmeier, 2021; Sangster, 2021). Therefore, it is important for health care professionals to convey the child's diagnosis in a sensitive manner (Mugweni et al., 2021). However, the results of some studies reveal that health care professionals do not always show sensitivity while informing parents (Brasington, 2007; Skotko, 2005; Van Riper & Choi, 2011). In several studies, parents of children with DS noted that

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they were not adequately informed at the diagnosis stage and the information provided after diagnosis was not provided in a sensitive manner (Mutlu, 2015; Skotko, 2005; Skotko, Bedia, & Taylor, 2005; Van Riper & Choi, 2011). Parents note that they seek (a) reliable information about their children's development and disability, (b) follow-up calls or visits by professionals, and (c) guidance to access services and social support groups (Bailey et al., 2004, 2005; Sarimski et al., 2013; Van Riper & Choi, 2011).

## EARLY INTERVENTION IN TURKEY

EI studies conducted in Turkey have gained momentum and importance in the last 40 years (Diken et al., 2012). There is an increase in the number of children receiving EI and early childhood special education services (Republic of Turkey Ministry of Family, Labor and Social Services, 2019, 2021). However, there is limited data on the exact number of children with disabilities, their disability type, demographic information, and access to services. Moreover, studies that were conducted to examine families in the EI system were limited in scope and used small group participants (Çitil & Doğan, 2019).

On a legal basis, children with disabilities are eligible to receive public services, and partial private services are also funded by the state. For example, children with disabilities between the ages of 0 and 6 years can attend private special education settings for up to 2 hours a week and 8 hours a month as appropriated by the state. Services beyond these amounts must be funded by the families. There are over 2,000 private special education settings that serve approximately 450,000 children. Children 36 months and older are eligible to attend inclusive settings. According a report released in 2019, there were approximately 1,300 children receiving inclusive early childhood special education (Ministry of Education, 2019). Although public and private EI services exist in Turkey, systemic issues within the provision of the services create barriers for many families to access the system (Er-Sabuncuoğlu & Diken, 2010).

## THE STUDY FRAMEWORK: CHILDREN WITH DOWN SYNDROME IN TURKEY

One in every 700 children is born with DS (National Down Syndrome Society, 2021). It is crucial to diagnose children with DS as early as possible and provide them with early access to EI services (Buckley & Sacks, 2012). However, Turkish parents of children with DS face challenges related to access to EI services and have to find their own way in the system with very little professional support or guidance (Mutlu, 2015). These challenges may lead to delays in the child's and parents' access to services in the early period and, more importantly, parents might access information and resources that are not evidence-based (Bailey et al., 2004; Mutlu, 2015). It is important to note that there has not been a study in Turkey that examined the perceptions of parents of children with DS on EI services on a large scale. We chose to focus on families of children with DS because there are systemic issues and barriers in accessing the EI services for children with DS. Thus, our goal was to examine the perception of the parents and disseminate their reports.

The current study conducted in this context gains originality as the first study in the country based on data obtained from a large sample group, with participation from different provinces of Turkey. This study contributes to both national and international literature in terms of revealing the current situation of EI services in Turkey according to the opinions of parents of children with DS and guiding services planned in the future. Therefore, the purpose of this study was to examine the views of parents of children with DS on the evaluation, diagnosis, education, and therapy processes. The following research questions guided the study:

1. What are the views of parents of children with DS on the medical evaluation and diagnosis process?

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2. What are the views of parents of children with DS on the educational evaluation and diagnosis process?
3. What are the views of parents of children with DS on education and therapy services?

## METHODS

### Research design

We conducted this study by using the cross-sectional research design among survey design methods. Survey design research enables the quantitative or numerical description of trends, attitudes, or views across the population through studies conducted on a sample selected from within a population (Creswell, 2014; Fowler & Cosenza, 2009). In cross-sectional studies, research data are collected from study participants in a single and relatively short period. Thus, data can be collected in a quick, functional, and economical way from large sample groups (Creswell, 2014). In the present study, data were collected from participants in a period of approximately 3 months.

### Participants

Participants in this study included 893 parents of children with DS in Turkey. Participants were recruited through a convenience sample by reaching out to the special education and rehabilitation centers that could be accessed from the website of the Ministry of National Education. The demographic information about the participants who voluntarily agreed to participate in the study and filled out the survey is presented in Table 1. As can be seen in Table 1, most of the parents were between 36 and 45 years of age, and most of those who filled out the survey were mothers. More than 40% of the participants held university degrees and were unemployed while more than 60% had medium-level incomes. All children were between 0 and 8 years of age, whereas most of them were between 0 and 3 years of age.

In this study, we compared the survey participation rates and the total population rates of the provinces in Turkey, and we investigated whether or not the participation was homogeneous. We used the data of the Address-Based Population Registration System for 2019 on the website of Turkey's Statistics Institute. We added the survey participation rates and the total population rates of the provinces to the Microsoft Power Bi software, then correlated and compared the rates. As seen in Figure 1, the survey was filled out by participants from at least one province representing each region of Turkey. Participation was higher from provinces with high populations (see the red points).

**Table 1.** Demographics of the Participants ($n = 893$)

| Variable | *n* (%) |
|---|---|
| Parental age | |
| 18–25 years | 22 (2.5) |
| 26–35 years | 345 (38.7) |
| 36–45 years | 457 (51.2) |
| 46–55 years | 55 (6.1) |
| >55 years | 14 (1.5) |
| Consanguinity to the child | |
| Mother | 700 (78.5) |
| Father | 180 (20.2) |
| Other | 13 (1.3) |
| Educational status | |
| Graduate school degree | 81 (9.1) |
| University degree | 374 (41.9) |
| High school degree | 230 (25.8) |
| Secondary school degree | 93 (10.4) |
| Primary school degree | 95 (10.6) |
| Without any education | 19 (2.1) |
| Employment status | |
| Employed | 493 (55.27) |
| Unemployed | 400 (44.73) |
| Income level | |
| Very high | 6 (0.6) |
| High | 73 (8.2) |
| Medium | 544 (60.9) |
| Low | 215 (24.1) |
| Very low | 55 (6.2) |
| Age of the child with Down syndrome | |
| 0–3 years | 434 (48.8) |
| 4–6 years | 267 (30.0) |
| 7 8 years | 192 (21.2) |

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**Figure 1.** Turkey heat map of parent participants.

### Data collection tool and data collection

We developed an online survey using the literature and expert opinions as a guide. The survey consisted of a total of 36 multiple-choice and short- and long-answer questions to obtain both quantitative and qualitative data. It comprised three main sections: personal information (e.g., age and education status), medical and educational evaluation and diagnosis process (e.g., "Do think you received proper guidance and referral for medical follow up examinations? Can you talk about the challenges you faced during medical diagnosis process?"), and education/therapy services (e.g., "Do you think you received relevant and appropriate early intervention services? What are your thoughts about the services provided to your child?").

With both types of the data gathered, we aimed to support and strengthen quantitative data with qualitative data and to provide diversification (i.e., triangulation).

We elicited expert opinions from six field experts for the content and construct validity of the survey. These experts included three special education teachers and three educational psychologists. A total of 10 parents with whom we were in constant contact completed the pilot survey and provided feedback. In their feedback, parents suggested to include further explanations for each item. Therefore, we added explanations and examples for each item. For example, "While answering the question below, think about the very first day you visited the evaluation center. What type of materials, objects and toys did the evaluator use?" We finalized the survey in line with their feedback.

After securing the necessary permissions for the study and the ethics committee authorization, we initiated the data collection process. We collected the data via an online survey link sent to the official e-mail addresses of special education and rehabilitation centers that could be accessed from the website of the Ministry of National Education, directors of institutions who could be contacted through e-mail or their personal telephone numbers, authorities of nongovernmental organizations (e.g., Turkish Down Syndrome Association, and Turkish Foundation for Individuals with Intellectual Disability), parents of children with DS, and special education teachers. Fifty-four private special education and rehabilitation centers that serve children with DS between ages of 0 and 6 years shared the survey with their parents. The Turkish Down Syndrome Association and the Turkish Foundation for Individuals With Intellectual Disability also

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shared the survey with the families they serve. Finally, a total of 893 parents of children with DS completed the survey. We included all surveys in our analysis because all parents provided the necessary information.

### Data analysis

The survey included both quantitative (e.g., multiple-choice questions, checkboxes, and yes/no questions) and qualitative data (e.g., open-ended answers). First, we analyzed each type of data separately. The, we downloaded the raw survey data to a Comma Separated Value file online and imported them into Microsoft Excel. Second, using the Microsoft Power Bi program, we descriptively analyzed the quantitative data obtained after we completed the data organization process in the Excel file. Third, we read all open-ended questions independently, and created a code list for the analysis of qualitative data. Next, we came together to compare and discuss the codes. Similar codes were grouped together, and the main emergent themes identified with consensus. Employing the descriptive analysis method, we analyzed all of the quantitative and qualitative data. At this point, we aimed to draw a general framework from the data obtained on these parents' views on EI services in Turkey and their application in the country.

## RESULTS

The data obtained through the survey are presented under three headings: medical evaluation and diagnosis process, educational evaluation and diagnosis process, and the process of education and therapy services.

### Medical evaluation and diagnosis process

#### *Prenatal process*

This study's results show that the majority of the expectant mothers ($n = 833$, 93%) had completed their regular prenatal doctor visits. Even though more than half of the participating parents were informed that their infants were at risk of having DS during pregnancy ($n = 484$, 54.3%), more than 40% of the parents were not informed about developmental characteristics, health problems, and education and legal rights of children with DS ($n = 472$, 41%). Of the informed parents, only 3% were informed on legal rights, 4% were informed on education, 9% were provided with developmental characteristics of DS, and 14% were informed on health issues.

#### *Postpartum process*

According to parents' report, the experts who made explanations to parents about the diagnosis of their children after birth were mainly pediatricians (46%), geneticists (29%), obstetricians and gynecologists (17%), child psychiatrists (4%), and pediatric neurology specialists (4%). The vast majority of the parents (87%) stated that experts explained to them the diagnoses of their children, whereas very few parents (3%) were informed by processes such as family training. When we asked, the parents, "What can you say about the way the specialist or staff informed you about the diagnosis of your child?", the parents' responses showed that not all experts showed the same sensitivity. A significant portion of the parents stated that experts informed them in a manner that was far from being polite and reliable. One of the mothers stated, "He (doctor) made an explanation in such a cruel and critical way as if it was a hopeless case ... He made this explanation to a mother, a mother who has just given birth to twins ..." Another mother shared similar experiences, "He (doctor) told us that very bad days were ahead of us. His attitude was negative ..."

Most of the parents stated that the medical evaluation and diagnosis process was not conducted with adequate and appropriate materials, equipment, and toys ($n = 502$, 56%), in an adequate time ($n = 604$, 68%) or in the appropriate setting ($n = 504$, 56%). Furthermore, most of the parents stated that they were not referred to the relevant persons and units in time for the medical evaluation and monitoring of their children ($n = 534$, 60%). When asked "How would you

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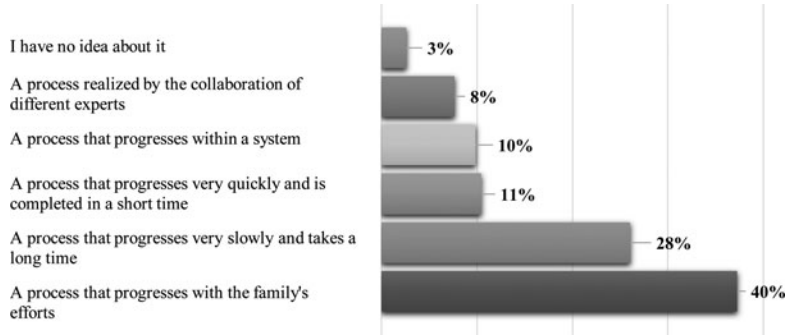



**Figure 2.** How parents define the process to diagnosis and access to services.

describe the process until your child was diagnosed and your and your child's access to early intervention services became definite?", the majority of the parents stated that this process was "progressing with the family's efforts" ($n$ = 745, 40%) and "progressing very slowly and taking a long time" ($n$ = 521, 28%), as can be seen in Figure 2.

We also asked the parents what they could say about the problems they encountered at the stages of the medical evaluation and diagnoses of their children. One of the parents said, "I don't think it is a planned follow-up ... It is a process that moves forward with the efforts of the family ..." Another parent noted, "It is an incredibly slow process ... The fate of a child should not be left in the hands of bureaucracy..." Another parent expressed, "Unfortunately, in our country, we blame the mom for giving birth to the child ... If you go to state (public) hospital, things are very slow and if you don't have money, things look bad for you ..."

As for referrals, the participating parents emphasized the need for a referral support system provided by professionals ($n$ = 168, 19%). Parents also cited the need for psychological ($n$ = 127, 14%), financial ($n$ = 108, 12%), educational ($n$ = 96, 11%), social ($n$ = 77, 9%), and legal ($n$ = 20, 2%) support. Moreover, according to our data, most of the parents reported that they received EI services from private special education and rehabilitation centers ($n$ = 793, 57%) in addition to the services they received at home ($n$ = 271, 33%).

## Educational evaluation and diagnosis process

A significant number of the parents ($n$ = 424, 48%) reported that their opinions as parents were not sufficiently included in the educational evaluation and diagnosis processes and that these processes were not performed with adequate and appropriate materials, equipment, and toys ($n$ = 557, 62%), in an adequate time ($n$ = 517, 58%) or in an appropriate setting ($n$ = 495, 56%). Furthermore, more than half of the parents expressed that appropriate education planning was not conducted for both their children and themselves ($n$ = 464, 52%). When we asked the parents, "What are the main problems you encountered at the educational evaluation and diagnosis stages of your child?", the following responses were elicited: the materials, equipment, and toys used in the evaluation and diagnosis process were not adequate or of appropriate quality, the time allocated to the child was short, and the evaluations were made in inappropriate settings and at inappropriate times without observing the children in their natural settings.

One of the parents followed up with "I did encounter major issues, but I think this evaluation was conducted in a wrong fashion ... Our children are special ... Evaluating a child in 20 minutes is wrong." Another parent expressed similar opinions, "The experts are inadequate. They look at your paper work but don't perform practice."

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### The process of education and therapy services

About 32% of the participants' children with DS in Turkey were diagnosed in their first 6 months and received the "Special Needs Report" whereas 27% were diagnosed between 7 and 12 months, 16% were diagnosed between 13 and 24 months, and 14% were diagnosed at 25 months or later. Although most of the children started to receive services between the ages of 7 and 12 months ($n = 260$, 29%), 26% started between 0 and 6 months, 19% between 13 and 24 months, and 18% at 25 months or later.

As can be seen in Figure 3, results reveal that almost all of the children ($n = 847$, 95%) received education. The majority of the children ($n = 793$, 37%) received educational services from private special education and rehabilitation centers funded by the state. Apart from that, we observed that most of the parents ($n = 468$, 22%) provided their children with education (e.g., special education at home, occupational therapy [ergotherapy], sensory integration, or aquatherapy) in accordance with their own means. Furthermore, data analysis revealed that these parents' children benefited from physiotherapy ($n = 378$, 17%), speech and language therapy ($n = 123$, 6%), and education in general education schools ($n = 343$, 16%).

When we asked the parents whether they found the educational services provided to their children sufficient, a great majority ($n = 735$, 82%) stated that they did not find these services sufficient. Also, the majority of the parents reported that they were not provided with the necessary education regarding what role they could play in the development and education of their children within the scope of EI services ($n = 696$, 78%).

When we asked the parents, "What is the most basic support you need in your child's development and education?", the parents' responses were concentrated on psychological, social, and educational support dimensions. For example, one of the parents stated:

> The most basic support should definitely be psychological support ... because it is very difficult to accept the current situation and to constantly think about what awaits you in the future. The healthier the parents are, the more beneficial they will be for their children ...

Another parent mentioned that "it is the support provided by the society and the social environment ... my son was loved very much in primary school. This affected him positively. It boosted his self-confidence and helped him socialize ..."

When we asked, "Do you think that EI services in Turkey are delivered within a system?", the majority of the parents ($n = 674$, 76%) responded, "No, I don't think so." When we followed up with, "What would

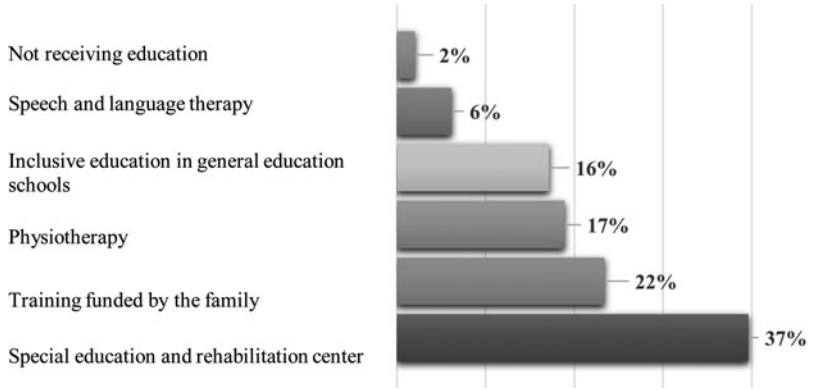



**Figure 3.** Education and therapies currently received by children.

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you recommend as a parent for the improvement of EI services in Turkey?", the parents emphasized that the gap between legal regulations and practice should be closed and that experts who would take part in all stages of medical and educational evaluation and diagnosis and education stages should be educated in the field of EI.

## DISCUSSION

The purpose of this study was to examine the views of parents of children with DS on the (a) medical and educational evaluation and diagnosis and (b) education and therapy services process in Turkey. The results obtained are discussed respectively within the focus of these basic components. How and how often regular prenatal doctor visits will take place, how and in what way parents will be informed in case of a possible risk as a result of screening tests, and what kind of support will be provided make up a process that includes different practices in many countries. This study demonstrates that the majority of surveyed parents attended their regular prenatal doctor visits and, as in many studies reported in the literature, they were informed that their infants were at risk of having DS during pregnancy (Natoli, Ackerman, McDermott, & Edwards, 2012; Skotko, 2005; Skotko et al., 2005). Which health professional should provide this information is among the most important issues discussed in the field conducted by Skotko et al. (2009); most of the participating parents reported that they preferred to be informed by obstetricians and gynecologists and pediatricians that their children had DS. Our survey results showed that pediatricians, geneticists, and obstetricians and gynecologists were the professionals to inform the parents about diagnosis. This finding is aligned with the findings of other similar studies in the literature (Skotko, 2005; Skotko et al., 2005; Van Riper & Choi, 2011).

On the other hand, how and in what way information should be conveyed to parents by the health care professionals has been discussed for many years (Skotko, 2005; Skotko et al., 2005; Van Riper & Choi, 2011). Consistent with the results of several other studies, the results of this study draw attention to the fact that parents were not informed by health care professionals in a satisfactory and appropriate manner, both in the prenatal and postpartum periods about the developmental characteristics of children with DS, their health problems, education, and legal rights (Skotko, 2005; Skotko et al., 2005; Skotko, Capone, & Kishnani, 2009; Van Riper & Choi, 2011). In a study conducted by Van Riper and Choi (2011), parents reported that they expected experts to make explanations in a suitable setting and in a sufficient period, and they wanted them to provide referral and information support to the appropriate units.

Participating parents of children with DS reported that they mostly needed support with referral to appropriate units and information support after their children were diagnosed. This is followed by psychological, financial, educational, and social support. This finding is consistent with the results of several other studies in the literature (e.g., Çiftçi, 2015; Gören, 2015; Leite & Pereira, 2020; Natoli et al., 2012).

In the current study, it is revealed that children received a definite diagnosis in the first 6 months after birth, and the age of starting their first education and therapy is mainly between the ages of 7 and 12 months. This finding is aligned with the findings of a study conducted by Mutlu (2015) in Turkey. Mutlu reported that children with DS were diagnosed within an average of 1.5 months after birth. However, at this point, it can be said that there is a slight delay in the time between making a definitive diagnosis and referral to EI services. However, it is argued that the EI system should be provided within a system planned in such a way that the family and the child can be referred to the most appropriate services as soon as possible in line with their needs (Bruder, 2010; Dunst, 2007; Guralnick, 2019; Odom & Wolery, 2003).

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Another finding that needs to be addressed is the lack of a system planning in the EI system. The participating parents noted that their opinions were not sufficiently included, especially in the planning of the education program, and that an appropriate education plan was not created in line with the basic needs of both themselves and their children. Further, the parents in the study stated that both medical and educational evaluation and diagnosis processes were not conducted with adequate and appropriate materials, equipment, and toys, in a sufficient time, and in a suitable setting. One of the most important elements in the planning of EI services is to ensure parent involvement (Dunst, 2007; McManus et al., 2020; Popp & You, 2016). Ensuring parent involvement in service planning provides significant contributions such as discovering the strengths of parents, cooperating with them in decision-making processes, and empowering them by allowing them to learn their own capacities (Dunst, 2007; McManus et al., 2020). Moreover, it is suggested in the literature that this process should be planned and conducted at an appropriate time, in a suitable setting, when family members are together, while informing parents about the situation and development of their children (Skotko et al., 2009).

One of the interesting findings in this study was about access to EI services. Most of the participating parents reported accessing more EI service hours depending on their own economic means. This can be due to the fact that state-funded services are perceived as insufficient. This finding confirms other studies that reported parents of children with DS found the EI service hours as insufficient and that they needed more educational support (e.g., Çiftçi, 2015; Gören, 2015; Toker, Başgül, & Özaydın, 2016). Contrary to the findings in our study, the results of several studies conducted in other countries reported that the majority of participating parents were satisfied with the EI services provided. However, we suggest that this satisfaction may vary by parents' socioeconomic background, race and cultural characteristics, or the child's age and disability (Ziviani et al., 2011).

## Limitations

The current study has two major limitations. First, the number of participating parents from each province was not normally distributed in the study and we did not conduct parametric or nonparametric statistical analyses. Therefore, a comparison between the variables could not be made. Nevertheless, we attempted to support the quantitative results regarding the parents' views with qualitative findings that emerged from responses to the quantitative and qualitative questions in the survey. In this regard, we observed that both quantitative and qualitative results obtained from the survey support each other.

The second limitation is concern about generalizability of the findings due to the convenience sampling method we have utilized. In this convenience sample, we were able to reach out to and recruit more "educated" and "connected" parents who had access to the internet and to specialized services for their children with DS in Turkey. Also, those parents who did not respond to our survey might have had children who were diagnosed later or not at all, and who could not afford transportation or costs or time necessary to procure services for their children. Reaching these hard-to-reach families should be a goal of future research in which internet surveys are not the only data entry means.

## Implications for practice and research

Within the scope of the results obtained from the current study, the following recommendations are presented under two headings: practice and research.

### *Practice*

Regarding practice of EI in Turkey, there is a need for systems that connect the basic components of EI to each other, such as screening, monitoring, evaluation, early diagnosis, referral, deciding on services to be provided, and intervention, and supplying

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these services in a short time to individuals and study models based on cooperation. Moreover, "EI units/centers" with common goals and standards can be established throughout the country in cooperation with important organizations (e.g., the Ministry of Health and the Ministry of National Education). Another recommendation is that emphasis can be laid on studies to eliminate the gap between legal regulations, scientific data, and practice in the country. In this context, the implementation of evidence-based interventions throughout the country and qualified inclusive EI issues can be based on legal sanctions. Furthermore, a national-scale data system based on standards can be established to meet the information needs of parents of children with special needs regarding the characteristics of their children and to ensure that they play an active role in the development and education of their children. Finally, programs for training personnel in the field of EI can be opened, and practice-based in-service training programs can be developed for specialists working with children with special needs in the young age group.

### *Research*

Regarding recommendations for research, this study can be replicated with a larger sample and strengthened by statistical analyses that compare participant variables (e.g., income status and education level) to be obtained within the scope of the studies and the satisfaction of parents with EI services. Another recommendation is that emphasis can be placed on studies that eliminate the gap between and among legal regulations, scientific data, and practice in the country. In this context, the implementation of evidence-based interventions throughout the country and qualified inclusive EI issues can be based on legal sanctions.

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