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Examination of views and suggestions about participation of families of children with special needs in individualised education programme

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Abstract

Individualised education programmes (IEP) will be practiced with children with special needs (CWSN) and their families. The main factor for IEP's success is the participation of the family and also, their children. In this study, views and suggestions about participation of families of CWSN in their IEP processes are examined. The research is based on qualitative research. Five mothers and a grandmother with CWSN were participated; data are collected via semi-structured interview technique and analysed with inductive analysis technique. This research uncovers that the participants didn't participate in their children's diagnosis, assessment, settlement and follow-up processes, and they were not content with the assessment results. Also, the participants who didn't participate in the IEP weren't even aware of the legal obligation that they had to and their children's IEP, they weren't in cooperation with the teacher in that process, and teachers didn't show the progress in the children to the families even if they recorded that.

Keywords: Children with special needs (CWSN), family, individualised education programmes (IEP).

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1. Introduction

Individualised education programmes (IEP) are planned version of educational services that will be practiced to satisfy the needs of children with special needs (CWSN), their families and teachers. IEP include student's powerful sides, available performance, purpose and goals, services provided for the child and assessment results (Kargin, 2009, 2011; Witherspoon, 2015). Improvement, practice and assessment of IEP are guaranteed with laws in Turkey. The articles 62, 63 and 64 of Special Education Regulation include the description of IEP, people that should take a part in IEP improvement team and explanation about duties of these people. When the people who should take a part in IEP are examined, it is seen that the team includes teacher serving excursively, classroom teacher, school counsellor, if needed branch teachers, the student and her/his family under the presidency of institution manager or an assistant manager charged by the manager. IEP improvement team is seen to be the decision making mechanism in the suitability and access of services planned to be provided for the CWSN and their families in the examined literature (Hirsh, 2012; Jones, 2006; Tike Bafra & Kargin, 2009; Witherspoon, 2015). Those families take part in decision making mechanisms and participate in the process make it obligatory to inform them about special education.

Educational institutions that the CWSN attending to should inform the families about legal rights and obligations in IEP team. However, the families may not utilise these services with different reasons (e.g. Communication difficulty between family-IEP team, IEP meetings don't satisfy family expectations, family is in lower socio-cultural and economical structure, there are more than one CWSN at home, institution doesn't provide information services etc.) (Coleman & Churchill, 1997; Flynn, 2006; Smith, 2001; Smith, Gartin, Murdick & Hilton, 2006). In the examined research studies, it is emphasised that as the family participation increases more, the educational output from the CWSN increases more (Desimone, 1999; Halle, Kurtz-Costes & Mahoney, 1997). Arastirmacilar (McCausland, 2005; Sopko, 2003; Stroggilos & Xanthacou, 2006; Valle & Aponte, 2002; Yanok & Derubertus, 1989) stated that family participation in IEP meetings is stated to be the key factor for this process and suggests that IEP team should be in clear communication with the family and make them feel equal with the other members. That IEP process is qualified and provides the opportunity to share the resources which had to improve a high quality educational programme, the CWSN, between the family and the IEP team. Families get information about their children's educational environment when they participate in the IEP process, teachers learn about children's house environment of CWSN and improve their skills of working in family–teacher cooperation (Smith, 2001; Stroggilos & Xanthacou, 2006). Accordingly, IEP process supports IEP team to act in cooperation, respect and faith for the purpose that the CWSN are successful in education and get positive outputs (Rock, 2000). In such a cooperation process, it is stated that CWSN show a high performance academically and socially (Christenson & Cleary, 1990).

Skinner (1991) emphasises the critical importance of family participation in IEP processes for two reasons. First of them, that the families have all information about their children. Families explain their children's health situations, behaviour problems, their likes or dislikes in terms of reinforcers. The second one is that the obligation of cooperation between family and teachers to get desirable (terminal) academic and social behaviour and to generalise them to the environment. Researchers (Allen & Cowdery, 2012; Debbag, 2017; Petrotty-Bryant, Deutsch-Smith & Bryant, 2008) state that one of the strengthening factors for IEP process is family participation, and argue that unless the family participate in the process, IEP process cannot function fully and the improvement of the CWSN are not adequate. In team, family has the responsibility and duty of stating the needs for IEP and the child's education, preparing suggestions for IEP and participating in the studies during the practice of education programme and, if necessary, provide the support of equipment (MNE, 1997).

In the examined literature in Turkey, it has been seen that studies with teachers and managers (Avcioglu, 2010; Can, 2015; Cuhadar, 2006; Debbag, 2017; Kucuker, Kargin & Akcamete, 2001; Kuyumcu, 2011; Ozturk & Eratay, 2010; Tike Bafra & Kargin, 2009; Yilmaz & Batu, 2016) were done

about IEP process but there is no study seen with the participation of families in the IEP process. Accordingly, this study is important to present the information on how important the participation of families of CWSN in IEP process and they cooperate with teachers and in terms of preparing action plan for supporting the services provided during this process and the goal of this study is determined as examining views and suggestions of families of CWSN in terms of their participation in IEP process.

2. Method

In this chapter, information about the design, participants, data collection technique, data collection process and data analysis of the research conducted to examine the views and suggestions of families of CWSN in their participation in IEP process.

3. Research design

Research is designed with descriptive approach based on qualitative research in the direction of research goals because we may focus on understanding the events and participants' point of view (Yildirim & Simsek, 2013). Descriptive approach is approaches aiming to describe a past or continuing situation as it is (Karasar, 2009).

4. Study group

Research participants consist of five mothers and one grandmother (*n* = 6) residing in Ankara, volunteering to participate in the research, having a CWSN and whose children's age range between 12 and 21. Before starting the research, authors of the article informed the participants about the content and goal of the research, roles and responsibilities that mother will take during the process. Also, an agreement was signed with these participants stating that they would obey codes of conduct and code names instead of their real names would be used during the process.

Table 1. Demographical information about the participants

Primary caregiver	Age	Educational status	Whole monthly income	Profession	Age of C.W.S.N	Diagnosis of C.W.S.N
Mother 1	50	University	4,000 tl.	Retired	16	Mental Deficiency
Mother 2	47	Illiterate	2,700 tl.	Unemployed	19	Autism
Mother 3	42	Illiterate	800 tl.	Unemployed	12	Mental and auditory deficiency
Mother 4	40	Primary School	No regular income	Unemployed	21	Mental deficiency
Grandmother 5	70	Primary School	1,400 tl.	Retires	18	Autism
Mother 6	48	Literate	No regular income	Unemployed	17	Mental, auditory and visual deficiency

As seen in Table 1, five research participants are mothers and one participant is a grandmother. Age of participants differ between 40 and 70. Two of the participants are illiterate, one of them is literate, two of them are those completed their primary education and one of them is university graduate. Whole income of the participants is not regular; maximum income is 4,000 Turkish Liras. Two participants are retired, four participants are unemployed.

4.1. *Data collection technique and data collection process*

Research data were collected via semi-structured interview technique which is among qualitative research techniques. The basic purpose in qualitative research is to examine the sample deeply (Bogdan & Biklen, 2003). The reason why we conducted this research via semi-structured interview technique is that limitedness of studies aiming to determine views of families of CWSN about their participation in IEP processes and the obligation of profound data collection.

Data were prepared by researchers in four sessions to get profound information in direction of research goals. Questions prepared were sent to academic members who are expert in their field via e-mail. Data were collected via semi-structured interview form which was put into its final form in accordance with expert opinion and their suggestions. After the form was prepared, pilot studies were conducted on two mothers of CWSN, necessary adaptations were made by determining comprehensibility of the questions and views on suitability of the content. Data collected from the pilot interviews weren't included in the research. Eight questions were asked to the participants in the research including questions concerning their children's assessment process, IEP process and improvement in their children, cooperation with teachers and their suggestions about the issue. Interviews were had in 17–36 minutes on average and in manager's room of institution where the CWSN have education, and during the data collection process, researcher and the participants weren't disturbed by other people.

4.2. *Data analysis*

Data collected via semi-structured interviews were recorded with a tape recorder after mothers' permission. Interviews took place in the dump of data and also, an interview in computer environment was checked in text by choosing it randomly. During pre-analysis preparations, a folder for each participant was created and the first version of the interview was printed out and put in the folder. Comments of the interviewer were noted on the print out. During the analysis of data via inductive method, all data were read by the researchers twice from beginning to end, categories were created, codes were collected under the related categories, themes and sub-themes were created by reading it again. Then, data which could be collected under certain titles were given titles and data were arranged with citations, validity and reliability studies were conducted.

In *validity study,* results coming from the interviews were tried to be supported with the literature, consistency of between-theme relations with the literature was examined and themes and sub-themes were tried to be supported with citations.

In reliability study, an outside expert read the dumps, created themes and sub-themes and then, researchers came together, compared themes and sub-themes and solved the disagreements by discussing on the dumps.

5. Findings

5.1. Theme 1: process of child's diagnosis and assessment

All the participants stated that their child weren't diagnosed and assessed in detail and qualitatively and their children's assessment was finished before the standard assessment duration (45 minutes) in Counselling and Research Center (CRC) finished. Also, they mentioned that since their children weren't accustomed to the environment in CRC, they behaved shy and had difficulty even in things they knew about and families weren't allowed in the assessment room.

Assessment results satisfied only Mother 3, other mothers emphasised that their children weren't assessed qualitatively and the reports didn't reflect their children's situation but they didn't know how to object to that.

· Mother 1 told her thoughts concerning the issue: *'The report didn't reflect my son's situation, according to the report there was a boy that couldn't do anything in front of me. When I told this to CRC employee, he/she told me that they wrote how it was and asked me what I was expecting'.*
· Mother 2 told concerning the issue: '*They handed me my child's report, I couldn't even know what to do, we are ignorant people, I wanted to go somewhere to change the report but there was no one to lead the way'.*

5.2. Theme 2: settlement process of the child

Majority of the participants (Mothers 2, 3, 4, 6 and the grandmother) told that they are content with the school where their children were placed even though they don't think their children weren't assessed adequately. Mothers stated that no one got their opinion when settling their children to the schools and they didn't know that they should be asked for it. The participants told that they couldn't adapt to the school where only CWSN attend, thought that their children were in a better level but later they got accustomed to the school and their children were happy at the school where they attend from now on, all the parents at the school showed consideration to each other.

· Mother 6 mentioned about the issue that: '*Firstly, I was sad that my child was enrolled to that school, my child didn't deserve that school but later I got accustomed to it. I and my children have good friends, I am content with the school now, and everybody have sympathy for each other'.*
· About the issue, Mother 2 told her thoughts *'... my child could be an inclusive student but we were late, even if we weren't late, whom would we ask for help, consult, who would lead us, if my child had been an inclusive student, they wouldn't want us there twist the knife in the wound (means her child's special needs)...'.*

5.3. Theme 3: IEP process

Mothers (Mothers 1, 2, 3, 4, 6) stated that their children haven't been in the IEP process during their whole education life, thus so far, they didn't see the IEP prepared for their children, they didn't make decisions with the teacher during the process and they didn't know they had to participate in the IEP process.

· Concerning the issue Mother 3 told her thoughts *'... do I have to participate in the process that you talked about? No one at this school told me that, I didn't know that, I heard about it when you asked about it'.*

The grandmother mentioned that she follows her child's improvement but not IEP, she maintains the process with the classroom teacher.

· The grandmother told about the issue that *'I don't know the IEP you said but I learn about the child's improvement from the teacher, we make decision about what to be taught to my granddaughter/son with the teacher'.*

5.4. Theme 4: improvement of child

Some of the participants (Mother 1, Mother 3 and grandmother 5) mentioned that they see improvement in their children but these improvements are only seen in school environment, their children don't behave at home as they do at home, they continue their problematic behaviour at home.

· Mother 1 said concerning the issue *'the teacher says that the child does everything properly at school. s/he listens to the lesson, answers the questions, doesn't scream as they tell me…but at home s/he doesn't even listen to us, screams, sometimes smashes whatever s/he gets, tears her/his hair. When I tell what s/he does at home to the teacher, s/he looks at me as if I'm exaggerating'*.

Other mothers mentioned they don't see any improvement in their children's situation and therefore, they lowered their expectations, education and school are just for time-wasting.

· Concerning the issue Mother 2 told her thoughts '…*Isn't there any improvement in the child's situation in so many years? This child learns the same lessons every year. We come here but we knock our head against a brick wall, come and go, come and go*…'

5.5. Theme 5: cooperation with teacher

Mother 2 and Mother 3 among the participants stated that since they are illiterate and cannot understand the lesson topics, classroom teachers don't talk about their children's lesson topics.

· Mother 3 about the issue told '…*my son's teacher doesn't ask, tell anything to us. S/he thinks that we don't understand because we are unlettered'*.

The grandmother said that they work in cooperation with the classroom teacher, sees the classroom teacher as her daughter and the teacher comes for home visits regularly and continues to talk about lesson topics also at home.

· The grandmother about the issue told *'I love my son's classroom teacher as my daughter, she talks about the topics my son didn't understand at school even when she comes for home visits'*.

Other participants (Mothers 1, 4 and 6) stated that the teachers know about the issues about their children better than them and for this reason they don't make co-decisions, they try to do what the teachers say but they especially fail to reduce problematic behaviour.

· About the issue Mother 1 told *'Our teacher was educated on that issue, I cannot give her/him idea because I have no information about the issue that s/he was educated for, I try to do what s/he says'*.
· Mother 6 told her thoughts *'I do whatever the teacher says, I say nothing but there is no improvement in hitting, pinching, throwing and running behaviours… I don't know what else to do'*.

5.6. Theme 6: suggestions

All of the participants suggest that they should be together with their children during assessment process and their children should be assessed not only in CRC but also in their natural environment, CRC environment should be made suitable for children's assessment and be an interesting place for children. Also, they want that their children are taught according to their deficiency levels in rehabilitation centres.

· About the issue Mother 1 told *'they don't give any chance in CRC, the employees are very impatient, the environment is not suitable for the child, they make assessment at a desk and the environment should be interesting for the child'*.

Majority of the participants (Mothers 1, 2, 3, 4 and 6) mentioned that they expect cooperation and support from teachers to learn how to support their children, the children cannot transfer what they have learned to home, they want to do something for their children at home but don't know how to do it and feel desperate.

- Mother 1 said about the issue *'I want to do something for my children with the teacher. I wait for her/him all day long at the school but no one says "I do that for your son, do this at home". It is not only me; they say nothing to no one. They don't lead the way, we feel alone and desperate'.*

More than half of the participants (Mothers 1, 2, 3 and 4) want them to record their childrens' improvement and see these improvements.

- Mother 2 said about the issue *'I wait for my child at school all day long but I have no idea about what s/he learned, will learn later. It has been like that for years, we cannot say anything; all in all, the child and the teacher are together in the class…'*

6. Conclusion and discussion

Data collected in the research reveal that the participants didn't participate in their children's diagnosis and assessment processes, their children didn't get the proper assessment and they are not content with the assessment. This finding is parallel to the findings of the study Avcioglu (2012) conducted. Avcioglu revealed in her/his study that families aren't directed during diagnosis, assessment of children with deficiencies and IEP processes and so there is no family participation in the processes. However, as known in Special Education Services Regulation (2006) among basic principles of special education 'Families should be ensured to participate in every dimension of special education and get education actively' takes a part. Also, in regulation's educational assessment and diagnosis principles in article 8, the expressions 'During the educational assessment and diagnosis, parent, school and specialists work in cooperation' and 'During educational assessment and diagnosis process, opinions of family and the individual, when necessary, are received' take place. Even though there are articles to be practiced about family participation in Special education services regulation which is taken as a base in education of children with deficiencies, that children's families don't participate in their processes shows that the practice is not conducted in accordance with the regulation.

Participants stated that at first they weren't content with the school where their children were placed but within the process they got accustomed to the school, the reasons why they easily get used to the school were that the other parents at the school sympathised them and they weren't excluded by other parents and students at the school. This finding is parallel to Sardohan Yildirim (2017), Kamenopoulou (2012), Romer and Haring (1994) and Mar and Sall's (1995) research findings. In all these research studies, it is stated that even if the mothers had some problems with the schools where only children with deficiencies attend, they still continued to send their children to that kind of schools. Possible reasons for this can be their worries that they will not care about their children's education, these schools have a more protected environment than the schools where inclusive practices were conducted, negative attitudes and abuses from school employees and peers were growing in a normal phase.

Other finding is that participants didn't participate in their children's IEP processes, didn't know legal obligations that they had to participate in these processes, weren't aware of their children's IEP and didn't cooperate with the teachers in that process. Research studies conducted in this context states that even if the importance of family participation in IEP processes is emphasised, families still don't participate in IEP processes (Garriott, Wandry & Snyder, 2000; Goldstein, Strickland, Turnbull & Curry, 1980; Poland, Thurlow, Ysseldyke & Mirkin, 1982; Rock, 2000). In addition, Katsiyannis and Ward (1992) emphasised that families hardly or never participate in their children's special education processes. Another finding supporting all these findings is the study conducted by Spann, Koehler and Soenksen (2003), even though the researchers make an emphasise on the necessity and importance of family participation in special education processes, they found out they rarely participated in these processes. Though, when the families are in cooperation with school and teachers, existing problems can be solved more easily, solution suggestions will be practical, family-centred and applicable.

That proves cooperation is for the good of everyone (Christenson, Palan & Scullin, 2009). When planning decisions about student's education family, school and teacher should make co-decisions for cooperation. Also, school personnel and teachers should support active family participation in IEP process, if they don't participate in IEP and cooperate, they should determine the factors affecting this situation and interfere in that and further should find preventive solutions to maintain that.

That mothers who see improvement in their children see them only in school environment, these learning outcomes aren't generalised in home environment is another finding. Basic indicator showing that individuals have learned these learning outcomes is that they can realise them in different times and different places, namely generalisation. That the research participants' children cannot generalise their learning outcomes into different environment or time should be evaluated as the indicator that they didn't learn these outcomes.

7. Suggestions

1. Assessment process, the first step of IEP process, should be conducted properly and in detail and assessment shouldn't be limited to CRC, it should be done at home, school etc. Environment and educational, formal, informal and ecological assessments shouldn't be ignored.
2. It is suggested that families should be informed necessarily to participate in IEP process, they should be ensured to participate, rearrangements should be done to make IEP process functional at school and in CRC.
3. Teachers should record the improvements in children and share results with family regularly. Informing families periodically is an important part of IEP process.
4. Teachers should ask families what they want to know about their children and support families about this issue.

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