THE DIFFICULTIES ENCOUNTERED BY THE MOTHERS HAVING CHILDREN WITH MENTAL DISABILITIES OR AUTISM IN PARTICIPATING TO COMMUNITY LIFE

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The purpose of the study was to compare the difficulties encountered by the mothers having children with mental disabilities or autism in participating to community life. The participants were 21 mothers who have mentally handicapped child and 21 mothers who have child with autism from Istanbul, Turkey. Data was collected through semi-structured interview technique. Nine community skill areas were determined. The results indicated that the mothers having children with autism had more difficulties in participating to the community life than the mothers having children with mental disabilities. While the mothers having children with mental disabilities declared that they experience most difficulties at visiting their neighbors or close relatives, the mothers having children with autism declared that they experience most difficulties in going to somewhere from another place as a pedestrian. When the declared opinions are analyzed, it is observed that caused to feel unwell by people's overlook *is repeated challenge of the both two groups.*

Community living skills are life skills that allow students to deal with current and future adult day-to-day demands and responsibilities. Usually, general education peers learn these skills as they participate in home and community activities. In contrast, students with disabilities many times require direct and intensive instruction in order to acquire and generalize these skills to school, family and community context (Bigge, Stump, Spagna, & Silberman, 1999).
Limited mental process skills, poor language development and unusual or inappropriate behaviors of children with mental disabilities and autism prevent them from interacting with others to a considerable extent (Heward, 2003). The inclusion of handicapped children into community programs enables them to see that they can succeed in community activities and makes them feel themselves to be valuable (Newman, 2002).

As with the education provided for all children, education for handicapped children aims to allow them to continue their lives without depending on others and to become self-sufficient in the future (Cavkaytar, 1998). Community life skills play a crucial role in enabling handicapped children to become self-sufficient, to participate in community activities, and to experience community interaction with others.

Community life skills were collected under 16 headings based on the classification devised by Luscre, Harden, Quale, Anglin, Ellis, Garrett, and Quin (1984),Dever's taxonomy (1987) and other classifications made in this field (Martin, Heal & Rusch, 1982; Dever, 1989; Browder & Bambara, 1993; Bigge et al., 1999; Westling & Floyd, 1990; Turnbull, Turnbull, Shank, Smith & Leal, 2002; Beakley, Yoder & West, 2003; Heward, 2003; Cavkaytar, 2004; Eripek, 2005). Accordingly, community life skills cover personal maintenance, personal development and community life, homemaking, shopping, pedestrian skills, use of public transportations, using restaurants, use of money and managing personal finances, using the phone, use of leisure time, involvement cultural activities, attending sports activities, use of community facilities, making use of public opportunities, banking skills, vocational life.

There are many studies examining the community life skills of children with mental handicapped and children with autism. Some of these studies are about determining the efficiency of training programs aimed at the development of various community life skills. The following skills can be given as examples from studies in which community life skills were taught: skills at using the phone and shopping (Drysdale, Casey,& Porter-Armstrong, 2008; Özen, 2008; Harin, Kennedy, Adams & Pitts-Conway, 1987; Matson & Long, 1986; Akgün, 2004), skill atusing a bank (Bourbeau, Sowers & Close , 1986), skills at using restaurants, publictoilets and stores (Blew, Schwartz & Luce 1985; Pol, Iwata, Ivancic, Page, Neef & Whitley, 1981) and pedestrian skills (Batu, Ergenekon, Erbaş,& Akmanoğlu, 2004; Matson, 1980; Page, Iwata & Neaf, 1976). Some studies concern the difficulties encountered by mentally handicapped individuals or individuals with autism in participating in community life. Some of these studies attempt to determine the difficulties encountered in participating in such activities as shopping, making use of leisure time, engaging in sports (Pretty, Rapley,& Bramston, 2002),and the sufficiency of traffic training provided for mentally handicapped individuals (Karabulut, 2007). Other studies generally examine the difficulties experienced by families with mentally handicapped children or children with autism. Some of these studies try to determine the difficulties experienced by families, the community support these families receive, and the support given by relatives to these families (Kahrıman & Bayat, 2008; Kavak, 2007; Sencar, 2007; Eisenhower & Blacher, 2006; Kaner, 2004). Some aim at determining how families cope with the situation created by having a handicapped child (Naseef, 1989), some examine the family needs (Evcimen, 1996), and others attempt to determine the experiences and needs of families after having a handicapped child (Cavkaytar, Batu,& Çetin, 2004; Şen, 2004; Vural, 2003; Özen, Çolak,& Acar, 2002).Although there are studies concerning the families of the handicapped children, the problems encountered by the families when they participate in community activities with their mentally handicapped or autistic children are not known.

The present study examines the difficulties encountered by mothers with mentally handicapped children or children with autism to community life. These community life skills are; pedestrian skills, use of public transportations, personal development and community life, using public opportunities and entertainment venues, involvement in cultural activities, attending sports activities, shopping, using restaurants and use of community facilities.

So as to take precautions towards the difficulties experienced by the families with mentally handicapped or autistic children in the process of becoming members of the community, the difficulties experienced when they participate in community activities need to be examined in the first place. The fact that mentally handicapped or autistic children have different limitations raises the possibility that these children and their families encounter similar or different difficulties in participating in community life. Therefore, there is a need for studies that reveal the difficulties experienced by families with mentally handicapped children or autistic children, in participating in community life in a natural environment in a realistic and holistic manner. Thus, it is hoped that the present study will make a contribution to the implementation of the necessary measures for decreasing the difficulties experienced by families with mentally handicapped children or autistic children, the planning of municipal services for the same purpose, the introduction of the necessary legal regulations concerning the topic, and the spread of activities raising public awareness of the issue.

The purpose of the present study was to compare the difficulties encountered by the mothers having children with mental disabilities or autism in participating to community life. Under this general purpose the following questions were tried to be answered: What kind of problems do mothers with mentally handicapped children or autistic children experience in the following community spaces when they are with their children? These are;(a) pedestrian skills, (b) use of public transportations,(c) personal development and community life, (d) using public opportunities and entertainment venues, (e) involvement in cultural activities, (f) attending sports activities, (g) shopping, (h) using restaurants(i) use of community facilities.

Method

Design

A descriptive study was conducted via collecting data using semi-structured interviews. According to Patton (2002);

> *The purpose of qualitative interviewing is to capture how those being interviewed view their world, to learn their terminology and judgments, and to capture the complexities of their individual perceptions and experiences. ….. The fundamental principle of qualitative interviewing is to provide a framework within which respondents can express their own understandings in their own terms (p.348).*

Interviews were employed to mothers with disabled children who live in Istanbul, Turkey.

Participants

Two main purposeful sampling determining strategies, criterion sampling and snowball sampling were employed for determining the participants. The purpose of the criterion sampling is to pick all cases that meet a particular criterion (Patton, 2002).Three criteria were determined within the framework of the present study: The first one was the existence of a single disability in the children of the participants (either a mental handicap or autism). The second criterion was the ages of the children (children should be older than 11 and younger than 22). The third criterion required that the children should be living in the same houses with their families. Purpose of the snowball sampling is identifying cases of interest from sampling people who know what cases are (Patton, 2002). The researcher proceeds by using initially selected participants to recommend other participants (Mertens & McLaughlin, 2004). In the present study, participants meeting the criteria were reached through recommendations and from following the leads of other mothers with whom interviews had been conducted. Interviews were conducted ona voluntary basis.

The participants of the study were 21 mothers who have mentally handicapped child (mild-moderate) and 21 mothers who have child with autism, totally 42 mothers. The average age of mothers who have mentally handicapped child was 43 (range= 35-55). The average age of mothers who have child with autism was 45 (range= 33-58). Over half of the mothers who have mentally handicapped child finished primary school (76%) and few of them finished secondary school (24%). On the other hand, nearly half of the mothers who have child with autism finished primary school (47%), some of them finished secondary school (43%) and a few of them finished a college or university (10%). The average age of mentally handicapped children 15 (range= 12-20). The average age of children with autism 16 (range= 12-21). The gender of mentally handicapped children was 43% female, 57% male. The gender of children with autism was 14% female, 86% male. The participants were mostly from a middle income level community.

Procedure

Data were collected through an interview form containing the questions indicated in purpose of the study, which was formed by the researcher. The literature concerning community life skills was reviewed before forming the interview questions, and nine community skill areas were determined in accordance with purpose of the study. These are; (a)pedestrian skills, (b)use of public transportations,(c)personal development and community life, (d)using public opportunities and entertainment venues, (e)involvement in cultural activities, (f)attending sports activities, (g)shopping, (h)using restaurants, (i)use of community facilities.

The interview questions were prepared in order to determine the problems encountered by participants in these areas. The prepared interview questions were presented to three special education experts and their opinions were obtained. The interview form was finalized after conducting 2 pilot applications. At the end of this process, 17 open-ended questions were included in the interviews (Appendix).

Phone calls were made to participants to set the date of the interviews. During these phone calls the place of interview was determined by asking the participants where they wished the interviews to be held. The interviews were conducted on the dates and in the places (school, home, training center) where the participants wanted to meet

At the beginning of each interview the data researcher explained the purpose of the study to the participants. The participants of the study were also told that the procedure was voluntary, they were free to withdraw from the study whenever they wished, and also that they had chance to refuse to answer any of the questions during the interview. Furthermore, the data would be used only for the purposes of the research results, and pseudonyms would be used instead of their real names.

The interview lasted from 30 to 60 minutes (average 40 mins.). Each interview was transcribed verbatim by the individual researcher sand checked for accuracy by the researchers by listening to the audio tapes and reading the transcripts.

Data Analysis

Being transcribed interview records were examined under two groups. These are; *the answers given by mothers with mentally handicapped children* and *the answers given by mothers with children with autism*. The answers given by mothers with mentally handicapped children were first read. Then the researcher identified categories that related to the answers to each question. The same process was applied to answers given by mothers who had children with autism. This was followed by the combination of categories set for each group. For example, two different categories, taking a vehicle which was comfortable for the mother and taking a vehicle which was comfortable for the child were turned into a single category: comfort of the child/mother.

Printouts and encoded keys of interviews conducted with 12 mothers, 6 of whom had mentally handicapped children and 6 of whom had autistic children, were randomly selected from among the interview printouts, for each one of which one copy had been taken previously, these were filled up both by a researcher and a field expert in order to obtain reliability among the evaluators. Firstly, the researcher independently marked the related title for each question of each participant. This process was also performed by the expert. Then the researcher compared the answers they marked and calculated the reliability of his/her analysis with the formula of the number of agreements divided by the number of agreements plus the number of disagreements multiplied by 100 (Cooper, Heron & Heward, 1987). The mean reliability between the two experts was 90.3% (range= 75-100%).

Results

The purpose of the present study was to compare the difficulties encountered by the mothers having children with mental disabilities or autism in participating to community life. The results of the study were grouped according to the research questions as mentioned under the general purpose. According to the research questions, nine headings emerged from the data gathered. While giving the results under the headings, the themes with a less than five frequency(in both groups)were not reported in this manuscript. The difficulties experienced by mothers while participating in the activities of community life with their children were written in the form of (difficulties experienced by mothers with mentally handicapped children / sum of the opinions expressed by mothers with mentally handicapped children; difficulties experienced by mothers children with autism/ sum of the opinions expressed by mothers children with autism) in order for them to be compared by the readers. Moreover, the interesting expressions used by mothers were recorded in the frequency data below. During data analysis, each mother was given a pseudonym. These pseudonyms were used when presenting the interesting expressions used by mothers, and these quotations were shown by referencing the page numbers.
The answers given by the participants to questions were examined. It was determined that an average of 80% of mothers (range= 19-100%) participated in community life.

Going One Place to Another As a Pedestrian

One hundred percent of mothers with mentally handicapped children and 95.2% of mothers who had children with autism stated that they went from one place to another as a pedestrian with their children. *Having to hold her child's hand* (13/38; 16/59) ranks first among the difficulties encountered by mothers while going from one place to another as a pedestrian. For instance, while Sevil, with a mentally handicapped daughter stated, 'I try, by any means, not to leave hold of Özge's hand' (Interview #3; p.3), Eda who had a child with autism said, 'I generally hold his hand as he has a tendency to jump suddenly'(Interview #30; p.2). Another difficulty derives from people's stares or reactions (10/38; 9/59). For example, Sevda, who had a mentally handicapped daughter, said, 'I am affected even by the looks of citizens'(Interview #18; p.2), and Sabahat, who had a child with autism, stated her problem, 'They sometimes tell me to take care of my child or they just look daggers at me'(Interview #38; p.3). Another problem expressed by mothers is the inability of their children to walk independently (5/38; 14/59). Melahat, who had a mentally handicapped daughter, explained the situation by saying, 'She unconsciously wanders off if I leave her, that's to say, you must hold her arm firmly like a bag'(Interview #41; 6/1). The problem experienced with crashing into people while walking, or the child's not giving way (5/38; 14/59) was expressed by Aydan, who had a mentally handicapped child, as follows, 'He does not give way, he is not careful, he does not look ahead, he crashes into people though he should stand aside, he is not careful when he has to give way'(Interview #22; p.3).

Using Public Transportations

When mothers were asked whether they used public transport, all of the mothers of mentally handicapped children and most of the mothers of children with autism 17/21 (81%) stated that they used public transport. Mothers were asked what they took into consideration when choosing the form of public transport. Mothers said that they paid attention to how full or empty the vehicles would be when choosing public transport vehicles (7/17; 7/18). For example, Ayla, with a mentally handicapped child, said,' I do not catch vehicles when they are overcrowded'(Interview #2; p.3). Another issue taken into consideration by mothers while making a choice among public transport vehicles is taking the vehicle that is favored by the child (5/17; 4/18). On this subject, Aylin, who had a mentally handicapped child, said, 'I take a cruise tour once every blue moon, and it is only because Kadir likes ships very much. I go to and return from Eminönü two or three times'(Interview #7; p.4). Hüsniye, who had a child with autism, stated the difficulty she experienced, 'He would not get on the other bus, he just cried blue murder when he got on it; he was fond of red buses'(Interview #10; p.3-4).

Fify-seven-81% of mothers stated that when they used public transport they experienced problems stemming from other people (12/21; 17/21).Mothers were asked what kind of problems stemming from other people they encountered on public transport. In this matter, most of the mothers (8/21; 12/25) mentioned the reactions of

people to the behaviors or words of their children. For instance, Aydan who had a mentally handicapped child stated, 'For example, I just try to drop the subject with him, but there are always people intervening between us. They say, *What kind of a child are you?*, *How can you speak to your mother in this manner?* '(Interview #22; p.10). Gül, who had a child with autism, related an event she experienced,

> He was little. He was 8-9 years old. He was hitting himself on the sea bus. While he was hitting himself, people thought I was hitting him. Everybody stood up and walked towards me, *How shameful is it that you are hitting your child?* (Interview #27; 13/10, p.4).

Another problem on public transport stemming from other people as expressed by the mothers was discomfort about people's stares (7/21; 7/25). Aylin, who had a mentally handicapped child, stated, 'When Kadir is talking everyone looks at us'(Interview #7; p.5), and Seda, who had a child with autism said, 'For example, people turn and look at us, which makes me depressed'(Interview #1; p.6). Another problem stemming from other people is that people on the vehicles do not give up their seats (4/21; 7/25). Eda, who had a child with autism, expressed this problem by saying, 'Young people do not give up their seats, even people over fifty understand the situation for me holding the hand of Berke, and will give us a seat'(Interview #30; p.7).

Fifty-seven to seventy-seven percent of mothers stated that they had a problem when they encountered an unexpected situation and when the vehicle got delayed (9/21; 13/21). Mothers were asked what kind of problems they encountered when the vehicle got delayed. Mothers firstly stated that their children got bored (3/10; 13/13). Serap, who had a child with autism, explained her experiences, 'He gets bored, he jumps and leaps on the seat if he gets bored'(Interview #29; p.4). Another problem concerns the reactions of children (7/10; 0/13). For example, Aydan, who had a mentally handicapped child said,

> When I should warn someone or react to them (on the bus), I cannot do that as I am afraid for my child. That is because when I react, he also takes courage from me and has an outburst. So, I try not to react when he is with me (Interview #22; 1/10, p.12-13).

When mothers were asked whether they went on long journeys by public transport with their children, (9/21; 13/21) 57-77% of both groups of mothers stated they went on long journeys by public transport with their children. Mothers were asked what kind of difficulties they encountered on long journeys by using public transport. Mothers stated that their children got bored (1/4; 2/17) and they had to travel at night (1/4; 2/17). For example, Nurten, who had a child with autism, said 'I prefer night coaches so that Burak sleeps and we do not experience so many problems'(Interview #25; p.4), while Berna, who had a mentally handicapped child, said, 'He gets very bored, he cries, wanting to get off the coach, so we cannot go in the daytime'(Interview #6; p.6)

Participating Community Life

When mothers were asked whether they made visits to neighbors or relatives with their children, the same ratio of mothers 19/21 (91%) from both groups of mothers said that they made such visits with their children When the mothers were asked what kind of problems they experienced during these visits, mothers firstly stated that their children made the house untidy or damaged objects (6/41; 9/23). For example, Şeyda, who had a mentally handicapped child, expressed the problems she experienced, 'They tell Kemal to stop, but he does not stop; they tell Kemal not to open the door of refrigerator without permission, but he opens the door of refrigerator without permission'(Interview #24; p.6), and Ülkü, who had a child with autism said, 'It is not as at your own home, you are sitting down, standing up, telling the child not to do, not to touch, because he is messing everything about and he is looking at everything.' Another problem experienced during such visits stems from the behavioral problems of the child (4/41; 5/23). Seda, who had a 15 year old child with autism, related her experience of this, 'Now, Faruk is swearing. He learns this at school; of course, I am anxious about this matter'(Interview #1; p.10).

Another issue is that children do not behave in accordance with their ages (7/41; 0/23). For example, Atiye, who had a 15 years old mentally handicapped daughter, expressed her experience by saying,

> I ask her about it when something happens, she says she did not do it, but she fails to explain what happened. People say that it was Begüm who did it, but she says that she did not do it, others gang up on her, and she cannot defend herself (Interview #23; 7/10, p.10).

Another problem in home visits is that children get bored very rapidly (5/41; 1/23). Kadife, who had a 20 year old child with autism, expressed her difficulty in this matter by saying,

> We do not make visits to neighbors and relatives very often. I make such visits, but I keep them very short. Yiğit harms himself when he gets bored, he cries for a long period. I get unhappy when he is unhappy (Interview #11; 17/6, p.4-5).

Another problem is the reactions of neighbors to the behaviors of children (5/41; 0/23). Aylin, who had a mentally handicapped child, related an event she experienced as follows,

> My upstairs neighbor, she was a psychopath, that woman! Kadir was shouting from the garden, *Muuum!, I am thirsty, Mum, come* and so on. Last year, the woman filled a washtub with hot water and poured it onto Kadir from the fifth floor! He was covered from head to toe(Interview #7; 26/5, p.11-12).

Attending Public Facilities And Entertainment Venues

When mothers were asked whether they went to ceremonies like wedding receptions, engagement ceremonies or hen nights with their children, (20/21;12/21) 95-57% of mothers stated that they went to such ceremonies with their children. Mothers said that difficulties were created in such situations since their children wanted to carry on playing throughout the events or ceremonies (6/20; 1/13).For example, Filiz, who had a mentally handicapped daughter, expressed the difficulties she experienced by saying, 'When she wants to dance, she tells me to stand up and dance with her. She does not have any friends. I ask her. How will you dance? You cannot keep pace with people, you will look foolish'(Interview #21; p.6), Hatice said of her mentally handicapped son, 'Yes he annoys me very much. He stands up and wants to dance unselfconsciously. While he is trying to dance, he is losing his self-consciousness'(Interview #9; p.6).

When mothers were asked whether they went to places such as amusement parks, children's parks or zoos with their children, (19/21; 15/21) 91-71% of mothers stated that they went to such places with their children. Among the problems encountered by mothers in these kinds of places, the inappropriateness of the playground equipment in the park for their children comes first according to the statements of the mothers (2/18; 7/18). For example, Lale, who had a 19 years old son with autism expressed her problem by saying, 'We go to playgrounds. We have a great problem as the swings in the playgrounds are not appropriate for us'(Interview #31; p.7). Yeliz, who had a 19 years old son with autism, expressed the same problem by saying, 'He likes swinging on a swing he can fit onto. It is difficult to find a swing on which a 115-kg citizen could fit '(Interview #32; p.4). Another problem encountered by mothers in these kinds of places is that their children can display obsessive or inappropriate behaviors (1/18; 7/18). Seda expressed her experience with her son by saying, 'Faruk's behavior was aimless, he did not know any of the rules, and he was taking what belonged to other children. Then, of course, we had certain problems.

We also failed to explain ourselves to people'(Interview #1; p.13). Another problem is that children cannot behave independently in these places (5/18; 0/18). Berna, who had a 14 year old mentally handicapped daughter, expressed the problems she experienced as follows,

> She likes parks and amusement parks very much, but one of us should always follow her. That is to say, we cannot be as other parents are, who say 'Let's go and sit on a bench, let our child have fun by herself(Interview #6; 25/5, p.9).

When mothers were asked whether they stayed in accommodation like hotels or lodging houses with their children, (7/21; 19/21) 33-91% of mothers stated that they stayed in these kinds of place with their children. The most frequent difficulty encountered by mothers staying in these kinds of accommodation was about the failure of their children to adapt to the rules (2/5; 6/16). For example, concerning rules, Seda, who had a child with autism stated,

> For example, he was going to the pool, the latest hour for the pool was 6 or let's day 7. He had great difficulty in obeying the rules. For example, you say no, but he insists, *I will go in the pool*. Finally, the attendant turns up (Interview #1; 16/5, p.15).

Another problem expressed by the mothers was the difficulties their children had in adapting to the environment (0/5; 5/16). Esin stated the problem she experienced when she went on holiday with her child with autism,

> It is a problem if the holiday is a long one, for example if it lasts up to 10 days, like our last one. We were in the village. Emre loaded all the bags into the car on the fourth day. He put all the bags into the trunk of the car as if he was saying, *Let's go* (Interview #33; 2/12, p.16).

When mothers were asked whether they went to beaches/sandy beaches or swimming pools with their children, (18/21; 21/21) 86-100% of mothers stated that they went to such places with their children. Mothers mostly complained about the behaviors of their children in these kinds of places (1/10; 13/32). Hülya, who had a 19 year old child with autism, related her experience of this situation by saying,

> The first two days were good, then he started to play with certain parts of his swimwear on the third day, as if he was fed up, he started to put his hands inside; we experienced these movements, such problems (Interview #26; 13/10, p.10).

Ülkü, who had a daughter with autism said, 'She wants to take off her clothes, but she is a young girl. She wants to take her swimwear off when it gets wet'(Interview #13; 19/6). The second problem is that some children did not want to go into the sea/swimming pool (5/10; 3/32). Among the mothers, Ayla, who had a mentally handicapped child, expressed her problem on this subject,

> He does not go into sea; he is scared of water. I used to take him on my lap when he was little, I used to put him into and pull him out of water, but I did not put him into the water this year. I simply wet his feet (Interview #2; 16/5, p.16).

Another problem concerns preferences for the children's/adult pools (0/10; 5/32). For example, Sibel, who had a 13 years old child with autism, related her experience by saying, 'He goes into the children's pool. Other children get scared and escape'(Interview #15; p.6).

Involving in Cultural Activities

When mothers were asked whether they went to places like the cinema, the theater or concerts with their children, (11/21, 9/21) 52-43% of mothers said that they went to such places with their children. Mothers were asked what kind of problems they encountered in such places. Mothers stated that the inappropriate behaviors of their children created trouble for them (3/8; 5/12). For instance, Sibel, who had a child with autism, 'related her experiences by saying,

> I used to take him when he was little, I took him many times, what did he do? 'beaaaaa!!!' He stopped people from being able to watch all the time. We just fought with people and then left the place. Once, he wanted to go onto the stage and swing on the swing (Interview #15; 26/6, p.5).

Attending Sports Activities

When mothers were asked whether they went to events like basketball games or football matches with their children, (4/21) 19% of mothers in both groups stated that they went to watch sports events like basketball games or football matches. When mothers were asked whether they engaged in sports activities with their children, (13/21; 14/21) 62-67% of mothers stated that they engaged in sports activities with their children. When mothers were asked what kind of problems they encountered while engaged in sports activities with their children, mothers stated that their children failed in games/did not obey the rules (5/8; 1/4) .

Doing Shopping

When mothers were asked whether they shopped at supermarkets with their children, all of the mothers from both groups stated that they shopped with their children. When mothers were asked what kind of problems they encountered when they were at supermarkets with their children, mothers mostly stated that children made them buy what they liked (9/28; 10/35). Hüsniye, who had a 19 year old daughter, related her experiences of this as follows, 'She selects everything she likes. She picked out macaroni for a while' (Interview #10; p.15). On the same subject, Sabahat said, 'She sometimes wants to buy inappropriate things; she just says that she will buy them'(Interview #38; p.12). Another problem experienced during shopping is that children do not wait at the cash point (3/28; 6/35). For example, Lale, who had a 19 year old child with autism, expressed her difficulties over this by saying, 'When we go into a supermarket, he does not wait at the cash point and he tries to damage everything in other people's baskets to make us leave ...' (Interview #31; p.12). Another problem experienced during shopping concerns the stares or reactions of other people (1/28; 5/35). Ülkü, who had a child with autism, related her experiences by saying, 'During that time, she murmurs while browsing around, and people look at her'(Interview #13; p.10), while Sibel, another mother who had a son with autism, related her experiences as follows, 'I put him into a -trolley. Our children are fat. A woman said, 'aaagh!' as if she was scared by a dog... I told her, 'Is this child an animal? I'll kill you!'(Interview #15; p.6). Another problem is that children want to eat what is sold in the supermarket (0/28; 6/35). For example, Gül, who had a 21 year old son with autism said, 'For example, my son likes coke very much. When my son finds a coke, he takes and opens it. He likes to drink (Interview #27; p.11). Another problem expressed by the mothers is that they are anxious that their children may damage the environment (5/28; 0/35). Ayten, who had a mentally handicapped child, expressed her anxiety over this by saying, 'We experience unease, restlessness. We are always alert to the fact that he may hit, break or drop something fragile'(Interview #5; p.14).

When mothers were asked whether they shopped at stores such as a grocery store, a greengrocer's, a bakery or in the bazaar/market with their children, (21/21; 18/21) 100-86% of mothers stated that they shopped in these kinds of places with their children. When mothers were asked what kind of problems they encountered while shopping in these kinds of places, mothers mostly stated the problem was that their children took some things from the shelves (4/18; 10/23). Serap, who had a child with autism, stated, 'He likes fruit. He takes a mandarin from there whenever I take my eye off him'(Interview #39; p.10). Another problem expressed by mothers is that

children do not want to go into crowded environments (4/18; 3/23). For example, Ayten, who had mentally handicapped child, said 'Sezer is scared of the crowd'(Interview #5; p.15); Filiz, who had a mentally handicapped daughter, said 'She gets bored of the crowd'(Interview #21; p.10).

When mothers were asked whether they shopped at stores where clothes or shoes were sold with their children, (21/21; 19/21) 100-91% of mothers said that they shopped at these stores with their children. When mothers were asked what kind of problems they encountered while shopping in these places, mothers mostly stated that they had to buy clothes or shoes without having their children try them on (5/17; 11/33). Mothers stated their preference for shopping in these kinds of stores without their children as follows: While Nazan, who had a child with autism stated, 'We never take or children to a store to buy clothes for them. We buy and bring them home and our children wear them'(Interview #14; p.20), Nurten said, 'We know the sizes our children wear, so we buy for them' (Interview #30; p.9). Another problem experienced in these kinds of places is that children get bored (2/17; 8/33). Ayfer, who had a son with autism, explained this as follows, 'If we stay somewhere for a long period, he gets bored'(Interview #8; p.18). Another problem expressed by mothers is the difficulty they had with their children trying on clothes or shoes (5/17; 2/33). Hatice, who had a 17 year old mentally handicapped son, related this incident,

> He does not know himself whether the shoes are the right size. Once, his father pressed his fingertips with his hand and said, *Son, these shoes are small for you, they may pinch your feet*. Then the boy took off the shoes, he also took off his own shoes and went down the stairs in bare feet (Interview #9; 13/6, p.16).

Using Restaurants

When mothers were asked whether they ate out with their children, (19/21) 91% of mothers from both groups stated that they ate out with their children. When mothers were asked what kind of problems they encountered while eating out, most of mothers stated that their children got bored while waiting for meals (3/8; 5/13). For example, Saliha, who had a mentally handicapped child said, 'He is somewhat impatient in this matter. He asks why the meals have not arrived yet. He always asks the same question, 'Why are we waiting, why have they not arrived?'(Interview #42; p.9). Kadife, who had a child with autism, stated, 'Impatience with waiting, or whatever happens when the meals arrive, the food gets eaten and finished. We have experienced such events many times over, but we must be patient in this matter '(Interview #11; p.13).

When mothers were asked whether they used public toilets with their children, (20/21) 95% of the mothers in both groups stated they used public toilets with their children. When mothers were asked what kind of problems they encountered while using public toilets, they mostly stated the problems concerning the selection of men's/women's toilets (8/19; 18/26). For example, Berrak, who had a 16 years old son with autism, said, 'It is surely somewhat difficult, but we do not have any problems when his father is with us …it is not considered appropriate for a woman to go into a man's toilet'(Interview #19; p.12). Esin, who had a 14 year old son with autism, took a different approach to the subject and said,

> Women may bring their children with them thinking, 'he does not understood anyway'; but let's think about the case of a father with his daughter. What will such a man do? Will he take his daughter to the women's toilet or to the men's? (Interview #33; 2/12, p.24).

Arzu, who had a 16 year old daughter with autism, gave an example of this situation, 'She sometimes goes with her father, he has to go into the women's toilet, he must surely experience great difficulties in doing that'(Interview #37; p.18).

Using of Community Facilities

When mothers were asked whether they went to health centers such as hospitals or health care centers with their children, all of the mothers from both groups stated that they went to these kinds of health centers with their children. When mothers were asked what kind of problems they encountered while getting service from health centers, mothers mostly stated that they had problems while awaiting their turn (9/26; 15/48). Mothers expressed their problems in this matter as follows, Nilay who had a 13 year old mentally handicapped son said, 'Baran gets very bored, ,and he wants to go without being examined'(Interview #40; p.13), and Aydan who had a 19 year old son said, 'our problem is the queue'(Interview #22; p.30).

Another problem experienced while getting service from health centers are the difficulties experienced during examinations (5/26; 13/48). Ayfer, who had a 13 year old son with autism said, 'During the examination, he either refuses to open his mouth or he gives the doctor a kick'(Interview #8; p.21) while Nurten, who had a 17 year old son with autism, reported that, 'he never wants a person with white coat to approach him'(Interview #25; p.10). Another problem is the near impossibility of giving medical attention to the child (4/26; 10/48). For

example, Kadife, who had a 20 years old son with autism said, 'It is very difficult to get a blood sample taken. Once, we had to get his blood sample taken by making him sleep, this situation is so serious'(Interview #11; p.14). Esin, who had a son with autism said,

> He cut his foot, so his foot was sutured. They did not anaesthetize him; they sutured his foot when he was conscious. All hell broke loose. Four medical attendants flew at him. I was the fifth person, and there was also the doctor who was suturing him in addition to a nurse. The child just suffered (Interview #33; 2/12, p.26)

Dental treatment is another problem area (3/26; 4/48). For example, Filiz, who had a 20 year old mentally handicapped daughter, expressed her problem in this area, 'Once, while the doctor was injecting her gum, she hit his hand. The dentist said, 'This needle could have hit her brain'(Interview #21; p.13).

When mothers were asked whether they went to hairdressers or beauticians with their children, (20/21; 17/21) 95-81% of mothers stated they went to hairdressers or beauticians with their children. When mothers were asked what kind of problems they experienced in these kinds of places, they mostly mentioned that their children did not want to remain at hairdressers or beauticians (4/6; 12/22). Hatun, who had a 20 years old son with autism, said, 'I cannot make him go to the hairdresser (Interview #16; p.12), and Lale, who had a son with autism, said, He will not have his hair cut, he pulls away or lifts his head up, he stands up, he overwhelms his father, the hairdresser and me, from top to bottom'(Interview #31; p.16). Another problem is that they always have to take the children to the same hairdresser (1/6; 6/22). Zülfiye, who had a 21 year old son with autism, described this situation as follows, 'He will not go to any hairdresser other than his own hairdresser'(Interview #28; p.14).

Discussion

The purpose of the present study is to compare the difficulties experienced by mothers with mentally handicapped children and those who have children with autism, in participating in community life activities in relation to getting from one place to another as a pedestrian, using public transportation, personal development and community life, using public facilities and entertainment venues, participating in cultural activities, attending sports events and activities, shopping, eating out and use of community facilities.

When the difficulties experienced by mothers with mentally handicapped children or children with autism while going from one place to another by foot with their children were compared, it was realized that most of the mothers in both groups stated that they always had to keep hold of their children's hands. The results obtained from the study carried out by Karabulut (2007) indicate that traffic education given to mentally handicapped children at schools is theoretical and it cannot be transferred into real environments. Mentally handicapped children cannot generalize what they learn in the classroom environment to the real world due to their intelligence levels; it was recommended in the same study that this problem, which stems from current traffic and first aid training, could be eliminated through putting an emphasis on applied training; and it was revealed in the same study that the only reason for the failure of mentally handicapped individuals to safely negotiate urban traffic was not training, environmental planning; and that urban services and lack of education also played a key role in the emergence of this problem. The results and recommendations in the study conducted by Karabulut (2007) may help explain some of reasons for the findings of the present study.

On examining the opinions concerning moving from one place to another as a pedestrian, it is seen that mothers with autistic children were more concerned about this problem than mothers with mentally handicapped children. The average age of the mentally handicapped children of mothers with whom the interviews were carried out was 15. Considering the high average age of the children, the fact that mothers had to keep holding the hands of their children can be regarded as a sign that shows that the handicap of the child is apparent. The fact that almost half of mothers stated that they were annoyed by the stares and reactions of people while out on foot supports the results obtained. This was also the case in the study carried out by Vural (2003), where some of the families said that they were annoyed by the stares of other people.

Mothers with mentally handicapped children, when they visited neighbors or relatives, mostly expressed problems deriving from the fact that their children did not behave in accordance with their ages. By comparison, mothers with children with autism mostly spoke of the problems with their children messing up houses or damaging objects in the houses. They made no mention of problems resulting from behaviors inappropriate for the ages of their children. That only mothers of mentally handicapped children said that this situation was a problem may result from the fact that the main problem for mentally handicapped children is understanding how to be with others over a long period, and understanding how to behave in community environments (Coulter, 2006).These findings parallel those concerning the community developmental characteristics of mentally handicapped children as reported in the literature (Bigge et al, 1999; Özgür, 2004; Eripek, 2005; Heward, 2003;

Turnbull, Turnbull, Shank, Smith,& Leal, 2002). In fact, the problems expressed by the mothers in the present study reflect the general developmental characteristics of their children.

It was seen that a great majority of mothers with mentally handicapped children made visits to neighbors and relatives, but some families, though few in number, made no such visits. In the study carried out by Cavkaytar, Batu & Beklan Çetin (2004), it was concluded that after participants had learnt that their children were mentally handicapped, their relatives and neighbors were unconcerned, and the families were supported only to a limited degree. These results are thought to indicate that the community lives of families are to a great degree limited and the burden on the mother in particular increases. In this matter, the above-mentioned findings correspond with those of the present study. Therefore, these findings can be regarded as the reasons for the limitations placed on mothers in their community lives.

Comparing the problems experienced by mothers saying that they participated in sports activities their children, it is seen that mothers with mentally handicapped children had more to say. Most of the mothers with mentally handicapped children stated that their children failed to play games with rules, such as basketball or football, or they did not obey the rules. It is seen in the study by Pretty, Rapley & Bramston (2002), that although young people without any mental handicap mostly spend their time playing games with rules such as basketball and football, mentally handicapped young people spend their time participating in activities such as coming together for barbeques, playing on the grassplot and bicycling. This finding is consistent with the results obtained in the present study. Unlike mothers with mentally handicapped children, some of mothers with children with autism stated that their children were isolated when taking part in sports activities.

All mothers from both groups stated that they took their children to public toilets when they were outside. Upon examining the problems experienced by these mothers, it is seen that the most frequently encountered problem was about the use of women's or men's toilets. Mothers who have children with autism experience this problem more in comparison with those who have mentally handicapped children. This problem is less frequent if the parent and child are of the same gender. It can be said that serious problems are encountered if the parent and child are of different genders. The reason why mothers who have children with autism express this problem more frequently may be associated with the features of the mothers with whom the interviews were conducted. Only three of the mothers, each with a child with autism, had daughters, while the others had sons. In that case, the parent and child were of different genders. However, mothers also stated that when their daughters had to go into toilets together with their fathers, they experienced great difficulties.

Conclusion and Recommendations

As a conclusion, it can be said that mothers who have mentally handicapped children and mothers who have children with autism have difficulties of varying degrees in attending or participating in different fields of community life. To facilitate the participation of families in community life along with their handicapped children, it is necessary to create activities specifically aimed to enable handicapped children to acquire skills, for their families to cope with any problems, and for a greater awareness to be created in society.

As a result of this study, it can be recommended for future researchers that they conduct studies with families who have children with mental handicaps of children with autism, across different age ranges (younger ages, or during the period of adulthood). Similar studies could be conducted by focusing on different skill areas such as personal maintenance, homemaking, using money, using the phone, making use of leisure time, using the bank, work and professional life skills. That is, studies on skill areas which are among the community skills, but which are not examined in the present study.

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