Abstract: The purpose of the paper was to research leisure in families with children with developmental disabilities from the parents’ point of view, a topic that has been marginally researched in Croatia as well as in the region. Qualitative methodology was used, and information was gathered by interviewing nine mothers of children with developmental disabilities. The results show that mothers achieve family leisure through a large spectrum of activities, during which they assign great importance to interaction. To organise family leisure, they face numerous challenges (e.g. stress, fatigue, difficulties in finding suitable activities) and use various strategies (e.g. planning carefully, obtaining materials, consulting other parents/experts). As benefits of family leisure, they report family member bonding, relaxation and fun for the child with developmental disability as well as maturity and empathy in the siblings of typical development. However, when asked whether they can use the family leisure as their own leisure, answers were contradictory.

Keywords: parents, challenges, strategies, benefits, qualitative research

Introduction

Families of children with developmental disabilities in the Republic of Croatia come across difficulties in exercising their rights to upbringing, education and social welfare. For example, they have difficulties in obtaining adequate financial aid, which in the Republic of Croatia is guaranteed by the Social Welfare Act and the Ordinance on the Rights of Parents of a Child with More Serious Developmental Disabilities to Leave or Work Half-Time to Care for the Child, as well as other regulations. Families also have difficulties in accessing expert help due to the lack of experts specialised in educational, rehabilitation and therapy work and to the lack of support in financing such experts (Rešetar, 2017). When talking about ensuring the right to education, it is clear that there are elements of segregation practice in education. There are also difficulties in achieving appropriate educational programmes and appropriate means of assistance for education, which should be regulated by the Primary and Secondary School Education Act as well as Regulations on Primary and Secondary Education of Students with Developmental Disabilities (Report on the work for 2017, 2017).

In addition to the difficulties in exercising the above-mentioned rights, the sphere of family leisure with a child with a developmental disability is an even more ignored area, so we can talk about difficulties in ensuring the opportunities for leisure, meaning insufficient possibilities for achieving family leisure at home, an inadequate availability of activities outside the home and difficulties in participating in those activities, as well as difficulties in ensuring resources for such activities (Clarke, 2006).

Speaking of family leisure, it is necessary to first begin with a generally accepted basic definition of leisure in scientific circles as “set of occupations to which an individual may freely devote himself, whether for rest, for fun, for personal development or disinterested formation…” (Dumazedier, 1962, according to Janković, 1973, p. 34). Extending it in the family context, over the past several decades there is also one basic, generally accepted defini-
tion of family leisure as time that family members spend together in free time activities (Shaw, 1997, according to Hodge et al., 2015). However, that immediately imposes the need for a deeper understanding of the phenomenon of “leisure”, which depends on whether family members even think of it as leisure (Shaw, 1997, according to McCabe, 2015). The above-mentioned implies that it is not always about freely chosen activities because family leisure is often seen as a duty and even though it can imply satisfaction, it often includes work, occasional frustrations and a possible lack of satisfaction of all family members (Shaw & Dawson, 2001). Hence, the above-mentioned authors call it “serious leisure”. Similar to that, it is also described as “purposive leisure”, which means that it should be not only entertaining but also developmental, primarily for the child’s development. It should give the child the opportunity to learn through family leisure. Therefore, family leisure should be planned and implemented in order to achieve certain goals, such as strengthening family cohesion. Lack of existence of a unique definition of family leisure is connected to the questions of whether it really is leisure (Shaw & Dawson, 2001), which family members talk about that leisure, and in which phase of the cycle of life the family is (Hebblethwaite, 2015). Therefore, family leisure is characterised by identity markers of the family and its members.

Families achieve their leisure through various activities, which Zabriskie and McCormick (2001) divide into “core” and “balance”. Core activities imply usual daily and relaxing activities that are done within or near the house. Balance activities are those more oriented toward gaining new experiences and achieving a change, and they demand more planning and resources from the family members. In addition, activities can be considered “joint” or “parallel” based on the level of interaction amongst family members. Joint activities are those defined by a high level of interaction amongst family members, while for parallel activities the interaction is low (Orthner, 1975, according to Melton, 2017). Melton (2017) integrates the above-mentioned differentiation into a family activity model by differentiating family leisure activities depending on the level of interaction amongst family members and the level of disparity between those activities and surrounding ones.

Leisure for families of children with developmental disabilities has been the subject of less research, and the interest for that area has grown along with the understanding about the benefits of family leisure and changes in the perception of people with developmental disabilities in terms of the spread of inclusion (Mactavish & Schleien, 2004).

**LEISURE ACTIVITIES OF FAMILIES WITH CHILDREN WITH DEVELOPMENTAL DISABILITIES**

In terms of previous research of leisure of families with a child with a developmental disability, what was researched was the type and the frequency of family leisure, and spending leisure was compared between families with a child with a developmental disability and families with a child of typical development. According to Mactavish and Schleien (2000), the most frequent leisure activities were the activities that fall into the category of physical recreation activities such as swimming, followed by passive activities such as watching TV and, least often, visiting family and friends. Axellson and Wilder (2014) report that the families with children with profound intellectual and multiple disabilities practiced passive activities more often, i.e. more peaceful activities inside their homes, compared to the families that have a child with typical development, who participated more in activities outside their homes. The above-mentioned results on rarely practicing activities such as a holiday in families with a child with a developmental disability were confirmed by the research of leisure activities in families with a child with autism spectrum disorder (Rodger & Umaibalan, 2011), which found that the balance activities of parties, celebrations and vacations were rarely practised.

Contrary to the above-mentioned identified differences in the quantity and the type of leisure activity in families with a child of a typical development and families with a child with a developmental disability, Dodd, Zabriskie, Widmer, and Eggett (2009) did not find differences in the level of participation in leisure activities between the above-mentioned family types, pointing to the same participation in core and balance leisure activities, just as Mactavish and Schleien (2004) did not find differences in the frequency of indoor
or outdoor activities in families with a child with a developmental disability.

Unlike the earlier mentioned findings on the rare frequency of outdoor activities, Downs (2008) reported on the wide variety of such activities, stating that activities such as trampoline jumping, going to the beach or camping were often practised in families with a child with severe disabilities. Unlike the question of whether it is about indoor/outdoor activities or core/balance leisure activities, the question of the level of family members’ interaction in leisure activities has not been researched.

CHALLENGES IN ACHIEVING LEISURE IN FAMILIES WITH CHILDREN WITH DEVELOPMENTAL DISABILITIES

Speaking of family leisure in families with children with developmental disabilities, what is often mentioned are the difficult family routines structured around the child’s disability (Boyd, Harkins McCarty, & Sethi, 2014). Along with that, Mactavish and Schleien (2004) found that parents saw the need to plan extra and found it challenging to locate additional resources to achieve leisure and a balance between work and leisure. An additional challenge was the difficulty to find suitable activities that could benefit various interests and the abilities of the family members, especially for a child with a developmental disability (Mactavish & Schleien, 2004).

Furthermore, Rodger and Umaibalan (2011) reported on the lack of formal and informal support to the families with a child with autism spectrum disorder as something that made achieving family leisure difficult. DeGrace (2004) stated that the difficulties in participating in joint activities in families with a child with autism can lead to parent dissatisfaction, especially guilt; it can hinder achieving family welfare; and it can have a negative influence on the family identity.

STRATEGIES ON ACHIEVING LEISURE IN FAMILIES WITH CHILDREN WITH DEVELOPMENTAL DISABILITIES

To face the challenges connected to organising and spending family leisure, families with a child with a developmental disability respond by creating strategies that make it easier to participate in family leisure activities (Dodd et al., 2009). Segal (2011) speaks about the careful planning of the entire family in order to ensure the space and the time for the whole family to be together. With the additional goal of including all family members in joint leisure, families practice strategies such as preparing different food, aids, planning alternate plans, locations, time and participants in the activities, or they structure daily routines in a way to help the children cope with possibly negative sensory experiences (Bagby, Dickie, & Baranek, 2012, according to Boyd et al., 2014). Families that have a child with autism often check and monitor the number of stimulations in the surrounding area and ensure routines with the goal of increasing the predictability of the experiences (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011).

Connected with those strategies, DeGrace, Hoffman, Hutson and Kolobe (2014) talk about the family going from the feeling of paralysis through a research phase, which is characterised by the search for information, studying and searching for meaning by the parents; to an application phase, which implies taking action and which is connected to the feeling of confidence, reflexivity and hope by the parents.

BENEFITS OF LEISURE IN FAMILIES WITH CHILDREN WITH DEVELOPMENTAL DISABILITIES

Lastly, in the context of the research of leisure in families with a child with a developmental disability, the benefits of family leisure activities have also been the subject of research. However, the greater part of the research has placed the focus on the benefits for the child with a developmental disability. These benefits include the child’s skill, confidence development, positive self-perception and the experience of fun, as well as the child’s detachment from a stressful experience (Mactavish and Schleien, 1998; Mactavish and Schleien, 2004).

When talking about the benefits of family leisure for a child with a developmental disability, we can also talk about the benefits of leisure family activities for the whole family. In that
manner, family participation in leisure activities is described as a chance for moments filled with happiness (Downs, 2008), a way of re-establishing the meaning of what is important in life, a way of improving communication amongst family members (Mactavish and Schleien, 2004), and as a way of connecting family members and developing the quality of family life (Mactavish and Schleien, 1998).

When talking about the benefits of family leisure for the parents themselves, Downs (2008) reported on parents’ statements, which described leisure activities as significant and useful for the feeling of their own parental efficiency, the feeling of normalcy and the feeling of control over life and environment. What is lacking are findings on the potential benefits of family leisure for other family members, primarily brothers and sisters of the child with a developmental disability, i.e. the children of typical development.

**Study Purpose and Research Questions**

The purpose of this research was to gain insight into the leisure experience in families with a child with a developmental disability from the parents’ perspective. The following questions were asked:

- In what way do families with children with developmental disabilities spend their leisure time?
- What challenges do the parents of children with developmental disabilities face in achieving family leisure?
- What strategies do the parents of children with developmental disabilities use for achieving family leisure?
- How do parents of children with developmental disabilities perceive family leisure benefits and do they perceive family leisure as leisure?

It is interesting to mention that, while searching for the sample of participants, it was important to emphasise to the parents of children with developmental disabilities that the research was not about solely the child’s leisure but that of the family as a whole. Their first question after hearing of the study’s aims was often, “Excuse me, whose leisure time??!” This was the first signal to the authors of how much the concept of family leisure as such has been neglected.

**METHODS**

The research was conducted by individually interviewing the female participants/mothers of children with developmental disabilities. Before the beginning of the interview, participants were informed about the study purpose and benefits, interview mode, duration and recording, their right to withdraw from participation and, if they wished, to learn of the research results. The participants signed the consent and thereby confirmed their voluntarily participation and familiarity with the research details. The average interview duration was 30 minutes.

The sample was convenience, non-probabilistic and was made by nine mothers of children with developmental disabilities (N=9) (Table 1). Six people questioned were interviewed in their family homes, two in a local café and one in a local family centre. Their age ranged from 32 to 49 years of age. Seven mothers were from a larger Croatian town (more than 50,000 inhabitants) and two from a smaller town (fewer than 50,000 inhabitants).

Five mothers had two children, three had one and one had three. Eight mothers had one child with a developmental disability, and one had two. Four mothers had a child with autism spectrum disorder, two had children with cerebral palsy, two had children with several types and levels of disability in psychophysical development, one had a child with chromosome deletion syndrome and one had a child with attention-deficit/hyperactivity disorder. Seven children with developmental disabilities were male and three were female. The age of children with developmental disabilities ranged from 5 to 17 years of age.

A semi-structured in-depth interview was used for collecting data, and exploratory research was conducted. The semi-structured interview was based on the literature overview and independently constructed questions based on the need of this research, and it consisted of questions on general features of the mothers (the age, place of residence, number of children in the family, number of children with developmental disabilities, the child’s disability, the gender of the child with a developmental disability, the age of the child with a developmental disability) and of questions that were related to the four research questions.
Table 1. Participant characteristics

<table>
<thead>
<tr>
<th>Participant ID</th>
<th>Participant Age</th>
<th>Place of Residence</th>
<th>Number of Children in the Family</th>
<th>Number of Children with Developmental Disabilities</th>
<th>The Child’s Disability</th>
<th>The Gender of the Child with a Developmental Disability</th>
<th>The Age of the Child with a Developmental Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>M1</td>
<td>35</td>
<td>LT*</td>
<td>2</td>
<td>1</td>
<td>Several Types and Levels of Disability in Psychophysical Development</td>
<td>F</td>
<td>7</td>
</tr>
<tr>
<td>M2</td>
<td>40</td>
<td>LT</td>
<td>2</td>
<td>1</td>
<td>Cerebral Palsy</td>
<td>M</td>
<td>16</td>
</tr>
<tr>
<td>M3</td>
<td>39</td>
<td>LT</td>
<td>1</td>
<td>1</td>
<td>Autism Spectrum Disorder</td>
<td>M</td>
<td>8</td>
</tr>
<tr>
<td>M4</td>
<td>32</td>
<td>LT</td>
<td>2</td>
<td>1</td>
<td>Autism Spectrum Disorder</td>
<td>M</td>
<td>8</td>
</tr>
<tr>
<td>M5</td>
<td>37</td>
<td>LT</td>
<td>3</td>
<td>2</td>
<td>Cerebral Palsy</td>
<td>F</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Attention Deficit/ Hyperactivity Disorder</td>
<td>M</td>
<td>15</td>
</tr>
<tr>
<td>M6</td>
<td>39</td>
<td>LT</td>
<td>1</td>
<td>1</td>
<td>Chromosome Deletion Syndrome</td>
<td>M</td>
<td>13</td>
</tr>
<tr>
<td>M7</td>
<td>36</td>
<td>LT</td>
<td>1</td>
<td>1</td>
<td>Autism Spectrum Disorder</td>
<td>M</td>
<td>9</td>
</tr>
<tr>
<td>M8</td>
<td>36</td>
<td>ST**</td>
<td>2</td>
<td>1</td>
<td>Several Types and Levels of Disability in Psychophysical Development</td>
<td>F</td>
<td>5</td>
</tr>
<tr>
<td>M9</td>
<td>49</td>
<td>ST</td>
<td>2</td>
<td>1</td>
<td>Autism Spectrum Disorder</td>
<td>M</td>
<td>11</td>
</tr>
</tbody>
</table>

*LT = larger town  
**ST = smaller town

The first research question was related to the way that families with a child with developmental disability spend their leisure and it encompassed questions on the types of family leisure activities, the location of these activities, the frequency, the level of interaction during those activities and the family members that participate in those activities. The second research question was related to the challenges that the parents of the children with developmental activities face in achieving their leisure, and it encompassed questions about the everyday obligations as something that can hinder achieving family leisure, the ease with which leisure activities that match the interests and the abilities of various family members are found, stress and fatigue as challenging factors and the resources necessary to achieve more joint family leisure. The third research question was related to the strategies that parents of children with developmental disabilities use to achieve family leisure and it included questions on family leisure planning, ensuring routines, additional materials and aids, reading literature that deals with the topic of developmental disabilities and community support in planning and achieving family leisure. The fourth research question was related to the benefits of leisure for families that have a child with developmental disability and the parents’ perception of the benefit of leisure for the family, for the child with a developmental disability, for the parent, for the child with typical development and the perception of family leisure as leisure.

The interviews were conducted according to the protocol, and the course of the interview was flexibly modified according to the answers, which means that the sequence of the questions was adapted during the interview and the mothers were encouraged to give more detailed responses and additional explanations of what was said.

Qualitative methodology was used for data processing, i.e. quality content analysis was conducted. Hsieh and Shannon (2005, 1278) define quality analysis as a “research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns”. More concretely, an interpretative phenomenological analysis
was conducted. Data process started by listening to audio files, transcribing and precisely reading transcribed interviews with the purpose of getting to know the data. The coding process was conducted, which means that the mothers’ statements were transferred to codes, i.e. related words, sentences or ideas put under the same code that links them. (For example when talking about the types of family leisure activities, some of the mothers mentioned playing on a playground, which was coded under GAM-PARK.) Then the frequency of the mothers giving that answer under the same code was determined.

However, the intention was not to quantify the results or to generalise them but to do the analysis of understanding the significance the mothers gave to the research subject. After determining the codes and their frequencies, similar codes were put into categories. Therefore, the coding was conducted manually and the codes and the categories were derived from the data.

RESULTS AND DISCUSSION

The received data were analysed according to the predefined research questions and compared to previous knowledge from earlier research. Therefore, the results overview is divided into four sections. The first section discusses the ways that families with children with developmental disabilities spend their leisure, the second section discusses the challenges to achieving family leisure in families with children with developmental disabilities, the third section discusses parents’ strategies used for achieving family leisure, and the fourth section discusses benefits of family leisure as well as parents’ experience of family leisure as leisure.

HOW FAMILIES WITH CHILDREN WITH DEVELOPMENTAL DISABILITIES SPEND THEIR LEISURE TIME

The first research question pointed to the wide spectrum of leisure activities in families with children with developmental disabilities. Mothers talked about various balance and core activities, but mostly they mentioned balance activities such as summer vacation or travelling in general; the core activities conducted outside the house, such as walks and playing in a park; and core activities inside the house, such as playing in the house and watching TV. Such results are similar to the findings of Downs (2008), who reported on the wide spectrum of outdoor activities amongst families with children with severe disabilities, such as jumping on the trampoline, going to the beach or camping.

We try to do it as many times as possible as a family, most often while walking the dogs in the park, now that the weather is nicer, and when the weather is not nice, when it is cold, then we are outside for a very short period of time or we go to the malls or playrooms. (M1)

 Somehow they like best the outside playtime together... Let's run, chase, race, hide. There they find they have some common interests. The place where we are all together as a family is a swimming pool. (M4)

When speaking of the place of spending family leisure, mothers reported places outside of the home, such as a park or a backyard, but also house or a flat. The place for achieving those activities was related to the possibilities it offered for achieving activities and the preparations it requires for conducting those activities. Family leisure activities were spent mostly outdoors because they enabled the child’s participation, or were more often conducted indoors because of the need for additional equipment necessary for outdoor activities.

In the flat. Indoors. That is the simplest, the most comfortable and everything I need is here. So, for any outdoor activity, I need additional equipment. (M6)

Well, I would say nature. Mostly we are in nature, somewhere in a park. Or, we can sit in the car and we go outside for a walk. But mostly we are in nature, where, let's say, he is free and where his problem is the least visible. (M4)

The frequency of core activities varied depending on the number of obligations, and such activities were usually conducted daily, although more time was found at the weekends, while balance activities such as traveling and excursions occurred several times a year. In relation to that, mothers mentioned the need for planning and organising,
as well as a routine when conducting such activities. Zabriskie and McCormick (2001) talk about balance activities as activities that are oriented toward gaining new experience and achieving a change, which they describe as activities that require more planning and resources from family members. Therefore, it is not illogical for the mothers to report on conducting balance activities less frequently in relation to core activities, as established earlier by Rodger and Umaibalan (2011) while researching family leisure in families with a child with autism spectrum disorder.

Every day, that happens every day. It just depends if it is more or less. So, it doesn’t necessarily mean I get to do everything with him every day, but we are here every day. Or we watch, comment on a cartoon, and there are picture books on the table. (M6)

Interaction during joint leisure activities was shown as something that mothers perceive as important for an activity to be successful and to which mothers pay attention during an activity.

You can’t let her go alone, she needs help and support, in the sense that you have to break every activity into smaller parts, and then you have to talk about a lot of things, and then we play. That is the only way in which you can have fun with her or she with you. To go down on all fours and act out whatever it takes so she can play as well. (M1)

When talking about the family members who participate in family leisure, some of the mothers talked about the participation of more family members, such as mother, father, and a child/children. Some of the mothers talked about the participation of fewer family members, in which case the mother participated more than the father. What is also described is the exchange between the mother and the father in the activities. Mothers’ answers suggest that not all members participate in family leisure, that the mother and child are the ones who participate more, which is similar to findings by Mactavish and Schleien (2004). Nevertheless, that previous study and ours found that fathers also participated, which cautions against overemphasising the greater participation of the mother in family leisure than the father (Visković, 2016).

Yes, mostly me because my husband works all day, he comes home around 8 o’clock. But at the weekend he spends more time with him, I don’t go to the swimming pool. The two of them spend all afternoon at the swimming pool. Most often until... the evening. That means that my husband is with him at the weekends. And I am on the work days. (M3)

CHALLENGES IN ACHIEVING FAMILY LEISURE IN FAMILIES WITH CHILDREN WITH DEVELOPMENTAL DISABILITIES

Responses to the second research question suggest that the everyday obligations that hinder achieving family leisure in families that have a child with developmental disabilities involve taking the child with a developmental disability to therapy and giving practical support to that child. Furthermore, the mother’s fatigue and stress were described as something that hinders achieving family leisure, so mothers reported not achieving planned activities and reducing family leisure from time to time because of fatigue. They also reported tension that might be present during family leisure.

So, I work only in the morning. So in the afternoon, we are free, but, there is this thing where we have therapy at some crazy time, so then either only one [parent] goes or we all go together. And then we play with ***... or we talk in the car or I don’t know. But it is, in a way, because the whole tempo wears you down and exhausts you, and not sleeping at night, so sometimes you are just too exhausted to go anywhere although you planned to do something. Then we stay at home and we play indoors. And we postpone activities for some other time. (M4)

Finding activities that suit the interests and the possibilities of various family members is something that not all mothers described as easily achieved. What is important is monitoring the interests and abilities of the child with a developmental disability and forming family leisure accordingly. Segal (2011) describes dedicated parents as those who focus on the child’s interests and subordinate their own interests to the child’s. We can ask the question whether the interests of the child with a developmental disability, in the context of family leisure activities, match those of other family members,
or whether the activities are easily found because they are mostly the ones that match only the child’s interests. Regardless, the second statement shows the importance of adapting family leisure activity to the child with a developmental disability, so that the family can practice activities that can satisfy a greater number of family members’ interests.

Well, it is not easy. It is not easy. I say when we only start with the board games, which are not adapted to everyone and where it is really difficult to find a board game that can be played by everyone. And I don’t know, going to the town where there are a ton of physical barriers. (M5)

Yes. She is a very interested child... whatever we do, we can do that with her. So she can participate in something, we simplify it as much as possible... There, for example, if we want to play the board game “Don’t get angry”, she cannot sit and follow the figures and all that. So we make it suit her needs. So we have made a giant board game with really big figures and with bright colors, with high contrast and in such a way that she has to walk around in circles to play it. In the end, we have achieved that she plays the board game completely. (M1)

As the most necessary resources, mothers mentioned the need for professional support and practical help. In addition, they reported the need for rest, more flexible work hours for the husband, time and health; and of material resources, they mentioned money. Mothers’ statements suggest the need for professional support and non-material resources in general, which differs from the results by Berc and Kokorić (2012), where parents indicated material resources, i.e. money, to be the most necessary. The authors of the present study suggest that the differences relate to the fact that the previous research did not focus on the parents of the children with developmental disabilities. However, that work is still worth mentioning due to the already mentioned lack of specific national and regional research.

In the whole story, maybe we would need the support of the system, personal assistants. Because we do not give our all to spend time together, far from it. But we definitely need the support of the system, we need assistants. Because you need help with bathing, you need help with taking him for a walk. (M2)

STRATEGIES THAT PARENTS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES USE FOR ACHIEVING FAMILY LEISURE

The third research question gives us insight into the strategies that mothers of the children with developmental disabilities use for achieving family leisure. Mothers plan the time and the place of the family leisure activity in detail as well as the necessary resources for achieving an activity, which enables them to ensure more successful joint leisure. The results about the careful planning agree with previous findings on planning to secure the space and time for the family with a child with a developmental disability to be together (Segal, 2011). In addition, according to Boyd et al. (2014), Bagby, Dickie and Baranek (2012) confirm that various strategies to prepare food, location and time are used by families with a child with a disability.

It takes a lot of planning in order for a family of children with developmental disabilities to spend their leisure in a useful and smart way. Yes, planning and organizing are extremely important words... (M9)

Ensuring routine was not a practice of the majority of mothers in our sample, and the statements of the mothers that do practise it suggest the importance of stimulation control in the environment and ensuring accessibility of the place where the activity is conducted. Not spending family leisure according to patterns is opposite to the findings of Schaaf et al. (2011), who found that families with a child with autism often ensure routines in order to increase experience predictability. The authors of the present study attribute this difference to the fact that the previous research was solely focused on families with a child with autism spectrum disorder, which is extremely specific considering that routine and ritualistic behaviour are one of the basic symptoms for diagnosing that condition (American Psychiatric Association, 2013), while the present research encompassed a broader spectrum of disabilities, as well as the need for routine.

Every day of the week is more or less the same. So, on Tuesdays, we visit the speech therapist on neurofeedback and swimming, and so, after school,
we know exactly who goes where, how long we will be there, what comes after that, what is in the middle and where to go after. Yes, it means, leisure, he knows he doesn’t go home, but that he will go somewhere and then we can sometimes talk in the car and say if we go to *. *(M7)

With the purpose of enabling and simplifying the participation of a child with a developmental disability in family leisure, the mothers ensure various materials and aids such as sensory materials, wheelchairs, therapy dogs, sports props and didactic games, taking into account the needs and interests of a child.

As an aid, we have a dog, he is very useful, he helps a lot and he really looks after her, but that is more or less that. We use only the things that help her and those are things like weights and massagers and those things... We are making her a sensory room. There was a sensory room in the previous flat too, with gym mats, a mirror, a hanging swing and such. And those are the things that really help because then you can play while doing something at the same time. *(M1)*

When talking about the contribution of the literature about the developmental disabilities for achieving family leisure, just a small number of mothers described ways in which the literature helps them organise family leisure. The mothers stated that the literature helps them better understand the child, which then has further implications on successful implementation of leisure.

Well, yes, as a young boy, *, I mean, he still has that general sensory integration disorder, so that the literature I used was completely on that subject. So, how to regulate a child so you could even play with him or go somewhere and such things. I learned there, from that literature, a lot about the strategies on how to reduce stimuli or how to activate them... or how to reduce sound stimulation or how to motivate him and such things. That means that there is literature and it has helped me a lot. *(M7)*

Speaking of the support they get in planning and spending family leisure, the mothers mention family members, especially the husband, grandmother and grandfather of the child with a developmental disability, then the exchange of experience with other parents and cooperation with experts in various fields. Consulting others, as well as finding a way in which other family members can help them in planning and organising family leisure, are the strategies that mothers use in order to ensure family leisure.

Therapists are actually the people who give the best guidelines on what and how to do with a child... Here, a specific example: one year we went to the seaside and my husband wanted to rent a boat... I was terrified how * will react, considering he had never been on a boat before... The first thing I did was to call his therapist who said nicely: “Ok, if he shows that [anxiety], sit, put a backpack on him.” I think I would have never thought of that, him holding a backpack, to feel something on his body. *(M6)*

**BENEFITS OF LEISURE IN FAMILIES WITH CHILDREN WITH**
**DEVELOPMENTAL DISABILITIES AND PARENTS’ EXPERIENCE OF FAMILY LEISURE**

When responding to the fourth question, when talking of the benefits for the whole family, the mothers recognised better connection amongst family members, better communication, strengthening trust and family feeling and developing conflict management skills. Similar to these results, improving communication and connecting family members was recognised earlier as contributions of leisure in families with a child with a developmental disability (Mactavish & Schleien, 1998; Mactavish & Schleien, 2004). The greatest contributions for the child with a developmental disability that the mothers state most frequently is in terms of socialisation, speech and motor skills development and developing self-confidence, then they talk about happiness and entertaining a child and the child’s relaxation. The above-mentioned is similar to recent findings according to which the most important benefits of leisure in families with a child with a developmental disability is the development of the child’s skills, development of self-confidence and positive image and the experience of fun as well as the child’s detachment from a stressful experience (Mactavish & Schleien, 1998; Mactavish & Schleien, 2004).
Similar to that, amongst the benefits for the child of a typical development the most recognisable is the contribution of family leisure to the child’s development, especially in terms of empathy and maturity. When describing the family leisure benefits for themselves, the mothers mentioned relaxation the most, i.e. as relaxing and a source of strength. In addition, they see family leisure activities as useful for developing parents’ competence, strengthening the sense of fulfillment and feeling of what is important in life, and they also mention their own happiness and an opportunity to have fun as positive outcomes. The feeling of parent’s competence as a benefit of family leisure matches earlier findings by Downs (2008), who reported that parents of children with severe disabilities described family leisure activities as significant for a feeling of parents’ effectiveness. When talking about the benefits for the child/children, the mothers in the present study stressed the developmental function of family leisure, and at the same time, when talking about the benefits for themselves, they mentioned “rest” more, which the authors connect to the notion of family leisure as leisure whose purpose is not just fun but also to develop the child’s skills. When asked if they can see family leisure as leisure, the mothers were divided. The mothers who described it as their own leisure described it as such for various reasons, suggesting that it represented a source of relaxation and strength in order for them to be able to see it as such. The mothers who did not describe the family leisure in terms of leisure explained that this was because of the number of obligations it entailed.

Definitely, as my leisure. I mean, that walk is, for me, like now, I am really looking forward to these nice days, to me that walk in the afternoon... Then let’s go to the wheelchair and let’s go for a walk, you know... That is something too, it is relaxing, because, I really just push the wheelchair and I walk... So, I consider it my leisure. (M6)

When you are with them, it is like you are on needles, you dread it, constantly running here and there, essentially... You are stressed all the time. It means you don’t really have completely leisure. (M4)

Most mothers mentioned the source of relaxation as a family leisure benefit for themselves, but at the same time some of them did not describe family leisure as leisure. The authors of the present study believe that these findings reflect the complexity of the phenomenon of leisure in families with a child with a developmental disability, in which there can coexist both positive and negative experiences; even though leisure can contribute to relaxation and mothers’ satisfaction in certain instances, it can also involve obligations and lack of satisfaction. Despite the latter, the statements on the recognised benefits suggest that mothers recognise family leisure as an important segment of family life that can contribute to each individual family member and the family as a whole.

CONCLUSION

All of the above-mentioned very clearly underlines the fact that primarily in the national framework, the topic of leisure in families with children with disabilities is very relevant, although the present research has only scratched the surface. This research generated some topics the authors believe to be valuable for further research. For example, it would be useful to research the level and the form of interaction of the family members during leisure in families with a child with a developmental disability using an observational method. The way that leisure in families with a child with a developmental disability differs amongst families with a child with a developmental disability considering various identification markers could be researched using a quantitative research plan. For example, are there any differences in leisure in families with a child with a developmental disability considering the gender or the level of education of the parents? The authors suggest such research could contribute to furthering the knowledge of leisure in families with a child with a developmental disability.

However, it is also necessary to point out the possible limitations of the present study. One is the small convenience sample, especially considering that four out of nine mothers were mothers with a child with autism spectrum disorder, which is specific, especially in relation to the activity classification used in the research. In addition, it is important to mention the lack of fathers’ perspective, the possibility of giving socially desirable answers and the subjectivity of the authors, especially in the data
analysis segment and especially when classifying leisure activities, which was based on the interpretation of the mothers’ statements. This may lead to bias when taking into consideration the perception of a certain activity as core or balance from the mothers’ perspective. The authors suggest introducing the parents to the notions of core and balance activities in further research, and asking parents to state whether certain activities were core or balance for them, since this assessment may differ from that of the researchers. In addition, the authors suggest an interpretation of core or balance in accordance with the child’s disability. For example, a core activity for a child with autism spectrum disorder cannot be interpreted in the same way as in a child with a different disability.

Furthermore, some disadvantages can be ascribed to the interview protocol, such as leaving out the option for mothers themselves to define their family leisure. In terms of testing the strategies at the end of each interview, the mothers were given an opportunity to add something that they considered to be associated with the topic but was not mentioned. They did not mention a new topic connected to the strategies. Despite that, the authors propose a new approach for further research. Immediately after the strategy questions, the mothers are to be encouraged to mention strategies they use that were not suggested in the interview protocol, and that would potentially enrich knowledge on subject. Lastly, to investigate the ease of finding certain activities, it is suggested that a question be added asking how easily family members agree on activities they will spend together, who participates in making that decision and in what way. All of the above-mentioned confirms the complexity and consequently the necessity of further research on the phenomenon of leisure in families with a child with a developmental disability.
REFERENCES


