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Perceived Stigma in Community-Based Leisure Activity Participation of Children With Autism: Perspective from Turkish Parents

Otizmli Çocuklarda Topluluk Temelli Serbest Zaman Katılımında Algilanan Damgalama: Türk Ebeveyn Perspektifi

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Abstract: In this research, the perceived stigma during community-based leisure activity (CBLA) participation of children with autism spectrum disorder (ASD) was investigated from the perspective of parents. The study group for the research comprised 10 parents of children aged 7-18 years. In the research designed with qualitative research methods, the conceptual framework comprised Goffman's (1963) 'stigma theory'. Data were collected with the face-to-face interview method using a semi-structured interview form. Analysis of data used the thematic analysis method. Within this scope, themes comprised an important necessity, tones of stigma, parents' reaction, wishes and reality and learned loneliness. According to the research findings, parents of children with ASD appeared to attach great importance to participation in CBLA. Due to CBLA participation being an effective socialization tool for children with ASD, parents saw it as a serious necessity. During participation in CBLA, children with ASD were exposed to many types of stigma and parents generally provided strong reactions to this situation. Perceived stigma negatively affected the CBLA participation of parents and individuals with ASD. In conclusion, CBLA participation is an important need for children with ASD, and by reducing the negative attitudes and behaviors affecting participation more children will experience participation in this type of leisure activity.

Keywords: Autism, perceived stigma, community based leisure, parents, children.

Özet: *Bu araştırmada, Otizm Spektrum Bozukluğu (OSB) olan çocukların, topluluk temelli serbest zaman aktivitelerine (TSZA) katılımında algılanan damgalamaları ebeveyn görüşleri aracılığıyla incelenmiştir. Araştırmanın çalışma grubunu 7-18 yaş arasında çocuğu olan 10 ebeveyn oluşturmaktadır. Nitel araştırma yöntemleri ile tasarlanan araştırmada, Goffman (1963)'ın 'damgalama teorisi'nden yararlanılarak kavramsal çerçeve oluşturulmuştur. Veriler yarı yapılandırılmış görüşme formu hazırlanarak yüz yüze görüşme yöntemi ile toplanmıştır. Verilerin analizinde tematik analiz yöntemi kullanılmıştır. Bu kapsamda, önemli bir ihtiyaç, damgalamanın tonları, ebeveyn tepkileri, dilekler ve gerçekler ile öğrenilmiş yalnızlık temaları oluşturulmuştur. Araştırma bulgularına göre, ebeveynlerin OSB'li çocuklarının TSZA katılımlarına oldukça önem verdikleri görülmektedir. TSZA OSB'li çocuklar için etkili bir sosyalleşme aracı olması sebebiyle ebeveynleri tarafından ciddi bir gereksinim olarak benimsenmiştir. TSZA katılımı sırasında OSB'li çocuklar pek çok damgalamaya maruz kalmaktadır ve ebeveynleri bu durumlar karşısında genel olarak sert tepkiler verebilmektedir. Algılanan damgalamalar, ebeveynler ve OSB'li bireylerin TSZA katılımlarını olumsuz olarak etkilemektedir. Sonuç olarak; OSB'li çocuklarda TSZA katılımının önemli bir ihtiyaç olduğu, katılımı etkileyen olumsuz tutum ve davranışların azaltılması ile birlikte katılım konusunda daha fazla çocuğun bu tür serbest zaman katılım deneyimleri yaşayacağı söylenebilir.*

Anahtar Kelimeler: *Otizm, algılanan damgalama, topluluk temelli serbest zaman, ebeveyn, çocuk.*

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INTRODUCTION

Participation in leisure activities is very important for all individuals in terms of health, quality of life and psychological well-being (Gürkan et al., 2021; Jones et al., 2013, Sarol and Çimen, 2015). At the same time, leisure activities reduce the risk of illness in individuals and are seen as an important necessity in terms of contributing to social relationships (Aitchison, 2003; Güngörmüş et. al., 2014). The importance of community-based leisure activities (CBLA) in increasing social interaction and interpersonal communication was emphasized in many studies (Navarro et al., 2018; Nieto et al., 2015).

This situation appears to indicate less participation in CBLA of individuals with special needs due to limited movement ability or mental disorders (Mihaila et al., 2020; Riggins et al., 2011). Factors forming the environment of individuals with special needs (parents, teachers, friends, etc.) are stated to have significant effect on the adjustment process to the social environment (Sarol et al., 2022; Hacıibrahimoğlu and Kargın, 2017). A diagnosis (American Psychiatric Association [APA], 2013) of autism spectrum disorder (ASD), a developmental disorder defined by repeated behavior modes and inadequacy of social communication and interaction, in individuals can be said to negatively affect participation in CBLA in a significant majority of cases (Obrusnikova and Miccinello, 2012).

When the leisure activities of individuals with ASD are examined, it appears individuals participate in social and physical activities suitable for their abilities about developing themselves. Physical activities are stated to be one of the most commonly used and enjoyed activities (e.g., swimming, walking pets, walking, dancing) by individuals with ASD and their parents among leisure activities (Eversole et al., 2016; Ku & Haegele, 2022). However, it appears individuals with ASD are faced with constraints like lack of friends during participation in leisure physical activities in addition to exclusion (Gürkan and Koçak, 2021; Healy et al., 2013).

Interpersonal factors appear to be very effective on participation of individuals in activities, especially leisure activities (Armstrong et al., 2022; Koçak, 2017; Sarol, 2017). Gürbüz and Henderson (2014) stated that lack of friends negatively affects participation of individuals in leisure activities. Kara and Özdedeoğlu (2017) concluded that social cognition and lack of a partner were each significant interpersonal constraints for participation in leisure activities by individuals. Brewster and Coleyshaw (2011), investigating leisure activities of individuals with ASD, stated that participation in leisure activities of individuals with ASD was more difficult compared to individuals with typical development. In this situation, the lack of tolerance by other people due to the disorders existing in individuals with ASD was concluded to be effective. Within this scope, the topic of stigma comes to the agenda as a result of qualifying individuals with ASD due to existing diagnoses and extraordinary behavior in society.

Stigma and Leisure Participation in ASD

Stigma appears to be a concept loaded with the meaning of 'a sign of shame or disrepute' leading to disapproval or negative beliefs about a person's qualities or conditions (Paananen et al., 2020). According to Coleman Brown (2013), stigma is a concept reflecting a characteristic, a process, a form of social categorization, and an emotional state. Goffman (1963), shaping the stigma theory in the present day, defined stigma as 'an attribute that is deeply discrediting'. In line with this discrediting, individuals are proposed to be rejected by society due to this attribute. After Goffman, Link and Phelan (2001, 2006) conceptualized stigma in several stages. Firstly, people identify differences observed in others and label that person. The second stage of personalization, involves assumptions made about the stigmatized group and these assumptions being applied to all individuals in the group without differentiation. In the next stage, people avoid the stigmatized group and see the group as being different from other people. The stigmatizing group generally experience feelings of fear, disgust or distress, while the stigmatized group experience feelings of shame, embarrassment and contempt. In the final stage, the determined stereotypes are used to discriminate against people in the stigmatized group and people act according to these stereotypes.

Stigma is very effective on the lives of individuals with ASD and it appears stigma applied to individuals with ASD is very common (Kinnear et al., 2016). Mitter et al. (2019) stated that parents of children with ASD frequently encounter a range of stigma forms due to their children's existing disorder and this stigma generally comprises a range of prejudiced attitudes, discriminatory behavior, cliches and prejudiced social attitudes. Corrigan and Watson (2002) defined this situation as 'public stigma'. According to this definition, individuals express their reactions against people they perceive as being different to themselves (e.g., individuals with ASD). Public stigma includes stereotypes, prejudices and discrimination. McMahon et al. (2020) stated that individuals with ASD are exposed to stigma during physical activity and sports participation and as a result individuals encounter negative outcomes like bullying, exclusion, anxiety and labelling. The same study communicated that parents whose opinions were taken felt they were also stigmatized.

Stigma, one of the problems experienced by individuals with ASD during social interaction, does not only affect the individual with ASD but also is encountered as a problem with the potential to spread to the family (Gray, 2002). Stigmatized individuals choose a variety of methods to cope with the experience of negative stigma and one of the most common responses when faced with this situation is to avoid public places due to the perception of not being liked by others or only going out when there is a person to accompany them (Bedini, 2000; West, 1984). Botha et al. (2022) completed research with the aim of understanding how individuals with ASD experienced stigmatization related to the "autism" concept and the results of this research concluded that the word autism acquired negative meaning in society in line with the opinions of individuals with ASD. Again, according to research findings, individuals with ASD communicated that they were continuously exposed to stigmatization in society. Additionally, individuals in society assigned different meanings to ASD and it was concluded that the stigmatization applied by each individual displayed differences in line with this attributed meaning. The study by Gray (1993) investigated the stigmatization perceived by parents of children with ASD. The research results stated that the majority of participants felt stigmatized and that the perceived stigmatization displayed differences according to mother/father. Another study researched the correlation between stigma and activity participation of parents with children with ASD. In line with the research findings, the stigma perceived by parents was concluded to have a negative effect on participation of children with ASD in community-based activities (Ng et al., 2020).

When the literature is examined, the concept of 'disability' has a relationship with culture. Cultural factors are effective in feeling the disability state of the individual himself and also relatives (parents, sibling etc.) (Anastasiou & Kauffman, 2012; MacKay, 2002). Disability in Turkish culture is perceived with the concepts of 'pity, excluded, useless/inadequate' (Burcu, 2011). This leads to differences in attitude towards disabled individuals (such as individuals with autism) (Batum & Aydın, 2021). In addition, individuals with disability and their relatives do not have equal opportunities compared to non-disabled individuals in accessing opportunities (physical, social, economic, cultural environment etc.) (Çağlar, 2012; İpek, 2020). In this context, in Turkish culture another effective factors are thought to have increased anxiety, intolerance, loneliness and alienation to each other in recently (Bumin et. al., 2008; Sarıçam et. al., 2020; Uğurlu, 2021). These factors can also directly affect CBLA participation of individuals with ASD.

CBLA participation of children with ASD occurs with more difficulty compared to children with typical development and the benefits they obtain from participation are known. When the literature is investigated, there are inadequate numbers of studies related to CBLA participation and stigma toward children with ASD. This research, and research that will be performed in the same field, appears to be important in terms of reducing existing constraints and creating awareness about children with ASD to adjust and be accepted by society. In facilities and areas where leisure activities are held together with the community, it is critical to acquire attitudes easing participation of children with ASD. In line with this, the aim of the research was to investigate perceived stigma during CBLA participation in line with the opinions of parents of children with ASD.

MATERIALS AND METHODS

Research Model

The research was designed with the qualitative research approach. The research was determined to be a case study, in order to investigate in depth, the question "have you experienced extraordinary behavior from people around you due to your child's differences during your child's participation in community-based leisure activities?" (Creswell and Poth, 2016, p.44-45). Yin (2003, p.13) defined a case study as "empirical research that explores a phenomenon in a real-life context, especially when the boundaries between phenomenon and context are not clearly evident". The conceptual framework of the research comprised Goffman's (1963) "Theory of Stigma".

Sample and Setting

The study group for the research was chosen with the criterion sampling method from among the purposeful sampling methods. According to Merriam and Tisdell (2015), as most qualitative research aims to understand a specific and original case in depth rather than obtain general information, purposeful sampling may be chosen. In the research, sample size calculations were not performed and data continued to be collected until the point of data saturation was reached (Corbin & Strauss, 2008). Participants for the research were determined according to the following criteria;

- No physical limitation in the child with ASD,
- Child with ASD being 7-18 years of age,
- Being diagnosed as in the group requiring support at secondary or tertiary level according to APA (2013) criteria,
- Child with ASD and mother/father participating in at least 2 different community-based leisure activities per week,
- Living in Ankara,
- Voluntary participation in the research.

The study group for the research comprised parents of children with ASD diagnosis receiving education in a special educational institution. Necessary permissions were obtained from the institution, parents were informed about participation in the research and researchers began to communicate with parents volunteering for participation in the research. Necessary information was shared with parents who would participate in the research. Within this scope, participation of 10 parents was provided for the research. Participant parents provided a consent form about participation in the research and all participation in the research was completed within a volunteer framework. The research received permission from Kırıkkale University Social and Human Sciences Research Ethics Committee. Demographic information for parents participating in the research and children with ASD are shown in Table 1. Code names were used to ensure confidentiality of the names of research participants.

Table 1: Demographic information for participants

Demographic information for parents					**Demographic information for child with ASD**			
Study Group	Mother	Age	Educati	Occupation	Age	Sex	CBLA Participation (Week/hour)	Favorite activity
Fatma	M	35	U	Teacher	9	Boy	10	Horse riding
Filiz	M	45	U	Trade	17	Boy	5	Walking
Damla	M	42	U	Unemployed	12	Boy	4	Playing in the park
Sakine	M	34	U	Housewife	8	Boy	5	Ice skating
Esma	M	40	Hs	Housewife	10	Girl	5	Swimming
Melike	M	51	Hs	Retired	10	Boy	7	Swimming
Duru	M	36	M	Doctor	7	Boy	4	Playing in the park
Dilek	M	45	D	Academic	17	Boy	5	Table tennis
Aysel	M	38	Hs	Housewife	9	Boy	3	Scooter
Tevfik	F	41	U	Technician	14	Boy	4	Going to a restaurant

M: Mother, F: Father, U: Undergraduate, H: High school, M: Master, D:Doctorate

Data Collection

With the aim of acquiring information about the sociodemographic characteristics of participants during collection of data in the research, a personal information form and semi-structured interview form were used. Additionally, participant individuals were informed and completed a 'pre-participation informed consent form' for the research. The procedures applied during the process of preparing the semi-structured interview form were as follows: a) creation of a conceptual framework as a result of detailed literature screening and investigation. b) Preparation of a semi-structured interview form with a total of 5 items for parents of children with ASD to be asked by researchers within the scope of the research. c) Investigation of the prepared interview form by two experts and reports about the form. One of these experts was an academic with experience of qualitative research methods and working with children with ASD, while the other was an academic qualified in the academic and implementation field for individuals with ASD. d) The prepared semi-structured interview form was given its final form and proven to provide a healthy interview process and interviews with participants began.

In order to reach the experiences of participants in the research in depth, face-to-face individual interviews were held. Interviews were completed in empty classrooms of the private education institution. Additionally, interview questions were prepared to determine stigma perceived by parents of children with ASD in line with Goffman's (1963) stigma theory forming the conceptual framework of the research. Interviews with each parent lasted nearly 15 minutes.

Data Analysis

Interviews with parents were recorded with an application and transcribed in the digital environment. Data were analyzed with the thematic analysis method. Thematic analysis was completed in six stages as defined by Braun and Clark (2012). Within this scope; a) 2 researchers read and investigated the responses related to perceived stigmatization during CBLA participation obtained after interviews with parents of children with ASD. b) The researchers independently used an empty coding table to code the responses given by parents and determined the initial codes. c) The researchers compared the codes and determined themes in line with these codes. d) After ensuring consensus between researchers about the potential codes, themes were shared with an expert in the field and discussions were held about whether the themes reflected the whole data set or not. e) After ensuring consensus about the themes, the names of the themes were investigated again within the scope of the topic and given their final forms. f) In the last stage, consensus was ensured between researchers and experts and all data were reported.

Credibility, Transferability, Dependability and Confirmability

Validity and reliability concepts in qualitative research are expressed by credibility, transferability, dependability and confirmability (Creswell ve et al., 2018; Guba & Lincoln, 1982). With the aim of increasing credibility in the research, the research process was explained in detail and information was given in detail related to the participants. The study was constructed by receiving the opinions of a field expert with experience of qualitative research and an expert in the field of special education, apart from the researchers. For transferability, the research used understandable language, and explained the data collection processes and reporting in detail. To ensure dependability, coding was performed separately by two researchers for analysis of data and comparative coding was performed. Different codings were discussed and common decisions were made by the researchers. The compatibility rate of the research was calculated using the reliability formula of Miles & Huberman (1994) (reliability=consensus/consensus+difference X 100) and the compatibility rate was .90. Within the scope of confirmability, information related to all procedures during the research (raw data, interview transcripts, etc.) were stored by archiving in the computer environment.

FINDINGS

In this research completed in line with stigma theory, 5 themes emerged as a result of the interviews. These themes determined under metaphoric headings were an important necessity, tones of stigma, parents' reactions, wishes and reality and learned loneliness.

An Important Necessity

The first theme in the research findings investigated the aims of participating in CBLA of participant parents and their children with ASD under the heading 'an important necessity.' Within the scope of this theme, parents appeared to participate in CBLA with the aims of socialization, adjustment to society, feeling good, communication, movement and spending quality time.

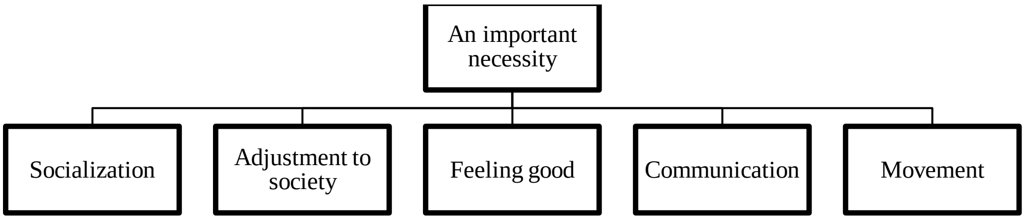

Figure 1: An important necessity theme and codes

In line with the opinions of parents, it is very important that their children spend time in social environments and with children with normal development. The primary aim of participation in CBLA was emphasized to be socialization of children.

"It is very important for me that my child be included in society and spend time with his peers. We try to spend as much time as we can in social environments. Socialization of my son is our highest priority aim." (Sakine, age 34)

Parents attached importance to the topic of children with ASD being able to adjust to society. They appeared to be very determined about the topic of inclusion of children with ASD within society and acceptance by society.

In line with aims of CBLA participation, parents stated that children with ASD felt good and they wanted to continue participation as a result. Again, they stated that with CBLA, children were active and used their energy positively. Additionally, parents stated that they had the chance to create awareness in society about children with ASD through CBLA.

The Tones of Stigma

According to the findings obtained as a result of our research, parents communicating their CBLA experiences with children with ASD stated they were faced with many negative experiences during participation. Within this scope, the negative experiences faced by parents during CBLA participation with children with ASD were investigated in the theme "the tones of stigma". Within this scope, they were identified to face negative experiences like disturbing looks, prejudice, protective attitudes, mocking, exclusion and bullying.

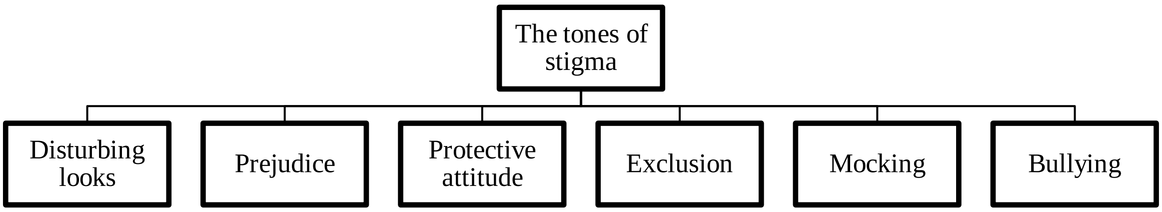

Figure 2: The tones of stigma theme and codes

The majority of parents participating in the research appeared to experience disturbing looks from people around them during CBLA participation. This situation was stated to negatively affect the CBLA participation of parents and children.

"The most important are the stares... People continuously look. For example, my sibling's wedding was last year. I had to go as it was my sibling's wedding. There I was very disturbed by the people's looks. I wanted to take my child and run away from there." (Sakine, age 34)

Parents stated they experienced significant degrees of prejudice from society due to the differences of their children with ASD and that they had much difficulty in overcoming this situation.

"For example, at that time, my son's interest in small children increased. When small children were running he noticed their hands and feet and went towards those children (...). For example, in those situations a mother/father appeared and said 'No, no! Don't attack.' What does attack mean? Why would he attack? Perhaps they'd experienced something different before, I can't know. But there is an attitude of 'they may attack, they may harm' against our children with autism." (Aysel, age 38)

Some behavior displayed by children with ASD that is different to children with normal development is seen as being unusual by other children in society and parents of these children were stated to display a protective attitude by avoiding children with ASD, especially due to this behavior.

"For example, my son was on the swing in the park or wanted to slide down the slide and there was a child ahead of him. My son had a movement like kicking his foot. He was doing it, I was trying to prevent it in the moment but there were families who reacted. They put on an attitude protecting their own child like 'Look after your child!', 'Take care!', 'Son, don't do that, why are you doing that?'" (Damla, age 42)

Parents' Reactions

Another theme in the research was 'parents' reactions'. The responses of parents when faced with extraordinary and negative situations during their children's participation in CBLA were investigated. In line with this, parents appeared to react with mainly anger, discussions, leaving the area, explaining and not reacting.

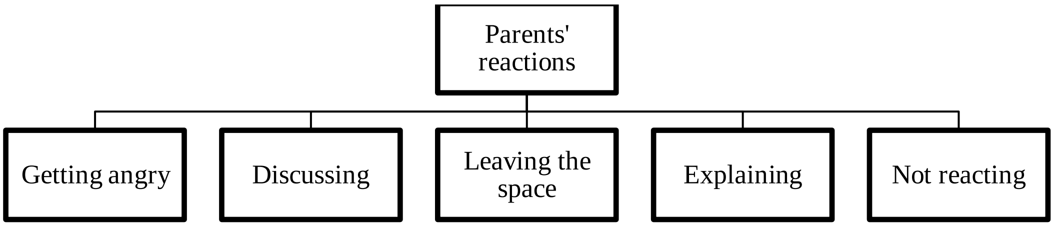

Figure 3: Parent's reactions theme and codes

Parents comprising the study group in our research appeared very sensitive to negative attitudes toward children with ASD and experienced during CBLA participation. Due to this sensitivity, parents may have increased violence in their reactions and may get angrier toward people against them.

Angry parents have an over-protective attitude to their children against people displaying negative attitudes and it appears that mutual communication transforms to conflict. Parents faced with some people in society continuously displaying negative attitudes become tired of this situation, cannot control themselves and stated they find themselves in the middle of conflict in a moment.

“We have to explain to people (...) We’re sick of it. If the reactions from the other side are strong, our reactions are equally strong, of course. For example, if they say ‘What’s he doing, there!’, if they say ‘Would you be quiet? You’re disturbing us!’, first we have to explain the situation. But if this attitude continues, then our reactions are stronger.” (Tevfik, age 41)

Parents stated that the general attitudes about children with ASD from people are negative during CBLA participation and that there is a judgmental attitude with cliched information, and they stated they felt hopeless in the face of this situation. They stated that some behavior of their children during the activity they participated in attracted attention and they chose to leave the area as they could not stand the general attitude of people.

“My son’s stereotypical movements increased a lot, and plainly we didn’t want to stay in that environment. When people begin to look at us strangely, generally we leave the space. For example, if we eat, we eat very quickly, we ask for the bill and leave. We choose not to stay in that area.” (Duru, age 36)

Some parents attempted to explain the situation and reasons to others with a calm attitude when faced with people’s negative attitudes and reactions. They stated that it was important to inform people to pay attention to their reactions in this and similar situations and that it was necessary to talk to people to create a general social awareness.

Some parents faced with negative experiences during CBLA participation appeared not to react due to being tired of explaining and discussing. Parents who continued CBLA participation without caring about people’s reactions thought that it was not easy not to react but people did not have adequate understanding about other people’s special situations. For this reason, they displayed this type of attitude. Additionally, among findings, some parents spoke to the child with ASD and attempted to calm them when faced with negative reactions.

Wishes and Reality

According to the findings in our research, another theme was determined to be ‘wishes and reality’. In this theme, the basic causes of negative and extraordinary behavior they encountered during CBLA participation of children with ASD were investigated. Within the scope of this theme, noting that parents and their children with ASD were on a different side to other individuals in society and that there was a clear distance between them, the basic behavior modes comprised lack of awareness, inability to be empathic and rumors and intolerance.

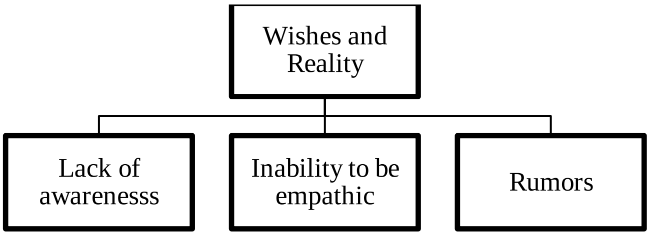

Figure 4: Wishes and reality theme and codes

Parents who considered that the basis of negative attitudes displayed against children with ASD during CBLA participation was not knowing ASD and not knowing the characteristics of children with ASD, stated that people in society lacked awareness. This lack of awareness was the actual source of many problems among our findings.

“There are still people who don’t know what autism is. They qualify it as an illness like flu, there are those who think like that. Even doctors pronounce it like this, as if it will pass and like there is a drug for it.” (Damla, age 42)

Parents stated that the number of people with an approach to understanding children with ASD and their families was very low in society in general. They emphasized that people needed to be empathic and thought they may be faced with a similar situation in the future.

It appears there are some negative rumors that spread in society about children with ASD and their characteristics and in line with these rumors people change their attitudes to children with ASD. Additionally, people’s inability to tolerate the behavior displayed by children with ASD was among other findings obtained.

Learned Loneliness

The final theme among our research findings comprised “learned loneliness”. In this theme, it was stated that children with ASD and their families avoided society in an unwanted way; however, they could not do anything about this situation. Within this scope, parents were revealed to have withdrawing attitude, selectivity of activities, pessimism, uneasiness and low motivation.

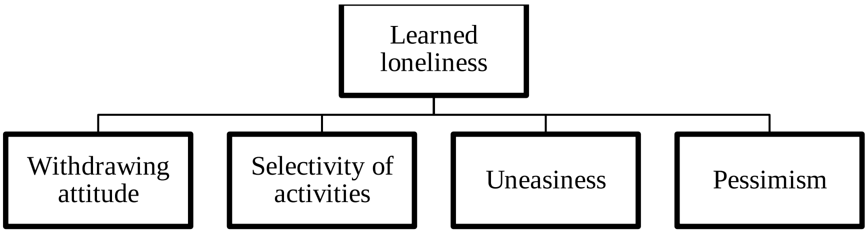

Figure 5: Learned loneliness theme and codes

Parents stated they had withdrawing attitudes before participation in activities in line with attitudes faced during CBLA participation. The anxiety felt about any negative situation that may be experienced as a result of participation in activities affected both parents and children.

"I think a lot before joining an activity. These thoughts don't keep me away from participation, I struggle for my child. But I think seriously before participating in an activity. I may not sleep the night before, because of an activity we will go to the next day... saying 'I wonder, will that happen, will this happen?'" (Aysel, age 38)

After negative experiences, parents carefully chose CBLA they will participate in with their children with ASD. In line with previous experiences of problems, reactions and withdrawing attitudes, they appear to be very selective about activities.

The behavior of children with ASD and reactions from people around them during CBLA participation was stated to cause parents to be pessimistic and uneasy about the future. The negative reactions given by people upset parents greatly and negatively affected them in the sense of participating in activities. Among the findings obtained, this situation lowered parents' motivation, created unwillingness to participate in activities and as a result was effective in children avoiding activities.

DISCUSSION AND CONCLUSION

This research was completed with the aim of investigating perceived stigma of children with ASD during CBLA participation. When the literature was investigated, it was considered that this research will contribute to the literature due to the few studies about children with ASD and stigma in the sense of leisure. CBLA has an important place in the lives of children with ASD and their families. CBLA may support children with ASD in terms of both physical and mental health. However, they are exposed to a variety of stigma from society and this affects CBLA participation. The conceptual framework comprised Goffman's (1963) theory of stigma and in the research, parents stated their opinions representing their children and the stigma experienced during CBLA participation of children with ASD was investigated. The findings of the research identified 5 themes of an important necessity, tones of stigma, parents' reactions, wishes and reality and learned loneliness.

In line with the findings obtained in the research, the first theme comprised "an important necessity". Within the scope of this theme, socialization appeared to be an important factor in CBLA participation of children with ASD. The findings obtained are supported by the literature. A study completed about supporting leisure activities of children with ASD within the scope of a university volunteer program by Nieto et al. (2015) concluded that CBLA participation increased the social communication of individuals with ASD and that CBLA was an important opportunity for socialization. Another finding in our research mentioned the effect of movement of children with ASD during CBLA. For children with ASD, CBLA comprised an important portion of their physical activity. In line with parental opinions, favorite activities of children with ASD were concluded to be walking, swimming, playing in the park and skating. Similar to the research findings, the study by Eversole et al. (2016) stated that physical activities were the activities that individuals with ASD enjoyed most during leisure. Within the scope of the research and the literature, CBLA may be said to be effective on the socialization, communication and movement of children with ASD. In line with this, increasing CBLA facilities and services offering the opportunity for children with ASD to be together with other individuals or their peers in society and informing families about this topic are important needs.

The second theme in the research comprised "the tones of stigma". In line with the related theme, it appears children with ASD encountered many negative situations during CBLA participation. Among the findings obtained were very disturbing looks from individuals in society when faced with extraordinary behavior of children with ASD (e.g., clapping, shouting, not talking, etc.) and the negative impact on children with ASD and their parents. Jones et al. (2021) stated that individuals in society had information about ASD; however, this information was not at adequate levels and so differences in attitudes may be experienced toward individuals with ASD. Another finding was the prejudice against children with ASD. With similar outcomes to our research, a study by Ellen Selman et al. (2018) investigated stigma against individuals with ASD with Somali roots in England and stated that individuals with ASD were stigmatized with negative definitions by society due to their disorder. This stigma was stated to affect the prejudiced behavior of society toward individuals with ASD. The effect of a similar attitude was observed in our research where mothers of children with normal development displayed a protective attitude by distancing their children from children with ASD. Additionally, in many public recreational areas, children with normal development mocked children with ASD and excluded them from activities and even bullied them, as included in the obtained findings. Cappadocia et al. (2012) stated that individuals with ASD frequently encountered similar situations and this negative behavior was connected to the age, difficulties in communication and health problems, etc. of the individual with ASD. To reduce and prevent the stigma against children with ASD and their parents, creating awareness about ASD in society is encountered as an important necessity. Educational institutions, media channels and state organizations should play an active role in creating this awareness. They can contribute to this role by organizing and completing informative announcements, ads, training and activities including children with ASD.

It appears that some parents responded to the situation with the effect of stigma from society against children with ASD during participation in leisure activities. The third theme in the research of "parents's reactions" discussed these behaviors in detail. McMahan et al. (2020) concluded that individuals with ASD faced stigma during physical activity during leisure and parents felt they were similarly stigmatized. Bonis (2016) stated that parents of children with ASD had higher stress levels compared to parents of children with normal development. Additionally, along with the special situations and responsibilities of children, another finding was stated to be the impact on mental health of parents. Parents of children with ASD may be considered to have higher anger levels, a problem linked to existing stress (Benson and Karlof, 2009). In the research, anger levels increased and they were even seen to enter discussions with individuals when faced with stigma during CBLA participation. Among the findings, some parents did not react in the face of stigma and left the space. Parents of children with ASD appear to feel general tiredness about coping with existing problems (Mount and Dillon, 2014) and were tired of expressing themselves to others. In line with research findings, individuals with ASD in addition to their parents were negatively impacted by stigma and may be said to create a defense mechanism. Within this scope, parents stated they chose to either overreact or not react at all. Social awareness came to the agenda again, for parents to be less exposed to these negative attitudes. Additionally, opportunities for parents to spend time alone without their children may offer the chance for parents to renew themselves physically and mentally. Counseling and activity services should be offered for parents. A healthy parent in physical and mental terms is thought to increase the quality of CBLA by participating with their child.

The fourth theme in the research comprised "wishes and reality". In this theme, parents assessed society as two sides of individuals with and without special needs. When the literature is investigated, it was stated that the concept of 'autism' had acquired a negative meaning for society (Botha et al., 2022) and negative rumors developed about individuals with ASD (Jones et al., 2022). Parents in the research stated there were common negative rumors within society about their children's disorder. The basis of these rumors was the lack of awareness of individuals in society, according to the findings obtained. Papoudi et al. (202) stated that information about ASD was not known by society and the source of negative perceptions about ASD was due to lack of awareness/lack of knowledge. Parents, additionally, stated that individuals in society avoided being empathic toward children with ASD. Mixing of children with ASD within society and increasing the quality and numbers of activities they can participate in within society will be effective in the public learning about children with ASD and their families. Creation of a society that is aware of ASD is thought to make CBLA participation of both children with ASD and their parents easier.

The final theme in the research comprised "learned loneliness". Within the scope of this theme, parents stated that children with ASD were exposed to stigma during CBLA and as a result they displayed a withdrawing attitude toward participation in CBLA. Kinnear et al. (2016) stated that individuals with ASD experienced stigma intensely and this stigma affected both children and their families. Additionally, due to the stigma faced by parents, they experienced anxiety before and during activities and appeared to act very selectively in choosing activities. Bedini (2000) stated that stigmatized individuals avoided society and felt uncomfortable. Due to this avoidance and discomfort, parents of children with ASD had pessimistic mental state (Hebert and Koulouglioti, 2010) and lowered motivation, which were among the findings obtained. This situation appeared to negatively affect the parents with low motivation as well as their children with ASD (Uljarević et al., 2021). It is very important to inform parents and sustain CBLA participation by emphasizing the benefits for children with ASD of CBLA participation. It is thought that informative activities completed to increase social awareness will be effective in reducing this situation.

RECOMMENDATIONS

The research was completed with parents of individuals with typical ASD, without any physical limitation, aged from 7-18 years and participating in at least 2 CBLA activities with their parents per week. The research included parents of 10 children with ASD living in Ankara. It is thought that all research completed in the name of including individuals with ASD in society and ensuring they and their families do not encounter negative attitudes during this process is very important. Every study included in the literature will contribute to the creation and development of awareness in society.

Within this scope, it is considered that research planned for completion in the future about stigma, social attitudes and leisure participation of individuals with ASD from different age groups, living in different cities or cultures will contribute to the literature. In addition, it is considered important to examine and interpret the perceived stigma in different groups with special needs. It is important to reduce negative opinions in order to adopt individuals with special needs in society. In this context, integrative leisure activities can be planned, projects can be created and policies can be developed.

Ethics

Participant parents provided a consent form about participation in the research and all participation in the research was completed within a volunteer framework. The research received permission from Kırıkkale University

Social and Human Sciences Research Ethics Committee (Ref 10-18.03/2022/03).

Conflict of Interest: The authors declare no conflict of interest.

Consent to Participate: Informed consent was obtained for all the recruited participants. Legal representatives (i.e., parents) gave consent for child participation.

Author Contribution Rate: In this study, all authors made an equal contribution

REFERENCES

Aitchison, C. (2003). From leisure and disability to disability leisure: Developing data, definitions and discourses. *Disability & Society*, *18*(7), 955-969. https://doi.org/10.1080/0968759032000127353

Anastasiou, D., & Kauffman, J. M. (2012). Disability as cultural difference: Implications for special education. *Remedial and special education*, *33*(3), 139-149. https://doi.org/10.1177/0741932510383163

Armstrong, M., Sharaievska, I., Crowe, B. M., & Gagnon, R. J. (2022). Experiences in outdoor recreation among individuals with developmental disabilities: Benefits, constraints, and facilitators. *Journal of Intellectual & Developmental Disability, 2022*, 1-12. https://doi.org/10.3109/13668250.2022.2104449

Batum, S., & Aydın, A. (2021). Otizm spektrum bozukluğuna yönelik toplumsal tutumlar ölçeğinin Türkçe'ye uyarlanması. *Dumlupınar Üniversitesi Eğitim Bilimleri Enstitüsü Dergisi*, *5*(2), 1-24.

Bedini, L. A. (2000). " Just sit down so we can talk:" perceived stigma and community recreation pursuits of people with disabilities. *Therapeutic Recreation Journal*, *34*(1), 55-68.

Bumin, G., Günal, A., & Tükel, Ş. (2008). Anxiety, depression and quality of life in mothers of disabled children. *SDÜ Tıp Fakültesi Dergisi*, *15*(1), 6-11.

Burcu, E. (2011). Türkiye'deki engelli bireylere ilişkin kültürel tanımlamalar: Ankara örneği. *Hacettepe Üniversitesi Edebiyat Fakültesi Dergisi*, *28*(1), 37-54.

Benson, P. R., & Karlof, K. L. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders*, *39*(2), 350-362. https://doi.org/10.1007/s10803-008-0632-0

Bonis, S. (2016). Stress and parents of children with autism: A review of literature. *Issues in Mental Health Nursing*, *37*(3), 153-163. https://doi.org/10.3109/01612840.2015.1116030

Botha, M., Dibb, B., & Frost, D. M. (2022). " Autism is me": an investigation of how autistic individuals make sense of autism and stigma. *Disability & Society*, 37(3), 427-453. https://doi.org/10.1080/09687599.2020.1822782

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brewster, S., & Coleyshaw, L. (2011). Participation or exclusion? Perspectives of pupils with autistic spectrum disorders on their participation in leisure activities. *British Journal of Learning Disabilities*, *39*(4), 284-291. https://doi.org/10.1111/j.1468-3156.2010.00665.x

Cappadocia, M. C., Weiss, J. A., & Pepler, D. (2012). Bullying experiences among children and youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(2), 266-277. https://doi.org/10.1007/s10803-011-1241-x

Coleman Brown, L. (2013). Stigma: An enigma demystified. *The Disability Studies Reader*, 147-162. https://doi.org/10.4324/9780203077887-19

Corbin, J., & Strauss, A. (2008). *Techniques and procedures for developing grounded theory*. Basics of Qualitative Research (3rd ed). Thousand Oaks, CA, USA: Sage.

Corrigan, P. W., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry, 1*(1), 16-20.

Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches*. Sage publications.

Creswell, J. W. (2018). *Qualitative inquiry and research design: Choosing among five approaches*. Sage Publications.

Çağlar, S. (2012). Engellilerin erişebilirlik hakkı ve Türkiye'de erişebilirlikleri. *Ankara Üniversitesi Hukuk Fakültesi Dergisi*, *61*(2), 541-598. https://doi.org/10.1501/Hukfak_0000001666

Doğusan, S., & Koçak, F. (2019). Women long-distance runners' experiences in serious leisure participation with respect to self-determination theory. *Sportif Bakış: Spor ve Eğitim Bilimleri Dergisi*, *6*(2), 230-249.

Driver B., Brown P. J., & Peterson G. (1991). *Benefits of Leisure*. Pennsylvania: Venture Publishing Inc.

Ellen Selman, L., Fox, F., Aabe, N., Turner, K., Rai, D., & Redwood, S. (2018). 'You are labelled by your children's disability'–a community-based, participatory study of stigma among Somali parents of children with autism living in the United Kingdom. *Ethnicity & Health, 23*(7), 781-796. https://doi.org/10.1080/13557858.2017.1294663

Eversole, M., Collins, D. M., Karmarkar, A., Colton, L., Quinn, J. P., Karsbaek, R., ..., & Hilton, C. L. (2016). Leisure activity enjoyment of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 46*(1), 10-20. https://doi.org/10.1007/s10803-015-2529-z

Fridolina, E. P., Deliana, S. M., & Pranoto, Y. K. S. (2020). The training of self-help eating ability of the autism spectrum disorder student using social reinforcement intervention in early childhood. *Journal of Primary Education, 9*(1), 85-91. https://doi.org/10.15294/jpe.v11i3.36055

Goffman, E. (1963). *Stigma*. Englewood Cliffs, New Jersey: Prentice-Hall.

Guba, E. G., & Lincoln, Y. S. (1982). Epistemological and methodological bases of naturalistic inquiry. *Educational Communication and Technology Journal*, *30*(4), 233–252. https://doi.org/10.1007/BF02765185

Güngörmüş, H. A., Yenel, F., & Gürbüz, B. (2014). Bireyleri rekreasyonel egzersize güdüleyen faktörlerin belirlenmesi: Demografik farklılıklar. *International Journal of Human Sciences, 11*(1), 373-386. https://doi.org/10.14687/ijhs.v11i1.2165

Gürbüz, B., & Henderson, K. (2014). Leisure activity preferences and constraints: Perspectives from Turkey. *World Leisure Journal, 56*(4), 300-316. https://doi.org/10.1080/16078055.2014.958195

Gürkan, R. K., & Koçak, F. (2021). Double punch to the better than nothing: physical activity participation of adolescents with autism spectrum disorder. *International Journal of Developmental Disabilities*, 2021, 1-13. https://doi.org/10.1080/20473869.2021.2009636

Gürkan, R. K., Koçak, F., & Başar A. (2021) Investigation on the relationship between the leisure satisfaction and psychological well-being in disabled athletes. *International Journal of Sport, Exercise & Training Sciences, 7*(2), 73–83. https://doi.org/10.18826/useeabd.890800

Gray, D. E. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health & Illness, 15*(1), 102-120. https://doi.org/10.1111/1467-9566.ep11343802

Gray, D. E. (2002). 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness, 24*(6), 734-749. https://doi.org/10.1111/1467-9566.00316

Hacıibrahimoğlu, B. Y., & Kargın, T. (2017). Determining the Difficulties Children with Special Needs Experience during the Transition to Primary School. *Educational Sciences: Theory & Practice, 17*(5), 1487-1524. https://doi.org/10.12738/estp.2017.5.0135

Healy, S., Msetfi, R., & Gallagher, S. (2013). 'Happy and a bit nervous': The experiences of children with autism in physical education. *British Journal of Learning Disabilities, 41,* 222–228. https://doi.org/10.1111/bld.12053

Hebert, E. B., & Koulouglioti, C. (2010). Parental beliefs about cause and course of their child's autism and outcomes of their beliefs: A review of the literature. *Issues in Comprehensive Pediatric Nursing, 33*(3), 149-163. https://doi.org/10.3109/01460862.2010.498331

İpek, E. (2020). The costs of disability in Turkey. *Journal of Family and Economic Issues, 41*(2), 229-237. https://doi.org/10.1007/s10834-019-09642-2

Jones, S. C., Akram, M., Gordon, C. S., Murphy, N., & Sharkie, F. (2021). Autism in Australia: Community knowledge and autistic people's experiences. *Journal of Autism and Developmental Disorders, 51*(10), 3677-3689. https://doi.org/10.1007/s10803-020-04819-3

Jones, S. C., Gordon, C. S., Akram, M., Murphy, N., & Sharkie, F. (2022). Inclusion, exclusion and isolation of autistic people: Community attitudes and autistic people's experiences. *Journal of Autism and Developmental Disorders, 52*(3), 1131-1142. https://doi.org/10.1007/s10803-021-04998-7

Kara, F. M., & Özdedeoğlu, B. (2017). Examination of relationship between leisure boredom and leisure constraints. *Sport Sciences, 12*(3), 24-36. https://doi.org/10.12739/nwsa.2017.12.3.2b0109

Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism and Developmental Disorders, 46*(3), 942-953. https://doi.org/10.1007/s10803-015-2637-9

Koçak, F. (2017). Leisure constraints and facilitators: Perspectives from Turkey. European *Journal of Physical Education and Sport Science, 3*(10), 32-47. https://doi.org/10.5281/zenodo.852540

Ku, B., & Haegele, J. A. (2022). Understanding parental physical activity behaviours in parents of children with disabilities: An expanded theory of planned behaviour approach. *Journal of Intellectual & Developmental Disability, 2022,* 1-10. https://doi.org/10.3109/13668250.2022.2104448

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27,* 363–385. https://doi.org/10.1146/annurev.soc.27.1.363

Link, B. G., & Phelan, J. C. (2006). Stigma and its public health implications. *The Lancet, 367*(9509), 528–529. https://doi.org/10.1016/S0140-6736(06)68184-1

MacKay, G. (2002). The disappearance of disability? Thoughts on a changing culture. *British Journal of Special Education, 29*(4), 159-163. https://doi.org/10.1111/1467-8527.00263

McMahon, J., Wiltshire, G. E., McGannon, K. R., & Rayner, C. (2020). Children with autism in a sport and physical activity context: a collaborative autoethnography by two parents outlining their experiences. *Sport, Education and Society, 25*(9), 1002-1014. https://doi.org/10.1080/13573322.2019.1680535

Merriam, S. B., & Tisdell, E. J. (2015). *Qualitative research: A guide to design and implementation*. John Wiley & Sons.

Mihaila, I., Handen, B. L., Christian, B. T., & Hartley, S. L. 2020. Leisure activity in middle-aged adults with Down syndrome: Initiators, social partners, settings and barriers. *Journal of Applied Research in Intellectual Disabilities, 33*(5), 865-875. https://doi.org/10.1111/jar.12706

Miles, M. B. and Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed). Thousand Oaks, CA: Sage.

Mitter, N., Ali, A., & Scior, K. (2019). Stigma experienced by families of individuals with intellectual disabilities and autism: A systematic review. *Research in Developmental Disabilities, 89,* 10-21. https://doi.org/10.1016/j.ridd.2019.03.001

Mount, N., & Dillon, G. (2014). Parents' experiences of living with an adolescent diagnosed with an autism spectrum disorder. *Educational & Child Psychology, 31*(4), 72-81. https://doi.org/10.53841/bpsecp.2014.31.4.72

Navarro, R. T., Tschöke Santana, D., & Rechia, S. (2018). Public leisure space and community-based action. *Leisure Studies, 37*(6), 747-762. https://doi.org/10.1080/02614367.2018.1535613

Ng, C. K., Lam, S. H., Tsang, S. T., Yuen, C., & Chien, C. W. (2020). The relationship between affiliate stigma in parents of children with autism spectrum disorder and their children's activity participation. *International Journal of Environmental Research and Public Health, 17*(5), 1799. https://doi.org/10.3390/ijerph17051799

Nieto, C., Murillo, E., Belinchón, M., Giménez, A., Saldaña, D., Martínez, M. Á., & Frontera, M. (2015). Supporting people with autism spectrum disorders in leisure time: Impact of an university volunteer program, and related factors. *Anales de Psicología/Annals of Psychology, 31*(1), 145-154. https://doi.org/10.6018/analesps.31.1.166591

Obrusnikova, I., & Miccinello, D. L. (2012). Parent perceptions of factors influencing after-school physical activity of children with autism spectrum disorders. *Adapted Physical Activity Quarterly, 29*(1), 63-80. https://doi.org/10.1123/apaq.29.1.63

Paananen, J., Lindholm, C., Stevanovic, M., & Weiste, E. (2020). Tensions and Paradoxes of Stigma: Discussing Stigma in Mental Health Rehabilitation. *International Journal of Environmental Research and Public Health, 17*(16), 1-18. https://doi.org/10.3390/ijerph17165943

Papoudi, D., Jørgensen, C. R., Guldberg, K., & Meadan, H. (2021). Perceptions, experiences, and needs of parents of culturally and linguistically diverse children with autism: a scoping review. *Review Journal of Autism and Developmental Disorders, 8*(2), 195-212. https://doi.org/10.1007/s40489-020-00210-1

Riggins, M. S., Kankipati, P., Oyster, M. L., Cooper, R. A., & Boninger, M. L. (2011). The relationship between quality of life and change in mobility 1 year postinjury in individuals with spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 92*(7), 1027-1033. https://doi.org/10.1016/j.apmr.2011.02.010

Sarıçam, H., Deveci, M., & Ahmetoğlu, E. (2020). The examination of hope, intolerance of uncertainty and resilience levels in parents having disabled children. *Global Journal of Psychology Research: New Trends and Issues, 10*(1), 118-131. https://doi.org/10.18844/gjpr.v10i1.4398

Sarol, H., & Çimen, Z. (2015). The effects of adapted recreational physical activity on the life quality of individuals with autism. *The Anthropologist, 21*(3), 522-527. https://doi.org/10.1080/09720073.2015.11891842

Sarol, H. (2017). Examination of the constraints and facilitators to physical activity participation of individuals. *Journal of Human Sciences, 14*(4), 4354-4364. https://doi.org/10.14687/jhs.v14i4.5121

Sarol, H., Gürkan, R.K., & Gürbüz, B. (2022). The road to championship: An example of an individual with autism spectrum disorder. *Baltic Journal of Health and Physical Activity, 14*(3), 1-17. https://doi.org/10.29359/BJHPA.14.3.02

Uğurlu, A. (2021). Investigating the relationship between loneliness and alienation levels of university students according to some variables. *Akdeniz Spor Bilimleri Dergisi, 4*(2), 308-319. https://doi.org/10.38021/asbid.976884

Uljarević, M., Frazier, T. W., Jo, B., Phillips, J. M., Billingham, W., Cooper, M. N., & Hardan, A. Y. (2021). Relationship between social motivation in children with autism spectrum disorder and their parents. *Frontiers in Neuroscience, 15*(660330), 1-9. https://doi.org/10.3389/fnins.2021.660330.

Yin, R. K. (2003). *Case study research: Design and methods.* (3rd ed., Vol. 5). Thousand Oaks, CA: Sage.

West, P. C. (1984). Social stigma and community recreation participation by the mentally and physically handicapped. *Therapeutic Recreation Journal, 18*(1), 40-49. 390.

Tyler, T. R. ve S.L. Blader (2001), Identity and Cooperative Behavior in Groups, *Group Processes & Intergroup Relations, 4*, 3, 207–226.

Van Dick, R. (2004). My job is my castle: Identification in organizational contexts. *International review of industrial and organizational psychology, 19,* 171-204.

GENİŞLETİLMİŞ ÖZET

Çalışmanın Amacı: Araştırmanın amacı, ASD'li çocuğu olan ebeveynlerin görüşleri doğrultusunda CBLA katılımda algılanan damgalamanın incelenmesidir.

Araştırma Soruları

- Çocuğunuz ile birlikte topluluk içeren serbest zaman etkinliklerine ne amaçla katıldığınızı açıklayabilir misiniz?
- Topluluk içeren serbest zaman aktivitelerinde çevrenizdeki insanlar tarafından çocuğunuzun farklılıklarından dolayı edindiğiniz olağan dışı deneyimleri ayrıntılı şekilde açıklar mısınız?
- Çocuğunuzun farklılığından kaynaklandığını düşündüğünüz davranışlara karşı verdiğiniz tepkiler neler olduğunu anlatabilir misiniz?
- Toplumdaki bireyler tarafından bu davranışların sebebinin ne olduğunu düşünüyorsunuz?
- Bu davranışların topluluk içeren serbest zaman aktivitelerine katılımınıza ne gibi etkileri olduğunu açıklayabilir misiniz?

Literatür Araştırması: Literatür incelendiğinde, ASD'li bireylerde damgalamanın yaşamları üzerinde oldukça etkili olduğu ve ASD'li bireylere yönelik olarak uygulanan damgalamanın oldukça yaygın olduğu görülmektedir (Kinnear et al., 2016). Mitter et al. (2019), ASD'li çocukların ebeveynlerinin, çocuklarının mevcut rahatsızlıkları nedeniyle sıklıkla çeşitli damgalama biçimleriyle karşılaştıklarını ve bu damgalamaların genellikle bir dizi önyargılı tutumlar, ayrımcı davranışlar, klişeler ve önyargılı sosyal tutumlardan oluştuğunu belirtmiştir.

ASD'li bireylerin sosyal etkileşim yoluyla yaşadıkları sorunlardan biri olan damgalama, yalnızca ASD'li bireyi etkilemekle kalmayan, aynı zamanda ailesine de yayılma potansiyeline sahip bir sorun olarak karşımıza çıkmaktadır (Gray, 2002). Damgalanmış bireylerin olumsuz damgalanma deneyimiyle başa çıkmak için çeşitli yöntemler seçtiği ve bu durum karşısında en yaygın tepkilerden biri olarak ise başkaları tarafından hoş görülmediği algısı nedeniyle halka açık yerlerden kaçınmak veya yalnızca kendisine eşlik eden bir kişi yanında olduğunda dışarı çıkmaktır (Bedini, 2000; West, 1984). Botha et al. (2020) ASD'li bireylerin "otizm" kavramına ilişkin damgalamayı nasıl deneyimlediklerini anlamayı amaçlayan bir araştırma gerçekleştirmiş ve bu araştırma sonucunda ASD'li bireylerin görüşleri doğrultusunda, "otizm" kelimesinin toplum içerisinde olumsuz bir anlam edindiği sonucuna ulaşmıştır. Yine araştırma bulgularına göre ASD'li bireyler sürekli olarak toplum içerisinde damgalamaya maruz kaldıklarını aktarmıştır. Ayrıca toplum içerisinde bireylerin ASD'ye farklı anlamlar yükledikleri ve yükledikleri anlam doğrultusunda her bir birey tarafından uygulanan damgalamanın farklılık gösterdiği sonucuna ulaşılmıştır.

ASD'li çocukların CBLA katılımlarının tipik gelişim gösteren çocuklara kıyasla daha zor gerçekleştiği ve katılımları sonucunda elde ettikleri faydalar bilinmektedir. Literatür incelendiğinde ASD'li çocukların CBLA katılımları ve damgalama ile ilgili yeterli sayıda çalışma bulunmamaktadır. Bu araştırma ve aynı alanda yapılacak araştırmaların ASD'li çocukların toplum içerisine adapte olmaları ve kabul görmeleri, mevcut engellerin azalması ve farkındalık yaratması açısından önemli görülmektedir. Özellikle toplumun bir arada gerçekleştirdiği serbest zaman aktivite tesis ve alanlarında, ASD'li çocukların katılımını kolaylaştırıcı tutumlar edinebilmeleri adına oldukça kritiktir.

Literatür incelendiğinde serbest zaman anlamında ASD'li çocuklar ve damgalamaya yönelik çalışmaların az olmasından dolayı, araştırmanın literatüre katkı sağlayabileceği düşünülmektedir.

Yöntem: Araştırma, nitel araştırma yaklaşımında tasarlanmıştır. Araştırmada *"Çocuğunuzun topluluk içerisinde katıldığı serbest zaman aktivitelerinde çocuğunuzun farklılıklarından dolayı çevrenizdeki insanlar tarafından olağan dışı bir davranış deneyimlediniz mi?"* sorusunu derinlemesine inceleyebilmek adına durum (vaka) çalışması olarak belirlenmiştir (Creswell and Poth, 2016, s.44-45). Araştırmanın çalışma grubu amaçlı örnekleme yöntemlerinden ölçüt örnekleme yöntemiyle seçilmiştir. Araştırmanın çalışma grubunu, bir özel eğitim kurumunda eğitim alan ASD teşhisi konulan çocuğa sahip 10 ebeveyn oluşturmaktadır. Araştırmada verilerin toplanmasında katılımcıların sosyo-demografik özellikleri hakkında bilgi edinmek amacıyla kişisel bilgi formu ile yarı yapılandırılmış görüşme formu kullanılmıştır. Ayrıca araştırmaya katılımcı bireyler araştırma öncesinde "katılım öncesi bilgilendirilmiş onam formu" doldurarak bilgilendirilmiştir. Görüşmeler yüz yüze gerçekleştirilmiştir ve yaklaşık 15 dakika sürmüştür. Ebeveynler ile yapılan görüşmeler uygulama üzerinde kaydedilerek dijital ortamda yazıya aktarılmıştır. Veriler, tematik analiz yöntemiyle analiz edilmiştir. Geçerlilik ve güvenirlik kavramları nitel araştırmalarda; inandırıcılık, aktarılabilirlik, tutarlılık ile teyit edilebilirlik kavramları ile ifade edilmektedirler (Creswell ve et al., 2018; Guba & Lincoln, 1982). Bu kapsamda araştırmada ilgili kavramların sağlanmasına özen gösterilmiştir.

Sonuç ve Değerlendirme: Bu araştırma, ASD'li çocukların CBLA katılımı sırasında gerçekleşen damgalamayı incelemesi amacıyla gerçekleştirilmiştir. Literatür incelendiğinde serbest zaman anlamında ASD'li çocuklar ve damgalamaya yönelik çalışmaların az olmasından dolayı, araştırmanın literatüre katkı sağlayabileceği düşünülmektedir. ASD'li çocuklar ve aileleri için CBLA, hayatlarında önemli bir yere sahiptir. CBLA ile ASD'li çocuklar hem fiziksel hem de mental sağlıklarını destekleyebilmektedirler. Ancak toplum tarafından çeşitli damgalamalara maruz kalmakta ve CBLA katılımları etkilenmektedir. Kavramsal çerçevesini Goffman (1963)'ın damgalama teorisi oluşturan ve ebeveynlerin çocuklarını temsilen görüşlerini belirttikleri araştırmada, ASD'li çocukların CBLA katılımları sırasında deneyimledikleri damgalama incelenmiştir. Araştırmanın bulguları "*önemli bir ihtiyaç*", "*damgalamanın tonları*", "*ebeveyn tepkileri*", "*dilekler ve gerçekler*" ve "*öğrenilmiş yalnızlık*" olarak 5 tema belirlenmiştir.

Araştırmada elde edilen bulgular kapsamında, ASD'li çocukların CBLA katılımları, ebeveynler için oldukça önemli bir konu olarak karşımıza çıkmaktadır. Araştırmamıza katılım sağlayan tüm ASD'li çocuklar ve ebeveynleri haftada toplam 2 farklı CBLA'ya en az 3 saat katılmaktadır. CBLA'lara bakıldığında, aktivitelerin büyük bir kısmının fiziksel aktivitelerden oluştuğu görülmektedir. Ebeveynlerin ASD'li çocuklarını CBLA katılımına teşvik ettikleri ve CBLA'ları önemli bir ihtiyaç olarak gördükleri vurgulanmaktadır. CBLA katılım amaçlarının başında sosyalleşmenin geldiği sonucuna ulaşılmaktadır. Araştırmamızda yer alan tüm ebeveynler, çocuklarının rahatsız edici bakışlar başta olmak üzere damgalamaya maruz kaldığını ifade etmektedir. Ayrıca ASD'li çocuklara yönelik olarak toplumda genel bir önyargının olduğu düşünülmektedir. Ebeveynlerin toplum tarafından uygulanan damgalamalara karşı öfkelendiklerini ve çocuklarına karşı olumsuz tavır sergileyen kişiler ile tartıştıklarını ifade etmişlerdir. Toplumdaki bu davranışların genel sebebinin bilinçsizlik olduğu ve ebeveynlerin CBLA seçiminde oldukça seçici oldukları, araştırmanın bir diğer sonucu olarak karşımıza çıkmaktadır.

Sonuç olarak; ASD'li çocuklarda CBLA katılımının önemli bir ihtiyaç olduğu, katılımı etkileyen olumsuz tutum ve davranışların azaltılması ile birlikte katılım konusunda daha fazla bireyin bu tür serbest zaman katılım deneyimleri yaşayacağı araştırmamız sonucunda söylenebilmektedir.