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#### **RESEARCH ARTICLE**

# Does Function Level of Individuals With Autism Spectrum Disorder **Affect The Family Impact?**

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#### Abstract

The aim of our study is to examine the effect of differences in the levels of functionality of individuals with autism spectrum disorder (ASD) on level of family involvement. Our study has been carried out with the relatives of ASD individuals attending Aydın Efeler Municipality Autism Sports and Life Center. The Pediatric Functional Independence Criterion (WeeFIM) has been used to determine the functional independence levels of children, and The Family Impact Scale (FIS) has been used to measure the impact on the families of children with chronic disabilities. Our study was completed with the assessment of 98 individuals diagnosed with ASD (age=10.17±5.11, gender=15 female/83 male) and 98 pairs of their parents. The total WeeFim score was determined as 94.73  $\pm 20.26$  (independent) and the family impact scale scores were determined as  $63.03 \pm 12$ . The correlation analysis showed the sub WeeFIM impact the financial burden my family, self-care, communication, social status were statistically significant and weak correlation score between the total score (p<0.05; respectively, r=-0.025, r=-0.027, r=-0.310, r=-0.273). There was also a statistically significant, negative and moderate correlation between the total impact score of the FIS and the social status of the WeeFIM (p<0.00; r=-0.402). This study shows that family influence on individuals with ASD affects their social status. In addition, self-care, communication skills, and social status negatively affect individuals with more financial problems. In families with individuals with ASD, the independence of children affects the quality of life of families.

#### Keywords

Autism Spectrum Disorder, Impact on the Family, Parents, Financial stress, Social communication

#### **INTRODUCTION**

The incidence of autism spectrum disorder (ASD) has increased significantly worldwide recently. Increasing awareness and advances in diagnosis are some of the reasons for the increase in this rate (WHO, 2018; Ulu and Karacasu, 2022). Although the incidence of ASD is statistically stated as 1 in 160 (Keogh et al., 2019), and even in less developed countries, these rates assumed to be higher due to the exact prevelence in not known.

ASD is defined as a neuro-developmental disorder in which brain function is affected. It is a widespectrum disorder affecting social communication, characterized limited by attention, repetitive involuntary movements, obsessive behaviors, learning difficulties (Giannopulu and Pradel, 2010; Lim et al., 2019; Masi et al., 2017; Mohajer et al., 2019).

Children with ASD have functional deficiencies in coordination, balance and motor control skills. Motor development has an

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important role in social communication. Thus, children with ASD who have deficiencies in motor development also experience difficulties in social communication (MacDonald et al., 2013; West 2019). Motor skills are closely related to daily activities that require coordination (Cuffaro, 2011). Although children with ASD have normal motor development, their motor competence differs compared to their peers (Sahan et al., 2022). Children with ASD have little or no ability to imitate. Therefore, they learn some gross motor skills including large muscle groups such as running, dancing, swimming, jumping rope in their later life (Korkmaz, 2003). Additionally, their fine motor skills (stringing beads on a string, throwing cubes into a box, cutting paper, etc.) are also more unsuccessful/inadequate (Darica et al., 2002). Like their peers, children with ASD need social skills in order to survive in society, interact with their peers in society (Aslan and Sahin, 2015). When considered from this point of view, it is necessary to develop social skills and reduce problematic behaviors in order for a person to be accepted in social environments.

Parents do not choose the role of being the parents of a child with different characteristics. Therefore, none of them prepares himself for this role (Coskun and Akkas, 2009). Many families with a child with ASD are worried about not knowing what they will do to their children or how it will affect their child's own life. Usually, there are some difficulties in ensuring the adaptation of this child, who has very special needs, to family life. The basis of all these worries is the fear fort he things unknown (Darica, 2002). This disability of their child is a condition that cannot be changed and is permanent. Therefore, meeting the needs of a disabled child involves a much longer period for the parents and can be difficult to bear. The needs of the disabled child care, education, financial requirements, increasingly, in social attitudes and barriers judgments about uncertainty about the current and future status of the child, families are important sources of stress (Dereli and Okur, 2000; Petrou, 2018).

Many studies were conducted to see the effect of the physical activity, motor competence and social skills issues on children with ASD separately (Bhat et al., 2011, Breslin and Rudisill, 2013; Kunzi, 2015). However, studies examining the effect of differences in the functionality levels of children with ASD on the family's level of affect

is still lacking.Our study was planned to investigate the effect of the functional level of individuals diagnosed with ASD on the level of impact of thefamily.

# **MATERIALS AND METHODS**

This cross over study was carried out with 98 children diagnosed with ASD and their parents in Aydın Efeler Municipality Autism Sports and Life Center between July 15, 2022 and January 15, 2023. The approval of the Non-Interventional Ethics Committee of Aydın Adnan Menderes University Faculty of Health Sciences was obtained for our cross-sectional study (E-15189967-050.02.04-196969).

The inclusion criteria were children diagnosed with ASD, who did not have any physical disabilities, and lived with their parents. Children with severe mental disabilities and those without an autism spectrum diagnosis were not evcluded. Parents of all children who met the inclusion and exclusion criteria were accessed. The number of children with autism spectrum disorder registered at the Autism Sports and Life Center in Aydın Efeler Municipality is 170. The families of all the children who met the inclusion and exclusion criteria were accessed for the study. As a result of the calculation made using the universe-known sample width formula, the prevalence of autism spectrum disorder was accepted as 1.69%, and when the deviation margin to be made was taken as d=0.02, it was found that it would be appropriate to include 83 people in the study at the 95% confidence level.(https://www.cdc.gov/media/releases/2018/p 0426-autism-prevalence.html).

The study was conducted at the Autism Sports and Life Center. Parents were informed about the study and their consent was obtained prior to assessment. Afterwards the individual demographic information form (including the child and parent), the level of functional independence of individuals with ASDs for determination of pediatric functional independence Measure (WeeFIM), chronic impact on families of children with disabilities in order to measure The Impact on Family Scale (FIS) was utilized for assessment.

## Assessment Form

Socio-demographic characteristics such as age, height, weight, educational status, marital

status, diagnosis of parents and individuals diagnosed with ASD were assessed via a form developed by researhers.

#### Pediatric Functional Independence Measure (WeeFIM-Functional Indepence Measure)

This scale is used to determine the functional independence levels of children can also be applied to children with developmental disabilities up to the age of 21. Under 18 headings, the child's self-care, sphincter control, transfer activities, movement activities, communication skills and cognitive skills are questioned (Msallet al., 1994).

Functions of the child are scored from 1 to 7 via WeeFIM.( 7: fully independent, 6: modified independent, 5: by observation, 4: minimal help, 3: light assistance, 2: maximum assistance, and 1: full assistance). Scores from 1 to 4 indicate the level of assistance a child needs to complete an activity. 5 points indicate the child's observation or adult cue to perform the skill. A score of 6 indicates that the child can complete the activity independently but needs an assistive tool. The lowest total score that can be obtained from the test is 18 (fully dependent on all skills), and the highest total score is 126 (fully independent in all skills), (Msall et al., 1994). This scale has beeen validated in Turkish population (Sonel Tur et al., 2009).

## The Family Impact

This questionnaire was developed to measure the impact of chronich childhood disease on the families. It was adapted into Turkish (Beydemir, 2008). The family impact scale consists of 27 items and four main headings that measure the level of influence of the family. These main headings are: financial burden, familial and social impact, personal strain, coping and the total impact formed by the sum of these parameters (Stein and Jessop, 2003). Appropriate answers are asked to the questions asked in the scale, in the order of 'totally agree 1, 'agree 2, 'disagree 3 and 'strongly disagree 4. The scale has a Likert-type rating ranging from 1 to 4. A minimum of 24 and a maximum of 96 points can be obtained from the scale. The items in the scale are generally related to the social, financial and emotional domains, and the higher the scale score, the higher the distress of the mothers (Stein and Jessop, 2003).

## Statistical analysis

SPSS 20.00 package program was used for data analysis. The functional levels of children and the levels of parental impact were detected as dependent variables of the study. The independent variables was; socio-demographic variables.

number, percentage distributions, The average, standard deviation values were presented for distribution of the data. The descriptive characteristics of individuals with ASD and their parents, number, percentage, mean and standard deviation, skewnes kurtosis test, Mann-Whitney U test, and Student's t test were used to compare binary groups. The variables that did not match the normal distribution according to the results, as well as if parametric assumptions were met in intergroup comparisons. In order to determine the correlation of the scales, pearson correlation analysis was used when the data showed normal distribution and spearman correlation analysis was used in variables having normal distribution. From the statistical point of view, p<0.05 level was considered significant. In order to group according their participants to level of independence, WeeFIM scale scoring was divided into Require observation (those scoring 18-90) and independent (those scoring 91-126).

# RESULTS

The number of children diagnosed with ASD in the center was 170. 58 parents out of 72 did not accept to participate in the study, and 14 children with autism were raised by one of their their relatives instead of their parents. The study was carried out with 98 children with one of their parents. The demographic information of the children and their parents are shown in Table 1. The mean age of the children with ASD participating in the study was 10.17, and 85 % of them were male. More than 30 % of the children with ASD were found to have primary school or higher education levels. 78 % of the parents who fullfilled the questionnaire were mothers, and more than 50 % had a high school education or higher. Demographic information of children with autism spectrum disorder and their parents are shown in "Table 1".

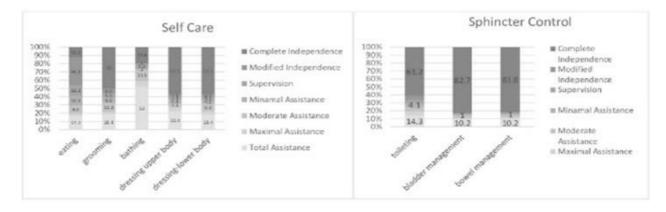
## Independence Levels of Participants

According to WeeFim results, children with ASD were most dependent on the self-care skills while taking a bath (52%); and in sphincter control, more than half of the participants were found to be fully independent. Likewise, it was determined that the participants were mostly dependent on bathtub and shower transfers in the sub-headin of trasfer and locomotion. In cognitive skills and communication, it was determined that the participants needed more help in the sub-headings of social interaction (26.5%), problem solving (34.7%) and expression (30.6%) "Fig. 1'.

# Table 1. Demographic data of the participants

| Participant | Measure         |                      | N (%)          |
|-------------|-----------------|----------------------|----------------|
|             | Age (M±SD)      |                      | $10.17\pm5.11$ |
|             | Gender          | Boy                  | 83 (85.7)      |
|             |                 | Girl                 | 15 (15.3)      |
| Child       | Education Level | Never gone to school | 16 (16.3)      |
|             |                 | Kindergarten         | 14 (14.3)      |
|             |                 | Primary school       | 24 (24.5)      |
|             |                 | Middle school        | 29 (29.6)      |
|             |                 | High school          | 11 (11.2)      |
|             |                 | Leave education      | 4 (4.1)        |
| Parents     | Age (M±SD)      |                      | $41.32\pm8.72$ |
|             | Parent          | Mother               | 77 (78.6)      |
|             |                 | Father               | 21 (21.4)      |
|             | Education Level | Primary school       | 19 (19.4)      |
|             |                 | Middle school        | 11 (11.2)      |
|             |                 | High school          | 21 (21.4)      |
|             |                 | University           | 37 (37.8)      |
|             |                 | Master/PhD           | 10 (10.2)      |
|             | Marital Status  | Married              | 94 (95.9)      |
|             |                 | Divorced             | 4 (4.1)        |

N:Number of participants, %:percentage, M: mean SD: standart deviation



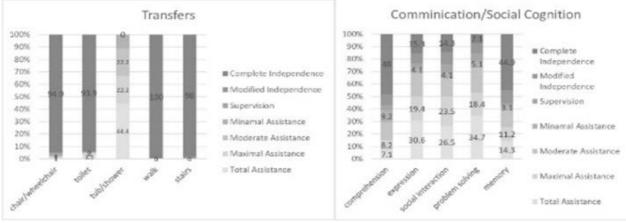


Fig 1. Participants' WeeFIM results

# The Relationship between Independence Level of Children and Family Impact Scale

The financial burden sub-dimension of the family impact scale decreased as WeeFim self-

care, communication, social status, and WeeFim total score increased (Table 2). This shows that as the independence of the children with ASD increases, the financial burden of the family decreases.

**Table 2.** Relationship between the family impact scale sub-dimensions and WeeFIM sub-dimensions (N=98)

| WeeFIM               | Family Impact score Sub-dimensions |                     |                           |                    |         |        |  |
|----------------------|------------------------------------|---------------------|---------------------------|--------------------|---------|--------|--|
| Sub-dimensions       |                                    | Financial<br>Burden | Familial/Social<br>Impact | Personal<br>Strain | Mastery | Total  |  |
| Sub-dimensions       |                                    |                     |                           |                    |         | Impac  |  |
| Self Care            | r                                  | -0.225*             | -0.251*                   | -0.156             | -0.106  | -0,233 |  |
|                      | р                                  | 0.026               | 0.013                     | 0.125              | 0.298   | 0.021  |  |
| Sphincter Control    | r                                  | -0.083              | -0.108                    | -0.109             | -0.191  | -0.118 |  |
|                      | р                                  | 0.418               | 0.290                     | 0.285              | 0.060   | 0.249  |  |
| Transfer             | r                                  | 0.058               | -0.080                    | -0.126             | -0.117  | -0.090 |  |
|                      | р                                  | 0.572               | 0.431                     | 0.216              | 0.252   | 0.378  |  |
| Transfers/Locomotion | r                                  | 0.051               | -0.061                    | -0.127             | -0.196  | -0.073 |  |
|                      | р                                  | 0.618               | 0.548                     | 0.214              | 0.053   | 0.476  |  |
| Communication        | r                                  | -0.270*             | -0.169                    | -0.063             | -0.182  | -0.16  |  |
|                      | р                                  | 0.007               | 0.097                     | 0.539              | 0.073   | 0.097  |  |
| Social Cognition     | r                                  | -0.310*             | -0.403*                   | -0,330*            | -0.135  | -0,402 |  |
|                      | р                                  | 0.002               | 0.000                     | 0.001              | 0.184   | 0.000  |  |
| Total Score          | r                                  | -0.273*             | -0.305*                   | -0,207*            | -0.183  | -0,294 |  |
|                      | р                                  | 0.007               | 0.002                     | 0.041              | 0.071   | 0.003  |  |

N:Number of participants, r: spearman correlation score p:p value

Additionally, statistically significant, negative and weak correlations were found between the familial/social sub-dimension of the family impact scale and WeeFim self-care (p=0.013 r=-0.251) and WeeFim total score (p=0.002 r=-0.305). In addition, a statistically significant, negative and moderate relationship was found between the familial/social sub-dimension of the family impact scale and the WeeFim social cognition (p<0.001 r=-0.403).

A statistically significant, negative and weak correlation was found between the family impact scale personal strain sub-dimension and WeeFim social cognition and WeeFim total score (p=0.003 r=-0.294).

A statistically significant, negative and weak correlation was detected between the family impact scale total impact score and WeeFim self-care (p=0.021 r=-0.233) and WeeFim total score (p=0.002 r=-0.305). In addition, a statistically significant, negative and moderate correlation was found between the family impact scale total impact score and WeeFim social cognition (p<0.001 r=-0.402).

When the family impact scale scores are examined according to their WeeFim status; There was no statistically significant difference in the total score and the scores obtained in the subdimensions between the situation requiring observation and the individuals in the independent state "Table 3".

|  | Inde            | ependent (91-126) |                   |                |                          |  |  |
|--|-----------------|-------------------|-------------------|----------------|--------------------------|--|--|
|  |                 | N=67              |                   |                |                          |  |  |
| Family Impact score  | $M \pm S.D$     | Med (25 75. Q)    | $M \pm S.D$       | Med (25 75. Q) | Between group comparison |  |  |
| Financial Burden   | $9.52\pm2.78$   | 10 (9 - 12)       | $9.45\pm2.26$     | 9 (8 - 12)     | 0.554<br>(z=-0.592)      |  |  |
| Familial/Social Impact   | $25.65\pm5.77$  | 26 (21 - 31)      | $23.4\pm5.78$     | 23 (18 - 28)   | 0.106<br>(z=-1.616)      |  |  |
| Personal Strain  | $27.87 \pm 4.9$ | 28 (25 - 31)      | $27.3\pm5.1$      | 28 (24 - 31)   | 0.602 (t=0.523)          |  |  |
| Mastery  | $7.13 \pm 2.28$ | 7 (5 - 10)        | $6.46\pm2.16$     | 7 (5 - 7)      | 0.152<br>(z=-1.432)      |  |  |
| Total Impact   | $63.03 \pm 12$  | 63 (56 - 73)      | $60.15 \pm 11.79$ | 62 (51 - 69)   | 0.266 (t=1.119)          |  |  |
| N:Number of participants 25 - 75 O: 25-75 Quartile values M: mean SD: standart deviation |                 |                   |                   |                |                          |  |  |

**Table 3.** The effect of group comparison according to children's WeeFIM score on family impact score

N:Number of participants, 25. - 75. Q: 25-75 Quartile values, M: mean, SD: standart deviation

#### **DISCUSSION**

As a result of this study, the disability experienced by children with ASD in self-care activities was negatively related to the financial burden of families and has a negative effect on familial and social impact. Additionally, as the communication skills and social cognition of children with ASD deteriorate, the financial situation of the families is adversely affected. Our study shows, the inadequacy of children with ASD in their social skills had a negative impact on the financial burden, familial social impact, personal strain and total impact scores of the families.

In our study, 84.7% of the children with ASD participating in our study were male. An increase in the prevalence of Autism spectrum disorder has been reported in the last decade (Fombonne, 2020; Myers et al., 2019). It is known that the rate of autism in boys is higher than in girls. In the literature, this rate has been shown as 3 to 4.3 boys versus 1 girl (Loomes et al., 2017; Maenner et al., 2020).

In our study, the number of mothers (N=77, 78.6%) who brought their children to the center was higher than the number of fathers (N=21, 21.4%). When the educational status of the parents is considered, we found that 37 parents (37.8%) are college graduates. The main care providers of children with ASD are mothers, and the burdens such as bringing them to and from education such as domestic care, special education, music and sports are mostly on mothers (Biffi et al., 2019). Especially when we look at their socio-economic levels, we see that either the mothers are not working or they have quit their jobs due to the condition of their children. Therefore, the burden of mothers is higher due to the effort they give for

the care of their children, while men are more income providers in the family (Bilgin and Küçük, 2010; Magalhães et al., 2021).

In our study, it is noteworthy that children with ASD are completely dependent on bathing and transferring to the bathroom. Our finding is consistent with studies in the literature (Kilinçaslan et al., 2019; Matson et al., 2009; Mouga et al., 2015). Although there is no precise definition of daily life activities, it can be defined as self-care, home care, social life (Pepperdine and McCrimmon, 2018) and includes more basic care activities such as tooth brushing, dressing and hygiene (Guo and Sapra, 2020). Adolescents and adults show lower levels of independence than their peers in activities of daily living (Cruz-Torres et al., 2020). Conflicts exist regarding the independence of children with ASD (Howlin and Magiati, 2017) and prognosis in adulthood (Kilincaslan et al., 2019). In the study by Duncan et al., only 12% of adults with ASD lived independently in their own homes, while the rest stated that they were dependent on family, friends, and support (Duncan et al., 2018).

As a result of this study, it was determined that children with ASD who had problems during self-care activities had a negative relationship between both the familial social impact and the financial burden of the family. According to this result, the increase in the inadequacy of self-care in children with ASD who participated in our study negatively affects the financial situation and social life of the family. According to Kilinçaslan, families face financial problems in order to meet the needs of their children(Kilinçaslan et al., 2019).

Sen and Yurtsever showed that in Turkey, 48 % of families with children with ASD experience financial difficulties (Sen and Yurtsever, 2007). A significant relationship was found between the independence of the children of families who have lower economic income in daily life. (Chan et al.,2017; Del Cole et al., 2017). This result shows, the independent living skills and higher family income are related. Having a lower income is associated with limited access to services (Shattuck et al., 2011). Kilinçaslan et al.'s study is the first study conducted in Turkey on the independence of children with ASD in activities of daily living has been a reference for us. Future studies on the influence of families are needed. In this context, the fact that our work has been done in this field closes this gap. This result shows the importance of supporting families with children with ASD who are inadequate in self-care, socially and economically (Kilinçaslan et al., 2019).

In the diagnosis of ASD, one of the determining factors is the inadequacies in social communication skills. In our study, we found that the families of individuals who had difficulties in social communication were moderately affected. This result is similar to the literatüre. Limitations in social communication are most negatively related to financial burden - familial social influence and personal strain. Perceptions of families about their difficulties: behavior problems, lack of communication skills and lack of adaptive skills (Colavita et al., 2014). Children with ASD have difficulty in learning social skills because their imitation and observation skills are limited (Töret, 2017). This situation results in negative emotions in parents. (Bodur and Soysal, 2004)

## Limitations of Study

Our study shows that physical disability in individuals with ASD negatively affects the financial and social lives of families. There are some limitations in our analytical cross-sectional study. Since our study was a cross-sectional study, a larger population with different education levels across Turkey could have given more meaningful results. This is a limitation of our study.

Our research was carried out to include individuals with ASD who continue special education in Aydın region. Since children with ASD who have physical disability in conditions that can attend a special education center are included in more studies, we estimate that the rates of physical disability are lower in WeeFIM results in our study. Similarly, higher education levels of parents participating in the study may have been observed. Due to this situation, different results can be reached in studies to be conducted in different populations.

In the study, the level of influence of the family was examined, the level of influence of the parents on both of them could be checked by reaching both the mother and the father. Studies comparing the effect on mother and father will contribute to the literature. These factors should be taken into account when interpreting the study, since it was conducted in a single center and with a small sample size and included parents in Turkey. In our study, it was concluded that the level of functionality of children with ASD affected the level of impact of thefamily. Supporting families both financially and with social support programs and rehabilitation programs in cooperation with social workers, physiotherapists and psychologists are thought to facilitate the lives of families and children with ASD.

## Conclusion

This cross sectional studyshows the independence of the children with ASD has a relationship with the familial/social status of the family. Physical activities are practices that can increase children's independence. Individuals who are independent will reduce the burden on families. For this reason, physical activities to be performed both in special education centers and by the family will increase independence, thus reducing the impact on the family.

## Conflict of interest

The authors declare no conflict of interest. No financial support was received.

#### **Ethics Statement**

The approval of the Non-Interventional Ethics Committee of Aydın Adnan Menderes University Faculty of Health Sciences was obtained for the study (E-15189967-050.02.04-196969).

## **Author Contributions**

Study Design, UC and NÖ; Data Collection, GÖK; Statistical Analysis, GÖK; Data Interpretation, NÖ and GÖK; Manuscript Preparation, UC and NÖ; Literature Search, GÖK, and NÖ. All authors have read and agreed to the published version of the manuscript.

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