

## Original Article

## Validity and Reliability of the Turkish version of the Affiliate Stigma Scale in Parents of Children with Intellectual Disability

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### Abstract

**Aims:** The study was conducted to test the validity and reliability of the Affiliate Stigma Scale in parents of children with intellectual disability in the Turkish culture.

**Methodology:** The methodological research was carried out in all special education and rehabilitation centers in the province of Erzincan, Turkey, between April 2016 and May 2017. The study sample consisted of 178 parents who agreed to participate in the research and met the research inclusion criteria. Data were collected using the Personal Information Form and Affiliate Stigma Scale with face-to-face interview method. In the analysis of the data, linguistic, content and construct validity, explanatory and confirmatory factor analysis, Cronbach's alpha coefficient, test-retest methods and percentage means for demographic data were used.

**Results:** Linguistic and content validity of the Affiliate Stigma Scale was provided. The explanatory factor analysis of the scale showed a one-dimensional structure with factor loadings in an appropriate range (0.585-0.857) and Cronbach's alpha coefficient of 0.965. As a result of the confirmatory factor analysis, the factor loadings of all items of the Affiliate Stigma Scale were found to vary between 0.45 and 0.77. According to the test-retest results, it was determined that the Affiliate Stigma Scale has time invariance and is a valid and reliable measurement tool in Turkish society.

**Conclusions:** It is advisable to use the scale as a data collection instrument in larger groups to determine the factors affecting affiliate stigma in parents of children with intellectual disability, and to conduct validity and reliability studies in other groups of disabilities.

**Keywords:** child, parent, nurse, affiliate stigma, intellectual disability.

### Introduction

Every couple wants to have children to complete the family. As the family constitutes the foundation of the society, having children is important for the parents. In society, children are perceived as the element that strengthens marriage and family ties as well as the parents' future security and the power to sustain descendants. However, having a child with a disability instead of a healthy child can be a very traumatic for all family members, especially parents (Barut, 2003; Bilal & Dag, 2005).

According to the World Disability Report (WHO, 2011), nearly 15% of the world's population has at least one kind of disability. The Global Burden of Disease (2010) study reports that there are 95 million children with disabilities between the ages of 0 and 14, of which 0.7% has severe disabilities (WHO, 2011). According to the Population and Housing Survey (2011) conducted by the Turkish

Statistical Institute, 6.9% of the population aged 3 years and over in Turkey has at least one disability. When we look at the distribution of the individuals (3 years and over) with at least one disability, it is found that Giresun (13.5%) and Erzincan (12.4%) have the highest population in Turkey in this regard (TUIK, 2013). The excess number of individuals with intellectual disability in the population makes the problems of these individuals and their families important. Stigma is expressed as a set of attitudes and behaviors resulting from negative thoughts, prejudices and attitudes of the society towards individuals with disabilities, resulting a social exclusion. In many societies, stigma has been first developed against patients with intellectual disability. Stigma experience is an additional burden on the disease that can lead to social isolation in individuals, limitations in their lives, delay in seeking help (Ucok, 2003). Stigma can affect not only the individual but also the family members, friends, the person's

dependents or other people associated with the individual. "Courtesy stigma" or "affiliate stigma" refer to the stigma that negatively affects the family members of the individual with disability. The adoption of the stigmatizing views of the society by the caregivers of the individuals with intellectual disability is called affiliate stigma. In this process, family members may experience low self-esteem, negative emotional state, withdrawal from the society and damage to family relations at varying levels (Buechter et al 2013; Mak & Cheung 2008).

Many studies conducted with parents of children with intellectual disability showed that parents had a high-level of affiliate stigma and that the stigma has been associated with variables such as social support, professional support, educational status, parents' perceived responsibility for the child's status, and caregiver burden ( Mak & Cheung 2008; Mak & Kwok, 2010; Ntswane & van Rhyne, 2007).

International Association for the Scientific Study of Intellectual Disabilities (IASSID) states that health professionals are inadequate in addressing the problems of families and individuals with intellectual disabilities and that the social institutions also fail to deal with the problems of individuals with disabilities and their families (WHO, 2001). Considering the measurement instruments that evaluate the stigma, the Affiliate Stigma Scale has been developed by Mak and Cheung in 2008 to evaluate the affiliate stigma status of caregivers two different groups of children with intellectual disability and psychological distress. This scale has not been adapted to Turkish language ( Mak & Cheung 2008).

This study was conducted to test the validity and reliability of the Turkish version of the Affiliate Stigma Scale in parents of children with intellectual disability.

## Methodology

In the study, the methodological research design was used, and the Affiliate Stigma Scale (ASS) was adapted to Turkish society. The study was carried out between April 2016 and May 2017 in all special education and rehabilitation centers in the province of Erzincan, Turkey. The study population consisted of all the special education and rehabilitation centers located in the province of Erzincan, and the sample selected by random sampling consisted of volunteer parents of children with intellectual disability admitted to four special education and rehabilitation centers and who met the research inclusion criteria. In order to perform factor analysis in the intercultural scale adaptation studies, it is stated that the sample size should be at least 5 times and at most 10 times the number of items in the scale. It is

also stated that at least 30 people must be retested in order to meet the parametric test assumptions (Esin, 2014). In this study, 178 (8 times the number of items in the scale) parents were reached by random sampling, and 51 parents were reached for the retest reliability. Parents of children under 18 years of age who were undergoing rehabilitation for at least 6 months, who were intellectually disabled who have no severe orthopedic disabilities and who were registered with the rehabilitation center were included in the study sample.

**Data Collection Instruments:** "Personal Information Form" and "Affiliate Stigma Scale" (ASS) were used to collect research data.

**Personal Information Form:** The "Personal Information Form" was prepared by the researcher in line with the literature, ( Barut 2003, Cangür et al., 2013, MEB 2011, Dönmez 2011). and consists of 11 items for the socio-demographic characteristics of the children with disabilities and their families.

**Affiliate Stigma Scale:** This 4-point Likert type scale has been developed by Mak and Cheung in 2008 to evaluate the affiliate stigma status of caregivers of two different groups of children with intellectual disability and psychological distress, and consists of 22 items scored between "1 - completely agree" and "4 - completely disagree". The scale items measure the cognitive, emotional and behavioral components of the affiliate stigma. There are 6 items questioning the emotional impact of the stigma on the scale, whereas 8 items question the behavioral impact and 8 items question the cognitive impact of the stigma. It is assumed that the affiliate stigma increases as the total score taken in the scale increases ( Mak & Cheung 2008).

**Data Collection:** Parents who regularly visit the rehabilitation centers and the parents in the waiting rooms in the rehabilitation centers were informed about the research and volunteer parents were asked to fill in the questionnaire individually. Parents who agreed to participate, but could not come to the rehabilitation center were visited at home. Each parent was interviewed for about 15-20 minutes. Legally, Individuals with disabilities and their parents receive an individual and physical rehabilitation 2 sessions (45 minutes) a week. ASS was applied for the second time to the parents (n = 51) who came to the rehabilitation centers, in their own sessions after 15 days.

**Data Analysis and Evaluation:** The data were evaluated with SPSS 17 and LISREL 8.80 package programs. In the evaluation of the data, KMO, Bartlett's test, Principal Component Analysis, internal consistency coefficient, item total correlation were applied for the validity and

reliability and the test-retest was carried out to determine the time invariance of the scale. In addition, values of  $\chi^2/SD$ , RMSEA, CFI, RMR, SRMR, GFI, AGFI and NFI compliance index were also examined for confirmatory factor analysis (Esin, 2014; Çapık, 2014)

**Ethical Principles of the Study:** For the scale to be used in the research, written permission of the author of the original scale was obtained for the Turkish adaptation, and a protocol for evaluation of the scale was kindly requested. The approval of the Atatürk University Faculty of Health Sciences Ethical Committee, and the written permissions of the Erzincan Provincial National Education Directorate and studied rehabilitation centers were obtained before conducting the study. The parents who agreed to participate in the research and met the research inclusion criteria were informed about the research and their verbal consent were also obtained.

**Limitations and Generalizability of the Study:** The limitation of the study is the disagreement of some parents of children with mild intellectual disability in the data collection since they perceived their children only have a learning disability or they couldn't accept the status of their children. And, since the study is single-centered, the results can only be generalized to the parents who have children under the age of 18 and receive training in the rehabilitation centers in the province of Erzincan.

## Results

The research results were presented in two parts: namely the results on the validity and reliability of the scale.

Of the parents who participated in the research, 55.6% was the mother of children with intellectual disability, 86.5% was married, 38.2% was primary school graduate and 60.1% was living in the city. Of the parents, 50.0% has a female child with intellectual disability. Of the respondents, 57.3% had balanced income, 55.1% was unemployed, and 73% has social security. Of the children of the parents included in the study, 43.8% had mild intellectual disability.

**Findings on the Validity of the Affiliate Stigma Scale:** In this study, the ASS was analyzed in terms of three different aspects: linguistic validity, content validity and construct validity.

**Linguistic Validity:** The Affiliate Stigma Scale (ASS) was first translated to Turkish language by the researcher. Then, the translation of the ASS into Turkish language was also performed by three instructors, who were experts in the field of foreign languages. After selecting the translations, by the

thesis supervisor and the researcher, of the items that best reflect the original scale items, the scale was translated back into English by a linguist whose native language was Turkish. Translation and back-translation of the scale items were compared by the researcher and the supervisor, and necessary corrections were made to finalize the scale. The suitability of the ASS to the Turkish language was assessed by a Turkish linguist. And, a pilot study was performed with 10 parents to assess whether the items were understood by the parents.

**Content Validity:** After the translation was completed, scale items were presented to an expert group consisting of academic nurses and midwives, expert in their fields, to revise clarity and cultural appropriateness of the items. Davis Technique was used in the evaluation of expert opinions. According to this technique, experts are asked to evaluate each item by scoring the items with: 1 point if "not appropriate", 2 points if "appropriate but requires minor changes", 3 points if "fairly appropriate" and 4 points if "completely appropriate". The CGI scores of the items of the ASS, evaluated for content validity using Davis technique, were found to vary between 0.8 and 1.0.

**Construct Validity:** After the content validity, factor analysis was performed to determine the construct validity of the ASS in order to obtain clearer results in the study. Before the factor analysis, KMO analysis was used to determine whether the sample size was adequate. The Bartlett's test was performed to determine the suitability of the data for factor analysis. The factor structure of the scale was then assessed by both Explanatory Factor Analysis and Confirmatory Factor Analysis.

In Table 1, it was determined that the value of KMO of the ASS was 0.939 and the value of Bartlett's Test was  $\chi^2 = 3494.797$ ,  $p = 0.000$ . These results show a correlation in the data, indicating that the data set is suitable for factor analysis.

### **Explanatory Factor Analysis Results**

Explanatory factor analysis is carried out to reduce the number of variables and to reveal new structures by exploiting the relation between them (Seker & Gencdogan 2006). As shown in Table 2, the factor loadings of the ASS items vary between 0.585 and 0.857. It is seen that the ASS, which has a one-dimensional structure in its original form, maintains its one-dimensional structure in the Turkish version as well.

As shown in Table 3, the ASS explains 58.262%

of the total variance with a single dimensional structure.

As shown in Figure 1, the threshold eigenvalue of the ASS in the one-dimensional structure is greater than 1, having a value of 12.7.

As a result of the confirmatory factor analysis, it was determined that factor loadings vary between 0.585 and 0.857 and the total variance was found to be 58.262% for the one-dimensional Turkish version of the ASS. At this stage, no items were removed from the scale since the factor loadings of all items were higher than 0.30. In order to obtain more accurate results in the study, CFA was performed after AFA.

As shown in Table 4, the goodness of fit index was used to analyze the model fit of the ASS. The  $\chi^2/SD$  value was 1.94, GFI 0.99, RMSEA 0.99, CFI 0.073, AGFI 0.99, RMR 0.039, SRMR 0.060 and NFI 0.97 respectively. As a result of the relevant goodness of fit index values, it has been decided that the model is suitable with its current form. Therefore, no change is required in the 22-item, one-dimensional Turkish version of the ASS,

compared to the original.

The factor structure obtained as a result of confirmatory factor analysis for ASS items is presented in Figure 4.2 as PATH Diagram.

As shown in Figure 2, it was determined as a result of factor analysis that factor loadings of all items of the ASS were in the range of 0.45 to 0.77. In addition, the "t" values of the items range from 2.09 to 4.58. For all these reasons, there was no need to remove any from the scale (Çapık, 2014).

### *Findings on the Reliability of the Affiliate Stigma Scale*

**Internal Consistency:** Table 5 shows the scale items, mean values, item total correlation, and Cronbach's alpha if item deleted. As shown in Table 5, according to the evaluations made to determine the internal consistency and homogeneity of the ASS, the Cronbach's alpha coefficient of the scale was found to be 0.965 and the item total score correlations ranged from 0.55 to 0.84. As shown in Table 6, the test-retest correlation value of the scale is 0.859 with a statistical significance

**Table 1. KMO and Bartlett's Test Results of the Scale Items**

KMO Value		0.939
Bartlett's Test Value	$\chi^2$	3494.797
	SD	231
	P	0.000

**Table 2. Scale Items and Factor Loadings**

Item	Factor Loadings
1.	0.670
2.	0.585
3.	0.627
4.	0.805
5.	0.704
6.	0.786
7.	0.719
8.	0.794
9.	0.782
10.	0.817
11.	0.755

12.	0.786
13.	0.689
14.	0.805
15.	0.816
16.	0.746
17.	0.797
18.	0.829
19.	0.857
20.	0.759
21.	0.825
22.	0.772

**Table 3. Total Variance Explained of the Scale**

Item No	Cumulative Variance Explained					
	Eigenvalues			Square Loads Total		
	Total	Variance %	Cumulative %	Total	Variance %	Cumulative %
<b>1</b>	<b>12.818</b>	<b>58.262</b>	<b>58.262</b>	<b>12.818</b>	<b>58.262</b>	<b>58.262</b>
2	1.359	6.179	64.440			
3	1.055	4.797	69.237			
4	0.855	3.888	73.126			
5	0.809	3.678	76.803			
6	0.633	2.877	79.681			
7	0.598	2.720	82.401			
8	0.522	2.374	84.775			
9	0.460	2.089	86.864			
10	0.422	1.920	88.784			
11	0.358	1.629	90.413			
12	0.306	1.392	91.805			
13	0.283	1.286	93.091			
14	0.265	1.203	94.293			
15	0.241	1.098	95.391			
16	0.194	0.880	96.270			
17	0.178	0.810	97.080			
18	0.164	0.745	97.825			
19	0.146	0.664	98.489			
20	0.141	0.639	99.128			
21	0.106	0.481	99.609			
22	0.086	0.391	100.000			

**Method:** Principal Component Analysis.

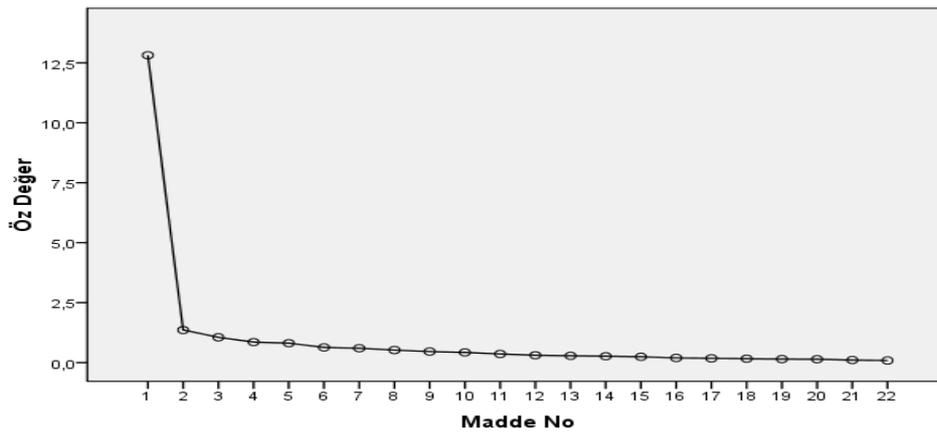


Figure 1. Eigenvalues Scree Plot Graph of the Factor Structure

Confirmatory Factor Analysis Results

Table 4. CFA Results of the Affiliate Stigma Scale

Goodness of Fit Indices	Found	Appropriate	Acceptable
$\chi^2/SD$	1.94	<2	<5
RMSEA	0.073	<0.05	<0.08
CFI	0.99	>0.95	>0.90
RMR	0.039	<0.05	<0.08
SRMR	0.060	<0.05	<0.08
GFI	0.99	>0.95	>0.90
AGFI	0.99	>0.95	>0.90
NFI	0.97	>0.95	>0.90

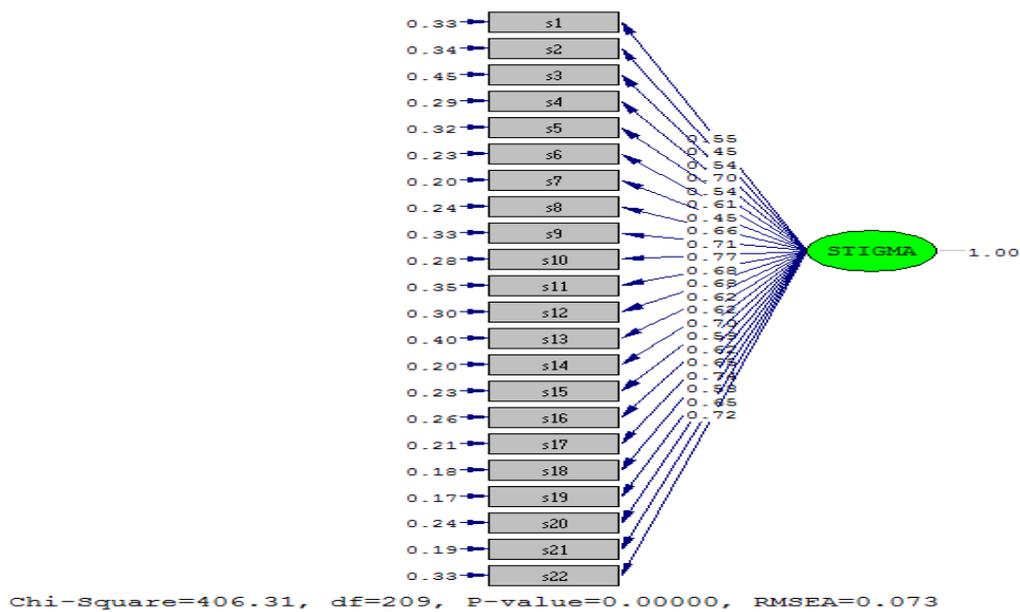


Figure 2. PATH Diagram of the Scale Factor Structure

**Table 5. Scale Items, Mean Values, Item Total Correlation, and Cronbach's alpha if Item Deleted**

Item No	n	Avg.	SD	Item Total Correlation	Cronbach's alpha If item deleted
1	178	1.56	0.80	0.64	0.96
2	178	1.47	0.74	0.55	0.97
3	178	1.77	0.86	0.60	0.97
4	178	1.76	0.88	0.79	0.96
5	178	1.52	0.78	0.67	0.96
6	178	1.59	0.77	0.76	0.96
7	178	1.38	0.64	0.69	0.96
8	178	1.67	0.83	0.77	0.96
9	178	1.77	0.91	0.76	0.96
10	178	1.77	0.93	0.79	0.96
11	178	1.79	0.90	0.74	0.96
12	178	1.65	0.87	0.77	0.96
13	178	1.77	0.89	0.66	0.96
14	178	1.55	0.77	0.78	0.96
15	178	1.69	0.85	0.79	0.96
16	178	1.53	0.78	0.71	0.96
17	178	1.54	0.77	0.77	0.96
18	178	1.57	0.78	0.80	0.96
19	178	1.65	0.85	0.84	0.96
20	178	1.51	0.76	0.73	0.96
21	178	1.52	0.78	0.80	0.96
22	178	1.75	0.92	0.75	0.96
Cronbach $\alpha$				<b>0.965</b>	

**Table 6. Test Re-Test Spearman Rho Correlation Analysis Results**

Test		First Test	Re-test
First Test	R	1.000	<b>0.859</b>
	P	-	<b>0.000</b>
Re-test	R	0.859	1.000
	P	0.000	-

## Discussion

The research results were discussed in two parts, namely the results on the validity and reliability of the scale.

**Discussion of the Results on the Validity of the Affiliate Stigma Scale:** The first step in the intercultural scale adaptation studies is to perform the language translation of the scale to be adapted. One of the most used methods in language adaptation is the translation-back translation method. In this method, the scale is translated into the language to be adapted from the original language, and then translated back to the original language in order to be able to improve the scale to achieve a semantic equivalence (Seker& Gencdogan 2006).

The Affiliate Stigma Scale (ASS) was first translated to Turkish language by the researcher. Later, ASS was translated into Turkish language by three foreign language experts in the field. After selection of the items that best reflect the original scale items by the researcher and thesis supervisor the translations, the final version of scale was translated back into English by a linguist whose native language was Turkish. Translation and back-translation of the scale items were compared by the researcher and the supervisor, and necessary corrections were made to finalize the scale.

The translated scale was revised by a Turkish linguist in terms of clarity of the items and suitability for Turkish language. A pilot study was performed with 10 parents to assess whether the items were understood by the parents.

In order to assess the content validity of the scale, the Davis technique was used and it was presented 13 academic nurses and midwives, expert in their fields. It is suggested in the literature that the number of experts to be consulted in scale adaptation and development studies should be between 5 and 40. The number of experts consulted for their opinions is in line with the literature (Alpar, 2010).

In this study, the KGI scores of all the items in the scale ranged from 0.8 to 1.0. In the literature, it is stated that the KGI score should be greater than 0.80 in content validity tests of the scales evaluated by Davis technique (Zamanzadeh, et al., 2014). Therefore, it can be said that the ASS is adequate in terms of content validity.

Construct validity of a scale is used to determine the extent to which a measurement instrument measures the abstract concept or behavior to be measured (Esin MN, 2014). In this study, exploratory and confirmatory factor analysis was used to assess the construct validity.

Before the factor analysis, the KMO analysis was performed to determine the adequacy of the sample size, and Bartlett's Test analysis was carried out to determine suitability of the data for factor analysis. A KMO value of 0.50 and above indicates that the sample size is sufficient for validity analysis (Esin, 2014). And, the KMO value in this study was found to be 0.939. This result shows that the sample size is sufficient for factor analysis. In the study, the Bartlett's Test value was  $\chi^2=3494.797$ ,  $p=0.000$ . These results show a correlation in the data, indicating that the data set is suitable for factor analysis.

In the literature, it is stated that the explained variance should be higher than 30% and factor loadings should be greater than 0.30 in one-dimensional scales (Yildirim, 2017). As a result of confirmatory factor analysis, it was determined that factor loadings changed between 0.585 - 0.857 and total variance was 58.262% when the Turkish form of the ASS was examined one-dimensionally. In line with these results, it can be said that the variance explained and the factor loads are adequate.

One of the methods used to test the validity of the factors identified by exploratory factor analysis in scale adaptation studies is to use confirmatory factor analysis (Esin, 2014). In the confirmatory factor analysis, many of the goodness of fit indices were analyzed to

determine the model adequacy of the ASS. According to the goodness of fit results,  $\chi^2/SD$  value was 1.94, RMSEA 0.073, CFI 0.99, RMR 0.039, SRMR 0.060, GFI 0.99, AGFI 0.99 and NFI was 0.97, respectively. It is stated in the literature that  $\chi^2$  "p" value should be  $p > 0.05$ ,  $\chi^2/sd < 2$ ,  $GFI > 0.95$ ,  $AGFI > 0.95$ ,  $CFI > 0.95$ ,  $RMSEA < 0.05$ ,  $RMR < 0.05$  and  $SRMR < 0.05$ .<sup>15</sup> According to the goodness of fit index results, 22-item one-dimensional ASS data are compatible with the model and do not require any changes in the Turkish form compared to the original.

As a result of the confirmatory factor analysis in the study, the factor loadings of all items of the ASS were found to vary between 0.45 and 0.77. In addition, the "t" values of the items range from 2.09 to 4.58. For all these reasons, there was no need to remove any from the scale (Capik, 2014).

#### ***Discussion of the Findings on the Reliability of the Affiliate Stigma Scale:***

Internal consistency is a method in scale development and adaptation studies to determine whether all aspects of the scale is measured and whether the scale only measures the desired concept. One of the most commonly used methods for evaluating the internal consistency of scale items is the Cronbach's alpha coefficient. It is stated in the literature that the Cronbach's alpha coefficient should be at least 0.70, indicating that the reliability of the scale increases as the alpha coefficient increases ((Esin, 2014; Alpar, 2010; Karakoc & Donmez, 2014). The Cronbach's alpha coefficient of the original scale is 0.95 (Mak & Cheung 2008). The Cronbach's alpha coefficient of the Turkish version of the scale is 0.956. In line with these findings, it can be said that the degree of internal consistency of the scale is high.

Another method used to determine internal consistency is item-total score correlation. By this method, the variance of each item of the scale and the variance of the total scale score are compared to examine the relation between them. It is stated in the literature

that item total score correlation should be at least 0.30 for each item (Esin, 2014). The item total score correlation of the original scale is between 0.47 and 0.78 (Mak & Cheung 2008). The item total score correlation of the Turkish version of the ASS was in the range of 0.55 and 0.84. These findings indicate that the total item total correlation score is sufficient and that the 22-item ASS has no problematic item.

When a measurement instrument is applied to the same individuals at different times, the similar and consistent responses of individuals indicate the time invariance of the measurement instrument. A correlation coefficient value greater than 0.80 is preferred between the scores of the two applications. In the study, the test-retest correlation value was found to be 0.859, indicating that a high-level correlation between the two measurements and that the measurements yield similar results (Esin, 2014; Capik, 2014 ).

All the findings on the validity and reliability of the scale indicate that the ASS is a valid and reliable scale in the Turkish language.

**Recommendations:** The validity and reliability of the Turkish version of the Affiliate Stigma Scale (ASS) adapted from English to Turkish were found to be high. For this reason, it is believed that the use of Affiliate Stigma Scale as a data collection instrument in larger groups to determine the factors affecting affiliate stigma in parents of children with intellectual disability, and conducting its validity and reliability studies in other groups of disabilities will be effective in identifying the problems of parents of children with disabilities.

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