



## Development of an indigenous social stigma scale for parents of children with special needs

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**Abstract:** The objectives of the study were to develop an indigenous Social Stigma Scale in Urdu language for the parents of children with special needs and by establishing the psychometric properties of indigenously developed Social Stigma Scale. The study was divided into two phases: In phase 1, indigenous Social Stigma Scale was developed while in Phase 2, psychometric properties of scale were established. Goffman theory of Stigma and Semi-structured interviews with parents of children with special needs were used for items generation. After expert evaluation, 63 items were administered on 30 parents in pilot testing. For field study sample of 500 participants were recruited by using Purposive sampling. EFA was fixed to six factor structure with 41 items. CFA yielded 20 item scale with Cronbach alpha of 0.94. Results of Test-retest reliability, divergent and convergent validity indicates the scale as a valid and reliable measure of social stigma for parents of children with special needs. The study has implications in clinical and counseling field.

**Keywords:** Social Stigma Scale, Parents of Children with Special Needs, Psychometric Properties

### I. INTRODUCTION:

Stigmatizing the parents of disabled children have become widespread in our society. The reason may be attributed to their close social, emotional and biological relationship. In current study, parents of the children suffering from Intellectual Disability Disorder (ID), Down Syndrome (DS) and Autism Spectrum Disorder (ASD) will be studied. These disorders are the developmental ones and children suffering from such developmental disabilities encounter functional impairment throughout their lives. These disorders can't be cured and consequently parents having these children are obliged to supervise and take care of them for longer periods of time than normal children (Levy, Mandell & Schultz, 2009). The term "special need child" refers to someone having physical, mental, emotional, sensory and learning impairment. Parents with children having special needs possess a diverse range of emotional responses such as embarrassment, inadequacy, distress and irritation (Haider & Khan, 2015). According to DSM V, Individuals suffering from autism experienced major impairment in social interaction and communication. These individuals also show pattern of behaviors that are monotonous. Autism can be diagnosed during early developmental ages (APA, 2013). Intellectual disability refers to impairment in intellectual working and adaptive behaviors. It occurs with the onset of early developmental period (Schalock, Luckasson & Shogren, 2007). Down syndrome results when there is defect in chromosome no. 21. It happens because of trisomy of chromosome no 21. The individuals with Down syndrome have features either physical or non-physical that may vary and these features can't be predictable at times. The major impairment is experienced during learning (Ahmed, Ahmed, Jafri, Raashid & Ahmed, 2015).

Stigmatization is a process through which individuals who seem to be 'undesirably different' in society are labeled and lose respect and value because of discrimination, labeling, societal separation, and negative responses from the majority of public (Kayama, Haight, Ku & Cho, 2017). Stigma, in the context of mental health, can be stated as the loss of position and elimination caused due to harmful labels to individuals having mental disorder (Link & Phelan, 2001). There are many types of stigma that have been theorized. Public stigma is the most common and primary type of stigma. It deals with the overall attitude of the society toward disordered individuals (Lin, Struening, Nuttbrock, Phelan & Rahav, 1997). The second type of stigma is known as perceived stigma or felt stigma, which focuses on perceiving negative attitude of the society toward one self and having the belief that other society members hold hurtful opinions that may result in discrimination (Corrigan & Watson, 2002). Family or courtesy stigma is referred as third type of stigma which states discredited experience of individuals related to stigmatized person (Goffman, 1963).

### **Perception of Social Stigma among Parents of Children with special needs (ASD, DS and I.D)**

Parents of special need children are very vulnerable to experience high levels of stigma. Ertem and Ergün (2012) studied to highlight the problems faced by mothers who had children with mental disabilities (I.D, ASD). The findings showed that 81% mothers faced problems in satisfying their childcare requirements, most mothers experienced sadness, anger and loneliness. Most of them were blamed for their child disability by their husband's family. They faced financial problems in taking care of their child, were worried about child future and need social support. Agyekum (2018) conducted a qualitative research to identified the Issues and coping techniques used by the parents of autistic children in Ghana. Outcomes reflected people stigmatized these children and their family members and its effect parents emotionally & how society's reaction to autistic child identified how stigmatized attitude of society discouraged them. In 2018, Duran and Ergun did a qualitative study with parents of children with IDD. The overall Results revealed that Children's parents have not been supported by family members, friends and society as a whole and feel stigmatized. Gobrial (2018) conducted a qualitative research on mothers having children with autism. Findings showed that for mothers' life with ASD was frightening and most mothers had depression, guilt, frustration and poor emotional wellbeing. Iseselo, Malima and Kajula (2016) performed study to identify the psychosocial problems confronted by the family members of the people with mental illness. Result revealed 7 major themes i.e., financial restraints, disturbing behavior of patient, disturbance in family functioning, limited social support, discrimination, stigma and coping strategies. Mukherjee and Shignapure(2016) identified the impacts of mentally challenged children on their parents and other family members and major finding of the study was that about 15.8% parents often wanted to commit suicide not because of their child disability but due to other reasons like financial problems, family and marital conflicts, societal attitudes and due to blaming by others. Iftikhar and Butt (2013) did a cross sectional study to assess level of psychological wellbeing and the extent of parental concerns among mothers and fathers of autistic children. Outcomes of research showed that the stress levels, anxiety and depression of mothers were higher because of financial problems, limited facilities, unavailability of specialists, unacceptance and discriminations from society and pressure from family. Taderera and Hall (2017) did qualitative research which results indicated that participants faced problems because of lack of availability of essential knowledge regarding child disability and most of family and community members distance themselves from parents of children with LDs due to stigmatization and prejudice towards learning disability. Due to these reasons the parents had limited emotional and financial support from others. Grasu (2015) identified the challenges faced by families of a child with ASD in Romania. Ludlow, Skelly, Rohlede (2012) did a qualitative research to Investigate the issues experienced by parents of autistic children. Results revealed 6 main themes lack of support, dealing with challenging behaviors, changing routine, impact on the family, judgements from others, the importance of appropriate support and coping were identified.

### **Need of Indigenous Stress Scale**

Stigma is assessed by different standardized scales among parents of children with special needs. Szmukler et al. (1996) used a stigma scale with 5 items that was part of a broader inventory evaluating the mentally ill family members' care-giving experiences. They found that stigma was one of the aspects reflecting the cons of the multidimensional model of "care-giving experiences". Struening et al. (2001) developed a scale with 7 items that analyzed degree to which families thought society ridiculed their family members with mental disorder. Researchers found that almost 70% of relatives thought that people degraded family members with a mental disorder, while 43% assumed that majority people were degraded because they had mentally unstable family members. Green (2003) has combined qualitative and quantitative approaches for evaluating stigma in families of children with disabilities (under 18) by association She found that motherly perceptions of stigma towards disabled persons increased motherly discomfort (subjective burden). Mothers who have experienced extreme level of stigma find themselves less involved in informal social settings. Mak and Cheung (2008) examined the perceptions of stigma in individual caregivers of teenagers and adults with either emotional or intellectual impairment. He proposed that the understanding of stigma by relatives recognized as an associate stigma, distinguishing it from stigma by association that may or may not be psychologically internalized at the level of the individual, even if it is reported existing. Saldivia et al. (2014) established an international measure of stigma for people living with schizophrenia and other psychotic disorders. The scale had 31 four-dimensional elements and good interior reliability and test-retest reliability (Cronbach's Alpha 0.89). The scale was a reliable measure for stigma of schizophrenia and associated psychotic disorders across cultures. Mourya, Singh, and Rai (2016) conducted research about stigma in social lives of mothers having children with I.D. The perceived stigma scale consisted of 10 items that had five-point Likert responses. Reliability on scale was 0.72. Morris et al (2017) established the scale of self-stigma for

mentally ill people of first degree relative. The tool was composed of 30 items and the answer pattern h, and the response pattern has 5-point Likert. The scale had outstanding reliability of 0.90). Mitter, Ali, and Scior (2018) conducted research on the stigma faced by families of intellectual and developmentally disabled members. Self-report stigma tool among families of disabled individuals (I.D and ASD) has been developed. The instrument consisting of 26 items and is organized by five factors. Reliability of the instruments was .84.

At the time of this study, however, no measuring instruments were recognized in the literature that specifically measure the perception of social stigma in parents of children with special needs in Pakistan. The only scale that directly measured the perceived stigma among parents of children with special needs is Mickelson (2001) 8 items perceived stigma scale. The scale had 5-point Likert response. The reliability of scale was reported as .76. Taking into account the available literature, a scale based on Pakistani culture was very much needed to assess social stigma for the parents of children with special needs. Consequently, the current study is designed to fill the gap. It aimed to establish an indigenous scale for evaluating social stigma among parents of special needs children. Items of the tools are formulated on Goffman stigma theory (Goffman, 1963) and through parental interviews. Aim was to develop a reliable and valid measure to study stigma among parents of autistic children, I.D and D.S in Pakistani culture.

## II. THEORETICAL MODEL OF SOCIAL STIGMA

The stigma scale is based on theory of stigma formulated by Goffman. Erving Goffman was one of the most dominant sociologists of the 20th century. He has carried out lot of research work on stigma. He defines stigma as the process in which people have an attribute that is often dishonored by his society is shown rejection because of that attribute (Goffman, 1963). The stigmatization of a child who is physically or mentally handicap is not the issue for the child with the disability only but for their parents as well. Goffman differentiates discreditable stigmas (the stigma is not obvious, unless revealed by the sufferer himself/herself) from discredited (the stigma which is already obvious). Goffman defines stigma as “a characteristic that is profoundly disapproving” (Goffman, 1963). He highlighted two main implications of stigma: (a) social rejection (b) status loss. Explaining loss of status, he describes that the marginalized individual is decreased in our imaginations from a normal person to a discounted and tainted one (Goffman, 1963, p. 3) (Goffman, 1963). In social rejection, stigma is characterized as the state of the individual not eligible for full societal acceptance (Goffman, 1963; preface).

### Objectives

The main objectives are:

1. To develop an indigenous scale of Social Stigma for parents of children with Special needs in the context culture of Pakistan.
2. To establish the psychometric properties of indigenously developed Social Stigma Scale.

### Method

Present study consisted of 2 phases. In Phase I, SSS was developed. Scale's Psychometric properties were determined in phase II.

**Phase I: Development of Social Stigma Scale (SSS):** Phase I of the study consisted of 3 steps. During first step items were generated on the basis of semi structured interview and Goffman theory of stigma. In the second step of phase 1 expert evaluation of items was conducted. During third step, pilot testing was conducted.

**Stage I: Generation of item pool.** Items were generated through the interviews were conducted with 15 parents (5 from each category ASD, Down Syndrome and Intellectual disability). Based on Semi structured interview a template was designed for detecting the stigma related aspects of their children with disability. Some questions that asked from parents during interview are: Describe your feelings and emotions about having child with disability; state challenges that you are facing for having child with disability, report about attitude of family and society towards your child with disability. On the other hand, Goffman theory of stigma was also used for developing items for the SSS. According to Goffman theory, Stigma is the undesirable appraisal of an individual as blemished or disgraced on the basis of traits for example mental illness, background, physical disability or drug abuse (Goffman, 1963). After thematically analyzed the qualitative data 9 themes were derived (see Table 1). On the whole 70 items in Urdu language were generated by following themes derived from semi structure interviews and Goffman theory of stigma (1963).

**Table 1: Parental understanding of Social Stigma**

Themes	Sub-theme
Psychological Distress	
Bullying/ Labelling	
Social Attitude Negative Attitude	Positive Attitude
Social Pressure Social Isolation Social detachment	Social avoidance
Social Exclusion Social discrimination	Social rejection
Lack of Social Support	
Future Concerns	
Impact on family Life	
Guilt/Blaming	

**Stage II: Content validity through experts' evaluation of items.** For content validity total 70 items of initial form of SSS were presented to a panel of 5 experts (two PhD and three MPhil in Psychology) of relevant field for content validity. The aim of expert evaluation was to get the experts' judgement about the contents of each item either it is measuring the social stigma related to children with disability. Through experts' evaluation, Items relevancy in the scale was assessed on 4-point Likert scale (1= not relevant, 2= relatively relevant, 3= relevant and 4= entirely relevant). They also described about the ambiguousness and unsuitability of words or items. Expert stated that most of the items were appropriate and reasonably developed on targeted areas under consideration. However, 7 items were deleted because of repetition of the idea and slight changes were ended in phrasing and wording of items as per their recommendations. Few words were replaced with words easier to comprehend for general public. CVR was measured by applying following formula:  $CVR = \frac{n_e - (N/2)}{N/2}$  (Cohen, Swerdlik, & Sturman, 2013).

**Table2: Content Validity Ratio of Items.**

No. of Items	Items	Range (from1-4)
35	2,6,7,8,10,12,13,15,16,17,18,19,20,21,22,23,24,25,26 ,27,28,29,30,31,32,33,34,35,36,37,38,39,59,60,61,63	3.8-4.0
22	4,5,9,11,14,40,41,42,43,44,45,46,47,48,49,50,51,52, 53,54,55,62	3.5-3.79
06	56,57,58,68,69,70	2.83-3.49
04	1,3,67,2	2.5-2.80
03	64,65,66	2.0-2.40

**Table 2** indicates the content validity of 70 items rated by 5 experts. When three or more experts rated items as very important to important, but not necessary were retained in item pool and items rated as unnecessary were deleted. Followings are some sample questions from SSS: People make fun of my child with special needs; I avoid to meet people due to their negative attitude toward my child with special needs; People look down upon my child with special needs.

**Stage III: Pilot study.** Pilot study was conducted on 30 parents of autistic children, I. D and DS. The sample for pilot testing was recruited from city Gujrat using convenient sampling technique. The

participants asked to fill the form according to their feelings and comprehension about the stated items. Data were collected by using the initial form of SSS. Age range of the parents was 25 years to 60 years. Initial form of SSS consisted of 63 items was used. The response format of SSS was Likert type based on 5-point scale with (1= strongly disagree, 2= disagree, 3= neutral, 4= agree and 5=strongly agree). High scores presented elevated the higher level of social stigma while low scores indicated lower level of social stigma. Pilot study was led in order to evaluate the items' understanding and best items depend upon rate of response. The data was collected from parents during their monthly visits at special education institutes. They were informed about the aims of conducting the pilot study. The participants were given instructions in Urdu and then requested to fill the forms. In pilot testing, the Cronbach' alpha was .86 which showed high internal consistency. In pilot testing, it was seen that parents wanted to talk more about the social stigma related to their children with disability and their level of stress due to social stigma in detail.

**Phase II: Establishing Psychometric Properties:** In Phase II, pilot tested initial form of SSS was administered to establish psychometric properties including; internal consistency; Confirmatory Factor Analysis and Exploratory Factor Analysis. Total 500 parents consented to participate in the study.

**Exploratory and Confirmatory Factor Analysis:** To conclude the basic structure of the newly developed stigma scale, EFA and CFA was conducted. Before EFA item total correlation of each item was calculated and item with correlation below 0.3 were deleted on the basis of criteria given by Andy Field (2005). Purposive sampling technique was used in selecting the sample of 500 participants (250 fathers & 250 mothers) having children (male & female) with down syndrome, ASD and intellectual disability (mild to severe) from Gujrat, Kharian and Lalamusa. Total 500 participants completed the questionnaire. Participants with age of 25 to 60 years were selected. Parents who had children with multiple disabilities, more than one child with disability, and severity unspecified were excluded from the sample. Parents of autistic children, Down syndrome and intellectual disability were approached in the special educational schools where their children were enrolled.

**Table 3: Frequencies and Percentages of Demographic Variables of Participants (N = 500)**

Variable categories	F	%
Parents		
Father	250	50
Mother	250	50
Parents marital status		
Married	500	100
Family system		
Joint	163	32.6
Nuclear	337	67.4
Residential Area		
Urban	258	51.6
Rural	242	48.4
Family income		
10000-30000	272	54.4
31000-60000	212	42.4
61000 or above	16	3.2
Special child age		
7 to 10	85	17.0
11 to 14	138	27.6
15 to 18	277	55.4
Special child gender		

Male	201	40.2
Female	299	59.8
Type of Specialty		
Autism	166	33.2
Intellectual disability	167	33.4
Down syndrome	167	33.4
Severity of child disability		
Mild	10	2.0
Moderate	94	18.8
Severe	396	79.2

**Table 3** indicates that the parental category comprising of fathers and mothers. The marital status parents are married. The table also showed that most of parents belong to urban areas and live-in nuclear family system. Further, it indicates that majority of parents have female children with special need as compared to male. Further, it also indicates that highest category of parents has children with severity level of disability following by the moderate and mild level of disability that is ASD, I.D and D.S. Maximum parents have children that fall in the category of 15 to 18 years of age.

**Measures.** For field administration, measures consisted of two parts: **Demographic form.** It was used to get information related to age, education, occupation, monthly family income, no of children, residential area, gender, and age of child with disability, family system, severity of illness and birth order of child with disability. **Initial form of SSS.** Social Stigma was measured by using initial form of Social Stigma Scale, consisting of 41 items. Response pattern was based on five-point Likert scale.

**Procedure.** Parents were called to school / institute in group of 8 to 12 parents according to the schedule provided by the relevant institute after obtaining permission from principal, heads, and directors of schools / special education institutes. The object of study was explained to the parents after giving a brief introduction. Every parent has given written consent. The data were collected by using self-reported questionnaire. They were requested to answer the items by their experience closely related to their feelings, attitudes, and cognition. On average, it took 15-20 minutes to complete Social Stigma Scale in each administration. The study was approved by the University of Gujrat Advanced Study and Research Board. The study has maintained the ethical standard of informed consent and confidentiality. Participants were also told about their right of withdrawal from study at any time. The research also measured the risk / benefit ratio. Participants were not required to reveal their name, they were assigned identification numbers instead.

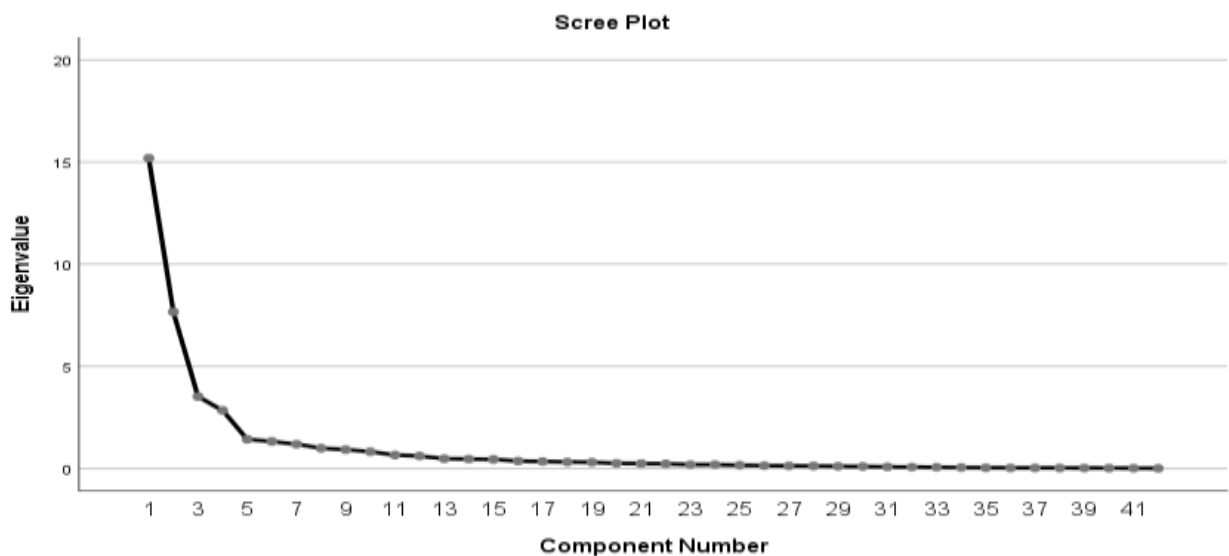
**Results.** Reliability of scale was obtained, frequencies, and percentages a cross different demographic variables were computed. Factors of the Scale were explored through EFA and further, factors were confirmed through CFA. Before conducting the EFA, sampling adequacy test was computed. Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy for pilot tested items (42 items) of Social stigma scale reveal that these set of variables was .87 falls in the range of being meritorious (.87>.80; Kaiser, 1970). Bartlett's test of sphericity showed X<sup>2</sup> value of 31985.400 (p < .000). It indicates the factorability of the R-matrix and data set of SSS is suitable for exploratory factor analysis.

**Table 4: Factor Loading on Social Stigma Scale after Varimax Rotation (N=500)**

Items#	Factors					
	F1	F2	F3	F4	F5	F6
1		.805				
3		.875				
4		.940				
5		.875				
6		.948				
7		.583				.553
8		.698				
9		.490				.823
11		.538				.445
12		.673				

13	.686			.547		
21	.622			.599		
22	.617			.629		
23	.839					
24	.854					
26	.895					
27	.625					
29	.722					
30	.679			.540		
31	.836					
32	.913					
33	.604					
35	.770					
36	.529		.683			
37	.660				.455	
38	.537		.438			
39	.551			.648		
41	.463		.482			
42			.898			
43			.905			
44			.897			
49		.622		-.439		
50		.535		-.513		
52		.493				.828
53		.471				.829
56			.688		.409	
59		.766				
60					.790	
61					.912	
62					.914	
63		.875				
Eigen value	9.417	8.771	3.742	3.488	3.178	3.145

**Table 4** indicates that most of the items have loadings between .4 to .9. Items were retained with the criteria of equal to or greater than .30 loading. If an item has loading more than .30 in more than one factor, then criteria for content relevance of that item with other items is used for item retention in respective factor. It further indicates that all factors have a reasonable number of items.



**Figure 1.** Scree plot representing factor solution.

The scree plot also indicates factor solution with a clear break after 7th component. Keeping in view the factor loading and theoretical relevance, only 6 well-defined factors were retained, which accounts the 75.57 of total variance.

EFA was run with varimax rotation and by using the Principal Component Analysis (PCA) in order to explore the factor structure in the scale. Initial Analysis with Eigen value > 1.00 (the Kaiser Guttman criterion) extracted 7-factor solution accounting for 78.91% of total variance. Items selected in certain factor based on high loading. Due limited number of items, factor 7 were deleted. Factor 1 had 14 items (13,21,23,24,26,27,29,30,31,32,33,35,37,38) with factor loading respectively .686, .622, .839, .854, .895, .625, .722, .679, .836, .913, .604, .770, .537. Similarly, factor 2 had 14 items as well (1, 3, 4, 5, 6, 7, 8, 11, 12, 49, 50, 59, 63) with factor loading .805, .875, .940, .875, .948, .698, .538, .673, .622, .535, .766, .846 correspondingly. Moreover, factor 3 a had 5 items (41,42,43,44,56) with factor loading .482, .898, .905, .897, .688. Both factor 4 and 5 had three items. Factor 4 include item no 22,36,39 with loading .629, .683, .648 and factor 5 includes item no 60,61 and 62 with factor loading of .790, .912, .914. Lastly, factor 6 had item no 9, 52 and 53 with factor loading, .823, .828, .829 respectively. However due to theoretical relevance item no 9 was placed in factor no 2 with factor loading .490 then in factor no 6.

Following the thematic understanding of the items in each factor, researcher labeled the factors as: Factor 1 was labeled as Social discrimination, Factor 2 as Bullying/Labelling, Factor 3 as Stigma of Dark future, Factor 4 as hopelessness/Psychological distress, Factor 5 as Stigma of Social Isolation and Factor 6 Stigma of Negative Impact.

**Confirmatory Factor Analysis.** Factors retained after EFA, CFA was run on data of 500 participants by using the 41 items for measurement of model, factor structure, and determination of dimensionality of initial form of SSS by using the AMOS-21. CFA run through AMOS. This structure did not indicate a good fit to the data (chi-square = 2257, df = 17.447, CFI = .605, RMSEA = .182, and GFI = .471) as the value of CFI was not in acceptable limit of .90. Modification indices were used to re-consider the model keeping in view the co-variance and regression weights. Items 5,6,7,8,9,22,22,49,50,59,63, 13,21,27,31,35,37,38,41,56,22 have high regression weights, hence, these were deleted due to their problematic status in the model. Covariances were drawn to have a fit model. CFA was run again on these 20 items to measure the model. The model indicated a good model fit with (chi-square = 573.821, df = 137, CFI = .964, RMSEA = .080, and GFI = .900). In final model, 6 factors were confirmed with 20 items.

**Table 5: Factors, Relative Items and Percentages of variance (n=500)**

Factor #	Factor Label	Items	%age of variance
1	Social Discrimination	13,21,23,24,26,27,29,30,31,32,33,35,37,38	22.4
2	Bullying/Labelling	1,3,4,5,6,7,8,9,11,12,49,50,59,63	2.8
3	Stigma of Dark Future	41,42,43,44,56	8.90
4	Psychological Distress	22,36,39	8.30
5	Stigma of Social Isolation	60,61,62	7.56
6	Stigma of Negative Impact	52,53	7.48

**Table 5** indicated the factor loadings for all 20 items of SS. It revealed that all of the items have factor loading > .30 in each factor. Model fit indices are also established (CFI = .964, RMSEA = .080, GFI = .900) indicating the values are in acceptable limit and indicating a good model fit. Pearson Product Moment correlation was used to measure the correlation among six factors.

**Table 6: Correlation among factors of Social Stigma Scale (N=500)**

Variables	SD	BL	SDF	PD	SSI	SNI	SSS
SD	1	0.482**	0.537**	0.537**	0.607**	0.337**	0.853**
BL		1	0.482**	0.537**	0.537**	0.607**	0.337**
SDF			1	1.00**	0.381**	0.305**	0.827**



PD	1	0.381**	0.305**	0.827**
SSI		1	0.399**	0.701**
SNI			1	0.545**
SSS				1

*Note\*\*.* Correlation is significant at the 0.01 level (2-tailed).

**Table 6** indicates that there is significant positive correlation among all six factors. Cronbach's alpha reliability coefficient of Social Stigma Scale of 20 items and subscales have high reliability.

**Phase II: Establishment of Psychometric Properties:**

**Discriminant and Convergent validity.** Convergent and divergent validity of recently designed SSS was established on 200 (100 fathers & 100mothers) respondents selected from Gujrat, Kharian and Jhelum special education schools / institutes. The age range of respondents was 21-60 years. The sample included parents who had children (boy or girl) between the ages of 7 and 18 with special needs. Families with serious physical disability or mental impairment, who have more than one disabled child or children with comorbidity of symptoms are excluded from the research.

**Measures.**For establishing the convergent and divergent validity of SSS, following measures were used:

**a) Perceived Stigma Scale (Mickelson, 2001).**for establishing convergent validity scores of SSS were correlated with scores of perceived stigma scale by Mickelson. It consisted of 8 items and has good internal consistency (.76) and test-retest reliability (.78). Following measures were used for establishing the divergent validity of SSS.

**b) Subjective Happiness Scale (Lepper & Lyubomirsky, 1999):** consisted of 4 items and has good test-retest reliability and excellent internal consistency (.90) **b) Satisfaction with Life Scale (Pavot&Diener, 2013):** consisted of 5 items and has good internal (.89) and test-retest reliability (.80).

**Procedure:**After obtaining permission from the administrators and heads of special education schools / institutes and clinical facilities, verbal parental approval was gained via telephone. Information from groups (10 to 15 participants) were collected in two halves after the instructions were given. In the first half the parents were given a convergent-validity questionnaire. On average, the parents had taken 5 to 10 minutes to complete the questionnaires. For divergent validity, two questionnaires were distributed among parents with the same instructions following a 25-minute break. On average, both questionnaires took between 5 and 10 minutes to complete.

**Results:** Statistically significant positive correlation ( $r = .87, p < .01$ ) between scores of SSS and Urdu translated version of original Perceived Stigma Scale (Mickelson, 2001) showed convergent validity of SSS. Discriminant validity of SSS was established by examining the correlation among scores of SSS and scores of Urdu versions of Subjective Happiness Scale (Lepper & Lyubomirsky, 1999) and Satisfaction with Life Scale (Diener&Pavot, 2013). Findings established discriminant validity by showing the statistically nonsignificant correlation between scores of SSS and Subjective Happiness Scale ( $r = -0.07, p > .01$ ); similarly, nonsignificant correlation between scores of SSS and Satisfaction with Life Scale ( $r = -0.11, p > .01$ ).

**Test-retest reliability:** Test-retest reliability of SSS was performed to see the reliability of scores on SSS with the three-week gap. Results suggest a strong high correlation ( $r=.89 p<.01$ ) with a difference of three weeks between two SSS administrations on the same sample( $n=150$ ).

### III. DISCUSSION

Present study was carried out to develop an indigenous SSS for parents/caregivers of children with special needs. The first aim of this study was to establish an indigenous SSS to evaluate the stigma among careers / parents of special needs children. In order to have an indigenous perspective, the method of generating the item pool suggested that items were developed based on commonly reported parental challenges along with the Goffman stigma theory (Goffman, 1963). The theory identified stigma, "a trait of significant disgrace" (Goffman, 1963). It stressed two major consequences of stigma: (a) loss of reputation and (b) rejection by society. The content of the items was based on aspects commonly reported from parents in Pakistan. Furthermore, five experts evaluated the content validity of the items in context of Pakistani culture. Newly developed SSS is different from already existing measures of social stigma among

parents of children with special needs. It consists of 20 items and is an indigenously developed scale in Pakistani culture. Second aim of the research was to determine the psychometric traits of the scale. Result indicated that the SSS had good internal reliability, test-retest reliability, and content validity. Similarly, test-retest reliability of SSS was also high. In test-retest reliability, environmental factors, for example, noise, temperature of room; and subjective factors, for example, participants' general health condition were controlled. Results are supported by McCrae, Kurtz, Yamagata, and Terracciano (2011) who reported that test-retest is a better index of the reliability. Churchill (1979) reported that value above .70 reliabilities is appropriate. **Table 6** indicated statistically significant positive correlation among all factors of social stigma.

Content-wise, findings supported the structure of the factors. Further, findings are also consistent with Baybaşa et al. (2017) who reported five factor structure consisted of social isolation, oppression, insufficiency, stereotypes and resistance to stigma. Gobrial (2018) supported the findings by notion that parent experienced stigmatization due to misdiagnosis, lack of health and educational resources, expensive therapies, social isolation and social discrimination. Perceived stigma scale (Mickelson (2001) consisted of two domains. One of the dimensions is measuring social or experienced stigma as social discrimination is measured in SSS, but another domain measuring the self-internalized stigma. Similarly, Zisman-Ilan et al. (2013) has factors (discrimination experience, stereotype endorsement and social withdrawal and alienation). Some of the indicators like discrimination and isolation are same in both measures.

Keeping in view the above-mentioned studies, results of the current study are consistent with the Pakistani culture perspective as in Pakistan; children are considered the direct responsibility of the parents in term of their physical and behavioral management. Financial problems, limited facilities, unavailability of specialists, unacceptance and discriminations from society and pressure from family the main factors confronted by parents of children with special needs in Pakistan. These results are also in line with the past researches (Iftikhar and Butt, 2013). They reported that factors contributing to stigma among parents who have children with special needs are lack of social support, limited facilities, negative attitude of society and social discrimination. Research evidences of Budaka et al (2018) and Duran and Ergun (2018) suggest that parents of children with special needs experience significantly higher level of stigma because of lack of social support, negative commenting, blaming by others and future concern of child.

SSS had statistically significant positive correlation with already established similar measures that is Urdu version of Perceived Sigma Scale. Findings identified the evidence of convergent validity. It can be concluded that parents who scored high on SSS, also experienced high scores on Perceived Stigma Scale. Findings are consistent with the Anastasi and Urbina (1997) finding that if there is a substantial positive relationship between similar constructs/scales, the convergent validity is expected to be determined. The non-significant correlation between SSS scores with Satisfaction with Life Scale and Subjective Happiness Scale has confirmed the discriminatory validity of SSS. Anastasi and Urbina (1997) have stated that if the dissimilar construct showed no significant relationship, the discriminating validity is said to be recognized. It can be concluded that parents with a higher level of perceived stigma tend to experience low subjective feelings of happiness as well as low level of life satisfaction.

#### IV. LIMITATIONS AND SUGGESTIONS

With regard to the research limitations, one of the limitations is that the target population was not accessible in all the special educational institutes/schools. Parents/caregivers were called to special schools, so data collection took time more than the specified timeline. One of the drawbacks of the study's is to label the factors by researchers on their own, following the theoretical perspectives of items, in this respect it is recommended to obtain the opinion of experts in the subject matter. After CFA many items were discarded that were retained in EFA at first place. If the data had been sufficiently large than in EFA, many stable factors would have been achieved at any one factor with more stable factor loading. Future scale development studies should also incorporate social stigma-related domain of siblings, so that the social stigma of family members of children with special needs can be assessed from the perspective of Pakistan on an indigenous scale. For future research, it is recommended that other cities in Pakistan should also include in order to obtain a more representative sample.

#### **Clinical Implications**

Present study is designed to develop an instrument which can be used to assess the level of stigma among parents/caregivers of children with special needs. Identifying parents with high level of stigma can help to recommend them for counseling sessions that helps them to cope with the stigma.

## V. CONCLUSION

It can be concluded that there was an intense need of an indigenous tool to measure social stigma among parents of children with special needs. Present study provided the reliable and valid instrument of measuring social stigma among parents of children with special needs in clinical settings. Study also emphasized on the need of special educational institutions, professional facilities, social support and training workshops for parents as these are the factors, which heighten stigma. It also emphasized on implementing anti-stigma strategies that may tackle the different social contexts in which parents are impacted.

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