



Development and validation of The Down Syndrome Stigma Scale in a Balinese sample

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ABSTRACT

Background: Prior to the study, instrument measuring stigma towards persons with Down Syndrome was not available in Indonesia language.

Purpose: The study aims to develop and validate the Down Syndrome Stigma Scale in the Indonesian language.

Method: An expert panel selected 27 relevant items from the Iranian version of the Stigma Scale towards Down Syndrome. After the translation process, the validity and reliability of the items were evaluated in 79 parents of children with Down syndrome. A factor analysis with factor loading greater than .40 was performed.

Findings: Three factors were identified from 23 items ($\alpha = .928$), namely social interaction (10 items, $\alpha = .881$), acceptance (8 items, $\alpha = .853$), and health-related factors (5 items, $\alpha = .821$). The psychometric quality of the Indonesian version of the Down Syndrome Stigma Scale is satisfactory and can be utilized in future research.

Implication: The Indonesian version of the Down Syndrome Stigma Scale provides a valuable tool for measuring stigma in future research within Indonesia. However, researchers should carefully consider cultural diversity when applying this scale in other regions, as the current validation was conducted exclusively with Balinese participants. Broader validation across different Indonesian cultural groups is recommended to ensure its generalizability.

KEYWORDS

Down syndrome; stigma; scale development; validity; reliability

Introduction

Down syndrome, a genetic condition resulting from the presence of an additional copy of chromosome 21, is one of the most common genetic causes of intellectual disability worldwide (Bull et al., 2011). The prevalence of Down syndrome in Indonesia is .12% according to the 2010 Indonesia Health Profile (Ariani et al., 2017). The global burden and trends of Down syndrome have not been reported in detail, but it is known that Down syndrome is the leading cause of genetically defined intellectual disability and congenital birth defects worldwide (Chen et al., 2022).

Stigma is a pervasive issue that affects individuals with various disabilities, including those with Down syndrome. Individuals with Down syndrome often face a multitude of challenges throughout their lives, but these challenges are not only medical or developmental; they are frequently compounded by the presence of social stigma. Stigma directed towards people with Down syndrome, characterized by negative stereotypes, prejudicial attitudes, and discriminatory behaviors, has been a persistent and concerning issue in many societies (Mitter et al., 2019; Yin et al., 2020).

The detrimental impact of stigma on people with Down syndrome is far-reaching. It affects various aspects of your life, including access and quality of healthcare, educational opportunities,

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employment prospects, and social inclusion (Mukolo et al., 2010). Additionally, stigma can have profound psychological and emotional consequences, leading to diminished self-esteem and well-being among people with Down syndrome (Szumski et al., 2020). Stigmatizing attitudes and behaviors towards this population not only hinders their full participation in society, but also perpetuates disparities in healthcare and social services.

Although stigma towards Down syndrome has been a subject of concern globally, it is essential to recognize that the manifestation and determinants of stigma can vary across different cultural and regional contexts (Andrewin & Chien, 2008; McLaughlin et al., 2010). Understanding and addressing stigma within specific cultural settings is crucial to the development of targeted interventions and policies that can effectively reduce its impact on individuals with Down syndrome and their families.

Stigma remains a pervasive challenge for individuals with Down syndrome, extending even to parents who suspect that their child may have this condition, often shouldering unwarranted blame and responsibility. Previous study comparing parental assessments of elementary school students in Asia-America and Europe-America revealed marked disparities in how parents from these regions perceived their children's abilities and efforts, with Asia-America parents generally rating their children lower (Ly, 2008).

Stigma, characterized by negative evaluations and social distancing of individuals viewed as "contaminated" or with disabilities, has significant economic, social, and psychological ramifications for those stigmatized. The nature and intensity of stigma vary widely between cultures and societal norms (Hemmati et al., 2010). Goffman's perspective underscores that stigma centers not solely on functional limitations but hinges on the perception of differences or deviations, invoking negative social reactions (Lai et al., 2000).

Stigma can manifest in various forms, including public, institutional, personal, and familial stigma, with the first two often coalescing into self-stigma (Mitter et al., 2019). According to (Mitter et al., 2019; W. Patrick et al., 2002) stigma encompasses stereotypes, prejudices, and discriminatory actions, beginning with labeling and culminating in the erosion and discrimination of social status.

The repercussions of stigma ripple beyond the stigmatized individual, affecting their immediate family and associates. These consequences include reduced quality of life, low self-esteem, persistent stress, impaired recovery, erosion of legal rights, healthcare discrimination, and diminished overall well-being (De Amorim & Shimizu, 2022; Deakin et al., 2018; Mitter et al., 2019; Pescosolido et al., 2008). Stigmatizing behaviors such as avoidance, reluctance to assist, suboptimal services, and institutional separation may arise (Patrick et al., 2002). Several factors, including disability type, capacity for social participation, gender, technique, and socioeconomic status, influence the occurrence of stigma in individuals (Rohwerder, 2018).

Numerous studies have revealed the emotional and anxious struggles experienced by parents of children with Down syndrome, particularly after the initial diagnosis. This adaptation process is intricately related to parental and family factors, as well as sociocultural elements such as family income, parental education, service provider relationships, and cultural and religious influences (Van Riper et al., 2021). Multiple sources of stigma can make an individual or group vulnerable, with potentially severe consequences.

In Indonesia, as in many other countries, limited research has been conducted on the stigma associated with Down syndrome (Maritska et al., 2018). conveyed the attitudes of 90 parents of children with Down syndrome living in Palembang who preferred to send their children to special schools rather than to inclusion schools to prevent discrimination. Unfortunately, the measure used in the study was only four questions and no psychometric properties was reported. There is a need to examine and address stigma on children with DS living in Bali, given the cultural diversity and unique social dynamics within the country. However, by the time the study was conducted, there is no validated instruments in Bahasa Indonesia was available to measure stigma toward Down syndrome in Indonesian samples.

The present study aims to fill this critical gap by developing and validating a stigma scale tailored to the Indonesian context. By doing so, Authors hope to provide a tool that will allow researchers, healthcare professionals, and policymakers to fully assess and address the stigma towards Down syndrome in Indonesia. This scale, grounded in empirical evidence and culturally sensitive considerations, will contribute to a better understanding of the factors that contribute to stigma and the design of interventions to combat it. Furthermore, the development of this scale signifies a crucial step in promoting the social inclusion and well-being of people with Down syndrome in Indonesia and similar cultural contexts.

Method

Ethical Approval

This study protocol had been approved by the Research Ethics Commission of the Faculty of Medicine of Udayana University (No: 1688/UN14.2.2.VII.14/LT/2022) before data collection was carried out. Parents of children with Down syndrome participated in the study. After obtaining information about the study from the researcher, they can express their willingness or unwillingness to participate. Parents of children with Down syndrome who consented to participate in the study then gave their written consent. After signing the informed consent form, participants can respond to the Stigma Scale for Down Syndrome using either the instrument booklet or an online form provided by the researchers.

Participants

The participants in this study consisted of parents whose children had been diagnosed with Down syndrome by physicians. These parents were registered at Sanglah Hospital Denpasar between January 1, 2017, and December 31, 2022. In addition to this, there are parents of people diagnosed with Down syndrome who are affiliated with the Association of Parents of Children with Down Syndrome (POTADS). The study involved the participation of a total of 79 fathers or mothers. All participants in the study were of Balinese ethnicity.

Scale Development

The Down Syndrome Stigma Scale is an adapted version of the Stigma on Down Syndrome Questionnaire, originally created to assess the perceptions of parents in Iran who have children diagnosed with Down syndrome. According to (Hemmati et al., 2010). The Stigma on Down Syndrome Questionnaire initially comprises 39 statements, each accompanied by five response alternatives on a Likert scale. These options include strongly disagree (score 1), disagree (score 2), neutral (score 3), agree (score 4), and strongly agree (score 5).

Procedure

There are various guidelines in adapting a scale across cultures, however no consensus could not been made (Epstein et al., 2015) therefore we should choose any adaptation method that seems the most appropriate in the context of the Down Syndrome Questionnaire. We decided to use common guidelines to conduct a cross-cultural adaptation or CCA (Epstein et al., 2015) of the Down Syndrome Questionnaire, but also considering opinion in conducting it (CCA).

First, we composed an expert panel to perform a substantial evaluation on the X. The expert panel comprised three experts representing various disciplines, specifically genetics (TIW), psychology (AE), and Balinese culture (IWS). TIW and AE speaks Indonesian and English fluently and understand both cultures, whereas IWS understand and speak Balinese very well. AE and TIW evaluated the Down Syndrome Questionnaire that was written in English and gave consideration whether the items were applicable in Indonesia culture. *Second*, a forward translation was performed so the researchers had the Indonesian translation of the scale. We decided not to conduct backward translation because it is not compulsory (Epstein et al., 2015) and due to financial constraints in the study.

Third, IWS and AE evaluated the Indonesian translation to determine whether the statements of each item were acceptable to the Balinese culture. Several items were excluded

because there were no possibilities to use in Balinese language, i.e. “Before his (her) birth, I know Mongol”, “When I hear the word “Mongol” in TV or cinema, distresses me”. The term of “mongol” is considered very rude for Balinese and there is no equivalent word for the substitution, therefore we excluded these items from the next step of CCA. Moreover, several items used the terms of “rehabilitation professionals”, “rehabilitation session” were unclearly defined the context in the Indonesian or Balinese setting, therefore we decided not to use these items. A total of 27 items were derived from the expert judgment conducted by IWS and AE.

Fourth, all panel members conducted harmonization and agreed to use the 27 items for testing in small samples. *Fifth*, we asked three parents who had children with DSD to read the instruments and asked questions if they do not understand. The pilot testing went well as all items were understood well. Thus, we decided to run a field testing on these 27 items (see Table 1). After the expert team agreed on the items to be included in the Down Syndrome Stigma Scale for testing, the next stage (6th) was to conduct field testing. We transformed all items to Google form for online data collection and format the booklet scale for offline data collection. To anticipate the willingness of the participants to answer questions on the Down syndrome stigma scale, online and offline data collection techniques were employed. For participants who are not comfortable filling out the scale online, a scale booklet is provided, while for those who prefer to use a smartphone, they can directly respond to the scale via the online form supplied.

Table 1

Down Syndrome Stigma Scale (English Translation; Prior to Field Testing)

No.	Items
1	Having a child with Down syndrome for me is a disaster.
2	Health workers did not sympathize with the birth of my child with Down syndrome.
3	After the birth of our child, I was rarely involved in various family activities.
4	I find it difficult to accept the condition of our child with Down’s Syndrome.
5	My partner finds it difficult to accept the condition of our child with Down syndrome.
6	Health workers have a negative attitude towards our child, making us reluctant to see a doctor.
7	My child’s treatment or examination at the health service makes me anxious.
8	We received unfavorable treatment when we checked our child at the health facility.
9	I feel more comfortable around other children with Down’s syndrome.
10	Thinking that children with Down syndrome are disabled makes me feel disappointed.
11	I am embarrassed to invite my child to a party organized by friends.
12	I am embarrassed to invite my child to big family events.
13	My friends have restricted themselves from asking me out after the birth of my child.
14	My friends have been negative towards me since the birth of our child.
15	My family has a negative attitude towards me since the birth of our child.
16	People’s negative attitudes make me feel depressed.
17	People’s negative attitudes make me feel disturbed.
18	I avoid my child for contact with friends/people.
19	I feel uneasy whenever I take my child to activities that involve a lot of people.
20	I feel uncomfortable with my child’s physical appearance (face shape).
21	I feel uncomfortable when people ask me why my child is different from other children in general.
22	Interaction with extended family is more difficult since the birth of our child.
23	My relationship with my partner has declined since the birth of our child.
24	Whenever I hear or read pr see photos about Down syndrome, I feel uncomfortable.
25	I feel worried when my child is in a public place.
26	I feel uncomfortable when my child is around other children with special needs.
27	I don’t like to talk about Down syndrome in family events.

The period of data collection was eight weeks. A total of 79 respondents were willing to complete the questionnaire (38 respondents completed the survey online and 41 respondents completed the scale booklet). After concluding data collection, the researcher scored the responses from the questionnaire provided by the respondents. Subsequently, the scores for each statement from each respondent were entered into an Excel file, along with data from Google Form. Next, prior to data analysis, the researcher examined the data to determine whether there was missing data. The researcher then assigns a new code number for the participants' identity and continues to the data analysis.

Statistical Analysis

The researcher performed Bartlett's test of sphericity and KMO measure of sampling adequacy (MSA) prior to conducting validity and reliability tests. If the results of Bartlett's test for sphericity are $p < .05$ and KMO MSA $> .5$, factor analysis can be performed (Santoso, 2000). The results of the analysis indicate Bartlett's sphericity test of sphericity $p < .001$ and KMO MSA ranges from .502 to .864 with an overall scale of .785. Therefore, it can be concluded that factor analysis can be performed.

To determine the structure of the scale, an exploratory factor analysis (EFA) test was performed using oblique rotation and the promax extraction method. It is anticipated that the factors that result from oblique rotation will correlate with one another. After selecting statement items with a factor load of at least 0.40 based on the EFA results, a number of factors are anticipated to be derived. The subsequent step involves conducting a reliability test on each factor (subscale) and the overall scale item. If the item coefficient is at least .30, the scale items are regarded to have acceptable validity. If the Cronbach's alpha coefficient is close to 1.0 or at least .80, the reliability is considered acceptable. These statistical calculations were performed using the JAMOVI statistical software (R Core Team, 2021). Factor loading of all items were shown in Table A1 (see Appendix).

Result and Discussion

The exploratory factor analysis (EFA) test using maximum likelihood (ML) extraction and promax rotation with factor loadings greater than .40. A total of 23 elements were extracted into three factors: social interaction (10 elements), acceptance (8 elements), and health-related factors (5 elements). There are four items that were not extracted into any factor because the factor loadings were less than .40, namely item 7 ("handling / examining my child in health services makes me anxious"), item 10 ("Considering Down syndrome children are disabled children, makes me feel disappointed"), item 21 ("I feel uncomfortable when people ask why my child is different from other children in general"), and item 27 ("I don't like to talk about Down syndrome in family events"). These four items were not included in the next analysis (reliability analysis). A total of 23 items were then included in the reliability test. Reliability tests were carried out on the items in each factor and all items in the scale. The results of the reliability test for each factor (subscale) are shown in Table A2 (Appendix).

Based on Table A2, it can be concluded that the Social Interaction Subscale consists of 10 items with good item validity ($r_{ix} = .464$ to $r_{ix} = .761$) and has a satisfactory reliability ($\alpha = .881$). The Acceptance subscale consists of 8 items with good item validity ($r_{ix} = .419$ to $r_{ix} = .732$) and has good reliability ($\alpha = .853$). Meanwhile, the subscale of Health-related factors consists of 8 items with good validity of the item ($r_{ix} = .485$ to $r_{ix} = .715$) and has good reliability ($\alpha = .821$).

The correlation analysis between the subscales showed that the social interaction factor was positively correlated with the acceptance factor ($r = .443$) and the health factors ($r = .330$). Likewise, the acceptance factor is positively correlated with health-related factors ($r = .510$). These three factors explain 48.2% of the stigma of Down syndrome. The results of reliability test of all 23 items on the Down syndrome stigma scale showed that the Down syndrome stigma scale has a relatively good item validity ($r_{ix} = .310$ to $r_{ix} = .754$) and a good scale reliability ($\alpha = .910$).

This study aims to develop an instrument to measure stigma from Down syndrome that has good validity and reliability so that it can be used in future research. Until this article was written, researchers had not found an instrument to measure stigma towards individuals with Down syndrome in Indonesian. The lack of a similar instrument has encouraged researchers to modify a similar instrument that was prepared in Iran in 2010. However, cultural differences require researchers to perform item selection first by considering the culture in Indonesia, especially Bali. From the results of the data analysis, it can be concluded that the Indonesian version of the Down Syndrome Stigma Scale consisting of 23 items has good validity and reliability as a measure.

The Indonesian version of the Down syndrome stigma scale can be used to assess stigma generally (using a total score of 23 items) or partially, by assessing stigma factors (social interaction, acceptance, and health-related factor subscales). The Social Interaction subscale contains 10 items regarding stigmatization that (might) occur when interacting with other people (i.e., friends, extended family, or public situations) where interactions with many people may occur and can cause feelings of embarrassment, social withdrawal, or social isolation. The Acceptance subscale consists of eight items on difficulties in accepting the reality of the presence of a child with Down syndrome, as well as concerns and feelings of discomfort if a child with Down syndrome experiences stigmatization. The health-related factors subscale consists of five items relating to the attitudes of health workers (doctors, nurses, or hospital staff) and events related to the birth of a child with Down syndrome. Social interaction, acceptance, and health-related factors are positively related to each other, especially aspects of acceptance and health-related factors have a stronger correlation.

The previous study emphasizes the significant impact of culture on stigma experiences and strategies to foster acceptance and belonging (Jansen-van Vuuren & Aldersey, 2020) During socialization, parents experience both negative and positive experiences. However, shame was found to be a significant barrier to social inclusion and to contribute to poor psychological health in people with intellectual disabilities (Marriott et al., 2020).

The present study confirmed the findings of previous studies reporting stigmatization by healthcare professionals against people with Down syndrome. Healthcare professionals may stigmatize people with intellectual disability (ID) based on other social identities, skepticism about community inclusion, and ambivalence about the balance of protection-or-empowerment. Stigmatization can occur on issues such as self-determination and privacy, and caregivers can stigmatize people with ID, potentially impacting the quality of support (Pelleboer-Gunnink et al., 2021). During the interaction with health professionals, parents of children with Down syndrome reported negative experiences that were associated with feelings of exclusion, negative information, and perceived lack of support (Deakin et al., 2018; Docherty & Dimond, 2018; Huiracocha et al., 2017).

The structure of the scale involving three factors in this study is different from the Iranian version of the Down syndrome Stigma Scale. On the Iranian scale, theoretical structure was used during the scale development phase, such as health professionals, interpersonal relations, acceptance towards children with Down syndrome, rehabilitation clinic, peer group (or other disabilities), social interaction, familial interaction, and mass media (Hemmati et al., 2010). Unfortunately (Hemmati et al., 2010), did not perform factor analysis to confirm the scale structure of the scale so that the results of the present study cannot be compared with the Iranian version of the Down Syndrome Stigma Scale.

The results of this study show that the Indonesian version of the Down syndrome stigma scale has good validity and reliability. However, because the study was conducted only on participants with Balinese ethnicity, subsequent research conducted on other ethnicities must first validate the scale on a group of respondents from the same ethnicity as the sample to be studied. At present, it is not possible to compare the findings reported in the study on stigma towards Balinese with Down Syndrome to similar studies from other cultures because of different

study methods. Whenever possible, future studies should carry out scale validation in a larger sample. Due to the limited instruments to reveal the stigma of Down syndrome, further research could also develop similar instruments based on the type of stigma such as public stigma, enacted stigma, self-stigmatization, and perceived stigma.

Conclusion

In this investigation, a valid and reliable Indonesian version of the Down Syndrome Stigma Scale was developed and validated. This scale, which contains a total of 23 items, can be used to obtain a general picture of the stigma experienced due to the presence of a family member with Down syndrome, or to focus on the following stigma components: the social interaction subscale (10 items), acceptance (8 items), and health-related factors (5 items). This scale can be used for further inquiry into the ethnicity of the Balinese. Validity and reliability evaluations are required for research on other ethnicities.

Conflict of Interest

The authors declare no conflict of interest.

Acknowledgement

We express our sincere gratitude to all those who participated in the study and were registered as patients at The Sanglah General Hospital or affiliated with the POTADS group. The researcher (NWS) expressed gratitude to Sanglah General Hospital for funding the study.

References

- Andrewin, A., & Chien, L. Y. (2008). Stigmatization of patients with HIV/AIDS among doctors and nurses in Belize. *AIDS Patient Care and STDs*, 22(11), 897–906. <https://doi.org/10.1089/apc.2007.0219>
- Ariani, Y., Soeharso, P., Sjarif, D. R. (2017). Genetics and genomic medicine in Indonesia. *Molecular Genetics and Genomic Medicine*, 5(2), 103–109. <https://doi.org/10.1002/mgg3.284>
- Bull, M. J., Saal, H. M., Braddock, S. R., & Enns, G. M. (2011). Clinical report - health supervision for children with Down syndrome. *Pediatrics*, 128(2), 393–406. <https://doi.org/10.1542/peds.2011-1605>
- Chen, L., Wang, L., Wang, Y., & Hu, H. (2022). Global, regional, and national burden and trends of Down syndrome from 1990 to 2019. *Frontiers in Genetics*, 13(July), 1–14. <https://doi.org/10.3389/fgene.2022.908482>
- De Amorim, B. Y. F., & Shimizu, H. E. (2022). Stigma, caregivers and the child with Down syndrome: A bioethical analysis. *Revista Bioetica*, 30(1), 72–81. <https://doi.org/10.1590/1983-80422022301508PT>
- Deakin, K., Moore, D. G., & Jahoda, A. (2018). Children and young people with Down syndrome: Their awareness of Down syndrome and developing self-perceptions. *Journal of Applied Research in Intellectual Disabilities*, 31(6), 1197–1208. <https://doi.org/10.1111/jar.12494>
- Docherty, F., Dimond, R. (2018). “Yeah that made a big difference!”: The importance of the relationship between health professionals and fathers who have a child with Down syndrome. *Journal of Genetic Counseling*, 27(3), 665–674. <https://doi.org/10.1007/s10897-017-0171-y>
- Epstein, J., Santo, R. M., & Guillemin, F. (2015). A review of guidelines for cross-cultural adaptation of questionnaires could not bring out a consensus. *Journal of Clinical Epidemiology*, 68(4), 435–441. <https://doi.org/10.1016/j.jclinepi.2014.11.021>
- Hemmati, S., Solemani, F., Seyednour, R., Dadkhah, A. (2010). Stigma in Iranian Down syndrome. In *Iranian Rehabilitation Journal Original Article* 8(11). <http://irj.uswr.ac.ir/article-1-87-en.html>

- Huiracocha, L., Almeida, C., Huiracocha, K., & Arteaga, J. (2017). Parenting children with Down syndrome: Societal influences. *Journal of Child Health Care*, 21(4), 488–497. <https://doi.org/10.1177/1367493517727131>
- Jansen-van Vuuren, J., & Aldersey, H. M. (2020). Stigma, acceptance and belonging for people with IDD across cultures. *Current Developmental Disorders Reports*, 7(3), 163–172. <https://doi.org/10.1007/s40474-020-00206-w>
- Lai, Y. M., Hong, C. P., Chee, C. Y., & Registrar, Mm., (2000). Stigma of mental illness. *Singapore medical journal*, 42(3), Article 11405561.
- Ly, T. M. (2008). Asian American parents' attributions of children with Down syndrome: connections with child characteristics and culture. *Intellectual And Developmental Disabilities*. 46. [https://doi.org/10.1352/0047-6765\(2008\)46\[129:aapaoc\]2.0.co;2](https://doi.org/10.1352/0047-6765(2008)46[129:aapaoc]2.0.co;2)
- Maritska, Z., Abdurrahman, F., Prananjaya, B. A., Parisa, N., Syifa, S., Triwani, T. (2018). Down syndrome: Through the eyes of the parents. *Jurnal Kedokteran dan Kesehatan: Publikasi Ilmiah Fakultas Kedokteran Universitas Sriwijaya*, 5(3), 138–142. <https://doi.org/10.32539/jkk.v5i3.6316>
- Marriott, C., Parish, C., Griffiths, C., & Fish, R. (2020). Experiences of shame and intellectual disabilities: Two case studies. *Journal of Intellectual Disabilities*, 24(4), 489–502. <https://doi.org/10.1177/1744629519844091>
- McLaughlin, K. A., Hatzenbuehler, M. L., Keyes, K. M. (2010). Responses to discrimination and psychiatric disorders among black, Hispanic, female, and lesbian, gay, and bisexual individuals. *American Journal of Public Health*, 100(8), 1477–1484. <https://doi.org/10.2105/AJPH.2009.181586>
- Mitter, N., Ali, A., Scior, K. (2019). Stigma experienced by families of individuals with intellectual disabilities and autism: A systematic review. *Research in Developmental Disabilities*, 89(August 2017), 10–21. <https://doi.org/10.1016/j.ridd.2019.03.001>
- Mukolo, A., Heflinger, C. A., Wallston, K. A. (2010). The stigma of childhood mental disorders: A conceptual framework. *Journal of the American Academy of Child and Adolescent Psychiatry*, 49(2), 92–103. <https://doi.org/10.1097/00004583-201002000-00003>
- Pelleboer-Gunnink, H. A., van Oorsouw, W. M. W. J., van Weeghel, J., & Embregts, P. J. C. M. (2021). Stigma research in the field of intellectual disabilities: A scoping review on the perspective of care providers. *International Journal of Developmental Disabilities*, 67(3), 168–187. <https://doi.org/10.1080/20473869.2019.1616990>
- Pescosolido, B. A., Martin, J. K., Lang, A., & Olafsdottir, S. (2008). Rethinking theoretical approaches to stigma: A framework integrating normative influences on stigma (FINIS). *Social Science and Medicine*, 67(3), 431–440. <https://doi.org/10.1016/j.socscimed.2008.03.018>
- Rohwerder, B. (2018). Disability stigma in developing countries *K4D Helpdesk Report. Brighton*. Institute of Development Studies <https://www.ids.ac.uk/publications/disability-stigma-in-developing-countries/>
- Szumski, G., Smogorzewska, J., Grygiel, P. (2020). Attitudes of students toward people with disabilities, moral identity and inclusive education—A two-level analysis. *Research in Developmental Disabilities*, 102(April). <https://doi.org/10.1016/j.ridd.2020.103685>
- Van Riper, M., Knafl, G. J., Barbieri-Figueiredo, M. do C., & Caples, M. (2021). Measurement of family management in families of individuals with Down syndrome: A cross-cultural investigation. *Journal of Family Nursing*, 27(1), 8–22. <https://doi.org/10.1177/1074840720975167>
- Patrick W., Corrigan, & Watson A. C., (2002). Impact of stigma on people with mental illness. *World Psychiatry*, 1(1), 1–5. <https://pubmed.ncbi.nlm.nih.gov/16946807>
- Yin, M., Li, Z., & Zhou, C. (2020). Experience of stigma among family members of people with severe mental illness: A qualitative systematic review. *International Journal of Mental Health Nursing*, 29(2), 141–160. <https://doi.org/10.1111/inm.12668>

Appendix A: Result

Table A1
Factor Loadings of All Items

Items	Factor 1 Social interaction	Factor 2 Acceptance	Factor 3 Health-related Factor	Uniqueness
1		.556		.581
2			.656	.451
3	.522			.605
4		.632		.452
5		.709		.290
6			.560	.463
7				.932
8			.456	.738
9		.488		.609
10				.783
11	.573			.388
12	.644			.442
13	.594			.642
14	.740		.506	.217
15	.849		.429	.158
16	.761			.402
17	.465			.805
18	.693	.407		.273
19	.425			.734
20		.697		.276
21				.626
22			.743	.444
23			.801	.336
24		.757		.401
25		.414		.805
26		.615		.519
27				.611

Table A2
Item and Subscale Reliability Statistics

Factors / Subscale	Items	Item Reliability Statistics				Cronbach's α Subscale Reliability
		Mean	SD	Item-rest Correlation	Cronbach's α if Item Dropped	
Social interaction	3	1.76	0.788	.578	.872	.881
	11	1.63	0.603	.661	.866	
	12	1.62	0.685	.637	.867	
	13	1.91	0.819	.570	.873	
	14	1.70	0.515	.660	.868	
	15	1.71	0.535	.714	.865	
	16	1.91	0.701	.761	.858	
	17	2.04	0.854	.464	.883	
	18	1.73	0.655	.731	.861	
19	1.87	0.806	.501	.879		
Acceptance	1	1.87	0.966	.614	.834	.853
	4	1.91	0.950	.533	.844	
	5	1.77	0.697	.732	.825	
	9	2.13	0.822	.599	.835	
	20	1.72	0.598	.722	.830	
	24	2.04	0.884	.726	.820	
	25	2.68	1.225	.419	.871	
	26	2.00	0.816	.650	.830	
Health- related factor	2	1.97	0.751	.618	.786	.821
	6	1.75	0.630	.715	.759	
	8	1.87	0.723	.485	.826	
	22	1.96	0.688	.588	.794	
	23	1.85	0.601	.704	.765	

Note. 'Maximum likelihood' extraction method was used in combination with a 'promax' rotation