

INTERNATIONAL JOURNAL OF
EDUCATION, PSYCHOLOGY
AND COUNSELLING
(IJEPC)<https://gaexcellence.com/ijepe>THE RELATIONSHIP OF AFFILIATE STIGMA AND
PSYCHOLOGICAL WELL-BEING ON PARENTS OF
CHILDREN WITH DOWN SYNDROMENur Farah Aqila Mohd Radzi¹, Nurul Ku Harmila Abdul Zalif^{2*}, Noor Amiera Alias³¹Centre of Occupational Therapy, Faculty of Health Sciences, University Technology Mara Puncak Alam, Selangor, Malaysia. nurfarahaqila.radzi@gmail.com <https://orcid.org/0009-0009-7873-1114>²Centre of Occupational Therapy, Faculty of Health Sciences, University Technology Mara Puncak Alam, Selangor, Malaysia. kuharmila@uitm.edu.my <https://orcid.org/0009-0006-5581-4919>³Centre of Occupational Therapy, Faculty of Health Sciences, University Technology Mara Puncak Alam, Selangor, Malaysia. nooramiera@uitm.edu.my <https://orcid.org/0000-0003-4321-0887>

*Corresponding Author

Article Info:**Article history:**

Received date: 30.07.2026

Revised date: 13.08.2026

Accepted date: 30.08.2026

Published date: 14.09.2026

To cite this document:

Radzi, N. F. A. M., Zalif, N. K. H. A., & Alias, N. A. (2026). The Relationship of Affiliate Stigma and Psychological Well-Being on Parents of Children with Down Syndrome. *International Journal of Education, Psychology and Counselling*, 11(64), 716-731.

Abstract:

Down Syndrome is a genetic condition caused by the presence of an extra chromosome 21, which affects the intellectual and developmental abilities of individuals and presents unique challenges for their caregivers. Parents of children with Down Syndrome often face not only caregiving demands but also social stigma, which may lead to internalized or affiliate stigma. This study aimed to examine the relationship between affiliate stigma and psychological well-being among parents of children with Down Syndrome. A quantitative, cross-sectional survey design was employed, with data collected from 100 parents registered with Persatuan Sindrom Down Malaysia (PSDM) across six states via an online questionnaire comprising the Affiliate Stigma Scale (ASS) and the Psychological Well-Being Scale (PWB). Findings revealed a significant negative relationship between affiliate stigma and psychological well-being ($r = -0.679$, $p < .001$), indicating that parents who experienced higher affiliate stigma tended to report lower psychological well-being. Significant differences in affiliate stigma were observed according to parental age and household income, with parents aged 26–35 years reporting higher affiliate stigma than those aged 36–45 and 46–55 years, while parents from households earning above RM11,820 reported lower affiliate stigma than those in lower-income groups. No significant differences were found according to employment status, child gender, child age, or parental relationship

to the child. These findings indicate that younger parents and parents from lower-income households may require greater psychosocial support to address affiliate stigma and promote psychological well-being. Therefore, targeted group support programmes should be developed to provide these parents with opportunities to share experiences, access peer support, and develop effective coping strategies for managing stigma associated with raising a child with Down Syndrome.

DOI: 10.35631/IJEPC.1164035

Keyword:

Affiliate Stigma, Down Syndrome, Psychological Well Being



© The authors (2026). This is an Open Access article distributed under the terms of the Creative Commons Attribution (CC BY NC) (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited. For commercial re-use, please contact ijepec@gaexcellence.com.

Introduction

Down Syndrome (DS) is the most common chromosomal disorder globally, caused by an extra copy of chromosome 21, resulting in varying degrees of intellectual and developmental disabilities (Antonarakis et al., 2020). Down Syndrome (DS) affects approximately 1 in 1,000 live births globally, while in Malaysia the occurrence is about 1 in 950 live births, with maternal age above 35 years constituting a well-established risk factor (Attali & Yogev, 2020). In Malaysia, DS is the common chromosomal cause of intellectual disability and other developmental issues, placing considerable caregiving demands on parents and families (Norizan & Shamsuddin, 2010). Other than difficulties experienced during caregiving, family members of children with Down Syndrome highlight the stigmatization experienced. This societal stigma arises from various factors, mainly from communities or neighbours who judge the parents based on their children's physical appearance and behavior (Eleptico et al., 2024). Usually, children with Down Syndrome have specific facial attributes. These include small, formed ears, small nose, an upward slant of palpebral fissures, mid-face hypoplasia, and a small oral cavity with a narrow palate (Agbolade et al., 2020). People may become socially distant from someone who has Down syndrome because of these distinctive physical traits, which can make them appear noticeably different from others and even physically unappealing to some (Agbolade et al., 2020).

Crucially, social implications of these obvious variations in children's behavioral and physical characteristics may not only affect the person with Down syndrome but also those who are close to them, especially their parents. Parents of children with Down Syndrome are not immune to the societal stigma that they encounter in their daily lives. In public, parents are

frequently criticised for their perceived lack of expertise or competence in addressing their children's socially inappropriate behaviour (Werner & Shulman, 2013). Affiliate stigma is the process by which individuals closely associated with a stigmatized person internalize the

courtesy stigma prevalent in society (Mak & Cheung, 2008). Unlike public stigma, which targets individuals with a disability directly, affiliate stigma is absorbed by family members and caregivers through prolonged exposure to societal judgement and blame (Ali et al., 2012). Due to these difficulties, parents of children with disabilities are more likely to experience mental and physical health problems than parents of typically developing children (Song et al., 2018).

According to Ryff (1989), PWB, or Psychological Well-Being, incorporates six interrelated dimensions which are personal growth, positive relations with others, autonomy, environmental mastery, purpose in life, and self-acceptance. Caregiving responsibilities related to intellectual disability have been shown to negatively impact parental Psychological Well-Being, and affiliation stigma has been found to be a particularly strong predictor of psychological distress (Werner & Shulman, 2013). Despite this research, nothing is known about the relationship between affiliate stigma and PWB in the Southeast Asian context, where socioeconomic inequality, cultural issues, and religious views may greatly influence the stigma experience.

Internalized stigma and its psychological effects have received little attention in Malaysian research on parental stress associated with Down Syndrome children, which has mostly concentrated on caregiving burden and service utilization (Norizan & Shamsuddin, 2010; Bahry et al., 2019). This gap is clinically significant because, to create successful, culturally sensitive psychosocial therapies, occupational therapists and other allied health professionals who work with families of children with DS need to have a solid grasp of stigma-related suffering information.

Accordingly, this study aimed to: (1) determine the status of affiliate stigma and psychological well-being among parents of children with Down Syndrome (2) examine the relationship between affiliate stigma and psychological well-being of the parents and (3) identify significant differences in affiliate stigma based on sociodemographic variables, including parental age, employment status, household income, child gender, child age, and parental relationship to the child. The findings are expected to contribute to the new knowledge regarding challenges faces by the parents of children with Down syndrome.

Literature Review

Down Syndrome and Parental Caregiving

DS is the most prevalent genomic disorder associated with intellectual disability, resulting from trisomy of Homo sapiens chromosome 21 (HSA21). Down Syndrome children present with physical features, mild to moderate intellectual disability, and a heightened susceptibility to comorbid health conditions, including congenital cardiac defects and hypothyroidism (Antonarakis et al., 2020). Beyond medical management, children with DS frequently exhibit repetitive and stereotyped behaviours, which are observed in approximately 40% of children aged 3 to 10 years and are particularly salient in public settings (Fucà & Vicari, 2024). These behavioral manifestations frequently draw unfavorable attention from society, which significantly increases the stigma experienced by caregivers. (Patel et al., 2018).

Parents of children with Down syndrome deal with a variety of difficulties in the social, emotional, financial, and physical areas. Parents are more likely to experience chronic stress, depression, and a lower quality of life due to the caregiving trajectory, which is marked by persistent demands that last well beyond childhood (Song et al., 2018). Additional contextual stressors, such as financial strain from frequent healthcare visits, a lack of specialized treatments in rural locations, and cultural expectations surrounding family responsibilities, have been identified by a Malaysian study (Norizan & Shamsuddin, 2010)

Affiliate Stigma: Conceptualization and Components

Stigma, as defined by Corrigan (2000), encompasses stereotyping, prejudice, and discrimination embedded within social structures. Researchers have identified four major stigma types: public stigma, self-stigma, associative stigma, and affiliate stigma (Corrigan & Watson, 2002; Mak & Cheung, 2008). Affiliate stigma is a conceptual evolution of associative stigma and refers to the negative societal appraisals by individuals closely associated with a stigmatized person, predominantly family (Mak & Cheung, 2008; Ali et al., 2012).

Mak and Cheung (2008) explain affiliate stigma across three psychological domains: (1) the cognitive domain, involving perceived discrimination and negative self-appraisals arising from societal labelling; (2) the affective domain, encompassing shame, embarrassment, helplessness, and emotional distress; and (3) the behavioural domain, expressed through social withdrawal, concealment of the child's condition, and reduced public engagement.

Affiliate Stigma and Psychological Well-Being

Various caregiver groups have been investigated in connection to affiliation stigma and psychological well-being. According to Shukla (2021), siblings of people with intellectual impairments who were subjected to more associated stigma reported considerably higher levels of anxiety, depression, and lower PWB scores. In a scoping assessment of caregivers of people with neurodegenerative illnesses, Becerra et al. (2024) found a strong correlation between increased affiliate stigma and higher caregiver burden, worse mental health outcomes, and lower quality of life.

Importantly, several aspects of Ryff's PWB paradigm seem to be compromised by affiliate stigma. Parental autonomy and self-acceptance are undermined by internalized societal judgment, and positive relationships with others and environmental mastery are restricted by the social isolation that follows stigma (Mak & Cheung, 2008; Hameed & SuphalaKotian, 2023). On the other hand, other research indicates that when parents grow resilient as a result of their experiences, caregiving difficulties may paradoxically promote personal development and an increased feeling of purpose (Findler et al., 2016).

Sociodemographic Influences on Affiliate Stigma

The stigma experience is significantly shaped by sociodemographic characteristics. Because they have fewer coping mechanisms and are more vulnerable to peer criticism, younger parents typically report higher levels of affiliate stigma (Mak & Kwok, 2010). Other than that, lower household income has been associated with heightened stigma internalization, as financial hardship compounds caregiving stress and restricts access to support services (Ali et al., 2012; Inglis et al., 2025). Due to their major caregiving responsibilities and societal expectations of

maternal competence, women have historically reported higher levels of stigma (Mak & Cheung, 2008). However, there is still conflicting research about how child-related factors, including the child's age and gender, affect parental affiliate stigma (Werner & Shulman, 2013; Mitter et al., 2019).

Material and Methods

The study design was a cross-sectional study in which to determine to examine the relationship between affiliate stigma and psychological well-being among parents of children with Down Syndrome in Malaysia. The participants of the study were parents of children with Down Syndrome who were registered with six branches of Persatuan Sindrom Down Malaysia (PSDM), namely Kuala Lumpur, Selangor, Putrajaya, Melaka, Perak, and Kedah. Participants were collected in this study using purposive sampling. Purposive sampling was used to recruit parents of children with Down Syndrome who met the predetermined inclusion criteria.

They were included in the study if they possessed the following criteria; (a) parents of children with Down Syndrome aged between 1 and 18 years, and (b) registered with Persatuan Sindrom Down Malaysia. They were excluded if (a) their child was living with someone other than the parents, or (b) the parent had a chronic medical illness that could potentially influence psychological well-being.

An online survey using social networks was used to distribute a set of online questions. Section A collected demographic information, including the child's age, gender, employment status, household income, relationship to the child, and participants' gender. Section B consisted of the 22-item Affiliate Stigma Scale (ASS) developed by Mak and Cheung (2008), which measures affiliate stigma across cognitive, affective, and behavioural domains using a four-point Likert scale. Section C consisted of the 18-item Ryff Psychological Well-Being Scale (Ryff & Keyes, 1995), which assesses six dimensions of psychological well-being using a seven-point Likert scale. Both instruments have demonstrated satisfactory validity and reliability in previous studies

Affiliate Stigma Scale (ASS)

The 22-item ASS developed by Mak and Cheung (2008) was used to measure affiliate stigma across three domains: cognitive (7 items), affective (7 items), and behavior (8 items). Items were rated on a 4-point Likert scale (1 = strongly disagree, 4 = strongly agree), with higher scores indicating greater affiliate stigma. Terminology was minimally adapted to suit parents of children with DS (e.g., replacing "person with intellectual disability" with "child with intellectual disability"). The original scale demonstrated excellent reliability (Cronbach's $\alpha = 0.95$). A validated Malay version of the scale has been established in Malaysian clinical settings (Yun et al., 2018).

Ryff Psychological Well-Being Scale (PWB)

The abbreviated 18-item version of the Ryff PWB Scale (Ryff & Keyes, 1995) was employed, assessing six domains: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance (three items each). Items were scored on a 7-point Likert scale (1 = strongly agree; 7 = strongly disagree), with higher scores reflecting greater psychological well-being. The scale has demonstrated robust internal consistency

(Cronbach's $\alpha = 0.86\text{--}0.93$) and strong convergent validity with self-esteem and life satisfaction measures (Akin, 2008).

Data Collection Procedure

Ethical approval was obtained and participants were recruited by PSDM branch coordinators. An online survey was disseminated through Google forms that included the PWB scale, ASS and demographic questionnaire. A participant information page was given and informed consent obtained electronically before completion of the questionnaire. One hundred valid replies were obtained from data collection.

Data Analysis

IBM SPSS Statistics Version 26.0 was used to analyse all of the data. To achieve the first two goals, descriptive statistics (means and standard deviations) were calculated. The relationship between affiliate stigma and psychological well-being was investigated using Pearson correlation. To find demographic differences in affiliate stigma are independent sample t-tests and one-way ANOVA with Tukey HSD post hoc tests were performed.

Ethical Considerations

The Universiti Teknologi MARA (UiTM) Research Ethics Committee gave ethical approval under reference number FERC/FSK/MR/2024/00378. Every respondent gave their informed consent, and participation was entirely voluntary. Anonymity and confidentiality were rigorously upheld during the whole investigation.

Results

Demographic Profile

Table 1 presents the sociodemographic characteristics of the 100 participants. The majority were aged 36 to 45 years ($n = 43, 43.0\%$), followed by those aged 26 to 35 years ($n = 29, 29.0\%$). Most were employed full-time (69.0%), with the largest proportion reporting a household income of RM 5,250 to RM 11,819 ($n = 36, 36.0\%$). The sample comprised nearly equal proportions of parents of male ($n = 49, 49.0\%$) and female ($n = 51, 51.0\%$) children with DS. Mothers constituted the primary respondent group ($n = 84, 84.0\%$).

Table 1: Demographic Profile of Respondents (N = 100)

Variable	Category	n	%
Age of Respondent	26–35	29	29.0
	36–45	43	43.0
	46–55	25	25.0
	56–60	3	3.0
Employment Status	Full-Time	69	69.0

	Part-Time	8	8.0
	Unemployed	23	23.0
Household Income	< RM 2,560	16	16.0
	RM 2,561–RM 5,249	31	31.0
	RM 5,250–RM 11,819	36	36.0
	> RM 11,820	17	17.0
Gender of Child	Male	49	49.0
	Female	51	51.0
Relationship to Child	Father	16	16.0
	Mother	84	84.0

Affiliate Stigma

Descriptive analysis revealed the total mean domain score of affiliate stigma among participants ($M = 1.68$, $SD = 0.59$). Among the three domains, the affective dimension yielded the highest mean score ($M = 1.85$, $SD = 0.65$), followed by the behavioral ($M = 1.60$, $SD = 0.62$) and cognitive domains ($M = 1.59$, $SD = 0.63$), as presented in Table 2. These scores suggest that emotional responses such as shame, embarrassment, and distress constituted the most prominent manifestation of affiliate stigma, while stigma-related cognitions were comparatively less reported.

Table 2: Descriptive Statistics of Affiliate Stigma Scores by Domain (N = 100)

Domain	Mean (M)	Standard Deviation (SD)
Affective	1.85	0.65
Behavior	1.60	0.62
Cognitive	1.59	0.63
Total Affiliate Stigma	1.68	0.59

Psychological Well-Being

The overall mean score for psychological well-being was 4.93 ($SD = 0.81$). The personal growth domain recorded the highest mean score ($M = 5.64$, $SD = 1.03$). The lowest mean was observed in the positive relations with others domain ($M = 4.60$, $SD = 1.13$). Full domain-level results are provided in Table 3.

Table 3: Descriptive Statistics of Psychological Well-Being Scores by Domain (N = 100)

Domain	Mean (M)	Standard Deviation (SD)
Autonomy	4.67	1.11
Environmental Mastery	4.91	1.05
Personal Growth	5.64	1.03
Positive Relations with Others	4.60	1.13
Purpose in Life	4.76	0.85
Self-Acceptance	4.97	1.10
Total Psychological Well-Being	4.93	0.81

Relationship Between Affiliate Stigma and Psychological Well-Being

Table 4.4 showed a significant negative correlation ($r = -0.68$, $p < 0.001$), indicating that higher levels of affiliate stigma correlated with lower psychological well-being among parents of children with Down Syndrome

Table 4: Pearson Correlation Between Affiliate Stigma and Psychological Well-Being (N = 100)

Variable	1. Affiliate Stigma	2. Psychological Well-Being
1. Affiliate Stigma	—	-0.68**
2. Psychological Well-Being	-0.68**	—

** $p < .001$ (2-tailed).

Differences in Affiliate Stigma by Sociodemographic Variables

Table 5 summarizes the results of one-way ANOVA and independent t-test analyses examining sociodemographic differences in affiliate stigma.

Table 5: Summary of Sociodemographic Comparisons of Affiliate Stigma (N = 100)

Variable	Groups	Mean (SD)	Statistic	p-value
Age of Respondent	26–35 (n=29)	2.02 (0.72)	F(3,96)=5.36	.002
	36–45 (n=43)	1.56 (0.48)		
	46–55 (n=25)	1.48 (0.43)		
	56–60 (n=3)	1.73 (0.51)		

Employment Status	Full-Time (n=69)	1.73 (0.57)	F(2,97)=1.07	.35
	Part-Time (n=8)	1.47 (0.48)		
	Unemployed (n=23)	1.59 (0.65)		
Household Income	< RM2,560 (n=16)	1.91 (0.69)	F(3,96)=6.05	< .001
	RM2,561–RM5,249 (n=31)	1.85 (0.67)		
	RM5,250–RM11,819 (n=36)	1.64 (0.45)		
	> RM11,820 (n=17)	1.22 (0.24)		
Gender of Child	Male (n=49)	1.66 (0.53)	t(98)=−0.34	.73
	Female (n=51)	1.70 (0.64)		
Age of Child	1–3 yrs (n=26)	1.62 (0.69)	F(3,96)=0.30	.83
	4–6 yrs (n=24)	1.66 (0.56)		
	7–12 yrs (n=30)	1.67 (0.49)		
	13–18 yrs (n=20)	1.78 (0.64)		
Relationship to Child	Father (n=16)	1.77 (0.42)	t(98)=0.69	.49
	Mother (n=84)	1.66 (0.61)		

A one-way ANOVA revealed a statistically significant difference in affiliate stigma across age groups, $F(3, 96) = 5.36$, $p = .002$, $\eta^2 = 0.14$ (moderate effect). Post hoc Tukey HSD comparisons indicated that parents aged 26–35 years ($M = 2.02$, $SD = 0.72$) reported significantly higher affiliate stigma than those aged 36–45 years ($M = 1.56$, $SD = 0.48$) and 46–55 years ($M = 1.48$, $SD = 0.43$). Affiliate stigma also differed significantly across household income groups, $F(3, 96) = 6.05$, $p < .001$, $\eta^2 = 0.16$ (moderate effect). Post hoc analysis identified the highest income group ($>RM 11,820$; $M = 1.22$, $SD = 0.24$) as reporting significantly lower affiliate stigma than all lower-income groups. No significant differences were detected for employment status, child gender, child age, or parental relationship to the child (all $p > .05$).

Discussion

Affiliate Stigma

This study's affiliate stigma domain score ($M = 1.68$, $SD = 0.59$) is consistent with results from similar demographics. The most prevalent aspect of affiliate stigma was found to be the affective domain, which reflects the importance of guilt, embarrassment, and emotional

suffering in Malaysian caregivers' experiences with stigma. This pattern is in line with the findings of Adithyan and Jacob (2017), who found that embarrassment was the main stigma response for more than half of Indian parents of children with intellectual disabilities, and Samsuddin et al. (2025), who found that negative emotional reactions were the main cause of parental distress in Malaysian families dealing with stigma related to disabilities.

There may be some adaptive resilience among Malaysian parents based on their somewhat lower results in the behavioral and cognitive categories. This could be partially explained by the cultural and religious background of Malaysian society, where faith-based coping and extended family networks may mitigate stigmatizing behaviors like social disengagement and concealment even in the presence of emotional distress. Werner and Shulman (2015), who discovered cross-cultural diversity in how stigma emerges across domains, with behavioral reactions more prevalent in Western populations, lend support to this hypothesis. These results highlight the significance of addressing the emotional aspects of affiliate stigma in caregiver support programs rather than concentrating just on behavioral outcomes from the standpoint of occupational therapy.

Psychological Well-Being

Given the difficulties of raising a kid with Down syndrome, the psychological well-being scores found in this study ($M = 4.93$, $SD = 0.81$) are notable. Findler et al. (2016) reported increased meaning and purpose among mothers of children with disabilities, which is consistent with the idea of post-traumatic growth. The elevated personal growth scores ($M = 5.64$) indicate that many parents experience meaningful psychological development through their caregiving roles.

On the other hand, positive relationships with others had the lowest PWB domain score ($M = 4.60$), indicating issues maintaining friendly, dependable interpersonal relationships. This result is in line with previous research that connects caregiver stigma to decreased social support and social isolation (Githara et al., 2020; Tinago et al., 2021). The relational things that promote caregiver well-being may gradually be undermined by social withdrawal, a behavioral manifestation of affiliate stigma, resulting in a vicious cycle of stigma and isolation. Occupational therapists are in a unique position to break this cycle by reconnecting parents with supporting networks through social engagement programs, peer support facilitation, and community integration initiatives.

Relationship Between Affiliate Stigma and Psychological Well-Being

The study's most clinically important finding is the substantial negative connection ($r = -0.68$, $p < .001$) between affiliate stigma and psychological well-being. Werner and Shulman (2013) found similar unfavorable relationships in a sample of family caregivers of people with developmental disabilities in Israel, which is consistent with our conclusion. Similarly, Zhang et al. (2018) found affiliate stigma to be a major determinant of quality of life across all domains in Singaporean caregivers of people with mental illness, while Zhou et al. (2018) showed that affiliate stigma was a significant predictor of depression in Chinese caregivers of children with autism.

Affiliate stigma may relate to environmental mastery by increasing caring demands, limiting positive relationships through social disengagement, and reducing parental autonomy and self-acceptance through internalizing societal judgments (Mak & Cheung, 2008; Becerra et al., 2024). The current research indicates that these processes function similarly among Malaysian parents of children with Down syndrome, supporting the affiliate stigma construct's cross-cultural applicability. Clinically, these findings support the inclusion of stigma reduction techniques such as community programs, psychoeducation, and group-based support in occupational therapy service delivery as well as the regular screening of affiliate stigma in caregiver assessments.

Sociodemographic Differences in Affiliate Stigma

Affiliate stigma differed significantly across parental age groups, with parents aged 26–35 years reporting higher stigma than those aged 36–45 and 46–55 years. This finding aligns with Mak and Kwok's (2010) assertion that younger caregivers possess fewer coping resources and are more susceptible to peer and community judgment. Younger parents may still be navigating the emotional adjustment to their child's diagnosis, rendering them more vulnerable to stigma internalization during a critical and emotionally demanding phase. Additionally, younger parents may occupy social environments such as active career networks and peer social circles where the stigma associated with disability is more acutely felt. These findings have direct implications for early intervention: psychosocial support and stigma-informed psychoeducation should be prioritized for parents at or near the time of diagnosis.

Affiliate stigma also differed significantly across household income groups, with parents in the highest income reported markedly lower affiliate stigma than those in lower-income groups. This pattern likely reflects the protective effects of financial security, including greater access to mental health resources, inclusive educational services, and professional support networks that mitigate stigma exposure and facilitate healthier coping (Ali et al., 2012; Inglis et al., 2025). Conversely, financial hardship amplifies the emotional burden of caregiving, limits social participation, and may intensify feelings of inadequacy and shame. The findings are consistent with Hastings et al. (2005) and Bunning et al. (2020), who identified socioeconomic disadvantage as a key risk factor for elevated parental stress and stigma in families of children with disabilities. These results emphasize the necessity of equitable access to caregiver support services, with targeted programs for economically disadvantaged families.

The absence of significant differences in affiliate stigma based on employment status, child gender, child age, and parental relationship to the child provides important contextual clarity. The non-significance of employment status suggests that paid employment does not inherently shield caregivers from stigma, as workplace environments may themselves be sites of stigmatizing experiences (Schnyder et al., 2017). The uniform affiliate stigma across child gender and age groups indicates that the DS diagnosis itself, rather than child-specific characteristics, is the primary driver of caregiver stigma experience a finding consistent with Werner and Shulman (2013) and Mak and Cheung (2008). Similarly, the equivalent stigma levels reported by mothers and fathers challenge traditional assumptions that maternal caregivers bear a disproportionate stigma burden, potentially reflecting evolving co-parenting norms in contemporary Malaysian families.

Implications for Occupational Therapy Practice

The findings have significant implications for occupational therapy practice, as occupational therapists always work with families. It is important for Occupational therapists working with families of children with DS to regularly assess the impact of affiliate stigma on the psychological health of parents. There is also a need for campaigns for community education to reduce public stigma and its downstream effects on affiliate stigma. Moreover, the socioeconomic disparity in stigma and well-being highlights the need for occupational therapists to advocate for equitable service provision to facilitate access to practical and psychosocial support services for young parents and those with low income.

Conclusion

This study shows that parents of children with Down syndrome in Malaysia experience considerable stigma. Higher levels of affiliate stigma were correlated with poorer levels of psychological well-being. Parental age and household income also had a substantial impact on affiliate stigma, with younger parents and those from lower-income families reporting higher levels of affiliate stigma. These results emphasize the need to acknowledge affiliate stigma as a pertinent psychosocial issue among parents of children with Down syndrome and the necessity of providing suitable assistance to address stigma-related experiences in the Malaysian setting.

The practice of occupational therapy and allied health is significantly impacted by these findings. In addition to creating stigma-informed, family-centered therapies that address the emotional and social aspects of the stigma experience, clinicians are urged to regularly check for affiliate stigma in caregiver assessments. Equal access to psychosocial assistance should be a top priority for families with recent diagnoses and those from low-income backgrounds.

There are a few limitations to be aware of. The sample's generalizability to unregistered caregivers and those in underprivileged areas was limited because it only included PSDM-registered parents from six states. Self-report techniques are vulnerable to social desirability bias, and the cross-sectional design prevents causal inference. In order to document changes in stigma and well-being over time and investigate mediating factors including social support, coping mechanisms, and service accessibility, future studies should use longitudinal designs and mixed methods approaches. The evidence base for caregiver-focused interventions would be strengthened by expanding recruitment to encompass a variety of Malaysian geographic and cultural contexts.

-
- Acknowledgements:** The authors express sincere gratitude to Persatuan Sindrom Down Malaysia (PSDM) and all participating parents for their invaluable contributions to this research. The authors also acknowledge the Faculty of Health Sciences, Universiti Teknologi MARA (UiTM), for institutional support.
- Funding Statement:** No external funding was received for this research. This study was conducted as part of an undergraduate thesis requirement at Universiti Teknologi MARA (UiTM).
- Conflict of Interest Statement:** The authors declare that there is no conflict of interest regarding the publication of this manuscript. All authors have reviewed and approved the final version for submission.
- Ethics Statement:** This study was conducted in accordance with ethical research standards. Ethical approval was granted by the Research Ethics Committee of Universiti Teknologi MARA (UiTM) under reference number FERC/FSK/MR/2024/00378. Informed consent was obtained from all participants prior to data collection. Participation was voluntary, and respondents were assured of full confidentiality and anonymity. All data collected were used solely for academic research purposes.
- Author Contribution Statement:** All authors read and approved the final version prior to submission.
-

References

- Abeasi, D. A., Nkosi, N. G., Suglo, J. N., & Badoe, E. (2024). Caring by default: Experiences of caregivers of children with developmental disabilities in Ghana in the context of the Stress Process Model. *BMC Nursing*, 23, Article 482. Doi: <https://doi.org/10.1186/s12912-024-02140-z>
- Agbolade, O., Nazri, A., Yaakob, R., Ghani, A. A., & Cheah, Y. K. (2020). Down Syndrome Face Recognition: a review. *Symmetry*, 12(7), 1182. <https://doi.org/10.3390/sym12071182>
- Adithyan, G. S., & Jacob, J. (2017). Positive and negative impacts on caregivers of children with intellectual disability in India. *Disability, CBR & Inclusive Development*, 28(2), 74–94. Doi: <https://doi.org/10.5463/dcid.v28i2.595>
- Akin, A. (2008). The scales of psychological well-being: A study of validity and reliability. *Educational Sciences: Theory and Practice*, 8(3), 741–750.
- Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities*, 33(6), 2122–2140. Doi: <https://doi.org/10.1016/j.ridd.2012.06.013>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Doi: <https://doi.org/10.1176/appi.books.9780890425596>
- Antonarakis, S. E., Skotko, B. G., Rafii, M. S., Strydom, A., Pape, S. E., Bianchi, D. W., Sherman, S. L., & Reeves, R. H. (2020). Down syndrome. *Nature Reviews Disease Primers*, 6(1), 9. Doi: <https://doi.org/10.1038/s41572-019-0143-7>
- Attali, E., & Yogeve, Y. (2020). The impact of advanced maternal age on pregnancy outcome. *Best Practice & Research Clinical Obstetrics & Gynaecology*, 70, 2–9. Doi: <https://doi.org/10.1016/j.bpobgyn.2020.06.006>
- Bahry, N. S., Mat, A., Kori, N. L., Ali, A. M., Abdul Munir, Z., & Salleh, M. Z. M. (2019). Challenges faced by Malaysian parents in caregiving of a child with disabilities. *Global Journal of Business and Social Science Review*, 7(2), 118–124. Doi: [http://dx.doi.org/10.35609/gjbssr.2019.7.2\(2\)](http://dx.doi.org/10.35609/gjbssr.2019.7.2(2))
- Becerra, N., Guasconi, M., & Barello, S. (2024). The impact of caregiver affiliate stigma on the psychosocial well-being of caregivers of individuals with neurodegenerative disorders: A scoping review. [Journal], <https://doi.org/10.1007/s00127-023-02579-8>
- Bunning, K., Gona, J. K., Newton, C. R., Andrews, F., Blazey, C., Ruddock, H., Henery, J., & Hartley, S. (2020). Empowering self-help groups for caregivers of children with disabilities in Kilifi, Kenya. *PLoS One*, 15(3), e0229851. <https://doi.org/10.1371/journal.pone.0229851>
- Corrigan, P. W. (2000). Mental health stigma as social attribution: Implications for research methods and attitude change. *Clinical Psychology: Science and Practice*, 7, 48–67. <https://doi.org/10.1093/clipsy.7.1.48>
- Corrigan, P. W., & Watson, A. C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice*, 9, 35–53. <https://doi.org/10.1093/clipsy.9.1.35>
- Eleptico, J. M., Gil, T. J. O., & Gonzaga, V. C. L. (2024). Unveiling Shadows: Stigma among family members of children with trisomy 21. *International Journal of Social Science and Human Research*, 07(11). <https://doi.org/10.47191/ijsshr/v7-i11-47>
- Findler, L., Jacoby, A. K., & Gabis, L. (2016). Subjective happiness among mothers of children with disabilities: The role of stress, attachment, guilt and social support. *Research in Developmental Disabilities*, 55, 44–54. <https://doi.org/10.1016/j.ridd.2016.03.006>

- Fucà, E., Costanzo, F., & Vicari, S. (2024). Characterising repetitive behaviours in children and adolescents with Down syndrome. *Journal of Intellectual Disability Research*, 68(11), 1287–1300. <https://doi.org/10.1111/jir.13179>
- Githara, M., Obondo, A., Tele, A., Thornicroft, G., & Kumar, M. (2020). Depressive symptoms and stigmatization among parents of children with intellectual disabilities. <http://dx.doi.org/10.21203/rs.3.rs-17992/v1>
- Hameed, P. V., & SuphalaKotian, S. (2023). Exploring leisure and quality of life in parents of children with intellectual disability: An analytical review. *International Journal for Multidisciplinary Research*, 5(5), 4–8. <https://doi.org/10.36948/ijfmr.2023.v05i05.7260>
- Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism*, 9(4), 377–391. <https://doi.org/10.1177/1362361305056078>
- Inglis, G., Sosu, E., McHardy, F., Witteveen, I., Jenkins, P., & Knifton, L. (2025). Testing the associations between poverty stigma and mental health. *International Journal of Social Psychiatry*, 71(3), 554–563. <https://doi.org/10.1177/00207640241296055>
- Isaksson, A., Corker, E., Cotney, J., Hamilton, S., Pinfold, V., Rose, D., Ruesch, N., Henderson, C., Thornicroft, G., & Evans-Lacko, S. (2018). Coping with stigma and discrimination: Evidence from mental health service users in England. *Epidemiology and Psychiatric Sciences*, 27(6), 577–588. <https://doi.org/10.1017/s204579601700021x>
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363–385. <https://doi.org/10.1146/annurev.soc.27.1.363>
- Mak, W. W. S., & Cheung, R. Y. M. (2008). Affiliate stigma among caregivers of people with intellectual disability or mental illness. *Journal of Applied Research in Intellectual Disabilities*, 21, 532–545. <https://doi.org/10.1111/j.1468-3148.2008.00426.x>
- Mak, W. W., & Cheung, R. Y. (2012). Psychological distress and subjective burden of caregivers of people with mental illness: The role of affiliate stigma and face concern. *Community Mental Health Journal*, 48, 270–274. <https://doi.org/10.1007/s10597-011-9422-9>
- Mak, W. W., & Kwok, Y. T. (2010). Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. *Social Science & Medicine*, 70, 2045–2051. <https://doi.org/10.1016/j.socscimed.2010.02.023>
- Mikami, A. Y., Chong, G. K., Saporito, J. M., & Na, J. J. (2015). Implications of parental affiliate stigma in families of children with ADHD. *Journal of Clinical Child & Adolescent Psychology*, 44(4), 595–603. <https://doi.org/10.1080/15374416.2014.888665>
- Mitter, N., Ali, A., & Scior, K. (2019). Stigma experienced by families of individuals with intellectual disabilities and autism: A systematic review. *Research in Developmental Disabilities*, 89, 10–21. <https://doi.org/10.1016/j.ridd.2019.03.001>
- Norizan, A., & Shamsuddin, K. (2010). Predictors of parenting stress among Malaysian mothers of children with Down syndrome. *Journal of Intellectual Disability Research*, 54(11), 992–1003. <https://doi.org/10.1111/j.1365-2788.2010.01324.x>
- Patel, L., Wolter-Warmerdam, K., Leifer, N., & Hickey, F. (2018). Behavioral characteristics of individuals with Down syndrome. *Journal of Mental Health Research in Intellectual Disabilities*, 11(3), 221–246. <https://doi.org/10.1080/19315864.2018.1481473>
- Ryff, C. D., & Keyes, C. L. M. (1995). The structure of psychological well-being revisited. *Journal of Personality and Social Psychology*, 69(4), 719–727. <https://doi.org/10.1037/0022-3514.69.4.719>

- Shukla, N. (2021). Psychological implications of affiliate stigma on siblings of individuals with intellectual disabilities (Doctoral dissertation). <https://scholarworks.calstate.edu>
- Song, J., Mailick, M. R., & Greenberg, J. S. (2018). Health of parents of individuals with developmental disorders or mental health problems: Impacts of stigma. *Social Science & Medicine*, 217, 152–158. <https://doi.org/10.1016/j.socscimed.2018.09.044>
- Werner, S., & Shulman, C. (2013). Subjective well-being among family caregivers of individuals with developmental disabilities: The role of affiliate stigma and psychosocial moderating variables. *Research in Developmental Disabilities*, 34, 4103–4114. <https://doi.org/10.1016/j.ridd.2013.08.029>
- Werner, S., & Shulman, C. (2015). Does type of disability make a difference in affiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability? *Journal of Intellectual Disability Research*, 59(3), 272–283. <https://doi.org/10.1111/jir.12136>
- Ye, Y., Deng, T., Chen, M., Huang, B., Ji, Y., Feng, Y., Liu, S., Zhang, T., & Zhang, L. (2024). Relationship between affiliate stigma and family quality of life among parents of children with autism spectrum disorders: The mediating role of parenting self-efficacy. *Archives of Psychiatric Nursing*, 49, 23–31. <https://doi.org/10.1016/j.apnu.2024.01.011>
- Yun, Y. S., Jaapar, S. Z. S., Fadzil, N. A., & Cheng, K. Y. (2018). Validation of the Malay version of the Affiliate Stigma Scale among caregivers of patients with mental illness. *The Malaysian Journal of Medical Sciences*, 25(6), 127. <https://doi.org/10.21315/mjms2018.25.6.13>
- Zhang, Y., Subramaniam, M., Lee, S. P., Abdin, E., Sagayadevan, V., Jeyagurunathan, A., Chang, S., Shafie, S. B., Fauziana, R., Vaingankar, J. A., & Chong, S. A. (2018). Affiliate stigma and its association with quality of life among caregivers of relatives with mental illness in Singapore. *Psychiatry Research*, 265, 55–61. <https://doi.org/10.1016/j.psychres.2018.04.044>
- Zhou, T., Wang, Y., & Yi, C. (2018). Affiliate stigma and depression in caregivers of children with Autism Spectrum Disorders in China: Effects of self-esteem, shame and family functioning. *Psychiatry Research*, 264, 260–265. <https://doi.org/10.1016/j.psychres.2018.03.071>