

Research Paper

## Unveiling The Layers of Stigma: An in-Depth Study on Affiliate Stigma and Life Satisfaction Amongst Caregivers and Teachers of Special Needs Children in Shillong, Meghalaya

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### ABSTRACT

**Background:** This study explores the multidimensional nature and prevalence of affiliate stigma and how it plays a role in the life satisfaction of caregivers and teachers of children with special needs. Affiliate stigma, or internalized stigma experienced by people associated with stigmatized groups, has serious consequences for the well-being of those who care for and teach special needs children. Despite its relevance, affiliate stigma remains unexplored in educational and caregiving settings. **Method:** A mixed-method method approach was opted for the research study in which the 'Satisfaction with Life Scale' was used for the quantitative component which assesses the global cognitive judgement of one's life satisfaction of fifty-four respondents from Nongthymmai locality, Bethany Society Shillong, Dwar Jingkyrmen Inclusive School and through 'Google Form' which is an online platform. On the other hand, for the qualitative aspect, a semi-structured interview questionnaire was utilized on twelve respondents from Nongthymmai locality and Bethany Society Shillong, for understanding and diving into the nature and prevalence of affiliate stigma. **Results:** The qualitative findings of the study show that, the prevalence of affiliate stigma ranges between 'Mild' to 'Moderate' where three out of the twelve respondents, have in fact encountered affiliate stigma and interestingly the rest of the nine respondents have reported of not experiencing any affiliate stigma throughout their period of either being a caregiver or a teacher for the special needs children. Conversely, the quantitative findings of the study using the 'Satisfaction with Life Scale' show that, 25% are 'Extremely Satisfied', 33.3% are 'Satisfied', 27.1% are 'Slightly Satisfied', 4.2% are Neutral, 10.4% are 'Slightly Dissatisfied' and none were either 'Dissatisfied' or 'Extremely Dissatisfied', this suggests a generally positive life satisfaction among the caregivers and teachers of the special needs children in Shillong, Meghalaya.

**Keywords:** *Affiliate Stigma, Life Satisfaction, Caregiver, Teachers, Special needs children*

Stigma refers to the "situation of the individual who is disqualified from full social acceptance," according to Canadian sociologist Erving Goffman (Fitzpatrick, 2008). Stigma has been defined as a symbol of dishonour or shame that distinguishes a person from society. Even if they're more frequently an effect of the situation than

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appearance, the stigma of mental illness is nonetheless a potent deterrent in all social interactions (Byrne, 2000).

Historically, stigma has been viewed as the responsibility of the mental health system, with those affected experiencing social exclusion and decreased possibilities in life due to receiving a diagnosis and identifying as a patient as a result of their interactions with psychiatric facilities.

Family members in Hong Kong with traditional Chinese culture view mental illness as biologically based. As a result, society stigmatizes persons with mental illnesses in their family (Hailemariam, 2015).

Mental illness at all phases is made worse by secrecy in both presentation and treatment. Therefore, persons with psychological disorders are cut off from potential assistance when community resources are mobilized, in contrast to physical illness. It has also been proven that stigma affects mental health professionals as well as the family or relatives of patients (Subu et al., 2021).

Family members have an important role in providing their mentally ill relatives with assistance and loving care. Their battle to deal with stigma and the responsibility of providing care is disregarded, underappreciated, and hidden from medical services (Ebrahim et al., 2020).

According to a review of the literature, caretakers who consistently help patients with chronic mental illness exhibit a range of stress-related behaviours (Anjum et al., 2010).

Life satisfaction is an overall assessment of one's feelings and attitudes towards life at a certain point in time, ranging from negative to positive. It is one of three key measures of well-being: life satisfaction, positive affect, and negative affect (Diener 1984).

There has been little research on affiliate stigma and subjective wellbeing. The majority of the evidence focuses on the larger idea of family stigma and almost entirely on mental disorders, demonstrating that increased awareness of stigmatization among family members of people with mental illnesses is related to poorer quality of life (Werner & Shulman, 2013).

The purpose of this study is to delve into the layers of stigma faced by these key figures in the lives of special needs children and to explore how this stigma affects their overall life satisfaction. By conducting an in-depth interview into the experiences of affiliate stigma amongst caregivers and teachers in Shillong, Meghalaya, it will help in filling the gap in knowledge around this specific area. Additionally, it seeks to provide insights that could inform policies and practices to enhance the support provided to these individuals, ultimately benefiting the special needs community as a whole. The present study uses a mixed-method approach, including quantitative surveys and qualitative interviews, to give a deeper comprehension of the complex nature of affiliate stigma.

### **METHODOLOGY**

The area of study is Shillong, East Khasi Hill District Meghalaya. It is the capital city of the state and cover over an area of 10.36 km, according to Unique Identification Aadhar India,

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revised May 31, 2023, the population of Meghalaya is expected to reach 33.49 lakhs by May 2023, from an anticipated 3.35 million (33.5 lakhs) in 2023 (Meghalaya Population 2023, n.d.). The main area of focus for this study are Nongthymmai locality, Bethany Society Shillong and Dwar Jingkyrmen Inclusive School located within Shillong, Meghalaya. The study adopted both qualitative interviews as well as quantitative surveys, in which semi-structured interviews with open ended questions will be used for a comprehensive understanding. For the quantitative surveys, standardized assessment tools are used.

- **Satisfaction with Life Scale:** A 5-item scale designed to measure global cognitive judgments of one’s life satisfaction (not a measure of either positive or negative affect). Participants indicate how much they agree or disagree with each of the 5 items using a 7-point scale that ranges from 7 strongly agree to 1 strongly disagree.

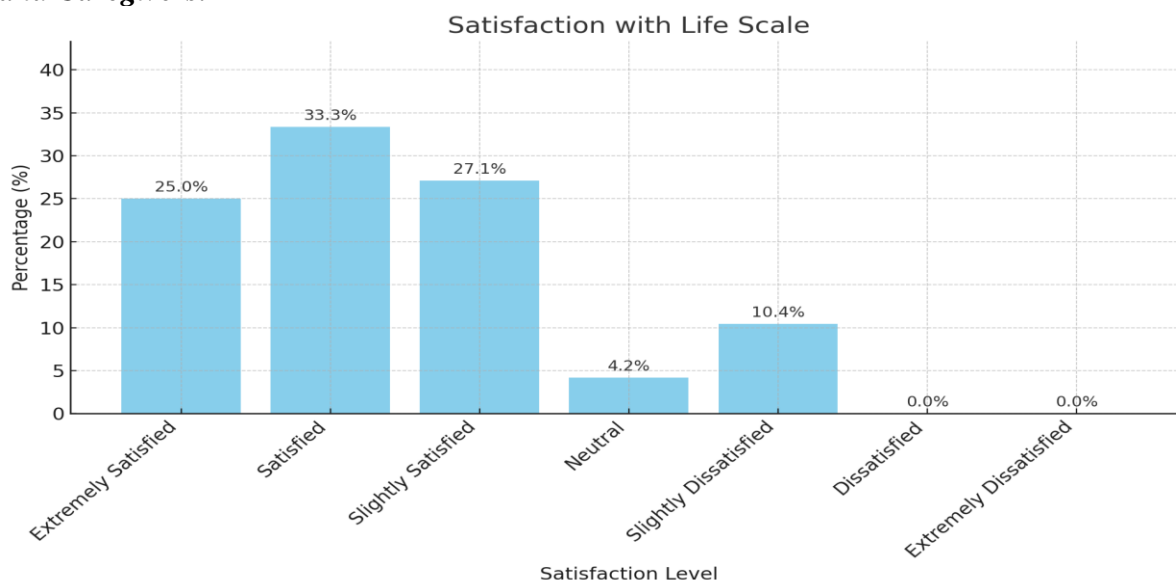
**RESULTS AND DISCUSSIONS**

*Table 1 showing the demographic profile of the study area*

OVERVIEW	DESCRIPTION	TOTAL
AREA: NONTHYMMAI	3 CAREGIVERS.	<b>QUALITATIVE:</b> 12
BETHANY SOCIETY	3 CAREGIVERS, 7 TEACHERS. 10 TEACHERS.	<b>RESPONDENTS:</b> <b>QUANTITATIVE:</b> 42
DWAR JINGKYRMEN	MIXTURE OF TEACHERS AND CAREGIVERS	<b>RESPONDENTS:</b> <b>OVERALL:</b> 54
OTHERS (GOOGLE FORM)		<b>RESPONDENTS.</b>

It is seen in Table.1 there are overall 54 respondents in Nongthymmai, Bethany Society, Dwar Jingkyrmen, where 3 caregivers are from Nongthymmai, 3 caregivers and 7 teachers are from Bethany Society, 10 teachers from Dwar Jingkyrmen and the rest is a mixture of teachers and caregivers attained through Google Form. For the quantitative data, there were 42 respondents and for the qualitative data, there were 12 respondents.

*Figure 1 Showing the Percentage of The Satisfaction with Life Scale of Both Teachers and Caregivers.*



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Figure 1, showing the results of the respondents selected from the four areas that is Nongthymmai, Bethany Society, Dwar Jingkyrmen, Shillong and through google form, it can be seen that, 25% are 'Extremely Satisfied', 33.3% are 'Satisfied', 27.1% are 'Slightly Satisfied', 4.2% are 'Neutral', 10.4% are 'Slightly Dissatisfied' and none were either 'Dissatisfied' or 'Extremely Dissatisfied'.

**Table 2: Table Showing the Thematic Analysis on Affiliate Stigma.**

**Main theme: Affiliate stigma**

<b>Sub theme: Hopelessness, Sadness, Gossip.</b>	<b>Statements</b>
The respondent shows sign of hopelessness when it comes to affiliate stigma because she feels that she's unable to change anything in that area but to leave it like that, she does feel sad about how people talk negatively about the situation that she is in, most of the talks are never positive where they would not address the respondent directly but would talk behind her back.	<p><u>Hopelessness</u>: "I cannot do anything about it".</p> <p><u>Sadness</u>: "It's sad".</p> <p><u>Gossip</u>: "People will always talk".</p>

**Main theme: Affiliate stigma**

<b>Sub theme: Lack of empathy, social and relational impact.</b>	<b>Statements</b>
The respondent states how some people can be ruthless to the extent of putting the blame on the mother that it was because through her the child has been cursed and they pass on judgements relating to the mother's past life where they stated that, it was because she had done something wrong, hence the consequence of the child is the result of the mother's sins.	<p><u>Lack of empathy</u>: "Ruthless people they say that it's like a curse for them".</p> <p><u>Social and Relational Impact</u>: "It's a curse from something the mother had done something in the past or something like that and they believe in that curse or generational curse".</p>

**Main theme: Affiliate stigma**

<b>Sub theme: Avoidance, feelings of guilt.</b>	<b>Statements</b>
The respondent states that she has not experienced affiliate stigma so far but she mentions how she feels that she is not able to socialise much and finds herself avoiding from going to any social functions and at times feel bad for missing social activities.	<p><u>Avoidance</u>: "Maybe because I cannot socialise much and at times I have to avoid only right".</p> <p><u>Feelings of guilt</u>: "I feel bad for not going out much like funerals or any social activities".</p>

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**Main theme: Affiliate Stigma.**

<b>Sub-theme: Respect, Acceptance, Belonging, Community support.</b>	<b>Statement</b>
<p>The respondent mentioned how she felt a sense of belonging in her neighborhood because according to her, they seem to be more concerned about her child's condition and are willing to accept them for who they are. According to her, they show their respect not only to her being a caregiver but also to her son and it can be seen that there is a lot of community support in her neighborhood.</p>	<p><u>Respect:</u> <i>"They accept us"</i>.  <u>Acceptance and belonging:</u> <i>"No, no they don't look at us differently"</i>.  <u>Community support:</u> <i>"Yes, they do talk but they would always say good things"</i>.</p>

**Main theme: Affiliate Stigma.**

<b>Sub theme: Experiences of normalcy, friendliness.</b>	<b>Statements</b>
<p>The respondent states how people around her are normal towards her and her daughter and most of them are always friendly and interactive whenever they meet them.</p>	<p><u>Experiences of normalcy:</u> <i>"For me it's always normal in the majority so far since I have taken here there and everywhere, people treat us normally only."</i>  <u>Friendliness:</u> <i>"From what I have seen they've always been friendly especially to her...and when it comes to my locality everyone is friendly"</i></p>

**TEACHERS**

**Main theme: Affiliate Stigma.**

<b>Sub theme: Social expectations, supportive environment, acceptance and need for patience.</b>	<b>Statements</b>
<p>The respondents state how being a teacher in a special school can be difficult at times because of the constant pressure from either friends or family members because of their career choice. Nevertheless, they never let what the others say affect them because they believe that teaching there and being together with the other teachers created a supportive environment for them. Another teacher mentioned that, the reason for her long tenure in the school was through her acceptance and lastly through their patience.</p>	<p><u>Societal expectations:</u> <i>"So many people used to say, why have you joined here or why don't you go to another school which is more comfortable, so that you don't have to pressurize yourself"</i>  <u>Supportive environment:</u> <i>"We really enjoyed here you know, that's why it did not affect us"</i>.  <u>Acceptance:</u> <i>"We are here till date because firstly it is acceptance, if you are able to accept those children you know, then only you'll be able to do well"</i>.  <u>Need for patience:</u> <i>"We need patience, very much patience more than the normal ones"</i>.</p>

## **CONCLUSION**

The purpose of this study is to delve into the layers of stigma faced by caregivers and teachers of special needs children and to explore how this stigma affects their overall life satisfaction. The research study used a mixed-method research design in which data was collected from 54 respondents using a standardized questionnaire that helps in assessing the life satisfaction, as well as a semi-structured interview questionnaire that helps in understanding the prevalence of affiliate stigma in caregivers and teachers.

In the final analysis, the study brought to light significant features of affiliate stigma and life satisfaction amongst caregivers and teachers. Looking at the life satisfaction, 25% are 'Extremely Satisfied' and 33.3% are 'Satisfied', showing their current life satisfaction.

On the other hand, through thematic analysis, the prevalence of affiliate stigma was understood and interestingly, the responses were positive and highlighted some key experiences of the respondents. In short, the research findings paved a way for further scope in future research studies and emphasizes the need for more research on the long-term impacts of affiliate stigma and the effectiveness of various treatments. Longitudinal research may give useful insights into how stigma and life satisfaction change. Furthermore, comparative research across cultural settings might shed light on how cultural views about disabilities influence the experiences of carers and instructors.

### ***Limitations***

The present study has the following limitations:

1. The sample size for the study was insufficient and there were fewer carers available for the research study.
2. The data-collection method turned out to be time-consuming and an ethical clearance was necessary, which took a month and a half to officially get the approval to begin the data collection.

### ***Scope For Further Studies:***

The following are some recommendations based on the study's findings:

1. To carry out a brief survey or screening before data collection to determine the availability of sample size within a certain area of research.
2. Arrange talks or interviews with community leaders, ASHAs, and Anganwadi to develop practical and effective initiatives to combat affiliate stigma and to provide support to caregivers and teachers of special needs children.

### ***Ethical Consideration:***

During the course of the study, the following ethical guidelines and consideration will be kept in mind:

- Research participant will not be harmed in any manner during the course of the study.
- Informed consent will be obtained from participants prior to the study.
- Respect for the participants' dignity will be prioritized during the course of the study.
- Adequate level of confidentiality for the data obtained from the participants will be ensured.
- The protection of the privacy of the research participants will also be ensured.

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- Participation for the study will be voluntary and participants has the freedom to withdraw from the study at any point of time.
- The study will be conducted with honesty and transparency in mind to eliminate any bias.

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### ***Conflict of Interest***

The author(s) declared no conflict of interest.

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