

# Research Progress on Affiliate Stigma in Parents of Children with Attention Deficit Hyperactivity Disorder

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**Abstract:** *Affiliate stigma not only affects the mental health of caregivers of children with attention deficit hyperactivity disorder, but also affects their care ability and family atmosphere. This article reviews the definition of stigma, the assessment tools, influencing factors and intervention measures of stigma in parents of attention deficit hyperactivity disorder, to provide theoretical reference for further research in this field in the future.*

**Keywords:** *Attention deficit hyperactivity disorder; ADHD; Affiliate stigma; Parents*

## 1. Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is a prevalent neurodevelopmental condition observed in children, marked by core symptoms of inattention, hyperactivity, and impulsivity. Globally, the average prevalence of ADHD in children is approximately 6.26%<sup>[1]</sup>, and it notably affects boys at a rate four times higher than girls<sup>[2]</sup>. A meta-analysis of 67 studies in China, involving a total of 642,266 children and adolescents<sup>[3]</sup>, found that the prevalence of ADHD in Chinese children and adolescents is 6.3%, similar to the global prevalence. On the other hand, the prevalence of ADHD in children is on the rise. A national population-based cross-sectional survey in the United States<sup>[4]</sup> revealed that the prevalence of ADHD in children and adolescents increased from 6.1% in 1997-1998 to 10.2% in 2015-2016. ADHD exhibits a genetic predisposition, and the likelihood of additional family members being affected rises if one individual within the family receives an ADHD diagnosis<sup>[5]</sup>. As scholars both domestically and internationally delve deeper into research, more and more people are beginning to focus on caregivers of children with ADHD. Caregivers often experience shame when dealing with the behavioral and emotional issues of children with mental disorders, which is referred to as affiliate stigma<sup>[6]</sup>. Affiliate stigma may prompt caregivers to experience a sense of helplessness in caring for children with neurodevelopmental disorders, subsequently impacting their mental well-being. Additionally, it can lead caregivers to withdraw from social interactions and even create a distance between themselves and the children with neurodevelopmental disorders<sup>[7]</sup>. Parents of children with ADHD may also experience affiliate stigma related to their child's ADHD symptoms and behavior. This can bring about emotional, cognitive, and behavioral negative effects, increasing their psychological distress and reducing their overall quality of life<sup>[8]</sup>. High levels of affiliate stigma in parents of children with ADHD can further impact the diagnosis, medication, and behavioral treatment of ADHD in children<sup>[9]</sup>, diminishing the parents' ability to care for their children and affecting their collaboration with healthcare professionals<sup>[10,11]</sup>. Parents play an essential role in the early diagnosis and treatment of children with ADHD<sup>[12]</sup>. Therefore, it is crucial to address the issue of affiliate stigma in parents of children with ADHD and provide early intervention to offer timely assistance to both parents and children. This article reviews the current research on the affiliate stigma experienced by parents of children with ADHD, providing a basis for future targeted intervention studies to reduce affiliate stigma.

## 2. Concepts of Affiliate Stigma

In 1964, American scholar Goffman<sup>[13]</sup> pointed out in his work that the concept of shame not only affects individuals possessing attributes of shame but also extends to those connected to them. Goffman defined shame as a social identity that violates societal norms and orthodox values. Scholars worldwide

have continuously refined and developed the concept of shame. Link et al.<sup>[14]</sup> consider shame as a process in which discrimination and the loss of social status lead to negative emotions and ultimately evolve into shame, attributed to individuals labeled with specific characteristics. Corrigan et al.<sup>[15,16]</sup> categorized shame into public shame and self-stigma. Due to its complex etiology, unique clinical symptoms, and limited public awareness, ADHD children often bear labels associated with disrupting school and societal order due to academic difficulties and hyperactivity, resulting in social exclusion and discrimination against ADHD children and their parents, leading to "public shame." Parents of ADHD children internalize this public shame, giving rise to negative behaviors and attitudes, referred to as "self-stigma." Public shame perceived by parents is easily influenced by societal factors, while their affiliate stigma is related to self-assessment<sup>[17]</sup>. Affiliate stigma, also known as secondary stigmatization, refers to caregivers who do not possess stigmatizing characteristics themselves but are discriminated against due to their direct association with the stigmatized group, resulting in a process of self-stigmatization involving negative emotional experiences and self-perception. Affiliate stigma comprises three interconnected components: cognitive aspects of stigma awareness, negative emotions (shame, embarrassment, and despair), and behavioral reactions (including withdrawal and self-deprecation resulting from internalized stigma)<sup>[7]</sup>. Norvilitis et al.<sup>[18]</sup> were the first to explore the issue of stigmatization within families of ADHD children, and their research indicated that when parents of ADHD children become aware of others' negative thoughts, they experience increased stress, leading to shame. As scholars delve deeper into the study of affiliate stigma in caregivers, it becomes evident that this negative emotion has serious implications for caregivers' physical and mental health, family relationships, social roles, and functioning<sup>[19]</sup>.

### 3. Assessment Tools for Affiliate Stigma

The conceptualization of affiliate stigma has laid the foundation for the development of dedicated tools for measuring shame. Currently, researchers both domestically and internationally have developed various assessment tools for affiliate stigma. However, there is no specific measurement tool designed to evaluate affiliate stigma in caregivers of children with ADHD. Currently, several scales related to the affiliate stigma of parents of children with ADHD include the following:

#### 3.1 *The Affiliate Stigma Scale*

Mark et al.<sup>[7]</sup> developed the Affiliate Stigma Scale (ASS) in 2008. This scale is a self-report questionnaire consisting of 22 items designed to measure the level of affiliate stigma in caregivers of individuals with mental illnesses. It has a Cronbach's  $\alpha$  coefficient of 0.95. The ASS comprises three dimensions: emotional (7 items), cognitive (7 items), and behavioral (8 items). Each item is rated on a 4-point Likert scale, ranging from 1 (strongly disagree) to 4 (strongly agree). A higher total score indicates a higher level of affiliate stigma. Mikami et al.<sup>[11]</sup> were the first to apply this scale to measure the level of affiliate stigma in parents of children with ADHD, and they made adjustments to the ASS scale items specifically for caregivers of children with ADHD. For example, in the emotional dimension: "I feel inferior because one of my children has ADHD"; in the cognitive dimension: "My reputation is damaged because I have a child with ADHD at home"; and in the behavioral dimension: "I am afraid to tell others that I have a child with ADHD." In 2015, Chang et al.<sup>[20]</sup> conducted psychological testing using Rasch analysis among family members of psychiatric patients in Taiwan, China, confirming that this scale is a robust psychological measurement tool. Yin Qunming et al.<sup>[21]</sup> conducted a reliability and validity analysis on the revised Chinese version of the ASS scale among parents of autistic children in China, with a Cronbach's  $\alpha$  coefficient of 0.883, indicating good reliability and validity.

#### 3.2 *The Parents' Self-Stigma Scale*

The Parents' Self-Stigma Scale (PSSS), developed by Eaton et al.<sup>[22]</sup>, is a scale specifically designed for assessing self-stigma in parents of children with mental health disorders. It comprises three dimensions and a total of 11 items. The three dimensions include self-blame, negative self-beliefs in parents, and self-shame. The definition of the third dimension, self-shame, aligns with the concept of affiliate stigma and refers to the loss of social status due to parents' association with stigmatized children, resulting in feelings of shame and embarrassment. The scale employs a 5-point Likert rating system, ranging from 1 (strongly disagree) to 5 (strongly agree), with higher scores indicating higher levels of self-stigma. The overall Cronbach's  $\alpha$  coefficient for the scale is 0.83, indicating sufficient

reliability. Serchuk et al. [23] used the PSSS scale to measure self-stigma in parents of children with ADHD.

### **3.3 The Family Stigma Stress Scale**

The Family Stigma Stress Scale (FSSS), developed by Chang et al. [24], consists of 2 dimensions and 8 items designed to assess stigma-related stress in caregivers of mental health patients in Taiwan. The FSSS scale employs a 4-point Likert rating system, ranging from 1 (strongly disagree) to 4 (strongly agree). Higher scores on the scale indicate greater stigma-related shame and stress experienced by family members. The overall Cronbach's  $\alpha$  coefficient for the scale is 0.85, demonstrating good reliability. This tool can assist healthcare professionals in gaining a better understanding of the psychological state of family caregivers and providing them with improved support and assistance. Currently, the scale is widely used among caregivers of individuals with mental illnesses, but it has not been applied to research on the affiliate stigma experienced by caregivers of children with ADHD.

### **3.4 The Family Stigma Instrument**

The Family Stigma Instrument (FAMSI), developed and validated by Mitter et al. [25], is an assessment tool designed to measure the stigma experienced by caregivers of children with developmental disorders. The scale has an overall Cronbach's  $\alpha$  coefficient of 0.84 and comprises five dimensions: perceived family stigma, emotional affiliate stigma, cognitive affiliate stigma, behavioral affiliate stigma, and positive caregiving aspects. It includes 26 items and uses a 5-point Likert rating system, with scores ranging from 1 (strongly disagree) to 5 (strongly agree). Higher scores indicate a higher level of stigma experienced by family caregivers. The FAMSI scale has been widely applied in research on the stigma experienced by parents of children with autism.

In the future, scholars may develop specific assessment tools for parents of children with ADHD to measure their affiliate stigma. This endeavor aims to provide a theoretical basis for devising appropriate intervention measures and alleviating affiliate stigma in this specific group.

## **4. Factors Influencing the affiliate stigma of Parents of Children with ADHD**

### **4.1 Parental Personal Factors**

The psychological well-being of parents of children with ADHD has been recognized as a significant risk factor in child psychopathology [26]. Research conducted by Chen et al. [27] on 400 parents of ADHD children in Taiwan found that parents with depression are more likely to experience affiliate stigma. Norvilitis et al. [18] demonstrated that affiliate stigma in mothers of children with ADHD leads to an increase in their anxiety and depression levels. Mothers of ADHD children with lower self-esteem experience more severe depression and higher levels of affiliate stigma [28]. Studies [10,29] indicate that the gender and educational level of parents of children with ADHD are positively correlated with their affiliate stigma, meaning that mothers have higher levels of affiliate stigma than fathers, and parents with higher levels of education often experience higher levels of affiliate stigma. A study in the United States suggests that overprotective parenting by parents of ADHD children can also lead to high levels of affiliate stigma [11], which aligns with the findings of Chang et al. [29]. Research involving 119 parents of children with ADHD [30] revealed that 52% of these parents believed that ADHD was a result of overindulgence by parents. Most parents of ADHD children are reluctant to view their child's attention deficit hyperactivity disorder behavior as a disease. Parents may even attribute the child's problems to their responsibility, blaming it on abnormal genetics or inadequate caregiving [31]. Prejudiced parents of children with ADHD may isolate themselves socially from colleagues, friends, and family members [32,33]. There is also evidence that when parents of children with ADHD are blamed for passing on bad genes, poor parenting practices, and failing to provide proper care for their child, it can lead to high levels of affiliate stigma [23]. Most studies have focused on ADHD children's mothers, and future researchers should invest more effort into considering the affiliate stigma of fathers and take into account gender differences to help fathers alleviate this emotion, thus contributing more to the well-being and happiness of family members.

### **4.2 Child Factors**

ADHD boys are more prone to symptoms of hyperactivity, impulsivity, and oppositional defiant

disorder, while girls are more likely to exhibit symptoms of inattention and comorbid anxiety/depression [34,35]. Several studies [36,37] have shown that a child's gender is an important moderating factor in the relationship between ADHD symptoms and parental stress, with higher stress observed in mothers of ADHD boys. On the other hand, the severity of a child's ADHD symptoms has a significant negative impact on parents' emotions and family burden [38]. A study of mothers of children with ADHD in France found a positive correlation between maternal affiliate stigma and the child's ADHD symptoms [39]. Research conducted in Taiwan, China, investigating factors related to the affiliate stigma of caregivers of ADHD children [10], supports this point as well. The more severe a child's ADHD symptoms, the more likely parents are to experience high levels of affiliate stigma [29]. For children, symptoms of inattention can increase the difficulty of learning, and parents of children with ADHD may face criticism from teachers and family members for not supervising the child's academic performance, thereby increasing affiliate stigma. Future research can explore differences in parental affiliate stigma among ADHD children at different age stages.

#### **4.3 Social and Family Factors**

Parents of children with ADHD may experience affiliate stigma due to pressure from the community, family, friends, or school. The results of a systematic review [40] show that the community's attitudes toward individuals with ADHD are generally negative, and there is a desire to maintain social distance from them. As a result, parents of children with ADHD may feel isolated, discriminated against, or misunderstood, leading to affiliate stigma. In school, because children with ADHD struggle to maintain attention in the classroom, their academic performance and adaptability suffer. Teachers often hold negative views and attitudes towards children with ADHD [41], and the pressure from school can also leave parents of children with ADHD feeling helpless and ashamed. Additionally, Chiu et al. [42] found that caregivers with lower socioeconomic status are more likely to experience affiliate stigma, and caregivers with lower social status often require more social support and assistance. In traditional Chinese families, the long-standing concept of "men working outside and women taking care of the home" prevails, making mothers the primary caregivers of children with ADHD [43]. Mothers are often criticized for neglecting their children's education, increasing maternal affiliate stigma. A qualitative study involving interviews with 13 parents of children with ADHD [44] found that raising children with ADHD has a significant negative impact on family and marital relationships. Parents of children with ADHD feel isolated, and rejected, and report experiencing stigma.

#### **4.4 Cultural Factors**

Cultural background influences the level of affiliate stigma in caregivers of children with ADHD [28]. In Asian societies, there is often a strong emphasis on interpersonal connections and a focus on the identification with "one's people" (including family and friends). Once an individual experiences stigma, not only does the person lose "face," but also those connected to them, which exacerbates the issue of shame [42]. The behavior of children with ADHD often causes trouble for those around them, leading to the threat of being criticized and "losing face" with their parents, increasing the risk of affiliate stigma [45]. In China, traditional gender role concepts and stereotypes still significantly impact daily life. Traits such as extroversion and liveliness are considered characteristic of boys, while introversion and stability are considered characteristic of girls. Shyness is even seen as a feature of traditional Chinese girls [46]. This exacerbates societal bias against ADHD girls and increases the level of affiliate stigma experienced by parents of ADHD girls. Future research, when implementing specific interventions to reduce the affiliate stigma of parents of children with ADHD, should consider cultural factors, including language, social customs, religious beliefs, and more.

### **5. Intervention for the affiliate stigma of Parents of Children with ADHD**

The affiliate stigma experienced by parents of children with ADHD is widespread and has many negative impacts on both the children and their families. Currently, there is a lack of empirical research on interventions specifically targeting the affiliate stigma of parents of children with ADHD. However, previous scholars have conducted numerous intervention studies related to factors influencing shame, which can be summarized into four main areas: psychological, educational, social support, and public interventions.

### **5.1 Psychological Intervention**

The affiliate stigma experienced by parents of children with ADHD is related to the ADHD symptoms in children<sup>[10]</sup> and the psychological well-being of parents<sup>[27]</sup>. Research suggests that providing psychological interventions to support families with ADHD children can reduce parental caregiving stress and improve the parents' psychological health<sup>[47]</sup>. Cognitive-behavioral therapy is a treatment approach that alleviates psychological and emotional distress by identifying and changing negative thought and behavior patterns<sup>[48]</sup>. Numerous randomized controlled trials<sup>[49-51]</sup> have demonstrated that cognitive-behavioral therapy not only improves the anxiety and ADHD symptoms in children but also effectively enhances the parents' quality of life and psychological well-being, increasing family happiness. Additionally, mindfulness-based psychological interventions can help reduce anxiety, depression, and other psychological health issues in parents of ADHD children<sup>[52]</sup>. Therefore, future research can focus on psychological interventions using cognitive-behavioral therapy, mindfulness therapy, and other methods to provide regular psychological counseling to parents of ADHD children, improving their negative emotions and alleviating affiliate stigma.

### **5.2 Educational Intervention**

The lack of knowledge among parents of ADHD children and their negative attitudes towards the diagnosis, treatment methods, and explanations of the etiology of ADHD are positively correlated with their levels of affiliate stigma<sup>[10]</sup>. Parent training is an evidence-based treatment that primarily focuses on parents' behavior, teaching them positive parenting skills and methods. It is currently one of the most widely used intervention measures. Parent training helps improve ADHD-related behavioral issues and parent-child interaction, enhances parenting skills, and reduces the stress of raising children, positively affecting the parents' mental health<sup>[54]</sup>. Additionally, Chang and colleagues<sup>[30]</sup> conducted interventions with ADHD children's parents through short educational workshops, and the results showed that parents gained more knowledge and information through the workshops, enabling them to better understand and support their children. This increased their willingness to collaborate with healthcare professionals.

### **5.3 Social Support**

Chang et al.<sup>[29]</sup> found that caregivers' coping strategies are related to affiliate stigma, and caregivers who tend to seek social support are less likely to experience affiliate stigma. A randomized controlled trial conducted in a school environment<sup>[55]</sup> demonstrated that school-based parenting interventions enhanced cooperation between parents of children with ADHD and the school, increased parenting confidence, and enabled parents of ADHD children to seek social support from others for sympathy and understanding, thereby reducing the negative consequences of stress events. However, research has shown that the support and needs of parents of children with ADHD are not being adequately met<sup>[44]</sup>. Therefore, at the community level, as the most basic service provider, regular group activities for children with ADHD should be organized, and ADHD children's clubs should be established, allowing parents of children with ADHD to share experiences and emotions, access beneficial information and advice, and reduce the level of affiliate stigma. The government should provide policy protection and support for children with ADHD to alleviate the stress on their families and reduce affiliate stigma. Medical institutions should improve healthcare services for children with ADHD, offering professional guidance and long-term support to their families.

### **5.4 Public Education**

In a qualitative study, parents of children with ADHD reported feeling isolated and stigmatized by the public due to a lack of understanding about the ADHD condition<sup>[44]</sup>. Obeid et al.<sup>[56]</sup> increased public awareness of autism by disseminating relevant knowledge, which reduced misunderstandings and discrimination against autism and subsequently lowered the affiliate stigma levels among caregivers of children with autism. Therefore, researchers can draw inspiration from this and promote knowledge about the etiology and related medical information of ADHD to the public through various platforms. This can enhance public understanding of ADHD, encourage people to be more accepting of children's unique behaviors, and promote a positive attitude toward ADHD. This, in turn, can lead to increased attention and support for children with ADHD and help reduce affiliate stigma.

## 6. Conclusion

In summary, the affiliate stigma experienced by parents of children with ADHD has various negative impacts on the children and their families and deserves attention. However, there is limited research on this topic in China. Therefore, researchers can conduct assessments, current status evaluations, and interventions related to the affiliate stigma experienced by parents of children with ADHD in China. This would enable the development of targeted interventions to support children with ADHD and their families and alleviate the affiliate stigma experienced by parents.

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