



# Social Dilemmas Faced by Parents of Children Diagnosed with Autism in China

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**Abstract.** The parents with autistic children in China now face a great deal of social dilemmas. The specific problem being discussed is that what kinds of dilemmas are they confronting. This study can systematically analyze the previous works and summarize different perspectives of existing dilemmas, which can lay a solid foundation of future studies on the same topic. The research analyzed 12 studies published concerning psychological stress and affiliate stigma among parents of children with autism from several journals. The results suggest that parents indeed experience huge psychological pressure and affiliate stigma, which have immensely affected their well-being from several ways.

**Keywords:** Parents · Autism · Affiliate stigma · Psychological stress

## 1 Introduction

Autism spectrum disorder (ASD) is a type of neurodevelopmental disorder, also known as autism. There is a huge number of children with autism in China, so the lifelong rehabilitation becomes their parents' responsibility. This is not only a great psychological stress for them, but also a costly one. Nevertheless, attention has been mainly focused on children with autism, but parents of children are also a high-risk group that needs attention and help.

The existing psychological pressure and affiliate stigma have immensely affected parents' well-being from several ways. So according to this research, public will have a better understanding of the current situations of those caregivers since this study can systematically analyze the previous works and summarize different perspectives of existing dilemmas, which can lay a solid foundation of future studies on the same topic. So, there will be more comprehensive and objective research on dilemmas of parents with ASD children in the future to further explore the influential factors and sound ways to better settle down this problem in various ways.

Preliminary work in this field focused primarily on the parental stress of caregivers with autistic children. As early as in 1991, Dumas, Wolf, Fisman, and Culligan mentioned that stress experienced by parents who care for offspring on the autism spectrum [1]. Furthermore, Dabrowska and Pisula found that parents of children with neuroticism had lower levels of stress than them of children with ASD [2]. Similarly, Miranda, Mira, Berenguer, Rosello and Baixauli explained that parents of autistic children experience

**Table 1.** Analysis of 12 papers containing the social dilemmas faced by parents of autistic children

No. of papers	Different types of social stigma	References
6	Parents with autistic children have psychological stress	[1–6]
6	Parents with autistic children confront affiliate stigma	[7–12]

more stress than those who have neurotypically developing kids. In addition to the existence of parental stress, Miranda et al. also investigated the stress levels of those who have kids with ASD. It is these researchers' aim to figure out the factors mediating behavioral problems and to enhance coping strategies [3]. Then, Magalhães and Pereira discovered various concerns and supports related to increased parental stress levels in autistic kids in Portugal [4]. However, previous work has only focused on mental dilemma or affiliate stigma. A neglected fact is that majority of the parents with autistic children face both psychological stress and affiliate stigma instead of only one of them. Based on this research status, this study will further supplement the previous studies and provide a theoretical basis for future studies.

A systematic literature search was conducted to find research that have been published on psychological stress and affiliate stigma among parents with autistic children. The following keywords were used to find 12 papers and online resources: psychological pressure, affiliate stigma, and parents of autistic children. For the studies of interest, full papers are collected, and only those that meet the criteria are included in the paper. Besides, all of the included papers' reference lists were searched for other relevant research, and some of the main journals on those terms were hand searched.

## 2 Classification Result of the Dilemmas

The following analysis will be concluded into two main perspectives-----psychological stress of parents with autistic children and the affiliate stigma experienced by parents. Further classification of the result can be seen in Table 1.

### 2.1 Psychological Stress of Parents with Autistic Children

Caring for a child with autism is not an immediate event, but rather a long-term negative event. In this way, the tone of the whole family tends to be slightly heavy when parents are raising this affected child, and it also tends to bring all kinds of stresses that damage the health of life. As early as in 1991, Dumas, Wolf, Fisman, and Culligan noted the stress experienced by parents by caring for children on the autism spectrum. Thus, autistic kids' parents or caregivers reported to have a higher level of parenting stress, both statistically and clinically. Dysphoria was found to be higher in children's mothers, both statistically and clinically [1]. Furthermore, Dabrowska and Pisula found that parents of offspring with neuroticism had lower levels of stress than caregivers of children with ASD. They also discussed issues such as dependence and restriction in relation to family opportunities. In particular, mothers with offspring with ASD maintained higher stress levels than

their husbands [2]. According to Miranda et al., who cited earlier study, mothers and fathers of children on the autism spectrum are more stressed than those of kids who are growing normally. As a result, stress levels reached clinically relevant levels in 77 percent of instances. Parents with children with other conditions, such as Down syndrome or ADD, are less worried than parents of children on the autistic spectrum [3]. Magalhães and Pereira conducted another important study in which they highlighted numerous issues and supports associated to increasing parental stress levels in children with ASD in Portugal. In this topic, issues such as grandparents' participation with ASD kids and the availability of formal and informal sources of knowledge are relevant. Decreased participation in parent-child groups, family friends, and social activities in general are attributed to parental concerns about possible judgment and bias when "sharing intimate information". Thus, the mothers' voluntary "protective choices" were understood to be somewhat justified. Their reluctance did not, however, prevent them from making friends or searching for information about ASD on the internet. As the authors explain, during the early stages of their children's development, moms require professional instruction and support. Mothers frequently believe that doctors ignore or postpone their child's development, a tendency that affects parents across cultures and countries. In addition to the existence of parental stress, Miranda, Mira, Berenguer, Rosello and Baixauli also investigated the stress levels of guardians of children diagnosed with ASD. Their final goal was to have a better understanding of the elements that influence behavioral disorders and improve coping mechanisms. Their research discovered that parents' stress levels were positively linked with ASD symptoms and behavioral issues in their children. Unfortunately, the mothers' stress levels rose in tandem with the severity of the children's behavioral issues and ASD symptoms. The less stressed parents were, according to Miranda et al., the more engaged in coping and supporting social functioning. The significance of this study can be seen in the authors' seemingly basic guidelines. Stress can be decreased if parents learn to buffer the impacts of stress" by using a variety of behavioral methods and promoting engagement orientation [4].

Additionally, those stress may lead to severe mental problems. Sun found that nearly 70% of primary caregivers of autistic children had psychological problems such as anxiety, depression, somatization, obsessive-compulsive disorder, hostility, interpersonal phobia, and paranoia, and had high social aggressive tendencies and irritability [5]. Foody, James, and Leader investigated parental stress, salivary biomarkers, and ambulatory blood pressure in caregivers of autistic children. Higher stress levels in parents of autistic kids can lead to increased health problems in them, according to the authors. The researchers looked at parenting duties, stress, nervousness, melancholy, adrenaline, alpha-amylase, and cardiovascular activity of 19 autistic children's mothers and fathers. Eventually, fathers exhibited higher blood pressure and changes in heart rate than mothers, while moms felt more parenting responsibilities, distress, worry, and depression than fathers [6].

## 2.2 Affiliate Stigma Experienced by Parents

The stigma associated with autism does not only occur in children with autism, but also in parents of them, resulting in affiliate stigma. Because of the stark contrast between the normal physical symptoms of kids with autism and their abnormal social behaviors,

caregivers of them with autism experience more affiliate stigma than caregivers of children with physical disabilities. In a qualitative study, Gray interviewed 32 parents of children with autism and found that 29 of these participants suffered from stigma. The complex etiology of the disorder and the lack of knowledge and understanding of autism in the general community contributed to the significant stigma that most guardians of children with autism experience. His study also found that mothers have more stigma than fathers, possibly because mothers are the direct caregivers, spend more time with their children, and take on more responsibility. The older the child with autism, the less often the parents felt stigma. Because of the stigma, many of them choose to isolate themselves and their entire family from social contact with the outside world [7]. After his first research, Gray's study of 53 parents of high-functioning youngsters with autism, conducted through semi-structured in-depth interviews, found that parents of children with autism experience significant stigma as a result of their child's inappropriate social behaviors. In social situations, children with autism are unable to conform to social norms as normal and engage in behaviors that defy social expectations, causing shame and embarrassment to their parents. Embarrassment is a major manifestation of the shame experienced by families. Some parents may feel hostile stares from others, and they may explain their child's behavior to alleviate the embarrassment and lack of understanding. Mothers of children with autism experience more actual stigma than fathers, mainly in the form of avoidance, overtly hostile looks, and rude name-calling. Gray also suggests that the normal physical appearance of most children with autism exacerbates parental stigma [8]. Farrugia, in a study of 12 children with autism, found that the stigma of the child's physical appearance was not only a stigma, but also a stigma. To further understand the affiliate stigma many parents confronted, Farrugia interviewed 12 parents of children with autism and found that all of them experienced stigma and had changed their social circles as a result of their child's disorder, and many had lost about half of their friends. In addition, he found that a child's autism diagnosis is an important factor in parental stigma and that parents can help counteract the stigma by learning more about the medical aspects of autism [9]. In addition to western findings, Due to cultural differences between the West and the East, Ai began to study the differences of autistic children's mothers in the US and Japan. She found that the group in Japan experienced more social stigma or rejection and felt more socially isolated than those moms in the United States [10]. For autistic children's parents in China, a study conducted by Parette and Brotherson found that they experienced significant stigma in China [11]. In 2010, Mak and Kwok studied 188 ASD children's parents in Hong Kong and found that parental stigma was prevalent and severe. The presence of stigma affected their mental health and the support from society and friends can help to alleviate parental stigma for them [12].

### 3 Conclusion

The key findings from primary research on the psychological stress and stigma associated with parents of autistic children are summarized in this systematic work. The study's first noteworthy finding is that most parents generally go through a psychological process of denial, self-blame and guilt, confusion, frustration, and acceptance from

the time they learn of their child's disability to full acceptance. Parents may experience a variety of mental problems during this long and difficult process. The psychological stress of guardians of children with disabilities was found to include lifelong caregiving, financial burden, family problems, and lack of achievement. Parents who accept their child's special situation behaviorally may blame themselves excessively. They are also reluctant to have contact with the outside world for fear of being asked about their child. In addition, parents may worry that their offspring will be discriminated against and bullied by other children in the outside world because of their disabilities, which may lead to overprotection of children with disabilities. Most caregivers of autistic kids have psychological problems such as anxiety, depression, somatization, obsessive-compulsive, hostile, interpersonal, and paranoia with high levels of socially aggressive tendencies and irritability. Such long-term negative beliefs immensely affect the physical and mental health of guardians of children with ASD.

Another finding of the research is that majority of parents with autistic children experience affiliate stigma, which refers to the negative internalized feelings of injustice and discrimination against people in vulnerable groups, such as relatives, friends, and caregivers. Caregivers' associative stigma reactions can have a direct impact on their family socialization and family member relationships, such as avoiding socialization, refusing social support, reducing help-seeking behaviors, and hiding and denying the fact that the family member has a disability. Almost all studies of affiliate stigma in this topic were qualitative or cross-sectional, concentrating mostly on the experiences of parents, particularly the mother. According to the studies included in this review, members of the family are subjected to negative treatment not just by people in the community, but also by relatives of their own family, resulting in a lack of support and isolation, particularly in eastern cultures. According to the studies cited, stigma impacts caregivers' psychological well-being and can lead to parental stress, higher caregiving load, and a reduced quality of life. More effort should be put into future studies to address stigma in fathers in order to quantify gender-based disparities in the experience. Following research should look into the complicated interactions between stigma and contextual factors, as well as individual traits and psychological effects. The development of theory-based models is a promising area for current study, as prior studies only reported descriptive data. Continued studies would have to include research objects that shift the emphasis away from parents and toward broader close family and friends. There is a lot of room for improvement, and perhaps future work will shift its focus away from investigations and toward interventions that help parents of children with autism feel less stigmatized.

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