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Autism Related Stigma and Psychological Well Being among Parents of Children with Autism

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Abstract

Parents of children with autism often manage not only the practical and emotional demands of caregiving, but also negative social responses toward their children and family. This literature review examines how autism-related stigma is associated with the psychological well-being of parents. Studies from Malaysia and other cultural settings were synthesised to explain the different forms of stigma experienced by parents, including public stigma, enacted stigma, courtesy stigma, perceived stigma, affiliate stigma, and self-stigma. The reviewed evidence indicates that repeated judgement, blame, exclusion, and misunderstanding may gradually be internalised by parents, contributing to shame, self-blame, social withdrawal, parenting stress, anxiety, depressive symptoms, and poorer family quality of life. Nevertheless, the relationship between stigma and well-being is not uniform. Its effects may vary according to cultural expectations, the child's behavioural and developmental characteristics, the availability of services, and parents' access to supportive relationships. Social support, resilience, parenting self-efficacy, self-compassion, mindfulness, positive meaning in caregiving, and adaptive coping appear to reduce the psychological burden associated with stigma. Existing literature remains dominated by quantitative and cross-sectional studies, while parents' lived experiences, particularly within the Malaysian context, have received less detailed attention. A qualitative approach is therefore needed to understand how parents interpret stigmatizing encounters, how these experiences influence their emotions and everyday lives, and what forms of support help them maintain psychological well being.

Keywords: Autism Related Stigma, Affiliate Stigma, Parents of Children with Autism, Psychological Well-Being, Social Support, Qualitative Research

Introduction

Raising a child with autism is often described through the practical demands of caregiving, such as arranging intervention, supporting communication, managing behavioural differences, and negotiating educational services. Yet these responsibilities do not take place in a social vacuum. Parents also have to respond to how other people interpret their child's behaviour and, by extension, how they judge the family. A child who becomes distressed in a public place may be labeled as undisciplined, while a parent may be criticized for being too permissive or incapable of controlling the child. These reactions can make ordinary family

activities emotionally demanding and may gradually affect how parents view themselves, their parenting role, and their place within the community.

The literature increasingly recognizes that autism related stigma is not limited to the autistic individual. It can extend to parents because of their close relationship with the child. Studies have used terms such as public stigma, enacted stigma, courtesy stigma, perceived stigma, affiliate stigma, and self stigma to describe different parts of this process. Although these concepts overlap, they capture an important progression: negative social attitudes may be observed or directly experienced, interpreted by parents, and eventually internalized as shame, self-blame, withdrawal, or a diminished sense of self worth. When this happens repeatedly, stigma becomes more than an unpleasant social encounter; it becomes a psychological burden that may influence stress, anxiety, depression, family functioning, social participation, and quality of life (Mak & Kwok, 2010; Werner & Shulman, 2013; Chan & Leung, 2021).

This chapter reviews literature on autism related stigma and psychological well being among parents of children with autism. The discussion first clarifies the main forms of stigma relevant to families, before examining parental psychological well being and the pathways through which stigma may affect it. Attention is also given to cultural context, characteristics of parents and children, and protective factors such as social support, resilience, parenting self-efficacy, self-compassion, mindfulness, and adaptive coping. Particular emphasis is placed on Malaysian evidence because social expectations, religion, family relationships, and access to services may shape how stigma is experienced and managed. The chapter concludes by identifying methodological and contextual gaps that support the need for a qualitative exploration of parents' lived experiences.

Understanding Autism-Related Stigma in the Family Context

Autism related stigma begins with social meanings attached to behaviours that depart from what is commonly expected. Difficulties in social communication, repetitive behaviour, sensory responses, emotional dysregulation, or intense distress may be visible to other people, but the reasons behind these behaviours are not always understood. In settings where autism awareness is limited, observers may interpret the child's behaviour as deliberate misconduct. Parents can then become targets of blame because child behaviour is often treated as evidence of parental competence. This is especially difficult when the child's needs are not immediately visible and when strangers expect the parent to explain or justify what is happening.

The experience is commonly described at several interconnected levels. Public stigma refers to society's negative stereotypes and prejudicial attitudes toward autism and families associated with it. Enacted stigma concerns actual discriminatory behaviour, including exclusion, ridicule, rejection, unfair treatment, or insensitive comments. Courtesy stigma occurs when negative judgement directed at the child extends to parents or other family members. Perceived stigma involves parents' awareness or expectation that other people hold negative views about their child and family. Affiliate stigma, sometimes discussed alongside self stigma, occurs when parents internalize these social reactions and apply them to themselves, leading to negative thoughts, painful emotions, and avoidant behaviour.

Mak and Kwok's (2010) study in Hong Kong remains influential because it explained internalisation as a process rather than a single reaction. Their findings suggested that courtesy stigma may develop into affiliate stigma directly or through parents' interpretations of controllability, responsibility, and self blame. In other words, parents may be particularly vulnerable when they believe that society considers them responsible for the child's behaviour or condition. The study also showed that different sources of support were related to affiliate stigma and psychological well-being in different ways, indicating that the social environment may either reinforce or interrupt the internalisation process.

Later research has supported the view that stigma is multidimensional. Yip and Chan (2022), using a longitudinal design, found that public and courtesy stigma predicted later self stigma, perceived stress, depression, and anxiety among parents of children with autism. Qualitative evidence adds depth to this pattern. Ng and Ng (2022) reported that Chinese parents encountered negative labelling from schools and health professionals, peer bullying directed at their children, stereotypes about autism, and judgement related to behaviour in the community. Parents responded in different ways. Some apologised, ignored comments, concealed the diagnosis, or withdrew, while others challenged unfair treatment. These responses show that parents are not passive recipients of stigma, but their options are often shaped by power differences, emotional resources, and the perceived safety of the situation.

Forms and Everyday Expressions of Stigma Experienced by Parents

In everyday life, stigma may be obvious or subtle. Direct experiences include insults, staring, blaming, exclusion from social events, rejection by schools, and dismissive treatment by service providers. Indirect experiences may involve awkward silence, avoidance, unsolicited parenting advice, or repeated suggestions that the child would improve if the parents were stricter. Such encounters can create a sense that the family is being watched and evaluated. Over time, parents may begin anticipating judgement even when no explicit comment is made.

Anticipated stigma can influence family decisions. Parents may avoid restaurants, religious gatherings, celebrations, playgrounds, or visits to relatives because they expect the child's behaviour to attract negative attention. They may conceal the diagnosis or provide incomplete explanations to reduce the risk of rejection. Although avoidance can provide short-term relief, it may also narrow the family's social world and reduce opportunities for support. The 2026 network analysis by Sun et al. identified behavioural stigma, including avoidance and withdrawal, as a central element linking affiliate stigma with parenting distress and poorer quality of life. This suggests that withdrawal is not merely an outcome of distress; it may also help maintain the wider stigma well being cycle.

The child's developmental stage may also change parental exposure to stigma. Ji et al. (2022) found that Chinese parents of school aged autistic children reported more affiliate stigma than parents of preschool children. One possible explanation is that social and educational expectations become more demanding as children grow older. Behaviours that were previously tolerated as age-related may become more noticeable, while school participation increases contact with teachers, peers, and other parents. The finding reminds researchers that stigma is not static. It can change across diagnosis, school entry, adolescence, and transitions to adulthood.

Psychological Well-Being among Parents of Children with Autism

Psychological well-being is broader than the absence of mental illness. It includes emotional balance, self-acceptance, supportive relationships, a sense of competence, meaningful participation, and satisfaction with life. For parents of children with autism, well-being is shaped by caregiving responsibilities, financial and service demands, family relationships, hopes for the child's future, and the social responses they encounter. A parent may continue performing daily responsibilities while feeling emotionally exhausted, isolated, or uncertain about personal identity. For this reason, research has used several indicators, including perceived stress, parenting stress, caregiving burden, depression, anxiety, self-esteem, life satisfaction, subjective well being and family quality of life.

Werner and Shulman (2013) found that subjective well being among family caregivers of people with developmental disabilities was below normative levels and was especially low among caregivers of individuals with autism. Affiliate stigma, self-esteem, social support, and positive meaning in caregiving were among the strongest predictors. Their findings suggest that well-being reflects both risk and protective processes. Stigma may reduce well being, but parents' sense of worth, available support, and ability to identify meaning in caregiving can influence how strongly it is affected.

Family quality of life is therefore an important outcome. It reflects not only individual mood but also family interaction, parenting, physical and material well being, disability related support, and satisfaction with family life. Dai et al. (2024) followed parents after a child's autism diagnosis and found that parenting self efficacy and social support predicted better family quality of life. The early period following diagnosis may be especially sensitive because parents are simultaneously learning about autism, making service decisions, communicating with relatives, and adjusting expectations. Stigma during this period may complicate adaptation by adding shame or fear of judgement to an already demanding transition.

Relationship between Autism-Related Stigma and Parental Psychological Well-Being

Across the literature, stigma is consistently associated with poorer parental psychological outcomes, although the strength of this relationship varies across settings and measures. Chan and Leung (2021) demonstrated that enacted and felt stigma helped explain the relationship between child autism characteristics and parental depression and anxiety. Their findings support a mediation pathway: child-related challenges may increase exposure to negative social reactions, and those reactions may contribute to emotional distress. This interpretation avoids the assumption that parental distress results only from the child's condition. It recognises that social judgement can add a preventable layer of burden.

Studies focusing on internalised stigma report a similar pattern. Öz et al. (2020) found that mothers' internalised stigma was positively related to depression and anxiety and negatively related to quality of life and life satisfaction. Gabra et al. (2021) likewise identified an interconnected pattern involving stigma, caregiving burden, psychiatric symptoms, and reduced quality of life among Egyptian parents. Parents with severe burden reported greater stigma and more psychological symptoms. Although cross-sectional designs cannot establish a definite causal order, the findings suggest that stigma, burden, and mental health may reinforce one another.

Longitudinal evidence strengthens this argument. Yip and Chan (2022) found that public and courtesy stigma predicted later self stigma, perceived stress, depression, and anxiety over a twelve-month period. Chan et al. (2023) further showed that self stigma predicted greater parenting stress, which in turn was linked to reduced parental warmth and increased hostility over two years. The implications extend beyond parents' private emotional experiences. When stigma increases parenting stress, it may influence parent and child interactions and the wider family environment. Supporting parental well being is therefore relevant not only for the parent but also for the quality of care and relationships within the family.

Recent studies have highlighted the seriousness of this pathway. W. Wang et al. (2024) reported that affiliate stigma and social alienation mediated the association between perceived discrimination and suicidal risk among Chinese parents. The prevalence estimates reported in that study should be interpreted within its specific sample and design, but the findings indicate that stigma related distress can reach clinically significant levels. They also underline the need for researchers and practitioners to assess parental safety and mental health rather than assuming that stigma is merely a social inconvenience.

Quality of life is another repeatedly studied outcome. Ye et al. (2024) found that affiliate stigma predicted lower family quality of life both directly and indirectly through reduced parenting self efficacy. Salleh et al. (2024) reported an inverse relationship between affiliate stigma and both resilience and quality of life among Malaysian parents, while resilience was positively related to quality of life. Sun et al. (2026) further showed that cognitive stigma was negatively connected with subjective quality of life and that behavioural stigma was strongly linked with parenting distress. Taken together, these studies suggest that stigma affects well being through thoughts, emotions, social behaviour, and beliefs about parenting competence.

Nevertheless, the relationship is not identical in every study. Chu et al. (2020), studying Malaysian parents, found low reported affiliate stigma and only weak associations with stress and quality of life after demographic factors were controlled. The authors suggested that cultural and religious beliefs may support acceptance of the child's condition. This finding does not mean that stigma is absent in Malaysia. Rather, it illustrates that parents may interpret, report, or manage stigma differently. It also supports the need for qualitative research capable of exploring contradictions that standardised scales may overlook.

Factors that Shape the Experience and Impact of Stigma

The impact of stigma depends partly on parent, child, family, and environmental characteristics. Child behaviour and autism severity may increase public visibility and the likelihood of negative reactions. Lyu et al. (2022) found that symptom severity was associated with parental affiliate stigma through self esteem and family functioning. This suggests that child characteristics do not influence stigma in isolation. Their effects are filtered through parents' confidence and the family's capacity to communicate, cooperate, and adapt.

The meaning parents assign to autism is equally important. In Mak and Kwok's (2010) attribution model, beliefs about responsibility and controllability contributed to self blame and internalisation. Parents who accept cultural myths that autism results from poor parenting may experience stronger shame. By contrast, accurate understanding can reduce

blame, although knowledge alone may not be sufficient. Pyszkowska et al. (2026) found a complex relationship between autism knowledge, cognitive fusion, social support, self stigma, and distress. This suggests that information should be accompanied by emotional and practical support. A parent may understand autism well and still feel distressed if the surrounding community remains rejecting.

Cultural context influences both exposure and response. Alhwaiti (2024) showed that stigma, emotion regulation, future anxiety, and quality of life need to be interpreted cross culturally. Social expectations regarding family reputation, gender roles, disability and obedience may shape what parents fear and how openly they discuss the diagnosis. Religious beliefs may provide acceptance and meaning for some families, as suggested by Chu et al. (2020), but they may also coexist with community misconceptions. It is therefore important not to assume that all parents from the same cultural or religious background experience stigma in the same way.

Protective Factors and Coping Resources

Although stigma is harmful, many parents demonstrate resilience and develop effective ways of protecting their well being. Social support is among the most frequently identified resources. Support can be emotional, informational, practical, or affirmational. Family members may share caregiving, friends may provide companionship, professionals may offer clear guidance, and other parents may provide understanding based on similar experience. Mak and Kwok (2010) found that different sources of support related differently to affiliate stigma and well being, while Dai et al. (2024) showed that subjective support and the ability to use available support predicted family quality of life.

Resilience refers to the capacity to adapt while facing ongoing demands. It does not imply that parents should tolerate discrimination without assistance. Rather, resilience develops through personal strengths, supportive relationships, accessible services, and opportunities to regain a sense of control. Salleh et al. (2022) identified themes of life adjustment, perceived stigma, resilience, and quality of life among Malaysian parents. Their findings portrayed resilience as part of a continuing adjustment process rather than a fixed personality trait. Salleh et al. (2024) later found that resilience was positively related to quality of life and inversely related to affiliate stigma.

Chen et al. (2025) further examined life satisfaction and ostracism in the relationship between resilience and affiliate stigma. The study suggests that resilience may support well being, but social exclusion can weaken its benefits. This is an important ethical point. Programmes should not place the full responsibility for coping on parents while leaving discriminatory conditions unchanged. Individual resilience and social inclusion need to be strengthened together.

Self-compassion offers a related form of protection. Wong et al. (2016) found that affiliate stigma was associated with psychological distress among parents with low self-compassion but not among those with high self-compassion. Self compassion involves responding to personal pain with kindness, recognising that difficulty is part of shared human experience, and avoiding excessive identification with negative thoughts. For parents who have been

blamed or judged, this approach may reduce the tendency to repeat society's criticism internally.

Mindfulness has also received considerable attention. Chan and Lam (2017) found that trait mindfulness reduced the strength of the associations between public and courtesy stigma and depression, anxiety, and caregiving burden. Yip and Chan (2022) reported similar longitudinal protective effects. Y.N. Wang et al. (2024) found that coping styles helped explain the association between mindfulness and affiliate stigma, suggesting that mindful awareness may support more adaptive responses to difficult social situations. Nonattachment, which involves relating to experiences without rigidly defining the self through them, was also found to reduce the longitudinal impact of experienced and anticipated discrimination (Chan et al., 2022).

General self efficacy may provide additional protection. Tong et al. (2024) found that courtesy stigma was positively associated with anxiety and depressive symptoms, whereas self efficacy was negatively associated with both. The association between stigma and anxiety was weaker among parents with higher self efficacy. These findings indicate that interventions should not focus only on reducing symptoms. They should also strengthen parents' confidence, coping flexibility, self-compassion, and ability to seek support while challenging the social conditions that produce stigma.

Evidence from Malaysia

Malaysian research remains limited compared with the growing literature from Hong Kong and mainland China, but the available studies offer several important insights. Chu et al. (2020) reported relatively low levels of affiliate stigma and weak relationships between stigma, stress, and quality of life. They proposed that cultural and religious beliefs may contribute to acceptance. This finding is valuable because it challenges a simple assumption that stigma produces the same effect in every setting. At the same time, self-report scores may not fully capture experiences that parents normalise, minimise, or hesitate to disclose.

Salleh et al. (2022) used qualitative inquiry to explore Malaysian parents' experiences and identified perceived stigma alongside life adjustment, resilience, and quality of life. Parents' accounts showed that stigma existed within the broader realities of caregiving and adaptation. The study was particularly important because it moved beyond measuring whether stigma was present and examined how parents understood it in their daily lives. In 2024, Salleh and colleagues reported that greater affiliate stigma was associated with lower resilience and quality of life in a larger sample from two public hospitals in Kelantan. The findings also showed that family and child characteristics were associated with these outcomes.

There is therefore a need for research that listens closely to how Malaysian parents describe stigma in their own words. A qualitative approach can explore who produces stigma, where it occurs, how parents respond in the moment, what feelings continue afterwards, and what helps them maintain well-being. It can also examine whether parents distinguish between judgement directed at the child and judgement directed at themselves. Such detail is difficult to obtain from total scale scores alone.

Methodological Limitations and Gaps in the Literature

A large proportion of the literature is cross sectional and relies on self report questionnaires. These studies are useful for identifying associations, but they cannot fully establish how stigma and well being influence each other over time. Parents who are already distressed may perceive social situations more negatively, while repeated discrimination may increase distress. Longitudinal studies such as those by Yip and Chan (2022) and Chan et al. (2023) provide stronger evidence of temporal relationships, yet more research is needed across different cultural contexts.

The literature also uses overlapping terminology and measurement approaches. Courtesy stigma, affiliate stigma, self-stigma, perceived stigma, and internalised stigma are sometimes treated as distinct constructs and sometimes used almost interchangeably. This makes comparisons difficult. Studies may measure beliefs, emotions, and behaviour within one total score even though each component may relate differently to well being. Sun et al. (2026) demonstrated the value of separating cognitive, affective, and behavioural components, with behavioural withdrawal emerging as particularly central.

Most importantly, quantitative associations do not fully explain lived meaning. A scale can show that stigma correlates with depression, but it cannot reveal whether a particular parent felt hurt by a relative's comment, stopped attending family events, questioned personal competence, or later found strength through another parent's support. Qualitative interviews are well suited to exploring these sequences. They can identify contradictions, turning points, and culturally specific language that may not appear in existing measures.

The literature also tends to focus more on negative outcomes than on how parents preserve dignity, meaning, and psychological well being. Protective factors are often tested as statistical moderators, but less is known about how parents actually cultivate self-compassion, use faith, negotiate family relationships, decide when to disclose the diagnosis, or challenge discriminatory treatment. Understanding these processes may support interventions that are both culturally relevant and grounded in parents' everyday realities.

Conceptual Synthesis for the Present Study

The reviewed evidence supports a conceptual pathway in which social attitudes toward autism create exposure to public and enacted stigma. Parents observe or experience judgement, blame, exclusion, and discrimination. These experiences may then become perceived or anticipated stigma, especially when parents expect similar reactions in future situations. When negative messages are internalized, affiliate or self stigma may develop through self blame, shame, reduced self-worth, or avoidance.

Internalised stigma can influence psychological well being through several connected pathways. Emotionally, it may contribute to stress, anxiety, depression, and caregiving burden. Cognitively, it may weaken self esteem and parenting self efficacy. Socially, it may encourage concealment, avoidance, social anxiety, and isolation. At the family level, it may affect family quality of life, parenting stress, and parent child interactions. These pathways are not inevitable. Social support, resilience, self compassion, mindfulness, non attachment, adaptive coping, faith, family acceptance, and professional support may reduce or reshape the impact.

This synthesis also suggests that stigma should be examined as a process situated within culture and daily life. The same public reaction may be interpreted differently depending on parents' beliefs, previous experiences, family relationships, and available resources. A qualitative study can therefore investigate not only whether stigma affects well being, but how the effect unfolds. It can explore the situations that parents find most difficult, the meanings they attach to those situations, their immediate and longer term emotional responses, the strategies they use, and the support they consider helpful.

Chapter Summary

The literature shows that parents of children with autism may experience stigma through public stereotypes, direct discrimination, judgement by association, anticipated rejection, and internalised shame. These experiences can affect stress, anxiety, depression, self esteem, parenting confidence, social participation, family relationships and quality of life. Longitudinal and qualitative studies indicate that stigma is not a single event but a process that may continue through parents' thoughts, emotion and behaviour.

At the same time, parental outcomes vary. Social support, resilience, self compassion, mindfulness, self efficacy, coping style, family acceptance and cultural or religious meaning can reduce or alter the psychological impact of stigma. Malaysian findings are still limited and somewhat mixed, which strengthens the case for a qualitative study that examines parents' lived experiences in context. By exploring how stigma is encountered, understood, and managed, the present study can contribute a more complete account of psychological well being among parents of children with autism and provide a basis for culturally responsive support.

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