



## Maternal Caregiving Stress in Autism and the Role of Awareness: Psychosocial Burden, Coping Mechanisms and Implications for Support Systems: A Review

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### Abstract

April, observed globally as World Autism Awareness Month (WAAM), provides an important platform to highlight not only the needs of individuals with Autism Spectrum Disorder (ASD) but also the often-overlooked experiences of their caregivers. Among these, mothers of young adults with ASD face persistent and evolving stressors that extend beyond childhood into adulthood. While early childhood caregiving has received significant research attention, the stress experienced by mothers of young adults with ASD remains comparatively underexplored, particularly in low- and middle-income countries. This review synthesizes interdisciplinary literature to examine the multidimensional stress experienced by mothers during the transition of individuals with ASD into adulthood. This review synthesizes existing literature on maternal caregiving stress in autism, focusing on psychological burden, social stigma and systemic gaps during the transition to adulthood. Importantly, the paper examines how awareness initiatives, especially those intensified during April, contribute to reducing stigma, enhancing social support, and promoting access to services. By linking caregiving challenges with awareness-driven interventions, the review underscores the transformative potential of sustained advocacy and public engagement in improving caregiver well-being and fostering inclusive societies.

**Keywords:** Autism Spectrum Disorder (ASD); Coping Strategies; Maternal Caregiving Stress; Psychological Burden; World Autism Awareness Month (WAAM)

### Introduction

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition characterized by differences in social communication and patterns of behaviour (American Psychiatric Association, 2013). As individuals with ASD increasingly transition into adulthood, caregiving responsibilities persist most often intensifying rather than diminishing.

April, recognized worldwide as World Autism Awareness Month, serves as a crucial period for reflection, advocacy and education. Anchored by World Autism Awareness Day, this month amplifies global conversations about autism, inclusion and support systems. While awareness campaigns frequently centre on children with autism, the lived realities of caregivers, particularly mothers of young adults, remain underrepresented.

This review synthesizes interdisciplinary literature to examine the multidimensional stress experienced by mothers during the transition of individuals with ASD into adulthood. Key stressors include persistent behavioral challenges, caregiving burden, social stigma, financial strain and uncertainty regarding long-term care (Bitsika & Sharpley, 2004). The review further evaluates adaptive and maladaptive coping

strategies, emphasizing resilience, social support networks, and institutional interventions. Drawing on global and Indian contexts, the paper highlights systemic gaps in adult autism services and aligns caregiving challenges with Sustainable Development Goals (SDGs), particularly those related to health, gender equality, and reduced inequalities. The review concludes with recommendations for policy, practice, and research to strengthen caregiver support systems.

Autism Spectrum Disorder (ASD) is characterized by persistent deficits in social communication and interaction, alongside restricted and repetitive patterns of behavior (American Psychiatric Association, 2013). Over the past few decades, increased awareness, improved diagnostic tools, and early interventions have led to a growing population of individuals with ASD surviving into adulthood. This demographic shift has profound implications for families, particularly mothers who often serve as primary caregivers.

In many cultural contexts, including India, mostly mothers assume the primary caregiving role. Their experiences are shaped by long-term emotional, social and economic pressures. Recognizing and addressing maternal caregiving stress is therefore essential, and awareness initiatives during April provide a strategic opportunity to bring these issues into public discourse.

### *Theoretical Frameworks of Caregiving Stress*

#### *Stress Process Model*

The Stress Process Model (Pearlin *et al.*, 1990) provides a useful framework for understanding caregiving stress. It conceptualizes stress as arising from primary stressors (e.g., caregiving demands) and secondary stressors (e.g., role strain, financial burden), moderated by coping mechanisms and social support.

#### *Transactional Model of Stress and Coping*

Lazarus and Folkman's (1984) model emphasizes cognitive appraisal, how caregivers perceive and interpret stressors (Biggs *et al.*, 2017). Mothers who perceive caregiving as meaningful may experience less distress compared to those who perceive it as overwhelming.

#### *Family Systems Perspective*

This perspective views caregiving stress as embedded within family dynamics. The presence of a member with ASD affects all family relationships, often leading to role shifts and emotional strain.

#### *Maternal Caregiving Stress Across the Lifespan*

##### *Psychological and Emotional Burden*

Mothers of individuals with ASD report significantly higher levels of stress, anxiety, and depression compared to other caregiver groups (Estes *et al.*, 2013). As children transition into adulthood, new uncertainties emerge, including concerns about independence, employment and long-term care.

Awareness campaigns during WAAM play a vital role in normalizing conversations around caregiver mental health. Public discussions, storytelling and advocacy reduce the invisibility of caregiver struggles, encouraging help-seeking behaviour.

##### *Behavioral Challenges and Lifelong Dependency*

Young adults with ASD may continue to exhibit behavioural and functional challenges requiring sustained supervision (Shattuck *et al.*, 2012). These demands contribute to chronic stress and limit caregivers' personal and professional opportunities.

Awareness initiatives can help shift societal expectations, from viewing autism solely as a childhood condition to recognizing it as a lifelong spectrum. This shift is critical for developing adult-centric services.

### *Social Stigma and Isolation*

Stigma remains one of the most significant contributors to caregiving stress (Gray, 2002). Mothers often experience social withdrawal due to misunderstanding and judgment.

During April, awareness campaigns, through media, educational institutions and community events help dismantle stereotypes. Increased visibility fosters empathy and inclusion, reducing social isolation for both individuals with ASD and their caregivers.

### *Financial and Structural Challenges*

The transition to adulthood often leads to a decline in institutional support, increasing financial burden on families (Taylor & Seltzer, 2011). In India and other low-resource settings, services for adults with ASD are particularly limited.

### *Awareness as an Intervention: Why April Matters*

World Autism Awareness Month (WAAM) serves as an advocacy platform to highlight these systemic gaps, encouraging policymakers to invest in long-term support systems such as vocational training, supported employment and residential care. Awareness is not merely symbolic; it functions as a social intervention with tangible outcomes.

### *Reducing Stigma*

Public awareness campaigns challenge misconceptions about autism, promoting acceptance rather than pity or exclusion. Reduced stigma leads to greater community participation and support for caregivers.

### *Enhancing Social Support*

Awareness fosters the development of peer networks and support groups. Mothers benefit from shared experiences, emotional validation, and practical advice.

### *Promoting Early and Continued Intervention*

Increased awareness encourages early diagnosis and sustained intervention across the lifespan. It also highlights the need for adult services, often neglected in policy frameworks.

### *Influencing Policy and Funding*

Advocacy efforts during WAAM can influence government policies and funding priorities, leading to improved services and caregiver support systems.

### *Coping Strategies in the Context of Awareness*

#### *Adaptive Coping Strategies*

#### *Social Support and Community Engagement*

Participation in awareness events—seminars, workshops, and campaigns, helps mothers connect with others facing similar challenges. This reduces isolation and enhances resilience.

#### *Knowledge Empowerment*

Awareness initiatives provide access to information about autism, rights and services. Informed caregivers are better equipped to navigate challenges and advocate for their children.

#### *Mindfulness and Emotional Regulation*

Programs conducted during WAAM often include stress management workshops, promoting techniques such as mindfulness and counseling (Dykens *et al.*, 2014).

#### *Advocacy and Meaning-Making*

Engagement in awareness campaigns allows mothers to transform personal struggles into advocacy, fostering a sense of purpose and empowerment.

### *Maladaptive Coping and the Need for Awareness*

Without awareness and support, caregivers may resort to maladaptive coping strategies such as withdrawal, denial, or neglect of self-care. Awareness initiatives help identify these risks and promote healthier alternatives.

### *Indian Context and Global South Perspectives*

In India, caregiving is deeply embedded within family structures, with limited institutional support. Mothers often sacrifice careers and personal aspirations to provide full-time care.

Key challenges include:

- Limited adult autism services
- Lack of trained professionals
- Social stigma and lack of awareness
- Financial constraints

NGOs and parent-led organizations play a crucial role in bridging these gaps through community-based programs, vocational training, and advocacy.

### *Indian Context: Awareness and Action*

In India, awareness about autism has grown significantly in recent years, yet gaps remain, especially regarding adult services. Observances of WAAM by NGOs, educational institutions and community organizations have contributed to:

- Increased public understanding of autism
- Expansion of parent support networks
- Advocacy for inclusive education and employment
- Recognition of caregiver mental health

Organizations working at grassroots levels play a critical role in translating awareness into action.

## **Discussion**

Caregiving in autism is not a time-bound responsibility; rather, it evolves across the lifespan. During childhood, the focus is on diagnosis, therapy, and education, whereas in adulthood, concerns shift toward independence, employability, social inclusion, and long-term care (Taylor & Seltzer, 2011). This transition phase is marked by a paradox: while societal expectations of independence increase, formal support systems often decline.

### *From Awareness to Acceptance and Action*

There is a growing global shift from “awareness” to “acceptance” and “inclusion.” Awareness is the first step (Lovell *et al*, 2012), The next steps are focussed sustained efforts:

- Building inclusive communities
- Creating employment opportunities
- Ensuring lifelong support systems
- Supporting caregiver well-being

April serves as a starting point, but meaningful change requires year-round commitment.

### *Research Gaps and Future Directions*

Despite increasing research (Ooi *et al.*, 2016) on autism caregiving, several critical gaps remain.

*Longitudinal studies on caregiver well-being:*

Most studies are cross-sectional, limiting understanding of how maternal stress evolves over time. Longitudinal research is needed to track changes across life stages, especially during key transitions such as entry into adulthood and to assess long-term psychological and physical health outcomes (Smith *et al.*, 2012; Taylor & Seltzer, 2011).

*Cultural Dimensions of Caregiving:*

Existing literature is largely based on Western populations, with limited representation from the Global South. Cultural norms, gender roles, and stigma significantly influence caregiving experiences, particularly in countries like India where mothers often bear primary responsibility (Gray, 2002). Future studies should adopt culturally sensitive and comparative frameworks.

*Intervention-based Research in Low-Resource Settings:*

There is a lack of evidence on scalable, cost-effective interventions tailored to low- and middle-income contexts. Community-based models, parent-led support groups, and low-cost mental health interventions require systematic evaluation for feasibility and impact (Dykens *et al.*, 2014).

*Integration of Caregiver and Individual Outcomes:*

Research often treats caregiver well-being and individual outcomes separately, despite their interdependence. Integrated, family-centered approaches are needed to examine how caregiver stress affects developmental outcomes in individuals with ASD and vice versa (Shattuck *et al.*, 2012).

*Role of Awareness and Advocacy:*

While initiatives such as World Autism Awareness Month have increased visibility, their direct impact on reducing caregiver stress and improving support systems remains underexplored. Future research should evaluate how awareness translates into measurable social, psychological, and policy-level outcomes.

In many socio-cultural contexts, including India, caregiving responsibilities are disproportionately borne by mothers due to entrenched gender roles. This sustained caregiving, often extending over decades, exposes mothers to chronic stress, emotional exhaustion, and social isolation. Understanding the nature of this stress and identifying effective coping strategies is critical for both caregiver well-being and the quality of life of individuals with ASD (Smith *et al.*, 2012).

*Linking Awareness to Sustainable Development Goals (SDGs)*

Awareness initiatives during April contribute to multiple SDGs:

- **SDG 3 (Good Health and Well-being):** Promoting caregiver mental health
- **SDG 5 (Gender Equality):** Recognizing unpaid caregiving work of mothers
- **SDG 10 (Reduced Inequalities):** Encouraging inclusion of individuals with ASD
- **SDG 4 (Quality Education):** Supporting inclusive learning environments

By integrating awareness with development goals, WAAM becomes a catalyst for systemic change.

*From Awareness to Acceptance and Action*

There is a growing global shift from “awareness” to “acceptance” and “inclusion.” While awareness is the first step, sustained efforts must focus on:

- Building inclusive communities
- Creating employment opportunities
- Ensuring lifelong support systems
- Supporting caregiver well-being

April serves as a starting point, but meaningful change requires year-round commitment.

### Conclusion

Maternal caregiving for young adults with ASD is characterized by enduring stress shaped by psychological, social, and systemic factors. While caregiving can be a source of resilience and meaning, the absence of adequate support systems places mothers at risk of burnout and compromised well-being. Addressing caregiving stress requires a multi-level approach involving families, communities, institutions, and policymakers. Strengthening coping mechanisms and expanding support structures is essential for improving the quality of life of both caregivers and individuals with ASD.

World Autism Awareness Month provides a powerful platform to highlight the often-invisible stress experienced by mothers of young adults with ASD. Awareness initiatives play a crucial role in reducing stigma, enhancing social support, and advocating for systemic change. By centering caregiver experiences within awareness campaigns, society can move toward a more inclusive and supportive framework that benefits both individuals with autism and their families.

### Conflict of Interest

The authors declare that they have no competing interests.

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