



# Impact Of Autism On Families: Challenges, Coping And Community Resources

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**Abstract:** The emotional bond between parents and their children is fundamental to family life. The arrival of a healthy, joyful infant into a family is a cherished moment, filled with hope for a typical, thriving child. However, when parents discover their child has a disability, it can be a devastating shock. Autism Spectrum Disorder (ASD) is a neurodevelopmental condition marked by social communication deficits and repetitive behaviours. Caregiving for individuals with ASD often involves substantial physical and emotional demands, with caregivers providing lifelong support. This extended caregiving has wide-ranging consequences for caregivers, including physical health issues, social isolation, financial strain, and psychological distress. Mothers, in particular, bear the brunt of these demands, experiencing higher stress levels and mental health challenges. The impact of caregiving extends to the entire family, affecting marital relationships, siblings, and even grandparents. This burden is referred to as 'caregiver burden' and encompasses various stressors. To alleviate this burden, healthcare providers should involve caregivers in care teams, promote self-compassion, provide education and support, and coordinate assistance. Initiatives like Ummeed Society Chandigarh, Mom's Belief by Nitin Bindlish, and the Sahyogi Scheme aim to support caregivers and create a more inclusive environment for individuals with special needs. Recognizing and addressing caregiver burden is crucial for enhancing the well-being of both caregivers and care recipients.

**Index Terms:** Autism Spectrum Disorder (ASD), caregiver burden, caregiving, family impact, psychological distress, support initiatives.

## I.INTRODUCTION

The emotional connection involving parents and their children lies at the heart of a family's existence. In a family setting, parents hope for a typical, healthy kid. A new, little, loveable, and healthy infant entering the family is a joyous occasion for both the parent and everyone else connected. When such parents discover their child has a disability, they are brutally shocked.

## 1.1 Autism Spectrum Disorder and its Challenges

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social communication and the presence of restricted interests and repetitive behaviours (American Psychiatric Association, 2022). ASD is a neurobiological disorder influenced by both genetic and environmental factors affecting the developing brain. In comparison to neurotypical children of the same age, children on the spectrum frequently require extensive care and there is an elevated amount of reliance on caregivers for almost everything. Due to their lack of interpersonal abilities, emotional intelligence, and physical control, these children may still be dependent on adults. The requirement of the caregivers goes beyond its usual pattern, frequently continuing into maturity as well. The impact of such dependency for prolonged care on the carer is undeniable, even though instances differ in severity and therefore in their outcomes. The profoundness of the impairment tends to raise difficulties for parents as well as the entire family and can occasionally lead to major disruption and dysfunction in the family

The term 'caregiver burden' pertains to the various strains endured by individuals, including physical, psychological, emotional, social, and financial stressors, arising from their caregiving responsibilities.

## II. CAREGIVER BURDEN RELATED TO ASD

Caregiver burden has been studied in severe mental illnesses (SMIs), with predictors often including factors such as illness duration, early onset, disability, lack of caregiving assistance, insufficient social support, low income, advanced age, limited education, depression, and having another family member in need of care.

Caregiver burden is a multifactorial construct. The distinction between 'subjective' and 'objective' burden also adds to the complexity of the issue. 'Objective burden' refers to the physical or instrumental provision of aid to care recipients (e.g. the number of hours of care provided) while 'subjective burden' relates to the emotional or psychological toll that 'objective burden' has on caregivers (e.g. stress, anxiety).

The caregiver burden in Autism Spectrum Disorder (ASD) is marked by various challenges, including communication difficulties, unpredictable behaviours, social isolation, and high levels of psychological distress among parents. This caregiving responsibility predominantly falls on mothers, who bear the brunt of their demands. Extensive research has consistently indicated that mothers of children with ASD experience higher levels of stress, reduced well-being, and heightened psychiatric issues like depression and anxiety in comparison to typically developing children (Eisenhower et al., 2005; Hayes et al., 2013; Hoffman et al., 2008; Hoffman et al., 2009; Singer et al., 2006).

## 2.1 Aftermath of Caregiving

The challenges posed by the child's behaviours can indirectly impact their ability to function effectively and adequately. The continuous demands of caregiving, both physical and mental, often lead caregivers to prioritize the needs of those they care for over their health, effectively making them invisible patients with severe health problems.

Here are the impacts of caregiving across various dimensions:

**a) Physical Impact:**

Caregiving encompasses tasks like assisting with daily physical needs such as toileting, feeding, dressing, and grooming. Caregivers, frequently experience chronic sleep disturbances and exhaustion. This can result in problems like gastrointestinal discomfort, headaches, migraines, and a weakened immune system, increasing the risk of infections and cancer. Fathers might experience elevated blood pressure and irregular heartbeats, while mothers may report higher levels of anguish, stress, and responsibility (Fletcher et al., 2012).

**b) Social Impact:**

The time and effort demanded by caregiving can lead to feelings of isolation from others. Families with a member requiring ongoing medical care often experience disruptions in their social lives.

**c) Financial impact:**

Families with lower incomes, particularly those without medical insurance, often bear a significant portion of these costs. In cases of developmental disabilities, mothers in particular tends to leave their job to care for the child. These financial burdens and unexpected expenses related to prolonged illness can contribute to caregiver stress.

**d) Psychological Impact:**

Families dealing with a significant illness in a family member frequently endure psychological distress. This distress arises from caregiving responsibilities, as well as from witnessing the medical condition of their child (Weitzner et al., 1999). Parents undergo emotional turmoil and grief due to the loss of future dreams, aspirations, and opportunities.

**e) Marital Relationship of parents:**

Parents of children with ASD also often report lower relationship satisfaction, less dyadic consensus, high divorce rates and more psychopathology in these families. Mothers in these families tend to experience lower marital satisfaction, reduced affection expression, and decreased family adaptability and cohesion (Brobst et al. 2009; Gau et al. 2012).

**f) Impact on the family members:**

Families often stop doing activities they engage in before the signs of ASD become prominent (Desai et al., 2012). Growing up in a household with an autistic sibling can be challenging for siblings. They not only have to deal with a sibling who is difficult to understand, has few interests, and is unsociable, but they also have to tolerate some very unusual behaviours. Additionally, siblings often resent that the other child receives more parental time and attention (Desai et al., 2012).

Grandparents find it hard to accept the reality and are sometimes uncertain about how to respond. They worry about the effects of autism on their adult children (the parents), other grandchildren, and future generations, unlike parents who tend to focus on the specific needs of the autistic child. Families often worry about who will take care of the child after their demise or when they are no longer able to assist.

### III. PRACTICAL RECOMMENDATIONS TO ALLEVIATE CAREGIVER BURDEN

**1. Involve caregivers on the care team:** Physicians caring for chronically ill patients should actively inquire about potential issues caregivers might be facing during clinic visits. Treatment plans should accommodate the needs of both the patient and the caregiver.

**2. Emphasise Self-Compassion:** Caregivers frequently have chronic health conditions and tend to neglect their well-being. Recommending respite care or other support can offer relief to caregivers, allowing them to engage in health-promoting activities such as exercise and other quality-of-life improvements.

**3. Provide Education & information:** Caregivers should be educated about the specific illness of the care recipient and their unique care requirements. Counselling on caregiver stress, its consequences, and coping strategies is crucial. Caregivers can find relief by learning how to seek assistance, participating in support groups, and prioritizing their health.

**4. Coordinate/ Refer for Assistance:** Caregivers may be unaware of available assistance or their eligibility for support services. Legal, financial, and individual and family counselling can be valuable. Structured cognitive behavioural interventions, such as problem-solving, can be effective in assisting caregivers.

Addressing the suffering of care recipients with chronic medical conditions can be challenging but important. Attention to symptom relief for these patients may enhance their quality of life and alleviate caregiver distress.

### IV. CAREGIVER SUPPORT INITIATIVES

#### Ummeed Society Chandigarh:

Ummeed Society, headquartered in Chandigarh and operating as a nonprofit entity under the Societies Act of 1860, has garnered significant national acclaim. It has outstanding contributions in driving awareness about individuals with disabilities, facilitating early identification and delivering crucial support and skill enhancement initiatives.

#### Mom's Belief by Nitin Bindlish:

Mom's Belief, founded by Nitin Bindlish, is a pioneering initiative that aims to alleviate caregiver burden, particularly among parents of children with special needs. It offers a holistic approach, encompassing assessment, intervention, and support services.

#### Sahyogi Scheme:

The Sahyogi Scheme is a government-backed program designed to provide essential support to caregivers, particularly those caring for individuals with disabilities. It recognizes the immense responsibility shouldered by caregivers and offers practical interventions to reduce their burden.

**Conclusion:** These initiatives exemplify the collaborative efforts of nonprofit organizations, individual initiatives, and government programs in addressing the multifaceted challenges faced by caregivers of individuals with special needs. Such approaches are instrumental in creating a more inclusive and supportive environment for both caregivers and those they care for.

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