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## Needs of Caregivers of Adolescents with Autism

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*India needs more focus on supporting adults with autism & their caregivers. While early diagnosis is important, autistic individuals need lifelong care. The government should ensure long-term access to quality health & social services for both, those with Autism Spectrum Disorder & their caregivers.*

Autism Spectrum Disorder (ASD) is a lifelong condition where children often diagnosed in childhood continue to have impaired social behaviour and require support throughout adolescence and adulthood (World Health Organization 2018). Individuals with ASD and their caregivers are a vulnerable group often bereft of access to quality health and social care.

Many studies have highlighted the factors leading to poor care for individuals with ASD, which include lack of access to educational and therapeutic interventions, social stigma and discrimination, lack of access to respite care, and inadequate government attention and policy aid, among other things. I aim to highlight some reflections and action points, which have been gained through my engagement with academic literature and field research in New Delhi, to aid the cause of strengthening ASD care and supporting caregivers of adolescents with ASD in India.

First, caregivers are faced with increasing behavioural issues due to the inability of maturing adolescents to express their bodily and emotional needs, including the need to explore and express their sexuality, or to express their need for “space”, that is, physical distance from their caregivers. Both of these are much easier to handle among adolescents who do not live with ASD.

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Adequate development of training resources for adolescents with ASD and their caregivers, and resources that make psychosexual education more accessible are essential to help caregivers manage the self-image and self-esteem of their adolescent offspring better. They also act as tools that reduce the stress and anxiety of caregivers when navigating these challenges of the adolescent phase (Tullis and Zangrillo 2013).

Second, there is a chronic sense of family dysfunction among caregivers of adolescents with ASD. Marital and extended family discord, early psychological stress to the siblings of the autistic offspring, and growing fatigue among ageing parents are some major narratives that I have come across in my interaction with families. These are well supported by findings in the literature.

In addition, mothers often succumb to being overburdened with the daily management of household chores, often at the cost of their careers and personal life. This is in line with previous literature, which has highlighted that mothers of autistic individuals are impacted by adverse employment outcomes and poor mental health. Psychosocial support resources must address chronic stress among mothers of adolescents with ASD, and consider the compounded burden of care that exists across geographies, especially in geographies where normative gender roles still have a strong influence on how families function.

Third, many families I have interacted with faced social neglect and stigma, and strained immediate and extended family relations. Community apathy, non-inclusion, or outright intolerance leading to decreased social mobility and increased isolation among families is a common narrative among families who live with an individual with ASD.

Families who receive support from their kin and social acceptance fare better in managing their autistic offerings and are more emotionally resilient to disability-related adversity. Psychosocial interventions and support groups focused on promoting the well-being of caregivers, along with relational care and inclusive initiatives by community members, are essential to facilitate social inclusion.

Fourth, autism care services remain uncoordinated and scattered, even in metropolitan urban spaces (Aluri and Karanth 2002). The economic cost of autism care contributes to the financial and mental burden of parents. Further, a lack of communication between parents and professionals, and a shortage of trained and trusted professionals has increased discord (Barua et al. 2017). There is an immediate need to develop more cost-effective interventions for autism care, which will also improve and maintain relationships

between parents and professionals.

An increased number of government-led initiatives for the education, rehabilitation, and psychosocial care for the autistic community are necessary to prevent privatisation and an increased financial burden on the primary caregivers of autistic individuals.

Last, siblings of individuals with ASD planning to invest in setting up rehabilitation homes and pursue careers in the field of special education are a recurring narrative I have come across in my field research. Although these are noble endeavours, it should be recognised that often these investment plans and career alterations within the family stem from a lack of external support for autistic care and rehabilitation (Vaidya 2016).

Hence, there should be increased support from the union government to rehabilitate adolescents with ASD. It must also provide support to their parents and family members thinking of investing in setting up rehabilitation homes or pursuing careers in the field of special education.

In conclusion, research on ASD care for adolescents in India remains scarce, and resources for health and social care are poorly coordinated. There is an immediate need to look beyond ASD only as an early intervention challenge and address the structural challenges that individuals and their families face all through their life. It is clear that autism accentuates the social deficit of the affected individuals, and increases their non-inclusion in society on various fronts.

Not only is it important to create inclusive policies, interventions, and aid access to facilities for this community, it is also essential that autistic individuals are given platforms to advocate for their rights because a better quality of life, resources, and support for stepping into adulthood is the right of every autistic individual. Further, it is the right of every primary caregiver to an autistic individual to lead a good quality of life and transition into old age with financial and emotional security. The community's access to psychosocial counselling and therapeutic interventions should be subsidised and abundant, both in quality and quantity.

An increased number of government-led initiatives for the education, rehabilitation, and psychosocial care for the autistic community are necessary to prevent privatisation and an increased financial burden on the primary caregivers of autistic individuals. There also needs to be a robust mechanism that can manage the many health issues that come with ASD at different stages of an autistic individual's and his or her family's lives. Increased media attention to the cause of autistic adolescents and their caregivers can aid this.

Even though autism awareness in India has increased in the last decade, most media attention is still geared towards early autism diagnosis and intervention, and the struggles of living with and caring for autistic kids in their childhood.

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