

# Challenges Faced by families of Autistic Children

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**Abstract:** Autism Spectrum Disorders (ASD) is a complex neurological disorder that affects brain function which causes impairments in multiple areas of development including social interaction, communication, and behavior and typically appears within the first three years of life. Families having children with ASD face many challenges as the disorder is associated with disruptive antisocial behavior. Parents with ASD children face extreme difficulties in dealing with challenging behaviors, teaching their child to communicate, teaching basic life skills, guarding their child from danger, and preparing their child for adult life. Besides, such families also experience high levels of stress, high recurrence risks, misconceptions and assumptions, feelings of guilt and blame regarding child's diagnosis. The social stigma attached to the disorder causes lot of discrimination not only of the autistic child but also of the family as a whole because the family is seen to be a part of the illness. The present paper highlights the major challenges and difficulties faced by parents having children with autism.

**Keywords:** Autism Spectrum Disorder, families with ASD children, challenges.

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## I. Introduction

Autism Spectrum Disorders (ASD) is a complex neurological disorder that affects brain function and typically appears within the first three years of life. It causes impairments in multiple areas of development including social interaction, communication, and behavior. These are often referred to as the triad of impairment. The Center for Disease Control (2012) reports, 1 in 88 children will be diagnosed with ASD: 1 in 54 boys, 1 in 252 girls (UNLV Center for Autism Spectrum Disorders 2012). ASDs are part of Pervasive Developmental Disorders (PDD) which includes Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Each of the behaviors associated with ASDs may range from mild to severe. Some individuals may have relatively good verbal skills and a minimal language delay but significantly impaired social skills while others may be nonverbal or have very little ability in communicating or interacting with others. People with ASDs often do not take part in pretend play, face difficulties in initiating social interactions, and engage in self-stimulatory behaviors (CDC 2007).

There is no medical test for ASDs and a diagnosis is made after a thorough evaluation. The evaluation might include clinical observations, parent interviews, developmental histories, psychological testing, speech and language assessments, and possibly the use of one or more autism diagnostic tests (CDC 2007). The *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) represents a new, more accurate, and medically and scientifically useful way of diagnosing individuals with autism-related disorders. Under the DSM-5 criteria, individuals with ASD must show symptoms from early childhood, even if those symptoms are not recognized until later. It encourages earlier diagnosis of ASD but also allows people whose symptoms may not be fully recognized until social demands exceed their capacity to receive the diagnosis. It is useful in identifying school-aged children with autism-related disorders, as well as diagnosing younger children (APA 2013). Autism is a neurodevelopment disorder caused by a number of different known and unknown biologically based brain dysfunctions

that affect the developing brain's ability to handle information. The different way of perceiving, processing and interpreting information, learning new things and behaving in a well-adapted way, leads to the behavioral deviations that can be observed (Zander 2004). Research suggests that both genes and environment play important roles in causing Autism Spectrum Disorder (ASD), ([www.nimh.nih.gov](http://www.nimh.nih.gov)).

Families with autistic children face a multitude of challenges because of the behavioural problems associated with the disorder. Having a child with autism in the family may have adverse affects on various domains of family life including marital relationships, sibling relationships and adjustment, family socialization practices as well as normal family routines (Greeff and Walt 2010).

## II. Parental stress in families with autistic children

Parents of disabled children are particularly vulnerable to stress. The levels of distress are higher in mothers than fathers of severely disabled children. Studies reveal that parental distress and family functioning impacts children in numerous ways, affecting their cognitive, behavioural and social development. Although there are many other developmental disorders which present parents with ongoing grief, autism is unique in several ways. First, this disorder has no clear biological marker, unlike many other developmental disabilities. Second, because it is characterized by problems of social interaction, such as forming attachments and showing affection, parents of children with autism are often denied some of the fundamental rewards of parenthood. Consequently, autism has been considered as one of the most complex and intractable developmental disorders with which families may have to cope. The common characteristics that contribute to parenting stress, include scattered intellectual abilities or isolated skills and pervasive problem behavior such as self-stimulatory behaviors. Other important factors associated with parental stress in families of children with autism, include, feelings of loss of personal control, absence of spousal support, informal and professional support. Family members of children with autism are often perceived to experience negative psychological effects which may include higher risk for depression, social isolation and marital discord. Many parents also experience periods of disbelief, deep sadness and depression and self-blame and guilt whereas others experience helplessness, feelings of inadequacy, anger, shock and guilt (Gupta and Singhal 2005). Specific stressors that contribute to parental distress include concerns over the permanency of their child's condition, poor acceptance of autistic behaviors by society and, other family members and low levels of social support received by other parents (Prince 2007). Mothers appear to be the most affected and experience distress, conflicting and even ambivalent emotions. Depression is often elevated at the time of diagnosis of a child's disability but may decline substantially over time. Chronic sorrow and a sense of failure are emotional states often reported by parents of autistic children (Kourkoutas et al 2012).

## III. Parenting an autistic child

Autism is considered to be a severe disability because of the intense lifelong effects it has on the individual and his or her family. Parents raising a child with autism face extreme difficulties in dealing with challenging behaviors, teaching their child to communicate, teaching basic life skills, guarding their child from danger, and preparing their child for adult life (Dyches et al 2004). There are high-risk factors that might induce acute or chronic stress and trauma to the parents of autistic children and, in turn, lead to dysfunctional parenting. These include: a) the ambiguity of diagnosis; b) the severity and duration of the child's disorder; c) a very low I.Q.; d) lack of congruity with the community norms, bizarre forms of communication and behavior; and, e) enduring disruptive or disorganized behaviors (Kourkoutas et al 2012). Families with autistic children have been perceived by their societies in different ways causing the families to be shaped by the beliefs systems of autism specific to their society. Because of social stigma, there is a lot of discrimination not only of the autistic child but also of the family as a whole because the family is seen to be a part of the illness. Fear of discrimination and the stigmas surrounding disabilities lead many families to refuse to go to professionals and receive a diagnosis for their children. By refusing to be diagnosed, families can avoid having disability identities (Ecker 2010). The troublesome symptoms such as tantrums, self-destructive acts and other inappropriate public behaviours associated with the disorder are difficult to cope with. Consequently, the parents with autistic children frequently encounter hostile or insensitive reactions from public,

mostly because of the inappropriate behaviour shown by their children. The public reaction to such families is often stereotypical and negative (Gray 1993). Because of delayed communication in autistic children, parents may experience positive and negative changes as the children grows and enters school system. The school system initiates a new involvement concerning the needs of the child and the parent. Parents and school personnel are closely related in pursuing the most appropriate education for the child (Hoppe 2005). Caregivers of autistic children may perceive their children as more difficult temperamentally than other children and therefore, use greater control strategies with their children. Thus, caregiver perceptions of their children's characteristics may influence the ways in which they interact with their children (Kesari et al 1997).The family social support from relatives, neighbors and friends relatives, neighbors, friends. Families with autistic children need social support for coping with stress and attunement due to having a child with developmental disabilities (Meral et al 2012).

#### IV. Siblings of autistic children`

The siblings of individuals with autism have a variety of adjustment, coping difficulties and impaired intimate relationships with their affected sibling. Different studies pertaining to parental characteristics relay a concern for the perceived stress in the health of family environment. Sibling behaviors of persons with ASD include their self-competence and experience of living with a brother or sister living with autism. The studies on sibling characteristics reveal a variety of influences on personality traits and they accentuate that an interaction of variables comprise the environment of families with persons of autism (Smith et al 2010).Research also indicates that siblings of children with autism are at risk of bearing the psychological and emotional brunt of growing up alongside a child with behavioural difficulties. Many siblings have felt that their parents perceived their needs as being secondary, with more time and attention given to the child with autism. Whilst they may have a deep love for their sibling, they may also harbor feelings of resentment at the amount of time their parents are spending with the child with autism, and feel that they are being treated unfairly. Thus, feelings of anger, embarrassment and guilt are as normal as is feeling very protective of their sibling. Siblings of children with autism are significantly more likely to experience depression than the general population. Apart from psychological problems, exhaustion may affect siblings who may be responsible for domestic tasks and physical care. Problems may also arise when the increased parental expectations are not accompanied by increased parental time or attention (Gupta and Singhal 2005).

#### V. Financial stress in families with autistic children

Autism can place financial strains on families in several different ways. Some families spend fortunes on therapies and a treatment for their child (Autism Society of America, 2005).The diagnosis of autism begins a journey that places profound demands on family human and financial resources for the remaining lifetime of the child. Autism is a biologically based developmental disorder that impairs an individual's ability to communicate, build relationships, and relate appropriately to the environment. Diagnosis is usually made in early childhood through a multi-disciplinary assessment of behavior, developmental level, and communication ability. Efficacy of early intervention depends on the specific nature and severity of autism. Intervention strategies are expensive and require long hours of one on-one interaction with a trained therapist or use of costly foods or drug supplements. Health insurance falls far short of covering these needs. Special education services do not fill the gap either. Although public school districts are legally obligated to provide a fair and appropriate education to children with autism, the educational programs that are provided are rarely sufficient to address the needs of school-aged children with autism and are not available to young adults with autism. Despite higher costs, most parents are forced to seek out and try early intervention strategies for the sake of their child's future. Costs associated with having a child with autism are not, only, limited to the cost of interventions. Like any other forms of childhood disability, parents of a child with autism often face greater outlays of time and money than they would for a neurologically typical child. Additional cost is also associated with extracurricular activities for children with disabilities. Health insurance may sometimes cover the cost of medical tests used in the diagnostic process and the cost of prescription medication, but won't pay for behavioral or other types of therapy for autism (Sharpe and Baker 2007).

## VI. Marital adjustments among parents with autistic children

Marriages of parents of children with developmental disabilities are portrayed as difficult, dysfunctional, and particularly likely to end in divorce (Sobsey 2004). Parents of children with disabilities experience more marital stress and discord than parents with normal children. Families with autistic children face many stressors and challenges, today's partnership in marriage is more challenging and more difficult than in the past years; especially couples with special needs children (Al Horany et al 2013). Marital stress around the child usually starts when one or both of the parents realize the child is not developing properly. Couples with a child who does not seek their attention in the usual way (i.e., eye contact, reaching out for or giving affection, seeking comfort when hurt) feel rejected or unimportant to the child. For those whose child develops normally and then regresses around 18-24 months, there is the added loss of the child they knew slipping away. When a couple looks forward to having a child, and each person had an idea of what the expected child would be like but the child does not match the expectation, or regresses, there is a loss and anguish felt by the parent. A marriage takes time to remain healthy, and all too often, time gets swallowed up by the autistic child's needs. Many children with an ASD have difficulty sleeping, and at least one of the parents is sleep deprived. In most of the cases, a role division takes place as one parent, usually mother, becomes the autism expert, while father works harder to earn money or opts out. Consequently, the father becomes frustrated at the demands of the mother to interact or play with a child who does not know how, and mothers become frustrated at the lack of involvement of their partners (Silice-Kira 2008). Because of the demands associated with caring an autistic child, parents do not have personal time which results in a weakened affectionate bond between parents, depression, withdrawal of one parent from care-giving responsibilities or even divorce (Greeff and Walt 2010). Mothers usually wonder what they did wrong—drinking or taking medications during pregnancy, exercising too much, allowing the child to be vaccinated; thus adding feelings of guilt to an already stressful situation. Eventually, the couple feels isolated because they feel it is hard to take an autistic child to people's homes and are uncomfortable inviting people over. The stress of dealing with autism and all it entails (the constant and necessary advocacy at school, fighting for services and support, added financial burden, trying to handle behaviors and meltdowns at home) becomes a wedge pushing the parents further and further apart (Silice-Kira 2008).

## VII. Conclusions

Autism Spectrum Disorders (ASD) is a complex neurological disorder which causes impairments in multiple areas of development including social interaction, communication, and behavior and typically appears within the first three years of life. Families with ASD children face extreme challenges in dealing with the behavioral problems associated with the disorder. The presence of an autistic child in a family has adverse affects on marital adjustments, sibling relationships and daily family routines. Besides the parenting stress accompanying the disorder, it has huge financial implications. Parents having autistic children experience periods of disbelief, deep sadness and depression and self-blame and guilt whereas others experience helplessness, feelings of inadequacy, anger, shock and guilt. Family members of children with autism are often perceived to experience negative psychological effects which may include higher risk for depression, social isolation and marital discord. The siblings of children with autism have a variety of adjustment, coping difficulties and impaired intimate relationships with their affected sibling. The financial resources required for the medical and therapeutic intervention lays heavy financial burden on families in several different ways. The diagnosis of autism places profound demands on family human and financial resources for the remaining lifetime of the child. Because of the demands associated with caring an autistic child, parents do not have personal time which results in a weakened affectionate bond between parents, depression, and withdrawal of one parent from care-giving responsibilities or even divorce.

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