

# The Impact of Pressure Upon Parents in Raising Children Diagnosed with Autism Spectrum Disorders

Anita Seeridaram, Syar Meeze Mohd Rashid

Faculty of Education, National University of Malaysia, Bangi, Selangor, Malaysia

Email: p112359@siswa.ukm.edu.my, cikgumeeze@ukm.edu.my

## Abstract

In 2017, the World Health Organisation (WHO) revealed that 1 in 160 children worldwide is diagnosed with Autism Spectrum Disorder (ASD), which continues to grow worldwide. This statistic proves that many parents worldwide continue to battle the challenge of raising and educating this select group of children. This paper is a comprehensive study, gleaned information from various pieces of writing and research focused on the pressure influencing parents of children diagnosed with Autism Spectrum Disorders (ASD) in terms of caregiving whilst finding a practical alternative in caring for children with special needs. This research has revealed that behavioral difficulties, financial constraints, and societal acceptance largely contribute to the pressure parents of children diagnosed with Autism Spectrum Disorders (ASD) experience. The result of this research shows that parents of children with ASD face a plethora of difficulties and require support from various entities in order to navigate them successfully. To lessen the caregiver's burden, spouses, typically developing children, the community, and the government must provide unwavering support and understanding. Hence, this research aims to provide insight into the struggles faced by parents of children with ASD or even serve as a guideline to develop support or intervention programs for children with ASD and their parents.

**Keywords:** Stress, Autism Spectrum Disorder, Behaviour, Stress, Challenges, Support Program.

## Introduction

The term Autism Spectrum Disorder (ASD), updated to the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), combines four previously separated disorders. Namely, Autism, Asperger's Syndrome, Childhood Disintegrative Disorder, and other developmental disorders (American Psychiatric Association, 2013). Autism Spectrum Disorder is a complex neurological developmental disorder involving the structure and function of the brain and nervous system. Among the apparent characteristics in children diagnosed with ASD are delays in language development, sensitivity to changes in routine, sensory-related sensitivity involving smell, light, sound as well as touch, unusual social interactions, atypical play patterns, patterns of stereotypical behavior, repetition of odd behavior, aggressiveness, hyperactivity and lack of concentration (Eshraghi et al., 2022). ASD

is known as a spectrum of delirium because its symptoms and severity are unique to each ASD individual (Vuijk et al., 2022).

Autism Spectrum Disorders can usually be identified as early as 6 to 18 months of age (Tanner & Dounavi, 2021) and can cause speech and development delays or vice versa (Kreysa et al., 2022). This disorder is very complex and covers many aspects of individual development. However, early detection followed by an early intervention by qualified experts can significantly reduce the symptoms experienced by ASD children. According to a study (Maenner et al., 2021), there has been a significant increase in the number of children with ASD throughout several decades.

A sharp rise in statistics of ASD awareness can be attributed to changes in diagnostic criteria and policies Zeidan et al (2022). Sadly, ASD lasts a lifetime and cannot be treated with a singular treatment regime (Siti Izani et al., 2017). Parents of children with ASD face great difficulty in raising and educating their children in this situation. According to (Fairuz, 2017), parents of children with ASD frequently report experiencing higher stress levels than parents of typical children and children experiencing other imbalances. As a result, undeniably, parents of ASD children face a variety of obstacles that ultimately result in the fragility of the familial constitution.

Research shows that parents of children with Autism Spectrum Disorder (ASD) are more likely to experience higher levels of stress as opposed to parents of children with other disabilities (Patel et al., 2022). A person can have autism spectrum disorder (ASD) regardless of race, education level, position or socioeconomic status. The number of children diagnosed with ASD is rising annually Mustafa (2017), and one in 160 children worldwide are diagnosed with Autism Spectrum Disorder (ASD), with the cause of this condition still unknown (Siti Izani et al., 2017). Despite the fact that the number of children diagnosed with ASD is rising, there is insufficient evidence regarding the causes.

This situation is very challenging for parents in raising and educating children with ASD. Various studies in the country have proven that the pressure and challenges are higher for parents of children with ASD compared to parents of typically developing children (Lee et al., 2017; Ainul et al., 2018), thus causing the fragility of family institutions. Therefore, these parents should be given social, emotional, communication, and behavioral support to continue to face the challenges of raising their special children (Ilias et al., 2019).

## **Literature Review**

### **Atypical Behaviour in Children with ASD**

Individuals with ASD and their parents were the focus of numerous previous psychosocial studies on developmental disabilities. Among the investigations included are (Ang & Loh, 2019; Wang et al., 2020; Yaacob et al., 2021). This study has looked at some factors that affect parental stress when raising children with ASD.

Parents of children with ASD constantly experience anxiety and pressure because they must be prepared for any circumstance to control their child's unpredictable behavior (Huang et al., 2019). Children with ASD may exhibit unpredictable out-of-control behavior. Regardless of the situation, these children typically exhibit challenging or aggressive behavior putting

parents in a constant state of worry. This finding is further supported by (Smith et al., 2021), which express that children with ASD behave unpredictably due to discrepancies in communication and social aspects, as the children are unable to relay their needs and feelings due to speech delays. As a result, they begin to exhibit dissatisfaction and act out of control when their wishes and feelings are not understood. These tendencies do not coincide with their age. They also tend to struggle to get along with each other or others, subsequently standing out from the vast majority. Significant social and emotional decline and an inability to adapt to a particular circumstance pose a significant obstacle and necessitate constant attention (Postorino et al., 2019).

Children who have been diagnosed with ASD, according to Siti Marziah and Nor Shahirah (2018), have difficulties with behavior, social skills, and communication. According to Mastura & Mimi (2014), this causes children with ASD to frequently exhibit antisocial behavior, such as being unable to control their emotions, losing focus, easily switching their attention, and a clouded perception and comprehension of others. According to Nurkhamimi (2017), some children with ASD do not communicate through language, and parents are constantly under pressure.

In fact, according to Clark et al (2019), parents are also pressured because they cannot act out of routine, as children with ASD have limited interests and repetitive behaviors. Thus, changes in the routine can frustrate them, adding to the Herculean task at hand (Newbutt et al., 2020). Another cause of stress is parents' lack of emotional stability when confronted with challenges beyond their control, such as environmental factors.

Surrounding conditions are of much importance to children with ASD. So much so that according to (Sulistyo et al., 2017; Shamsudin et al., 2017) loud noises, including even the barking of a dog can lead to distress in autistic children. Parents absolutely have no control over this, and it ultimately contributes to emotional stress in such situations of uncertainty. Parental stress is also exacerbated by a child's lack of motor skills and inability to complete daily tasks like eating, dressing, and hygiene routines.

In addition, a study by Martin et al (2019) argued that a lack of sleep or rest has been linked to stress among parents of children with ASD. Due to the majority of ASD children's sleep issues, excessive activity, irregular sleep times, and lack of sleep are undeniable consequences parents must bear. The parents' deterioration of health contributes to stress as this situation persists. (Rodriguez et al., 2019; Siu et al., 2019) state that parents' pressure to manage their children with ASD is also greatly affected by their internal and external behavioral tendencies and symptoms.

Lastly, parents also experience stress when they discover their child's condition. A report by (Ilias et al., 2018) shows that parents of children diagnosed with ASD in Malaysia are initially very stressed when they first learn about their child's diagnosis but that stress is reduced when they start to learn and accept their child as they are and try to help them.

### **Financial Constraints**

Another aspect playing towards parental pressure is financial constraint. A child diagnosed with special needs adds challenge and becomes a stressor for family members

whose finances are unstable (Kartini et al., 2018). Children with special needs require a significant financial investment from their parents to meet their treatment, support equipment, medication, and other requirements. The majority of financially disadvantaged parents send their children to government hospitals for therapy. However, they must wait a considerable amount of time for their turn (Ilias et al., 2019) adversely affecting children with special needs requirement of ongoing therapy and treatment. As a result, parents are forced to look for other options, such as sending their children to expensive private therapy centers (Kartini et al., 2017) causing parents to feel much pressure in this situation naturally.

The high cost of living also affects parental pressure, according to a study by (Kamaralzaman et al., 2018). In addition to meeting the requirements of their children with special needs, parents must meet numerous other requirements to carry on with their daily lives. In some cases, the expense of treatment to address the child's condition surpasses the guardians' monthly wage. In this case, parents who receive assistance from third parties, such as professionals, family members, and schools, can better mitigate financial stress (Kartini et al., 2018).

Additionally, a study by (Sharif et al., 2019) argues that parents frequently have to forego time, effort, and resources to deal with their child's needs. Additionally, children with ASD require specialized medical care, which affects family income causing families with low incomes especially to shoulder a heavy burden.

Next, children with ASD benefit significantly from early intervention (Fuller, 2019). They are able to acquire fundamental abilities that will enhance their physical, social, self-management, and pre-academic development. In addition, many parents stated that they had to wait a long time for their turn to be admitted to government intervention centers and for early diagnosis process by medical professionals. This procedure is time-consuming. Parents have difficulty finding an early intervention support system due to the high cost of private early intervention services (Sazlina, 2019). Depending on the child's performance, the cost of the therapy can even span over months. As a result, it is critical for parents to keep their financial resources stable.

It is undeniable that parents' involvement in early intervention can lessen the challenges faced by ASD children (Sazlina, 2019). This is due to the fact that parents are the best role models for children with ASD and the closest people to them.

A study by (Ali et al., 2020) has shown that many mothers of children with ASD had to quit their jobs to become homemakers to help their children at home. Working mothers also are forced to organize their time in terms of career and managing children. Working full-time and taking care of children with special needs is undeniably challenging as parents need to find a balance between work and taking care of their children (Norliza et al., 2019), making this one of the factors contributing to stress.

Furthermore, children with special needs require a high level of commitment from their parents. These children need to be sent for therapy and intervention sessions. They are also unsuitable for sending to regular childcare centers due to unpredictable behavior. Therefore, often mothers tend to quit work and hand over the responsibility of earning a living to their

husbands. Working parents must organize work schedules or apply for unpaid leave to meet their children's needs (Ilias et al., 2019). Therefore, pressure and burden are felt more by parents with children diagnosed with ASD, especially parents with low incomes (Lineker et al., 2016).

Additionally, their children's therapy and hospital appointments typically take a long time, requiring working parents to plan their work schedules around these times. According to Norliza et al (2019), not all local or private hospitals in Malaysia provide sufficient specialized services for children with special needs. Due to the fact that a child with special needs requires both parents' full attention, mothers typically give up their careers to care for their children and delegate all financial responsibility to the father. As a result, the source of the family's income is affected, as is parental pressure to manage these children.

### **Lack of Societal Awareness**

Community stigma, or a lack of community awareness, has been identified as a third factor contributing to parental pressure in managing children with ASD. As many as 33.7% of respondents in the study conducted in Riyadh, Saudi Arabia, stated that they were depressed as a result of societal criticism (Kahlid et al., 2019). According to Mukolo et al. (2019), stigma is the negative attitudes, stereotypes, and discrimination that target a subgroup. Society's various negative perceptions and interpretations of ASD result from a lack of awareness and exposure regarding ASD, regrettably in a frustrating manner that affects the family's quality of life because their children are frequently criticised and ostracised. Children with ASD are oblivious to the consequences of their actions. Describing these children are labeled abnormal and mentally ill (Lam, 2016, 2017). Such stigmatization generally leaves guardians of kids with ASD feeling embarrassed, judged, and disconnected (Broady et al., 2017).

According to (Shamsudin et al., 2017), some communities discriminate against children with ASD and their families or sometimes exhibit negative attitudes towards them. Parents are put under more stress as a result of negative feedback and society's treatment of children with ASD and their families. Due to this indifference to the behavior of children with special needs, parents of children with autism tend to feel inadequate and ostracised by friends and family. The behavior of children with special needs, including their use of medication and educational methods, continues to elude society. These parents tend to be ostracised from their families, robbing them of a reliable support system if family members cannot accept the presence of their children with special needs (Leitch et al., 2019).

Stigma and discrimination against children with special needs also negatively impact parents' mental health and psychological well-being. In addition to children with special needs, caregivers and family members are also affected by this societal stigma (Ng et al., 2020). Families with special needs children are also more likely to isolate themselves and withdraw from society due to the stigma that society places on them. Due to the child's condition, these parents do not have many opportunities to gather with other friends or participate in activities involving family members (Ilias et al., 2019).

In a study of Japanese mothers with children diagnosed with ASD, it was found that they experienced significantly higher levels of stress than mothers of normal children and children with other special needs. Their stress is reported to be related to challenges with attachment,

lack of parenting, effectiveness, and insufficient support that reflect Japanese parenting and gender ideology (Porter & Loveland, 2019).

### **Discussion and Suggestions**

Alluding to previous studies, researchers have provided a clear and complete definition to aid with readers' comprehension. In order to make the search for meaning easier, keywords have also been specified. The fact that parents of children with ASD experience high levels of stress and depression are supported by the fact that the aforementioned studies share a significant amount of similarities. These studies suggest that parents of children with autism require moral support in addition to the assistance and treatment they receive for their children. Children's anxiety episodes have been linked to stress from parents (Allen et al., 2018). It has been discovered that the quality of the parent-child relationship is also mediated by parental mental health. Additionally, parents' mental health problems raise the likelihood of child abuse.

The causes of parental stress and depression are successfully brought to light in each of these journals that meld well together. According to Zuckerman et al (2018), family pressure is high when discussed. Several other elements lead to parental tension, the most significant being the unpredictable behavior exhibited by children with ASD. Behavior that is out of control is caused by communication barriers, according to (Sulistyo et al. 2017; Shamsudin et al.2017). As a sign of discomfort in a new environment that may be too noisy or too crowded, children with ASD act aggressively or out of control (Lee et al., 2017). According to (Manap et al., 2016) parents of children with ASD are the closest people to their children and play a significant role in their children's development and acquisition of skills. As a result, parents need to receive education and training in effective communication techniques with their children, such as using body language, body signals, and the Picture Exchange Communication System (PECS). When it comes to nurturing and raising a child with ASD, parents can benefit significantly from applying educational knowledge so that the child's development and skills can be honed to deal with out-of-control behavior effectively.

Moreover, the involvement of parents is emphasized in research conducted by (Broady et al., 2017). It is defined that parental involvement is the interaction and communication with students, teachers, speech therapists, occupational therapists, doctors, or any other party involved in their child's life, either directly or indirectly. According to Georgiou (2021), parental involvement includes participating in school activities, learning at home, and making decisions regarding schools or early intervention programs. According to the aforementioned studies, parents' involvement in the care and education of their children with ASD is crucial to ease challenges they may face and, in turn, the pressure they feel.

Stress among parents of children with special needs is said to be exacerbated by low family socioeconomic status. This is consistent with the opinion of (Kamaruddin et al., 2015). Stress is caused by the fact that caring for children with special needs is more expensive than caring for typically developing children (Prata et al., 2019). Having a child with special needs is a challenge and adds to the pressure, disrupting the well-being of the family (Ilias et al., 2018) in a family dealing with financial constraints, especially those in the B40 category. Parents must contribute a significant amount of money to cover the costs of requirements such as early intervention, treatment, support equipment, and medication. Many less

fortunate parents send their children to government hospitals for therapy. However, some stated they had to wait a considerable amount of time for their turn. In addition, they had no choice but to wait for a new appointment date, which takes a very long time, if they miss the appointment due to unavoidable circumstances (Ilias et al., 2019).

Children with special needs require ongoing therapy and treatment. As a result, parents are forced to look for other options, such as sending their children to expensive private therapy centers (Kartini et al., 2017). Naturally, parents are under much pressure in this situation and are strongly encouraged to plan their finances strategically. In recent years, as a result of the rise in ASD diagnoses, numerous intervention centers funded by the government have opened. According to Kamaralzaman (2019), 'Genius Kurnia' is one of the nation's earliest government-run intervention centers for children with ASD and their families. However, due to the thousands of children waiting for their turn as of the present, admission to 'Genius Kurnia' is not easily obtained. This predicament urges parents to act proactively if they intend to enroll their child in government-funded or semi-governmental organizations that do not charge exorbitant fees in order to prevent opportunities from being lost.

Parents are forced to make lifelong efforts to combat the complications their children are bound to face, as ASD is typically diagnosed in early childhood and is described as a condition that lasts a lifetime (Ali et al., 2020). As a result, the existing body of research demonstrates that parents of children with ASD experience a more significant number of negative experiences than parents of children with other special needs (Meral & Cavkaytar, 2012; Walsh et al., 2014). Several factors, including unemployment, workplace competition, uncertainty, and health issues, exacerbate financial difficulties. In addition, having a child with autism can negatively impact the labor supply and affect parents' attention and commitment to work. This phenomenon results in a reduction in working hours, a change in current working hours, a shift from a full-time to a part-time position, or an exit from the workplace when parents spend more time taking care of their children. From a financial standpoint, reducing work hours or leaving the workplace will undoubtedly cause pressure and distress.

A study by (Zakaria et al., 2019) qualitatively and quantitatively studied parents' health-related quality of life and found that the majority of parents reported financial pressure related to parenting a child with ASD, both directly and indirectly, with more than half of parents admitting to trouble juggling caregiving responsibilities with day-to-day activities. Many parents have also admitted to the inability to work because they have to take care of their children. Such issues should be taken into consideration because they can reduce a family's income and have a negative effect on social relationships as a result of unemployment.

Civil servants in Malaysia who have children with special needs have few options. They can, however, request permission to care for their children during work hours if they require it. Depending on the circumstances outlined in letter JPA (S) 1619 Klt. 11 (29) dated August 30, 2004, this authorization could be utilized when the need arises. In addition, the government would permit officials with disabled children to work flexible hours to ensure their children's well-being. Choosing to arrive at work at 7.30 a.m., 8.00 a.m., 8.30 a.m., or 9.00 a.m. is crucial, especially if the parent wants to send the child to school and the child has trouble sleeping at night or wakes up late. In Kedah, Kelantan, Terengganu, and Johor, office hours are set from 7.30 a.m. to 6 p.m., except for Thursdays. This change was announced in

Service Circular No. 5 on August 1, 2019. However, in the private sector, it is up to the employer to provide their employees with any flexibility (Laili et al., 2021).

Employers are aware of the numerous obstacles faced by parents of children with ASD, mainly working parents, compared to non-working parents (Amin et al., 2016). However, only a small amount of research has examined the workplace support for these children's parents. When it comes to working parents, there are two kinds of support at work that can help them feel more motivated: from their managers and their collaborators (Pinna et al., 2020). In the workplace, coworkers and employers should support one another to benefit both. Saidi et al. (2019) claim that the organizational environment has the potential to satisfy individuals' requirements and influence their level of satisfaction with the organization.

Consequently, job satisfaction is essential for developing highly motivated and productive employees. Parents of children with ASD also benefit from the support of coworkers in enhancing their quality of life. According to (Rosli et al., 2015), a coworker's duty is to share work to aid in task completion. Because of the conducive and comfortable working conditions, this teamwork helps parents of children with ASD reduce stress and achieve job satisfaction. Parents of children with ASD are encouraged to continue working without having to quit or take unpaid leave as a result of this.

Lastly, society as a whole has a significant impact on a person's life Agyekum (2018). It is hypothesized, based on research to determine the relationship between social support and parental stress and community support and family coping, that a lack of community awareness and support for children with ASD and their families causes them to be unable to adapt to the community and predict higher levels of parental stress (Egilson et al. 2017; Krieger et al. 2018). As per a review in Tokyo, guardians of children with ASD experience greater difficulties and stress than guardians of typically developing children and are more likely to punish their children. This finding is decidedly connected with parental emotional well-being (CDC, 2016; Kimura & Yamazaki, 2016).

A society unaware of ASD fosters a variety of interpretations and negative perceptions that are extremely disappointing and disrupt the family's quality of life because their children are frequently criticised. According to (Zuckerman et al., 2018), one of the stressors was the community's lack of awareness. The parents of these children are not seeking mercy but rather an awareness and the space to allow their children to lead a social life without being looked down. According to Lindor et al. (2019), children with ASD exhibit abnormal behavior, such as being withdrawn, aggressive, and frequently disturbing their parents. As a result, they are typically referred to as troubled children, and their parents are viewed as incompetent in controlling and disciplining their children. The fact is that children with ASD do not comprehend the consequences of their actions. These children are portrayed as poorly raised and undisciplined by a society that is unaware of ASD. Hence, the pressure on parents is exacerbated by the community's negative perception and treatment of ASD children and their families.

Undeniably, ASD is also often associated with religion and culture. The parents of these children are often accused of having done wrong and causing their child to suffer a particular fate. This comprehensive study is able to enlighten the reader's mind and change their distorted perception. A study conducted by Chan et al (2018) reported that cultural



stigma and society's negative perception of ASD contributes to parental stress. They are accused of wrongdoing and the child suffers a consequential fate. Some also go as far as to say the child is possessed and needs to be treated accordingly. This mystical belief is more significant in Asian nations, further contributing to the challenges and stress of parents (Ilias et al., 2018). According to Sharif & Jamil (2019), the social system plays a crucial role in motivating and cultivating positive attitudes among parents of children with ASD in the course of their daily lives. Parents will experience increased stress due to the responsibility of caring for a disabled child. As a result, they will look for, develop, and employ strategies to deal with these stresses. Consequently, having a robust social network enables parents to share responsibilities and concerns with others to receive emotional support and stress management from friends, family, and neighbors (Rehab & Mona, 2019).

### **Conclusion**

According to the literature review conducted, the conclusion that caring for a child with ASD is not an easy task can be drawn because these children exhibit a variety of behaviors that go beyond what is expected of them and are challenged to mitigate effectively. The entire family, particularly the parents, are affected by ASD. When it comes to providing care, nurturing, educating, or raising children with ASD, parents face a more complex challenge. Therefore, it is evident that, as a result of the stress they have experienced, these parents require professional financial and mental support. To overcome obstacles, parents of children with ASD need to be in good mental health, aside from being physically strong.

In general, the community's lack of awareness and support makes this challenge even more difficult. Due to the high cost of therapy or intervention, parents are also pressured because of financial issues and the family's socioeconomic status. As a result, the parents of children with ASD should receive support and attention from various parties, including community members, social workers, and non-governmental organizations (NGOs). All parties must assume their part to provide help, empathy, and support to ease the burden of shouldering a Herculean task.

However, family members are the closest and always present in a child's life. Home is part of a micro system, the immediate environment. Parents' presence is not only important because they provide the most basic needs of the child, but also because they provide the basic structure of the child's social life. They are mediators between children and the larger world. ASD has a profound impact on family life and dynamics. The presence of a child with autism forces changes in the family to accommodate the child's challenging behavior. Bronfenbrenner's Ecological Theory supports parental involvement and explains the importance of this involvement in child development. Bronfenbrenner Ecological Theory is ideal for describing phenomena that influence stress in the involvement of parents managing children with autism. Since parents are very important people in the lives of these children. Therefore, their mental health is very important as they are the closest people, understanding and contributing to the development of these children. Hence, this theory takes a greater perspective on the environment of the child. Obviously, the Theory of Ecology illustrates that if parents are happy, the children will be happy, which equals a happy environment. Parents who experience emotional distress are often depressed and cannot be directly involved in their child's daily routine. If researched more deeply, there is a strong link between the emotions of parents and the early development of children. In conclusion, children with

Autism can develop well in a positive environment. At the same time reduce the stress that parents face.

This study is expected to provide an important overview and awareness of parenting stress to related parties such as family members and the local community, further helping parents in managing the stress they face. In fact, this study is expected to give a clearer and more accurate picture to the community about the behavior of ASD children, so that the community can understand the symptoms of ASD children and not throw or give various negative interpretations and perceptions that are very disappointing and disturbing the quality of life of the family because their children are often used as objects of reproach.

Finally, it is also hoped that this study can be a guide and a source of inspiration for researchers in the future to carry out related research. It is hoped that the findings of this study can help other researchers in an effort to improve, expand the scope of the study and find effective strategies in an effort to deal with the pressure experienced by parents of children with educational needs.

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