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# Cultural Beliefs and Stigmatization on Early Diagnosis of Children With Autism Spectrum Disorder

### Dr. Muhammad Javed Aftab

Assistant Professor (Special Education), Department of Special Education, Division of Education (DoE) University of Education, Township, Lahore, Punjab, Pakistan, Email: drmjavedaftab@ue.edu.pk
<a href="mailto:drmjavedaftab@gmail.com">drmjavedaftab@gmail.com</a>

### Arslan Haider

M.Phil. Scholar (Special Education), Department of Special Education, Division of Education (DoE), University of Education, Township, Lahore, Punjab, Pakistan, Email: <a href="https://haiderarslan318@gmail.com">haiderarslan318@gmail.com</a>

### Hina Shoukat

M.Phil. Scholar (Special Education), Department of Special Education, Division of Education (DoE), University of Education, Township, Lahore, Punjab, Pakistan, Email: <a href="mailto:Shoukathina335@gmail.com">Shoukathina335@gmail.com</a>

### **Abstract**

Autism Spectrum Disorder (ASD) presents a complex landscape of cultural beliefs and stigmatization, particularly concerning early diagnosis in children. Unlike conditions with visible physical markers, ASD lacks overt signs, leading to unique challenges in recognition and acceptance. This study aims to cultural beliefs and stigmatization on early diagnosis of children with autism spectrum disorder. Descriptive research is the research method of choice for this study. This study will use a structured questionnaire with a 5-





point Likert scale as part of its quantitative research strategy. With reference to cultural views, stigmatisation, and the early diagnosis of children with autism spectrum disorder (ASD), this strategy seeks to collect numerical data for analysis and statistical judgements. A quantitative evaluation of participants' viewpoints and attitudes is made possible by the questionnaire structure, which enables the systematic and uniform collecting of replies. The study examined how cultural beliefs and stigma impact early intervention for children with Autism Spectrum Disorder (ASD). Most respondents aged 3I to 40 and equally representing both parents, had intermediate to bachelor's degrees. While some faced stigma and negative perceptions due to their child's ASD diagnosis, others were less affected. Despite challenges, most did not report significant social isolation or emotional distress. Statistical analysis found no notable differences between mothers and fathers. Overall, the study underscores the complex interplay of cultural factors, stigma, and early ASD intervention.

**Keywords:** Autism Spectrum Disorder (ASD), Cultural beliefs, Stigmatization, Early diagnosis

#### Introduction

Stigma is one of the hardest social conditions for families to deal with when a family member has a physical or mental disability. It is a perception that has been shaped by society and is associated with guilt, shame, or humiliation (Goffman, 2009). Globally, stigma exists in all cultures towards parents of children with ASD (Liao et al., 2020). You will be able to comprehend stigma more fully if you can distinguish between "enacted" and "internalised" stigma (also referred to as self, affiliate, or felt). According to Scrambler G. (2004) and Jacoby A. (1994), the former describes unjust treatment of an individual because of a stigmatising illness, while the latter describes the embarrassment and humiliation that result from such treatment as well as the fear that it may occur again. Stigma surrounding autism differs from other types of stigmas because, despite a child's appearance, the illness's symptoms may be easily recognised, and there is a dearth of public information about it. People tend to adjust better when they become more knowledgeable about the illness, decide to ignore negative





comments from others, focus on their work, or look for spiritual and religious support (Reddy et al., 2019). Over the past 30 years, estimates of the prevalence of ASD have significantly grown. Certain children who have been seen by researchers to exhibit signs of ASD but have never gotten a diagnosis have been included in certain recent studies to compute high prevalence rates (Baird et al., 2006; Baron et al., 2009).

A large percentage of children who are not diagnosed with autism show signs similar to those who have been diagnosed with Asperger's syndrome (AS) or autism, according to a recent UK study (Russell et al.,2010). Understanding the diagnosis process, its ramifications, and the variables affecting the experiences of parents with an ASD diagnosis is crucial. The current study aims to investigate the stigma and societal perceptions surrounding early ASD diagnosis.

Autism is perceived in Western countries as an incurable, debilitating disorder that restricts a person's capacity to do several daily tasks. Prevalent cultural beliefs hold that bad spirits, the mother's mistreatment of the child, or past transgressions within the family are the causes of autism (Kwang Hwang et al. 2010; Grinker 2007). In Eastern psychiatry, for example, Grinker (2007) reports that psychiatrists were more likely to conclude that the child's autism was caused by "bad" mothers, that is, by depressed and reclusive mothers, than to consider the possibility that the mother's depression was caused by the challenges of raising an autistic child for an extended period of time. These psychiatrists also argued that the success Korean women had at work caused them to ignore their children, which in turn caused the latter to develop autism. Due to the historical tendency to blame mothers for their children's misbehaviour, even when it originates from their spouses, mothers are more likely than fathers to face stigma (Broady et al., 2015, Mak et al., 2010).

Not many cultures held the same severely unfavourable perceptions of autism; in fact, Pakistan had quite the opposite opinion. According to Jegatheesan et al., (2010), some Pakistanis thought that an autistic kid was a pure and innocent gift from Allah. There were also strong spiritual convictions on the family's involvement in autism. The families felt that because of Allah, they were able to comprehend the complexities of raising an autistic kid, which in turn helped them become more devoted to their faith. Though opinions on the precise rationale for this decision differed among Sunni and Shiite Pakistanis, Allah chose to give the kid to the family because of their kind attitude. Shiite Pakistan believed in reincarnation as the cause for being selected to care for an autistic kid, but Sunni Pakistan believed in fate as an irrefutable act of Allah predetermined before the birth of the parents (Jegatheesan et al. 2010). In Pakistan, there was a belief that Allah had given them the child to test their family's morals and their own morality towards the child, in addition to fate or reincarnation (Jegatheesan et al., 2010).

Research on the specific cultural belief that links autistic children to sins or spiritual elements is lacking in the present literature on cultural beliefs and stigmatisation associated to the early diagnosis of autism spectrum disorder (ASD) in





the Pakistani setting. Furthermore, little study has been done on the ways in which stigmatisation takes the form of bullying aimed at parents of autistic children. Understanding the links between these cultural ideas and stigmatisation is essential to creating specialised therapy and support networks. To support the development of workable strategies that promote early detection of ASD and improve family well-being in the context of Pakistani culture, this research gap has to be closed. This will clarify the particular challenges faced by parents who are Pakistani due to these cultural standards and the shame associated with them.

The purpose of this study is to look at how stigmatisation and cultural views affect children with autism spectrum disorder (ASD) and early intervention. The research looks at a variety of cultural contexts in an effort to find trends that influence attitudes, spot obstacles to early diagnosis, and investigate possible approaches, such teaching cultural competency, to improve understanding and lessen the stigma associated with ASD. Offering insightful data to support the development of culturally sensitive therapies that support early intervention for children with ASD in a range of cultural contexts is the ultimate objective. Following were the objectives of this research study: 1) to look at how cultural views affect children's early diagnosis of autism spectrum disorder (ASD), 2) to examine how stigmatisation affects the time it takes to diagnose ASD and 3) to pinpoint the cultural elements that affect how well-understood and accepted ASD is in communities.

This study is important because it sheds light on the critical connections between cultural perceptions, stigma, and early detection of autism spectrum disorder (ASD) in children. Understanding these correlations is essential to developing targeted treatments that address specific cultural factors influencing the acceptance and recognition of autism spectrum disease. The outcomes might improve support systems, speed up the diagnosis process, and boost the effectiveness of early intervention. The ultimate aim of the research is to promote inclusion and cultural awareness in the treatment of ASD, with the objective of assisting affected children and their families in achieving positive results in a range of cultural setting.

### Review of the Related Literature Autism Spectrum Disorders

According to the 2013 Diagnostic and Statistical Manual of Mental Disorders (DSM-5), autism is a neurodevelopmental condition with many facets, a broad distribution, and complexity. The DSM-5 identifies eye-contact avoidance, difficulty making friends, repetitive activities, delayed language development, abnormal behaviour that hinders social interaction, inability to initiate and carry on a suitable conversation, communication difficulties, and language impairment as the main characteristics of autism. According to Masi et al. (2017), the condition is now widely recognised as a complex and diverse illness that manifests with coexisting medical and psychological





issues, including intellectual disability, epilepsy, and social anxiety disorder. In addition to their lack of initiative and linguistic problems, they may respond angrily, withdraw, or behave in an antisocial way to stress or changes in their daily routine (WHO 2019, Liao et al., 2019). Estimates of the prevalence of ASD have increased dramatically during the last 30 years. It is essential to comprehend the diagnostic procedure, its implications, and the factors influencing the experiences of parents whose kid is diagnosed with autism spectrum disorder. The current study attempts to look at how society views early ASD diagnosis and the stigma associated with it.

A medical test, such a blood test, to diagnose autism spectrum disorder (ASD) does not exist, hence diagnosis might be difficult. When diagnosing a child, physicians take into account the child's developmental history and behaviour. On rare occasions, children as young as 18 months old may exhibit signs of ASD. A diagnosis made by a qualified specialist can be trusted by the age of two (Lord C et al., 2006). By the age of two, a diagnosis provided by a licenced professional is considered reliable (Lord et al., 2006). According to (Brentani et al., 2013), three domains are utilised to develop the specific criteria used today for ASD diagnosis.

- i. Impaired social interaction is demonstrated by the following symptoms: a) diminished ability to use nonverbal cues (such as eye contact, facial expressions, and body postures); b) inability to form peer relationships that are appropriate for the individual's age; c) lack of spontaneous sharing of interests and affect with others; and d) lack of social or emotional reciprocity (limited interest in or awareness of others' reactions, interests, or feelings).
- ii. Qualitative deficits in communication abilities, demonstrated by: a) delayed or nonexistent language learning (absence or decreased frequency of early language development as babble and sound play, and later, absence of phrase speech); b) incapacity to start or carry on a conversation; c) repetitive and stereotyped language use or idiosyncratic language (echolalia, oddly formal speech, neologisms); and d) lack of development of pretend play or social imitative play development.
- iii. Restricted and repetitive patterns of behaviour, interests, and activities, as evidenced by: a) a strong obsession with one or more peculiar and limited interests; b) rigid adherence to particular routines or rituals; c) motor stereotypies (flapping, flicking, pacing, and jumping); and d) an obsession with specific object parts.

#### Cultural Belief

Cultural differences in spirituality and belief systems seemed to have an effect on family resilience (Greeff et al.,2013). In reality, research indicates that families from collectivist cultures—like those in Korea—have different perspectives on their well-being and the things that have the most impact on their quality of life (Kang-Yi et al., 2018). Kang-Yi and colleagues (2018) found that traditional forms of assistance from religious leaders and organisations had a significant impact on helping families with





disability children manage and find acceptance in their communities. Krys et al. (2019) claim that within collectivist cultures, an individual's well-being is significantly influenced by their social position and social interdependence. Across individualist and collectivist societies, autonomy and independence are seen less highly. Additionally, other cultural factors like stigma, which is present in Western cultures but has been reported to be especially salient in several Asian cultures due to its association with shame and dishonor, are also present (Green 2003; Kinnear et al., 2016; Yu et al., 2020). (Hwang et al., 2010; Mak et al., 2008; Mak et al., 2010; Zhou et al., 2018). According to Hwang and Charnley (2010), the notion of resilience is helpful in facing hardships because it helps evaluate how the family reconciles their own experience with ASD with societal perceptions of the disorder. This community's cultural view on autism is that the mental illness is caused by previous wrongdoings in the family. Abuse by mothers and the presence of demonic spirits rank lower. When it comes to the reason why children develop autism, this is the most frequently accepted theory. Most narratives claim that an autistic kid in a family result from the family being punished for past transgressions by themselves or their ancestors (Kwang Hwang et al. 2010).

#### Cultural Perspectives on Asd Symptoms, Diagnosis, and Characterization

It is well acknowledged that having a kid changes one's life. The majority of people feel both excitement and anxiety when their child is born. Expectations about the child's traits, personality, and developmental trajectory inevitably emerge from desires and prior experiences. The choice to have a child evaluated may be triggered by observations of aberrant repetitive habits, delayed speech development, and difficulties with reciprocal social engagement. The amount of time it takes to diagnose an illness might vary significantly depending on the culture and the diagnostic tools and standards used (Bernier et al.,2010).

Some instances of misinterpreting symptoms that resulted in a delayed diagnosis are included below (Bernier et al., 2010).

- i. A parent thought their 3-year-old daughter was a mature kid as she interacted effectively with adults, despite the fact that she did not socialise with peers her age.
- ii. Since Indian males speak later, a mother was not concerned that her 4-yearold son was still nonverbal.
- iii. Because they are trouble-free, kids who remain quiet and to themselves are viewed as nice kids.

The social norms surrounding physician recertification and continuous education are another example of macro cultural elements that might cause a delay in diagnosis. The absence of recertification standards and obligations to stay current with new medical information might lead to a delayed diagnosis. It was hypothesised that the respected and older Indian doctors may have had an antiquated understanding of





autism, which is why some of the patients in the review were misdiagnosed or came in later than expected (Bernier et al.,2010).

### Cultural Influences in Diagnosis and Assessment of ASD

The Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Interview are the gold standard diagnostic instruments for ASD. The assessment and characterisation of ASD have become much more standardised thanks to these tools, although cultural factors and variables were not taken into account during their creation. Despite the fact that the behavior-based ADOS has been translated into twelve languages, it has not yet been fully determined how possible cultural confounds may affect the validity and reliability of the tool (Bernier et al., 2010). Research on the diagnosis and characterisation of ASD in non-Western nations is scarce. This might be partially due to the fact that ASD is not specifically named or labelled in many cultures. For instance, rather than being described by a single phrase, ASD is characterised by lengthy descriptions of actions in Native Hawaiian and Native American languages. Furthermore, some Asian languages do not have a label for ASD, while others have a phrase that is inaccurate given current knowledge of the illness (Dobson et al.,2002).

Religious healers are frequently sought before medical experts in many regions of India who specialise in ASD. Although this tendency is shifting, when medical assistance is sought, prescription drugs or vitamins are frequently the primary line of treatment rather than referrals for behavioural therapies that have been proven to be successful (Grinker et al., 2007). Parents and professionals in the US are more likely to notice language skill regression or overall developmental delays (Coonrod et al., 2004). Because boys learn to speak later than girls, some Indian parents and doctors do not view language delays as a fundamental characteristic of ASD. According to Daley TC and Sigman MD's (2002) theory, the reason for these variations in the behaviours that are initially seen and deemed fundamental to ASD is that Indian culture places a greater emphasis on social conformity than does the dominant US culture, which places a greater emphasis on language development.

### Cultural Influences in Parental Adjustment of ASD Diagnosis

The reaction to an ASD diagnosis is among the most challenging duties a parent must do. Because autism is a lifelong diagnosis, the challenges faced by a family raising a kid with the condition are real and result in more significant changes to the family structure. Cultural considerations have an impact on the family's capacity to welcome the kid and offer the tools required to support the child's growth and adaption. Following an autism diagnosis, many parents go through shock, anguish, and grieving for their lost typically developing kid (Bernier et al., 2010). Common emotions to the diagnosis include denial about the diagnosis, rage about how unjust it is to have to raise a kid with developmental delays, and dread for the child's future. A kid with autism causes a family to deal with multifaceted problems and demands for the rest of their lives, unlike other illnesses or incidents that may have a temporary





effect. Families may be defined by a particular sense of tragedy even as they grow in resilience and self-organization. Parents' capacity to accept and care for their kid with ASD is greatly impacted by the differences in their coping skills. Asian parents, in contrast to White parents, employ reframing tactics and focus their energies on constructive activities such primary coping mechanisms (Twoy et al., 2007).

Concerns about inadequate care and resources for their children were also voiced by carers, who noted that the stigma may deter families from getting evaluated and informing the school of a diagnosis. There are other cultures where people report being reluctant to seek assistance or treatment for a handicap due to the stigma. Due to the stigma attached to the diagnosis, South Asian families expressed reluctance to send their children for assistance. They also expressed concerns about potential detrimental effects on arranged marriages, especially for females (Bernier et al., 2010).

#### Stigmatization

When someone behaves in a way that deviates from the norms of a social group, they risk being rejected by them and excluded from it. This is known as stigma (Whitehead, 2001). The stigmatised are, at best, seen as human but imperfect, which can be used as an excuse for discrimination. This is hurtful and stunts the growth of the stigmatised person. The "normal" may justify hostile behaviours by pointing to the phobias and terror that these people instill in them (Goffman, 2009). According to Green et al. (2005: p.197), biological differences are socially meaningful, and they use Link and Phelan's previous (2001) work labelling as a means of indicating difference or by disregarding individuals who are different in social contexts. The allocation of a negative value to socially suppressed differences is known as stereotyping, according to Green (2003). Stigmatisation has two distinct origins and targets: perceived and enacted stigma, according to Link and Phelan (2006). Enacted stigma is the result of discrimination against those who possess a stigmatising feature, whereas felt stigma is related to the sentiments of people who have a socially unacceptable behaviour. Refusing or navigating the experience of felt stigma is one approach to challenge the social hierarchies that are currently in place (Aggleton et al., 2003). Enacted stigma creates and perpetuates these inequalities.

Because of this stigma, the family experiences a significant deal of discrimination because they are seen to have contributed to the child's illness. Fearing discrimination and the stigma attached to disabilities, many families decline to have their children seen by professionals for a diagnosis. Families who refuse to be diagnosed may be able to escape having identities associated with disabilities. The name originated from the withdrawn conduct that stems from the perception that individuals with autism are so lost in their own world that they are unaware of what is going on in the outer world. Knowing that autism, as a disease, has different meanings in different nations and causes a variety of different experiences of autism, as an illness, across cultures, is crucial to understanding how autism is seen in a particular country (Ecker, 2010).



The experience of obtaining a diagnosis can be impacted by the stigma associated with having a kid with a disability, thus in order to ensure a successful diagnostic procedure, physicians must employ coping methods that are culturally appropriate. Asian families, for instance, tend to frame things differently and focus their energies on constructive activities like coping mechanisms. Clinicians should expand on this strategy by looking at constructive ways to channel family behaviours, such focusing energy on treatment or taking part in studies to increase knowledge of the condition (Bernier et al., 2010). In the end, following the diagnostic evaluation, clinicians can support the families by educating them about the disorder, going over the differences in the developmental trajectory of children with ASD, and—above all—supplying information about family support services, educational opportunities, speech therapy, behavioural interventions, and doctors who are at ease treating ASD patients locally. Clinicians must take into account the stigma that is attached to autism in many cultures and how it affects how they interact with families that have a child with autism as well as how the family views their kid. Clinicians need to be conscious of their own cultural prejudices towards the diagnosis and treatment of autism in order to address stigma at the social and cultural levels (Bernier et al., 2010).

#### Research Methodology

This study aims to cultural beliefs and stigmatization on early diagnosis of children with autism spectrum disorder. Descriptive research is the research method of choice for this study. This study will use a structured questionnaire with a 5-point Likert scale as part of its quantitative research strategy. With reference to cultural views, stigmatisation, and the early diagnosis of children with autism spectrum disorder (ASD), this strategy seeks to collect numerical data for analysis and statistical judgements. A quantitative evaluation of participants' viewpoints and attitudes is made possible by the questionnaire structure, which enables the systematic and uniform collecting of replies. The main objective of this chapter is to describe the study's procedures.

This study aims to assist a wide range of people, such as Punjabi parents, guardians with children with ASD. A total of 35 participants—parents, carers, community leaders, and professionals living in Lahore—were chosen at random to comprise the study's sample using a random sampling technique. The Stigmatisation and Cultural Beliefs about Autism Spectrum Disorder (SCBASD) survey is the main instrument used in this investigation. This standardised tool has two components and uses a 5-point Likert scale:

- i. Stigmatisation about ASD: Eleven items on a 5-point Likert scale are used to gauge participants' perceptions of how society sees ASD.
- ii. Cultural beliefs about ASD: This part, which consists of 10 items on a 5-point Likert scale, examines how cultural values and customs affect how people perceive and react to ASD.





The SCBASD survey is conducted in a number of ways to accommodate participant preferences, including in-person, online, and paper-based techniques. An extensive informed consent form explaining the goals, methods, possible dangers, and advantages of the study was given to each participant. The Statistical Package for the Social Sciences (SPSS) is used to analyse the data in order to find patterns and connections between views on ASD, stigma perceptions, and cultural origins. This study attempts to offer a thorough knowledge of the complex interaction between cultural beliefs, stigmatisation, and the early diagnosis of ASD in children through the examination of quantitative data.

### Data Analysis

Thirty-five surveys were correctly filled out and examined. The survey was divided into two sections: one examined societal perceptions about autism spectrum disorder (ASD), and the other examined ASD-related stigma. The statistical package for the social sciences, or SPSS, was used to analyse the collected data. The 5-point Likert scale surveys on cultural beliefs and stigmatisation were subjected to descriptive analysis. Additionally, an independent sample t-test was used to determine if there was a significant difference between the mean scores of mothers and dads. The following tables provide an overview of the analysis' findings.

Table I. Socio-Demographic Characteristics of Respondents

Variable	Frequency(N=35)	Percentage	
		(%)	
Age			
20-30	6	17.1	
31-40	14	40.0	
41-50	7	20.0	
51-Above	8	22.9	
Relationship			
Mother	18	51.4	
Father	17	48.6	
Level of Education			
Illiterate	2	5.7	
Primary-Matriculation	6	17.1	
Intermediate-Bachelors	24	68.6	
Masters and above	3	8.6	
Children with ASD			
1Child	31	88.6	
2Children	4	11.4	
Religion			
Islam	32	91.4	
Christian	3	8.6	



Table I indicate the socio-demographic characteristics of respondents.

### Stigmatization about Autism Spectrum Disorder

Following table indicate the data analysis about stigmatization people felt about Autism Spectrum Disorder ASD.

Table 2. Perceptions and Attitudes towards Autism

Statement	Never%	Rarely %	Some times %	Often%	Always %
People think less of those with ASD.	7(20.0)	14(40.0)	9(25.7)	4(11.4)	1(2.9)
An average person is afraid of someone with autism.	7(20.0)	11(31.4)	9(25.7)	6(17.1)	2(5.7)
My experiences with stigma have affected my family's quality of life.	4(11.4)	4(11.4)	21(60.0)	4(11.4)	2(5.7)

Table 2 indicated that majority of responses tells us about respondents sometimes felt negative perception and attitudes towards Autism.

Table 3. Stigmatization and Discrimination

Statement	Never%	Rarely %	Some times %	Often%	Always %
People think less of me or my family because of my autistic child(ren).	5 (14.3)	6(17.1)	12(34.3)	8(22.9)	4(11.4)
My child has been stigmatized because of his/her autistic diagnosis.	5 (14.3)	8(22.9)	12(34.3)	7(20.0)	3(8.6)
I have been stigmatized because of my child's(ren)'s condition.	4(11.4)	4(11.4)	17(48.6)	8(22.9)	2(5.7)
Other members of my family have been stigmatized because of my	6(17.1)	11(31.4)	7(20.0)	11(31.4)	00



child's condition.

Table 3 indicated that majority of responses tell us about respondent sometime felt stigmatization and discrimination to Autism Spectrum disorder.

Table 4. Impact on Interpersonal Relationships

Statement	Never%	Rarely %	Some times %	Often%	Always %
People ignore me or take me less seriously because I have a child with autism.	10(28.6)	4(11.4)	10(28.6)	7(20.0)	4(11.4)
Negative stereotype has affected my family's ability to make or keep friends.	8(22.9)	6(17.1)	11(31.4)	7(20.0)	3(8.6)
Negative stereotype has affected my ability to interact with other relatives.	8(22.9)	9(25.7)	11(31.4)	4(11.4)	3(8.6)
People discriminate against me because I have a child with autism.	9(25.7)	6(17.1)	9(25.7)	8(22.9)	3(8.6)

Table 4 indicated us that majority of responses told us about respondents sometime feel that Autism spectrum disorder impact their interpersonal relationship.

Table 5. Stigmatization about Autism Spectrum Disorder

Statement	Never%	Rarely %	Some times %	Often%	Always%
Perceptions and Attitudes towards Autism.	18(17.1)	29(27.6)	39(37.1)	14(13.3)	5(4.7)
Stigmatization and Discrimination.	20(14.2)	29(20.7)	48(34.2)	34(24.2)	9(6.4)
Impact on Interpersonal Relationships.	35(25)	25(17.8)	41(29.2)	26(18.5)	13(9.2)





Table 5 shows that 39 (37.1%) respondents sometimes face negative attitudes towards ASD, while 18 (17.1%) never do. Discrimination and stigma affect 48 (34.2%) respondents sometimes, with 20 (14.2%) never feeling discriminated against. ASD impacts interpersonal relationships for 41 (29.2%) respondents sometimes, while 35 (25%) report no impact.

#### Cultural beliefs about Autism Spectrum Disorder

Following tables indicated the data analysis about cultural beliefs about Autism Spectrum Disorder ASD.

Table 6. Personal and Emotional Well-being

Statement	Never%	Rarely %	Some times %	Often%	Always %
I am disappointed in myself for having a child with ASD.	14(40.0)	13(37.1)	5 (14.3)	3(8.6)	00
People without a child with ASD could not possibly understand me.	11(31.4)	11(31.4)	5 (14.3)	7(20.0)	I(2.9)
Having a child with ASD exerts a negative impact on me.	14(40.0)	7(20.0)	9(25.7)	4(11.4)	I(2.9)

Table 6 indicated that majority of responses tell us that they never feel any impact of having an autistic child on their personal and emotional well-being.

Table 7. Unfounded Beliefs and Misconceptions

Statement	Never%	Rarely %	Some times %	Often%	Always %
Families with children with ASD have done something wrong in their past life.	14(40.0)	5 (14.3)	6(17.1)	5 (14.3)	5 (14.3)
People with ASD are possessed by evil spirits.	16(45.7)	9(25.7)	8(22.9)	I(2.9)	1(2.9)
People with ASD cannot lives independent lives	11(31.4)	9(25.7)	9(25.7)	5 (14.3)	I(2.9)



Table 7 indicated that majority of responses tell us about parents never face any unfolded belief and misconceptions about having an autistic child.

Table 8. Social Isolation and Emotional Impact

Statement	Never%	Rarely %	Some times %	Often%	<b>Always</b> %
Negative stereotypes about my child's condition keep me isolated from social gatherings.	5 (14.3)	14(40.0)	10(28.6)	5 (14.3)	I(2.9)
Being around people who do not have a child with ASD makes me feel out of place or inadequate.	17(48.6)	5 (14.3)	8(22.9)	3(8.6)	2(5.7)
Having a child with ASD makes me think I am less important to others.	12(34.3)	10(28.6)	10(28.6)	1(2.9)	2(5.7)
Nobody would be interested in getting close to me because I have a child with ASD.	16(45.7)	8(22.9)	6(17.1)	4(11.4)	I(2.9)

Table 8 indicated that majority of responses does about parents never feel any social isolation and emotional impact about having an autistic child.

Table 9. Cultural beliefs about Autism Spectrum Disorder

Statement	Never%	Rarely %	Some times %	Often%	Always %
Personal and	39(37.1)	31(29.5)	19(18.1)	14(13.3)	2(1.9)
Emotional Well-					
being					
Unfounded Beliefs	41(39)	23(21.9)	23(21.9)	11(10.5)	7(6.7)
and Misconceptions	` ,	, ,	` ,	, ,	` ,
Social Isolation and	50(35.7)	37(26.4)	16(11.4)	13(9.3)	6(4.3)
Emotional Impact			. ,	. ,	

Table 9 outlines the impact of having an autistic child on parents' well-being, misconceptions about autism, and experiences of social isolation. Majority (37.1%) reported parents never felt emotionally affected, with 29.5% rarely feeling it. About





misconceptions, 39% reported never encountering them, with 21.9% rarely experiencing them. For social isolation, 35.7% indicated parents never faced it, with 26.4% rarely, 11.4% occasionally, 9.3% frequently, and 4.3% always experiencing it.

Table 10. Independent Samples Test on Stigmatization about Autism Spectrum Disorder

	Relationship	N	Mean	SD	t	Sig.
Perceptions and	Mother	18	8.06	2.817	.577	.568
Attitudes	Father	17	7.59	1.839	.584	.564
towards Autism						
Stigmatization	Mother	18	11.44	3.552	118	.907
and	Father	17	11.59	3.675	118	.907
Discrimination						
Impact on	Mother	18	11.22	4.772	.644	.524
Interpersonal	Father	17	10.29	3.636	.649	.521
Relationships						

Table 10 presents an analysis of responses regarding negative perceptions and attitudes toward Autism Spectrum Disorder (ASD) ( Mother, N=18 M= 8.06 SD= 2.817 t= .577 Sig.= .568 / Father N=17 M= 7.59 SD= 1.839 t= .584 Sig.= .564 )as well as experiences of stigmatization and discrimination ( Mother, N=18 M= 11.44 SD= 3.335 t= -.118 Sig.= .907 / Father N=17 M= 11.59 SD= 3.675 t= .118 Sig.= .907 ) and the impact of ASD on interpersonal relationships, categorized by mothers and fathers( Mother, N=18 M= 11.22 SD= 4.772 t= .644 Sig.= .524 / Father N=17 M= 10.29 SD= 3.636 t= .649 Sig.= .521 ).

Table II. Independent Samples Test on Cultural beliefs about Autism Spectrum Disorder

District						
	Relationship	N	Mean	SD	t	Sig.
Personal and	Mother	18	6.277	2.585	290	.774
Emotional Wellbeing.	Father	17	6.529	2.552	290	.774
· ·						
Unfounded Beliefs and	Mother	18	6.94	3.316	.483	.632
Misconceptions.	Father	17	6.47	2.375	.488	.629
-						
Social Isolation and	Mother	18	9.388	4.354	.955	.346
Emotional Impact.	Father	17	8.176	2.984	.965	.342

Table 11 presents an analysis of responses concerning the impact of having an autistic child on parents' personal and emotional well-being (Mother, N=18 M= 6.277 SD= 2.585 t= -.290 Sig.= .774 / Father N=17 M= 6.529 SD= 2.552 t= -.290 Sig.= .774 ) as well as beliefs and misconceptions about autism (Mother, N=18





M= 6.94 SD= 3.316 t= .483 Sig.= .632 / Father N=17 M= 6.47 SD= 2.375 t= .488 Sig.= .629 ) and the experience of isolation and emotional impact faced by parents ( Mother, N=18 M= 9.388 SD= 4.354 t= -.955 Sig.= .346 / Father N=17 M= 8.176 SD= 2.984 t= -.965 Sig.= .342 ).

### **Findings**

The purpose of the project is to look at how stigmatisation and cultural views impact early intervention for kids with autism spectrum disorder (ASD). The bulk of respondents, according to demographic data, are between the ages of 31 and 40, and both parents equally participated in the survey. The majority of families only have one kid with ASD, and their educational backgrounds range from intermediate to bachelor's degrees. Furthermore, a sizable percentage of the responders identify as Muslims.

In reference to the stigmatisation of ASD, it was noted that respondents occasionally had unfavourable opinions and attitudes towards the condition. They also say that because of their child's diagnosis of autism spectrum disorder, they have faced prejudice from society, which has affected their life and their connections with others in their communities. In general, parents who have an ASD child experience stigma, especially when the diagnosis is made early. Regarding societal perceptions about autism spectrum disorder (ASD), it was shown that although the majority of parents are unaffected by these perceptions, some do suffer consequences for their mental and emotional health. This implies that parents' emotional states may be influenced by cultural perceptions about ASD. The study discovered that although a large number of parents did not run across false assumptions and preconceived notions about raising a kid with autism in their cultural setting, some did. In terms of emotional impact and social isolation, most participants said that having a kid with ASD had no appreciable influence on their life. According to the study's findings overall, some parents did, perhaps as a result of cultural variety, run into misunderstandings regarding cultural beliefs linked to ASD, but the majority of parents did not.

Furthermore, there were no discernible variations in the replies of mothers and dads regarding stigmatisation and cultural ideas about raising a kid with ASD, according to the results of independent sample t-tests.

#### Discussion

The research shows how stigmatisation, cultural views, and early intervention for kids with autism spectrum disorder (ASD) are intricately related. Notwithstanding the more elevated educational attainment of the participants, adverse attitudes and prejudice towards Autism Spectrum Disorder were documented, signifying extensive social obstacles. Culturally sensitive therapies are important because of the impact that cultural beliefs have on parents' emotional health. Although many parents did not come across misunderstandings, certain strategies are required to address issues that some parents confront. Variations arise depending on things like availability to support





resources and societal views, even though the majority of participants did not experience substantial social isolation or emotional effect. The study highlights the difficulties and common experiences that parents of all genders face, pointing to the necessity of inclusive support techniques. The fact that mothers and dads respond to stigmatisation and cultural ideas similarly, despite their gender distinctions, emphasises the difficulties and problems that all parents confront. This shows that all family members' needs must be met while providing support and intervention using inclusive methods. In general, this study emphasises how critical it is to address stigmatisation and cultural views in order to enable early intervention and provide support for families with children who have ASD.

#### Conclusion

This study sheds important light on the complex difficulties that families of children with autism spectrum disorder (ASD) encounter, especially in relation to stigmatisation and cultural views. The results highlight the necessity of early intervention and support programmes that are culturally aware, taking into account the varied experiences and backgrounds of the impacted families. The majority of parents did not significantly experience social isolation or emotional damage, despite some reporting unfavourable judgements and prejudice connected to ASD. The fact that some people face difficulties, nevertheless, emphasises how crucial it is to implement focused interventions to dispel myths and advance knowledge across groups. In addition to offering complete assistance, we may work to overcome cultural stigma and attitudes in order to create inclusive environments that empower families and advance the wellbeing of children with ASD. It is important that forthcoming studies and endeavours persist in investigating these matters in order to guarantee fair distribution of resources and cultivate more acknowledgment and assistance for persons with ASD and their families in varied cultural environments.

#### Recommendations

The study's research suggestions include more investigation into how cultural differences affect how people perceive autism spectrum disorder (ASD) and how early intervention might help, ideally by conducting comparison studies between various cultural groups. Studies that follow the experiences of impacted families over time might be able to shed light on how cultural attitudes and stigmatisation are changing or persisting. To acquire a more nuanced knowledge of parents' perspectives, qualitative inquiry methodologies should be used. Culturally sensitive approaches should be given priority when developing intervention development strategies to address identified issues. Key stakeholders can work together on collaborative, community-based projects to create and execute culturally relevant solutions.

Assessing the efficacy of current support networks and interventions in tackling cultural obstacles and stigma, as well as taking intersectionality into account to





comprehend the ways in which different identities influence the experiences of families, are crucial. The goal of these research projects is to aid in the creation of evidence-based therapies and policies that enhance the assistance provided to families of children with ASD.

#### References

- Aggleton, P., Parker, R., & Maluwa, M. (2003). Stigma, discrimination, and HIV/AIDS in Latin America and the Caribbean.
- American Psychiatric Association, D. S. M. T. F., & American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (Vol. 5, No. 5). Washington, DC: American psychiatric association.
- Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). The lancet, 368(9531), 210-215.
- Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., Matthews, F. E., & Brayne, C. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *The British journal of psychiatry*, 194(6), 500-509.
- Bernier, R., Mao, A., & Yen, J. (2010). Psychopathology, families, and culture: autism. *Child and Adolescent Psychiatric Clinics*, 19(4), 855-867.
- Brentani, H., & Paula, C. S. (2013). de, Bordini D, Rolim D, Sato F, Portolese J et al. *Autism spectrum disorders: an overview on diagnosis and treatment. Rev Bras Psiquiatr*, *35*, S62-S72.
- Broady, T. R., Stoyles, G. J., & Morse, C. (2017). Understanding carers' lived experience of stigma: The voice of families with a child on the autism spectrum. *Health & social care in the community*, 25(1), 224-233.
- Coonrod, E. E., & Stone, W. L. (2004). Early concerns of parents of children with autistic and nonautistic disorders. *Infants & Young Children*, 17(3), 258-268.
- Daley, T. C., & Sigman, M. D. (2002). Diagnostic conceptualization of autism among Indian psychiatrists, psychologists, and pediatricians. *Journal of Autism and Developmental disorders*, 32, 13-23.
- Dobson, S., Upadhyaya, S., & Stanley, B. (2002). Using an interdisciplinary approach to training to develop the quality of communication with adults with





- profound learning disabilities by care staff. *International Journal of Language & Communication Disorders*, 37(1), 41-57.
- Ecker, J. (2010). Cultural belief systems in autism and the effects on families (Doctoral dissertation, Barnard College).
- Greeff, A. P., & Nolting, C. (2013). Resilience in families of children with developmental disabilities. *Families, Systems, & Health, 31*(4), 396.
- Green, S. E. (2003). "What do you mean 'what's wrong with her?": Stigma and the lives of families of children with disabilities. *Social science & medicine*, 57(8), 1361-1374.
- Grinker, R. R. (2008). *Unstrange minds: Remapping the world of autism.* Basic Books.
- Hwang, S. K., & Charnley, H. (2010). Making the familiar strange and making the strange familiar: Understanding Korean children's experiences of living with an autistic sibling. *Disability & Society, 25*(5), 579-592.
- Hwang, S. K., & Charnley, H. (2010). Making the familiar strange and making the strange familiar: Understanding Korean children's experiences of living with an autistic sibling. *Disability & Society*, 25(5), 579-592.
- Jacoby, A. (1994). Felt versus enacted stigma: A concept revisited: Evidence from a study of people with epilepsy in remission. *Social science & medicine*, 38(2), 269-274.
- Jegatheesan, B., Miller, P. J., & Fowler, S. A. (2010). Autism from a religious perspective: A study of parental beliefs in South Asian Muslim immigrant families. *Focus on autism and other developmental disabilities*, *25*(2), 98-109.
- Kang-Yi, C. D., Grinker, R. R., Beidas, R., Agha, A., Russell, R., Shah, S. B., ... & Mandell, D. S. (2018). Influence of community-level cultural beliefs about autism on families' and professionals' care for children. *Transcultural psychiatry*, 55(5), 623-647.
- Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of autism and developmental disorders*, 46, 942-953.
- Liao, X., Lei, X., & Li, Y. (2019). Stigma among parents of children with autism: A literature review. *Asian journal of psychiatry*, 45, 88-94.





- Link, B. G., & Phelan, J. C. (2013). Labeling and stigma. *Handbook of the sociology of mental health*, 525-541.
- Lord, C., Risi, S., DiLavore, P. S., Shulman, C., Thurm, A., & Pickles, A. (2006). Autism from 2 to 9 years of age. *Archives of general psychiatry*, 63(6), 694-701.
- Mak, W. W., & Cheung, R. Y. (2008). Affiliate stigma among caregivers of people with intellectual disability or mental illness. *Journal of applied research in intellectual disabilities*, 21(6), 532-545.
- Mak, W. W., & Kwok, Y. T. (2010). Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. Social science & medicine, 70(12), 2045-2051.
- Mak, W. W., & Kwok, Y. T. (2010). Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. Social science & medicine, 70(12), 2045-2051.
- Masi, A., DeMayo, M. M., Glozier, N., & Guastella, A. J. (2017). An overview of autism spectrum disorder, heterogeneity and treatment options. *Neuroscience bulletin*, *33*, 183-193.
- Mason-Whitehead, E., & Mason, T. (2007). Stigma and exclusion in healthcare settings. *Multidisciplinary handbook of social exclusion research*, 59-78.
- Reddy, G., Fewster, D. L., & Gurayah, T. (2019). Parents' voices: experiences and coping as a parent of a child with autism spectrum disorder. *South African Journal of Occupational Therapy*, 49(1), 43-50.
- Russell, G., Ford, T., Steer, C., & Golding, J. (2010). Identification of children with the same level of impairment as children on the autistic spectrum, and analysis of their service use. *Journal of Child Psychology and Psychiatry*, 51(6), 643-651.
- Shilubane, H., & Mazibuko, N. (2020). Understanding autism spectrum disorder and coping mechanism by parents: An explorative study. *International journal of nursing sciences*, 7(4), 413-418.
- Twoy, R., Connolly, P. M., & Novak, J. M. (2007). Coping strategies used by parents of children with autism. *Journal of the American association of nurse practitioners*, 19(5), 251-260.





- World Health Organization. (2019). The WHO special initiative for mental health (2019-2023): universal health coverage for mental health (No. WHO/MSD/19.1). World Health Organization.
- Yu, L., Stronach, S., & Harrison, A. J. (2020). Public knowledge and stigma of autism spectrum disorder: Comparing China with the United States. *Autism*, 24(6), 1531-1545.
- Zhou, T., Wang, Y., & Yi, C. (2018). Affiliate stigma and depression in caregivers of children with Autism Spectrum Disorders in China: Effects of self-esteem, shame and family functioning. *Psychiatry Research*, 264, 260-265.

