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ABSTRACT

This qualitative study explored the experiences of stigma and responses to stigmatization among 13 South Asian parents of children with extensive support needs (ESN). Existing research indicates that students with intellectual disabilities often experience negative emotions such as shame, powerlessness, and frustration due to their disability status. Cultural beliefs significantly influence the experiences of disabled children and their families, with stigma perceived and felt differently across cultural groups. Participants were interviewed about their family and cultural beliefs, perceptions of disability, and experiences with school collaborations and social stigma. Thematic analysis revealed that South Asian families with children with ESN faced stigmatizing narratives about disability from their families and community. Responses to stigma included social exclusion, forming supportive communities, resistance to stigmatizing narratives, and turning to spiritual practices. This study indicated the need for culturally sensitive support and educational strategies for South Asian families with children with ESN.

KEYWORDS

extensive support needs, stigma, families

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*S*tudents with extensive support needs (ESN), or those children with significant disabilities who need on-going support to participate socially and academically throughout their lives, experience stigma when they are consistently viewed as less valuable and not fully accepted by the community because of a specific trait or condition, causing feelings of shame or disgrace (Goffman, 1963). According to Link and Phelan (2001), stigma exists when: (a) human differences are recognized and labeled; (b) stereotypes are associated with these labels based on cultural beliefs; (c) labeled individuals are viewed as outsiders; and (d) this labeling results in inequity and loss of status. Self-

stigma occurs when individuals internalize these negative labels and the associated reactions and attitudes.

Research suggests that most students with intellectual disabilities (ID) experience negative emotions such as shame, powerlessness, and frustration due to their disability status (Logeswaran et al., 2019). Moreover, research shows that the experiences of disabled children and their families are influenced by the cultural beliefs about disability in their community and particularly the extent of stigma associated with disability (Cartledge & Kourea, 2008; Jindal et al., 2018). Disability and the stigma linked to it are thus, cultural constructs, perceived and felt in diverse ways across cultural groups (Varenne & McDermott, 2018). Intersectional factors like socioeconomic status, parental education levels, and gender also play a role in how stigma is experienced in different cultural contexts (Darling, 2013; Dawn, 2014). Besides, scholars have noted that resilience, or the ability to navigate and overcome challenges by using resources from families, friends, communities, and society at large also plays a crucial role in shaping families' experiences of stigmatization (Conder et al., 2015; Kayama et al., 2021; Murray & Doren, 2013).

Stigma associated with disability can result in social exclusion of disabled children and their families, thereby decreasing the likelihood of caregivers or families seeking help for or advocating for their children (Thara & Srinivasan, 2000). Scholars have pointed out that while physical inclusion in communities is essential, it is insufficient for achieving true acceptance and meaningful social inclusion for children and adults with intellectual disabilities (Cummins & Lau, 2003; Merrells et al., 2018). Along with physical and spatial inclusion, scholars have recommended researching and understanding the various perceptions of disability and stigma across different countries, cultures, and religious communities before embarking on public initiatives (Zeilinger et al., 2020).

South Asian communities in the United States have cultural characteristics that uniquely influence the experiences of families with children with disabilities, particularly those with ESN. These cultural characteristics include religious beliefs concerning disability, use of traditional medicines, and social stigmas around disability (Jindal et al., 2018; Krishnagiri, 2013). However, there is limited research on perceptions of disability in this community, even though it is the fastest-growing ethnic community in the United States (SAALT, 2015). This study examines the experiences of stigma and responses to stigmatization among 13 South Asian parents of children with extensive support needs.

Literature Review

Cultural attitudes toward individuals with disabilities are influenced by the culture's explanation for the disability, the value placed on the affected skills (e.g., physical labor, speech, independent living), and the adjusted expectations for the individual's adult role in society. For instance, some cultures may be accepting of certain disabilities based on their explanations., e.g., sorcery, past actions, chance (Groce, 1999; Scheer & Groce, 1988). Additional factors like socio-economic status, education level, marital status, and individual temperaments can also influence perceptions of disability (Groce & Zola, 1993).

Research on families from various cultural backgrounds indicates that their perceptions of disability significantly affect a child's school participation. For instance, Ganotti et al. (2001) discovered that Puerto Rican families believed disabilities were hereditary and associated them with guilt or shame. These families felt sympathy for their children’s conditions and believed that disabled children should not be required to do much or attend school all day. Parents saw

themselves as caregivers and their children as dependent, which made them less likely to advocate for teaching independent living skills.

Numerous early studies have documented cultural differences in perceptions of disability. For example, Mardiros (1989) found that many Mexican-Americans viewed a disabled child as a divine choice, believing they were chosen by God to care for the child, suggesting that stigma might be less pronounced in such cultures. Florian and Katz (1983) suggested that members of Arab-Israeli communities with disabled family members often experienced intense shame and embarrassment. By contrast, Native Americans, have been shown to focus less on disability and more on an individual's societal contributions viewing illness as a natural part of life, where community members are valued regardless of their physical condition (Groce & Zola, 1993).

Researchers studying Asian views on disability indicated that many Asian communities have disempowering attitudes toward disability, often seeing it as a punishment for past sins (Groce & Zola, 1993). Westbrook et al. (1993) suggested that collectivist societies might stigmatize disabilities more due to the perceived spread of stigma within the collective.

Regardless of specific cultural beliefs, disabilities associated with behavioral disorders (schizophrenia) generally carried more stigma than physical disabilities, such as blindness (Albrecht et al., 1982). Severe motor disabilities and non-remission epileptics also faced greater stigma (Chaplin et al., 1998). Studies consistently show that physical disabilities are stigmatized based on their visibility and deviation from cultural ideals.

The South Asian Community

Not only do the South Asians, originating from Afghanistan, Bangladesh, Bhutan, India, Nepal, Pakistan, Sri Lanka, and the Maldives, make up about 27% of the Asian-American population, they are also the fastest growing ethnic group in the country (APIGBV, 2022; SAALT, 2015). Additionally, Asian-American students with disabilities constitute 7% of all students identified with disabilities in U.S. schools and 5% in California (NCES, 2019), making them a significant demographic entity. Researchers have noted that South Asian cultural characteristics uniquely influence the experiences of families with children with disabilities and how they interact with health services and educational professionals (Krishnagiri et al., 2013).

South Asian immigrants in the United States often grapple with navigating between two worlds, facing mixed feelings toward Westernization while trying to uphold their South Asian community values (Jindal et al., 2018; Okazaki, 2018). For instance, South Asian families often prioritize family hierarchical relationships and rely more on extended family support than on professional service (Naeem et al., 2015). Further, research has shown that experiences of South Asian families with children with disability depend upon their cultural assimilation and religious beliefs regarding disability (Krishnagiri et al., 2013). Studies have indicated that many South Asian believe that past lives' actions (karma) may be the cause of disability in the current life (Methikalam et al., 2015). These beliefs can influence how they view disability and their experiences in dealing with disability. Jindal et al. (2018) suggested that to avoid the cultural pressure and fear of judgment, parents may be downplaying or ignoring disabilities, ultimately hindering their children's access to appropriate care and support.

It is important to recognize the intersecting cultural identities of families with children who have significant support needs in the United States in order to understand their experiences and the reasons behind their educational and social decisions. However, there has been limited research into how these families perceive disability and their encounters with cultural pressures or stigma

(Jindal et al., 2018). Recognizing and addressing these cultural beliefs can lead to better support and more effective educational strategies for South Asian children with disabilities.

Existing research has demonstrated that cultural beliefs shape perceptions of disability and how families with children with ESN experience and respond to disability stigma. Given the significant presence of the South Asian community in the United States, it is necessary to investigate the cultural beliefs of this group. The research questions that this study explored were as follows:

1. In what ways do South Asian families with children with extensive support needs experience disability stigma within their communities?
2. How do South Asian families with children with extensive support needs respond to disability stigma within their community?

Positionality Statement

My personal experience as a South Asian parent of an autistic child was integral to every aspect of my research, from framing inquiry questions and conducting interviews to analyzing data and developing themes. My prior experiences with my child's disability and commitment to my community undoubtedly influenced my inclination toward a specific theoretical framework (Herndl & Nahrwold, 2000). Thus, my research became a means to challenge practices within my community, connecting theoretical frameworks with the practical challenges I have encountered to achieve tangible societal change. My research with its focus on inclusive practices and their interaction with institutional and cultural power structures, can be seen in the context of what Blyler (1995) described as complex questions of ideology, including whose interests our research serves and the types of social and institutional contexts it sustains.

However, to ensure that the themes emerging from interviews remained distinct from my own experiences and to provide triangulation of codes, I enlisted a research assistant to code the interview transcripts as well. She identified as an Asian-American of Vietnamese descent with an interest in working with families of disabled children. She added a valuable perspective different from mine in looking at the transcripts. I also used reflective memos to understand and reveal my assumptions throughout the study.

Method

The data were analyzed using thematic analysis a method well-suited for qualitative research due to its flexibility in identifying, analyzing, and reporting patterns within data (Braun & Clarke, 2006). The six steps outlined by Braun and Clarke (2006) were diligently followed in the study. The researcher and the research assistant first familiarized themselves with the data by mindfully reading the data transcripts multiple times. Then, they independently coded the meaningful segments of the data. This step was facilitated using NVivo software, chosen because the software can organize and manage large datasets effectively. The use of NVivo also enabled researchers to efficiently track and refine codes during the analysis. Third, the researcher and research assistant grouped the codes into broader categories based on their relevance to the research questions and data patterns. Fourth, the themes were reviewed to ensure internal coherence and consistency. Fifth, the themes were defined and labeled to align with the research questions. Finally, the themes were written as a narrative with supporting direct quotes from the data.

An inter-coder agreement assessment was conducted to check for reliability. While the initial agreement ranged from 35% to 51%, discrepancies were addressed through iterative discussions and consensus-building within the research team. These discussions aimed to refine the coding framework and ensure alignment in the interpretation of the data.

The decision to use NVivo was further justified because it allowed for streamlining the coding process, maintaining an audit trail, and facilitating collaborative analysis, thereby improving the credibility and dependability of the findings. By adhering to these rigorous analytical steps, the study ensured a methodologically sound approach to thematic analysis.

Participants

After obtaining IRB approval, the researcher interviewed 13 parents (10 mothers and 3 fathers) of children with extensive support needs in Northern California. The participants were recruited through a combination of convenience sampling and snowball sampling (Miles et al., 2014). Initially, the researcher contacted parents of children with extensive support needs (ESN) from her former district. Then, she expanded the recruitment through social media sites, including a group associated with a parent organization supporting South Asian parents of children with disabilities. These parents were also asked to refer other parents they knew who had children with extensive support needs.

The researcher emailed consent notices to the participants and verbally reviewed the contents of these notices during the interview. The participants, aged 40-60, were all of South Asian descent and had immigrated from India in their 20s. All the women had moved to the United States after marrying husbands working or studying there. All participants held undergraduate degrees, and four had master's degrees. Six participants (four women and two men) were employed at the time of the interviews, with two working women starting their jobs after their children entered high school. Eight of the women had been employed when their child with a disability was born but had since left their jobs. The participants' children were between the ages of 12 and 27 at the time of the interviews.

Data Collection

Data were collected through semi-structured interviews conducted via Zoom™, with interview durations ranging from 64 to 127 minutes (Seidman, 2019). The interviews were subsequently transcribed using a professional human transcription service. Questions covered various aspects, including family and cultural beliefs about disability, perceptions of individuals with disabilities within their community, views on the causes of disability, and decisions on educational placements for their children, and their experiences with school collaborations. Participants also shared their perspectives on assistive technologies, accommodations, and approaches to placing students with disabilities in educational environments. These questions served as a guide, allowing participants to discuss their experiences without interruption freely.

During all interviews with parents, strong emotional responses were evident, prompting the researcher to reassure participants that they could choose to skip questions that brought up painful memories. Concurrently with data collection, the researcher kept memos to track emerging patterns (Saldaña, 2013). Immediate coding of interviews helped inform subsequent ones, allowing the researcher to validate or challenge emerging data patterns, such as the impact of social stigma on preferences for segregated placements. Recruitment continued until thematic saturation was

reached, indicating no need for additional participants to offer new insights (Creswell, 2013). Before analysis, all data were anonymized, and participants were assigned pseudonyms for confidentiality.

Data Analysis

Methodological rigor was achieved through member checking at two levels and multiple coders. Frist, the transcripts were shared with all participants for validation. Thematic coding of the interviews was conducted by both the researcher and a graduate research assistant. Initially, the researcher mindfully reviewed all transcripts and applied open coding using NVivo software, resulting in the identification of 106 distinct codes. Subsequently, a coded interview and research questions were provided to the research assistant, who independently coded all transcripts using Microsoft Word's comment feature. While the researcher's coding was more extensive and detailed compared to the assistant's, agreement in coding ranged from 35% to 51% across the transcripts. Discrepancies were resolved through consensus during meetings between the researcher and assistant (Campbell et al., 2013).

Using two coders enhanced the study's reliability and consistency, allowing for the identification of coding errors or misinterpretations of participants' statements. Additionally, the diverse backgrounds and expertise of the coders facilitated a comprehensive analysis of the data, although some discrepancies in interpreting participant statements persisted throughout coding. To address this, member checking was conducted with six participants on fifteen instances within the transcripts, focusing on codes related to social stigma (11 instances), negative perceptions of their child's disability (2 instances), and experiences in Individualized Education Program (IEP) meetings (2 instances), ensuring accuracy and validity (Creswell, 2013).

Following member checking, the initial 106 codes were consolidated into 17 codes during focused coding using NVivo software, with detailed descriptions developed by the researcher for each code. Throughout the coding process, the researcher wrote memos and actively sought disconfirming evidence or alternative explanations (Saldaña, 2013).

Results

During the final coding process, the researcher refined themes by merging, separating, or renaming categories to create meaningful themes that represented the data. The researcher revisited the data in an iterative process, adjusting the themes to ensure that they were clear, well-supported, and reflective of participants' experiences. Finally, the researcher categorized the focused codes into four themes for research question one (experiences of stigma, Table 1) including, (1) disability as an exceptionality, (2) disability as misfortune, (3) disability as maternal failure, and (4) disability as a punishment for the family’s past actions. The data analysis revealed five themes for research question two (response to stigma, Table 2) including, (1) social and family exclusion, (2) forming a community with families with disabled children, (3) resistance to stigmatizing narratives, (4), spiritual turn, and (5) putting pressure on themselves to secure or provide educational opportunities for their child.

Table 1. Definitions and Descriptions of Themes in Experience of Disability Stigma

Theme	Focused Code Categories	Definition	Example
Disability as an exceptionality	1. Families had never experienced disability 2. Stories of institutionalization of the disabled	Participants' words indicated disability was not experienced as a normal occurrence in communities	"…these things have never happened in our family. Is it a US thing?"
Disability as misfortune	1. Being told they had a curse, were unlucky 2. Being told it was a big loss	Participants expressed that they heard from family and friends that disability was bad, unlucky, loss, result of a curse, or happened to bad people	"one of my friends said, "check if there is any curse in your family, maybe somebody in the past must have put a curse, that's why this is happening.""
Disability as maternal failure	1. Mother is to blame	Participants expressed that they heard that the mother's actions could have caused the disability.	"She said, "did you eat papaya? I told you so many times not to.""
Disability as punishment for past actions	1. Karma as cause for disability	Participants heard or believed that the disability was because of actions that they or their child had done in their past lives.	"…he had hurt some people in his past life and he was suffering in this life because of that."

Research Question 1: Experience of Stigmatizing Narratives

Disability as Exceptionality

Disability was seen as an exception in families even at the time of the initial diagnosis. Many participants said that their immediate or extended families claimed that this had never happened in their families. For example, Neha said, "They (family) had never heard of autism before. My mom said, "these things have never happened in our family. Is it a US thing?"" Along the same lines, Pratham said, "There were rumors of a distant cousin having some mental problems, but nobody ever talked about it." In another instance, Kavita said, "my mother-in-law knew of a relative whose child was not okay and their parents visited all the temples and Sadhus (religious men) for their child. We never asked what happened to that child, they said."

Vivek stated his family's confusion over the diagnosis, saying:

> My mother was very confused. She said, this has never happened before in our families. She knew that my dad's cousin had some kind of problem, but we don't know anything about it. In my whole life, she had not seen this so close to her. It has always been like beggars on the street without legs or mental institutions. Maybe polio victims or like that. But a family member with autism, no, nobody had heard of it, and nobody knew anyone in their families with any condition. It was a very different experience to them.

Kavita, when describing her experience with her family, said:

> They were astounded. They had heard of Down syndrome, but they said those kids don't really survive very long. They had heard of people who were in mental institutions because of madness, but that was my child's condition. They kept saying, something is wrong. This cannot happen to people like us. It happens to people, who are poor, who don't take care of themselves. We are not like that. When they talked like that, it seemed that we were really in something very bad. I felt that I had to face a challenge that no one had faced before. It made it very difficult for me.

Disability as Misfortune

Disability was also seen as a misfortune for the family. Many participants reported that their friends and families saw individuals with disabilities as unlucky, cursed, or pitiable. Friends and family frequently expressed condolences upon learning about the diagnosis. For example, Maya said, "...we started hearing, oh maybe she's really unlucky, that's why she's suffering? Or whether because of our past mistakes, she's suffering? I started to wonder, is it true?" Similarly, Neela remembered:

> Friends would call and say that I was so shocked and sorry to hear that my child was not okay. They would say things like, it must be very hard for you, such a big loss in your life. Someone said, you must be grieving, it's like the death of your child. All these things make you think that it is worse than it is.

Along the same lines, Kiran said, "one of my friends said, "check if there is any curse in your family, maybe somebody in the past must have put a curse, that's why this is happening."

There was also stigma revealed through the disbelief that their family could be affected by disability. For example, Ishita said:

> It was too much for us to handle. It could not be true. My mom said, you have not done bad to anyone and no bad will come to you. These things don't happen to good people you know. It cannot be true.

Other participants echoed these sentiments. Neela said, "I could not understand it. This cannot happen to me. My whole life was ruined at that point-that's what I felt. I kept telling myself. This is not happening." Likewise, Karthik said, "How could this happen? We were both smart, educated, high achieving parents. We could not have a child like this. What would we tell everyone?"

Disability as Maternal Failure

Many participants indicated that disability was talked of as a result of something the mother had done. For instance, Kiran said, "Even my in-laws, they didn't really blame, but they were loudly wondering, "Oh, was it because you were doing computer engineering, and you were always having computer with you?" Then, Neela said:

> My mother asked if I had gone out during the solar eclipse during the pregnancy or eaten something I was not supposed to eat. She said, "did you eat papaya? I told you so many times not to." Things like that. Somehow, I felt so guilty about it. Something that I had done that caused this. You look at your child and you are thinking, what did I do to give you this life? And that hurts a lot. You can never get over it, you cannot talk to anyone about that because you think somehow you were at fault.

Further, participants noted that the mothers were blamed for their choice to work outside the home. Many of the participants (8 out the 10 women) were first in their families to work outside the house and this was pointed out as a possible reason for the child's disability. For instance, Preeti said, "This is what happens when women work outside the home, said my father-in -law." Or as Kiara said, "My mother-in-law said, that's why we say that pregnant women should be home taking care of themselves."

Disability as Punishment for Past Actions

Disability was often talked about as a result of *karma*, or past actions. Kiran noted:

> The first thing that my in-laws did was to visit astrologers. They visited many and one of them said that we were going through all this because of my child's past life *karma*. He had hurt some people in his past life and he was suffering in this life because of that. I looked at my baby and felt, why, why blame you for this? I could not do that.

Karthik noted:

> Yes, of course, they (parents) went to every astrologer they knew. They visited all the holy people. They were told that there was a problem in the horoscope because of some past life. The astrologers told my parents to visit a big list of temples and then everything would be fine.

Tanvi did her own research into the spiritual remedies. She said:

> So, I started studying the ancient, the Shiv Nadi, and all of that, and their remedies. So, I believe there's a component of that, because what was interesting is I contacted two or three completely different astrologers, and some people do it by the birth chart and all of that. And there is a component where they go into the past life and then they say, "If you committed some, whatever," in her case they say that she's not committed a sin which she knew, but it is come out a couple of times that she was a doctor and she accidentally hurt people by the wrong medicine that she gave them, or something like that. Now again, I don't get deeply into the philosophy of what did she do wrong, but they say because of that she was born into a family where she could expire her karma, where we would put every penny that we had towards that. But the fact that she had committed something that caused grievous harm to someone else means that her journey is a lot longer than it should be. And I think when you hear something like that, it also gives you rationale for, again, when you face something insurmountable it's like, what can you do? And then you realize maybe you can't.

Research Question 2: Response to Disability Stigma

Data indicated that participants responded to the stigmatizing narratives in different ways. However, some common themes emerged in their reactions, primarily those of social and family exclusion, forming community and friendships with only other parents of disabled children, resistance to disempowering narratives, spiritual turn, and pressurizing themselves to secure and provide additional services outside of school for their children.

Table 2. Definitions and Descriptions of Themes in Response to Disability Stigma

Theme	Focused Code Categories	Definition	Example
Social and family exclusion	1. Cutting off ties from extended family 2. Cutting off ties from friends 3. Cutting off ties from broader South Asian community	Participants expressed that they excluded themselves from. Interacting with family, friends, or the broader community because of the stigmatizing language they heard.	"…I was very decisive about cutting off connection with a lot of people. If they were not treating my son well, or they showed any kind of negative stuff…"
Forming community and friendships with other parents of disabled children	1. Being part of a parent organization for South Asian parents with disabled children 2. Bonding with other families with disabled children	Participants expressed that they preferred to interact or socialize with other parents with disabled children	"I felt that families that have children with a disability were so easy to be with. We don't judge anyone, we know everyone has problems. Let them be… that's what I heard."
Resistance to disempowering narratives	1. Telling people to stop 2. Frustrated at being disappointed with alternative medicines	Participants expressed that they did not want to participate in the actions to find the religious origin/remedy of the disability	""Whatever it is, keep it with yourself. You can do whatever, but don't come to me telling, that, oh the astrologer, I'm not going to do anything."
Spiritual turn	1. Seeking solace in religious groups, scriptures	Participants expressed that the experience of raising a disabled child initiated their interest in spiritual pursuits	"…So, I think this experience has led me to spirituality."
Pressure to secure and provide additional services	1. Giving up job to stay home with child 2. Training themselves to teach their child 3. Hiring tutors, online educational services	Participants described how they provided or obtained services for their child outside of school to supplement their education	"So, after he comes (back from school), I used to just do all the work with him. I used to do grade level work with him, but I never asked the teachers to step up."

Social and Family Exclusion

Participants indicated that these stigmatizing narratives from their family and friends made them want to isolate themselves socially. Maya expressed how these insinuations made her feel when she said, "So, every time I doubted myself, I thought I was responsible for this, I could not face people or interact normally with anyone." Kiran was more deliberate in distancing herself from family and friends who made her feel uncomfortable, saying:

> I was very decisive about cutting off connection with a lot of people. If they were not treating my son well, or they showed any kind of negative stuff…After the phone call, I said, okay. If that is what the phone call is doing to me, no more. They're out of my life.

> So, I just ruthlessly cut off so many relations, so many friendships. Only if they made me feel good, I wanted to be with them.

Participants also preferred separate settings for their children at school. For example, Neha said, “We live in an area with a lot of people from the Indian community and if we had chosen inclusion, we would have to deal with them every day.” Along the same lines, Kiara said, “My older son was also in the same school; I could not let other parents gossip around him about my disabled child.”

Forming Community and Friendships with Other Parents of Disabled Children

All participants mentioned that they were more comfortable with other parents of disabled children and organizations where their children were accepted and welcomed. Many of the participants were members of a South Asian organization for parents with disabled children and made deep connections and friendships through that organization. Maya noted:

> The organization really helped me. We had a place to go on weekends; we met with other families with similar problems like us. Our children could play together, and we were not always being hurt by what others were saying or our child being compared to those of the other parents. The truth is that when Indian parents get together, they mostly talk about their child doing this or that or how well their child is doing at school, and my husband and I would feel so bad. But this organization was a place that we could hang out without facing that kind of trauma. And who needs the extra trauma in life? We were already going through so much. So, we made our lives easier, I think.

Similarly, Preethi said:

> It is all very well to say let them play with typical children. But there is so much stress involved. I had to be constantly on guard when they were interacting, making sure nobody got hurt, my child did not do anything that others would make fun of. Then, I would see the other parents also looking at each other, making eyes, and I would feel very bad. I felt that families that have children with a disability were so easy to be with.

Other participants similarly echoed the sentiment that most of their social interactions were confined to other parents of children with disabilities. Maya noted, “they are the only ones who understood my problems, what I was going through.” Similarly, Tanvi remarked, “we joined the other parents in the organization where we felt comfortable with others like us. We could talk about the school, the IEP, therapy and things that were meaningful to us and not listen to all the negativity.”

Resistance to Disempowering Narratives

There were several participants who voiced rejection of the stigmatizing narrative and responded with anger and frustration toward it. For instance, Kiran said, “I think my parents did all that, but I was just like... "Whatever it is, keep it with yourself. You can do whatever, but don't come to me telling that, oh the astrologer, I'm not going to do anything. I became an agnostic at that point as well.” Neha similarly expressed, “I had a lot of s*** thrown at me. I said, I don’t believe in all this, please don’t tell me anything.” Ishita noted:

> I knew they were trying all the religious things. I am also religious, but it was not helping. I tried telling them. You do everything, don’t tell me. I cannot keep getting my hopes up with every promise of cure and then be disappointed again. How much can one person

> take? I used to get very upset when they would send me this medicine or that medicine that someone recommended and nothing would work. Please stop, that is what I told them. These things don't work. I felt bad also that they were spending all their time and money to do all this.

Spiritual Turn

Many participants shared that the challenges of raising a child with a disability, grappling with stigmatizing narratives, and enduring social exclusion prompted them to introspect and seek solace in spirituality. They described how these experiences led them to delve into their religious teachings, seeking answers to their circumstances. As a result, they devoted more time to studying their scriptures, actively participating in religious discussion groups, and finding comfort in attending spiritual talks. As Karthik said:

> This was like an eye-opener for us. We all need a trigger to start our path into spirituality, and this was our trigger. I knew that my mind was very troubled, and I knew that I needed to calm myself down in order to take care of my family and my son. I needed to meditate. I looked for how I could do all that. So, I think this experience has led me to spirituality.

Tanvi explained her growth spiritually in these words:

> And I realized that there's a karmic component to it. And I actually started studying astrology at that point myself. I said, "Okay, now I have to understand this," because that's when I became a deep believer in this. I also went into the ancient science *Brahma Vidya* (Hindu scripture), and I realized that she's come for a reason to make me change from what I would've been yet another Silicon Valley tech person, because my entire team joined Facebook™. I had a group of engineers and all of them were in the founding team at Facebook™ as well. So, I was the only one who stayed back and became a stay-at-home mom. So, I realized that maybe more financial success, I would never gone down this path. So, she's come into this world to change the trajectory that would've been defined for me. And I think being the strong-willed personality that I was, I wouldn't have changed my trajectory had it not been for her either.

Pressure to Secure and Provide Additional Services

All the parents mentioned providing extensive support to their child to support or supplement what they were doing in their programs at school. This support ranged from arranging home therapy, self-training to assist their child, hiring private tutors, to even leaving their jobs to provide full-time care. They demonstrated their advocacy through a commitment to teaching their child a variety of academic, social, and vocational skills, striving to enhance their child's overall quality of life. For instance, Neela said "I think I gave up my career and everything basically just to keep him going." Similarly, Kiran said:

> So, after he comes (back from school), I used to just do all the work with him. I used to do grade level work with him, but I never asked the teachers to step up. He was happy, and he was so supported. And then that's all I wanted because I thought anytime I put him in these kinds of mainstream settings, he just used to get super anxious.

This excerpt from Tanvi's interview illustrated parents' dedication and willingness to go to great lengths to support their child.

> Then I went back and looked at every phonics program that was there, every dyslexic program, dyscalculia, everything that was there under the sun…So, I read his book and I read her book, What to Do with a Brain Damaged Child, and I realized that one of the things that she still wasn't doing is her finger isolation wasn't good…So, I took some lessons in piano, I educated myself, and then I also got a teacher who was actually very pushy instead of being very gentle about it…I've done every therapy, every doctor under the book. In the meanwhile, all this was going along with every diet, every raw diet, this diet…I tried, if I remember correctly, the one that worked for her was a AIT, the Auditory Integration Therapy. And I tried two other therapies before that…I also taught her, because I went back to our traditional modes of music, and Carnatic music, and Bharatanatyam, and I wasn't superbly accomplished in anything, but I figured I would start everything.

In summary, participants revealed that they experienced stigmatizing narratives characterizing disability as exceptionality, misfortune, maternal fault, and punishment for past actions. They responded to these narratives by isolating themselves from family and friends who made them uncomfortable, joining with families with children with disabilities, resisting such narratives by talking back to the source, finding solace in spiritual pursuits, and in putting pressure on themselves to secure additional services for or provide these services to their child.

Discussion

The findings from this study pointed to the complex interplay between cultural beliefs and the experiences of stigma in South Asian families with children with ESN.

Experiences of Stigmatizing Narratives

The findings revealed that South Asian families with children with ESN often have to endure stigmatizing narratives about disability from their extended families and community These views resonate with the broader cultural attitudes toward disability documented in various studies. Groce (1999) and Scheer & Groce (1988) highlighted how cultural explanations, such as sorcery or past actions, influence the perception of disability. The belief that disability could be a result of past actions (karma) aligns with Methikalam et al.'s (2015) findings, where South Asian cultural beliefs often attribute disabilities to karmic consequences from past lives.

Moreover, the perception of disability as a misfortune or a curse, as reported by participants, is consistent with the narratives from various cultural backgrounds noted by Ganotti et al. (2001). These researchers found that Puerto Rican families associated disabilities with guilt or shame, which is similar to how South Asian families perceive disabilities as bad luck or punishment. The sentiment that disabilities happen to other families or are the result of maternal actions echoes the findings of Florian and Katz (1983) who reported intense shame and embarrassment among Arab-Israeli families with disabled members.

Responses to Disability Stigma

The responses to disability stigma observed in this study—social exclusion, forming supportive communities, resistance to stigmatizing narratives, spiritual turn, and providing additional services—mirror the coping mechanisms documented in the literature. Social exclusion and

isolation as a reaction to stigmatizing attitudes have been noted by Groce and Zola (1993), who found that families often withdraw from social interactions to avoid negative judgment.

The formation of supportive communities with other parents of disabled children is a coping strategy that reflects the findings of Krishnagiri et al. (2013), who noted that South Asian families often rely on extended family support rather than professional services. The creation of informal networks for support and sharing experiences is crucial in mitigating the feelings of isolation and helplessness that arise from stigmatizing cultural attitudes.

Resistance to stigmatizing narratives was demonstrated by some participants who rejected religious explanations and negative societal attitudes. However, many participants also turned toward religion to seek solace in the scriptures. Spiritual explanations for their experiences resonate with the inclinations noted by Groce and Zola (1993) among Native Hawaiian and Native American communities, where illness and disability are integrated into the natural order of life, and spiritual practices are seen as part of the coping mechanism.

These findings are significant because they reveal that the families chose to isolate themselves from their extended families and broader community. This isolationism could result in a lack of social support, which is essential for the well-being of both the child with ESN and their family. The social isolation experienced by these families can lead to feelings of loneliness, stress, and helplessness, making it more challenging to cope with the demands of raising a child with special needs (Holt-Lunstad et al., 2010). Further, the cultural beliefs attributing disability to karma or past actions can place an immense psychological burden on parents, especially mothers, who may be blamed for their child's condition. This can lead to intense feelings of guilt, shame, and inadequacy, negatively impacting their mental health (Methikalam et al., 2015).

Moreover, within the family unit, stigmatizing beliefs can strain relationships. Extended family members who hold negative views about disability may distance themselves, leading to fractured family ties and a lack of familial support. This can be particularly challenging in South Asian cultures, where family is a central support system. The primary caregivers, often mothers, may bear the brunt of caregiving responsibilities without adequate help, leading to burnout and further isolation (Green, 2003)

Additionally, the stigma associated with disability can deter families from seeking necessary medical, educational, and social services for their child (Jindal et al., 2018) Fear of judgment and discrimination may cause parents to hide their child's condition, resulting in delayed diagnoses and interventions. This can hinder the child's development and reduce the effectiveness of any potential support they might receive. Finally, children with ESN might be excluded from community events, religious activities, and educational opportunities due to prevailing stigmas. Social isolation of children with ESN not only affects their social development and sense of belonging but also deprives them of important cultural and community experiences that are integral to their identity (Bray & Gates, 2003).

Implications for Research

Future research is needed identifying how cultural beliefs about disability vary among different subgroups within the South Asian diaspora and other communities in the United States. There is also a need for more in-depth research on the coping mechanisms employed by South Asian families dealing with disability stigma, including the examination of the effectiveness of forming supportive communities, resistance to stigmatizing narratives, and the role of spiritual practices. Understanding these coping strategies can help in designing interventions that leverage existing

strengths within the community. Moreover, further studies could investigate the psychological impact of cultural stigma on parents, particularly mothers. Research could focus on the long-term mental health consequences of guilt, shame, and social isolation, and how these affect the overall well-being of the family. Studies are also needed on the barriers that stigma creates in accessing medical, educational, and social services. Research could identify effective strategies to encourage families to seek early diagnosis and intervention without fear of judgment or discrimination.

Implications for Practice

Recognizing and addressing the cultural beliefs of South Asian families with children with ESN is crucial for providing effective support and educational strategies. Educational and health professionals need to be culturally sensitive and aware of the unique challenges faced by these families. Cultural sensitivity must include understanding cultural explanations for disability, the associated stigma, and how families navigate these challenges. By doing so, professionals can better support families in advocating for their children and accessing necessary services (Kalyanpur & Harry, 2012). Training programs could include modules on understanding cultural explanations for disability, the associated stigma, and how families navigate these challenges.

Besides, schools can facilitate the formation of supportive community networks across communities and ability where parents can share experiences and support each other. These networks can help mitigate feelings of isolation and provide a platform for advocacy. Further, mental health services can be routinely recommended and ever tailored to address the specific needs of South Asian parents, particularly mothers, who may experience intense feelings of guilt and shame. Efforts to reduce the barriers to accessing medical, educational, and social services for South Asian immigrants would be very helpful including creating safe spaces where families can seek help without fear of judgment and ensuring that services are culturally appropriate (Riza et al., 2020). Finally, schools and community organizations should implement policies and practices that promote the inclusion of children with ESN in community events, religious activities, and educational opportunities. Inclusion should be seen as integral to the child's identity and social development.

In conclusion, this study examined cultural beliefs regarding disability and the resulting stigma on South Asian families with children with ESN, revealing social isolation, stress, and limited support faced by these families. Families chose to isolate themselves from their extended families and broader community, resulting in lack of social support and feelings of loneliness, stress, and helplessness. Cultural beliefs that attribute disability to karma or past actions can place a heavy psychological burden on parents, especially mothers, leading to guilt, shame, and feelings of inadequacy. Stigmatizing views within the family also strained relationships, creating fractured families and increased caregiving responsibilities for primary caregivers, often mothers, without adequate support. This isolation restricted children with ESN from accessing community events, religious activities, and educational opportunities, essential for their social development. For practitioners, the study showed that they must support families by creating supportive networks that promote inclusion in schools and communities to alleviate isolation and improve access to necessary services. Future research should further explore subgroup variations within the South Asian diaspora and investigate coping mechanisms to develop interventions that are culturally attuned and effective, ultimately creating an inclusive environment for these families and their children.

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