



Young Girls with Developmental Disabilities in the Himalayas: A Closer Look

Shubha Nagesh^{1*}, Amanda Dorsey², Colin Weiss³, Ashley Darcy-Mahoney⁴, Megha Girdhar¹, Spoorti Chimmalgi¹

1 Latika Roy Foundation, Dehradun, Uttarakhand, India

2 Washington and Lee University, Lexington, VA, US

3 George Washington University, Autism and Neurodevelopmental Disorders Institute, Washington DC, USA

4 George Washington University School of Nursing / Autism & Neurodevelopmental Disorders Institute, Washington DC, USA

Received on: January 14, 2021. Accepted on: December 21, 2021

ABSTRACT

Background: Research exploring disability and gender are limited in India. The documented few opine largely about the double discrimination, impacting access and utilization of intervention services. The Latika Roy Foundation, a non-profit providing intervention services for children with developmental disabilities, found that proportionally more young males compared to females utilize their services. Consequently, these researchers aim to understand why. **Procedure:** 24 families participated in a semi-structured home-based interview. All their daughters had been assessed to have a developmental disability, were aged 3-10 years, were living in and around Dehradun, India, but were not currently accessing intervention services. **Results:** Families had a reduced knowledge about the disability, poor understanding about the urgency of early intervention, and yet a keenness to do everything possible. Limitations included remote locations, unavailable transportation, and impeding family structures. All the families reported significant concern for their daughter with a disability and had a positive approach to the challenges they faced, though they had difficulties physically accessing services. **Implications:** The study data challenges the predominant dialogue around the intersection between gender and disability in the region. These findings are optimistic for the future of disability and gender equality and India.

Keywords: developmental disabilities, gender, access, barriers, intervention services

INTRODUCTION

Disability in India

Public awareness about advocacy for developmental and mental disabilities did not arise in India until the 1990s (Mehrotra, 2011; Addlakha & Mandal, 2009). Beforehand, people with disabilities (PWD) lacked basic rights including the ability to marry, vote, and adopt children (Addlakha & Mandal, 2009). As a relatively novel social movement, prejudices and misunderstandings from the past continue to linger, inhibiting the enforcement of basic human rights for Indians with disabilities (Disability Rights Promotion International, 2009). The Indian government's initial perception of disability understood PWD as individuals to be pitied and manifestations of bad karma (Mehrotra, 2011), as opposed to contributing members of society. While social improvements are occurring, the country's history of disability perception perpetuates a marginalization of individuals with disabilities in India still today (World Bank, 2009).

This marginalization is in part maintained because of a lack of understanding of what it means to have a disability and how to detect it. India's disability prevalence rate is one of the lowest worldwide, 2.13%, significantly lower than Western, developed nations like the United States, which has a prevalence rate of around 19.4% (World Bank, 2009). This is more likely suggestive of a lack of awareness by caregivers and healthcare providers than a realistic representation of the prevalence. Other research suggests that disabilities, particularly neurodevelopmental disabilities, are in fact more commonly present in India. Arora et al. (2018) found 13.6 % of children ages six to nine sampled from five different Indian cities had at least one neurodevelopmental disability.

Instead, disabilities are not being reported and properly supported because of a lack of understanding about their existence and implications. Early symptoms are perceived as temporary behavior, sometimes treatable with traditional medicine (Daley, 2002; Desai et al., 2012). Daley (2004) found that some Indian parents take up to six years to recognize symptoms of Autism within their child, even though some symptoms emerge before eighteen months of age (Johnson et al., 2007). This lack of awareness about disability clearly creates a delay, and in some cases, a complete barrier to necessary interventions and proper reporting.

*Corresponding Author's Email: shubha.nagesh@gmail.com

Cite as: Nagesh, S., Dorsey, A., Weiss, C., & Darcy-Mahoney, A. (2021). Young girls with developmental disabilities in the Himalayas: A closer look. *Journal of Disability Studies*, 7(2), 75-83.



Even if families are aware of their child's disability, a diagnosis holds stigmatizing weight. Mothers of children with an intellectual disability, for example, often receive blame for their child's behavior, and teachers and community health workers perceive the disability as the parents' doing (Edwardraj et al., 2010). Parents of a child with a developmental disability are faced with the concern about how other family members will perceive their child (Dhar, 2009).

The culture surrounding developmental disabilities does seem to be improving. In big Indian cities, Autism awareness efforts are being implemented, like teacher training programs, inclusion in the pediatric residence curriculum, and the development of more parent support groups (Krishnamurthy, 2008). But support for those with a disability in India has clear room for improvement.

Gender Bias in India

Another portion of the Indian population that traditionally faces limited rights and support is the female population. There are only 943 girls to 1,000 boys in India (Indian Census, 2011), due to factors such as sex selective abortions, neglect of daughters, and poor access to healthcare (Fikree & Pasha, 2004). Jejeebhoy and Sathar (2001) sampled women in both Uttar Pradesh (Northern India) and Tamil Nadu (Southern India) and found that in both regions, the potential of women is limited because of less educational attainment, paid work experience, and autonomy. The researchers found this disadvantage to be particularly prevalent in the northern region. In Uttar Pradesh, 59.1% of participating Hindu women reporting fearing their husband, and 57% of these women reported requiring an escort to go to a health center.

Women have a literacy rate of 53.7%, whereas men have a literacy rate of 75.3% (Disability Rights Promotion International, 2009). Additionally, only 24% of the workforce is women, and 48% of these working women discontinue their job before they have reached the middle of their career (Khambatta & Inderfurth, 2012). While women have potential to be successful in their education and career, they often lack the opportunity to prove such capabilities.

As in the field of disability, improvements are being made to the culture surrounding women. In 2015, the gender gap between girls and boys' access to primary and secondary education was closed, and now the same can be said for tertiary education (World Economic Forum, 2018). On the other hand, only 11.8% of parliament consists of women, and only 0.1% of firms have a female as the top manager (World Economic Forum, 2018). Progress is being made, but the resulting culture has yet to prove entirely inclusive, regardless of an individual's gender or ability level.

Correlation Between Disability and Gender

A female with a disability is assumed to be especially disadvantaged in India due to two stigmatizing labels. The following research supports this claim in a broader Southeast Asian context. In India, Bangladesh, and Nepal, women with disabilities have astonishingly low employment rates due to reasons including a lack of education and training, an absence of family, teacher, and peer support, patriarchal norms, and

limited knowledge about available options (Buettgen et al., 2015). In Bangladesh, women with disabilities were found to be less likely than men with disabilities to access healthcare services, especially if they did not bring in income for the family (Hosain & Chatterjee, 1998).

In India specifically, empirical evidence transparently shows the effects of discrimination. Males with disabilities in India have an illiteracy rate of 43%, but even more staggering is the female with disabilities illiteracy rate of 64% (World Bank, 2009). Furthermore, after age 12, boys with disabilities have a school attendance rate of about 8-10% higher than girls with disabilities (World Bank, 2009). Women with disabilities also face more critiques from family and others than men with disabilities (Disability Rights Promotion International, 2009).

If factors are limiting the education and employment of girls with disabilities, it is possible they are affecting their access to intervention services, as well. The Latika Roy Foundation, a non-profit in Dehradun, India that provides services for children with a developmental disability and their families, noticed that in July of 2019, 186 males with a developmental disability are accessing their intervention services, whereas only 69 females are utilizing their intervention services. Despite the gender disparity in this statistic, Arora et al. (2018) reports no significant difference in the prevalence of neurodevelopmental disorders between males and females in this region. Also, Lakhan and Kishore (2016) reports that the gender of a child does not correlate with the degree of their problem behavior for intellectual disability. A study with Kuwaiti mothers found that the gender of a child with a disability did not influence the severity or type of parenting stressors experienced (Al-Kandri, 2006). Despite gender's insignificant correlation with developmental disability prevalence, the child's behavior, and its effect on the family, there is still a distinct difference in the number of boys and girls that are accessing the Latika Roy Foundation's intervention services, potentially due to greater cultural factors.

Barriers Impeding Access for Healthcare: Conceptual Model

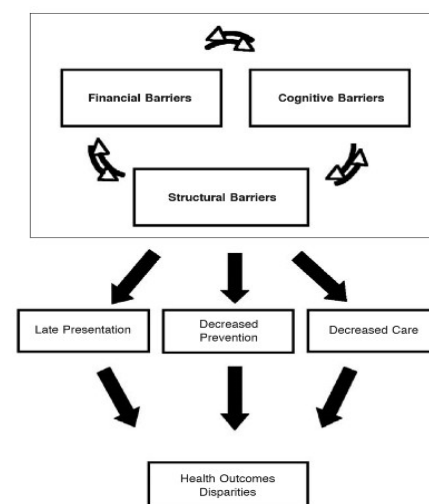


Figure 1. The Health Care Access Barriers Model (Carrillo, 2011).

A multitude of factors are known to affect a child's access to intervention services for a developmental disability, with gender and disability norms both reinforcing and being reinforced by other barriers. Carrillo et al. (2011) created the Health Care Access Barriers Model, which identifies three domains of barriers: Financial, Cognitive, and Structural, each of which strengthen one another, and are also modifiable. Cognitive barriers include a misunderstanding about what the disability is, not recognizing the importance of early intervention, and stigmatizing cultural norms. One cognitive barrier seen to be prevalent in India is degree of awareness. Families in India have a range of understanding about what it means to have a disability. While some seek help right away, others wait with hopes the disability will resolve itself, delaying intervention service access (Daley, 2004). Even if healthcare providers are sought, this does not guarantee that caregivers retain all the information provided to them. When Varghese et al. (2015) interviewed caregivers of children with Intellectual Disability, some of them referred to the child as just *dungi* (dumb) or *motadimag* (thick brained). Additionally, when Shah et al. (2019) talked to parents of children with attention-deficit/hyperactivity disorder, over a third did not know the diagnosis of their child. Not understanding the origin of a disability and the inability to perceive it as a problem both decrease the likelihood that the family will seek healthcare services (Hosain & Chatterjee, 1998). Even if families understand, this does not mean the rest of society does. Dhar (2009) interviewed families in West Bengal, India and discovered that one of the family members' greatest concerns regarding their child with a disability is how the rest of society reacts to them, whether it is by providing unwanted sympathy, avoiding their family in marriage, or allowing the disability to manifest the entire image of the family.

Cognitive barriers not only exist in the homes, but in professionals, as well. According to the World Bank (2007), over half of the healthcare providers in Orissa, India, were not knowledgeable about entitlements for PWD, and over a third reported working with PWD as burdensome. Even if they have a general understanding of developmental disabilities like Autism, not all professionals are equipped to make observations and detect symptoms on their own, without the guidance of the parents (Daley, 2004).

Financial barriers include the inability to pay for the intervention or healthcare services. In low- to middle-income countries such as India, the expensive price of these services and costly distance it takes to reach them are particularly inhibitive (Gudlavalleti, 2018). To exacerbate the issue, families often lack knowledge about health insurance to assist with payment (Varghese et al., 2015). A lack of awareness about developmental disabilities, particularly autism, is especially prevalent among low income and less educated families, and very few organizations in India providing disability support offer subsidized care (Krishnamurthy, 2008). Therefore, in families where intervention services would be most beneficial, they are the most unobtainable. Plus, when money is scarce, families find that it is difficult to allocate money for an

intervention program especially when they are not even sure if it will benefit the child (Edwardraj et al., 2010).

Structural barriers contain logistical and physical limitations to accessing services, because of a lack of facilities, not enough providers to meet the demand, insurmountable distance, or a family structure that restricts accessibility. When the World Bank surveyed PWD in Uttar Pradesh and Tamil Nadu, India in 2007, physical access to healthcare facilities was a significant barrier for 20% of the population. Given the massive size of India and the scarcity of resources, transportation is surely an issue (Daley, 2004). Furthermore, when mothers are expected to fulfill abundant domestic duties, in addition to any other family and economic responsibilities, time invested in the child with a disability is limited.

Current Study

The present study investigated whether biases against girls and women and biases against PWD in India affect the rate at which intervention services are being utilized by young girls at the Latika Roy Foundation in Dehradun, India. In addition to initial assessments, the Latika Roy Foundation provides intervention services such as schooling opportunities, therapy sessions, vocational training, parental guidance, support groups, and remote follow up programs for children with disabilities and their families. The Latika Roy Foundation found that since 2014, more boys than girls aged 3-10 have not continued accessing services after their initial assessment for reasons other than an age-appropriate diagnosis. This research strives to further understand the evident gender disparity. Furthermore, this research seeks to gather whether gender influences how the families perceive the disability, how the family has been impacted, what they expect for the future, and what their desires are for the child. We anticipate that pervasive norms disadvantaging women and persistent norms disadvantaging PWD will intersect to significantly contribute to the reason why young girls with a developmental disability in Dehradun are not all continuing to access intervention services after an initial assessment. We hypothesize that these biases will interact with other cognitive, financial, and structural barriers, reciprocally reinforcing one another to prevent the female population of interest from accessing necessary intervention services.

METHODS

This study was conducted in and around Dehradun, the capital city of Uttarakhand, the Himalayan state of India. The district has a population of 1,696,694, with a sex ratio of 902 female to 1,000 males. (Census of India, 2011). Approximately 84% of the population is Hindu, and the literacy rate is 69% for females and 79% for males (Census of India, 2011). This study entailed conducting qualitative in depth semi-structured interviews with families who lived in urban and rural settings, in and around Dehradun, all of whom had a daughter with disability not enrolled in intervention services at the time of commencement of the study ($N = 24$).

The population of interest was defined utilizing a database by the Gubbara Center, an initial assessment center for developmental disabilities as part of the Latika Roy Foundation. For the purpose of this study, the children assessed were filtered

Table 1 Demographic Information for the Research Sample

Demographic Characteristics	# Subjects (N = 24)	% Subjects (N = 24)
Age of the daughter (years)		
3	3	12.5%
4	4	16.7%
5	5	20.8%
6	3	12.5%
7	2	8.3%
8	3	12.5%
9	0	0.0%
10	5	20.8%
Caregiver Relationship to the Daughter		
Mother	8	33.3%
Father	1	4.2%
Both Parents	5	20.8%
Grandmother	1	4.2%
Combination of Family Members	7	29.2%
Others [†]	2	8.3%
Mother Education Level^{††}		
Class 5 Complete	4	16.7%
Class 8 Complete	1	4.2%
Class 10 Complete	4	16.7%
Class 12 Complete	1	4.2%
Graduate	6	25.0%
Postgraduate	2	8.3%
Illiterate/ Never been to school	6	25.0%
Father Education Level		
Class 5 Complete	4	16.7%
Class 8 Complete	4	16.7%
Class 10 Complete	3	12.5%
Class 12 Complete	3	12.5%
Graduate	6	25.0%
Postgraduate	1	4.2%
Illiterate/ Never been to school	3	12.5%
Religion		
Hindu	17	70.8%
Muslim	5	20.8%
Sikh	2	8.3%
Monthly Income (INR)		
5,001-10,000	9	37.5%
10,001-15,000	8	33.3%
15,001-25,000	1	4.2%
25,001-35,000	2	8.3%
Did not disclose	4	16.7%
Daughter's diagnosis		
Autism Spectrum Disorder	3	12.5%
Global Developmental Delay	4	16.7%
With Cortical Visual Impairment	1	4.2%
Global Developmental Impairment	1	4.2%
With Dyskinetic Language Impairment and Movement Disorder	1	4.2%
Intellectual Disability	3	12.5%
Cognitive Delay	1	4.2%
Cognitive Delay with Attention Deficit Hyperactivity Disorder	1	4.2%

according to the following criteria: i) female ii) aged 3 to 10 years at the time of recruitment iii) living in Dehradun iv) diagnosed with a developmental disability v) assessed between 2014 and 2018, and vi) we were not currently accessing intervention services at the Latika Roy Foundation, or another similar organization, to our knowledge.

In this case, a developmental disability was operationalized as a physical, cognitive, or behavioral impairment that will persist throughout the child's development. Therefore, if a child was given a diagnosis such as "Late talker" or "Late walker" during their assessment, they were removed from the study population because the assessor was not certain that the child's state would persist throughout the entirety of development.

Of this defined population, a convenience sample ($N = 24$) was collected (families who responded to the call and families willing to meet the team). Families who were contacted but did not participate either had an unreachable phone number, are currently accessing intervention services somewhere else, their child passed away, or they did not have time to participate. Demographic information of the families is detailed in Table 1.

All families were initially contacted through a phone call to explain the scope of the study and to obtain their verbal consent. Semi-structured interviews were conducted with parents' and/or caregivers from each of the 24 families, following informed written consent for participation and audio recording of the interviews. All interviews were conducted in the families' homes. During each interview, participants were first asked about demographic information, followed by a history of the child's birth, initial disability symptoms, and discovery of the Latika Roy Foundation assessment center. Participants were then asked about their experience and what they understood from their initial assessment, and what they are doing with their daughter now. Further questions were asked regarding their concerns and expectations for the future, the impact of the daughter's gender, and lastly, how the Latika Roy Foundation can provide them with further support.

All interviews were conducted in Hindi, the most widely spoken language of Dehradun, and later transcribed to English by another staff member of the Latika Roy Foundation who is fluent in both languages. After reading and re-reading the transcripts, a list of codes were constructed based on the themes that emerged. The interviews were qualitatively analyzed using ATLAS.ti to code for recurrent themes.

Confidentiality was maintained throughout the research process by removing the daughter and family members' names from the transcripts and using exclusively an identification number to link demographic information with the interview transcripts. Ethics approval was received by Washington and Lee University's Institutional Review Board.

RESULTS

The research findings are organized into sections based on themes discussed during the interviews: Attitudes, Enablers/Barriers, Impact on the Family, and Planning for Future. After discussing general trends observed within each category, special attention will be drawn to the impact of the daughter's gender on the parent and caregiver responses.

Attitudes

The most common attitude amongst the caregivers was that their daughter is a beloved member of the family, irrespective of her ability level. While there were a few exceptions, the majority of families interviewed reported pampering their daughter, and expressed her value within the family. One mother stated, "*I take her to weddings with me, and very quickly she makes herself known. She makes friends with everybody; everybody starts loving her- saying that she is a good child.*" Instead of emphasizing their child's limitations, many proudly highlighted their capabilities, including a sharp memory, ability to shop independently, enjoyment of books, or independent daily living skills.

If a family is not accessing any intervention services, this does not mean that it is due to a lack of care for the child. Some families simply accept and love the child for who she is and the abilities she was born with. One family, for example, had eight children and two parents living together in a one-room house. Their impoverished condition and remote location made intervention service access unfeasible, but the mother still said, "*We all live together and we all will take care of her. She is the way she is, and she is part of our family.*"

Even in the families with the most love, there was still a common gap of knowledge about the origins of the child's developmental disability. The majority simply accepted that their daughter's disability is something that they cannot explain, while one mother was told her daughter was in dirty water at birth and one grandmother thought that her daughter's walking delay was remedied when a therapist tickled her foot with a pen (eliciting the plantar reflex). Very few families had an in depth understanding of their daughter's diagnosis.

When families were asked whether decisions would be different if their child was a son, 23 out of 24 of them replied with conviction that nothing would be different. If their daughter were a son, they would have treated him exactly the same. As a father of a daughter with cerebral palsy explains, "*What could we do differently? We think that a daughter is equal to a son; a daughter in fact gets more attention than a son does... we can go hungry, but we can't see her suffer.*"

About half of the families further explained that because their child with a developmental disability is a daughter, they actually paid her *more* attention. Because she is a girl, it is more important that she studies, understands her identity, and is protected. In addition, one mother said that she feels closer to a daughter. The grandmother of a young girl with Down Syndrome said, "*[her brother] has pneumonia from childhood and he is ill but still all our focus is on her because she is a girl.*"

Barriers/ Enablers

Since each of the interviewed families had approached the Latika Roy Foundation for an initial assessment and were not able to return, the results help describe an array of barriers families faced to access intervention services. The most prevalently mentioned barrier to obtaining services for their daughter was a misunderstanding or a lack of information provided by healthcare providers. Most families, when they first

noticed a problem, visited multiple medical practitioners, seeking treatment, some supplements, an operation, or a scan. A mother said that an Ayurvedic doctor told her, *“With my medicines, she will become okay later,”* but then the mother said, *“But we didn’t see a difference even after three years.”*

During this time, the child did not receive intervention services, and none of the healthcare professionals advised the mother on the need for or the significance of early intervention. Even when families did reach the Gubbara assessment center, parents commonly reported not being given adequate information on the child’s disability, or there was a gap in the understanding of the home-based recommendations.

This gap in understanding, whether it is from the healthcare professional or the family, interacts with other mentioned barriers, such as a lack of perceived importance of early intervention and a lack of awareness about developmental disabilities. Knowledge about developmental disabilities and early intervention was not common. A particularly educated and involved mother even recounted the beginning of her daughter’s development and said, *“As soon as I saw Autism on the computer screen, I was like ‘what is this? I don’t even know what this is? I don’t know anything about it.”*

This delayed many parents from recognizing initial symptoms and taking further action. Instead, while some parents were convinced that the child would improve on their own with time, others attributed the issue to her generalized debility, perceived physical weakness, or the need for medicines.

A prevalent structural intervention service barrier was the lack of transportation and easily accessible services. Some of the homes visited were incredibly remote, making the Latika Roy Foundation or any similar organization quite difficult to reach. In some cases, the transportation barrier was further compounded with other factors such as the caregiver’s poor health or the time required for domestic or wage-earning duties, making it difficult for family members to accompany the daughter. Many families reported the transportation costs and the intervention service charges to be steep or even impossible to afford. One father disclosed, *“I have done everything I could... I have drowned myself in loans and debts... for her... now my situation is very bad. There are other children too, I have to look after them also, and there is one person to earn and her reason is the first.”*

Other valid, yet less frequently mentioned intervention service barriers included unsupportive family members, the child’s uncooperative behavior, unsupportive schools, general fatigue, and unsuccessful past attempts at intervention services.

At the other end of the spectrum of responses, trends were noticed amongst the parents and caregivers that were incredibly promising for the daughter’s overall wellbeing. This included caregiver resilience- so many parents were doing everything they could within the scope of what they have and what they know to best support their daughter, irrespective of anything negative that others have said about their daughter or her abilities. A mom stated, *“I realized that no matter what has happened, I have to fix my child. Not just change things for the better, but for the best. Compared to others, I want to do the*

best for my child, no matter what happens. I feel I have to make things better for her.”

This child has shown great improvement as her mother works with her constantly at home and seeks out a plethora of services for her, outside of the Latika Roy Foundation, which she says is too far.

The majority of primary caregivers had beneficial support from extended family members, so there was a large network of support for the young girls’ needs. In one instance, the in-laws of one family sent the mother to live in Dehradun while the father worked in Mumbai so that he could earn enough money to support the family and she could focus on supporting her daughter with Down Syndrome in an area with more resources, without the distraction of village work. With more sources of support, it becomes easier to comply with intervention exercises at home, leading to improvements in the child, reinforcing the importance of early intervention.

Other enablers include support from the school and others and informational conversations with healthcare providers.

The influence of gender was not particularly prevalent in this section. While one parent mentioned that she did not want to put her daughter in a school for kids with disabilities because all the other students were boys, there were no other mentions of gender-related reasons for or against accessing intervention services.

Impact on the Family

While every family reported additional challenges resulting from their child’s disability, most families still socialized, attended events, and went out with their children. In several cases, this even meant bringing their daughter along everywhere they went. One mother said, *“She anyway likes going out; even when her sister goes to dance class in the evening. She starts crying saying, ‘Even I want to go, Papa, take me along,’ and she goes there and dances in her dance class....”*

Sometimes these parents are dependent on supportive family members or their child’s cooperative behavior to continue going on outings, but other times they just want their daughter to be happy no matter what others think when they see her.

Other families, however, are not able to socialize and attend events as liberally, whether it is because their daughter’s behavior is more severe, or the family is more attuned to others’ perceptions, tainted with a cultural stigma. In one occurrence, a mother said, *“It’s when people including her teachers tell me that she doesn’t have much of a brain that I get really upset,”* and another reported, *“the moment I mention Autism, [the school is] going to tell me to take the child back home. She will disturb the other kids. They will say she will beat the other kids, while I know she won’t.”*

Within the household, while the consensus is that the families are doing everything they can to accommodate the daughter and her disability, families still reported interfamilial tensions as a common aftermath to the diagnosis. The daughter’s behavior, the amount of money and attention required, perpetual worry for the child’s wellbeing and future, sleep deprivation, sibling relationships, and unanswered questions were all cited as sources of straining stress for the family.

The fact that the child is a daughter, as opposed to a son, heightens daily worries for parents. Several parents were concerned about their child's safety, especially if their daughter struggles to differentiate between strangers and families. *"If anyone tells her, [daughter's name], let's go- she will go with them... she will sit in the vehicle with them. She will go with anyone, she won't use her brains."* If the daughter is inclined to wander or fall victim to predatory behavior by others, this requires more time and supervision from the parents, adding another layer of stress and responsibility.

Gender did not, however, surface as a direct or indirect reason influencing the family's decision to attend social events with their daughter. The majority of families still took their child with them on outings, even though she is a girl.

Planning for the Future

Regarding expectations for their daughter's future, the most common emotions shared were those of hope and worry. Most parents were optimistic that in the future, something will change for the better for their daughter, whether they gain the ability to walk, talk or gain complete independence. This hopefulness does not prevent parents and caregivers from worrying, however. The future is a weighty concern for many parents, as it is so uncertain. One mother expressed, like many others, *"The same thought keeps going on in my head- if anything happens to me, then what about her?"*

As worried as the parents are, many had no plans or idea about what is going to happen in the future. Thoughts about, future care, further education, employment and marriage were pushed aside in the minds of almost all parents who we interviewed. In some cases, it is because the child was very young, but for others, the families just did not know what to think. A few thought the future was so far away, they would think of crossing the bridge when they got to it.

Very few parents thought that time would bring no improvement within their child, just as only a few parents thought that the future will work out the way god intends it to, and it is not worth worrying about.

In terms of what the families desire for their daughters in the future, the most common response was academic improvement, as academic success was correlated with independence and being able to take care of oneself. As stated by one mother, *"Studies are the thing for us, that's all; we want her to study and become something."* Otherwise, families commonly desired an improvement in a symptom by her daughter, like in her behavior, speech, or level of understanding. Less commonly, parents said that they wanted their child to become "okay" or "like how a lot of children are." Or they sought guidance on how to better fulfill their parental role.

The fact that their child is a daughter was very influential for families who had been considering the future. These families felt more responsible to ensure that things are established, and their daughter is taken care of. These select parents either said that they would take care of their daughter as long as they are around, or they have mentally prepared their sons for this task in the future. One particularly prepared mother said, *"Her father tells her brother that we won't keep anything for you, you are a*

boy. I will do everything for her... I will build two rooms upstairs for her and you will serve her, too."

As for gender-specific sources of concern, three families mentioned their daughter's menstrual health, one family mentioned the living conditions at her future in-law's house, and two families made generic statements about more concerns arising because she is a daughter. In addition, several families expressed concern about safety.

DISCUSSION

The intention of this research was to understand perceptions, decision-making, impact of disability and future expectations from parents of young girls with developmental disabilities, all accounting for the influence of gender. The results of this research are an optimistic contrast to recent literature discussing the prevalence of biases against females and individuals with disabilities in India (Disability Rights Promotion International, 2009; World Bank, 2009). While this research does not reject the existence of prejudices and discrimination against women and PWD in India, it brings a positive light to disability research in this context, suggesting a hopeful cultural shift that is less commonly reported.

Overall, we found parents to be doing everything they can within the scope of what they have and know, even though, as previous literature reports, there is often a significant gap in the knowledge of parents and healthcare providers about developmental disabilities (Desai et al., 2012; Edwardraj et al., 2010; Gudlavalleti, 2018). For some parents, this resilience meant they were complying with the home plan, seeking appropriate schools, or trying to find other services for their daughters. But for families who faced more constraints, this simply meant treating their daughter with love and fulfilling her basic needs. Either way, almost every family interviewed had some struggle fulfilling optimal early intervention services for their daughter, whether it was because they were not informed about the urgency of early intervention, did not have the means of transportation, lived in a remote location with no available services, or had other domestic and financial demands.

Despite these struggles, very few families had given up hope for their daughter's growth and improvement. Many were optimistic, some realistic, but very few pessimistic. In general, these caregivers wanted and expected the best for their daughters, but in most cases, lacked the awareness or the physical means to best support this improvement. While these anecdotes support other literature that suggest a cultural stigma surrounding disability to still exist (Mehrotra, 2011), this research did not find a disability bias, nor a gender bias, to permeate within the families to impede their efforts or hopes for their daughter's wellbeing.

While the daughter's gender was not found to be a source of discrimination against intervention service access, it was still influential in the family's level of stress and worry, the primary reason being the daughter's safety. For young girls that cannot differentiate between family and strangers or young girls lack a complete sense of self-awareness, they could be particularly susceptible to harm.

Another source of gender-dependent stress for families is maintenance of menstrual hygiene. Wilbur et al. (2019) compiled research suggesting that people with disabilities still experience pre-menstrual symptoms, and caregivers had additional problems in assisting with menstrual health management, such as a noncompliance by the daughter to wear a pad and her inability to understand the importance of menstrual health maintenance.

Because of these increased safety risks and menstrual health concerns, families were mainly unsure about how to approach the future, yet worried all the same. Lee et al. (2019) interviewed 10 parent-sibling pairs of individuals with Intellectual and Developmental Disability (IDD) and found that conversations about their child's future had been vague thus far, and families faced barriers while planning such as uncertainty about the future, difficulty getting the family to agree on what is best, and a lack of available resources for adults with developmental disabilities. While this study was conducted in the US, these are concerns that families in our study also had, validating a worldwide need for resources to assist families with future planning for their daughter with a disability. Providing these resources could be an effective way to ease families' worries, while also helping a person with a disability be more equipped for a safe, healthy future that is suitable for the entire family.

This consideration for a holistic focus on the family is also essential for improving equitable access to intervention services. When giving families a home plan to follow, it is important to give not only the plan, but support for a holistic plan that works around the family's time constraints and the child's behavior, with supplemental knowledge about why compliance is important. Consistent tracking and follow-up with parents immediately after the initial assessment may have also kept families motivated to continue practicing the home plan and seeking intervention services as they are reminded of the importance of what they are doing for their child, even if it takes time for results to show. Any support provided to assist with transportation will also be beneficial, as this was found to be one of the most prevalent barriers for accessing intervention services.

It is urgently important to build off this research to understand what factors make the difference in intervention service access, and where the levers of success are amenable to government or donor interventions. While this sample was only a small representation of India as a whole, they challenge the negativity and prejudice that surrounds disability and the female gender in India. This warrants further investigation into how the culture surrounding perception of gender and disability are changing, and how access to intervention services can be optimized.

To follow up on these findings, a quantitative study utilizing case-control methodology that is representative of more girls with disabilities could be conducted to understand the differences between those individuals who achieve success and those who are unable to overcome barriers. This study could also operationalize the severity of the child's disability and analyze whether this is influential for the families' responses.

Researchers could also conduct a longitudinal study observing how a family's attitude towards disability, their expectations for the future, and their level of impacted changes over time, and whether there is a gender disparity.

LIMITATIONS

Knowing that the interviewers are affiliated with the Latika Roy Foundation, an organization providing resources for children with disabilities, could have influenced parent responses, stating what they believed the researchers wanted to hear. Responses may have also been shaped by the presence of a foreign researcher, impacting their level of comfort or inclination to disclose sensitive information. Even if families attempted to provide all information, they were asked to recall information about their child's development, so the lapse in time could impact their recall accuracy.

While efforts were made to achieve a cross-sectional sample, there remained gaps in the population representation. For example, none of the families sampled earned over 35,000 rupees per month, and the majority of the children in the sample were diagnosed with a global developmental delay (whether this could change later if the child catches up with the developmental milestones and new concerns leading to an additional diagnosis, remains to be seen). The sample size was relatively small, impeding the external validity of this research even though the researchers felt that a saturation of responses were eventually reached after the 20th interview.

While the interviews were conducted in Hindi, the local language, transcripts were developed along with simultaneous translation to English, so it is possible that nuances in the interview responses were lost during translation, even though the translation and immediate transcription was conducted by a third-party research assistant fluent in both languages, in one sitting.

Furthermore, almost all interviewee's may have responded that they would not treat a daughter and a son with a disability differently, but the transcription and translation process does not register implicit biases. The interviewer perceived all families to give genuine responses, particularly in this answer, but she also had to focus on facilitating the interview. Stating whether they would treat their daughter with a disability differently if she was a son is also hypothetical and may not reflect what would be the reality under different circumstances.

Source of Funding: None

Conflict of interest: None

ACKNOWLEDGMENTS

Thank you to Washington and Lee University's Institutional Review Board for providing ethical approval to conduct this research.

REFERENCES

- Addlakha, R., & Mandal, S. (2009). Disability law in India : Paradigm shift or evolving discourse? *Economic and Political Weekly*, 44(41), 62-68.

- Al-Kandari, H. (2006). Parenting stressors of mothers of children with and without disabilities. *Journal of the Social Sciences*, 34(3), 11-30.
- Arora, N. K., Nair, M. K. C., Gulati, S., Deshmukh, V., Mohapatra, A., Mishra, D., Patel V., Pandey, R. M., Das, B. C., Divan, G., Murthy, G. V. S., Sharma, T. D., Sapra, S., Aneja, S., Juneja, M., Reddy, S. K., Suman, P., Mukherjee, S. B., Dasgupta, R., . . . Vajaratkar, V. (2018). Neurodevelopmental disorders in children aged 2-9 years: Population-based burden estimates across five regions in India. *PLoS Medicine*, 15(7), 1-19.
- Buettgen, A., Gorman, R., Rioux, M., Das, K., & Vinayan, S. (2015). Employment, poverty, disability, and gender: A rights approach for women with disabilities in India, Nepal and Bangladesh. In N. Khanlou & F. B. Pilkington (Eds.), *Women's mental health: Resistance and resilience in community and society* (pp. 3-18). Springer Publishing.
- Carrillo, J. E., Carrillo, V. A., Perez, H. R., Salas-Lopez, D., Natale-Pereira, A., & Byron, A. T. (2011). Defining and targeting health care access barriers. *Journal of Health Care for the Poor and Underserved* 22(2), 562-575.
- Daley, T. C. (2002). The need for cross-cultural research on pervasive developmental disorders. *Transcultural Psychiatry*, 39(4), 532-551.
- Daley, T. C. (2004). From symptom recognition to diagnosis: children with autism in urban India. *Social Science & Medicine*, 58(7), 1323-1335.
- Desai, M. U., Divan, G., Wertz, F. J., & Patel, V. (2012). The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. *Transcultural Psychiatry*, 49(3-4), 613-637.
- Dhar, R. L. (2009). Living with a developmentally disabled child: Attitude of family members in India. *Social Science Journal*, 46(4), 738-755.
- Disability Rights Promotion International. (2009). *Monitoring the human rights of persons with disabilities country report India*. www.yorku.ca/drpi/files/IndiaCountryReportSum.pdf
- Edwardraj, S., Mumtaj, K., Prasad, J. H., Kuruvilla, A., & Jacob, K. S. (2010). Perceptions about intellectual disability: a qualitative study from Vellore, South India. *Journal of Intellectual Disability Research*, 54(8), 736-748.
- Fikree, F. F., & Pasha, O. (2004). Role of gender in health disparity: The South Asian context. *BMJ*, 328, 823-826.
- Gudlavalleti, V. S. M. (2018). Challenges in accessing health care for people with disability in the South Asian context: A review. *International Journal of Environmental Research and Public Health*, 15(11), 2366. <https://doi.org/10.3390/ijerph15112366>
- Hosain, G. M. M., & Chatterjee, N. (1998). Health-care utilization by disabled persons: A survey in rural Bangladesh. *Disability and Rehabilitation*, 20(9), 337-345.
- Jejeebhoy, S. J., & Sathar, Z. A. (2001). Women's autonomy in India and Pakistan: The influence of region and religion. *Population and Development Review*, 27(4), 687-712.
- Johnson, C. P., Myers, S. M., & the American Academy of Pediatrics Council on Children with Disabilities. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120(5), 1183-1215.
- Khambatta, P., & Inderfurth, K. (2012). India's economy: The other half. Washington, DC: Center for Strategic and International Studies.
- Krishnamurthy, V. (2008). A clinical experience of autism in India. *World Perspectives*, 29(4), 331-333.
- Lakhan, R., & Kishore, M. T. (2016). Behaviour problems in children with Intellectual Disabilities in a resource-poor setting in India - Part 1: Association with age, sex, severity of Intellectual Disabilities and IQ. *Journal of Applied Research in Intellectual Disabilities*, 31(1), 43-50.
- Lee, C., Burke, M. M., & Stelter, C. R. (2019). Exploring the perspectives of parents and siblings toward future planning for individuals with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 57(3), 198-211.
- Mehrotra, N. (2011). Disability rights movements in India: politics and practice. *Economic and Political Weekly*, 46(6), 65-72.
- National Crime Records Bureau. (2016). *Crime in India- 2016*. <https://ncrb.gov.in/en/crime-india-2016-0>
- Retherford, R. D. & Roy, T. K. (2003). Factors effecting sex-selective abortion in India. *National Family Health Survey Bulletin*, 17.
- Shah, R., Sharma, A., Chauhan, N., Jhanda, S., & Grover, S. (2019). Understanding parental causal explanations and help seeking in attention-deficit/ hyperactivity disorder: Perspectives from a developing Asian nation. *Asian Journal of Psychiatry*, 41, 54-59.
- Varghese, J., Grills, N., & Mathias, K. (2015). Barriers in health care access faced by children with intellectual disabilities living in rural Uttar Pradesh. *Journal of Social Inclusion*, 6(1), 56-70.
- Wilbur, J., Torondel, T., Hameed, S., Mahon, T., & Kuper, H. (2019). Systematic review of menstrual hygiene management requirements, its barriers and strategies for disabled people. *PLoS ONE*, 14(2), 1-17.
- World Bank, World Development Unit. (2009). People with disabilities in India: From commitments to outcomes. <http://documents.worldbank.org/curated/en/358151468268839622/pdf/415850IN0Disab1ort0NOV200701PUBLIC1.pdf>
- World Economic Forum. (2018). *The global gender gap report*. World Economic Forum. Retrieved from https://www3.weforum.org/docs/WEF_GGGR_2018.pdf