



# “We Need More Power to Stand Up”: Designing to Combat Stigmatization of the Caregivers of Children with Autism in Urban Bangladesh

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## ABSTRACT

Stigma, a critical challenge for social justice, has not received much attention in ICTD literature. Most existing designs that aim to combat stigma draw on an ‘information and awareness’ approach that is often inadequate to address stigma’s deeper roots. To address this gap, we have conducted an interview and design study in five special needs schools<sup>1</sup> in Dhaka, Bangladesh, involving twenty-nine parents and nine teachers. Based on our study, we present how the primary caretakers of children with autism face the stigma associated with autism spectrum disorder (ASD) and how misogyny, economic apprehension, and misinformation generate this stigma. Drawing from a range of scholarly work in sociology and psychology, we demonstrate how those factors are rooted in the colonial history and contemporary social hierarchy of Bangladesh. Based on our participatory design sessions, we introduce and analyze potential design directions and connect our findings to the politics of inclusion and social justice in the context of the developing world.

<sup>1</sup>There have been suggestions for using ‘disabilities’ instead of ‘special needs’ in the West [35]. However, we follow the Bangladeshi custom where these schools are called ‘special needs schools’.

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## CCS CONCEPTS

• **Human-centered computing** → **HCI theory, concepts and models**; *Empirical studies in collaborative and social computing*; • **Social and professional topics** → **People with disabilities**.

## KEYWORDS

Stigma; Autism; Mental health; Bangladesh; LMIC; Design; Social Justice.

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## 1 INTRODUCTION

Stigma impacts the lives of its victims in various ways, including hindered opportunities, increased financial burdens, and discrimination in multiple domains [21, 87]. Specifically, stigmas around mental illnesses [82] and neurodevelopmental disorders [66], such as autism spectrum disorder (ASD), are prominent areas of concern for their damaging impacts on the affected population. Today, there are more than 7.5 million people worldwide who struggle with ASD [92], and many of them suffer from the stigma toward it (see [17, 45], for example). The prevalence and severity of stigma towards ASD and mental disorders in many countries in the Global South, including Bangladesh, are considerable [56, 87]. However,

little research has been conducted towards reducing stigma to ASD and mental disorders<sup>2</sup> in the Global South.

The challenge in designing technology to combat autism and mental disorder stigma is not bounded by the understudied geographical location of Bangladesh; rather, it is universal. While the approach for combating stigma towards a particular race or physical disease is often based on a critical understanding of social orders and a call for their readjustment [2, 18], the stigma of mental disorders is predominantly fought through raising individual awareness [18, 82]. This approach often leaves the stigma's root causes unaddressed [52]. Furthermore, existing research around autism stigma, or stigma in general, is mostly conducted in high-income countries [37, 95], leaving a gap in low- and middle-income countries (LMICs), where historical and cultural issues heavily influence the shaping of the problem [26, 98] and its impact on the family members [40]. Thus, existing approaches are inadequate to be extended to and implemented in the Global South.

To this end, this paper examines the roots, impacts, and interventions of stigmatizing circumstances with regards to autism in Dhaka, Bangladesh, and discuss their connections with ICTD from the point of their caretakers. Building on an eight-month-long interview and design study in five special needs schools in Dhaka, this paper makes three core contributions to ICTD. First, we present a comprehensive description of how autism stigma manifests in development contexts such as urban Bangladesh and the damaging impact on people with autism (PWA)<sup>3</sup> and the families, especially the mothers. Second, drawing from a rich body of work in sociology and psychology, we explore the roots of the stigma that stem from misogyny, economic apprehension, and misinformation, and their connections to the country's colonial past and contemporary social hierarchy. Third, based on ideas shared in our design workshops, we infer design implications about how caretakers can fight against stigmatizing scenarios and how scholars can continue this line of research on interventions for autism and mental illness stigma. These design ideas focus on empowering parents and PWA themselves and uniting them to create social movements to redress societal power imbalance. Additionally, we discuss the broader implications of our findings for the politics of inclusion and social justice in the context of the developing world.

## 2 RELATED WORK

### 2.1 Stigma, Mental Health, and Power

The definition of stigma underwent a dramatic transformation in the past few decades, with the focus shifting from stigma as a person's attribute to stigma as a social condition. Erving Goffman initially defined stigma as: “[an] attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted and discounted one” [39]. This definition considers stigma as a person's attribute, operationalized through their relationship

<sup>2</sup>Due to ASD's association with various physical and neurological complexities, it is debated whether ASD should be considered a mental disorder [11, 71]. However, to an uninformed observer at least, the ‘visible behavioral differences’ that are often demonstrated by people with autism and the ‘visible behavioral differences’ that are often demonstrated by people with some of the mental disorders look similar. From that point of view, we bring the discussion on mental disorder stigma to situate the discussion of ASD stigma.

<sup>3</sup>We are aware of the controversy regarding people-first language [81]. However, we are resorting to an acronym to be concise.

with others. While Goffman's conceptualization does include social relations as a factor, it still places the root of stigma in the ‘visual’ or ‘behavioral’ differences between a stigmatized person and others. In their seminal work *Conceptualizing Stigma*, Link and Phelan address this limitation and shift the definition from revolving around the victim's attribute to a social condition [51]. They define stigma as an outcome of social, economic, and political context, saying, “*stigma exists when elements of labeling, stereotyping, separation, status loss and discrimination occur together in a power situation.*” They argue that stigma works as a ‘label’ that is applied to one of multiple candidate human traits to reflect and reproduce existing power relations in society [52]. Thus, stigma can work as a tool of discrimination for powerful people to identify, monitor, and control certain less privileged groups [36]. Building on this definition, Phelan, Link, and their colleagues find three major reasons behind stigmatization: (a) *keeping people down* to achieve domination, (b) *keeping people in* to enforce social norms, and (c) *keeping people away* to avoid diseases [74].

The concept of stigma as a tool of social marginalization was later extended to explain mental disorder stigma. Drawing from Bourdieu's notion of *symbolic power* [16] and Scheff's *residual rule-breaking* [85], Link and Phelan state that the primary reason for which people stigmatize the mentally ill is to maintain social norms through direct and indirect measures that produce inequality [52]. Corrigan and his colleagues delineate this impact by classifying mental illness stigma in two categories: *public stigma* and *self-stigma* [23]. Scholars argue that the intention of *keeping the mentally ill in* is reflected in people's behavior and is often enforced by powerful authorities such as governments [22]. For example, Corrigan and his colleagues claim government offices, laws and policies, and other infrastructures are often organized to create structural stigma, which intentionally or unintentionally discriminates against people in marginalized communities [22].

### 2.2 Mental Illness, Politics, and Colonialism

To better understand the politics around mental illness that is reinforced through stigma, we need to look at the history of mental illness stigma in Europe, which had an intimate relationship with Bangladesh through colonization starting in the seventeenth century. During the middle ages, people with mental disorders were thought to be ‘different’ and were, therefore, isolated by local authorities [32]. This type of isolation exacerbated during the early modern period. Following the decline of leprosy in Western Europe, these people started to be detained in the now-empty Lazar houses, which were previously occupied by lepers. Thus, the confusion and fear attached to the leper transferred to people with mental issues: they began to be seen as carriers of diseases and thus were marginalized and stigmatized [12].

Additionally, during this time, any behavior that breached the prevailing social norms was usually treated as a product of demonism and witchcraft by the Catholic Church and medical practitioners alike [31]. Furthermore, the ruling elite deemed idleness as dangerous. The mentally ill, unable to work and integrate into society, therefore found themselves imprisoned alongside indigents and criminals in newly created hospitals [12, 86]. Due to mental patients' lack of capacity for psychological reasoning, the ruling

class abrogated the civil responsibilities of them and justified the control, detention, and surveillance of them [19, 31].

The European psychiatry system, through colonial rule, heavily influenced how mental illness was treated in the Indian subcontinent. Contrary to previous subcontinental tradition, the British government developed mental asylums to exert more social control and surveillance [30, 65]. The subcontinental doctors, practising Unani and Ayurveda, used to take care of the mentally sick portion of the population before colonization [88] and this caring environment ensured that that just before the arrival of the British East India Company in 1600, no mental asylums were required in the Indian subcontinent [89].

The local community gradually embraced the concept and the associated moral values during the long colonial rule and started admitting locals into these asylums [59]. More specifically, after the 1857 revolution, the British believed that promoting their own structure on India would achieve dominance over the local population. Therefore, the British began promoting ‘institutions of a superior society’ [107] in psychiatric network domains, among other [58]. Ernst remarks that the development of mental asylums in British India is a ‘less conspicuous form of social control’ [30]. With that, the transfer of mental illness stigma, originating from Western Europe, was completed with modifications for social control benefiting the colonial rule. Bangladesh, which only gained its independence in 1971, suffered historically from the same colonial influence regarding how mental illness is perceived and shunned.

### 2.3 Designing against Stigma

Prior research has monitored physical and mental well-being [50, 90, 103]. However, design for fighting stigma presents significantly different challenges. Relevant studies have looked into stigma concerning HIV/AIDS [70, 93], physical disabilities [91], mental health [5, 34], sex workers [83], sex education [9, 101], among others, that emphasize that designing against stigma encompasses understanding and tackling challenges with respect to the population, social practices, and identity. Designing against stigma related to autism similarly would require addressing the social norms that play an active role in producing and intensifying stigma, along with prior knowledge about existing work on stigma and autism. Intervention for stigma is an active area of research; however, autism stigma is understudied in ICTD. Quadri et al. argue for leveraging celebrity star power on Twitter to help educate and raise awareness about autism stigma in India [76]. Other interventions for autism stigma [37, 95] and mental illness stigma in general [24, 82] also follow a similar ‘information and awareness’ approach. Scholars have looked at the disclosure of stigmatizing information on social media as well as the role that anonymity plays in it [10, 29, 42]. However, all these works focus on increasing awareness of mental illness in populations, either through education or face-to-face interactions with the mentally ill.

Scholars have also discussed the movement against HIV stigma in Brazil to show the importance of social empowerment in assuring citizens’ rights in stigmatizing contexts [2]. In this work, Abadía-Barrero and Castro argue that the association between AIDS-related stigma and power differentials is enabled by structural inequality, which is partially redressed by government initiatives through transforming the experience of HIV in society from “fatal and incurable”

to “chronic and manageable.” They further argue that solely educating the unaffected people, without changing the experience of the stigmatized or stigma’s structural sources has limited effects [2]. Additionally, Abadía-Barrero describes how a broad social movement transformed the power relationships by creating a bridge between the extreme ends of power and new practices of democracy regarding AIDS in Brazil [1]. Building on these studies, and looking beyond information dissemination approaches, our paper focuses on intervention strategies for stigmatizing circumstances.

### 3 BANGLADESH, AUTISM, STIGMA

In this section, we outline the infrastructures, local beliefs, and initiatives in Bangladesh to better inform contextualized design interventions concerning autism stigma. Like other LMICs [46, 69], Bangladesh suffers from a lack of resources, planning, and execution related to mental health care. The situation regarding ASD is in a similarly vulnerable state [28]. The prevalence of ASD in Bangladesh ranges between 0.15% and 0.8% of a total population of 160 million according to different sources [8]; however, there are very few specialized medical facilities to treat this significant population [102, 106]. Further, the number of special needs schools is not sufficient [20, 28], which creates a problematic situation for PWA and their families in urban regions. Due to the mentioned lack of structural assistance, people frequently turn to religious healers or rural witches for treatment [67, 97]. Despite the provision of special identity cards for all PWA to obtain monthly allowance and priority boarding in some vessels [68, 100], so far, only around 12,000 cards have been issued [63].

In addition to the shortage of resources, there is a strong stigma and lack of awareness related to mental health problems in Bangladesh [44, 72]. Social stigma prevents the patients and their families from seeking care [44], which is compounded by the lack of resources [43]. Not many people can be accommodated in these medical facilities which are scarce in number. Moreover, in most cases, due to stigma toward asylums, the people with mental illness do not take help from these facilities voluntarily [46]. People with autism face similar obstacles due to the existing stigma and discrimination [15, 73, 78]. The government is taking some steps, such as establishing some service centers, conducting awareness campaigns, and signing declarations [94]. However, these steps are inadequate in addressing the challenges.

Research on autism in Bangladesh only addresses a subset of the existing issues faced by PWA. A few works discuss the prevalence of autism and the current dire state of services [60, 102]. There is also work on rapid autism assessment instruments and behavior intervention tools [15, 48]. However, there has been insufficient research on the roots and consequences of stigma concerning both PWA and their family members [77]. Researchers conduct interviews and discussions with parents, caregivers, relatives, and neighbors of PWA in Bangladeshi cities to find out the challenges of parents and family members of PWA to gain social acceptance [49, 78]. Pervin surveys 300 regular primary school teachers in Dhaka with an adapted inclusivity attitude scale in Dhaka City to discuss the inclusion of students with autism in the regular curriculum [73]. These works do not address many fundamental issues related to autistic people and how technology and power are intertwined.

## 4 METHODS

To identify the diverse manifestation of autism stigma to mothers of PWA through various sources and venues, we conducted seventeen semi-structured interviews, three focus group discussions (FGDs), and two participatory design sessions with parents and teachers in five different special needs schools in Dhaka, Bangladesh. The objective of interviews was to understand the nature and severity of autism stigma in urban Bangladesh. The objective of FGDs and design workshops was to get design ideas that can help combat stigma in the aforementioned context. Our fieldwork spanned eight months: the first phase was conducted between August 2018 and February 2019, while the second phase took place in July 2019. Some of the schools were not open to the general public; however, we obtained access to teachers and parents of these schools through the contacts of the authors. To recruit the participants, we used the snowball sampling method [14] for our convenience. Twenty-nine parents and nine teachers participated in our study. We also consulted two religious leaders and facilitators in the local community. All of our participants, as well as research team members, were native Bangla speakers. Each parent participant in our study had an offspring with autism; all but one of the offspring were under 18 years of age.

The participant pool consisted of parents and teachers due to the practical constraints of working with PWA. First, schools as well as parents explicitly and actively discouraged the inclusion of PWA in our study as interviewees, because they believed that: a) most PWA had communication disabilities and would have trouble understanding as well as properly conveying emotions and information, b) all but one offspring of the parent participants were minors and mostly unable to articulate their thoughts, and c) PWA tended to become stressed when faced with unusual routine or unknown people. Both parents and teachers were careful not to impose an additional emotional burden on PWA. It is the inconvenient nature of conducting research with such a marginalized population in a setting like Bangladesh. As authors, we strive to broaden participation and believe that learning from this study can help expand future studies to PWA. Additionally, our study included fathers in a very limited capacity, because we wanted to focus on the perspective of the mother and mothers informed us about fathers' discomfort in talking about the condition of their children. It was also noted by the participants that, in all families, mothers were primary caregivers, which is a reflection of the patriarchal culture of Bangladesh. However, we did include fathers when they came forward. Teachers were important stakeholders as they were the primary caretakers during school and irrevocably intertwined with stigma (both as instigators and recipients). Our field observations and interviews suggest that PWA spent a significant amount of time with their teachers during school days, and hence, teachers had intimate knowledge that we would otherwise hope to learn from PWA themselves. These two groups - mothers and teachers - are familiar with the stigmatizing environments that PWA go through and thus had excellent ideas about the roots, consequences, and fighting strategies associated with autism stigma.

In the first phase, We explored the venues and sources of stigma. This phase involved twenty-six volunteering participants, including seventeen parents and nine teachers (M 2, F 24). We conducted

seventeen one-on-one semi-structured interviews (M 1, F 16) and one focus group discussion (FGD1) with five parents from among the interviewees (all female). The teachers (M 1, F 8) participated in two separate focus group discussion sessions (FGD2 and FGD3, respectively). Interviews and FGDs in this phase took more than 25 hours in total: the average duration for the interviews was 44 minutes (maximum 95 minutes, minimum 19 minutes), and each group discussion session lasted around one hour. The busy schedule of some participants did not allow them to partake in both interviews and FGDs. However, we noticed no significant difference in data generated from these two methods.

We conducted interviews with participants from diverse socioeconomic standings in Dhaka. Among the female participants, fourteen were housewives, one was a physician, and one was a janitor. The only male participant was a university lecturer. Six of the housewives previously had other occupations, which they had to leave due to the demand of raising a child with autism. Three interview participants belonged to low and lower-middle-income families with little or no formal education. Fourteen participants were from middle or higher-middle income families and had college degrees. Interview participants' age ranged from 30–47 years (average 39), and their children, who had ASD, were aged between 5–19 years (average 11). The caregiver participants of our study were teachers at special needs schools.

The special needs schools for this phase are Autism Care and Advancement Centre (ACAC), Proyash Institute of Special Education and Research, Society for Education and Inclusion of the Disabled (SEID), Society for the Welfare of the Intellectually Disabled (SWID), and Society for the Welfare of Autistic Children (SWAC). The numbers of students in these schools are 30, 460, 150, 250, and 116, respectively.

Findings from the first phase were used to design two participatory design workshops (PDW1 and PDW2) for discussing stigma-resistance technologies, policies, and movements. The design workshops took place in Dhaka in July 2019. Five parents (M 1, F 4) participated in PDW1 and seven parents (all female) in PDW2; none of them interviewed with us before. The only male parent was a businessman, while all the female participants were housewives. The age range of participants was 29–55 years. Each workshop lasted around one hour. PDW1 took place at SWID, and PDW2 took place at SWAC.

All the researchers were born, brought up, are living in Bangladesh, and closely tied to the local culture. Additionally, some of us have autistic relatives and consider themselves a part of the stigmatized community. All interviews and design workshops were conducted in Bangla. Apart from the basic demographic questions about themselves and their family members, We asked the participants about how PWA in their family or class behave in various situations, how other people—both known and unknown—behave toward them in public and private spaces, and how PWA and participants react in those situations. The questionnaire used for parents and teachers were largely identical, except that we asked about how each of these groups views the others in terms of emotional support for PWA. Before going into questionnaire, we started with a brief description of our research work and its purpose. We then shared a few stories from parents from earlier interviews and personal experience. We

then asked about their overall experience of being stigmatized, and then we move into specifics about stigma in venues and sources.

Interviews, discussions, and field notes were transcribed, anonymized, translated to English, and coded based on grounded theory [96]. In the open coding phase, we identified abstract representations of objects, happenings, interactions that were repeatedly mentioned. We identified quotes from participants and respective codes, e.g., *inaccessibility to regular schools*, *misbehavior from students*, *misperception of teachers*, etc. In the axial coding phase, these open codes gave rise to higher conceptual phenomena, e.g., the codes mentioned above fell under the broader concept of *stigma in educational institutions*. Finally, in selective coding, we built relationships among axial codes. Consequently, the final codes belonged to either venues or sources of stigma, which we discuss in our findings. Two authors participated in the coding of data, who mostly agreed on codes. Since none of the major approaches of grounded theory [38, 96] require intercoder reliability [41, 57], we did not perform any such computation. Instead, in the few cases of disagreement, the authors discussed and came to a consensus.

The protocol of this study was examined and approved by the ethics review board of the authors' institutions, where we detailed the careful procedure we would adopt given the sensitive nature of the participants and the data. Additionally, all participants and their children are assigned pseudonyms.

## 5 VENUES OF AUTISM STIGMA

Our fieldwork shows that stigma to mothers of PWA is manifested in two major ways. The first way is through the display of stigmatization and discrimination to PWA, and the other is through the display to mothers themselves. When PWA are stigmatized, mothers are also made victims as primary caregivers and emotional supporters. We explore how these two processes happen in urban Bangladesh in this section.

### 5.1 Stigma within the family

Our study shows that the members of immediate and extended family, close and distant relatives, and friends and acquaintances often display harsh stigmatizing attitudes toward PWA. Eight of our female participants (mothers of PWA) reported that fathers of PWA were not willing to take any responsibility for the child and considered them a burden on their family life. Not receiving support from their husbands in raising a child with ASD was very frustrating for these mothers, who shared how their husbands often used religious sources or cultural sayings to justify their negligence. As such, PWA may not get paternal care, and on some occasions, may be subject to physical abuse from their fathers. One mother said:

*One morning, my husband locked my son [person with autism] in the kitchen for two hours. I was sick and woke up late that morning. Then, I was looking for him everywhere in the house. When I turned on the lights of the house, he understood that it was me and started banging on the kitchen door from inside. I opened the door, and he came to me running from inside the dirty kitchen, scared and sweating profusely. (Female, 32 years, mother)*

Many participants also lived with their extended families, including grandparents of PWA. Ten participants reported that grandparents were often harsh to their grandchild with ASD. The power dynamics of these families, shaped by the power of paternal grandparents, make the consequences worse for PWA. They are often not allowed to take part in family discussions, events, and gatherings because of the rule set by the grandparents. Besides people living with PWA at their home, other relatives often looked down upon the condition of PWA, which was evident from eight of our participants' stories. These relatives keep telling PWA how 'worthless' they are, creating a substantial negative impact on their minds. Furthermore, those relatives often do not invite PWA to their homes and do not allow their children to play with them. Taken together, our data show that PWA often face stigmatizing scenarios in their homes and from members of their immediate and extended families. One participant said:

*When we went to an open space, my child started to run. His grandmother, who was accompanying us, told us that my son was solely my responsibility. Then I had to catch him; his grandmother did not let his father come. [...] I found negative attitudes from the relatives. I did not get positive behavior. All the people gave us strange looks. (Female, 38 years, mother)*

### 5.2 Stigma in Educational Institutions

Our study shows that stigmatizing circumstances occurring in educational institutions fall into two categories. First, seven of our study participants encountered stigma and discrimination from the school administration, and five participants encountered such situations from teachers. In mainstream schools, the administration is often either unwilling to admit PWA even when they had empty seats, or charge more than regular school fees despite doctors' suggestions. Parents emphasized that even when schools had empty seats, they were often unwilling to accommodate their children. One participant explained her failure to admit her child, who had autism, in a regular school:

*The doctors in India advised me to get my son Manik [all names are pseudonyms] admitted into a regular school. I tried, but the schools here did not allow that. (Female, 31 years, mother)*

Our participants also argued that teachers in regular schools were not adequately trained in handling PWA or responding to an unexpected situation involving them. They opined so based on their experience, as some of them had their children with autism admitted into regular schools for certain period of time. Besides, participants shared similar concerns with teachers in special needs schools. We noted in our interviews that these teachers were often negligent and frequently did not perform their duties adequately. Participants shared how this was due to a lack of proper accountability and, in the case of government schools, teachers holding quasi-permanent positions at the schools. In some participants' view, these issues might indicate an unwillingness by policy-makers to train and prepare PWA for financially productive activities. A mother narrated her experience with educational institutions:

*The principal agreed to admit my son to his school. However, the classroom teacher denied to teach my son;*

*she did not even enter the class while my son was sitting there. I assured her that I would also be in the class to avoid any unexpected situation. However, the teacher turned down even the [school] principal's request to teach. I still remember her condescending attitude. So many years have passed by, but this incident is still in my memory.* (Female, 47 years, mother)

Second, seven of our participants noted how their children were stigmatized by their classmates and their classmates' parents. Five participants who had experience in regular schools described the situation as worrisome, as other parents were afraid that their children would 'catch' autism. Thus, other parents stigmatized PWA. Even in special needs schools, due to the negligent monitoring by teachers, parents often feared that their children might be involved in violent situations. One child with autism had to go through such an experience, as his mother described:

*One day after Komol [child with autism] came back from school, I found marks of physical torture in his body: blood clots and a scratch on his leg. He had been despondent while returning home, although he usually is cheerful. I showed the scratches and blood clots to the class teacher and also asked the class in-charge, but they replied that they had not beaten him. I accept that they did not beat him, but the question is if other students had done this to Komol, where were the teachers at that time? After two weeks, he was beaten by another student. Now, I reiterate my question: why cannot the teachers manage them [other children]?* (Female, 33 years, mother)

### 5.3 Stigma in Public Places

Almost all of the parent participants agreed that they had faced stigmatized beliefs and attitudes from people in public places and described discriminatory behaviors in two broad categories. First, half of our participants received harsh treatment due to the 'abnormal' behavior of PWA. Second, our participants saw people forbid their children from interacting with PWA during playtime for fear of those children 'catching' the condition. By doing so, they utilized stigma to discriminate against PWA who are certainly less privileged due to their lack of abilities and motor functions. A mother lamented about the inability of her son to participate in regular social activities with other children:

*He [child with autism] wanted to play with them [other children], but they were not willing to play with him. The environment here is different because parents also do not want their children to play with my kid. So, they keep their children inside the home. They think it [ASD] is a contagious disease. My son is not welcome when we visit someone, and that is why I keep him inside our home.* (Female, 34 years, mother)

Another consequence of the stigma faced by our participants in public places was that they had to maintain restriction in behavior and attitude. They needed to carefully curate their every move and show the utmost humility to avoid problems. In their opinions, this vigilance hampered the family's free movement and, in some cases,

led to missed opportunities for them. Below is an example of highly restrictive behavior as described by a participating mother:

*Since my son [with autism] sometimes becomes hyperactive and hypersensitive, I always inform the restaurant staff about it before ordering food. We would also select a quiet corner to sit where he is not conspicuous. It is not like people do not stare. They stare with much curiosity, but I always try to ignore it. I also apologize to people if my son causes any problems.* (Female, 46 years, mother)

### 5.4 Stigma in the Healthcare Sector

Participants informed us of scarce medical facilities, resources, and funding towards mental illness and autism due to policy-level discrimination. They also noted how this discrimination affects and also operates through the personnel employed at these facilities. For example, two of our participants described doctors as not helpful or empathetic to their situation. Other participants then argued that this was because doctors were often overworked and lacked resources and training. Therefore, physicians might not realize the importance of treating PWA with empathy. Nonetheless, participants agreed that harsh treatment and behavior from doctors resulted in parents' loss of confidence in the medical system to treat their loved ones. One participant summarized her viewpoint about doctors:

*We entered the doctor's chamber. Immediately afterward, the doctor said, "I understand that your son is autistic! I can see the symptoms!" and she said it in an annoyed tone. It could be that she was annoyed after seeing my son. If you react to my son's condition without prejudice, I can see it in your face. But I can also understand the slightly derogatory sentiment by the dull or annoyed expression on your face.* (Female, 33 years, mother)

## 6 ROOTS OF AUTISM STIGMA

### 6.1 Misogyny

Our study shows that family members, including fathers of PWA, relatives, and acquaintances, and even strangers in public places, engage in blaming mothers of PWA for the disorder their children suffer from. Female participants shared their experiences of being criticized in various situations, feeling that they were held responsible for any mistakes or annoyance caused by their children. Most participants agreed that this behavior was rooted in misogynistic beliefs held by many in Bangladeshi society, which was why mothers were blamed significantly more than fathers. Again, we report the opinion of participants (mostly mothers) in this section, which is less about being a representation of the entire society, but more about the perception of certain social groups. One participant commented that people always tried to find someone to blame, rather than looking at the state of the child without prejudice:

*They do not take it normally: they have to find me to blame. My brother-in-law said that 'you have sinned, and that is why God did this to you. Offer your prayer and ask for forgiveness from God.' My sister-in-law also*

*blamed me about my son’s condition.* (Female, 32 years, mother)

Our study also illustrates the constant financial struggle mothers of PWA experience. Six participants who had already been employed had to leave their jobs to take care of the child full-time. This sacrifice is a common incident for mothers in Bangladesh, which reduces their financial capacity and power in family and society. Our participants mentioned that in this situation, some people began expressing their misogynist mentality, which only came to light after the decline of the mothers’ financial status. Our study also finds that people sometimes turn violent towards PWA and their mothers. By maintaining this attitude, they try to satisfy their inherent misogynist beliefs. Our participants argued that, through abusing the child and making them suffer, people wanted to hurt the mothers. .

Overall, the misogynistic approach lurking in society is often provided with an opportunity when a mother is in her most vulnerable stage with a child who is on the autism spectrum. In this case, the participants agreed, the people with misogynistic agendas came forward with mechanisms to repress the rights and freedom of the mothers.

## 6.2 Economic Roots

Our study shows that stigma associated with economic roots comes from financial insecurity and negligence from the government. First, due to the scarcity of well-paying jobs in Bangladesh, PWA are perceived to have low chances of generating income. Influenced by this, parents feel helpless and burdened about their children. Participants in our study indicated that this might result in social pressure and mental stress for parents and maltreatment of PWA. One participant said:

*When we took Komol to our hometown, my uncle told me that this child was a curse to my husband and me. My uncle explained that, since Komol had no future and would not be able to take any responsibilities of his parents, he was a curse to his family. [...] The response of my friends was also neutral or altogether negative and included showing pity towards my kid or ignoring him. Because of these reactions, I stopped communicating with them.* (Female, 33 years, mother)

The financial restriction faced by mothers after the birth of a child with autism is worsened by the misogynist approach of a significant section of society. As a result, PWA and their mothers are cornered into a financially precarious position, where they need to depend on fathers, other family members, or people in society. The financial dependency leads to these victim groups being treated harshly and as a burden. This phenomenon was evident from mothers who had to leave their jobs to provide better care of their children who had autism.

Second, based on the definition of structural stigma, we found that policies in both government and private institutions that restricted opportunities for PWA. For instance, participants lamented that the government had historically regarded PWA as financially unproductive and, thus, did not build enough schools and medical institutions for them. Participants mentioned the negligence of the government as the chief cause for lack of jobs, as well as lack of

laws to help allocate more jobs to PWA. Additionally, participants reported that buildings and vehicles in the country were generally not designed for accessibility, limiting the opportunities available to PWA. Taken together, these practices and policies pointed to the power hierarchy’s apprehension of spending money and effort for PWA, as discussed by our participants. Participants also held the opinion that such structural stigma and discrimination were unlikely to be solved without active government initiatives.

## 6.3 Misinformation

**6.3.1 Autism Stigma Generated from Religious-Cultural Misinformation and Superstition.** A large number of our participants faced rumors associated with religious beliefs and practices that often had very little to do with authentic religious teachings. Instead, the participants argued, those had roots in long-standing cultural practices. Islam is the most widely practiced religion in Bangladesh, and one adherent of this religion narrated a telling story:

*Many people said that Noor [person with autism] had evil’s influence, and because of that, he was abnormal. I did not find any reason to believe their words since I did not see any such signs.* (Female, 34 years, mother)

To gain a better understanding of such supernatural beings in Islam, we consulted local Islamic scholars and facilitators. They confirmed the concept of a race of supernatural beings called the *Jinn*, but also mentioned that many abilities often associated with the *Jinn* in folklore were outside of Islamic teachings. Here, we found the assimilation of long-standing cultural beliefs regarding evil spirits with the teachings of Islam to create an amalgamation of myths about magical beings that are evil who can harm humans at will. We found that PWA were sometimes believed to be possessed by these *Jinns*.

Twelve of our participants were told that exorcism through religious healers was a way of healing their children that would drive the *Jinn* away. Participants shared that most people in rural areas had this belief and often influenced their own relatives and acquaintances, including close family members of PWA, to adopt such notions. Sometimes, family members of PWA were convinced to place their trust in these religion-influenced myths. While these beliefs and suggestions might not look harmful on the surface, belief in alternative treatment shows distrust in the traditional medical system, undermining the medical treatment of PWA. One participant shared such a story:

*I knew a mother of one child with autism. She used to believe that the Jinn possessed her child, who could only be cured through exorcism and prayer. She gradually became more religious to pray for him [child]: she performed Umrah Hajj [Islamic pilgrimage performed in Mecca] and told me that only after the main Hajj [more lengthy than Umrah Hajj], he would be completely normal. She also told me that she saw in a dream that the Prophet had come to see him and had blessed him. She spent most of her time visiting Pirs (religious figures) and Mazars (religious shrines) in all parts of Bangladesh to pray for her son.* (Female, 36 years, teacher)

**6.3.2 Autism Stigma Generated from Pseudo-Scientific Misinformation and Superstition.** We found that some stigmatizing beliefs



stemmed from non-religious perceptions. These beliefs attempt to present causal relationships among autism and other factors in a pseudo-scientific manner, without any reinforcement from facts and figures. For example, one participant described that her highly educated ex-colleagues and friends commonly believed in two pseudo-scientific theories that were believed to be the cause of ASD in children: having parents who were first cousins, or if there was a lack of care from a working mother. In both of these cases, people who believed in and presented these explanations could not highlight any scientific evidence as proof. However, the dearth of evidence did not hamper them from creating a stigmatizing situation. Another mother, from a lower socioeconomic stratum, shared a similar story:

*People often make derogatory comments regarding my daughter's status. Some people say that Popi's [person with autism] father was old, and because of his age, Popi was born abnormal. They do not have any proof; they just gossip. (Female, 48 years, mother)*

Some mothers mentioned cases where their husbands blamed them for giving birth to a child with autism. They reported that the husbands thought their wives' genes were responsible for the disorder; however, these husbands neither presented nor looked for any scientific evidence behind the claim. The charge puts an emotional burden on the mother, negatively affecting her ability to care for her child. One participant's husband, who was a doctor himself, had this mentality, indicating that this stigmatizing belief is not easily removable through education alone:

*My child's father blames me for autism. It was unexpected, but he sometimes makes criticizing comments. Among all the people, it is he who blames me. (Female, 46 years, mother)*

Our study shows that people propose solutions to parents that did not originate from research. Five participants argued that since people viewed PWA as a burden and their condition as a disability, they tried to propose various unscientific solutions that, in their view, were likely to 'cure' the situation. Participants also noted that this misinformation could slowly manipulate others' behavior, influencing them to consider PWA as outcasts and thereby negatively affecting them. One such method for 'curing' a child with autism was described by his mother:

*An acquaintance of mine suggested putting a betel leaf in my son's mouth and slapping him mildly. She said that it would make my son speak. I was unsure but still asked her to do it. She did that, and yet no words came out of my son's mouth. She said that my son would never speak or recover from this state. (Female, 43 years, mother)*

## 7 PARTICIPATORY DESIGN WORKSHOPS

The objective of the two participatory workshops was exploring the design of possible interventions with the parents of PWA. We started the sessions by explaining the objectives of this research and the goal of the session to participants. We also briefly illustrated findings about the stigmatizing scenarios from the first phase of this study. The participants were explained various ways for them to contribute: through verbal suggestions, drawing, constructive

criticism, storytelling, or general discussion. The first author of this paper moderated these sessions.

During the session, we wanted to learn what the participants saw as the main challenges to overcome the problem of stigma around autism. These challenges would, in turn, help find solutions to and approaches for fighting against stigmatizing scenarios. These solutions may not necessarily involve technologies, depending on the nature and severity of the problem. To depict the current stigmatizing scenario, our participants shared stories that demonstrated how they struggled to fight against stigma. All of them concurred that their main challenge was lack of power. One of them summarized the situation:

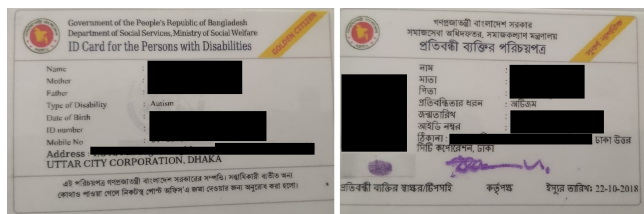
*Making people aware is often not the most useful tactic in fighting stigma. The most useful method would be to allocate more social power to our children and ourselves. We need more power to stand up to the stigmatizers, and this principle should be incorporated in any new approach. (Female, 32 years, mother)*

Next, we encouraged them to come up with ideas that might give them more power to fight stigma. Thus, we drove the conversation towards a more design-level discussion. The participants started brainstorming, proposing ideas, and discussing among themselves. The moderator also joined them by informing them of some of the existing services available in Bangladesh and other countries and encouraged the participants to come up with technical and non-technical solutions. The participants were encouraged to think of a holistic and sustainable solution. In the end, the participants of the first design workshop together suggested one design, and the participants of the second workshop suggested another that we describe below.

### 7.1 Powerful Special Card

An interesting blend of how technology influences the physical world is illuminated through the first design idea. Currently, in Bangladesh, PWA are issued a 'Special Card' that, besides identifying them, helps them claim special rates on public vehicles. Our participants envisioned a new digital card for PWA for obtaining special treatment in various other ways, e.g., (a) allotment of sufficient monthly allowance, (b) special airfare rates, (c) recognition as special status holders in the court of law, and (d) expedited services in government offices. Additionally, replacing the existing paper-based card (see Figure 1) with a digital card would help ensure expedited services and foolproof authentication of their identity when needed. Participants emphasized that, through these privileges, PWA would have more agency in their daily lives that would enable them to become less dependent on others and, as a result, would improve their self-confidence and outlook on prospects of life. Our reasoning is that the special card will expedite government services leading to less dependency. Study participants were eager to emphasize that a faster rate of service equated additional prestige in the eyes of society, leading to higher self-esteem with the consequence of having an elevated social status that would help facing stigma less likely from other portions of society.





**Figure 1: The Ministry of Social Welfare provides the existing card to PWA in Bangladesh. No digital chip or RFID technology is included.**

## 7.2 Online Platform for Parents

For the second design idea, participants stressed making resources and information about caring for PWA more accessible and understandable, which in turn would enable this victimized group to overcome stigmatizing scenarios. There are a few web applications containing information on autism in the Bangladeshi context; however, those are inadequate since they do not provide much information about ASD care and are not regularly updated. Additionally, making any modifications to these existing systems would require substantial effort and time. The participants thought that creating a new online platform, informed by insights from PWA and their families, could help them in various ways. Our participants listed three helpful design components in their suggestions. First, they wanted the platform to be easily accessible to everyone. The information available on the platform should be written in Bangla and should, at the same time, be accessible by people with little or no literacy through voice commands and text-to-speech functionalities. The information needs to be comprehensible by the general population, and therefore, the platform should avoid medical jargon. Second, in addition to formal information, participants wanted the platform to include an open forum to share and discover stories that would help alleviate their mental burden. They emphasized that such stories were important not only for receiving mental support, but also to learn about the quality of available services from the perspectives of other parents. Third, they wanted to use this web platform to determine which services were missing in an area or locality, so that individuals could report this aggregated information to the appropriate authorities. Our participants suggested that this platform would help decrease the dependency of PWA and their families on others.

Apart from these ideas, however, parents acknowledged that technology alone is not the panacea for the problem of stigmatization, which would require an integrated approach from various facets. Therefore, parents also suggested promoting awareness campaigns and infrastructural changes, which are crucial as parts of this holistic approach to fight stigma. One participant, for instance, emphasized on adding more information about ASD in the textbooks utilized in the national curriculum:

*We know that recently some information has been included in a textbook in one of the upper-level classes. However, for this approach to be successful, every grade*

*should have some information, so that there is a gradual buildup of proper mentality regarding autism and disabilities. (Male, 39 years, father)*

Similarly, some participants also suggested amending existing policies and treating stigmatizing behavior as a punishable offense. Others recommended the creation of large-scale audio-visual campaigns and the involvement of media celebrities to reach a large audience. Finally, there were a few parents who proposed a focus on religion to combat stigma, since the religious figures are widely respected and can play a crucial role in the fight against stigma. These ideas play a crucial role in developing awareness and creating a level playing field for the stigmatized groups of PWA and their parents.

## 8 DISCUSSION AND CONCLUSION

In previous sections, we discussed the existence and prevalence of autism stigma and its consequences as pertaining to mothers of PWA and PWA themselves in urban Bangladesh. By analyzing a large body of literature, we explained how stigma works as a tool for social injustice and misogyny. We have also traced the roots of stigma back to the colonial history and contemporary power hierarchy of Bangladesh. Then, by presenting the discussion with parents and teachers of PWA, we demonstrated how autism stigma frequently impacts PWA and their families in direct and indirect ways. Furthermore, we have presented the design ideas that participants in the workshops have developed to combat the existing social stigmas. Our findings thus suggest several vital lessons for ICTD that we elaborate on in the following paragraphs. We discuss various ideas that would enable mothers directly or, in some cases, by first equipping PWA with tools necessary to uplift their status in the society. When the status of PWA is strengthened, mothers would enjoy better privileges as a caretaker and parent and would hopefully confront stigma less frequently.

### 8.1 Implications to Design

Our study demonstrates that stigma against autism in specific, and against mental and neuroatypical conditions in general, exists. Our study shows that PWA are often viewed—due to their dependency—by others as a ‘burden’ or ‘curse’ which adds to the struggle of mothers. If designs can find a way to avoid this dependency, a significant problem with stigma would be alleviated, and that, in turn, would enable mothers to be stronger. Our participants have already shown two examples of how we can advance towards that goal, including a powerful special card.

National ID cards in Bangladesh are already digital, and most nationwide services are accessible through the card by digital means. Therefore, the digital form of this card is not a novel idea; rather, the novelty lies in the additional privilege that PWA would get from the card. While other countries are benefiting from similar existing systems [99], Bangladeshi people would require a clear demonstration of the benefit of adopting such designs with proper modifications [47, 104], along with low-cost and sustainable design approaches to tackle weak infrastructure in the country. We acknowledge the challenges of privacy breach through biometric identifiers [6] and surveillance and call for future studies should

dwell deeper in understanding the tensions between privacy and visibility with respect to stigmatized populations.

Our data also show that the dominant power hierarchies of society often perpetuate stigma, and parents are often unable to protest against stigmatized behaviors due to their lack of power, as demonstrated in the case of misogyny. In ICTD, there is a substantial amount of work to address a wide range of issues related to social injustice and power struggles that we can leverage to address this problem. Here, we highlight two design frameworks that are relevant to our case.

First, the feminist design offers a framework for promoting women through design [13], which can be extended to empower mothers and PWA themselves. This extension will require, *inter alia*, input from both these groups in the design process, representing them respectfully through design, creating environments for them so that they feel included, and encouraging manufacturers to indicate if their products are PWA-friendly. We argue that such an initiative will contribute to reducing power imbalance and stigma. Furthermore, the misogyny that often results in autism stigma can also be addressed through this framework implemented with mothers of PWA. However, implementing such design interventions in places like Bangladesh will require a significant effort to accommodate existing cultural constraints and infrastructural limitations. The second design framework is Adversarial Design [25], which denies the supremacy of any ideological doctrine [64]. This framework suggests design interventions to find, document, and represent the injustice and oppression done by the ‘opposition.’ In our context, we can think of a critical design initiative [27] such as a public database to chronicle and publicly demonstrate people who engage in stigmatizing behavior. Echoing and extending the concept of Rho et al. [79], our participants have already suggested an online platform for them to unite and fight against stigma in local communities. Drawing on the approach that Link et al. suggest that to fight stigma effectively [53] and based on our study, we speculate that such designs would help reduce stigmatizing behaviors in public to some extent as well as would improve social awareness of the issue. In this regard, we would propose the creation on tools to test this in a subsequent work. On the other hand, due to the similarities in their experiences, parents of PWA are likely to be very co-operative with each other. As an extension to this study, we are currently doing a field study on how parents find solace in each other’s company and love sharing and listening to children’s success stories.

Finally, we see that misinformation and misinterpretation play a critical role in sustaining and strengthening stigma. For example, pseudo-scientific claims like “autism is contagious” stems from misinformation. We recommend awareness campaigns. Along with that, we suggest empowering parents and PWA so that people cannot ignore who they are and what we are preaching regarding them. In our study, we have also found that various Islamic teachings are misinterpreted and modified to justify stigmatizing PWA. We argue that to be compatible with and leverage the culture of Bangladesh, we need to involve religious leaders in local communities to help correct the existing notions that generate stigma. We draw inspiration from the role of organized religion, religious beliefs, and institutions in fighting the stigma of HIV/AIDS in Brazil, where one in five organizations involved in HIV/AIDS programming is

now faith-based [4]. Additionally, recognition of local religious symbols and their interpretations is key to a fruitful understanding of the local context in fighting stigma, as was the case with HIV [80]. However, religious cultures have sometimes reproduced the existing stigmatizing values and practices [61], for which the government needs to be careful in designing strategies.

## 8.2 Broader Lessons for ICTD

Besides the design implications mentioned above, our study generates several broader lessons for ICTD. First, we turn to the politics that sit at the core of stigmatization. As we have seen in the European history of mental illness stigma, and our findings, stigma is introduced in society to impose control over a group, and this is usually achieved by confining their access. A rich body of social science work on racial discrimination [54, 84, 105] demonstrates the politics of stigma in the history of the West.

We build on Foucault [33] to argue that designing intervention should not only be concerned with victim-centered designs, which frames the problem as merely a social phenomenon and hence, serves as an apparatus for the dominant sections of society to control victims further. Instead, ICTD research should take the central role in revealing the stigma-power dynamics both by tracing its roots and identifying its contemporary apparatus. For this, using Foucault’s work, ICTD research should focus more on finding the ways stigmatized populations are monitored, surveilled, controlled, and judged, both online and offline [62]. In the same vein, we argue that ICTD research should develop ‘political enclaves’ [55] for victims to protect themselves and grow their political voice.

Second, we propose a connection between stigma in the Indian subcontinent and its root in colonialism. This historical understanding enriches our knowledge of how problems introduced by colonial forces are still operating in postcolonial states through perpetuating social norms. This realization helps ICTD researchers extend their knowledge in postcolonial computing to find the novel process of stigmatization over computing technologies. In the Global South, IP addresses are frequently blocked by servers [3], transnational digital finance is restricted for many countries [75], and hacking and repairing are often stigmatized [7]. ICTD researchers should identify and design against such politics of stigma in novel ways. Additionally, this realization also strengthens the postcolonial computing’s call for focusing on local creativity and collaboration. Our data demonstrate how parents wanted informational and communal support that are local and easily accessible. They also demanded that the online platform be a venue for communication, collaboration, and unity against stigma. By analyzing these requirements, we argue that any sustainable design against stigma in a postcolonial context needs to be grounded in local communal resistance.

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