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Autism Spectrum Disorder in an Indian Context: Impact of Socioeconomic Factors on the Experiences of Individuals with ASD and Their Families

Kendall Harman

SIT Graduate Institute - Study Abroad, kharman@pugetsound.edu

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AUTISM SPECTRUM DISORDER IN AN INDIAN CONTEXT: IMPACT OF SOCIOECONOMIC
FACTORS ON THE EXPERIENCES OF INDIVIDUALS WITH ASD AND THEIR FAMILIES

Kendall Harman

Academic Director: Dr. Azim Khan

Project Advisor: Garima Srivastava, Approach Autism Society

SIT Health and Human Rights

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Abbreviations Used in this Paper

DSM – Diagnostic and Statistical Manual

ASD – Autism Spectrum Disorder

CDC – Center for Disease Control

MR – Mental Retardation

AFA – Action for Autism

ABA – Applied Behavioral Analysis

Abstract

While Autism Spectrum Disorder (ASD) is a condition that appears in comparable rates across social, ethnic and geographic groups, the quality and quantity of ASD-related resources and services is significantly lower in developing countries, including India. Moreover, sociocultural factors play a major role in the experiences of people with ASD. Yet, the bulk of ASD-related research has been conducted in developed countries. This study aimed to examine how social, cultural, political and economic factors impact the experiences of people with ASD living in India and their families. Seventeen parents of children with ASD were interviewed, and semi-structured observations of different ASD-related organizations in Jaipur and New Delhi were conducted. This study found that socioeconomic and cultural factors did have a significant influence on ASD experiences. In India, very few appropriate ASD-related resources are available, much less accessible, to those who need them most. Moreover, stigma and lack of awareness further hinder quality and accessibility of treatment and intervention. While many non-governmental organizations are working to address these issues, their efforts are limited by lack of governmental support and funding.

Introduction

What is Autism Spectrum Disorder?

Autism spectrum disorder (ASD), as defined by the DSM-5, is an umbrella term describing a group of neurodevelopmental disorders including autism, Asperger's disorder, pervasive developmental disorder not otherwise specified (PDDNOS) and child disintegrative disorder. In prior editions of the DSM, these conditions were classified separately. The term ASD will be used throughout this paper, because it is the term used in the most current DSM.

ASD is characterized by social, communicational and behavioral impairments. Common symptoms of ASD include avoiding eye-contact, difficulty reading non-verbal cues, repetitive behaviors, and dependency on routines. (DSM-5, CDC) Approximately twenty-five percent of people with ASD are non-verbal. (Autism Speaks) About sixty percent of people with ASD also have some level of cognitive impairment, while others individuals with the condition have normal or above average intelligence. (Autism Speaks) The first signs or symptoms of ASD are usually evident in early childhood. It is not unusual for a child with ASD to appear to develop normally for the first few years of life and then regress. ASD is, as the name suggests, a spectrum, meaning that the symptoms and severity of ASD can vary dramatically from one individual to another.

While the exact cause of ASD is unknown, it probably results from a combination of environmental, biological and genetic factors. There is virtually no reliable evidence that ASD is either the result of either poor parenting or childhood vaccinations. Unfortunately, however, such myths have pervaded public discourse regarding and reaction to ASD. ASD is a lifelong condition, and there is currently no cure. However, it can be treated and managed through

behavior and communication therapy including Applied Behavioral Analysis (ABA), occupational therapy and speech therapy. In some cases, medication may also be used to help to manage certain symptoms of ASD, such as hyperactivity or depression. Early intervention, ideally before the age of three, is critical to ensuring that individuals with ASD are able to lead the most fulfilling, socially integrated lives possible.

Various studies have estimated that anywhere from one in one hundred and fifty to one in sixty-eight people has some form of ASD. (National Trust; CDC) Boys are approximately five times more likely to be diagnosed with ASD than girls. The rate of ASD is relatively comparable between social and ethnic groups and by geographical regions. (Feinstein 2011; CDC; National Trust) The number of reported ASD cases has increased over time. However, it is unclear as to what degree the true prevalence of the disorder has changed. The increase in reported could also be attributed to a number of factors, including a broader definition of ASD, increased awareness surrounding the disorder, and improved diagnostic methods. (CDC) Regardless of what accounts for the growing number of cases, what is undeniable is that while the number of diagnosed ASD cases continues to increase, more resources must be dedicated to meeting the needs of people with ASD.

Disability as a Social Problem

Although ASD, like any disorder, certainly has its own inherent set of challenges or impairments, socioeconomic factors play a key role in the experiences of individuals and families living with ASD. Moreover, because ASD affects behaviors and social interactions, social constructions of and reactions to ASD are especially significant. Sociologist Chloe Silverman examines the social construction of autism in her article “Fieldwork on Another

Planet,” and emphasizes the importance of conceptualizing ASD in terms of the social context in which the disorder occurs. (2008) She states that “All members of a family are affected and most adapt in response to the disability and to an often-hostile society that makes few provisions for full-time caregivers,” and that,

“Individuals with autism whose life histories suggested the most resilience and best overall quality of life were often those who, rather than being independent, benefitted from accommodations in their surroundings and a complex network of social and family supports” (2008 p.328)

To best help those with ASD, and those who care for them, it is necessary to create an accepting, supportive, and empowering social environment. However, stigma and lack of awareness are barriers that frequently impede the ability of individuals with ASD and their families to access resources or to feel fully integrated into their communities.

Disability truly must be addressed at a society wide level. As prominent Indian disability scholar and activist G.N. Karna articulated,

“such terms as, ‘impairment,’ ‘disability,’ and ‘handicap’ are generally used in an ambiguous and very often interchangeable way. The World Health Organization (WHO), ... makes a clear-cut distinction between these terms... impairment could be defined as the loss of physical or sensory functioning in certain organs of the body and disability implies limitations affecting, wholly or partly, to meet the necessities of a normal individual as a result of either congenital or physical disabilities. Handicap, on the other hand, signifies the socially disadvantageous situation arising out of the cumulative effects of impairment or disability as well as societal response.” (1999, p.3)

In other words, it is, at least in part, when a society fails to meet the needs of those who fall outside of social norms, that impairments – physical, mental, or cognitive – become debilitating. Moreover, if disability is a social problem, then the solutions must, at least to some degree, be social in nature. Therefore, the study chose to examine ASD in the context of disability as a social problem.

Overview of ASD in an Indian Context: Policy, Culture, and Society

In India alone, it is estimated that approximately 2 million people have some form of ASD, although, it is difficult to accurately assess the disorder's true prevalence as it is often under-diagnosed and under-reported. As autism researcher, and parent of a son with ASD, Adam Feinstein phrased it,

“It is now widely accepted that autism knows no geographical or social boundaries. The rates are virtually identical in most parts of the world...What is certainly true, however, is that the cultural attitude to autism is dramatically different in the developing nations, where in some cases the condition was not acknowledged until the early 1990s.” (2011, n.p.)

People living with ASD in India, like any developing nation, face a unique set of challenges in addition to those impairments which are considered inherent to their condition.

It was not until 1999 that ASD was officially and legally recognized in India. Under the Persons with Disabilities Act passed in 1995, ASD was broadly classified as mental retardation; which has pervaded the way the country has continued to conceptualize ASD. This is not only inaccurate, but detrimental. Such misclassifications increase stigma and mean that, even today, there are few resources adapted to the specific needs of individuals and families affected by

ASD. Thanks largely to the efforts and advocacy of groups like Action for Autism, the 1999 National Trust for Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act was the first legislation to recognize ASD specifically. Some state policies are also attempting to improve the situation that individuals and families living ASD face. Bangalore, for instance, recently passed a policy that would increase ASD funding and extend disability benefits to people with ASD. (Kurup, 2012) Yet such progressive measures generally occur at a state-level, rather than nationally.

In 2012, a new bill was proposed that would overturn the 1995 Persons with Disabilities Act. Although the new legislation still has significant problems and has yet to actually pass. Furthermore, a disability certificate is necessary in order to receive any government benefits. However, it is not currently possible to get a disability certificate specifically for ASD, but rather Autism with MR (Mental Retardation). (Action for Autism) Currently, there are no government schemes which specifically address ASD, leaving non-governmental organizations responsible for providing the bulk of ASD-related services and resources.

Beyond the lack of government support, a number of social, economic, and cultural factors also make the experiences of individuals with ASD in India, and the experiences of their families, exceedingly difficult. There are very few resources available, much less accessible, to individuals with ASD and their families. Certain sociocultural factors also make it very difficult for individuals with ASD and their families to access appropriate treatment. ASD only really entered the public's attention ten or twenty years ago, and has yet to gain wide recognition. There are few resources available, and the majority of India remains unaware of what ASD is. The condition is widely stigmatized and attributed to bad parenting or superstition. Although this

situation is improving, it is improving too slowly for individuals and families living with ASD in a system that has failed to meet their needs.

Field Methods and Objectives

Questions and Goals

While ASD does not discriminate based on geography or socioeconomic group, the bulk of ASD-related research has been conducted in Western countries. Some studies have been conducted to assess the experiences of individuals living with ASD, or their families, in developing countries including India. (Bashir et al. 2014) However, such studies are relatively rare, and only cursorily examine the influence of social, economic, and cultural factors on ASD experiences. Therefore, this study aimed to address the gap in knowledge about experiences specific to those living with ASD in India, and their families.

The overarching question of this study was: how do social, cultural and economic factors impact the experiences of individuals living with ASD and their families in Rajasthan and New Delhi? Other sub-topics and secondary research questions included the effect of parent's socioeconomic status on the quality of their child's treatment, the overall availability of ASD-related services, and how factors like stigma and lack of awareness surrounding ASD impact the experiences of those living with the condition. The goal was to assess how Indian society's conceptualizations of and responses to ASD affect the quality and availability of ASD-related services and resources and to ascertain which social, political, cultural and economic factors might otherwise act as barriers to the successful utilization of those services.

Methods

To study the proposed question, semi-structured interviews were conducted with seventeen parents of children with ASD. Their children ranged in age from early childhood to mid-twenties. Note that while the term ASD is used throughout this study, the exact diagnoses of the children may vary from the most current DSM-5 definition of ASD. Many were diagnosed before the DSM-5 was published, and their parents chose to stick with their initial diagnoses. Moreover, a number of social and cultural factors affect the classification diagnosis of ASD. However, all parents interviewed had a child who was diagnosed by a professional to be somewhere on the autistic spectrum. Among the parents interviewed, many were also special educators, advocates and volunteers. Some names have been changed to protect the identity of respondents.

For both ethical and logistical reasons, it was not possible in this study to speak with individuals who themselves have ASD. Therefore the study will focus on the perspectives of caregivers, and the socio-economic factors that shape their experiences and challenges. However, by extension, the study also hopes to better understand the experiences of children and adults with ASD, as understood and articulated by those who are closest to them. The majority of interviews were conducted in English, but three required the aid of a translator. A basic set of interview questions can be found in the appendix. Semi-structured observations of different ASD-related programs and institutions were also conducted.

All interviews and observations were conducted with the aid of three different organizations; Action for Autism in New Delhi, Approach Autism in Jaipur, and DISHA Foundation. The particular institutions utilized in this study were chosen for a number of reasons.

Action for Autism (AFA) is the leading organization in India when it comes to ASD-related research, services, awareness and advocacy. They offer a wide range of services to individuals and families living with ASD including diagnostic services, schooling, vocational training and parent training. They have also organized a number of campaigns and outreach events in order to raise awareness about ASD. More than any other organization, the NGO has been hugely influential in shaping national attitudes regarding ASD. Preliminary research and many of the interviews were conducted at Action for Autism in New Delhi, while the majority of research for this study was conducted in Jaipur, Rajasthan, where there are significantly fewer ASD specific services and resources.

Garima, the director of Approach Autism in Jaipur was trained as a special educator at AFA before her family was transferred to Jaipur for her husband, Anurag's job. Recognizing the lack of ASD-related services in Rajasthan, they founded Approach Autism as a support group for families living with ASD. Approach Autism offers parent training and classes and vocational training for children and adults with ASD. In terms of philosophy, Approach Autism is very similar to AFA. However, in terms of resources, the two NGOs could not be more different. Approach Autism received a decent amount of initial support, financially and otherwise, and originally had its own facilities and site. However, due to lack of funding they lost their building. Garima and Anurag are operating out of their own home.

The DISHA Foundation, unlike AFA or Approach Autism, is not an autism specific resource. Rather DISHA Foundation is a school, founded in 1995, that serves children with a variety of disabilities including ASD. Classes are offered at different levels based off of children's age or ability levels, and vocational training is provided for adults with disabilities.

By working through three different organizations that varied in size, scope and policy, this study hoped to gain insight into a wider range of experiences of individuals and families living with ASD. Unfortunately, due to time constraints of this study, it was not possible to conduct a full comparative study of different regions or institutions. Moreover, while it would have likely offered valuable insight to study the experiences of individuals and families living with ASD who are living in rural areas, and the unique challenges that they face, this was unfortunately not possible. Because there is such vast diversity in the experiences of individuals and families living with ASD in India, it may not be possible to generalize results beyond the context examined in this study.

Brief Statement of Findings

This study did find that social, cultural and economic factors played a significant role in the lived experiences of individuals with ASD and their families, and their ability to access appropriate diagnosis, treatment and intervention. While early intervention is key to making sure that individuals with ASD At the most primary level, very few diagnostic, educational, or vocational resources are available to appropriately help or support children with ASD. Fewer resources still are available to assist adults with ASD, much less offer support to their families. Furthermore, many families, due to their own socioeconomic status are unable to access what few resources and services are available. Lack of awareness negatively impacts the likelihood that families will fully understand their children's ASD, much less seek appropriate intervention. A number of NGOs, and individuals, are ardently working to improve the situation for individuals with ASD, and those who care for them— however due to lack of general awareness, social stigma, and lack of government involvement, the results of their efforts are limited.

Results:

Availability of ASD-Related Services and Resources

Of the social, economic and cultural challenges that individuals and families living with ASD face, one of the most fundamental is the sheer lack of appropriate and available resources. With sufficient resources and social support, many individuals with ASD are certainly able to lead fulfilling lives and be integrated into their communities. Appropriate intervention from an early age is critical to ensuring that this is possible. (Action for Autism, CDC) Proper support systems and education are also vitally important to parents who are coping with the additional stress of raising a child with ASD. (Bashir 2014) However, in many cases, it is virtually impossible for parents to obtain diagnosis, treatment or education for their children, much less find proper support systems for themselves, because the appropriate resources simply do not exist in many parts of India.

While the national government has instituted schemes with varying degrees of success to combat a number of health issues from malnutrition to tuberculosis, it has fallen short in ensuring that individuals and families living with ASD are properly taken care of. When asked about government policies or interventions to help those with ASD, one father simply laughed and said “there are none.” (Personal Interview 12, 2014) If this statement is an exaggeration, it is not much of one. Disability policy tends to favor physical disability, meaning that legislation protecting those with developmental, cognitive or mental disabilities is minimal. (Feinstein) Although measures like a recent policy which ensures that parents of children with ASD will not have to transfer for their government jobs are helpful, they are simply not enough. Moreover, to access what few government benefits are available it is first necessary to acquire a disability

certificate. There is a waiting period ranging from weeks to months to obtain a disability certificate, and children have to undergo a battery of testing at a government hospital. The entire experience can be very stressful for a child with ASD. (Personal Interview 12, 2014) Furthermore, the government does not even offer disability certificates for ASD alone, but rather for “Autism with MR (Mental Retardation).” (Action for Autism) The choice to pursue a disability certificate is a difficult one for many families of children with ASD, because it means choosing between rejecting an inaccurate, stigmatizing label, and the ability to access government benefits. (Feinstein 2011) In 2012, a new bill was proposed to overturn the problematic Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act of 1995. This bill would increase the amount of funding and number of resources available to those with disabilities, including ASD. However, it too has significant problems, including the fact that it would not increase the number of schools for children with special needs, but rather attempt to mainstream them into an education system that is ill-equipped to meet their needs. The act has yet to pass. Ultimately, the lack of government measures has meant that NGOs and other independent interests have had to compensate in order to meet the needs of individuals and families living with ASD.

Since AFA was founded in 1991, the organization has been the primary source of help and support for families and individuals living with ASD throughout India. (Feinstein 2011) The NGO offers a range of services and resources, including diagnosis, special education, vocational training and parent training. Not only do they focus on the needs of children, and adults, with ASD, they recognize the importance of equipping caregivers with knowledge and support. All of the parents interviewed through AFA said that they were tremendously satisfied regarding their experiences with the NGO. While AFA staff and volunteers are clearly passionate and dedicated,

and have done amazing work to support and empower individuals and families living with ASD, their efforts alone are nowhere near enough. AFA is one NGO and there are two million people with ASD living in India. While the number of ASD-related institutions has increased since AFA was founded, most major organizations are centered in a few big cities.

It was in response to the lack of available ASD-specific resources in Rajasthan that Garima and Anurag founded Approach Autism. According to their website “the absence of Autism specific centers in Jaipur and the will of a group of parents to do the best and make a difference in the lives of children on this spectrum, led to the inception of Approach Autism.” (Approach Autism Society) Garima was trained at AFA, and used the knowledge and skills she gained there to start a support group for parents. Both Garima and Anurag have since dedicated a great deal of their own personal time and resources to their cause. However, the NGO has struggled to maintain itself. While they once had sufficient resources and facilities, initial enthusiasm for the project died down, and they lost funding. Ultimately this meant that they also lost the building that Approach Autism was operating out of. (Personal Interview 9, 2014) The NGO is trapped in a brutal catch-22: because they do not have sufficient funding they cannot afford their own building, however no one will support or donate to an NGO without its own facilities.

Of course, the struggles that individuals and their families face in the lack of available resources are equally exhaustive and have a significant effect on ASD outcomes. Outside of certain major cities, even obtaining a diagnosis can be difficult. One mother, unable to get a diagnosis for her son in India, flew to the U.K. for a month where he was diagnosed with autism. Another mother, Divya, whose son is now in his twenties, said that over two years passed between when she and her husband realized that there was something different about their son

and when they finally received a diagnosis. (Personal Interview 1, 2014) While she said that things are improving, and that the age of diagnosis has decreased, things are not moving quickly enough for families who are living with the uncertainty of not knowing what condition their children have. The implications of this are especially striking when considering how critical it is that children receive intervention as early as possible.

The dearth of ASD-related services and resources is also readily apparent in the educational sphere. Although many children with ASD can thrive academically if given the proper support, there are relatively few educational resources available for them. In the majority of cases, mainstream schools, both government and private, are not appropriately structured or sufficiently staffed to deal with the needs of children who have ASD. As Professor Aadil Bashir and colleagues said of the matter,

“Although public school districts are legally obligated to provide a fair and appropriate education to children with autism, the educational programs that are provided are rarely sufficient to address the needs of school-aged children with autism and are not available to young adults with autism.” (Bashir, Bashir, Lone & Ahmad 2014)

Even special needs schools often do not have appropriate resources. Most special educators are not trained to deal specifically with ASD, and the needs of a child with ASD can be very different from those of a child with Down syndrome or Cerebral Palsy. One mother, Sangita, shared her concern that many institutions that many institutions are “intimidating or abusive.” (Personal Interview 6, 2014) Many parents expressed that they would prefer to enroll their children in ASD-specific schools because the staff at such institutions are often better equipped to handle the exact needs of children with ASD. However, ASD-specific schools are, as one

parent stated, “few and far between”. Only twenty-five of approximately three thousand special needs schools in India are ASD-specific. (Feinstein 2011) Furthermore, because so few schools exist there are long waitlists at the ones that do. Since there are so few appropriate educational resources for children with ASD, many parents have taken the responsibility of educating their own children, as well as other children with ASD. Of the parents interviewed for this study, the majority were also trained and certified in special education. Sanjukta, a mother who chose to participate in AFA’s special education certification program, said that she did so “for the betterment of my own child,” and because so few teachers are well-equipped to handle ASD. (Personal Interview 7, 2014) By any standard, the dedication of parents who go to such lengths to make sure that their children’s needs are met is admirable. However, the fact that they are forced to do so is reflective of a system that has failed to provide individuals and families with even the most basic resources.

If the number of resources available for children with ASD is limited, services devoted to adults with ASD are virtually nonexistent. Parents commonly expressed that they were worried about what would happen to their children after they were gone. Some expressed concern, that in the absence of institutions for adults with ASD, their other children would be required to devote their adult lives caring for their siblings. (Personal Interview 16, 2014) ASD is a lifelong condition; however, the number of options for individuals with ASD drastically decreases once they are past school age. Garima and Anurag discussed a move among the ASD towards starting a residential community for adults with ASD. However, the project lacks funds, and they could not see it happening in the foreseeable future.

Socioeconomic Status and the Accessibility of ASD-Related Services and Resources

Beyond outright unavailability, a number of socioeconomic factors prevent individuals and families living with ASD from either seeking or being able to access ASD-related services and resources. There is virtually no government funding for individuals, families, or organizations dealing with ASD. This means that treatments and interventions, which can be very expensive, must be funded privately. As Professor Bashir articulated,

“The diagnosis of autism begins a journey that places profound demands on family human and financial resources for the remaining lifetime of the child... Intervention strategies are expensive and require long hours of one on-one interaction with a trained therapist or use of costly foods or drug supplements. Health insurance falls far short of covering these needs. Special education services do not fill the gap either.” (2014, p.66)

The cost has proven to be prohibitive to a significant number of families. The vast majority of the parents interviewed for this study were financially stable, lived in urban areas, were English speakers, and had some level of college, post-graduate or professional education. However, these types of privilege are not representative of all, or even the majority of, individuals and families living with ASD. Although ASD does not discriminate based off of socio-economic status, access to ASD-related services and resources certainly does depend on social and economic factors. From the point of diagnosis onward, being able to access appropriate ASD-related services and resources hinges on having sufficient financial resources and socio-cultural capital.

Even among such a (relatively) privileged group of families, the financial strain of having a child with ASD was readily apparent. The concerns of families with more money and a higher socio-economic status did vary somewhat from the concerns of families without the same level

of social and financial stability. Another mother, Sanjukta, said that “in our country, the government is not supporting anything,” but because her family had money, her son was able to get the treatment he needed. However, she worried that other families would not have the same privilege. She also clarified that if she could afford it her son would take two or three sessions a week, as opposed to the one session he was currently taking. (Personal Interview 7) In addition to the lack of educational options, another reason why many parents go on to work in special education themselves is because they can get reduced tuition at special needs or ASD specific schools if they work there themselves. (Personal Interview 11) Perhaps one of the most shocking examples of how the socio-economic strain of having a child with ASD came from one mother, Ashni, who said that she stayed in an abusive marriage, despite her family urging her to get a divorce, because her husband had a well-paying job and she wanted to make sure her son was taken care of. (Personal Interview 15, 2014) Not every family can travel outside the country to obtain an accurate diagnosis, and not every parent has the time or money necessary to get certified in special education. These children too deserve proper attention and support regardless of whether their parents are in a socio-economic position to advocate for them.

For individuals and families living in rural poverty, the challenges of being able to access resources and services increase exponentially. One study, though it was conducted in the United States rather than India, resulted in statistically significant evidence that children with ASD who lived in rural areas were diagnosed at a later age than children who lived in urban areas. (Mandell 2005) Researchers attributed this finding to a relative lack of appropriate resources in poor, rural areas.

Unfortunately, no comparable study could be found that was specific to India. However, one could speculate that such disparities would be even more salient in India, where the small

number of ASD-related services and resources that do exist are located in major cities, like New Delhi or Bangalore, while approximately seventy-five percent of the country lives in rural areas. Other factors that would contribute to an individual or family's marginalization or socioeconomic vulnerability, such as educational status, caste, or religion, would also presumably have a significant effect on their experiences with ASD. However, this was less evident throughout this study due to a sample group that was, in these senses, relatively homogenous. Ultimately, increasing the number of ASD-related resources and services will be fruitless, presuming that the underlying social factors that make them inaccessible to the individuals and families who most need them are not addressed.

ASD Awareness

Even families who are, from a socioeconomic standpoint, able to access ASD-related services and resources, often do not do so because they do not fully understand ASD, or else they do not comprehend that intervention is necessary. ASD only really entered the public consciousness in the last decade or so, and awareness is still very low. The process of learning that one's child has ASD is all the more difficult for parents who are not themselves aware of what the condition is or what it entails. Anurag shared that he and his wife initially thought that their child was deaf. However, from a young age, the boy had loved music and game-show host Amitabh Bachchan, making deafness seem like an unlikely explanation. When he was diagnosed, and Garima and Anurag looked up the definition of autism, Anurag said that they both started crying. (Personal Interview 9, 2014) This experience was, unfortunately, not unique among families who have children with ASD.

None of the seventeen parents interviewed for this study said that they had ever even heard of ASD, much less understood the condition or its implications, before their own children were diagnosed. Another father mentioned that his wife and her family compensated for his daughter's ASD by overfeeding her, because they did not fully understand the condition and were not sure what else to do. Other parents admitted that while they were trying their best to educate themselves about ASD, a lack of widely available information had prevented them from fully understanding the condition. Fortunately, Anurag said, that parents were becoming more and more aware. It is increasingly common for Approach Autism to see a younger generation of parents who know about ASD before, rather than after, their own children were diagnosed.

In addition to affecting how parents interact with their children, lack of awareness also exacerbates the problem that there are so few available resources, because it means that families fail to utilize what resources are available. One father, Sundeep, said that he was not aware that they would need a disability certificate in order to receive government benefits until the principal of DISHA advised them to apply for one. He exclaimed, understandably frustrated, “Personal Interview 12, 2014) In order for parents to be the best advocates and caregivers for their children, they first must be educated themselves not only about their children's needs, but about the resources that exist to meet those needs.

While lack of awareness among parents and families of children with ASD hinders their understanding of the condition and reduces the impetus to seek intervention, the general population's lack of awareness too plays an important role in experiences with ASD. Of course, the level of awareness among the general population is, expectedly, much lower than it is among parents of children with ASD. One AFA employee estimated that only two percent of people in India knew what ASD even was. (Personal Interview 2, 2014) Because there is so little

awareness, many parents have taken it upon themselves to educate themselves, their families and friends, and even complete strangers. When parents go out with their children, they get stares from people who don't know what ASD is, or why children with ASD would be behaving differently. Some find this difficult to deal with, while others have taken strangers' stares and comments as an opportunity to spread awareness about ASD.

Many parents said that they were very fortunate, and that their families, friends, and communities had come to accept and support their children, but that they misunderstood what ASD was, at least initially. They believed that ASD could be cured, or thought it was something that a child would grow out of. (Personal Interviews 4, 7 2014) Although it was not difficult for communities to love and accept children with ASD, the road to understanding was a long one and the responsibility for generating awareness fell on parents rather than society as a whole.

Unfortunately, the medical and educational sectors, where appropriate knowledge and sensitivity would be most beneficial, also remain largely uneducated about ASD. It has really only been over the past decade or so that the medical community has begun to recognize ASD, and still has far to come in terms of understanding the disorder. (Feinstein) This lack of awareness plays a significant role in the experiences of individuals with ASD and their families from the beginning; starting with the diagnostic process.

Several parents interviewed said that when they sought diagnoses they were told that their children might get better, and to just wait it out. This meant that their children's diagnoses were further delayed. Subsequently, this means that crucial interventions are delayed as well. Too often parents will be told that their children are "just slow." (Action for Autism, Personal Interview 4, 2014) The level of awareness among special educators is, unfortunately, not much

better than it is among the medical community. Another explanation for the lack of appropriate educational options for children with ASD is the fact that many special educators are not trained to deal with ASD specifically, but continue to treat it as a form mental retardation. The legal, social, educational and medical conflation of ASD with mental retardation is inaccurate, stigmatizing and detrimental to the process of obtaining proper treatment. Unfortunately, it is a stubborn myth, with sociocultural understandings of ASD not changing to meet increased knowledge and improved understandings of the condition.

Recognizing the need for ASD awareness at all levels of society, a significant component of AFA's mission has consisted of outreach and awareness building. Staff, volunteers, representatives, and beneficiaries of AFA's services have attended, and organized, rallies, fundraisers, and other outreach events. One product of AFA's outreach mission, the Autism Awareness Jamboree, is celebrated annually and remains a visible reminder that ASD exists, and that individuals with ASD will not be silenced, nor will those who care for them and advocate for them. AFA has also been highly involved in lobbying for improved legislation that actually recognizes ASD with accuracy and sensitivity. Furthermore, the NGO continues to work with educational, psychiatric and health professionals, training them to recognize signs of the condition and how to appropriately treat individuals who have ASD. While AFA has been vital in the fight for ASD awareness, the NGO is not alone in its efforts. Through Approach Autism, Garima and Anurag have extended the range AFA's mission to educate parents, professionals, and society as a whole. Garima said that she meets with psychology students to talk with them about ASD. Otherwise, she said, they would not really have the opportunity to learn about the condition.

Some individuals have also taken it upon themselves to help garner awareness on a broad scale. One mother, Reva, said that she approached the employees of a McDonald's in Jaipur to ask if they would contribute to an ASD outreach event. She said that they, like most people, did not know what ASD really was. Yet, they were more than willing to help once they were educated about the condition and the challenges faced by individuals and their families living with ASD. Reva has also utilized social media to extend ASD outreach and education, with unexpected success. She asked her all of her friends and family to send her pictures of themselves and their families dressed in blue, the color of ASD, and to spread the word via Facebook. She and her husband Sundeep said that they were pleasantly surprised to receive hundreds of photos, far more than they knew what to do with. (Personal Interview 12) Another mother was a school principal who organized a number of awareness events, allowing children from special and mainstream schools to interact with each other. (Personal Interview 15) Though the scope of these awareness building efforts is more limited than that of organizations and institutions, it is nonetheless impressive.

Without question, popular media has been at least partially responsible for increased public consciousness regarding ASD. Indian films *Barfi* (2012) and *My Name is Khan* (2010) both feature title characters with ASD. (Action for Autism) While these films may be questionable in terms of the accuracy and sensitivity with which they portray ASD, or disability in general, positive representation of those with ASD is undeniably important. Television has also contributed to growing ASD awareness. One television program, "Aap ki Antara", reserved three-minute time slots at the end of each episode, during which they would invite children with ASD and their families to talk about their experiences. (Action for Autism) Of course, popular media like film or television is less likely to reach certain social or economic groups, who could

perhaps benefit most from such knowledge. Moreover, while awareness is increasing it is increasing slowly, and more steps must be taken before ASD is truly understood by the majority of the country.

ASD Stigma, Myths and Misconceptions

Closely related to the lack of awareness regarding ASD is the tremendous amount of stigma surrounding the condition. Stigma as defined by Erving Goffman, in his pivotal work *Notes on the Management of a Spoiled Identity*, is a process through which individuals become socially marginalized, or that which “reduces a person from a whole and usual person to a tainted, discounted one.” (1963,p.3) This is certainly the case with how India as a whole perceives ASD, whereby individuals and their families struggle with being assigned a label of “other,” and being socially disregarded as such. One mother, Kavita, said that as most of Indian society sees it, there is “‘normal’ and ‘abnormal’ and nothing in between. Such dichotomies leave little room for people like her now 17 year-old daughter, who has ASD. (Personal Interview 3, 2014) Moreover, while some parents said that their extended families came to be supportive, others said that their families did not react positively, and “were embarrassed.”(Personal Interview 6, 2014) Many parents expressed frustration with a society that could not accept that their children were different. Unfortunately, “otherness” is a dominant part of the reality that individuals with ASD and their families experience.

While part of the stigma surrounding ASD results from an inability to accept difference, stigma and lack of awareness go hand in hand. A significant part of the stigma surrounding ASD stems from a host of myths and misconceptions about ASD, like the equation of ASD with mental retardation or the idea that ASD is the result of bad parenting. Actor Prithviraj offered his

opinion on the stigma he and his family have faced as a result of his son's ASD, saying "Autism is a disability and not a disease. Nor is it retardation. Treat an autistic child with sensitivity." (Feinstein, 2011) ASD-related stigma affects not only the individual with ASD, but also that person's family, as "family is seen to be a part of the illness" and "parents with autistic children frequently encounter hostile or insensitive reactions from public." (Bashir et al. 2014 p.65) Many parents have had a hard time with others assuming that they are responsible for their children's behavioral problems. This means that even going out in public can be a gamble: for children with ASD and their families, stares and snide comments from total strangers are almost routine. However, the negative effects of stigma are not limited to emotional harm to parents of children with ASD.

Too frequently, the stigma surrounding ASD negatively affects the treatment process, and means that parents will be less likely to seek intervention early on – or at all. Recognizing that one's child has a problem, and receiving a diagnosis of ASD is one thing - but accepting the stigma, severity, and permanence of the condition is another. One couple Reva and Sudeep said that they were "always in denial." They wanted to believe that their now 13 year old son, Saksham, was a "late bloomer." (Personal Interview 12, 2014) Anurag said that it is often hard for parents to deal with their children's diagnosis, and admitted that his own process of coming to terms with his son's ASD was a difficult one. For about a year after their son was diagnosed, Anurag and Garima sought solutions from anyone but psychiatric professionals, partaking in religious rituals and visiting a number of spiritual healers and informal practitioners. (Personal Interview 9, 2014) While Anurag and Garima clearly reached a place of understanding, acceptance, and determination regarding their son's ASD, not every parent reaches that place.

This is a significant problem, because it means that intervention and treatment are further delayed. Several of the parents interviewed through DISHA said that their children did not have ASD at all, but rather a more socially acceptable diagnosis of ADHD. Another couple said that their child had ADHD “but only five percent qualities of autism.”(Personal Interviews 14, 15 and 16, 2014) However, an employee who had worked with these families clarified that all of their children had been placed on the autistic spectrum by diagnostic professionals. She explained that these families clung to a diagnosis of ADHD because it was easier for them to deal with. Of course, among the parents interviewed, all had sought some sort of intervention for their children, and levels of acceptance were, in all likelihood higher than they are among a typical group of parents. Many individuals with ASD go their entire lives without proper intervention - or even worse - are hidden and isolated from the rest of society, because their parents fear social backlash or judgment. Professor Bashir offers one likely explanation for such behaviors, saying that “By refusing to be diagnosed, families can avoid having disability identities.” (2014) While a diagnosis is a necessary first step in making sure that a child with ASD receives necessary help and support, it also indicates the start of life with a marginalized identity. In order for more families to openly advocate for their children, general society first reach a place where ASD is not surrounded by stigma.

While having solid community ties and strong support systems is critically important for parents facing the additional stress of having a child with ASD, stigma often means that they cannot find full acceptance or support in their communities. Fortunately, some families of children with ASD have found, and created, this sense of community in each other. Approach Autism is one poignant example of this. The organization is no longer operating on the same scale it once did, however it continues to exist as a safe haven for children, and adults, with ASD

as well as their families. While the NGO provides a variety of services, as Garima and Anurag phrased it, Approach Autism is at its essence a “self-help group.” (Personal Interviews 9 and 10, 2014) When society fails a marginalized group – as it has clearly failed to accept or support individuals with ASD – it often falls on that group, and those who care about them, to find strength in each other, and themselves.

Hope for Individuals with ASD and those who care for them

The problems facing individuals and families with ASD are serious, and such issues require immediate and thorough intervention on a wide social, and political, scale. However, the situation is far from hopeless. Individuals with ASD can, and often do, thrive if given the proper resources and support. The number of productive, successful individuals living with ASD is proof of this. (National Trust) Poet Tito Rajarshi Mukhopadhyay is one particularly notable individual who thrived in spite of significant social obstacles. He attributes much of his success to his mother’s tireless dedication towards his education. His memoir *Beyond the Silence, My Life, The World and Autism* details his experiences and the challenges he faced living with ASD in India. He has learned to recognize the value in his unique way of seeing the world, saying

“Why shouldn't the things of this world, which neurotypicals often blithely pass over, be keenly, even fiercely, observed? Perhaps the medium of poetry best captures with its interruptive force the rapt attention of autistic engagement.” (Savarese 2010)

Tito’s success is a prime illustration that when individuals with ASD are given opportunities and support, their condition can be an asset rather than a liability.

With the exception of one mother, Anvita, who wanted her son to take home a medal in Special Olympic skating, the hopes that most parents had for their children with ASD were far

more modest than international literary acclaim. (Personal Interview 11) They wanted their children to be able to live independently, and to be able to take care of themselves. They wanted their children to feel safe and secure and comfortable in their own bodies and minds. They wanted their children to live with dignity. More than anything else, they wanted their children to be happy. Ultimately these are the things that all parents want for their children, and these are goals that should not be considered too lofty. However, it is the job of society as a whole to make sure that these dreams are within reach.

Fortunately, there *is* reason to be hopeful. The situation for individuals with ASD is improving, though slowly, making these and other dreams possible. The level of awareness among the general population, as well as the medical and educational sectors, continues to increase. Subsequently, the age of diagnosis continues to decrease, as more and more pediatricians are taught to recognize the signs of ASD. Educational resources, though still far from sufficient, are increasing in number, and improving. While national disability policy has done little to help those with ASD or their families, advocates are dedicated to replacing existing legislation with more helpful, less problematic, legislation that recognizes cognitive, developmental and mental disabilities as well as physical disabilities.

NGOs like AFA and Approach Autism continue to work tirelessly towards supporting and empowering individuals with ASD, and their families. Organizations like these continue to be a source of hope to families of children with ASD, as they see their children grow and progress. Since receiving appropriate help and support, parents said that their children are calmer and happier, knowing that their needs will be met. (Personal Interviews 3, 6, 8) In many cases, they have learned how to perform necessary activities of daily living (ADLs) or how to better

communicate their needs, verbally or otherwise. (Personal Interviews 3, 5, 6, 7, 8) Equally important is the education and support that parents have received.

The support systems that parents find, and establish, through these NGOs means not only that they will be able to cope with the social, financial, and emotional stress of having a child with ASD, but also that they will be able to be the best possible advocates for and caretakers of their children. Furthermore, these organizations are also working to build awareness and acceptance of ASD, on both a local and national level, so that individuals and families need not be alone in the fight to educate the public about ASD. As the number of organizations working to help, support and empower individuals with ASD increases, as it is, presumably these benefits will only increase in range and scope.

Conclusion:

ASD, regardless of sociocultural or economic context, is a challenging condition to live with, for both individuals and their families. However, many individuals with ASD can certainly thrive if given the proper care and support. Families of children with ASD, too, benefit from additional support systems and educational resources. Yet, in many scenarios, it is social, economic and cultural factors, even more than innate cognitive, psychological, or developmental deficits, that make experiences with ASD so difficult to manage. In India as a whole, and certain regions in particular, the challenges of ASD are exacerbated by a number of social factors.

While early treatment and intervention is crucial, the lack of available resources makes it difficult for even the most financially stable, urban dwelling, highly educated, socially powerful families to get their children the support that they need. However, for families who are not financially stable, have a lower level of education, are socially vulnerable or live in rural areas,

the challenge of accessing ASD-related services and resources becomes all the more daunting. Lack of awareness is also a significant barrier to positive outcomes for individuals with ASD. Parents who are unaware of what ASD is have a harder time understanding and accepting their child's diagnosis and are consequently less likely to seek appropriate help or support. They are also less likely to receive support from their extended families or communities, while lack of awareness among the medical and educational sectors negatively influences the quality and availability of ASD resources, from the process of diagnosis onward. Stigma, in part arising from lack of awareness, also negatively the experiences of people with ASD and their families, and decreases the motivation of parents to seek treatment for their children.

In the absence of sufficient government support or recognition, non-governmental organizations have been the driving force in efforts to reduce stigma and increase awareness, while providing the resources, services and support that are otherwise inaccessible, or outright unavailable, to those who need them most. Among these organizations, AFA stands alone as the first, and still the most powerful, voice of ASD advocacy in the country. Their model has been incredibly effective in making sure that the needs of individuals with ASD are met, while also helping to educate caregivers and establish support systems. Moreover, AFA's public outreach measures have been hugely influential in shaping national policy and attitudes toward ASD. Through founding Approach Autism, Garima and Anurag have extended AFA's services and principles to Jaipur, where there are very few ASD-specific resources. Though the NGO has struggled to maintain itself financially, Garima and Anurag hope that with proper support and funding they can continue to serve individuals with ASD and their families throughout Rajasthan.

However, if individuals with ASD are to be able to thrive to their fullest capacity – and if they and their families are to be integrated into their communities – then much work has yet to be done. Moreover, the work of building awareness and providing support needs to fall on society, not just a dedicated but relatively small collective of individuals and organizations. One parent, Sundeep, stated it well when he said, “It is not just autism, six percent of the country has some sort of disability... this means that it is society’s job – government included – to find solutions for them.” (Personal Interview 12, 2014) Disability is a social problem. It is a problem of stigma, a problem of lack of awareness, a problem with the lack of available and accessible resources. Individuals with ASD, and those who care about them, have too often felt the sting of a society, and government, that refuses to understand and accept them for who they are, and for how they think and process the world. They have, for too long, dealt with a society that too often fails to meet their needs at the most fundamental level. This can, and will change. However, the burden of change must fall on everyone, not merely those who have been most acutely and personally affected.

Limitations

This study had a number of limitations. For one, it was ethically and logistically impossible in this study to speak with any individuals who themselves had ASD. Their perspectives would, of course, have been invaluable, and their voices are too often silenced. This study did not formally examine the perspectives of other stakeholders, such as psychologists or pediatricians, although many parents were also special educators, volunteers and advocates. The study instead chose to focus on caregivers’ perspectives regarding the challenges both they and their children have faced.

It is also important to note that the group of parents interviewed through this study was, by no means, representative of all parents of children with ASD living in India. Nor were they necessarily representative of the particular regions in which the study was conducted. The majority of parents interviewed were English speakers and had financially stable jobs. They had all received at least some level of undergraduate or post-graduate education. The majority of parents interviewed were mothers. It is possible that fathers' perceptions of their children's ASD would vary, on average, from the perceptions of mothers. Perhaps the most fundamental distinction between these parents, and the general population of parents of children with ASD, was that all had sought some type of intervention for their children. Because of the one month time limit of this study, all interviews and observations were conducted through different NGOs. This of course limited the likelihood of speaking to parents who did not seek intervention.

Furthermore, because most NGOs are centered in urban areas, it was not possible to conduct any fieldwork in a rural setting. It is likely that the experiences of people with ASD living in rural areas, and their families' experiences, would be significantly different from those of individuals and families living in urban areas like Jaipur or New Delhi. While this study did work through multiple NGOs, the time constraint meant that it was not possible to conduct a full comparative study. Therefore, any conclusions drawn about differences between the NGOs looked at remain relatively superficial.

Cultural barriers may also have affected the quality and quantity of information gathered. First of all, different social positions may have influenced interviewer-respondent dynamics. Furthermore, psychological jargon does not necessarily translate well across languages or cultures.

Recommendations for Future Study and Action

In addition to the gaps in ASD-related resources and services in India, there are also significant gaps in research. Much work has yet to be done in order to better understand the experiences of people with ASD and their families. While many parents expressed frustration with the lack of appropriate ASD-specific resources, a formal comparison of different institutions, both ASD-specific and non ASD-specific, would likely validate their claims. Additional studies examining the difference in accessibility and availability of ASD-related resources across social and economic groups would also likely be insightful. Speaking more extensively to professional stakeholders, such as teachers, pediatricians and psychologists would also provide different perspectives that were lacking in this study. Of course, it would be invaluable to actually speak to those most personally affected; people who themselves have ASD.

Based off of these findings and the insights offered by the parents interviewed, this study can offer some tentative recommendations for future action. The most effective NGOs, like AFA, seem to be those with a multi-faceted approach towards ASD; empowering individuals with ASD, while simultaneously educating and supporting their caregivers, and working to increase awareness at a society wide level. As the number of organizations following AFA's model continues to increase, presumably these services will benefit a broader social and geographic range of people with ASD and their families. However, the effectiveness of individuals and NGOs alone, no matter how committed or dedicated, is limited without sufficient government support or funding. While these agents continue to support and advocate for individuals with ASD and their families, change needs to occur at a national, policy level to make sure that their goals are possible.

Appendix

Interview Questions

Below are some of the basic questions asked to parents, interviews did deviate from these questions to some degree, and follow-up questions were asked?

Basic demographic information:

What is your name? What is your child's name?

What is your child's age?

Where are you from?

What is your profession? What is your spouse's profession, if applicable?

What is your highest level of education? What is your spouse's highest level of education, if applicable?

Questions related to diagnosis:

What is your child's diagnosis?

At what age were they diagnosed?

Can you describe the process of getting a diagnosis? (i.e. How long did the process take? How many different doctors did you visit? How did you feel that you were treated by the doctors and psychologists that you did see?)

Questions related to education:

What were your experiences with the education system like?

Is your child enrolled in a mainstream school? or, Have they ever been enrolled in a mainstream school?

Is your child enrolled in a school for children with special needs? or, Have they ever been enrolled in a school for children with special needs?

Is your child enrolled in an autism-specific school? or, Have they ever been enrolled in an autism-specific school?

What is your general opinion on the education system? (i.e. How well has it worked for your child? How well equipped are teachers to handle the needs of children with ASD?)

Questions related to policy:

What is your opinion on national and local disability policy?

Is the government doing anything to support people with autism or their families?

Questions related to social factors:

Have you faced any social challenges since your child was diagnosed?

How have your friends and extended family responded to your child's diagnosis?

How has your community as a whole responded to your child's diagnosis?

How would you describe the level of autism awareness in your community?

Questions related to economic factors:

Have you faced any financial challenges since your child was diagnosed?

Does the government offer any financial support to families of children with autism?

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