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Places of Autism: Influences on Experiences of Autism in Atlanta, GA USA and Kerala, India

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M.Ed., Vanderbilt University, 2005

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An abstract of
a dissertation submitted to the Faculty of the
James T. Laney School of Graduate Studies of Emory University
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy
in the Graduate Institute of Liberal Arts
2014

Abstract

Cross-cultural comparisons of psychiatric and cognitive differences are rare, due to methodological and analytical complexities, yet can provide unique and valuable information about the universality of psychiatric symptoms, treatment approaches, human rights, and best practices for international collaborations in global mental health. Research in this area is particularly salient for issues related children and to Autism Spectrum Disorders (ASDs), which are steadily increasing in global awareness as myriad nations encounter and adapt to Western definitions, concepts, and treatments for ASDs. This current project compares parental and professional experiences of children with autistic characteristics in Kerala, India and Atlanta, GA USA. A total of 112 interviews (76 in Kerala, 36 in the Atlanta area) were completed. They were comprised of parents who have children with pronounced traits of autism and professionals who work with this population (i.e. pediatricians, teachers, therapists, traditional healers). Pulling on theories and methods from disability studies, medical anthropology, and human geography, I compare these populations, focusing on three places of autism: the clinic, the home, and the school. After two chapters describing the background and development of my research questions, analytical method, and research design, there is one chapter for each place listed above. These chapters provide an analysis of the architectural, social, and temporal aspects of each place then presents results from interviews and observations to highlight a specific issue found in each place. The conclusion includes guidelines for future researchers, interventionists, or advocates hoping to engage with individuals associated with autism in different cultures or in culturally diverse families in their own communities. This section includes suggestions for how to 'read' each place of autism and outlines what information can be gleaned from clinics, homes, and schools. Next, there is a discussion of the ethical dilemmas of researching autism in different cultures using examples from the current research. Thus, this dissertation guides future international workers through the practical issues of work on or with children with intellectual, behavioral, and/or psychiatric differences while also fostering consideration of possible ethical challenges.

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Dedication

I dedicate this work to the memory of my grandmother, Yvonne Meade. She taught me to appreciate and harness the tenacity and courage needed to chase my dreams and reach my goals.

Acknowledgements

I would like to thank my dissertation committee, Drs. Howard Kushner, Rosemarie Garland-Thomson, Chikako Ozawa-de Silva, and Tamara Daley. Additionally, I am grateful for the scholarly guidance over the years by numerous Emory faculty, including Drs. Sander Gilman, Kevin Corrigan, Benjamin Reiss, Karen Rommefanger, Paul Wolpe, and Kimberly Wallace-Sanders. I would like to thank the Organization for Autism Research for partially funding my research. I want to recognize the efforts of my translator and research assistant, Joypaul. He was instrumental in the recruitment, data collection, and analysis process of my research in Kerala. I am grateful for the support and guidance of my fellow graduate students, who gave me constant support, particularly Shan Mukhtar, Sarah Franzen, Michael Hall, Anson Koch-Rein, Megan Friddle, Tawni Tidwell, Hilary King, Melissa Creary, and many, many other friends across campus. I also appreciate the support of my friends around Atlanta and, most importantly, my parents and siblings, whose unwavering love and encouragement nourished me over the past six years. Thank you to all!

Table of Contents

Chapter 4: Homes: Therapeutic Use and Choice....147

Chapter 1: Why Culture Matters

Introduction: Project Description

The current project is a cross-cultural comparison of parental and professional experiences of autism in Kerala, India and Atlanta, GA USA. As will be described more fully in the next chapter on methods, these sites are representative of the wider culture they are situated—that of a Westernized location and a developing location respectively—and also uniquely tout variable access to autism-related resources. Both regions contain areas where families and professionals can easily access autism-related information and resources and areas where this is significantly more difficult. By comparing these sites, I am able to illuminate the most important issues that impact how autism and autistic children are identified, understood, and regarded within their local communities and wider culture.

The overarching question for this dissertation is: how does culture influence parental and professional experiences of autism. I rely on Cecil Helman's definition of culture as "a set of guidelines (both explicit and implicit) that individuals inherit as members of a particular society, and that tell them how to view the world, how to experience it emotionally, and how to behave in it in relation to other people, to supernatural forces of gods, and to the natural environment. It also provides them with a way of transmitting these guidelines to the next generation—by use of symbols, language, art, and ritual" (Helman, 2000, p 2). I prefer this definition because it goes beyond definitions that simply identify the dynamicism of culture, noting that culture is always changing, and/or the various tools and artifacts that represent certain features of a community. This definition makes explicit one of this study's fundamental assumptions: that culture influences how people behave. This feature is paramount to an analysis of how children with clear autistic characteristics come to be considered and treated in their home communities. Helman's definition also ties culture to the interactions within which people learn how to behave, including those with other people, with physical surroundings, and with emotions. I will explore these interactions to understand how local geographies and social hierarchies influence the ways in which parents of autistic children and the professionals who work with them come to understand autistic children's differences, current needs, and futures.

To fully explore how these understandings of autistic difference are developed and replicated, this work traces children with autistic characteristics through the places in which autism can be found—clinics, homes, and schools. These places are important for families with autistic children and the professionals who interact with them, and so deserve critical examination. Here, I explore the ways autism interacts with the architectural, temporal, and conceptual structures of these places to illustrate how local values of differences, normality,[1] childhood, and autism are reflected. This information can be harnessed into useful strategies for interventionists, researchers, and advocates interested in embarking on work with autistic children in a cultural environment different from their own.

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[1] This work is informed by Lennard Davis' exploration of the development of *normal* as a product of Western industrialization and the influence of science, including statistics and the bell curve. As it applies to childhood, it could be argued that autism is playing an increasingly important role in the normalization of children. For more, see Davis' 1995 book, *Enforcing Normalcy: Disability, Deafness, and The Body* (New York: Verso) or his shorter work in *The Disability Studies Reader, 3rd Edition* (Ed. Lennard Davis, 2010) titled "Constructing normalcy: The bell curve, the novel, and the invention of the disabled body in the nineteenth century" (pp. 9-28).

As I looked at children with autistic characteristics in clinics, homes, and schools, I discovered ways local factors influence the experience of parents and professionals at the micro, individual level and through the macro, sociopolitical level. I learned, for instance, how variations in the socioeconomic and geographic profiles of families and professionals impact the process of obtaining diagnoses. These profiles, however, do not stand alone. The characteristics of the child also intervene in this process in ways beyond that of the diagnostic assessment.Critical cultural factors such as the level of reliance on familial or biomedical structures are also involved in the process of diagnosis. I also considered how educational policy and training impact the way autistic children are treated in schools, and how they reflect cultural expectations of children with intellectual and developmental differences.

I used ethnographic research methods to explore these issues. In each research site, I interviewed and observed caregivers of autistic children and individuals who interact with families and children with autism in a professional realm. These techniques were used to answer my questions on how familial structure, socioeconomic factors, child characteristics, and urbanicity impacted diagnostics and treatment practices. Data gathered through these techniques also led to questions about parental acceptance of autism and local expectations for the future of autistic children. I also exploited the tools of human geography, which considers how people interact with their environments. To understand the ways in which Atlanta and Kerala reflect and direct attitudes and behaviors about autistic difference, I generated and analyzed detailed descriptions of the clinics, the homes, and the schools I encountered. Finally, I studied the educational, medical, historical, and social dimensions of these questions to better understand how autism and related disabilities are situated within the wider community.

Part of my findings confirm the understanding in global psychiatry and psychiatric anthropology that psychiatric syndromes are not uniformly exhibited, described, or responded to across cultures. This work is described more fully in a later section of this chapter titled “Multiple Influences: Culture, Mental Illness, and Autism.” One of the important findings of this work is that the Western way of describing the collection of behaviors and traits called *autism* is being overly relied upon in other cultures. Western professionals assume the universality of autism and this assumption is brought into communities new to the concept of autism. Thus, the world is defaulting to a Western way of conceptualizing this particular set of differences. The consequences of this may be a global ‘epidemic’ of the use of the diagnosis of autism, even in areas where the label is not useful or inappropriate. The best way to avoid this consequence is to ensure that scholars, interventionists, and advocates are able to identify, accept, and work with variations in how communities talk about, define, and treat behavioral and developmental differences.

As such, I propose that individuals and groups interested in engaging in international autism-related work can take certain steps to ease the transition into new communities or diverse groups within one’s own community. These steps are outlined in a series of practical guidelines in the dissertation’s conclusion and include the importance of working with a cultural liaison, how to ‘read’ places for important and useful information, and the types of important cultural details that can be learned in the places of autism discussed here. My conclusion also adds to the important but unresolved discussion of international research ethics for projects studying intellectual, developmental, and psychiatric disabilities. I conclude that learning from the moral challenges researchers have encountered in the field can aid in the development of specific ways to engage in this work with well-defined ethical templates.

This work is primarily meant for researchers, interventionists, and advocates interested in engaging in autism- or intellectual disability-related work. Although the theoretical background presented in the first two chapters may not be relevant to all individuals interested in this work, the final four chapters, which contain the data analysis and conclusion, are relevant and accessible to those working directly in this area in any capacity. It is my hope that, as autism becomes a more universally recognized term and concept, global autism work proceeds with an awareness of the ways familial, educational, medical, and traditional aspects of a culture changes how autism is discussed, considered, and treated.

A Note on Language

This dissertation aims to follow and illustrate the language of neurodiversity and disability studies. In other words, I will avoid using medical model, deficit-focused language to describe the differences and characteristics associated with autism and related conditions. This way of talking about disability and difference in regards to autism is constantly evolving to become more respectful and detailed as needed. Throughout the work, I will use words such as ‘differences’ and ‘significant’ rather than ‘deficit’ or ‘severe,’ unless the use of these words serve to emphasize a particular perspective. By employing a language of difference rather than deficit,[2] an ethos of acceptance and tolerance can be fostered through more appropriate and respective linguistic representation of disability and differences.

In the field of disability studies, there is an ongoing conversation about the use or nonuse of ‘people first language’ (Shapiro, 1993, p. 197). Through conversations with friends and colleagues involved in the neurodiversity movement, I now understand the complexities and meanings behind using the phrases ‘autistic people’ and ‘people with autism.’ The latter follows the precepts of ‘people first language’ by verbally demonstrating the person as primary and more important than the disability, thus rejecting the notion that a disability subsumes a person’s entire identity. This inaccuracy is most pronounced in phrases like ‘an autistic’ or ‘autistics.’ However, there are many self-advocates who prefer the use of the term ‘autistic person’ because autism is a central element to identity formation and the phrase ‘people with autism’ seems to serve as a reminder to others that autistic people are, in fact, people. Throughout the dissertation I will rely primarily on ‘autistic people’ with the caveat that this phrase is meant to respect the identity of autism.

Nevertheless, there are many in developing areas for whom the identity and diagnostic label is entirely new and unrecognizable. I began this research understanding the likelihood that, especially in India, autism is not a frequently used label and so I often rely on phrases such as ‘people who exhibit autistic characteristics’ in order to

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[2] I would like to personally thank Dr. Rosemarie Garland-Thomson for having several conversations with me about how to most appropriately talk about autism using disability friendly language. Her persistent reminders to pay attention to the words I use and how I use them has guided the development of the language used throughout this dissertation.

demonstrate a focus on the behaviors and not the application or consequences of the label. While this dissertation frequently states a focus on the influence of culture on *autism*, the use of the diagnostic label is meant to represent the range of traits and characteristics associated with this particular state of being. Many of the children I interacted with in Kerala were not diagnosed with autism, yet displayed many characteristics of autism such as the use of a non-verbal communication method, unique social interaction styles, and finding comfort in repeating certain bodily movements. If I were to rely on the presence of an autism diagnosis, many children and families would not be represented in this research. This is an issue that I discuss again later; readers should recognize the way *autism* is being applied to represent those with and without a formal diagnosis and to understand that this work is not intended to explore the ways being labeled 'autistic' influences the experiences of children, families, and professionals.

It is also important to discuss the various ways in which autism is conceptualized and the different ways the term is used. One way autism is thought about comes from the biomedical, scientific position. From this perspective, autism is a scientific, objective, and biological entity. The fact that scientists do not, as of yet, fully understand the neurological, genetic, and biological bases behind autism does not change the strength of this position. This dearth of knowledge, combined with strong convictions that autism is essential in nature (i.e. is directly connected to biological events), motivates vast amounts of research on genetic and neurological correlates with and on cures for autism. Although it is becoming more common for professionals to consider that there are several different autisms with several different causes, the essentialism of autism remains a very strong and influential position.

The other way to think about autism is that it is a construct that is illustrative of a certain range of characteristics, yet is largely created in society and culture. In other words, rather than being a biological entity, autism is a set of characteristics and traits that are deemed pathological by members of a community. What exactly constitutes pathological behavior is reliant on cultural factors and so varies. This perspective conflicts with the above perspective and works to explain why diagnostic criteria change and why a universal, objective diagnostic system or tool cannot be created. This perspective, often referred to a social constructionism, is, in my view, more correct than the above perspective. As is described below, autism is a Western term with Western concepts that is now finding homes in very non-Western locations. As this happens, professionals and families are discovering myriad problems with this new global spread. This is the fundamental problem this dissertation is addressing.

Throughout this work, I will occasionally rely on the first perspective in order to illustrate or adequately describe certain findings related to autism research. When necessary, I will identify these times for the reader to avoid confusion. Again, I hold the perspective that autism is a useful, yet variable, diagnostic category that is dynamic, nebulous, and reliant on specific, Western ideals of the mind, disability, and childhood.

An Overview of Autism

Autism was first defined by Leo Kanner in a 1943 article, "Autistic disturbances of affective contact," wherein he described eleven children showing a similar "inability to relate to themselves in the ordinary way to people and situations from the beginning of life" (Kanner, 1943, p. 242). Kanner described these children as displaying extreme autism (meaning a preference for aloneness), obsessiveness, stereotypies (repetitive behaviors), and echolalia (repetitions of other's words and phrases; Kanner, 1943). This constellation of traits is still relevant to some manifestations of autism, and is often called classic or Kanner's autism, however the current Western nosological system also considers children and adults with less significant impairments and having a wider variety autistic traits "on the autism spectrum."

A common biomedical definition of autism is that of a neurodevelopmental disorder with deficits in social behavior and communication with the presence of repetitive and restricted behaviors (Frith, 1991). The DSM-5 includes the diagnosis Autism Spectrum Disorder (ASD). This diagnosis accounts for four diagnoses in the previous edition's Autism Spectrum Disorders category: autistic disorder (autism), Asperger's syndrome, childhood disintegrative disorder (CDD), and pervasive developmental disorder – not otherwise specified (PDD-NOS). In order to be diagnosed with ASD, a child or adult must demonstrate differences (described as deficits in the DSM) in early childhood in two areas: (a) social communication and social interaction, and (b) restricted, repetitive patterns of behavior, interests, or activities. These traits must "limit and impair everyday functioning" (American Psychiatric Association, 2013). The shift from having four distinct diagnoses that differed primarily on significance of impairment to one spectrum diagnosis occurred after the data was collected for this project. As will be described in the next chapter, this is one reason why I recruited caretakers of children who exhibit traits of autism: I aimed to include caretakers who had children with fairly significant impairments such as non-verbal or idiosyncratic communication, behavior repetitions, and unique social interaction styles.[3]

A diagnosis of autism is based solely on behavioral observation and caretaker reports. Because the behaviors that must be present are both social and, as described above, relational, it is a uniquely appropriate condition with which to study cultural influence. Cultural variations on norms of childhood and social interaction make both the expression of atypical social behaviors and identification of pathology in childhood an interesting reflection of local values (Daley, 2002). Autism is present around the world regardless of the popularity or obscurity of the term. The collection of traits, particularly in their more significant form, is identified, though not always called autism, in all cultural locations (Grinker, 2008; Feinstein, 2010). What varies, as the current project demonstrates, are the ways a community interprets the presences of these traits, which traits are deemed in need of treatment, and the ways and by whom the person exhibiting these traits is accepted or rejected.

Autism is also a particularly suitable condition to discuss the ways a range of differences and disabilities interact with a society. Its presence in psychiatric nosological systems such as the DSM align autism with the field of psychiatry and other psychiatric

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[3] Despite this requirement, some families whose children were not significantly impaired were interviewed. The next chapter discusses why I decided to keep their data.

diagnoses. As a condition that has historically been associated with cognitive impairment, either in the sense of qualitatively lower IQ scores or based on misunderstandings of communication differences, autism is relevant to the issues related to intellectual disabilities. Finally, as many people on the autism spectrum have unique gaits or find comfort in repetitive body movements such as rocking, hand flapping, or jumping, autism is a physically obvious disability and is associated with physical differences and disabilities. Thus, the study of autism in culture is relevant to a wide variety of states of being, disabilities, and differences (Sarrett, 2012).

Diagnostic criteria in the DSM-5 (American Psychiatric Association, 2013) allow for a wide range of children and adults to qualify for a diagnosis of autistic disorder, from the mildly socially awkward to the significantly cognitively impaired. The breadth of diagnostic criteria, changing definitions since the introduction of autistic disorder into the third edition of the DSM in 1980 (Feinstein, 2010; Grinker, 2005), and widespread deinstitutionalization of children with intellectual differences (Eyal et al., 2010) have contributed to a rapid rise in rates of autism, from 1 in 10,000 children in the 1980s (Eyal et al., 2010; Feinstein, 2010; Grinker, 2005) to the Center for Disease Control and Prevention’s (CDC) most recent estimates of 1in 88 (Center for Disease Control and Prevention, 2012). This rise has coincided with growing public awareness of autism in the West as a “public health crisis.”

What has become known as in America as the autism epidemic is now being repeated in nations new to the diagnosis (Daley, Singhal, & Krishnamurthy, 2013; Grinker, 2005). Although prevalence rates have not been calculated for most non-Western countries, anecdotal evidence supports rising rates in several nations (Kim, 2011), including India. While there is no definitive evidence attributing this rise to any one cause, the popularity of the term means that many nations are learning about and applying this diagnostic label as it has been conceived of in America since the 1940s. In other words, with an increasing influence of Western biomedicine around the world comes a new word for children and adults who demonstrate particular constellations of traits and behaviors. And with it comes the interventions, explanatory models, and values attached to label.

Autism: Coming of Age Around the World

Autism, as a concept and diagnostic category, was born and raised in the West. General globalization practices have helped autism become a more familiar term around the world. More countries are being introduced to the term and have begun to apply it to increasing numbers of children and adults every year. The Indian-based Action for Autism's website has the most current and comprehensive list of autism organizations worldwide. Presently, it lists 127 countries with at least one autism related organization or facility specifically for autistic people (Action for Autism, 2012). There is also now a "World Autism Awareness Day" sponsored by the United Nations (Autism Speaks, 2012) and an increasing presence of culturally related research at major autism conferences such as the International Meeting for Autism Research (IMFAR). IMFAR is a yearly conference that brings together professionals, caregivers, and researchers from around the globe to learn about and present new findings in autism research (International Society for Autism Research, 2012). Additionally, a well-known anthropologist, Roy R. Grinker, recently published *Unstrange Minds: Remapping the World of Autism, the* first widely disseminated work on autism in non-Western locations. In it, Grinker looks at specific families and their experiences obtaining diagnoses and treatments for their autistic children in Cholla-do, South Korea; Delhi, India; and KwaZulu-Natal, South Africa (Grinker, 2007). Although this work fails to consider the use of local treatment options, it signals the spread of autism and the need to investigate the consequences of this spread.

All the events listed above illustrate the increasing recognition and importance of autism around the world. The concepts behind the term *autism* being globally adopted are primarily situated within a biomedical perspective—the mode with which American clinicians, care providers, and lay public talk about and understand health and illness. Biomedicine is also the theoretical environment in which understandings of autism have been developed.

Medical anthropologist Arthur Kleinman illuminates the bias inherent in the biomedical approach, especially in relation to psychiatric conditions. He explains that it "offers a stratigraphic view of disorder in which biology is the foundation, and psychological and social dimensions of sickness are seen as epiphenomenal, suprastructural layers to be stripped away to get at the infrastructural, i.e., biological, base" (Kleinman, 1988, p. 143). This is the essentialism I described in the beginning. Because autism (1) is defined primarily based on relationality (i.e. the majority autism-related traits refer to how the person does or does not interact with others) and (2) is reliant on a narrow definition of child and adult behavioral and communicative normality that disregards important social dimensions situated within cultural contexts, the biomedical perspective is problematic. Yet this is exactly the notion being introduced to societies around the world.

What is not fully considered are the ways a Western concept of autism and the biomedical baggage it comes with may or may not be translatable into a new cultural environment. Diagnostic tools have been linguistically translated with some reported success (unsuccessful translations are likely not published), yet cultural translations lag far behind. Biomedical descriptions of autism suggest universality,[4] but the behaviors comprising evidence for an autistic disorder are particularly susceptible to cultural influence. Subtleties in how a local community values behaviors such as eye contact, sociability, verbal development, and repetitive behaviors—behaviors frequently noted as hallmarks of autism in early childhood—can strongly influence how this condition is identified along with the application and evaluation of treatment efforts. This is especially true for those who have less conspicuous manifestations of autism, such as those who are identified as having Asperger's syndrome,[5] which primarily influences a person's social behaviors and understandings. These children, however, are not likely to be identified and labeled under the autism spectrum in cultural locations that have yet to begin to

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[4] There are currently no biological tests for autism. In other words, you can not use a gene array, blood test, or brain scan to detect autism.

[5] Asperger's Syndrome is no longer a valid diagnosis as it was subsumed in the DSM-5 by the larger category of "Autism Spectrum Disorder."

pathologize more subtle behavioral and social differences,[6] especially if these children are academically successful, as is often the case with Asperger's syndrome.

The study of how autism is situated in cultures around the world and how various cultures situate autism within their own communities allows for a wealth of practical and theoretical information about how local values and cultural structures influence a range of human differences; how the role of children in different societies impact the ways childhood success and failure is determined; and how the influence of contemporary biomedical constructs of deviance are being adapted within localities with more holistic or traditional approaches to education, health, family, and normality. As international efforts in health and education travel unidirectionally from the Global North (Western or developed nations) to the Global South (non-industrial or developing nations; Aginam, 2000; Bemme & D'souza, 2012), normalization and biomedically based practices and values are being exported on the backs of well-meaning teachers, physicians, and volunteers.[7] Meanwhile, evidence for the need to consider local culture when interacting with populations of differences is mounting.

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[6] While there are no specific statistics on the types of autism diagnoses being used around the world, research in areas new to the concept of autism that looks physician perceptions and understandings of autism show discrepancies in the understanding and application of the diagnosis. A lack of speciality clinics and the dissemination of accurate autism information has led to findings that physicians often confuse autism with schizophrenia or emotional disorders. This work has also shown that many of the children brought in to these physicians most often display externalized behaviors and aggression, which are more often associated with significant autism. Thus, it can be inferred that children with more subtle manifestations of autism, such as Asperger's or PDD-NOS are not diagnosed (Bakare, et al., 2009; Imran, et al., 2011; Kharti, et al., 2011).

[7] For example, see the Autism Speaks Global Autism Public Health Initiative at http://www.autismspeaks.org/science/research-initiatives/global-autism-public-health.

My Story: The Portuguese Gypsy Camp

I first realized the need to consider culture in autism related issues in 2004 while watching children dance in the middle of a Portuguese gypsy camp. It was the middle of June and, as a master's student in early childhood special education, I was participating in the TransAtlantic Consortium of Early Intervention. This program brought together graduate students and faculty members from a handful American and European universities to participate in courses related to special education and early intervention for children with disabilities. My institution, Vanderbilt University, hosted a class earlier that summer and in June a handful of my colleagues and I traveled to Porto, Portugal for a three week course on policies and practices of early intervention for children with disabilities at the Univdersidade do Porto.

Every day we wearily sat in an un-air conditioned classroom for several hours during a heat wave that stretched across the Iberian Peninsula. Each week, we looked forward to field trips as an opportunity to escape the stale inside air. The day before the trips, the options were listed on the chalkboard, each allowing a specific number of students to attend. The final week of the course there was an exciting new trip with only two coveted spots—a visit to a local gypsy camp to observe an early intervention session. The next morning, the lucky participants would go with the interventionist, herself a student in the class, for a few sessions with children with development disabilities who were living at the camp. Through a lottery system, I was luckily awarded one of the slots and the next morning found myself along with the interventionist and one other student headed on the Metro towards the coast.

We got off at one of the last stops and stepped into an affluent-looking neighborhood. The camp lay in the shadows of a large, economically diverse neighborhood. As we walked through the area, the buildings became noticeably more worn down. Finally, we came upon the camp; it was made up of a circle of about fifteen mobile homes and trailers that comprised the exterior wall of the community. The entrance was defined by a gap in the trailers, allowing residents to easily observe the comings and goings of each other and any visitors. There were some tents and other temporary housing structures scattered around, but it seemed most of the inhabitants lived in the trailers. The dirt-floored area at the center of the camp served as a common area and the end opposite the entrance held an outdoor bathing area consisting of a few scavenged tubs and hoses. The interventionist explained to us that morning that, not being in the habit of attending school, there were almost always several children at the camp. The mothers were gone during the day selling trinkets and other goods by the seaside. The fathers, often drunk, remained at the camp, sleeping or wandering the city but otherwise in charge during the days. She recognized that this was not an ideal situation, yet was pleased that this extremely private community was beginning to accept help from outsiders such as herself.

I was overwhelmed with the clutter and chaos of the camp. The homes were haphazardly built and children and men of all ages were milling around. I had hardly a minute to take quick purview of the area before a throng of small children came barreling towards us yelling out the interventionist’s name and asking her questions in rapid Portuguese. These children were happy, energetic, and clad in brightly colored but worn clothing. One child anxiously shouted from the open tub where she was being bathed, clearly upset to be missing the action. These kids looked forward to the visits by the interventionist but seemed not to know when she would arrive, leading to the element of happy surprise.

The interventionist greeted the kids and introduced the other visiting student and myself before attempting to single out the children for whom we made the visit. I still cannot remember the reason we were seeing these children and I am not even sure I left knowing which kids were receiving the services. All I knew is that we were supposed to observe a typical intervention with a few of the children. I was expecting to be brought into one of the homes with the target kids one at a time and get to work encouraging language and play skills while taking data on their progress. I quickly realized these expectations would not be fulfilled.

My first surprise was that the session occurred outside; the second was that it was to occur on a piece of old cardboard spread out to produce a makeshift floor in the shade of a tarp attached to a trailer. I hid my shock, not wanting to seem culturally insensitive to the obvious poverty, and waited for the interventionist to shoo the other children away. She laid out some toys and called a couple of children over but made no attempt to clear the area of child spectators. The rest of the children were excited to hang out, watch, participate, and enjoy the new materials and activities. It was clear that this visit was somewhat more chaotic than usual due to the exciting presence of two unknown foreign women, but the interventionist assured us that she had long ago stopped trying to keep the other children away; she allowed them to hang around and participate when possible. The complete privacy required for an uninterrupted session would have been an unrealistic goal. She had begun to use the other kids as much as she could as examples and social partners and hoped to teach them a little something along the way.

Eventually, we abandoned the original intent of the session and succumbed to the children’s request to have their pictures taken and dance for us. One of the older girls disappeared into a nearby trailer and placed a radio up to the window and began to play a Portuguese pop song. A handful of the other children ranging in age requisitioned the cardboard floor and began to dance. I looked around at the camp and tried to imagine how I would execute an intervention session here. All aspects of a session would be affected by the physical, social, historical, and cultural environment. Any interventionist would have to consider the clothes she wore, the materials she brought, who she spoke to and the ways she spoke to them. Given the gender roles described to me, you could forget about any male interventionist entering the camp. I was astounded at how I could have missed such critical, cultural aspects to early intervention and childhood disorders, including and especially my specialty, autism. When our time was up, we said our goodbyes and left the camp. It was only when we got to the Metro station that I realized we had not spoken to a single adult.

My time at the camp stuck with me throughout the remainder of my master’s program and into my travels the follow year. I had begun to realize the myriad ways a person’s culture, home environment, and background could influence interactions with children with disabilities and their families. I started to think about the ways services commonly used with autistic children, such as early intervention, were influenced by different cultural environments and the challenges cultural collisions could create. The next logical step was to start thinking about how these interactions could be improved and cultural adaptations made more efficient.

My lesson that day at the gypsy camp was that cultural background and home environment will influence the ways that services are delivered, goals are developed, and progress is determined. Through this experience, I learned that the goals of the sessions had to match the home environment—in this case, one of immense child freedom and little outward, daily organization. Arriving to that intervention session with data sheets and aspirations of quiet, focused interactions designed to build a child's vocabulary, work on proper pencil grip, or build appropriate play skills would result in frustration and disappointment, not to mention a push towards goals that were not appropriate or useful for this cultural group. The type of parental involvement I was used to seeing—with parents close by or in the session to observe the techniques used or requesting frequent meetings with the instructors to get an update on progress—was also not the way things happened in this camp. Parents are far from negligent (I was told that children are quite revered in gypsy culture), but there is more of an appreciation for childhood freedom and less of an emphasis on creating a retinue of normalizing skills early in a child's life. This difference needed to be respected.

The interventionist taught me that if you enter into another cultural group with inflexible expectations and strategies of your own cultural group you not only will fail at your task, and fail the children, but you are subtly expressing that you consider the traditions and values of the receiving community wrong, inferior, or even unhealthy. As I spent time abroad over the next few years, I began to wonder how to create an environment where cross-cultural autism-related work could be done more efficiently and without the dangers of alienation and dogmatism. Assuming the universality of autism-related concepts and structures in an international context where professionals from a resource-rich setting enter into a resource-poor fosters a relationship haunted by Foucauldian power structures. In this situation, the medical gaze[8] (Foucault, 1994) of the incoming professionals is turned upon the cultural group to examine and judge local practices and principles as they are filtered into understandings of and interactions with autistic people and community members with related intellectual and developmental disabilities.

Since that summer, I have observed and interacted with children on the autistic spectrum and their families in New Zealand, Thailand, Peru, and India as well as various minority and socioeconomic groups in the U.S. The more culture I encountered, the clearer it became that the word and concept of autism is spreading and colliding with cultural structures that may not accept the baggage that comes along with the label. The rising global recognition of autism is unstoppable, but perhaps that ways professionals structure this spread can be improved. This dissertation, therefore, aims to discover ways that cultural elements are most influential to autism-related issues and experiences and to think about how to use this information to improve future international work. Autistic people and their families are constantly encountering barriers to high qualities of life

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[8] The “medical gaze,” also called the “clinical gaze,” refers to the ways the medical establishment is able to look at a person’s body, physicality, and symptoms as completely separate from the person’s identity. Here I am suggesting that when outsiders enter into a new, and presumably less affluent, society with the intention of interacting with health- and illness-related structures, the concerns related to the particular issue, here it is autism, as completely separated from the community’s history and identity. (Foucault 1994, p. 94).

around the world. This work is also partly designed to educate professionals working in the area of global autism about factors that lead to disenfranchisement.

My experiences interacting with autism-related structures, families, and children around the world has also convinced me of the inevitability of ethical dilemmas and the importance of describing and discussing these events. Autism, childhood, family, resource availability, and cultural difference all have specific and sensitive issues related to them and so when combined, the issues are uniquely complicated. Failing to openly address personal experiences and choices in times when I felt morally challenged neglects a critical aspect to international autism and disability-related work. I find the lack of attention in ethical issues to be a disadvantage to the field and so, as mentioned above, I directly address these issues in this dissertation.

With these goals in mind, I use information and data collected in Atlanta, GA, USA and Kerala, India from caretakers of autistic children and the professionals who work with autistic children to develop a some guidelines for how to ensure appropriate interactions and collaborations for future international autism researchers, interventionists, and advocates. Atlanta was chosen as a research site because it is a good reflection of many Western values related to autism and because there are several autism-specific facilities from which I could recruit participates. Additionally, I had previous knowledge of and experiences with these facilities and the common practices and policies important to autism throughout the state. Kerala was chosen primarily because, like the rest of India, the notion of autism is just gaining in recognizability, yet the state's uniquely high level of Western educational and health care access provides insight into how areas with an increasing access to these services will begin to treat and understand autism. Chapter Two provides more details of each research site.

The guidelines developed from this research aim to equip others with the skills to enter into a new cultural environment, or interact with families from diverse cultures, and quickly assess how to best proceed with respect to the families, children, and wider community. This work also purposefully identifies sources of stigma for autistic children and their families as well as ethical challenges commonly encountered in cross-cultural autism work. In order to contextualize this work within the fields of medical anthropology, disability studies, global mental health, and bio- and neuroethics, the remainder of this chapter provides a description of the theoretical concepts employed in the analysis and conclusion of my research.

Multiple Influences: Culture, Mental Illness, and Autism

In the 1970s, the World Health Organization (WHO) began publishing the surprising results of their International Pilot Study of Schizophrenia (IPPS). Not only did the WHO find people with schizophrenia in Columbia, Czechoslovakia, Denmark, India, Nigeria, China, the Union of Soviet Socialist Republic, the United Kingdom, and the United States of America, but the data showed that people with schizophrenia in the less developed, industrialized areas had better prognoses in terms of relapses, psychotic episodes, and hospitalizations. This finding shocked the world of psychiatry by suggesting that modern techniques of managing and treating severe psychosis, including psychopharmaceutical interventions, were perhaps not the most effective (Sartorius et al., 1986). In the aftermath, this work garnered as much criticism as acclaim for methodological and theoretical failings, including being highlighted in Kleinman's work on 'categorical fallacies' (Kleinman, 1977). Kleinman explains that the WHO researchers were using a term native to Western culture (schizophrenia) that was developed to define a particular group of people. Using psychiatric terms outside the West, he says, leads to a categorical fallacy "because by definition it will find what is universal and it will systematically miss what does not fit in tight parameters" (p. 4).

This "most basic and certainly [most] crucial error" (p. 4) can be easily applied to most contemporary investigations of autism across cultures. However, identifying the presence and extent of categorical fallacies in relation to autism is profoundly difficult because the concept and definition of autism is largely reliant on Western psychiatric and developmental constructs. As will be described in the third chapter, the novelty of the diagnosis of autism in Kerala is leading to variable diagnostic applications. Some clinicians identify children as autistic who would not qualify for a diagnosis in an American clinic and other children who would certainly be diagnosed in America are instead labeled mentally retarded or understood to have only features of autism.

The WHO report, which was published in the midst of a disciplinary battle on methodological and analytical validity between psychiatry and anthropology that resulted in a dramatic drop in international investigations into mental illness,[9] showed that international investigations were not only important but feasible. This was increasingly

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[9] This will be explained in detail below, however refers to the dramatic drop in international investigations in the mid- and late-1900s that resulted from the primarily disciplines involved in this line of research—psychiatry, psychology, and anthropology—disagreeing on methodology, analysis, and validity (Bains, 2005; Miller, 1997).

true after the focus shifted from simply finding people with psychiatric differences in other cultures to studying the constructs and influences surrounding an ill person. Through this work, medical and psychiatric anthropologists and cross-cultural psychiatrists gained insight into the role of the family, doctor-patient relationships, the role of traditional healers, and the various ways people in a particular cultural environment express psychic distress (Nichter, 1981). In other words, the notion of complete universality of mental illness was complicated by considerations of a person's social, political, and personal worlds. Most of this work focuses on psychiatric illness, however is also relevant to people with intellectual and social differences, including autism.

ASD is perhaps more complicated because this diagnosis is unusually situated in the fields of psychiatry, psychology, education, and developmental disability. The continued presence of autism spectrum disorders in the DSM keeps the condition closely related to issues in psychiatry; literature in this field can easily be extended and applied to autism related issues. Similarly, educational and developmental literature is applicable to the diagnosis and the lives of people with autistic characteristics. The mutability of autism issues across disciplines is one reason why investigating the relationship between autism and culture is relevant to a wide range of professionals. It is also a reason why a multitude of social and cultural issues are critical to the lives and expressions of people who display the range of behaviors and traits associated with autism. These issues are interactive and dynamic, creating culturally specific experiences for the people diagnosed, their families, and the professionals interacting with them.

Although autism is a lifelong state of being and so autistic children grow up to become autistic adults, most research and attention, including the present project, focuses on autism in childhood and autistic children. However, given the wide range of affiliation with various disabilities described above and a relative lack of research about childhood psychiatric, cognitive, and physical differences in relation to cultural variation, this project will be filling a gap in both the disability literature and the psychiatric and anthropological literature. Adding the factor of childhood into conversations on global mental health increases the complexity of this work by necessitating considerations of the role of childhood, expectations of childhood development, sibling relationships, socialization, learning, and the role of the family.

These factors also influence the complexity of the ethical issues involved in research autism across cultures and so I have chosen to pay close attention to how ethics and morality entered into my work and how these experiences are generalizable to related work. After a discussion the use of research-related ethics in this dissertation, I will provide an overview of humanist geography, a field that looks at the relationship between people and the built environment, and its relationship to disability. This perspective will be used throughout the dissertation to demonstrate how future autism-related interventionists and researchers can use cues in the architecture, use of time, and behaviors observed in places where autism is found to better proceed in a new cultural environment.

Ethics, Morality, and Fieldwork

“The anthropologist is not immune” (Biehl, 2005, p. 97). This statement, from João Biehl’s 2005 ethnography, *Vita: Life in a Zone of Social Abandonment*, succinctly affirms the influence fieldwork can have on the qualitative researcher. This wonderfully written ethnography focuses on one subject, Catarina, and the political, medical, familial, and personal events that led to her being left in Vita, a home for abandoned people in Porto Alegre, Brazil. Biehl recounts his initial encounters with Catarina and her ‘dictionaries', which are more poetry than anything else, and how, over the course of several years, he visited Vita and traced Catarina’s past. In the process he reconnected her with her family and obtained an accurate diagnosis for her mysterious and misdiagnosed condition. Throughout the book, Biehl sporadically describes his personal reactions, motivations, and challenges in navigating the health and social systems of Brazil and encountering the sometimes horrific conditions of Vita and other institutions for the poor and ill. These reflections are necessary; it would be nearly impossible and completely ineffective to write this ethnography without some description of his personal investment.

Historically, anthropologists constructed ethnographies with an underlying sense of objectivity, facticity, and actual truths. In the wake of feminist and reflexive ethnography in the 1970s and 1980s, which began questioning this approach and rejecting the inherent colonialism of early ethnography, scholars have begun to account for themselves in and their influence on the ethnographic field (Abu-Lahgod, 1990; Lawless, 1992; Mahmood, 2003). This self-reflection occasionally enters into discussions on the ethical and moral dilemmas inherently scattered throughout one’s time of immersion in another culture. Works such as Anne Fadiman's *The Spirit Catches You and You Fall Down* (1997),[10] Roy R. Grinker's *Unstrange Minds: Remapping the World of Autism*, Tanya Luhrmann's *Of Two Minds: The Growing Disorder of American Psychiatry* (2000), Jason Throop's *Suffering and Sentiment: Exploring the Vicissitudes of Experience and Pain in Yap* (2010), Jarrett Zigon's *HIV Is God's Blessing: Rehabilitating Morality in Neoliberal Russia* (2010), the various works of Arthur Kleinman (1980, 1986, 1988a, 1988b), and João Bielh's *Vita* (2005) all explore cultural issues of health, illness, and disability. All include some references to ethical and moral issues the author encounters in the research process. While these works are engaging, they are often presented in passing; in-depth analyses of the meaning and implications of these events and feelings are rare, though incredibly informative.

The 2007 WHO Special Report on ethical challenges in health research in low and middle income areas, or "resource-poor settings," emphasizes the importance of training researchers on ethical practices and providing practical advice on following ethical guidelines (Marshall, 2007). This is particularly critical as relationships across national borders are easier to forge and maintain with travel and communication technologies. These relationships have a built-in power imbalance between the incoming, presumably richer, research team and the noticeably poorer, in-country partner and informants (Marshall & Batten, 2004). When looking at autism, this power imbalance is even more prominent as autism information is scant in other countries (and confusing in the West). This knowledge imbalance has serious implications for those that participate in research,

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[10] This is the only work not written and published by an anthropologist, however it is a highly ethnographic work.

especially in regards to how researchers react to this level of authority (Daley et al., 2013). As Arthur Kleinman has suggested, ethnographic methods and approaches could be a mode through which the practical implications of the moral issues and power dynamics researchers encounter are accounted for in future research (Kleinman, 1998).

Issues related to research ethics in anthropology were spotlighted during the ongoing Yanomami controversy. This began in 2000 when journalist Patrick Tierney accused anthropologist Napoleon Chagnon and geneticist James Neel of unethical practices in their collaborative research with the Yanomami tribe of Brazil and Venezuela during the 1970s and 1980s. Among the many accusations, Tierney accused the two of exacerbating a measles outbreak and Chignon of misrepresenting the ferocity of the tribe by provoking wars among the various Yanomami sects and outside tribes. In the aftermath of these accusations and the ensuing investigation, ethical investigations by individuals and the Anthropological Association of America (AAA) led to updated ethics codes and brought discussions of research ethics to the fore (Borofsky, Albert, Hames, & Martins, 2005; Tierney, 2002).

As this event demonstrated, ethics are critical to qualitative research yet often overlooked. This is likely because ethics are inherently complicated, yet they remain critical to social order and are complimentary to morals. Morals are well defined rules and guidelines on how to act; morality is action. Alternatively, ethics are the abstract principles guiding moral action (Kleinman, 1998; Zigon, 2010). In his 2010 book, *‘HIV is God’s Blessing’: Rehabilitating Morality in Neoliberal Russia*, Jarrett Zigon describes three types of morality. Institutional morals are guides for how to publicly interact with various institutions, such as those set out in religious institutions. Public discourse morals are those stated in the public realm that are not directly associated with any institution; for example, the way we talking about lying. Lastly, embodied morals are nonconscious, unreflective moral acts that are our everyday ways of being in the world that allow us to navigate our social worlds. Ethics, on the other hand, are more conscious reflections on how to be more morally appropriate for yourself and for others. These acts are more complex, reflexive, and ambiguous and are best discussed through cases studies. Their complicated nature makes storytelling the most ideal venue through which to discuss ethical issues.

Zigon's delineation between morals and ethics is not the only way in which philosophers and scholars have discussed morality and ethic.[11] Even so, his and Arthur Kleinman's focus on the complexity and ambiguity of ethics, have greater affinities with the way ethics is used in this work. In the second half of the conclusion, I will discuss the ethics of studying autism across cultures using stories of challenges I encountered in the field. In particular, I will use instances in which I navigated my roles as an observer, an expert, and an advocate to explore uncertainties of when to give advice and help to those encountered in the field. I will also talk about when my own beliefs about the privacy of health care and the sanctity of pain were challenged to discuss how to put one's own cultural assumptions beside another's. Finally, I will use questionable events, ones that, without context, could be considered inhumane, to work towards the idea that humanness is granted on a gradient that relies on cultural tools, histories, and resources.

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[11] For example, philosophers have historically described morals variously as more or less personal or universal and definite or fluid (Gert, 2012).

Spaces and Places and Disability

"…given the primacy of embodied perception, we always find ourselves in places. We are, in short, placelings" (Escobar, 2001, p. 143).

According to anthropologist Arturo Escobar (2001), the recent globalization "craze" has led to a drop in consideration of specific communities, localities, and places. This shift away from considering the local as different from the incoming global, he argues, has diminished or halted our knowledge about and understandings of culture, economy, and epistemology (p. 141). Cultural difference is now assumed to be increasingly diffuse, spread out along the flow of media and commodities. Beginning in the 1980s, this spread meant communities began to be "deterritorialzied" (p. 146) as cultural lines and boundaries started to fade. This global shift, however, does not mean that looking at specific localities as unique and culturally distinct is a useless project (Escobar, 2001). Social change and the influence of merging cultures means differences between societies can be explored through global connections (Gupta & Ferguson, 1992). There is an increasing "global sense of place" (Escobar, 2001, p. 147) that makes movement and blurred boundaries new places to find cultural uniqueness and influence.

Globalization also does not mean that all localities are becoming homogenized. The Global South does not simply accept the ideas, customs, commodities, and ways of life coming in from the Global North and put them into practice (or *vic versa*). Instead, as Escobar (2001) explains, there is a process of "cultural hybridization" that he defines as the ways and degree to which communities actively shape and utilize outside information and practices alongside and in collaboration with existing structures (p. 155). Localities have networks of power, mores, practices, and structures that continue to exist even in the presence of mass global processes (Escobar, 2001). In other words, globalized ideas and acts, rather than be passively accepted, are encountered then customized to fit within existing cultural structures. In part, this dissertation is an effort to improve the understanding of a global recognition of autism, including the ways autism and related concepts have been received, understood, and adapted in disparate cultural structures.

This process of active adaption and accommodation of globalized ideas is especially noticeable in the use and application of Western psychiatric processes. Almost all psychiatric diagnoses are syndromes, which are conditions defined by a set of characteristics that all diagnosed individuals may or may not exhibit. In contrast to a diseases, which have well-defined symptomatology and known causes, syndromes allow subjectivity into the diagnostic process. Clinicians often rely on their professional judgment leading to occasional contradiction in diagnostic definition and application. This is certainly the case in autism, where diagnosis has not only change through time but also across clinicians. When the concept of autism enters into another culture, it is highly susceptible to alteration by local professionals to ensure the concept and label fits within a new environment. For example, in places like Kerala, where subtle differences in social interaction may not be as frequently pathologized, adopting the diagnosis to apply primarily to children who have very physical and somewhat disruptive behavior may be most useful.

Beyond cultural norms, the adaption of globalized concepts is closely tied to societal structures that are constructed in place and space. In a 1979 chapter, “Space and

Place: Humanistic Perspective," philosopher and geography Yi-Fu Tuan explored the concepts of space and place and generated definitions of each, which I utilize in this work. Space, he explains, is closely tied to experience and the senses. It is related to the conceptual ways humans interact with and understand the natural and physical world. Depending on one's approach (e.g., geography versus philosophy) it can be tied to geometric rules or be conceptually boundless and ephemeral. Regardless, space is intangible. It is also reactive to cultural difference, and so can vary between cultural sites. Because of this, space gives us cues as to how we are to behave and, in a sense, who we are.

Place, on the other hand, is more tangible and apparent. Tuan says: "All places are small worlds" (p. 421). In his definition, a locality cannot be a place unless there is some memory associated with it; places have a temporal, as well as a tangible, requirement. He goes on to describe two kinds of places: public symbols and fields of care. The former are "places that yield their meaning to the eye," "have high imageability," and "command attention." The latter, on the other hand, are places "that are known only after prolonged experience," "do not seek to project an image to outsiders," and often "evoke affection" (p. 412). Many of the places of autism I will discuss in the chapter, particularly homes, are both public symbols and fields of care.

This distinction between space as abstract and diffuse and place as concrete and local is discussed in other texts of social geography (Escobar, 2001; Gupta & Ferguson, 1992). Place helps to construct the experiences of space, which in turns informs the structure of place (Escobar, 2001; Tuan, 1979). Both are sites that inform humans how to act and impart values that Bourdieu would categorize as part of one's "*habitus"*[12] (Bourdieu, 1998, p. 77). Space and place are critical to the avenue through which one's *habitus* imparts message about, for instance, normality and the body (Scully, 2008; Edwards & Imrie, 2003). Thus, throughout the dissertation, I look at how the places of autism are influenced by and reflective of particular cultural and social values related to autism and the messages inherent in these structures. Each chapter includes a detailed description of the physical and temporal aspects of the place of autism (the clinic, the home, and the school) and a consideration of how cultural factors are embedded in and expressed through these places.

The physicality and meaning of places are constructed from cultural practices and social structures, which in turn means that culture has particular "emplacements" (Escobar, 2001, p. 143) that allow people in those places to understand how certain acts, events, people, and objects are considered and valued. For disability, especially in America and similar cultures, this often means certain places convey a sense of inadequacy, of disablement. Schools, clinics, and many homes are constructed around rehabilitative or adaptive needs, the presence of which communicate that disabled bodies and minds are unacceptable (Gleeson, 1999; Snyder & Mitchell, 2006). Further, within the space of science, research is built upon a notion of disability as socially and culturally unacceptable. When research into physical, intellectual, and psychiatric differences

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[12] Bourdieu describes the "*habitus*" as the underlying systems of, "cognitive and motivating structures" (p. 77) that are developed from a history of individual and collective actions which are observed and internalized by community members then re-demonstrated back into the habitus, after being filtered through individual experience.

begins with this premise, its findings can only reaffirm and reveal the unwantedness of differences (Snyder & Mitchell, 2006).

In reference to the social construction of autism, Ian Hacking (2000) goes as far to as to suggest that autistic differences influences the places in which autism is found. Places are saturated with emotions and judgements about autistic traits that are expressed through behaviors, reactions to behaviors, materials, evaluations, et cetera. These behaviors and evaluations in turn loop back and influences the parents, therapists, psychiatrists, and children themselves. Their behaviors towards (or expressions of) autism as well as the values placed on autistic differences are greatly influenced by the places in which autism is found. Hacking argues that autism is not simply situated and created by genetic and neurological differences, but is also socially constructed by environments (Hacking, 2000). This is why the sites in which autism is positioned are critical places to explore and understand.

Similarly, geographers Chouinard, Hall, & Wilton (2010) claim that disability is embodied but impairment is social. In other words, differences, or impairments, become attached to a value, usually a negative value. These values are communicated to the impaired person and those surrounding this person through the places and spaces associated with impairment, from hospitals and special education rooms to poverty and unemployment. These connotations of impairment are disabling for the impaired person, turning impairment into disability as an embodied experience. As we will see, both Atlanta and Kerala are locations in which the behaviors and characteristics associated with significant childhood autism are usually deemed inadequate and unwanted. These understandings generate the creation of segregated locations and structures for health care (e.g., special dentists' offices, developmental pediatricians, doctors familiar with autism, traditional healers) and educational placements (e.g., special education rooms or schools; the presence of a paraprofessional in a child’s classroom) and homes where time, schedules, and relationships convey the differentness of autism. However, when one begins to look at the rehabilitative options, claims of cures, and consequent understanding of the permanence or impermanence of a child’s current autistic behaviors, the structures and acts within places of autism change. Diagnostic practices vary in focus, specificity, and intensity; educational materials, time, and goals are altered; household schedules and caregiving efforts are impacted.

Instead of looking at spaces of autism as sites that disable individuals—as in traditional texts looking at geography of disability—here, I want to look at place more objectively. This does not mean that I reject the notion that particular places of autism are imbued with a culturally sanctioned repudiation of the behaviors and characteristics associated with autism, such as non-verbal communication styles, public repetitive and unusual behaviors, or levels of independence that seem to warrant full dependence. Rather I am beginning with the understanding that places of autism communicate these values along with more specific, culturally nuanced values that are respondent to local and individual traits and to socioeconomic factors such as access to information and urbanicity. I am looking at the application and enactment of this premise. I want to understand the realities of these spaces and places in order to enable deeper understandings of how autism influences environments and how these environments influence experiences of autism. I want this understanding to encourage future work to proceed with an awareness that looking at specific structures, behaviors, and materials provide rich information about the values of autism and difference.

A Preview of the Chapters

After a chapter dedicated to describing the importance of a cross-cultural approach and specific information about the research sites and methodology, the remainder of this dissertation focuses on detailed analyses of the places in which autism is found. Specifically, I focus on the clinic, the home, and the schools. Although autistic people are occasionally found in public, this is not a regularly considered place of autism because autistic people and their families often find it difficult to spend time in public. Unfortunately, communities in both Atlanta and Kerala are unprepared and, perhaps, unmotivated to accommodate and fully integrate autistic individuals. Working towards full acceptance and integration in communities is a common goal among advocates, parents, and professionals. There is much work to be done. Here, however, we focus on these three common places of autism to more fully understand how autism is considered and treated in particular microcosms within variable cultural structures. The first half of each chapter provides a detailed analysis of the physical structures of each place of autism in each research site. The second half of the chapter utilizes the qualitative data collected to describe important elements of experiences of autism related to that particular place.

The clinic.

This chapter provides several clinic descriptions. Included are detailed descriptions of the temporal and architectural elements of the traditional healer’s clinic, the Āyurvedic clinic, and the Western-style clinic in Kerala followed by descriptions of the diagnostic clinic and the therapeutic clinic in Atlanta. The analysis focuses on the ways the use of time and the physical barriers between patents and providers shape the types of interactions within the clinic and the level of sociality. Specifically, elements of Western-style clinics communicate to patients and professionals that these are places of authority where sociality is not encouraged.

This chapter goes on to describe and compare the diagnostic journeys of families and professionals in each research site. In particular, I analyze the relationships between urbanicity and socioeconomic class and the number of clinics a family must visit before obtaining a diagnosis for a child. I then discuss the particular diagnostic practices that are used within each site. I propose that the different diagnostic practices influence the population of autistic individuals identified in each area. This information is important for researchers or interventionists to consider when exploring autism or developmental disabilities in international contexts.

The home.

For this chapter, I provide descriptions of a typical family home in Kerala and in Atlanta. As is the case with all descriptions, these are developed from composites from the many homes I visited during fieldwork and, in the case of Atlanta, previous experiences working in the field of autism.[13] With these descriptions, I propose the presence of two types of homes: therapeutic homes and custodial homes. Custodial homes are characterized by a dedication to care for the basic needs of an autistic child while therapeutic homes are dedicated to changing the autistic traits of a diagnosed child. This designation is determined based on amount of autism- and child-related materials in the home, the schedule of the home, and the daily activities of the home.

Next, I describe how the therapeutic choices in each area, which are significantly fewer in Kerala, lead to differences in the way caretakers describe and discuss their child's differences. Relatedly, I explore the composition of caretaker explanatory models and the ways these are shaped by experiences of stigma. Interestingly, the high access of Western-style medical care in Kerala, in comparison to the rest of India, means that caretakers rely on more biologically-influenced explanatory models[14] than spiritually based ones. This information is closely related to parental acceptance of a child's autistic characteristics, which is important to understand when interacting with families of autistic children in different cultures.

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[13] Aside from the description of the traditional healer's clinic, of which I only visited one, all descriptions of places are composites. This was done to ensure that a generalizable set of analyses about the roles of achitectural and temporal structures of places of autism was generated. It also ensured I maintained the anomynity of my informants. In other words, rich descriptions of specific homes, schools, or clinics may have provided private details and irrelevant to other researchers. Thus, I chose features of these places that were common and important to consider when entering a new place of autism. This method is not unique, it is used in anthropology for the very reasons I listed: to ensure privace, allow a focus on shared characteristics, and also to condense a wealth of data into an easy, digestable format (Murchison, 2010).

[14] Explanatory models will be discussed more fully in the following chapter but, briefly, are the ways people explain the cause of an illness and the meaning of that illness in their lives, including why they contracted the illness.

The school.

In this chapter, I describe how the physical and geographic locations of the places autistic children are educated facilitate the segregation of autistic children. Despite this similarity between research sites, there is a difference in the intent of the daily activities at these schools. Much like the section on homes, schools can be separated into those that serve a custodial purpose, with little advancement in academic skills, and those that work towards normalization of autistic characteristics.

The remainder of the chapter explores the sources of educational stigma in education policy and teaching training practices. An analysis of No Child Left Behind (NCLB) and the Individuals with Disabilities Education Act (IDEA), the two most critical American policies for the education of students with disabilities, points to systemic processes of disability stigma that are pervasive throughout the country and felt by my Atlantan informants. Then, a look at Indian and Keralan education policy demonstrates a difficultly in the application of resources for students with significant impairments. Part of the difficulty is related to teacher training practices, which focus heavily on non-cognitive impairments.

This dissertation concludes with a set of practical guidelines for future international researchers, advocates, and interventions. These guidelines, which include how and why to ‘read’ places of autism, are applicable to and useful for research on other intellectual, developmental, and psychiatric impairments in childhood. Following these guidelines, I describe some of the ethical dilemmas I encountered in the field in order to add to and hopefully progress the discussion of how to generate ethical practices in cross-cultural research on issues related to the brain and disability. In the words of Clifford Geertz: “Even a glancing examination of a few fragments of my own experience offers some leads in this direction […] Discussing them as such, as aspects of a métier, will not put an end to dispute, but it may help to make it profitable.” (2000, p. 38).

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Chapter 2: Methodological Background and Approaches

Introduction

The re-emergence of biological psychiatry in the second half of the twentieth century, called the Second Biological Psychiatry, focused heavily on genetic and neurological research (Shorter, 1997) and re-invigorated beliefs in the universalism to psychiatric conditions. The assumption that psychiatric conditions were primarily the result of neurological, biological, and genetic anomalies that occurred similarly across the human population led to the internationalization of nosological tools such as the DSM and the ICD-9 (Grinker, 2010). Many anthropologists and cultural psychiatrists, however, challenge this assumption and the ability for these tools to travel across cultural borders. For example, in 1999, psychiatrist Leon Eisenberg and his colleagues stated: “Psychiatric diagnosis and classification cannot be decontextualised [*sic*], and neither ICD-10 nor DSM-IV is entirely free of theoretical assumptions and underlying ideological beliefs” (p. 52). This is perhaps especially true for ASD, for which the diagnostic criteria regularly changes and are based on relational, social factors. Despite research showing that psychiatric differences vary in expression and definition around the world and over time,[15] these tools overtly support the use of Western-based mental health diagnoses and treatment approaches around the globe.

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[15] For example, see: Arthur Kleinman, *Rethinking Psychiatry: From Cultural Category to Personal Experience*, (New York: Free Press, 1988) 143-4.; Arthur Kleinman, *Illness Narratives: Suffering, Healing, and the Human Condition*, (New York: Basic Books, 1989)*;* João Biehl, Byron Good, & Arthur Kleinman, *Subjectivity: Ethnographic Investigations*, (Berkley: University of California Press, 2007); Eisenberg et al., *Promoting Mental Health*; Cecil Helman, *Culture, Health, and Illness, 4th Edition*, (Oxford: Butterworth Heinemann, 2000), “Chapter 10: Cross-cultural psychiatry”.; Roland Littlewood, *Pathologies of the West: An Anthropology of Mental Illness in Europe and America*, (London: Continuum, 2002).

Cross-cultural and culturally comparative research in mental illness has, however, fallen in popularity in recent decades (Miller, 1997). This is largely due to conceptual, cross-disciplinary battles between anthropology and psychiatry and psychology and the consequent methodological difficulties. Conceptually, anthropologists see mental illnesses as largely responsive to social and cultural factors, perhaps best exemplified through the concept of idioms of distress. This term came out of anthropologist Mark Nichter's analytical approach to analyzing illness in South India. He argues for "an assessment of patients' social relational and economic, as well as 'cultural,' context and adaptive/maladaptive strategies for coping within these nested contexts" (2010, p. 402).

Psychiatry, on the other hand, views mental illnesses and diagnoses as factual entities that are identifiable with careful assessment and analysis. For example, the National Alliance on Mental Illness defines mental illness as "a medical condition that disrupts a person's thinking, feeling, mood, ability to related to others and daily functioning. Just as diabetes is a disorder of the pancreas, mental illnesses are medical conditions that often result in a diminished capacity for coping with the ordinary demands of life" (National Alliance on Mental Illness, 2013). Where anthropology understands the powerful role of culture on psychic distress and the ways mental illness is understood, defined, identified, and treated, psychiatry universalizes mental illness, often ignoring the ways an individual's cultural environment can shape how mental distress is expressed, responded to, and explained. These differences lead to contrastive approaches to studying and understanding at mental illness around the world.

The main methodological problem is one of interpretive validity: psychiatrists do not accept ethnographic methods, citing low standardization and a heavy emphasis on local ontologies as a complicating factor. Anthropologists do not accept diagnostic and assessment tools for mental health that have not been culturally validated. While one field aims to discover and use widespread treatments and definitions for mental health and illness, the other aims to discover how cultural nuance influences the ways mental health and distress are developed and expressed. Differences about methodological validity and overall goals of the field make cross-cultural investigations in mental illness and intellectual disability a contentious and divisive practice (Bains, 2005; Miller, 1997). However, the globalization of psychiatry alongside a growing awareness of the importance of cultural background for mental health is forcing these fields into a more fluid and cordial discussion.

Research from scholars such as Arthur Kleinman (1988b), Horacio Fábrage (1973), and Laurence Kirmayer (2001) promotes the importance of culturally comparative work in mental illness and has brought scholarly awareness to the need to understand the role of culture in global mental health. Methodology continues to be challenging and many questions remain. How does a researcher discover comparable states of mind within vastly differing nosological systems? Does the expression of a set of behaviors across cultures actually mean similar pathology? Can differing interpretations of normality be considered without particularizing local expressions of psychological distress to the extent that a valid comparison is impossible? Understanding ASD as a conceptual category that, although neurologically situated, is largely reliant on cultural factors such as notions of child development, definitions of abnormality, and social-interaction norms, I considered these and other issues when developing my research methods. Some of these difficulties were addressed by looking at particular behavioral profiles rather than specific diagnostic labels and focusing on identifying local ideologies and vernaculars to discuss and think about mental health and illness.

Questions such as these continue to plague the field. Yet philosophical discussions surrounding method, the appropriate application of theory, and the ethics of international research fail to overcome the benefits of international comparisons of mental illness. Looking at instances of psychological of distress that are comparable on either behavioral expression or etiological factors can bring these issues to the attention of public and private efforts related to global mental health. Because mental health issues are rapidly becoming the most pressing global health issue (Patel, 2010), this research needs to proceed regardless of disciplinary differences.

By understanding the similarities and differences of local psychiatric illnesses, research and intervention efforts can proceed with a fuller understanding of specific needs and cultural influences on the expression and contraction of mental illness. This goes beyond thinking about how culture influences mental health issues to using the outcomes of this research to help improve the quality of life for those associated with mental illnesses. For example, psychologists Suzanne King’s and Mike Dixon’s research on outcomes of schizophrenia found that differences in regression rates across cultures are associated with the levels of stress and attention expressed towards a person with mental illness experiencing psychosis. Their work suggests that families of people with schizophrenia in Western countries, where regression rates are higher, respond to psychotic episodes with treatments, hospitalizations, and hunts for environmental triggers. Families in many non-Western locations, on the other hand, often respond by providing more personal space and fewer demands on the ill person. In other words, heightened levels of expressed emotion (EE), or intense emotion expressed by those in the immediate social world of an ill community member, though expressed out of concern and care, may exacerbate a person's schizophrenia (King & Dixon, 1995; 1999).[16] This work clarifies some social factors involved in outcomes for people with schizophrenia and can be used to help customize and drive intervention efforts in various cultural regions.

Attending to the ways individuals, families, and entire communities interact with and rely on healthcare resources, to healing preferences, and to definitions of personhood and normality helps scholars and healthcare professionals think about how mental illness develops and progresses. Helping professionals obtain such information about (and around) ASD is the overall purpose of the dissertation. This information can also be used to discover more efficient avenues to increase the quality of life for people who express psychiatric distress and for their families. The emerging field of global mental health demands this work. International comparisons can vastly improve international efforts for conditions like autism, which has been neglected in both research and policy efforts. The 2001 World Health Organization (WHO) report on mental health, which claims to be "a

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[16] Expressed emotion has also been extensively studied by Janis Hunter Jenkins (1991, 1992) and scholars such as Byron Good (1990, 1997) and Arthur Kleinman (1980, 1988) argue that both the individual and their families have culturally specific ways of responding to mental illnesses, which impact the expression and course of the illness.

comprehensive review of what is known about the current and future burden of [mental] disorders," (p. 10) contains the word autism only twice: once in a pop-out box listing some of the mental and behavioral disorders of the ICD-10 (p. 36) and once in a parenthetical example of a pervasive developmental disorder, again as a reference to what the ICD-10 includes as disorders in childhood and adolescence (p. 50). Since then, autism has become more of a concern for the WHO; it developed a resolution on "Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders" in 2013.[17]

The historic lack of attention to autism in global mental health is likely due to several factors. It is associated, for example, with childhood, a stage that is neglected in international mental health literature. The 2001 WHO report mentions childhood frequently, however it is mentioned almost exclusively in reference to families or to lifelong conditions with childhood onset, like epilepsy. Its authors actually note this problem, stating: "Inadequate attention is paid to this area of mental health" (p. 50). While autism is not a mental illness, it is present in the DSM. Though generally considered to be a disorder of cognition, intellect, or 'mind', the precise way autism is and is not related to psychiatry is ambiguous. Like psychiatric disorders, autism is diagnosed by observable behaviors and information from close family members. This means that autism is susceptible to many of the pitfalls of cross-cultural comparison, including personal interpretations of behavior and local definitions of behavioral

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[17] A summary of this resolution can be found on the WHO website at http://www.who.int/mental_health/action_plan_2013/eb_resolution_childhood/en/index.html.

deviance. Autism-related research is thus particularly prone to be neglected by but also to benefit from international comparisons.

Most autism research and literature to date has been conducted within (and reflects) Western ideals of independence, autonomy, productivity, and biomedicine. A large majority of the world's autistic population remains unconsidered. It has been established that the constellation of traits and behaviors called autism in the West occurs in all global regions (Grinker, 2008; Feinstein, 2010). Research on autism across cultures can produce information about both the condition and the culture surrounding it. For example, international autism research might discern which traits are most salient and which may be a response to cultural shaping, how a family's cultural background influences assessments of which trait is most concerning. And it might lead to more specific and culturally acceptable treatment approaches. We can also learn more about variations in how children are socialized, the ways local communities identify behavioral and psychiatric differences, pathways of deciding amongst treatment options, and how family function is affected by chronic childhood disability. As Daley notes, if autism and its related traits are largely universal, then "similar symptomotology would allow for a purer comparison of the contextual factors of the disorder by holding 'differentness' constant" (2002, p. 537).

These important issues are among the reasons I chose to embark on a comparison of experiences of adult (i.e., caretaker and professional) experiences of autism in Atlanta, GA, USA and Kerala, India. I interacted with the adults associated with diagnosed children because (1) comparing experiences of autistic children (or adults) is nearly impossible given intra-autistic variations in communication methods and (2) future international autism-related work is more likely to interact with caretakers and local professionals rather than directly with diagnosed children. While I firmly I believe in the importance of working directly with identified children and adults, I also understand that more information is needed about how to access this population around the world through the critical professionals and families who, in many instances, are in the best position to improve the lives of autistic individuals.

Therefore, this project compares the ways caretakers of autistic children and the professionals who work with them understand, identify, and approach autism. In order to evaluate the exact impact of particular cultural factors on how autism and autistic traits are experienced, the crucial cultural factors to be examined must be put under a comparative lens. These particular cultural sites were chosen to discover which aspects of a person's local environment are most instrumental to how autism is experienced and to discern the paths of influence these factors follow. Below is a detailed description of each research site.

Research Sites

Kerala, India.

Located along the Arabian Sea and into the Western Ghats, Kerala is the most Southwestern state within India. Touted as "God's Own Country" by the local tourism department and marketed for the beautiful beaches and backwater river tours, Kerala is comprised of 14 districts with the city of Trivandrum, also known as Thiruvananthapuram, serving as the capital. Despite its small size—only 39,000 square kilometers (Franke & Chasin, 1991) or roughly the size of Montana—Kerala has an overwhelmingly large population, with just over 30 million citizens (Parayil, 2000), which is comparable to the population density of Boston. The state's astounding population is only overshadowed by its most unique feature: a democratically elected communist government. First elected in 1957, shortly after the formation of the state, it was briefly dismissed by the Indian government in 1959, only to be reinstated in 1967 (Franke & Chasin, 1991; Heller, 2000).

The Kerala Model, the Kerala Paradox.

Even in its nascence, Kerala's government was dedicated to enacting a series of social and economic reforms aimed at reducing inequalities, most of which began as grassroots efforts within local communities. The result, known as the "Kerala Model of Development," has garnered the attention of development scholars; the state achieved high indicators of social development without a precursory rise in per capita income (Parayil, 2000). Kerala has the highest life expectancy (74 years), highest literacy rate (90.92%), lowest infant mortality (15.3 deaths per 1,000 live births; Kumar, 2011), and lowest birth rate (14.7 per 1,000; Nair, 2010) in the entire country of India. These development indicators, however, are countered by poverty and related social difficulties. Kerala has a high suicide rate (10.1% of all suicides in India), is ranked highest in alcohol consumption per capita, and is seventh-highest in reported incidences of violence to women in India. These discrepancies create what is known as the "Kerala Paradox" (Nair, 2010, p. 405). Thus, the Kerala Model of Development has gained significant quality of life improvements without an overall increase in personal wealth or alleviating some serious social ills (Franke & Chasin, 1995). The uniqueness of this model generates a culturally and socially unique location within which to study experiences of health, illness, disability, childhood, and normality.

Kerala's impressive health care and educational indicators were produced through reforms in food via ration shops for fair prices, advances in the public health sector, public education with a focus on literacy, land-to-tiller land reforms, and an early assault on the caste[18] system that placed untouchables—a low caste and highly stigmatized group—into political positions. Development scholars have suggested that the success of Kerala's reforms are the result of three primary factors: ecology, history, and workers' movements. People are evenly distributed across the state, ensuring access to resources for all citizens. An historical trading center, Kerala has been a continuous site of international interactions, yet has maintained low levels of violence with outsiders for millennia. Finally, hired plantation workers in Kerala felt more confident creating a worker's conscious movement against British bosses than workers elsewhere, who were controlled by priests, higher caste employers, or landlords who could implement serious social and economic sanctions (Franke & Chasin, 1991).

Most of the advancements gained through the Kerala Model began as strong grassroots movements. It is this "human factor" (Franke & Chasin, 1991, p. 26) that has persisted over time and created an ethos of community and of individual dedication to enacting the changes one desires for that community. Kerala meets the needs of its people

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[18] Castes in India are groups into which a person is born into based on one's family. Historically, they defined the jobs one could hold, places one could travel, and who one could marry. They also define one's place in a community's social hierarchy. Even though India has made efforts to eliminate caste discrimination, it continues to have a strong influence on the lives of Indian families and individuals. As mentioned here, Kerala was one of the first states to make attempts to eliminate caste distinctions, however my time in Kerala proved that caste is still an important social factor that can strongly influence access to resources and social status.

by providing access to medical care and education, but does so without altering persistent poverty. As the current project demonstrates, this access influences the ways persons with disabilities, including autism, are identified, treated, and understood.

Education.

Since the early 1800s, education has been a primary emphasis throughout Kerala. Both missionaries and local governments built schools for all children to attend, not just those of higher caste families. In 1860, Kerala was the first state to make educating girls a priority, and in the early 1900s the state began formally educating lower caste children. At this time, popular people's movements pushed to extend the right to literacy to all citizens. While there is a persistent tension between private and public schools, grassroots movements have ensured that all children have access to education. Kerala's historic emphasis on education for all children was only recently paralleled throughout the country with the passage of The Right of Children to Free and Compulsory Education Act of 2009. This act ensures free and appropriate education for all children ages 6 to 14, including those with disabilities (Government of India, 2009). Kerala's educationally focused atmosphere, in combination with early missionary education work, fortified a social commitment to education for all children, with little regard to caste, gender (Dilip, 2010; Franke & Chasin, 1991), or, perhaps, disability.

While the high literacy rates are one of the government's finest achievements, my experience was that schooling efforts are not always altered based on the presence of a disability. Children who attend the public schools instead of the many private, English-medium schools (i.e., schools that use the English language) are all educated together with little to no attention to learning differences. As will be discussed more fully in the fifth chapter on schools, teacher textbooks and training included scant information on childhood disability, suggesting there is little instruction for working with these children. Many parents do not send children with differences to public schools due to fears of familial shame and stigma or because educational or medical professionals instructed them to send their child to a 'special school.' Often, facilities that cater to children with disabilities, especially those with cognitive or intellectual differences, were created and run by religious organizations, mothers, or educators who saw a need for a more specialized learning environment for this population.

Medical and healing clinics.

Another main achievement of the Kerala Model is a pervasive presence of medical and healing clinics and hospitals throughout the state. All villages are within five kilometers of a hospital or clinic, the highest per capita concentration in India (Franke & Chasin, 1991). These facilities are easily accessible and regularly frequented by Keralans. The state also has the most extensive array for hospitals, doctors, and beds per person and, thus, the highest health-related service utilization of the country (Franke & Chasin, 1991; 1995). Western-style facilities exist alongside numerous Āyurvedic facilities, including the Government Āyurvedic College in Thriuvananthapuram. As seen in Fluekiger's (2006) description of pluralistic healing practices in Hyderabad, Andar Pradesh, traditional healing and biomedicine often coexist collaboratively in India. This is also the case in Kerala, and the relevance of Āyurveda to help-seeking among families in Kerala in particular is important for the current project: it is a well-respected approach, and its concepts and practices are often considered alongside Western medical practices.

Although professionals from both healing traditions (especially in the urban area) are aware of the diagnostic label of autism, they define and apply it somewhat unevenly. Rural children rarely obtain an autism diagnosis; rural children with autistic characteristics tend to be diagnosed with ‘mental retardation’ by Western professionals, or with a specific constitutional imbalance by Āyurveda professionals.

A healing tradition dating before 1500 BCE, Āyurveda relies on holistic assessments the body, spirit, and mind referring to how all aspects are affected for diagnosis and treatment of disease. Disease and illness are seen as imbalances of the body’s three *doshas*, or constitutions—the *pitta*, the *vata*, and the *kapha*—each of which produce unique characteristics within a person and have consequences for the body and mind. Every person is in a constant state of imbalance and continually strives for, yet rarely achieves, complete balance—a perfect state of health. In the Āyurvedic tradition, both the body and mind of a child are involved in different states of being, among which is autism. Treatments usually include physical, herbal, and spiritual prescriptions.

As noted above, Keralans—also called Malayalis to reflect the local language, Malayalam—utilize both biomedical and Āyurvedic healing practices for all states of disease. They also frequently use religious rituals, such as Hindu *pūjās* and pilgrimages to particular temples. While Āyurveda and biomedicine suggest their own explanatory models for the traits associated with autism, Hindu concepts of *dharma* (cosmic moral order), *karma* (predetermined action), *puṇya* (spiritual merit), and *pāpa* (spiritual demerit; Parpola, 2000) are also influential on interpretations of different bodily and mental states. These notions are discussed and interpreted throughout India with slight variations depending on local practices, yet there is a general understanding that one’s *karma*, which is determined by the gods and based on actions in a person’s past lives, determines one’s current state of being and destiny. Through particular tangible acts, some aspects of *karma* can be altered, leading to the occasional reliance of Hindu *pūjās,* or rituals, to alleviate states of distress or dis-ease (Keyes & Daniel, 1983). Located in the traditional heart of Āyurveda medicine, in a state with a large Hindu population and the most accessible biomedicine, Malayalis have easy access to a range of healing traditions, explanatory models, and idioms of distress that the locals and practitioners navigate expertly and concurrently.

Selfhood.

Kerala’s uniqueness is formed by and reliant on a community-wide ethos of social and human rights that extends to all members, regardless of caste, gender, or economic ability. This ethos is related to local definitions of selfhood, which are the ways a community collectively considers the state of being a person, individual, and community member. Traditional anthropological research has shown differences in definitions of selfhood between the individualistic West and the collectivist East. While this research has been problematized, contemporary work supports the community-based perspective of Indian selfhood. Scholars such as psychoanalyst Sudhir Kakar (1981) and anthropologist E. Valentine Daniels (1984), whose work focused on Kerala’s neighboring state Tamil Nadu, describe how Indian selfhood is shaped through community connectedness and a delicate equilibrium of self with time, space, and place. These traits have also been noted to be of upmost importance for Keralan selfhood as well; homes, for example, are often designed to conform to a specific balance and to relationships between the family members, daily activities, and the earth (Parpola, 2000).

Community connectedness interacts with a more Western, liberal sense of equality and political rights to create the unique Keralan reliance on regular grassroots movements, public demonstrations, and close interactions with political officials that result in the development indicators described above.

Atlanta, GA USA.

Atlanta's public education system is representative of that of the rest of the county, including the enactmentment of No Child Left Behind (NCLB). This policy was passed in 2001 and was designed to "close the achievement gap with accountability, flexibility, and choice, so that no child is left behind" (No Child Left Behind [NCLB], 2002, p. 1425). The law requires all states to bring their students up to a full proficiency in math and reading by 2014. All academic achievement and content standards apply to all children, including those with disabilities. States are required to provide assessment results of all children by subtype, one of which is students with disabilities who are eligible for certain accommodations but must be tested using regular grade-level state assessments (Cortiellea, 2006). When states do not meet the requirements of achievement set forth by the act, "the Secretary may withhold funds for the State administration under this part until the Secretary determines that the State has fulfilled those requirements" (NCLB, 2002, p. 1457).

Outside of and prior to NCLB, U.S. education policy guaranteed education for all children with disabilities through the Individual with Disabilities Education Act (IDEA).

This act describes two important provisions for student with disabilities: a free and appropriate education (often referred to as FAPE) and education in the least restricted environments (known as LRE). All children in the U.S. must and can go to school and receive an education that is appropriate for their individual skill and social level. Reflecting an ideology of rehabilitation, recovery, and individualized education, the law mandates that children with disabilities have an Individualized Education Plan (IEP). Developed by their educational team and caretakers, the plan describes the specific academic skills to be taught and the necessary accommodations needed to ensure academic progress. These provisions, described more fully in the fifth chapter, often dictate that schools educate the child separately for some or all of the day, or that additional adult aids be assigned to classrooms of children with disabilities (National Research Council, 2001). These provisions allow for an individualized education experience. However, with ambiguous standards and uneven funding, public educational provisions for autistic children frequently vary between schools districts and states. While private schools with a direct focus on autism can provide richer educational experiences, these are often financially or geographical inaccessible, even with scholarships.

The focus on rehabilitation and intervention in the U.S. special education system is built from the preponderance of biomedical perspectives of illness and disability, which are entrenched in American culture. Professionals in Atlanta rely on diagnostic tools that are based on DSM definitions of autism, such as the Autism Diagnostic Schedule (ADOS), Autism Diagnostic Interview-Revised (ADI-R), and the Childhood Autism Rating Scale (CARS). My experience within the Atlanta autism community during and before the current project is that local facilities utilize familiar Western intervention techniques, including Applied Behavior Analysis (ABA), Floortime, and Treatment and Education of Autistic and Communication Related Handicapped Children (TEACCH).[19] Often, these tools and interventions are saturated with deficit-based approaches that largely focus on areas in which the child lacks skills. As such, many families and professionals in Atlanta perceive autism as a hinderance or fault to be fixed or improved, often using pharmaceutical interventions alongside intense educational and therapeutic approaches. Families also often employ alternative treatments such as dietary restrictions, chelation, or vitamin therapy alongside research-based interventions (Offit, 2008) which is most often done under the direction of a physician (Golnik & Ireland, 2009) and under the guise of biomedical justification. Hence, Atlanta is a location relying on a biomedically based healing system; one that promotes an organically driven explanatory model.

Significantly, Atlanta is also the home of the Centers of Disease Control and Prevention (CDC) as well as many well known autism research and intervention facilities, such as the Emory Autism Center (EAC) and the Marcus Autism Center. As a result, professionals in the Atlanta area conduct a good deal of autism-related research, including part of the CDC's epidemiological research that sets the nation's current autism prevalence rates ("Autism and Developmental Disabilities (ADDM) Network", 2012). In

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[19] Similar to Jack Levinson's reference to and use of his prior experience working on group homes in his ethnographic work on freedom in adult group homes, my previous experience as a special educator provides me with what sociologist Harold Garfinkel termed "unique adequacy." This means that my time teaching autistic children in homes and schools and working as an autism consultant in a Georgia public school system ensures my competency in autism related settings in Atlanta. As autism related personnel and families are often difficult to access in Atlanta, this experience will supplement and aid in analysis of the data I collected in Atlanta (Levinson, 2010, p 60).

recent years, some of the top researchers in the field of autism, including Dr. Ami Klin from the Yale Child Study Center, have relocated to Atlanta to pursue their work in collaboration with these top-tier institutions. Similar to how Kerala is a location boasting elevated healing resources, Atlanta is becoming an epicenter of research about autism in America, which allows families the opportunity to enroll their children in clinical studies looking for causes of or interventions for autism. Both locations inherit norms and beliefs of their respective countries, yet are also unique in sources relevant to the current study, making the two locations particularly ideal for comparison.

Common Western values of independence, personal achievement, and productivity are strongly represented in public narratives of disability and differences in the U.S. and Atlanta. Often stories about autism in the media focus on a person's ability to overcome one's disability to regain identity. This is true of autism representations. From the very first parent memoir, *The Siege: A Families Journey Into the World of an Autistic Child* (Park, 1982), to more recent fictionalized accounts widely read throughout the U.S. autism communities such as *The Curious Incident of the Dog in the Night-Time* (Haddon, 2004), autism is constructed as a state of being that is a barrier to a person's true self that can be fought and conquered.[20] These "quest narratives" (Frank, 1995, p. 115)[21] suggest a disapproval of the traits of autism and a desire to normalize the

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[20] This is a way of talking about autism that is reminiscent of Susan Sontag's renowned work describing the metaphors used to talk about cancer and, later, AIDS. She describes the harmful consequences of talking about illnesses in this context such as serving to distance people from illnesses and preventing ill people from seeking treatment (Sontag, 1990).

[21] A "quest narrative" is one in of three ways Arthur Frank describes how illness stories are told, the other two being the "restitution narrative" and the "chaos narrative". Quest narratives are characterized by the use of the ill person's voice and the illness is described as a journey on which the narrator must travel; Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics*, (Chicago: The University of Chicago Press, 1995), 115.

population. The influence of these strong narratives of recovery is pervasive throughout America and shape perceptions of the condition as a broken state of being. However, autobiographies of adults with autism, such as those by Temple Grandin (Grandin & Scariano, 1986; Grandin, 1995), Donna Williams (1992; 1994), and Kamran Nazeer (2006) suggest that traits of autism are not entirely disabling and can be re-inscribed as personality traits with high value. The extent of influence of these works is minimal, as they fail to capture the public's imagination as strongly as a recovery narrative.[22] Published accounts and media representations are deeply influential on public understandings of what autism is and how those diagnosed and their families are affected by the condition.

Kerala and Atlanta share some characteristics that enable a balanced comparison. Given both the stark contrasts and limited overlaps, the ways in which particular variations in cultural environment influence the places of autism and the experiences of those associated with autism can be easily illuminated. This information can then be applied to contexts around the world that are just beginning to learn about and apply the diagnosis of autism, as well as the diverse communities in which autism is a familiar term and concept.

Recruitment Facilities and Informants

To gain a comparative perspective of the impact of critical social structures on autism-related issues, I recruited caretakers of children with autism and professionals who work with this population in rural and urban locations in both research sites. Data

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[22] The 2010 HBO movie, *Temple Grandin* (Ferguson & Jackson, 2010) may have reached a wider audience, however the impact of this film has not yet been evaluated.

collection for each location lasted for approximately six months—from June to December of 2011 in Kerala and late March to September 2012 in Atlanta. A total of 112 families and professionals participated in the current research; 36 from Atlanta and 76 from Kerala.

Professionals were simply required to have been working directly with children exhibiting autistic characteristics, with or without a diagnosis, for at least one year. A range of professionals were recruited, including physicians, psychologists, educators, behavior, speech, and occupational therapists, and traditional healers. Initially, caretakers must have had a child who was under the age of eighteen and presented significant autistic traits and behaviors (e.g., nonverbal communication style, frequent behavioral self-regulation, noticeably unique social interactions). Despite explaining this requirement to recruitment partners and possible participants, some parents had children who demonstrated only a few autistic traits. Until I completed the behavior profile with these parents, I was under the impression these children qualified for my initial requirement of having more significant impairments. I kept these informants in the data pool because they are illustrative of caregivers' attitudes toward research recruitment, and because they point to two important complications: different children express autism in different ways, and the same child frequently expresses autism in different ways over time.

Because of the relative novelty of autism in Kerala, the presence of autistics traits in children was primarily identified by teachers or related professionals; in Atlanta, a diagnostic label of autism (not Asperger's syndrome or PDD-NOS) served as an indication of significant autism traits. With all caretakers, behavior checklists designed after the DSM IV TR diagnostic criteria for autism were completed during the interview to determine the presence of autistic traits and behaviors in thier children. Most children displayed numerous diagnostic traits; out of twenty possible autistic traits, only five children exhibited five or fewer traits, two of whom were of the Atlanta data pool.[23] The presence of children with few autistic characteristics was primarily a reflection of (1) a misunderstanding of my research needs by the administrative personnel in charge of identifying participants in the initial stages of recruitment in Trivandrum and (2) changes in autism manifestation as a result of early and intense interventions in Atlantan children. It is also important to note that a quantitative measurement of traits is often a poor representation of a child's level of autistic impairment.

Data recruitment in Kerala.

Language and translator.

The primary language of Kerala is Malayalam, a complex language with 13 vowels and 36 letters. I used translators for any interviews not conducted in English. In addition to the use of translators, interactions and discussions with participants were facilitated by my training in Malayalam—including an intensive summer course in Trivandrum during the summer of 2009, a semester-long independent language course directed by a Malayalam professor from the University of Pennsylvania, and ongoing study throughout my research.

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[23] See Appendix 1 for checklist.

My first translator was hired through a contact at the language school in Trivandrum I attended through the American Institute of Indian Studies (AIIS). He completed several interviews with me before I encountered Joypaul, who would become my translator and research assistant for the remainder of my time in Kerala. Joypaul is a yoga instructor and travel coordinator who had learned English during his time in seminary and through a course in business English. His command of the language exceeded that of my original translator, and I hired him to travel with me to Wayanad and to retranslate the recordings of the interviews my initial translator had attempted to transcribe. Joypaul transcribed all of the interviews conducted in Malayalam and also assisted me in basic research tasks, such as contacting facilities, organizing talks, and navigating to research appointments. He also served as a cultural liaison by helping me understand subtle cultural practices and ensure that I acted properly with my informants. His participation in this project was invaluable.

Trivandrum.

In the Keralan capital of Trivandrum, families were recruited through three primary institutions: the Child Development Clinic at the Government Medical College (CDC-MC), the National Institute of Speech and Hearing (NISH), and the Abhayam School. The CDC-MC was founded as a project by the Government of Kerala with the aim of improving early childhood and adolescent health care and education, women's health, and pre-marital counseling. It opened its doors on August 1, 1987 and in 1995 became an autonomous center. Although the center is independently managed, it is associated with the Government of Kerala through the Travancore-Cochin-Literary, Scientific, and Charitable Societies Registration Act-XII of 1955. Societies under this act must follow certain regulations, like publicizing accounting ledgers, members, and the minutes of general meetings ("The Travancore-Cochin Literary, Scientific and Charitable Societies Registration Act, 2012). The director of the center, Dr. M.K.C. Nair, is a professor of pediatrics who has published articles on autism and childhood disability (Nair, 2004; 2009). He is dedicated to raising the status of developmental disabilities as an area of concern at the clinic.[24]

In addition to the clinic, the CDC-MC hosts training opportunities and several undergraduate, post-graduate, doctoral, and post-doctoral courses in human and child development. Many of the staff at the clinic were previous students. The clinic also hosts lectures and workshops featuring outside professionals and has an impressive publication history. In addition, at the time of my fieldwork, the clinic professionals were in the process of developing the Trivandrum Developmental Screening Chart (TDSC), which will be used to screen for developmental delay in children under 2 years of age. Clinic psychiatrists and pediatricians are currently working on a Trivandrum Autism Behavioral Checklist (TABC; Nair, 2004).

At CDC-MC, I recruited and interviewed a total of five professionals: three physicians, a researcher, and a behavior therapist. I collaborated with the head administrative assistant to identify families who might be eligible for my research. Through this collaboration I recruited and interviewed seven families at the CDC-MC.

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[24] Each day of the week focuses on a different issue: Mondays is the pre-school clinic; Tuesday is the at-risk baby clinic; Wednesdays is the developmental evaluations clinic; Thursday is the high-risk baby clinic; Friday is for developmental screenings; and Saturday is the adolescent care clinic. Wednesday serves as the unofficial autism clinic day, though children with autism come in throughout the week to accommodate the families' schedules

NISH was founded through the Kerala State Social Welfare Department in 1997. The center gained accreditation as an Excellent Institution through The Rehabilitation Council of India (RCI) in 2002, making it the youngest institution to gain this recognition. Initially set up to provide services for children and adults with hearing impairments, services have expanded to other disabilities, and it currently hosts an Autism Intervention Unit (AIU) that provides individual speech therapy and group communication, sensory integration, and play therapies (National Institute of Speech and Hearing, 2012). NISH's beautiful campus is located about six miles (10 km) from Trivandrum's center, making it somewhat difficult for many families to reach. The closest bus stop is still several kilometers (about a mile and a half) from the actual building, meaning families without their own transportation must hire an auto rickshaw (a small, three-wheeled vehicle) to complete the trip. Similar to recruitment at CDC-MC, families were identified in collaboration with a head staff member, here a social worker. No staff members were interviewed and three families were interviewed at NISH.

I first encountered the Abhayam School, meaning "shelter,"[25] through a contact at CDC-MC during my first visit to Trivandrum in 2009. By 2011, when I began collecting data, the school had been open for roughly fifteen years, including the years the director, Ms. Fathima, was teaching a few children in her home by herself. Ms. Fathima is a retired teacher who never had children and decided to dedicate her free time to helping, as she describes, "the most needy." She started by teaching the child of a family friend who had significant intellectual and learning disabilities and then moved on to a teacher's

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[25] The name of the school and the school's director has been changed.

training program. Upon completion of this program, another parent requested that she teach her child, and within a few years her student population grew and diversified such that she needed to employ other teachers and assistants.

At the time of data collection, the school had twenty-one students enrolled, twelve of whom were autistic. The students ranged in age from four to fifteen years. All were educated in the basement of Ms. Fathima's home, which is divided into three classrooms. Students are grouped based on age and level of impairment. Two classrooms share a large room with no definite physical boundaries and house children with significant impairments. The third, an adjacent, smaller room separated by a doorway, houses children with learning disabilities. Each classroom is led by a head teacher; two *ayahs* ("helpers") assist all three classrooms, going where needed. A speech therapist and a behavior specialist come to the school one to three times a week to work with students individually. From this facility, three professionals and four families were recruited. Professionals in Trivandrum were also recruited from an Āyurvedic facility, Snehalayam (one physician and three assistants), the State Institute for Mental Retardation (one psychologist), and the Institute for Communicative and Cognitive Neuroscience (ICCONS; one therapist at the Trivandrum location and three therapists, a teacher, a psychologist, and an *ayah* at the Shoranur location). ICCONS has two campuses. The Trivandrum location provides outpatient speech and behavior therapy as well as a variety of other neurological services. The second campus is in Shoranur, located in the middle of Kerala, and provides the same services along with an in-patient facility for children and adults with neurological disorders, a special education school, and both a master's and doctoral training program.

Wayanad.

The bulk of my rural data was collected in Wayanad, a rural agricultural district in the northeast corner of the state covering a total of 823 square miles (2,131 square kilometers). As noted in the description of Kerala, autism is especially new and unfamiliar in Wayanad and so most children are officially diagnosed as mentally retarded. Pediatricians I spoke with insisted that there were no autistic children in the district, showing the low level of physician awareness of autism in Wayanad. As mentioned above, many special education teachers had received information about autism through various trainings or readings and so were able to identify which of their students were autistic versus those with other cognitive or learning disabilities.

Thus, I recruited most of my informants from seven semi-private schools for children with intellectual disabilities, a Block Resource Center (BRC), and an Āyurvedic hospital. The schools were scattered throughout the district; five were founded and run by nuns, the remaining two were run by charity organizations. All schools receive some level of government funding as well as some private funding; most charge a small tuition fee. To recruit at these schools, Joypaul or myself would contact the facility by phone or in person and describe the goals of the research. We were often invited to visit and tour the school, at which time the head mistress would identify the students who are likely autistic. Once possible children were identified, a teacher or head mistress would contact the child's family by phone either immediately or within a few days and assist us in setting up an interview. Other times the teachers did not seem to feel comfortable contacting the families, thus we recruited significantly more teachers (10) than families (2) this way. Several teachers recruited through other means had children attending these schools.

Each of Kerala's fourteen districts is further divided into 63 *taluks*, 1018 revenue villages, and 978 *grama panchayats* (Government of Kerala, 2012). Wayanad has three main taluks, each of which has a Block Resource Center, or BRC, that provides a variety community services including prosthetic devices for children with physical impairments and special education services to children with disabilities within that *taluk*. The BRC at Sulthan Bathery, one of the three major cities of Wayanad, specializes in educating autistic children. Though it teaches in its resource room and in children's homes, this BRC is known for its resource room, which is stocked with a variety of educational and therapeutic materials. Every day, one to three of the BRC teachers would staff the resource room and work with mothers. These visited with their children on a daily or weekly basis for intervention and education. Through the BRC at Sulthan Bathery, I recruited three teachers and nine families. My total recruitment for Wayanad was seventeen families—sixteen mothers and nine fathers[26]—and twenty-two professionals—one doctor, six traditional healers or assistants, fourteen educators, and one therapist.

Table 1 summarizes the total informants recruited in Kerala. Some of the families who were recruited in Trivandrum had traveled in from another region of the state, but

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[26] In one family I interviewed only the father and in one family I interviewed the mother and father separately. The rest of the recruited fathers were interviewed at the same time with as the mother. In 9 families I interviewed only the mother.

actually lived in a rural area of the state, thus reflecting the relative unbalance of rural and urban informants.

Table 1: Keralan Informants

	Trivandrum	**Wayanad**	**Other**	**Totals**
		Professionals		
Physicians (incl. psychologists)	4	1	1	
Educators	5	14	1	
Therapists	3	1	3	
Healers (incl. assistants)	4	6		
Other	1		1	
Total	17	22	6	**45**
		Families		
Rural	4	17		
Urban	10			
Total	14	17		**31**
TOTAL				**76**

Data Recruitment in Atlanta.

In Atlanta, recruitment occurred primarily via emailing recruitment fliers out to various local autism-related listservs. Fliers were also brought to and displayed at local autism related events and facilities. Family members, primarily mothers, and professionals would see the flier on email or at a facility in the community and contact me if interested in participating. If deemed eligible, the first meeting was arranged. About every six to eight weeks, new fliers would be sent out electronically to remind people of the project. Physicians and facilities were also contacted directly by phone or email and asked if they or their staff would be interested in participating. I also made announcements at two Autism Awareness events in the month of April, and attended a support group in Putnam County, located roughly 75 miles outside of Atlanta.

The Emory Autism Center was particularly helpful in allowing me to contact staff directly about participating, resulting in five professionals recruited. Although not every participant stated how they were informed of the study, the vast majority reported that they learned about it through electronic means. A total of seventeen families were recruited—primarily mothers[27]—and nineteen professionals participated. As recruitment generally covered informants living within 100 miles of Atlanta, informants were divided into those within metro Atlanta and those outside of Atlanta by at least fifteen miles, who had more difficulty accessing Atlanta autism resources. Participants who lived at least fifteen miles outside of the metro-Atlanta area included Eatonton (Putnam County; about 75 miles distance), Winder (55 miles distance), Stone Mountain (17 miles distance), Lithonia (18 miles distance), Ellenwood (15 miles distance), and Snellville (25 miles distance). Table 2 summarizes the subject recruitment in Atlanta.

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[27] One widowed father participated and one other father participated in the interview along with the mother. Therefore, 15 interviews were with only the mother.

Table 2: Atlantan Informants

	Metro Atlanta	**Outside of Atlanta**	**Totals**
	Professionals		
Physicians (incl. psychologists)	4	1	
Educators	6		
Therapists	5	3	
Total	14	4	**19**
	Families		
	9	8	**17**
TOTAL	23	12	**36**

Data Collection Methods

The current project builds on Arthur Kleinman's (1988a, 1988b) methodology by completing 'mini-ethnographies' with all informants. Mini-ethnographies use ethnographic methods to gain detailed, individualized information about an important aspect of a person or family's life, in this case the occurrence or presence of autism in a child. By completing open-ended, semi-structured interviews[28] with parents of autistic children, I gathered pertinent and nuanced information about current and future goals for their children, behaviors of most concern, interactions with professionals, explanations for their child's autism, and diagnostic and treatment journeys. Interviews with professionals yielded information about pathways into working with children on the

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[28] See Appendix 2 for the guiding questions of these interviews.

spectrum, professional goals for children, and the benefits and difficulties of working with autistic children. Both populations discussed their thoughts on major autism-related issues such as causation, rises in rates, treatment approaches and cures, and autistic adulthood. The interviews were designed to cover major autism-related issues and experiences that, when compared between two disparate cultural locations, reveal important discrepancies that influence how this condition and the behaviors associated with it are approached by both parents and professionals. These major differences are important considerations for researchers, clinicians, and advocates who are hoping to interact with parents or professionals from various cultural locations and backgrounds.

The interviews also revealed differences in perspectives between caregivers and professionals within a singular cultural location. Discrepancies between emic, or local ideologies of the general public, and etic (Weiss, 1997), or professionally based perspectives coming from outside the lay public, can cause contention between the service consumers (e.g., parents, caregivers, children, adults) and the service providers (e.g., teachers, physicians, healers, therapists; Borgen & Knudsen, 2003; Goin-Kochel, Mackintosh, & Myers, 2006; Randall & Parker, 1999). Parents have reported the difficulty in obtaining a diagnosis, learning about services, and making treatment decisions (Osborne & Reed, 2008; Ryan & Salisbury, 2012). Negotiating treatment provisions and navigating difficult professional interactions are not ideal for the care of an autistic child, making the discovery of primary points of disagreement a critical consideration for the improvement of caregiver-professional interactions.

Interviews and Observations.

Interviews lasted between twenty minutes and two hours. Professional interviews averaged forty-five minutes and parental interviews averaged one hour. Both groups completed demographic forms identifying household members, education level, employment status, ethnicity or caste, yearly income, and religion. When asked, participants were told that they should only provide information they felt most comfortable revealing. Demographic omissions occurred more frequently in Kerala and primarily included income and caste information. Based on observation of homes or comments made during interviews it is clear that these omissions came primarily from lower class/caste families in India. Autism behavior checklists were most often read to caretakers during the interview to gain more detailed descriptions of the child's behaviors and to assess caregiver perspectives on these behaviors. At the conclusion of the interviews, informants were asked if they would like to participate in the observation portion of the research.

Like the interviews, observations occurred at a time and location that worked best for the informant. Most informants who agreed to observations, and for whom observation times could be arranged, were only observed once, however occasionally several observations occurred. Multiple observations most often occurred due to overlap of participants (e.g., came to observe one teacher and returned to observe another teacher in same classroom) or because certain families invited several visits. One family in Wayanad participated in three formal and several informal observations.[29] Most

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[29] This family became friends of myself and Joypaul and so we visited with them several times. During these informal visits, I did not bring my notebook and only recorded notes once I returned home.

observations lasted between one and three hours and took place in homes, schools, clinics, and out in the community (e.g., restaurants, cars, stores).

Several Keralan and a few Atlantan families were unfamiliar with an observation format, meaning some observations were more interactive than others. It became clear rather quickly that the family was unsure as to their role and my purpose, despite frequent explanations. I relied on my previous experience as an interventionist and consultant for autism services in order to give the observation session purpose and to ease the discomfort felt by the families. Noting a family's unease and changing my behavior and purpose during an observation created a more trusting and relaxed environment.

Supplementing the qualitative data, I gathered relevant cultural and historical information from each research site. This process was more involved in Kerala, with which I am less familiar and therefore required more effort to understand educational, medical, and familial structures. In addition to library research,[30] I spoke with officials at universities, government education and welfare offices, and policy institutions in Kerala. These interviews provided more in depth and current information about educational structures and services available to families with disabled members. This information helped to contextualize the data collected through informant interviews and observations. Similar information was gathered from public documents and publications on Atlantan and American educational, medical, and welfare services.

Data Analysis.

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[30] In Kerala, I did library research at the Vyloppilli Samskriti Bhavan (a cultural heritage site), the The State Council Educational Research and Training (SCERT), and the Centre for Development Studies.

Shortly after an interview, it was transcribed by myself, Joypaul, or a hired transcriber and the recording was erased. As described above, interviews conducted in Malayalam were transcribed by my research assistant and translator, Joypaul, who was present during the majority of the interviews. Once transcribed, interviews were coded using a codebook (described below) with 284 codes organized into 32 parent code groups. Coding reliability was completed using a consensus coding process for which I trained a coder (another interdisciplinary graduate student at Emory University) through detailed descriptions of and discussions about the codes and coding an example interview. Once I felt confident in the coder's understanding of the codes, we both coded two interviews after which we met and went through the interview and came to a consensus on all codes applied to that particular interview. We then repeated this process with two more interviews to ensure code reliability and validity. By the end, we had obtained consensus on one parent and one professional interview from Atlanta and one parent and one professional interview from Kerala.

Codes reflect major autism issues (definition, cause, behaviors) and issues specific to either parental or professional informants. Codes were developed both based on my previous experience with and knowledge about autism and on a grounded theory approach. Grounded theory is an inductive technique in qualitative research to generate theory from data by (1) coding concepts from the raw data that is used (2) to create analytical categories which, (3) form the basis of theory (Bernard & Ryan, 2010). To generate the codebook, I began with concepts and issues I was certain would be covered in the interviews, like definitions and treatments, and was supplemented these with additional codes after reviewing the transcripts for recognizable themes. In this way, I was more able to include emic concepts and a wider variety of opinions and experiences as well as more abstract, implicit notions such as local and personal definitions of selfhood and normalcy as they related to children and autism.

The remainder of this dissertation is dedicated to comparing the places of autism —clinics, homes, and schools—and an analysis of findings critical to the shaping of parental and professional experiences in each place. My conclusion describes both the practical guidelines I developed through this work and the ethical challenges, or moral breakdowns, encountered. It is my hope and aim that this combination of application and ethical exploration is useful to a range of individuals and groups interested in engaging in international or cross-culturally based work on developmental and intellectual disabilities in childhood.

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Chapter 3: Place: The Clinic

Introduction

Clinics and hospitals are logical first points of contact for researchers and interventionists looking into autism in new cultural environments. As such, these places of autism are the initial locations in which information about how the differences associated with autism are valued and understood. Clinics are often assumed to be the locations where the highest authorities on health and illness are situated. They may reflect the places most knowledgable about the location of autistic children and autism itself. The clinic is the first place of autism to be explored here for ways in which future interventionists, researchers, and advocates can utilize the architectural, temporal, and organizational structures of these locations to best facilitate interactions with professionals, parents, and children in the autism community.

The built, architectural environment of healing spaces and places first came into deep consideration in the nineteenth century with the advent of moral treatment for the mentally ill. The Kirkbride Plan was one of the first architecturally focused methods of treatment. It ensured that an asylum was assessable by train, but situated far from any city, and that it was built on idyllic, agricultural grounds. The idea was that form followed function—that the beauty of the landscape and buildings would enhance therapeutic effects (Grob, 1994; Trent, 1994). More recently, medical geography has focused on the spatial effects of health care systems.[31] Less attention has been paid to "the micro-

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[31] For example, see Kelvyn Jones and Graham Moon. (1993). "Medical geography: Taking space seriously." *Prog Hum Georg, 17*(4): 515-524. DOI: 10.1177/030913259301700405; Peter Drury. (1983). "Some spatial aspects of health service developments: The British experience." *Prog Hum Georg, 7*(1): 60-77. DOI:10.1177/030913258300700103.

spaces" (Gesler, Bell, Curtis, Hubbard, & Francis, 2004) of health care, like treatment rooms and doctor's offices, though it is well understood in the field of human geography that there is a relationship between the physical structures of a clinic and the behavior of the people traversing these spaces. For instance, hospitals and health clinics set up distinct and separate areas for medical personnel and patients, designing the front desk area such that the receptionist can act as the 'gatekeeper' to the professionals (Gesler, Bell, Curtis, Hubbard, & Francis, 2004).

Though not expressly building from the perspective of space and place from humanistic geography perspective, Arthur Kleinman also emphasizes the importance of the look and feel of a place of healing in *Patients and Healers in the Context of Culture: An Exploration of the Borderland Between Anthropology, Medicine, and Psychiatry* (1980). Within the first few pages, he provides a rich description of a Taipei street scene that focuses on the various healing and medical clinics and pharmacies. He argues that "to understand patients and healers we must study the particular cultural environments and then make cross-cultural comparisons to seek generalizations about these fundamental human experiences" (p. 8). He later goes into more detail about the different types of healing places, including descriptions alongside notes on the professionals' training and the relative prestige and variability within each approach. Placing descriptions such as these at the forefront of his work demonstrates the value Kleinman places on the structures that comprise a place of healing. He explains that, like any other cultural system, medical and healing centers are systems imbued with symbolic meanings that are reflected through social arrangements, institutions, and personal interactions. At the center of these systems stand the patients and healers who are in a symbiotic relationship with healing spaces, who take cues from a clinic's various structures on how to behave (Kleinman, 1980).

Kleinman also speaks of the way "cultural hybridization" takes place in the clinic. "Indigenization" occurs after Western medicine and psychiatry are introduced into a non-Western context and are adapted to be more appropriate for the cultural location. This response changes a Western approach into one that better aligns with existing cultural structures. "Popularization" is a related process that occurs when certain aspects of medicine, like health concepts, are altered and diffused as they enter the popular realm (Kleinman, 1980). The latter concept most closely describes the situation in Kerala where frequent contact with Western medicine is common and alters the ways the public talks and thinks about illness.[32]

This chapter explores the ways in which clinical places of autism are experienced and navigated by caretakers and professionals. First, I will provide detailed descriptions of commonly accessed clinical places of autism in Kerala and Atlanta. These descriptions explore how the structures of these places direct and influence behavior and expectations of individuals traversing the clinics. Next, I focus on the diagnostic process and explain how a child's characteristics and a family's socio-economic status intersect to influence the number of clinic visits needed to obtain a diagnosis. I also describe why diagnostic tools and practices differ between Kerala and Atlanta and how this difference impacts the autistic population and the expectations of caretakers.

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[32] The next chapter will discuss how this influence has impacted the ways my caretaker informants talk about and explain their child's differences.

For the purposes of this chapter, clinics include facilities that provide assessments, diagnoses, or treatment for health care concerns. They may attend to a broad array of issues, physical and psychiatric, or provide specialized care for developmental disorders. They are also the places caretakers go to first for answers about and help with their child's differences. Thus, within clinics are critical and valuable pieces of data that provide information about cultural values of diagnostic and rehabilitative efforts. Clinics are also a necessary place with which autism researchers, interventionists, and advocates must interact. Information garnered from clinical places of autism is necessary for cross-cultural work with autistic individuals, their families, and the professionals working with autistic individuals. It is particularly helpful for addressing caretaker needs, professional practices, and for forming initial relationships with both clinicians and caretakers.

The Healing Places of Autism

In 1973, Arthur Kleinman noted that "Healing occurs along a symbolic pathway of words, feelings, values, expectations, beliefs, and the like [*sic*] which connect events and forms with affective and physiological processes" (210). Diagnostic and treatment practices are symbolic for practitioners and their patients. They inform the community about salient features related to health and illness. Clinics and healing places are imbued with structures that communicate the purpose of the place (e.g., healing, answers, consultation), the approach being used (e.g., traditional medicine, Western medicine), what one can expect from the place (e.g., diagnosis, treatment, neither), and how to behave within that place (e.g., professional, casual). As one encounters the structures of clinics and healing places this information is being subtly communicated.

The structures I explore in these clinics are time, physical structures, documentation, and professionals. Time is perhaps the most informative structure of a place, both in terms of the time required to access a professional and the way time is used in a clinic. Time is used differently across clinics, used differently between and within research locations. The physical structures also vary. As is described in the next section, biomedical (Western-style) clinics exhibit a structural uniformity that conveys scientific and medical legitimacy, while the distinctive rustic structure of the traditional healer's clinic suggests a less businesslike, more personal style of healing.

Documentation is a central source of biomedical legitimacy. More so in Atlanta, but also in certain clinics in Kerala, healers and caretakers often consider clinical documentation a source of objective truths. They grant these documented truths a special place in decisions about education, treatment, accommodation, and prognostic decisions are made. Reports and physical pieces of paper are a transient structure that are created by clinicians and given to caretakers, adding to a clinic's expression of truth, answers, and direction.

Professionals in these clinics are another defining structure. They generate the official documents relating a child's current developmental and diagnostic situation and actively create an atmosphere of expertise and efficiency. Caretakers, however, often come to experience the clinic differently. As described by many of my informants, the clinic can quickly become a place characterized by some combination of mistrust, confusion, expense, and frustration. In this chapter, I describe the structures of some common clinical places of autism in both Kerala and Atlanta and the influence they have on caretaker and professional experiences of the place. All of these descriptions are composites, built from observations and experiences at various clinical places of the same type, including some from outside my official field work, and thus do not constitute an exact description of any one place.

Kerala, India.

The Western-Style Clinic.

In Kerala, Western-style clinics are located in or around a hospital and are the places where Western, biomedical diagnoses and treatments are provided. Many of my informants in Kerala, both professionals and caretakers, expressed a belief that Western-style medicine is powerful, truthful, and highly valuable, yet overly potent and, thus, dangerous. These contradictory perspectives are held simultaneously. Biomedical clinics are usually the public's first point of contact, as these places are considered best for diagnostic answers, technologically advanced assessments, and easy, mild treatments. However, the prescription of Western medicine is heeded with caution as these treatments are frequently considered likely to be harmful and associated with a range of side effects from additional illness to chronic disability. In other words, this type of medicine was often the most highly regarded and sought out, yet often the medicines and procedures provided are cautiously considered and may be blamed for other illnesses or injuries, including autism.[33] Thus, while people desired the information about illnesses from Western medicine and often believed this approach could provide cures, the treatments, particularly medications, were frequently questioned . Caretakers of autistic children

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[33] Some parents believed that their child's autism was causes by the Western medicines they took while pregnant.

expressed anxious expectations of cures but were more often disappointed when only a diagnostic label of some sort was provided without any definite or quick remedies.

The neighborhood surrounding the Western-style clinic is a concentrated medical space where one can access many Western-trained doctors, medicines, and medical technologies (e.g., body scans). The clinic is surrounded by companies providing various assessments, such as x-rays, brain scans, and blood analyses, and a multitude of pharmacies at which to fill prescriptions. Though the clinic and hospital buildings are constructed with concrete walls and tile floors that express cleanliness and permanency, older clinic buildings show considerable wear. This suggests available funding is not directed to outward appearances and upkeep, a feature more highly valued in Atlantan clinics. To enter the clinic, patients and families often pass a uniformed security officer who sits or stands near the entrance. He is the first ‘gatekeeper’ through which patients must pass.

Patients proceed to a reception area that is marked by a tall desk that seperates the receptionist from the waiting area. A young woman in a white coat and name tag staffs the desk. She has a clipboard or a computer showing upcoming appointments, as well as a phone with which she takes calls to make future appointments, answers questions, and forwards calls around the clinic. She is the first point of contact for a clinic appointment and directs caretakers and patients to the appropriate waiting area. Although the second ‘gatekeeper,’ she is the primary person providing patients access to the medical personnel.

The indoor waiting area is filled with rows of plastic chairs; fans circle above. Families[34] wait quietly, occasionally speaking to their child or spouse, rarely speaking to other waiting patients. They may ask the clinic staff questions about forms or appointments but do not otherwise interact with nurses or staff members. The separating structure of the desk and the various tasks staff are urgently attending to communicates that they are not able to spend much time with each patient outside of their required tasks. If the waiting room is full, some families wait outside the clinic doors, where there are stalls selling *chai* (tea) and snacks. There is more socializing in these open areas, however usually at least one family member will stay inside so as to not miss their appointment. All patients and families have an appointment, which may or may not be kept on time.

Once the family is called for an appointment, they follow a nurse or other staff person wearing a white coat and carrying a clipboard or stack of papers to a large room for the intake interview. Several families may be in the same room at the same time, all sitting at individual plastic tables and chairs. They provide detailed information about the child's developmental and medical history and answer questions about family medical history. There are no attempts to separate the families as they provide this information; there is no expectation of ensuring medical information is kept private. The openness of the room and the public nature of the intake interview communicates that this information is neither shameful nor serious, a practice that serves to lessen illness-related stigma. As one Keralan physician explained, once doors are closed and these discussions become

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[34] Often the father will attend hospital clinic visits. The mother is almost always present. Occasionally a sibling or grandparent is also present.

confidential, people assume there are serious medical issues occurring. In Kerala, health and illness are topics that pervade daily discussions; even the most common greeting, “Sukham anno?”, meaning “Do you have health?”, demonstrates the community’s openness towards personal health. Only serious and possibly stigmatizing health concerns occur behind closed doors. Taking medical histories in communal areas is an acceptable practice.

Once the intake is finished, the family is taken to a clinician's office for assessment or consultation. Following the Western style of care, these consultations occur in closed offices, though this is more suggestive of the authority of the professional than a need for privacy. It is not uncommon for unknown professionals to sit in on these visits or enter without notice to pass on messages or ask questions. Offices have a large desk with a chair on one side for the professional and a few chairs on the other side for the families. Lights are kept off and windows are kept open, likely to save electricity, and so appointments proceed in the natural light and with outdoor breeze. The office is used by several professionals; it does not contain any permanent personal items, creating a transient and short-term feel to the interaction. The clinician—a pediatrician, psychiatrist, psychologist, or behavior therapist—wears a white coat and stethoscope and sits at the desk with assessment forms, writing instruments, and stacks of documents. There is no computer, phone (apart from a personal cell phone), or other technological or medical equipment present.

The clinician interviews the families about their child, makes notes, interacts with the child, and fills out documents. At the end of the interaction, which lasts between five and fifteen minutes, the documents are given to the family with further directions and advice. The advice may concern topics ranging from more assessments to school placements to medical interventions. These hand-written documents are to be brought with the family every time they interact with a Western-style clinicians; families are seen at these clinics with folders filled with their various documents. Unlike typical American practices, the child's primary documentation is also kept by the family and it is their responsibility to maintain and provide their copies.[35] As will be discussed further in the next section, families are rarely given a diagnostic label at this time. Families may leave this interaction feeling disappointed, frustrated, or more confused than when they arrived.

The need for an appointment, the documentation, front desk, white coats, and staff leading patients through the experience are all structures of the Western-style clinic that communicate to professionals that they in charge of a venue of knowledge and directors of the interaction that occurs. Caretakers understand that this is a place for modest behavior, efficiency, and answers. The types of questions caretakers asked during interviews when in clinics versus when in homes is one indicator of the frame of mind being in a clinical setting puts them in. Thirteen of the thirty-four caretaker interviews I conducted in Kerala took place at a clinic. When I asked if they had any questions for me, eleven answered yes. Eight (73%) of this eleven asked about treatment, rehabilitation, or educational options; six (55%) asked about their child's development, diagnosis, or future; six (55%) asked about autism in general; and one (9%) asked about America. This contrasts with the twenty-one interviews I conducted in the informant's

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[35] Some documentation is kept at the clinic but they are brief and often difficult to locate.

home, where sixteen had questions. Nine (56%) asked me about treatment rehabilitation, or educational options; five (31%) asked me about their child's development diagnosis, or future, seven (64%) asked about autism in general; five (51%) asked questions about America; four (25%) asked questions about me or my research; and one (6%) asked if I could advise the child's teachers. While only one caretaker (9%) interviewed in the clinic asked a non-clinical question (about me or America), all asked clinical questions (related to autism information, a child's autism, or rehabilitation). However, seven (64%) of the sixteen caretakers interviewed in the home asked a non-clinical question and only fourteen (88%) asked a clinical question. These questions are a reflection of the thoughts of the caretakers at the time of the interview, which seems to differ somewhat based on location. This suggests that the clinic is understood to be a place to gain clinical answers and to avoid socializing, whereas the home is a place that allows for more conversational questions.[36]

The Āyurvedic Clinic.

Āyurvedic clinics are similar in structure to the Western-style clinic or hospital. Built with concrete and tile, these dual-storied structures contain several treatment rooms and long-term patient rooms. They are clean in appearance and usually employ several technicians,[37] identifiable by their blue smocks. There is no front desk; instead, patients arrive during walk-in hours (usually held for a few hours several days a week) for a consultation with the primary practitioner. Depending on the size of the clinic, waiting

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[36] The high level of clinical questions in both locations could be explained by the fact that I was seen as a professional from America who had a lot of experience with and information about autism.

[37] I am using this term for those who actually give the Āyurvedic massages and treatments. This term will also be used for those who give treatments at the traditional healer's clinic.

rooms have anywhere from five to twenty chairs. Here, patients read newspapers or chat with each other. The small waiting rooms here are more amenable to socializing than those in Western-style clinics.

Patients enter the practitioner's office on a first-come, first-serve basis. Usually the practitioner escorts the patients to his or her office. Whereas Western-style clinics tend to keep instruments outside of the physicians office, these offices house assessment instruments. There are bookshelves filled with books, posters and diplomas on the walls, and telephones. These offices are clearly used by one practitioner and suggest continuity and the possibility of a longer, more detailed interaction. With families, the Āyurvedic practitioner will observe the child and ask caretakers questions about the child's difficulties. He will decide on what, if any, assessment needs to be done at that point. Often, he will take a pulse analysis, for which he places three fingers in specific places along the patient's wrist and forearm to measure several attributes of the pulse (e.g., speed, intensity, consistency). This assessment is used to diagnose the patient's condition. Practitioners make their diagnosis based on their observations and analysis with little consideration of parental assessment or opinion.

After a diagnosis is given,[38] the practitioner prescribes a series of treatments that involve either repeat visits or a long-term stay at the facility. He may provide a written prescription to the family, which can be filled onsite or at one of the many Āyurvedic

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[38] In the case of autism, the Āyurvedic practitioners interviewed diagnosed *vata roga*, which is an aggravation of the *vata dosha*. Āyurvedic medicine notes that the body is comprised of three main *doshas,* or constitutions. Perfect health is characterized by the three *doshas* being in perfect balance. Illness arises when one or more of the *doshas* is out of balance because they are aggravated or diminished. *Vata roga* is characterized by physical and cognitive traits such as nervousness, fearfulness, insomnia, cold hands, eye and muscle twitching, coordination, and changes in muscle tone. It is also the diagnosis most closely associated with schizophrenia (Lad, 2002).

pharmacies in town. The practitioner makes notes about individual cases, but the overall amount of and emphasis on documentation is less than that of the Western-style clinic. When the patient arrives for treatment, they go back to the waiting area and are led into the treatment room by one of the technicians. The treatment rooms have a long shelf on which several herbs and tonics are kept. There is also a sink and a collection of bowls for mixing herbs and medicines. Medicines are prepared before the patient enters the room. There is a small gas burner on which the medicines can be heated in oils or water can be warmed for cleansing the body. In the middle of the room, there is a long table with a hole at the top where the patient's face lays. The table is covered in brown plastic or leather for easy cleaning with a ridge around the table to catch the medicine as it drips off the body. Hanging above the head area is a copper container that is used for *shirodhara* treatments, which involve slowly dripping medicinal oil onto the forehead. The walls of the clinic room are often light blue or off-white and show many oil streaks and scrapes. There are usually two technicians in the room giving the treatment, which might include massages with different herbal and oil-based mixtures, head oils, enemas, or expectorants. During treatment with autistic children, the technicians give verbal directions, scold when directions are not followed, tell jokes to the child, comfort the child, and chat with the mother.

Some patients stay for several days or weeks at the Āyurvedic clinic. In the case of children, the mother stays in a room with the child. Adults sometimes stay alone but are equally as likely to stay with their spouse, parent, or other close family member. Patient rooms have two single beds and a small burner with which to make *chai* or coffee.

More expensive, private rooms have their own bathrooms; cheaper rooms share a common bathroom. There is an indoor common area with a small television, a plastic table, several plastic chairs. There are a few outdoor common areas where the patients congregate throughout the day as they wait for their treatments. They read the newspaper, drink *chai*, and chat with other patients and staff members. The onsite kitchen provides daily vegetarian meals to residential patients and staff, which are eaten in the common area or in the patient's room. This kitchen is also the place for cooking and mixing some of the herbal medicines, and for providing *chai* throughout the day. The sharing of meals and *chai* as well as the traversing of common areas fosters a familiarity amongst patients and with technicians, who often play with the children and joke with the patients.

The Āyurvedic clinic, in comparison to the Western-style clinic, is designed less starkly and requires more touching between practitioners and patients. Research shows that touch in therapeutic settings, such as a clinic, reduces stress and allows for more intimacy, connectedness, and familiarity in clinical encounters (Wilkinson, Knox, Chatman, Johnson, Barbour, Myles, & Reel 2002; Ventegodt, Morad, & Merrik, 2003). Touch got passed along from Āyurveda to Tibetan medicine as a central component to the focus on compassion in doctor/patient relationships and treatment in Tibetan mediccal practice (Garrett, 2008; Ozawa-de Silva & Ozawa de-Silva, 2011). The use of touch contributes to an increased comfort in socializing at the Āyurvedic clinic—social distance is closed when touch is occurs frequently. There is a general, familial feel between the long-term patients that the technicians and the daily visitors may also experience. There is little sense of time or immediacy, even amongst the technicians. The other structures within the Āyurvedic clinic—the lack of a front desk or need for appointments; the presence of books and other healing materials in the practitioners office; the somewhat dirty walls in the treatment rooms; the blue smock of the technicians; a decreased focus on documentation—all signify a less objective, more personal space where touch and sociality are allowed. As with neighbors and family members, one can drop in at allowed times, unannounced, chat with peers, and be touched.

The Traditional Healers Clinic.

Unlike the Western-style clinic and the Āyurvedic clinic, the clinics of traditional healers, or *vaidyas*, are most often located in rural areas where local plants and herbs are easy to harvest on roadsides and in the forests. Successful *vaidyas* are known to patients through word of mouth and, except in the case locals living near the clinic, are used as a last resort. Most patients report visiting Western-style and Āyurvedic clinics before coming to a traditional healer. It is considered less effective because the cost is low,[39] yet many also reported a *vaidya's* ability to cure any disease. I visited only one traditional healer's clinic, and so this section is somewhat more idiosyncratic than the others. It can be found at the end of a dirt road on the outskirts of a small town, surrounded by modest houses. The *vaidya* lives there with his extended family (who also work at the clinic) and his apprentices and their families. Although many of the male technicians wear orange *mundas*, or sarongs, this is not required and does not apply to the women. The rest of the technician's clothing is often worn and dirty from the treatments, similar in style and

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[39] The *vaidya* explained that they are only allowed to take enough payment to allow them and their family to live on; any material profit would diminish their healing powers. In this way, there is no set fee as families are also allowed to pay what they can afford.

quality to their patients'. The effect is an equalizing of patient and healer, where one is almost indistinguishable from the other.

The traditional healer's clinic is built of woven bamboo walls, a less secure barrier between inside and outside than that of concrete or brick buildings. There is no external wall that surrounds the entire clinic, the walls do not reach the corrugated tin roof, and the floor is compacted dirt. These features combine to create a sense of natural fluidity between inside and outside of the clinic. Though small, there are several rooms in the clinic: a women's treatment room, a men's treatment room, a unisex 'exercise' room, waiting areas, and a kitchen where prescribed herbal medicines are mixed and cooked. It is a busy place, teeming with patients and technicians by mid-morning. Patients requiring an initial consultation wait in a small, semi-outdoor waiting area to see the primary *vaidya*. As there are no appointments and treatment is on a first-come, first-serve basis, patients often wait several hours for consultation. To pass the time, they socialize in one of the waiting areas or one of the few *chai* shops across the dirt road. These shops also sell the containers, oils, and fabric wraps needed to apply medicines. A technician periodically visits the front waiting area to take down names of those who need to see the practitioner. This practice is informal and the interaction is short. When a patient's name is called, they are brought into a small room comprised of very few instruments and a wooden table. They sit on the wooden table, answer the healer's questions about their health, and submit to various assessments, including pulse diagnosis.

There are separate waiting areas for the men and the women and children. As patients wait, they chat and discuss their or, on the women's side, their children's various medical ailments. If they are familiar with each other, they may discuss other aspects of their lives such as marriages or work. This is not a infrequent occurrence as many patients either live in the area or are prescribed repeated treatments. Families will stay in local hotels (there are no patients' rooms at the clinic). Male patients wait in the front room while female and child patients wait on a long bench in the back of the clinic. Once they are called into the treatment room, they hand the technician the prescribed herbal medicines and give any directions the *vaidya* provided.

The treatment room,[40] though small, has three distinct areas. The first area is where the women get undressed and prepare to receive their treatment. They undress, hang their clothes on a string hung against the bamboo wall, and wait for their turn at the *kizhi* area. *Kizhi* treatments comprise of packs of cloth that are dipped into warmed, medicinal oil and vigorously patted onto the body. The *kizhi* area is run by a woman technician who sits on a low stool next to a small gas burner and metal pot in which to melt oil and mix in medicine. After one medicinal mixture is used, the remainder is tossed on the dirt floor, near the bottom of the wall. In front of the technician, there is another stool on which the patient sits as the technician pats her body with the medical pack. Across the small room is the next area, defined by a long wooden table on which oil massages are given. This area is less frequently used, but may be staffed by a male technician. The only other men to enter the room are the *vaidyas* who may come to give directions or get a patient update. At the end of the treatment, the patients wipe the excess

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[40] What follows is a description of the women's treatment room. I was not given access to the men's treatment room.

oils from their bodies and re-dress. When in this room, the women are comfortable and easily chat, gossip, and laugh. The room has a warm and welcoming feel to it.

The exercise room contains two wooden tables on which exercises are performed. Two male technicians provide treatments, which consist of moving limbs and body parts of a patient in specific ways and directions. Here, the patients remain clothed, as there are no oils or massages provided. There are a few plastic chairs for family members to sit and observe the treatments. The men in the room, including fathers and husbands of patients, talk and joke. The women are quieter and often remain silent. This room also has a relaxed feeling, even in the presence of obviously painful treatments.

The last room in the traditional healer's clinic is the kitchen. This room has two or three technicians performing various tasks. There is a desk where handwritten records of the prescribed medicines and herbal inventories are kept. There are several shelves with various herbs and oils and a very large metal pot over a fire that burns constantly, sending a stream of smoke to the roof, staining the walls, and filling the clinic with the earthy scent of the medicines and herbs. Patients wait outside the room in no particular order, handing over prescriptions and receiving packs of medicine.

The behavior of patients and staff at the traditional healer's clinic is informal and sociable. Technicians and practitioners come in and out without a clear schedule. As they are not distinguished by their clothing, it is unclear how many people are working at any one time. The staff intermingle with the patients easily and comfortably. The structure itself is porous, allowing practitioners and patients to both hear what is happening in adjacent rooms and shout to each other. There is little expectation of privacy here, which is reflective of many aspects of Indian communities (Kumaraguru, Cranor, & Newton 2005; Perez 2009).

The structure of the traditional healer's clinic is rustic and casual. In this type of environment, more comfortable interactions between patients easily occur. Interactions with technicians and healers are eased by this structure and by the lack of uniforms, apart from the occasional orange *mundu*, both of which are features that serve to differentiate and separate professionals from patients on other clinical environments. As with the Āyurvedic clinic, touch appears to be a central feature in assessment and treatment. I observed many clinicians providing touch-based treatments and assessments. Again, touch likely attributed to the closeness and relaxed nature of the clinic. Patients expect to wait, but also expect to receive attentive care and permanent cures. Many patients are familiar with each other, but they return to the town after treatment, and so do not regularly eat together as at many Āyurvedic clinics. The presence of *chai* shops and the long waits contribute to a social atmosphere in the waiting areas. The intimacy of nudity, the familiarity of the treatment practice, and the introductions made in the waiting area allow the treatment room to be a social, casual place where treatments occur alongside personal connections and laughter. The technicians are comfortable and partake in the discussions as they give treatments. The women's treatment room is a place of comfort as much as it is one of healing. Finally, the transient presence of the *vaidya* along with the word-of-mouth recommendations and success stories create a quality of mysticism and potency, generating a trust, or perhaps faith, in his methods and ability to cure.

Atlanta, GA.

In contrast to Kerala, which, as seen above, is a medically pluralistic society, Atlanta has one primary medical approach: biologically and scientifically derived medicine, or biomedicine. Treatments are rooted in this approach. Spiritual, traditional, or herbal medicines[41] are not commonly consulted for autism spectrum disorders. Thus, while the previous section portrayed various clinical approaches, this section portrays two clinical settings, both biomedically defined, yet different in intention: diagnosis or treatment.

The Diagnostic Clinic.

Diagnostic clinics in Atlanta can be in the form of a physician's office in an office park, an autism-specific facility that houses several clinicians and therapeutic services, or a child development clinic within a larger hospital. In the physician's office, the decor is designed to be unique and comforting—there are soft chairs, tables with magazines, a play area with some simple children's toys, generic landscape or floral paintings, wallpaper and a water cooler or coffee station. The waiting area is small and there is usually only one family waiting at a time. Hospitals or larger facilities will have a distinct waiting area for assessments of developmental delays, often on a separate floor from other services. The rooms are brightly lit and the furniture is comprised of plastic chairs or wooden chairs with soft covered seats. There are magazines on the tables and posters and notices hanging on the walls. The children's play area is larger than those in physician offices and filled with simple toys such as bead mazes, puzzles, or a train table. At any time, there are several families here. The caretakers are largely mothers with the

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[41] While many of my informants reported praying for their children, they did not engage in any rituals or consultations specifically designed for healing. Also, famlies may use herbal medicines, but usually under the guidance of a nutritionist or herbalist with a biomedically perspective

occasional grandparent or father. When not interacting with their children—usually by giving them a direction, entreating them with toys or food, or calming them from crying—or filling out forms, they are interacting with a cell phone or looking at a magazine. Rarely do these families interact with each other.

The larger facilities have several front desks lined up with separators along one wall. The single-physician's office has one front desk with a sliding glass separator between the patient and the staff person at the desk. In both locations, there is a clear distinction between the staff area and the patients' area, as was seen in the Western-style clinic in Kerala. The staff wear medical scrubs with various patterns, usually child-friendly patterns like balloons or cartoon characters. Upon entering the diagnostic clinic, the patient's caretaker approaches an available front desk, has her appointment verified, and receives a clipboard with a stack of forms to fill out. The forms ask for demographic information (e.g., address, family members), a privacy statement (e.g., HIPPA),[42] and medical history (e.g., allergies). There is also a developmental questionnaire (e.g., when did the child first sit, walk, speak, etc.). Once these forms are complete, the caretaker provides them, along with any insurance information, to the staff person at the front desk. Completing and returning these forms is the beginning of the documentation generated through the diagnostic process.

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[42] The U.S. Department of Health and Human Services is charged with enacting the privacy statement of the 1996 Health Insurance Portability and Accountability Act (HIPPA). This statement is designed to ensure a person's medical and health information that is individually identifiable is protected and is not disclosed to anyone not considered a covered entity, which include those in the individual's insurance plan, without a person's written consent. This privacy is thus directed towards individuals with insurance (United States Department of Health & Human Services, 2005).

Appointments are necessary and may be made based on a referral from a local family pediatrician or general practitioner. The appointments are usually made several months in advance. Appointments depend upon availability and the wait is typically longer in these larger facilities than in smaller clinics. These delays frustrate caretakers and instill a fear that the diagnosis and, thus, intervention will occur too late to be as effective as possible.[43] Additionally, the long waits for appointments suggest to families that these clinicians are busy because they are experts that families from around the state are trying to see. Humanist geographer Yi-Fu Tuan (2010) explains that "there is no clearer indicator of status than who waits for whom" (107); this waiting period serves to place the physician at a higher status than the families. One mother called the clinicians at a popular autism facility the "autism spearheads;" another well-known pediatrician in a hospital-based clinic is generally thought to be "a very good pediatrician," despite appointments that often last between four and six hours, mostly comprised of wait time. Although these facilities and clinicians are well regarded, the many months wait for appointments as well as the long appointment times were a frequently cited source of frustration. Families only persevered through this frustration in order to obtain the

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[43] There is an emphasis on early diagnosis and intervention in the American autism community. Efforts, such as the "Learn the Signs. Act Early." campaign from the Center's for Disease Control and Prevention (CDC; http://www.cdc.gov/ncbddd/actearly/index.html) stress the importance of recognizing autism and starting intervention as early in the child's life as possible. The suggested implications are that autistic children who are unable to get early intervention have poorer outcomes. The CDC's campaign fact sheet states: "Early intervention (before school age) can have a significant impact on a child's ability to learn new skills as well as reduce the need for costly interventions over time" (http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/LTSAE-factsheet_508.pdf). However, research shows that income level is correlated with age at diagnosis such that children in families with lower incomes get diagnosed significantly later than that of higher income families. One 2005 study found that the average age at diagnosis for autistic diagnosis is 3.1 years, however "near-poor" children receive a diagnosis 0.9 years later than those with incomes ">100% above the poverty level" (Mandell, Novak, & Zubritsky, 2005).

appropriate diagnosis with the appropriate documentation so that appropriate intervention could begin.

Once called by the nurse, the caretaker and child walk through a door separating the waiting room from the clinical rooms, indicating the appointment has begun. The caretaker (again, usually a mother) and child are brought to the clinician's office and initial introductions are made. The clinician, who wears office-appropriate attire without a physician's white coat, and whose office is filled with books and toys, brings the patient into an assessment room to begin a series of developmental or autism-specific assessments.[44] These rooms are sparsely decorated to reduce distractions and are furnished with a small table and chairs and a container with assessment materials. The caretaker observes the assessment either in the room or from an adjacent room with a one-way mirror. The assessment itself, administered either by the head clinician or a trained staff person, involves presenting the child with various activities and giving the child directions to perform certain actions, such as following a point, repeating words or phrases, or jointly interacting with a toy. The tasks presented to the child depend on his or her age and current social and communication style. Throughout the assessment, the clinician records responses in an assessment booklet. These assessments may take up to several hours. The caretaker is also asked to fill out an extensive questionnaire about the child's developmental history, which will be scored by the clinician at a later time. The clinician may give the caretaker a brief overview of the purposes of the day's assessments

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[44] Because of issues related to confidentiality, I was unable to observe an assessment during field work. I have however, performed similar assessments on children myself and seen videos of assessments being done during my time as a special educator.

and his initial appraisal of the child’s results, however these are often stated with the caveat that, until the results have been analyzed, an official diagnosis cannot be given.

Although some clinicians are able to give a diagnosis to families quickly, it is common for families to wait several days or weeks to return to the clinic for the results of the assessment. The clinician goes over the results of the assessments, pointing out areas where the child showed strengths and weakness. Documentation of the child’s assessment scores is provided to the parent along with prescriptions and referrals for any medications or therapies. This often concludes the diagnostic process. If the diagnosing clinician is a developmental pediatrician or psychologist, this may be the only time the child and caretaker will interact with this clinician. If the clinician is a pediatrician or a psychiatrist (and the child is prescribed psychiatric medicine) they regularly return for check-up appointments.

Although there are important physical structures of the diagnostic clinic to take into account—such as the distinct separation between waiting and assessment areas, the ubiquity of documentation, and the sterility of the building—time is the most salient feature of the diagnostic process. Obtaining a diagnosis may involve several stages of waiting. Families must wait to get a referral for the diagnosis, then wait up to several months for a diagnostic appointment, then wait until they are called from the waiting room to the assessment area, and finally wait until the assessment results are available. Apart from the frustration and fear this waiting instills in families, this process also conveys a sense that autism is a highly prevalent and immediate concern for many families. The professionals in these contexts report feeling overwhelmed by the number of appointments and, more so, the amount of documentation per child. Scoring assessments and writing reports are steeped in a sense of immediacy and lack of time. For the clinicians and caretakers, documentation is the goal of the diagnostic encounter—there must be physical reports and assessment scores verifying not only the child's diagnosis (or lack thereof) but also the veracity of the clinician's techniques. There is ample room for subjectivity in an autism diagnosis; documenting the process grants the diagnosis more authority and facticity, enabling other professionals, including therapists, educators, and insurance companies, to proceed with confidence in the validity of the autism diagnosis.

The Therapeutic Clinic.

Because the therapeutic clinic is similar in structure to both types of diagnostic clinics (i.e., are large facilities with multiple services and smaller, single-practitioner/-service facilities) I will not go into great detail describing them here. The main differentiating features of the therapeutic clinic are (a) time, (b) multiple visits, and (c) type of professional.

Most caretakers are referred to at least one type of therapeutic clinic: speech therapy, occupational therapy, physical therapy, behavior therapy, Floortime therapy,[45] or an alternative biomedical type of therapy such as hyberbaric oxygen therapy.[46] Socio-economic class, however, interferes with access to these services. Families without the

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[45] Floortime is a educational and rehabilitative approach that works with children by meeting them at their developmental level and interests. The therapist will use what a child shows interest in to teach particular skills. The name reflects the common practice of getting on the floor with a child to interact with toys and games

[46] Hyberbaric oxygen therapy is designed to increase blood flow to critical areas in the brain thought to be related to autistic behaviors. Children must have several treatments during which they sit in a chamber with high levels of oxygen for several hours (Feinstein, 2010).

time to take children to repeated visits, the money or insurance coverage to pay for visits, or reliable transportation forgo private therapies and rely solely on public school-based services. Public school services, however, may or may not include these strategies.[47] Research has shown that those in high social classes utilize health-care services more than those with low SES's (Coburn, 2004; Drury, 1983; Lasser, Himmelstein, & Woolhandler, 2006). Those who can follow through with the referrals make initial assessment appointments that are similar to the diagnostic process. During this first appointment, therapists identify which skills on which to work. Regular appointments are then made to receive services. In terms of time, there is much less waiting and so less frustration for the families.

Multiple visits to these facilities breed familiarity between the caretaker and the child's therapists. Although some relationships may develop between caretakers with similar therapeutic schedules, this is rare. Rather than sitting in a waiting area, caretakers either attend therapy sessions or watch them on closed-caption television in another room. This practice is designed to protect the therapists against litigation, to assure caretakers that therapists are acting appropriately, and to demonstrate the therapeutic skills so that the caretaker can mimic them in the home.[48] Thus, as with other Western-style facilities presented here, there is little opportunity for families to interact.

During the therapy session, the therapist will take notes and record data detailing the child's performance and responses during the session. This data is then added to a

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[47] See Chapter Five on schools for an overview of services available in American public schools.

[48] See Chapter Four for more on the home as a therapeutic space in America.

now growing collection of documentation on the child's autistic experience. It should be noted here that, while every professional with whom an autistic child interacts creates some sort of documentation about that child, there is no central place for this documentation and it is rarely shared between professionals. This is another parental frustration. Multiple professionals in a child's life do not seem to know what is happening with other professionals and may not be working towards the same goals or agree on the approaches of other professionals. Many Atlanta caretakers communicated a desire for a team-based approach in which a team leader directs the child's therapeutic and educational activities. Usually, the caretaker acts as a team leader (Carbone, Behl, Azor, & Murphy 2009), however, usually has neither the time nor access to the resources this role should require. In other words, caretakers are usually forced into a situation in which they must learn about what therapeutic resources are available in their community, how to access and pay for them, and organize a child's various appointments and progress. Because of little time, money, or education, families with a low socio-economic status are not likely to be able to fully explore and access the therapeutic options.

At the end of a therapy session, the therapist will provide a brief (two to five minute) overview of the session with the parent, often while walking back towards the waiting area, including some tips on what to work on until the next appointment. Caretakers have more interactions with these professionals than any other in the child's life, apart from any long-term aides a child may have, and often see them as a key expert on their child's behavior and progress. There is a relaxed feel between the therapist and the caretaker, who may feel more comfortable approaching the therapist with questions and concerns than the child's doctor or teacher. The caretaker may get to know some personal information about the therapist, particularly if it is a long-term relationship, and express much gratitude for their services and any communicative, social, or academic progress the child makes while under the therapist's care.

The professionals here are predominately young women, which may also add to the ability for caretakers, again, usually mothers, to feel comfortable with a therapist as she may be considered a natural caregiver. If she is working out of a hospital based clinic, she will be wearing medical scrubs. Otherwise therapists wear comfortable street clothes (e.g., jeans, sneakers, comfortable shirt), presenting themselves as professional yet approachable. Therapists, especially those with long-term relationships with specific children, report feeling connected to the families more so than other important professionals. A child may only see his pediatrician once a year or when ill, his psychiatrist only briefly to check on medications, and even teachers rarely get the same one-on-one time with the child or the caretakers.

There are, however, frequent disruptions to this care when insurance or money runs out. This is yet another time when documentation becomes a critical structure within the autism experience. Documentation is required to file for insurance claims; it tells the therapist when to continue or halt services; it convinces clinicians that another referral is warranted and appropriate. Therapists are highly involved in these processes—from documenting a child's time in therapy to guiding the documentation through various systems of funding, which itself is a form of validation. As with the clinicians involved in the diagnostic process, therapists feel overwhelmed and frustrated with the amount of paperwork and documentation involved in their work while simultaneously realizing the critical role it plays in the life of an autistic child.

Clinics in Comparison.

There are clear similarities to be drawn between the Atlanta clinics and the Keralan Western-style clinic. Biomedical facilities have a distinct identity, noticeable in structures such as physical and temporal separations between the professionals and patients. The front desks are built to divide the space between patients and non-patients; assessments are done across desks and table; except in the case of the therapeutic clinic, patients only see these professionals for brief times with months or years between visits; documentation is critical and can only be generated by the professionals and received by caretakers.

Temporally and in terms of familiarity, the therapeutic clinic shares some features with the Āyurvedic and traditional healer's clinic. Touch and multiple visits by patients are more common in these places, leading to more intimacy and comfort. It can also be considered an important aspect of compassionate care (Ozawa-de Silva & Ozawa-de Silva, 2011), however this does not mean that Western clinics lack compassion. The primary distinction between these places is the frequent socialization in the Keralan clinics that is almost entirely absent in the Atlanta therapeutic and diagnostic clinics. This is as equally related to the structures allowing more socialization as it is to a cultural difference. American culture is more geared towards individualistic time and space. People keep to themselves and mind their own business, whereas in Indian culture, strangers are more likely to interact and socialize.

This socialization becomes particularly salient when encountered in medical places. As noted in the description of the Western-style clinic, privacy in health care is not a primary concern. Often, medical histories are reported in semi-public spaces, such as shared room in hospitals or at medical camps, which are day-long events, usually held at schools, with a particular medical focus (e.g., vision, developmental delays) where families can bring their children to be assessed by several professionals. During field work, I was frequently invited to sit in on consultations and was even asked to give my opinion a few times (though I managed to avoid doing so). Teachers felt comfortable pointing to children and publicly identifying their disability to me during school visits. These occurrences left me feeling uncomfortable, even after I understood the cultural differences that lead to less privacy in health care settings. I felt as though something I considered to be central to disability-related ethical practices was absent. However, as will be discussed more fully in the conclusion, in Kerala, openness about health and illness serves to lessen illness-related stigma and so it is protective and appropriate to avoid the level of privacy on which Americans rely. Thus, difference in health care privacy is another important consideration for future researchers or interventionists interested in interacting with autistic populations in new cultures.

Diagnostic Journeys

While certain structures in clinical places of autism communicate particular behaviors and expectations of experience, individual experiences vary based on individual and cultural circumstances. Below, I use interview data to describe how class, child characteristics, facility funding, and diagnostic practices influence the ways caretakers and professionals experience autism. For this section, I am focusing on the diagnostic clinics, defined here as any non-intervention-based place designed to provide initial assessments and diagnostic needs to families with children showing behavioral or cognitive differences. These are the places first contacted when families become concerned with their child's development or behavior. They can include hospitals, doctors offices, specialty clinics, and, in Kerala, Āyurvedic and homeopathic facilities.[49] These are the places where families and professionals seek information and answers.

As noted in the second chapter, Atlanta and Kerala are both unique to their wider cultures because of a high access to resources for children considered to be on the autism spectrum, especially for those living in urban areas. Atlanta boasts the Marcus Institute, the Emory Autism Center, Children's Health Care of Atlanta, and numerous other facilities offering a range of services and specialities for families and children with autism. They are primarily found within Atlanta city limits. Families living outside of the city, particularly for those in low-income neighborhoods, have significantly fewer resources and rely primarily on public school special education services, which tend to vary in quality. Caretakers often report traveling for several hours to access high-quality diagnostic services. Similarly, within the city limits of any of Kerala's three major cities —Trivandrum, Cochin, and Calicut—families with questions about a child's behavior and development can access clinics familiar with autism, however rural areas do not have

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[49] Schools can be considered clinics only in the moments when assessment for the purposes of diagnostic labeling takes places. For example, in Atlanta schools, the school psychologist can be called in to assess a child the teacher has deemed atypical to perform at least one formal or informal assessment with the purpose of either (a) referring the child's caretakers to an appropriate facility for further assessment, (b) qualifying a child for services within the school system, or (c) garnering information about a student's (dis) abilities in order to provide some information for teachers about the child's educational needs.

such clinics. Citizens outside of metropolitan areas must travel several hours, often by bus or train, to clinics in these cities or to cities in a neighboring state, such as Bangalore or Mysore, to find professionals familiar with autism.

In metro Atlanta and Kerala, caretakers reported visiting several clinics to gain appropriate and clear answers about their child's differences. The reasons behind these multiple differences reveal important information about the influence of class on obtaining a diagnosis. Barriers to obtaining a diagnosis ranged from an inability to *get* an appointment to an inability to *get to* an appointment. Upon closer examination, the data here reveals two specific connections with difficulties in getting a diagnosis: socio-economic status (SES)[50] and child characteristics.

Regardless of urbanicity, all of my Atlanta informants with high SES had difficulties in obtaining a diagnosis and visited at least three clinics before a professional used the label *autism* with regards to their child. When discussing her difficulty in getting a diagnosis for her child, one mother surmised:

> ….the ethics and liability concerns have driven everybody to say that they need to pass the buck to somebody else […] there are very few people who are willing to make a diagnosis and stick with it. They all like to pass it off to somebody else. It's very hard to deal with people, but some people will talk off

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[50] Socio-economic status (SES) was calculated in Atlanta based on the informants education level and income as compared with national standards. Similar procedures were used to calculate SES for Keralan informants, however caste was also considered when that information was provided and state-level, instead of national level, data used because Kerala overall has a higher average socio-economic status than the rest of the country (Franke & Chasin 1991).

> the record, even if they won't put it on paper, and you need their input, and its too bad that a lot of them are afraid to get it.

As suggested here, the hesitancy of professionals to give families with high access to resources a diagnosis of autism may be related to fear that these families are able to hire lawyers if the diagnosis is unwanted or wrong. Since an autism diagnosis is given based on behavioral observations or caretaker interviews, there is room for subjective clinician evaluation, mistakes, and dispute, making an autism diagnosis mutable and fallible.

Some professionals, on the other hand, explain this tendency differently. They believe that families go searching for an autism diagnosis, motivated by information garnered on the internet or popular books on autism. This search is undertaken to gain access to services through the school system and, in some states, insurance coverage for various therapies. Regardless, these families tend to be those with high access to resources that enable them to use the time and afford to travel to multiple clinics.

The evidence from this research showing that high-income Atlanta families had more difficulties obtaining a diagnosis differs from previous research which showed that families with high incomes are able to obtain a diagnosis in fewer clinic visits and earlier than lower income families (Mandell, Novak, & Zubritsky 2005; Goin-Kochel, Mackintosh & Myers 2006). The type and clarity of a child's autistic characteristics, however, may be the stronger influence. My data showed that less significant autistic characteristics guide the amount of time caretakers spent in obtaining an autism-related diagnosis. Caretakers of children who communicate verbally or tended towards more frequent and spontaneous social interactions were more likely to visit several clinicians—including pediatricians, speech therapists, developmental pediatricians, neurologists, or psychologists and psychiatrists—before a diagnosis of autism was given. These Atlantan caretakers reported professionals telling them that their child was fine or would 'grow out of' their differences. One mother living in a rural area outside of Atlanta approached professionals because her son had less verbal language than his peers and acted out violently towards her and his sibling. She expressed her frustration in getting a diagnosis of Aspergers Syndrome: "After you go from pediatrician to pediatrician, they're like, 'Oh, he's just a little boy. There's nothing wrong with him.' 'Well, he screams all night.' [she would tell them] 'Well, there's nothing wrong with him. He's growing too fast for his body. He's having leg cramps and feet cramps' [the doctors replied]."

The children with less significant autistic characteristics who were included in this study were also from families with a higher SES, however not all the high-income families had children with less significant autistic characteristics. Families with lower socio-economic status' do not have the financial and temporal resources to make the multiple clinic visits when a child's difficulties are more subtle and less problematic for the family's daily lives. This indicates that the combination of high SES and low autistic characteristics increases the chances a family will visit multiple clinics with concerns about their child's behavior and development.

Keralan caretakers reported similar experiences. Many families attempted to get answers from their local physicians but were referred to multiple clinics thereafter. Fourteen (45%) of my informants reported visiting several clinics (as opposed to six

(35%) of all my Atlanta informants). Again, it was primarily informants with a higher SES who visited multiple sites for assessments, suggesting that financial and time resources are necessary for these visits. Additionally, informants with lower incomes, education, or caste affiliations tended to live in rural areas without clinics (apart from the local pediatrician or physician) that perform child development assessments. When visiting a pediatrician in one of the small villages in Wayanad, I entered into a waiting room full of mothers with sick children patiently waiting on benches for their turn. Each patient and mother saw the doctor for only a few minutes. This was all the time he had to look at each child, ask the mother a few questions, and write out a prescription or give care-taking directions. When I interviewed him later and asked what he would recommend for a family with an autistic child he responded, “To be frank, I don’t have much time and expertise to assist in a detailed manner […] It would take some time, more than some hours actually […] And to assess the child that is not enough […] In some cases I send them to the Child Guidance Clinic, CGC, at the medical college in Calicut.” Calicut is the closest metropolitan area, however traveling to Calicut from Wayanad can take anywhere from three to six hours and multiple bus rides.

Additionally, physicians and pediatricians in Wayanad were largely unfamiliar with the characteristics of autism. The pediatrician I quoted in the above paragraph invited me to speak to the Wayanad Brand of the Indian Academic of Pediatrics about autism. Prior to my talk, the pediatricians I spoke with told me they had never seen an autistic child and were surprised that I had. Yet after my talk, during which I explained the range of characteristics included under the autism spectrum, these same pediatricians reported that they had, in fact, seen autistic children in their practice but were unaware at the time that it was autism. It is only with experience that one is able to identify and interact with the wide variety of autistic individuals in their practice. Professionals who worked with autism in both Atlanta and Kerala reported that the textbook definitions of autism are unhelpful; those who were comfortable identifying autism were those who had had been out of their training settings and working directly with children and families for many years. To be most effective, training professionals to work with children on the autism spectrum must include interactions with autistic children in a range of settings. This is a critical consideration when establishing services in new and familiar cultural settings.

The understanding of autism amongst the professionals in Wayanad affected the types of diagnoses children in the area received. For instance, caretakers in rural Wayanad—where the pediatricians told me they had not seen an autistic child—who were of a low SES tended not to get a diagnosis. They were often told that their children's brains "developed slow" or was "not developing." These families, along with those in Trivandrum, were largely uninterested with how or if their child was diagnosed. Additionally, several of the families I encountered, particularly from rural areas, had never heard the word autism before, thus the label had little meaning to them. Those whose child was diagnosed with autism or autistic features remained unfamiliar with the characteristics associated with autism.

Regardless of what, if any, diagnosis a child had, Keralan caretakers were more interested in learning whether their child could be fixed or, as one father put it, "returned to normal." Yet because treatment options were scarce, particularly in the rural areas, families soon ran out of options and came to understand that their child would continue to have intellectual and behavioral disabilities throughout his life. Though initially focused on cures and returning the child to 'normal,' rehabilitative goals eventually became more pragmatic. Caretakers were soon only interested in ensuring their children could take care of their basic needs, their "self-helps." This finding, which is discussed in detail in the next chapter, mirrors that of a 2012 study of the experiences of parents in Goa, India[51] caring for their autistic child. The authors found four stages: (1) excitement over the new child, (2) noticing some differences and difficulties, but assuming they are temporary, (3) noting that differences should be address and continued hope for cure, and (4) accepting child's differences and trying to both work with child's characteristics to fit into the social reality and change the social reality for the child (Desai, 2012). Once the families reached the fourth stage, efforts to change the child diminish and efforts to increase accommodation and acceptance increased.

Regardless of their casual approach to diagnosis, caretakers in Kerala who had the financial means and available time to visit several clinics persisted longer in their attempts to get answers about their child's differences. As described in the pediatrician's comment above, clinic visits were made after referrals from the professional initially contacted by the family. Often, a family would take their child to a local pediatrician or physician who would then refer them to any number of local or nearby clinics. These clinics would then refer them to other clinics. It was not unusual for families to travel for

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[51] Goa is the state immediately north of Kerala.

several days to months at a time to get assessments and initial services for their children. Again, most low SES families were generally unable to make these extended trips. When they could travel for an assessment, they had to return home before the clinician provided the information they sought.

Many children in Kerala were eventually referred to a neurologist for a brain scan. Ten caretakers reported their child received an electroencephalography (EEG) scan, which measures the electrical activity of the brain, two caretakers mentioned a magnetic resonance imaging (MRI), which provides an image of the brain, and two reported a computed tomography (CT) scan, which generates images of sections of the brain. Informants reported mixed results. Some were told by the clinicians that the results were normal and others were told that the child's brain was abnormal. Some children were diagnosed with autism based on one of these brain scans. To my knowledge, there is no published research supporting the use of brain scans to diagnose autism, though some neurological differences have been noted.[52] Regardless, it is a common practice in India for patients to be referred to get some sort of brain scan (personal communication, Tamara Daley, May 3, 2013).

These scans were performed much less frequently with my Atlanta informants. When they were requested by a clinician, they were usually used to monitor seizures, never as a diagnostic tool. While both locations reflected multiple visits for families in

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[52] For a summary of neurological findings related to autism see: Anagnostou, E., & Taylor, M. J. (2011). Review of neuroimaging in autism spectrum disorders: what have we learned and where we go from here. *Molecular Autism, 2*(1), 4. doi:10.1016/j.biopsych.2006.07.022; Saxena, V., Ramdas, S., Ochoa, C. R., Wallace, D., Bhide, P., & Kohane, I. (2012). Structural, Genetic, and Functional Signatures of Disordered Neuro-Immunological Development in Autism Spectrum Disorder. (V. N. Uversky, Ed.)*PLoS ONE, 7*(12), e48835. doi:10.1371/journal.pone.0048835.s008.

higher SES groups, the services accessed in these facilities differed. Atlanta children primarily received developmental or diagnostic assessments. When visiting Western-style clinics with Western-trained professionals, Keralan children had quick, informal, observational assessments and were often referred for a brain scan. While fear of legal retribution or a desire for an autism diagnosis led to multiple site visits for some families in Atlanta, in Kerala, multiple visits were related to general unfamiliarity with autism and a lack of time for in-depth assessment, which led to a more frequent use of technology like EEG and MRI machines. Biomedical clinics are the point of first contact for families in both Kerala and Atlanta. As noted in the beginning of this chapter, they are considered to be places of truth, science, professionalism, and answers; both clinicians and caretakers behave with a certain level of reverence. Yet, as just described, the answers sought out differ, as do the steps along the diagnostic journey for caretakers. The diagnostic journey differs for professionals as well and, again, there are important economic and temporal factors involved.

Diagnostic Practices

Western-style clinics in Kerala share a problem with many clinicians who have limited time and financial resources: they can not to afford the diagnostic tools considered the ‘gold-standard’ in America—the ADI-R and ADOS (Grinker 2008; Feinstein 2010; National Research Council 2001). The Autism Diagnostic Interview-Revised (ADI-R; Rutter, Le Coeur, & Lord 2003) is a series of questions to be answered by a caretaker familiar with a child’s developmental history. The interview takes 1 ½ to 2 hours and is later scored by the trained professional. The entire ADI-R kit costs $230.00, or Rs 12,411. The Autism Diagnostic Observation Schedule (ADOS; Lord, et al. 2000)) is a diagnostic tool based on structured observations of the child. It has four modules, each of which is comprised of various tasks that are implemented or skipped based on the child's current communication style and age. This assessment takes two hours to complete. Each module costs $45.00 (Rs. 2,428) and the manual is $65.00 (Rs. 3,507); the total costs of the ADOS is $245.00 or Rs. 13,220. In Atlanta and throughout the United States, many developmental pediatricians, psychiatrists, and psychologists use both of these tools to diagnose a child with autism. Diagnostic practices that do not use these tools usually rely on a detailed observations of the child and parental reports of developmental history. Reports from these diagnostic practices and tools validate a child's diagnosis and become a central piece of a child's documentation generated from the clinic. As noted in the first section of this chapter, documentation is not only critical to a child's future but is a defining structure of biomedical-based places of autism.

Because of the time commitment involved and, more so, the high cost, physicians in Kerala are unable to access these instruments. Thus, Keralan clinicians diagnose using at least one of the following three methods: (a) speaking to parents and perhaps watching the child for a short time and referring to the DSM IV TR or ICD-10 criteria, (b) using the Childhood Autism Rating Scale (CARS; Schopler, Reichler, Devellis, & Daly, 1980), a tool that can be found free on the internet that rates a child from 1 to 4 on fifteen items and is frequently used to screen children in America, or (c) a self-developed test like the Trivandrum Autism Behavior Checklist (TABC). I was introduced to the last of these methods during my initial visit in 2009. At this time, a physician at the Child

Development Clinic at the Trivandrum Medical College showed me the tool and explained that they had developed it so that pediatricians could diagnose a child as quickly and efficiently as possible. Based primarily off the DSM IV TR diagnostic criteria, the tool was reported to have been validated against the CARS, however this research was not made available to me.

Initially, my reaction to the TABC was one of disappointment. An autism diagnosis in America is generally thought to be a delicate and highly involved process and so this quick assessment tool seemed designed to fail. However, after spending time in clinics and with doctors and families (who, again, are less interested in obtaining an actual diagnostic label than in treatments), I understood the need to provide a structured, fast assessment method to local pediatricians. While this tool may address the time and financial issues of Keralan physicians, the use of this and various other diagnostic measures contributes to the problems of cross-cultural comparison.

While there are several reports validating the use of diagnostics tools created in the West in various countries, the use of different techniques to diagnose autism could reduce the cross-cultural validity of the diagnoses. In other words, a child may get diagnosed as autistic in one country using their diagnostic practices and yet not meet the criterion for autism in another. Even within the same culture, there is always room for subjective assessments during on the part of the clinician during an autism diagnosis, which leads to some variation in the characteristics considered indicative of autism. This effect was demonstrated by the Atlantan caretakers who visited several clinics for a diagnosis. Diagnostic variation is enhanced when diagnoses are happening in communities with varying degrees of knowledge about autism and values related to childhood normality, development, and role in society.

I am not arguing for the widespread use of expensive, time-consuming techniques to diagnose autism in every clinical encounter. As described in the second chapter, variation in diagnosis is a persistent issue in cross-cultural work on mental health related issues and one that has yet to be adequately resolved. Medical anthropologist Byron Good noted: “Mental health, mental illness, and mental health care remain social, psychology, and cultural to the core; they are powerfully influenced by macrosocial processes, shaped by local worlds of power and means, and constituted as distinctive cultural psychologies” (Good, 1997, p 231). Similarly, Kleinman (1988) argues that the ways these factors influence issues and practices related to psychiatric and intellectual differences has yet to be fully realized. But rather than cite these differences as a reason to standardize diagnostic practices by arguing for consistency in diagnostic tools, information about possible variations in diagnostics practices and outcomes can be used to understand how social factors enter into identification, diagnosis, and treatment. Some scholars, including theorist and philosopher of science Ian Hacking, have been working on this problem.

Hacking describes the consequence of using different diagnostic tools and practices as contributing to a “looping effect” (2000), in which information about an item or person changes that item or person, thereby discrediting what was initially known. In one use of this concept, he describes how the process we, as humans, categorize each other can change over time. These changes alter the population being labeled. The history of schizophrenia is one example of this process. Schizophrenia was ‘discovered’ (i.e., named) and popularized in the early 1900s by psychiatrists Emil Kraepelin and, later, Eugene Bleuler. In the original diagnostic conceptualization, flat affect (i.e., low or little emotional reactions) was a central feature of a schizophrenia diagnosis. Noticeably absent for modern audiences is the mention of audible or visual hallucinations as a diagnostic feature. Hallucinations did not become an important part of the diagnostic profile of schizophrenia until just before World War II. The addition of this symptom led to more individuals being diagnosed as schizophrenic. In other words, the symptom profile of schizophrenia—a condition that, like autism, is generally considered to be a biologically or neurologically based—was altered and as a result, the population of people with schizophrenia changed (Hacking, 2000; p 114).

Currently, clinicians in different parts of the world are using different diagnostic tools to identify autism—a diagnosis that is heterogeneous even within countries, communities, and individuals. The consequence is that the biomedical certainty of what *autism* is is challenged and, perhaps more important, the populations considered autistic change and vary between places. The changing rates associated with different diagnostic definitions further demonstrates this phenomena.[53] In a place like Atlanta, you get a wider range of manifestations of autism because the diagnostic tools are designed to identify subtler expressions of autism and clinicians are familiar with less immediately evident forms of autism. In Kerala, most children diagnosed with autism will show obvious and

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[53] In the 1980s, autism rates were 1 in 10,000. Since the 1994 revision of the DSM, which made changes to the diagnostic criteria for autism, rates have risen at a dramatic pace (Eyal, et al., 2010; Feinstein, 2010). Current accepted rates are 1 in 88 (Centers for Disease Control and Prevention, 2013) meaning that a large portion of currently diagnosed children would likely not have been diagnosed at earlier times.

significant autistic characteristics, like non-verbal communication styles, aggression towards self or others, and frequent use of self-regulation techniques such as rocking or spinning. Children I encountered at the Western-style diagnostic clinics who did not display significant autistic characteristics yet were identified as possibly be autistic were (a) located in the city, (b) brought to the clinic for a wider range of difficulties, and (c) in my opinion, did not have autism and so would not have been identified as autistic in America. This suggests that some physicians in Kerala may have been exploring autism as a diagnosis with a population of children with a wider range of disabilities, yet without the use of a standardized instrument or training similar to that of clinicians in Western countries, where autism was originally defined. These differences increase the chance that when seeking out children diagnosed with autism in various cultures, one may encounter children who, according to one's own cultural definition of autism, are not autistic. Although it is impossible to know if this effect is happening and how much variation it is causing, the possibility of 'looping' is one reason my research aimed to recruit families with children who exhibited the traits of autism, rather than those with a diagnosis of autism.

As noted above, doctors and clinicians as well as caretakers in Kerala were much less interested in obtaining a diagnosis than those in Atlanta. While ten of my Keralan caretaker informants reported obtaining a diagnosis of autism at some point, eight received a diagnosis of autistic features, four reported mental retardation, four were diagnosed with general brain delay, two with PDD, two with behavior problems, and two with minimal autism.[54] Many families were given multiple diagnoses by multiple professionals. Five of my families, all low SES families living in a rural area of the state, were never given a diagnosis.

The practice of diagnosing is vastly different in Kerala than in Atlanta, where families were given the name of their child's diagnosis shortly after the assessments and clinicians immediately begin discussing what the diagnosis means and what resources the family should seek out. Clinicians in Kerala, on the other hand, frequently do not provide a diagnostic label, explain a diagnosis, or offer information about a child's differences until they have met with the family several times. To Western audiences, this may seem callous, however, as one psychologist in Calicut explained, it was meant to lessen a family's discomfort:

> If not the first sitting then at least the second sitting, we do give them a word of this condition, that this is part of a spectrum. We don't really go into the details of autism in the first or second sitting so they don't get scared. But we definitely tell them what they have to do. So we don't want to scare them saying your child is autism [sic], we see that the most problem is once you tell them, label the child as autistic, then they get worried then they start going to various doctors, various centers, then they start losing time.

In Kerala, it is not uncommon for clinicians to decide how much information a person receives about their diagnosis. This practice has been noted in other cultures as

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[54] Most of the children from Wayanad had 'mental retardation' listed on their official disability certificate—the government provided documentation of a disability that allows certain concessions, such as free travel on buses and trains. These children were unofficially identified to me as autistic by their teachers.

well, including Korea, Japan, France, Italy, and around Africa (Benowitz, 1999). Medical anthropologists Arthur Kleinman reported observing this practice with Chinese medicine practitioners in Taiwan (Kleinman, 1988). Physicians consider the power to decide what a patient does and does not know as an act of compassion. This power is also inline with the perception of Western-trained physicians as high authorities who direct doctor-patient interactions. For Western outsiders, however, this practice is reminiscent of medical paternalism and largely rejected in developed nations like America as part of bioethical policy development (Beauchamp and Childress, 2009). For families in Kerala with the ability to make several clinic visits, this arrangement may not be a problem. They will eventually obtain diagnostic information. However, for those families living outside of the city for whom it is difficult to find the time and money to return to a clinic, the additional information slotted for later visits is never received. This is why five of my families never received a diagnosis; they had neither the time nor financial ability to return for several visits.

These routines are starkly different from those in Atlanta, and across America, where a critical practice in the clinic experience is the application of a correct diagnosis. It is the stress on a *correct* diagnosis that some parents feel leads to the hesitancy of clinicians to apply an autism diagnosis. If the diagnosis is wrong or discredited by another clinician, there may be fiscal consequences and the reputation of the ‘wrong’ clinician will be harmed. And yet it is widely known amongst professionals that there is professional subjectivity in autism diagnoses. One well-known clinician and researcher, Judy Rappaport, is quoted in Grinker’s 2008 book as saying that in research she ensures her participants strictly fit the official diagnostic criteria for autism in the DSM IV TR. In her practice, however, she would diagnose “a kid a zebra if it will get him the educational services I think he needs” (Grinker, 2008, p. 131).[55]

Children misdiagnosed with autism are a concern for some of my professional informants in Atlanta. Both inside and outside of my research, professionals and parents have informally discussed with me the vast benefits of an autism diagnosis, such as individual adult aides (paraprofessionals); speech, occupational, and physical therapies; access to various environmental modifications and special education services; and a general understanding and acceptance of the presence of a disability. These benefits increase as more and more states are pushing insurance companies to cover private therapy services for children on the autism spectrum.[56]

Contrary to many parental understandings, a teacher in Atlanta believed that clinicians were too quick to provide an autism diagnosis. “They’re not as scared to diagnose” she explained, “but at the same time, because of the spectrum, they may be diagnosing to get some of the treatment packages that come with it. Because if you get that autism diagnosis, immediately you have this treatment package of OT [occupational therapy], PT [physical therapy], you know. And they may not be autistic. But then again, the diagnosis keeps changing.” Intuitively, this teacher understood Hackings’ complex

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[55] Misdiagnosis, whether purposeful or not, is widely considered to be one factor in the recent rise in autism rates (Grinker, 2008; Feinstein, 2010).

[56] As of August, 2012, 37 U.S. states and the District of Columbia had laws pertaining to insurance coverage for autistic individuals. In the early spring of 2013, Georgia legislators began to look at a similar law.

notion of the influence diagnostic practices has on the actual population of something popularly considered to be a stable, neurologically based condition like autism.

Conclusion

The clinic as a place of autism has several important structures: professionals, assessment tools, documentation, and appointments. These structures indicate that the clinic is a professional environment in which one should be able to access answers about a child’s differences. It is through these structures that the clinic becomes an inscribed space in which the meaning of the clinic becomes clear—that it is a place for professionalism, truth, and help. Low and Lawrence-Zúñiga (2003) define inscribed spaces as those that have been ‘written’ on by the people who inhabit them. The term describes “how people form meaningful relationships with the locales that they occupy, how they attached meaning to space, and transform ‘space‘ into ‘place’” (p 13). Clinics start out as amorphous spaces that families know to approach for answers and help. But as they inscribe places, the relationships people have with the clinic as place becomes more nuanced and reliant on personal experience and memory. This is how memory can imbue a place with personal meaning, as Tuan (1979) suggested.

Between my research sites, familial SES status and the characteristics of the child converge to influence a caretaker’s ability to get questions answered and the help they are seeking. Financial resources also influence the diagnostic practices by determining the clinic’s tools. This, then, shapes the autistic population of each site. In combination with an understanding of how the structures of a clinical place of autism convey practices and behavioral expectations, this information can greatly improve clinical cross-cultural interactions and so is critical for incoming interventionists, researchers, and advocates to understand before entering into a new community. The types of children identified will vary as will the importance caretakers and professionals place on exact diagnosis and the amount of information a family has about their child's differences. The structures within these places of autism communicate vast amounts of information about the experiences of autism in a particular locality. This is as true for clinics as it is for the topic of the next chapter, homes.

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Chapter 4: Homes: Therapeutic Use and Choice

Introduction

In 1979, humanist geographer, Yi Fu Tuan, described the home as a locality that is both a public symbol (i.e., a place easily imagined and identifiable) and a field of care (i.e., a place with little formal structure but evoke affection; Tuan, 1979). As a field of care, it conveys tranquility, power, and support. As a public symbol, we recognize the home as having areas for cooking, sleeping, bathing, and assembling with loved ones. Earlier texts describe the home as a place designed to allow for rest, peace, health, personal expression, family interaction, and intimate behavior. Homes allow for the expression of personal values and "social reproduction more generally" (Gilman, 1903; reprinted 2002; p. 3). When one can control personal space, routine, and environment, homes allow for the expression of one's identity and interests (Imrie, 2010). While the structure of and structures of homes vary widely both within and between cultures—ranging, for example, from chairs to mats and small structures to large, expansive buildings—the purpose and comfort of the home is communicated through these structures. "The physical design of dwellings is 'thoroughly embodied' in that each part of the domestic environment can be thought of as a 'body zone'" (Imrie, 2010, p. 26). This close corporeal relationship means that with the entry of bodies or minds that are different and unexpected, the relationship a home's dweller has with the space is drastically changed.

Geographer Rob Imrie (2010) notes how the body is unnoticed in the home as long as it remains comfortable. Once in pain, diseased, or disabled, the home becomes a place where the relationship between the temporal and physical structures of the home and the body becomes heightened and complicated. The disabled body or mind must adapt to or adapt the home, a task that, as the data in this chapter demonstrates, is eased with financial means and complicated without (Imrie, 2010). This practice is further complicated when the body or mind is that of a child who cannot easily communicate with caretakers. When a child's disability is primarily intellectual or developmental, parents have a more difficult time maintaining their pre-child routine or leaving the home regularly. The home is institutionalized as disabled individuals are contained inside or becomes a therapeutic space when typical, daily activities become teaching moments and therapists or educators cycle in throughout the day (Power, 2010). Any home is impacted with the introduction of autism, however, as demonstrated below, the educational and financial means to fully convert the home into a therapeutic space is closely tied to socio-economic class. This chapter describes how the introduction of autism into a home changes the structure, place, and meaning of the home and communicates cultural values of familial roles, autism, childhood, and normality. After a description of homes as places of autism in Kerala and Atlanta, I will describe how and when the home becomes a therapeutic or custodial space, how this shift influences parental acceptance of autism, and how parental and public acceptance is facilitated by the ways caretakers explain their child's differences.

Disability in Homes

When a home is altered by the introduction of disability and a need for caregiving, as in the case of caring for an elderly parent or a disabled child, the public and the private merge as outsiders begin to regularly enter the sacred space of the home. Particularly in Western homes, where care-taking extends beyond family members, the purpose of the home becomes the center for disability services and the inherent privacy of a home is diminished. Caregiving becomes a new and immediately central feature and purpose of the home (Wiles, 2003) which changes the way the home is physically designed and temporally organized. The connection between the body, the person, and the home ensures that its inhabitants are deeply affected by these changes. Outsiders rarely have a full understanding of the changes caregiving has on the home and the emotional life of the family (Wiles, 2003). This is particularly true in the case of children with disabilities, which is arguably more unexpected than the presence of an elderly parent. For some, these changes are easy to adapt to, some parents value the meaning and compassion this change adds to the home,[57] and other parents find these changes more difficult.

American laws such as the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA) are written with the expectation that most children with disabilities reside in their family's home with the parents as the caregivers. While this arrangement is in line with the preference of most parents, the requisite services for these families to adequately care for their children are rarely satisfactory. Not only is the availability and organization of services under par, but private and public insurance provisions further frustrate the ability of parents to sufficiently and comfortably care for their children (Hogan, 2012). As will be described

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[57] David Goode's close work with children born with rubella, which resulted in multiple disabilities, both in a state ward and in one girl's home describes how intimate connections are made between caretakers of children who do not communicate verbally. The parents he worked with felt deeply connected and enriched with their daughter, with whom they communicated through routines, layout of the home, likes and dislikes, and her bodily position and responses (1994).

below, my Atlantan informants reported insurance and financial difficulties as barriers to accessing services they feel their children need. In Kerala, services beyond special education schools are scant, especially in rural areas. However, since special education is available, which is not the case throughout India, children are less likely to stay in the home throughout the day.

In large cities like Atlanta, where a range of therapeutic and educational resources are available, one challenge for caretakers is the coordination between the various services, which for autism can be vast and overwhelming. Carbone, Behl, Azor, and Murphey (2010) describe the current systems of care as existing in “silos” with various eligibility requirements and little to no communication between systems. “This lack of coordinated care results in confusion for families, mixed messages from different treatment providers and promotes adversarial relationships between various disciplines” (p. 322) and, I would argue, within the home itself. Many of my Atlantan informants reported the need for a central location where services can be coordinated or more of a team-based approach can be established. One mother described this idea as having a a “hub” for her child’s services. Without this, she says, she has to do “just do what [she] can.” Caretakers usually find themselves having to act as service provider, having to learn how to navigate systems of care and manage their child’s needs and providers. Even though parents often ardently seek out and acquire this knowledge, professionals rarely consider parents to be experts in their child’s care. When parents sense this belief, as they often do, it causes tension between families and professionals

(Read, 2000; Benson, Karlof, & Siperstein, 2008; Carbone, Behl, Azor, & Murphy, 2010).

This tension is heightened when service providers have different approaches or beliefs about autism that cause conflict with other providers. These conflicts also cause confusion for parents on what is the best approach for their child. Parents find themselves having to explain to professionals how other therapeutic approaches work and the benefits their child may gain from them. In other words, the behavioral therapist may not understand or value the work of the art therapist who may disregard the benefits of a special diet. Caretakers of children with multiple disabilities—which was the situation for three of my Atlantan families—have the more pronounced difficulties in this arena. For example, a mother living in metro Atlanta struggled with getting services for her deaf, autistic son. She approached several facilities for either children with hearing impairments or for children with intellectual and developmental differences. Each, however, seemed to believe the disability they were not equipped to serve was the primary impairment. She recognizes that the combination of autism and deafness is rare and knowing which disability to address when can be confusing, but she was disappointed when professionals were even unaware of contradictory approaches. She explained: “A lot of the autism programs I’m recommended are like music therapy and you need to be very verbal with him and get him to talk back to you. So a lot of centers we go to, they’re like ‘There’s nothing we can really do with him here, maybe you can try another place.’ [And] if we go to a hearing impairment center it’s all about, ‘Well, he can’t make eye contact, he can’t focus.’” A lack of coordination and awareness between service providers leads to confusion and frustration amongst parents in communities where multiple treatments are available. In regions without services, caretakers are left to their own devices to figure out how to interact with and care for their disabled children. In either case, caretakers are left little confidence in their ability to care for children at home or find appropriate services in the community.

Caretaker experiences such as these are a good indication of how autism impacts the home. And they help suggest some steps to be taken to improve the quality of life for families of children with disabilities. When looking at households with children with disabilities in Goa, an Indian state just north of Kerala, Desai, Divan, Wertz, and Patel (2012) noted that the processes and phases parents of autistic children go through are similar to that of Western parents. However, the authors noted that caring practices "are flavored by the local cultural customs and dynamics" (p. 629). It is this "flavoring" that is looked at in this chapter to explore how caring practices, along with physical and temporal structures in the home, communicate locally specific practices for and values about autism, autistic children, and their families.

Previous research in South Asia has shown that caretakers are primarily concerned with a child's self-care and ability to live in society, that social support outside of the family is largely absent, and that services are scant (Desai et al., 2012; Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012; Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010; Maloni, et al., 2010). Parents in America have reported social isolation (Hogan, 2012), but also high levels of educational and therapeutic involvement (Benson, Karlof, & Siperstein, 2008; Lutz & Patterson, 2012). These efforts and struggles are supported by the data presented here in the informant comments and in the routines and materials of homes. Focusing on salient structures of the home—the people, the physical features, and use of time—I will explore how the home as a place of autism is intimately respondent to local cultural norms and values. As in the previous chapter, I will begin with a description of the physical structures of the homes of autistic children in Kerala and Atlanta. Again, these descriptions are composites of the many homes I have visited and, while I focus on describing generalities, I include the ways class and family structure contribute to variations within each location. Following this section, I will use interview data to describe uses of therapies, parental acceptance, and parental explanatory models.

Keralan Homes.

In urban areas, Keralan homes are located in small neighborhoods scattered throughout the city. These neighborhoods have at least one pharmacy (either biomedical or Ayurvedic), a few small shops with a range of basic home and grocery items, and at least one restaurant. Most families live in individual houses, although apartments are becoming more familiar in urban areas. Upper class families will have access to a car, however most travel is done by auto-rickshaw (a small, three-wheeled taxi) or bus. Rural homes are further apart but are located around a central shopping area that has vegetable, meat, and fish markets, bakeries, restaurants, and usually a bank, pharmacy, and internet cafe. Some homes in rural areas are located down dirt paths and are inaccessible to cars; these are approached on foot. Buses are the most common form of transportation in rural areas. Bus stops are up to ten or fifteen minutes' walk from rural homes. Regardless of location, basic home needs are accessible to most families, yet specialized items and services, including many medical and therapeutic services, can be difficult to access.

Keralan homes have a front patio or a constructed front porch where people spend time outside. For high-income families, this area may be gated to ensure the safety of vehicles parked there overnight. Plastic chairs or built-in benches are available so individuals can congregate outside. Men sit here to read the paper and chat. Women, who are usually busy cleaning or cooking, may sporadically find time to sit outside, relax, and talk to neighbors. Children play in this front area, making it easy to monitor their activities. Men will occasionally play with children here, kicking a ball or playing cricket. These spaces are most often used in evenings and weekends, when men are not working and children are not at school. Regardless of the ease with which men can monitor children's activities during these times, it is still the women who are in charge of ensuring children are staying out of trouble or doing their school work.

Apart from fans, which are ubiquitous, air conditioning in Kerala is rare in homes and public spaces; in order to ease the South Indian heat, people spend considerable time outside and leave windows open when inside. Thus, physical barriers between inside and outside, private and public, are less clear. As was the case in the previous chapter on clinics, fewer physical barriers mirror the general sociableness of people in Kerala and India; people are comfortable traversing spaces that more individualistic and enclosed communities, such as the United States, consider to be private and thus off-limits without specific invitation. These opens spaces also mean that mothers need to be hyper-vigilant with an autistic child, who may be prone to running or wandering off. Caretakers occasionally expressed concern about the possibility of their children getting lost. However, particularly in rural areas, the neighbors are often extended family, or at least familiar with the family, and so if they happen upon the child far from home, they can return him to his family. Urban families are more likely to have a fenced in front area or not leave doors open to prevent these incidents.

One enters a Keralan home through a front door that leads into a living room area. This room varies in size based on the size of the house and either doubles as or is adjacent to the dining area. The front room has several seating options, such as small, wooden framed couches and arm chairs or a table with a table cloth and several plastic or wooden chairs. Sometimes there is a television in this room, however many families keep televisions out of sight in bedrooms. These rooms often have a bookshelf with glass doors built into the wall. These shelves holds documents, knick knacks, pictures, or a few small toys. Apart from these items and perhaps some religious iconography, front rooms do not contain any other entertainment or personal items. These rooms are meant for meeting with visitors and having conversations, which may be why distractions are kept to a minimum. This allows easy access for visitors, who frequent throughout the day, especially on weekends. Neighbors or family members frequently come by to say hello, have a chai, or deliver some news or goods.

Indoor bathrooms are located near this common area or adjacent to a bedroom. Some homes have a sink for hand washing located near the dining area. Homes without indoor plumbing have water in buckets for hand washing located near the front or back doors and outdoor, outhouse style toilets. Hand washing before meals is a requirement in

India as one eats with one's hands, without utensils. Bedrooms are located behind or off of the sitting room or upstairs in two-story homes. They contain twin- or queen-sized wooden beds and a dresser. Personal items are kept here, but bedrooms are not decorated with paint or special items to indicate the bedroom's occupant, as is often the case in Western homes. Some bedrooms also have small desks, radios, or televisions. Generally, bedrooms are not designed to spend time in when not sleeping or changing clothes. This adds to the frequency of congregation in the living rooms or porch. Older children may do homework in their bedrooms but are just as likely to do so in the sitting room or main dining area.

The kitchen in located towards the rear of the house and is where women spend most of their time. There is a refrigerator, a long concrete or stone shelf on which to cut and prepare foods, a gas-powered stove, a sink, and storage areas for food, cookware, spices, plates, and utensils. These rooms often look out onto the back or the side of the house. All meals—breakfast, lunch, and dinner—are prepared here and take two or more hours from start to finish, particularly when feeding large numbers of people as is the case with joint family living situations. Meals require this time whether one or several women are preparing the food. In between preparing meals, women clean, do the household shopping, and do the laundry, which is usually done by hand and must be done several times a week.[58] As Keralan women are the primary caregiver for all the children they must ensure they are all bathed, clothed, and fed. Outside of taking care of the home

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[58] Many households have *velakkaran* (servants) who help prepare meals, do laundry, and clean houses. This is more common in urban areas and in middle- and upper-class households. Occasionally, these servants also help care for the children but mostly they are responsible for the more physically demanding household tasks.

and the children, women have very little time to socialize or, in the case of autism, engage in therapeutic activities. Mothers are known to be very indulgent with young children, particularly males (Kakar, 1981), meaning they often predict and take care of a child's needs. If a child is developing differently the mother is less inclined (or able) to teach and encourage independence in the way that many Western parents would.

When a visitor arrives in the home, he is immediately offered *chai* and snacks or invited to stay for the next meal of the day. Visitors are always served first, as are the men in the family. Women do not sit and eat with the rest of the family or visitors but will wait until the meal is completed and eat what is left in the kitchen before cleaning up from dinner. Children may be served first, at which time the mother can help those who are unable to feed themselves, such as infants or children with disabilities. All family members eat the same meals; children are not served more 'child-friendly' foods. Although, as is discussed more fully below, some autistic children are very selective about their food and will only eat certain food items, mothers rarely prepare separate meals for them and instead serve them the food items from the meal that their child is most likely to consume.

According to Indian psychoanalyst and author Sudhir Kakar (1981), the Indian home is hierarchically organized by age and gender. This ranking is reflected in the order in which family members and visitors are served. Older family members rank higher than younger ones and men rank higher than women. Regardless, the wife of the family patriarch is incredibly important and though she "may indeed pay a formal, and often perfunctory deference to her husband, especially in front of strangers, she may exercise considerable domestic power, not merely among the other women of the household, but with her husband, and she often makes many of the vital decisions affecting the family's interests" (p. 118). For homes with an autistic child, mothers are the primary caretakers and decision makers, but the fathers ultimately make decisions for which treatments to pay or not to pay for. This holds true in Kerala which, though a matrilineal society, remains patriarchal (Jeffery, 2004).

As described above, the mother’s time is a valuable and scant resource. When observing in the homes of my informants in Kerala, the mother was always engaged in some sort of household task, usually cooking. Children played in the house or the yard while she tended to her tasks. Eleven of the families in this study were living in an extended family home situations and many more had family living in the same neighborhood or village. Thus, a female sibling or grandparent is often present to help watch after an autistic child, however they are just as likely to be engaged in other home-care tasks, such as cleaning, cooking, or running errands.

While the presence of extended family can be incredibly helpful in raising an autistic child in India, it can also create certain stresses. Some mothers reported other family members blaming her for the child’s differences or otherwise not understanding or accepting the child. One mother reported being kicked out of her in-law’s home because they did not want to deal with her autistic son, whose differences they blamed on her. Another explained, “Most of our relatives and friends can not cope with [my autistic daughter] being hyperactive. If we go to their houses, she runs around and makes a mess with the things at their houses and they say she should be sent to a residential special school. They think it is my fault for not taking care of myself during pregnancy." This was a fairly common experience in Kerala and one that is shared with many mothers in the U.S. as well. Historically, American mothers of autistic children were called 'refrigerator mothers,' a term that referred to mothers who were so cold and unresponsive to their children in infancy that the child turned inward and became autistic (Bettelheim, 1967; Feinstein, 2010, Grinker, 2008). Contemporary maternal blame, however, is more subtle and is present in statements about mistakes a mother made during pregnancy, such as eating tuna or using the microwave (Gray, 2002; Sarrett, 2010). Even when interactions with family members and neighbors are not antagonistic, there is a discernible gap in the understanding and acceptance of the child. Within the community, there is considerable stigma accorded to the entire family when a child has a disability. Thus, families can be both a source and a victim of stigma (Lauber & Rössler, 2007), leading to, as will be discussed in the next section, social isolation and specific ways to talk about a child's differences.

Because of the way time is structured in the Keralan home, particularly that of the mother, children have periodic unstructured, unsupervised time. Autistic children may spend this time engaging in self-stimulatory behaviors for self-regulation and entertainment, such as exploring leaves or cloth, rocking, or jumping. In the home, these behaviors are tolerated more so than when the child is in public. Even if the behaviors are unwanted by the family, the mother is unable to devote the time to frequently interrupt these behaviors and redirect the child to another activity.

Along with maternal time, toys are scant in Keralan homes. This holds true regardless of the family's income level. There may be some evidence of children living in the home in the form of small toys or, perhaps, some crayons or books in the front room or the front yard, but these items are often kept in a cabinet rather than left out around the home. Toys are not a primary household expense; Kerala has very few toy stores though some are available at general stores. Because of this, children have very few personal toys, particularly in comparison to Western children, and do not expect many personal play items. They play outside with each other, listen to music, draw, read, study, watch TV, or help out around the house. The Keralan homes with autistic children involved in this study did not have autism-specific materials such as charts, educational items, or visual displays.

These factors—maternal time and child-specific items—are important considerations for anyone interacting and working with families of autistic children. A Keralan home would not be able to begin or continue a home-based program that requires many materials or the attention and inclusion of a caretaker. Programs and interventions used by families in Western areas are rarely translatable or feasible for families in communities that do not have the financial, temporal, or material resources of those in Western nations. This is a critical point for anyone interested in working with autism in developing areas and will be discussed more fully throughout the chapter.

Child-specific materials and maternal time serve as the primary distinguishing factors between Keralan homes and Atlantan homes. Understanding the ways a home's time and resources are utilized in the presence of a child with autistic characteristics can drive and direct interactions with families. Without the time or material resources to do so, Keralan homes are far less rehabilitation focused than, as will be described in the next section, those in Atlanta.

Atlantan Homes.

Homes in and around Atlanta are organized in distinct neighborhoods and are all accessible by car. As opposed to Kerala, the preferred mode of transportation in Atlanta is a car; the public transportation system is often difficult to navigate but is available to families without cars. Similar to Kerala's homes, there is an outdoor seating area in the front and, upon entry into the home through the front door, one enters into a communal seating area, the living room. The outdoor area is less frequently used in Atlanta as most homes are equipped with indoor heating and cooling systems. Because the interior temperature of homes is easy to manage and control, spending much time outdoors, particularly in the summer heat and the winter cold, is rare. Additionally, homes in Atlanta are likely to have a fenced-in backyard or clear property boundaries such that when children play outside, they are physically contained on the premises. Aside from those homes with fenced-in parking areas, homes in Kerala generally reserve fences for animals, such as chickens, dogs, or even cows, that are kept at the home. Thus, in comparison to Keralan children, Atlantan children and families have fewer opportunities to engage in unplanned interactions with neighbors.

Some families rely on the front door as the primary entry point and others rely on garage or side doors to ease the transition from the car. Through the front door, one enters into the living room whereas the side door often brings one into the kitchen. Living rooms are usually decorated with family photos and contain a couch and a few arm chairs and small tables. These furnishings are usually organized around an entertainment center holding a television. Sometimes bookshelves with various reading materials are also present. Upon entry into an Atlanta home, the presence of children is clear. The entertainment center in the living room will have children's movies and video games; the living room will have a toy area containing trucks, doll houses, puzzles, and art materials; bedrooms will be decorated for the child with painted walls and bedsheets made of the child's favorite cartoon characters or bright colors. Food preferred by children, such as cereals, macaroni and cheese, and juice boxes, are present in the kitchen as are plates and utensils designed for children.

The presence of an autistic child is evident from the various toys and educational materials. Families whose children do not communicate verbally may place Picture Exchange Communication System (PECS) symbols around the house. PECS symbols—which are simple, line drawings depicting everyday items or activities—hang on the wall or refrigerator so a child can easily access a picture of a food or drink item she would like and hand it to a caretaker as a way to request this item. Children who are learning to manage their self-care skills may have visual schedules comprised of PECS symbols located around the house to help them perform the task with little or no adult help. For example, a child learning how to wash his hands will have a visual schedule indicating to first turn on the water, then run his hands under the water, then get soap, and so on.

When needed, other forms of visual aides are scattered around the house for various reasons. In the kitchen, visual symbols, such as red and green cards, are seen on the wall or refrigerator indicating when it is and is not time to eat. For children on specific diets (see below for more information about these diets), a list of foods approved by the diet is displayed. Often, a large calendar is hung in the kitchen or other some common area indicating the schedule of any therapies, in-home care, doctor's visits, and school meetings as well as other family events and activities. These calendars are coordinated and maintained by the mother, who is the most common program manager for an autistic child (Grindle, Kovshoff, Hastings & Remington, 2009; Carbone, Behl, Azor & Murphy, 2010). These calendars include activities for all family members to ensure siblings and caretakers are able to perform their activities and ensure the autistic child is being watched. Doors, windows, and cabinets have special, child-proof locks and staircases are blocked with baby gates, even if there is no baby in the house. These measures are taken to ensure the safety of an autistic child, who may be prone to running out of the house or still learning to avoid areas containing dangerous items, such as knives or cleaning materials.

Autism-specific materials are more likely to be present in the homes of families with higher socio-economic status and, thus, the financial ability and educational awareness to access these resources. Yet, even homes that are not replete with rehabilitative materials have some indication of the presence of autism or disability in the home. This is especially true for families where all caretakers work, including and especially single-parent homes. Research has shown that mothers of children with disabilities are less likely to return to work the first two years of their child's life but may go back once the child begins school (Hogan, 2012). Managing work and income is much more difficult for single parents, of which this study included five. Only four of my Atlanta informants had one stay-at-home parent, meaning thirteen families required all caretakers to be working outside the home. These families have significantly less time to spend organizing the home, making it difficult to repair areas an autistic child disarranged or damaged. Often, one can see broken furniture, small holes or markings on the wall, or items in disarray. Keralan homes have fewer of these indicators because most mothers do not work (four of the mothers I interviewed worked outside of the home) and many homes had extended family members living in the home or nearby to help with home maintenance and upkeep.

Maternal time and material resources are used differently in Keralan homes versus Atlantan homes. Atlantan homes are much more therapeutic, evidenced through the autism-specific educational materials scattered throughout homes and/or frequent disarray from an autistic child's behaviors. Mothers report spending significant time engaging with their children in therapeutic manners during everyday activities from having conversations with an express purpose to encourage a particular social or communicative skill, to explaining the details of changes in a schedule several days in advance. Building on knowledge garnered through books, the internet, trainings, and discussions with professionals, caretakers in Atlanta constantly look for ways and times to work on improving certain skills or reducing certain behaviors. Everyday activities are instinctively turned into therapeutic encounters.

The shift in a home's time and materials towards being a therapeutic space, both visible and invisible, indicate the importance of this child's safety and rehabilitation.

Human geographer Yi-Fu Tuan (2012) explains that “there is no clearer indicator of status than who waits for whom” (107). Differently than space, time is limited so the ways people choose to use it, splice it up, and organize it reflects personal and cultural values and hierarchies. The emphasis of the autistic child’s progress or, for some, cure, is noticeably more central in Atlantan homes than Keralan homes. The same can be said for material resources, which, in Atlanta, are far more likely to be dedicated to the education and treatment of autism than in Kerala. One mother in Atlanta described how she and her husband took their retirement and ‘rainy-day’ money to pay for their child’s autism-focused private school. For her, and for many families, addressing autism becomes a primary concern for the entire family system. Rather than indicating a family’s or community’s perspective on the importance of these children, this difference is indicative of variations in families’ access to treatment and service options.

Atlantan homes are easily turned into a therapeutic space while Keralan homes focus on management, often becoming an custodial space. The former is rehabilitative while the latter is focused on basic care. Therapeutic Homes are tied to a different availability and type of resources than custodial homes. Most homes have characteristics of both types of homes—Atlantan homes sometimes must focus entirely on just getting an autistic child fed or bathed and Keralan mothers may find some time to engage in speech building activities suggested by a professional—but overall, the homes in each region are more distinctly rehabilitative or custodial. Predicting and confirming which approach a home is will greatly enhance the ability of a researcher, clinician, or advocate to generate realistic and trusting relationships with caretakers. After presenting data reflecting these differences and which families are able to access services, I will describe how the availability of treatment and educational options are critical to both parental acceptance and the ways caretakers talk about and explain their child's differences.

Therapeutic Choices, Stigma, and Parental Acceptance

Kerala and Atlanta differ greatly in terms of the availability of autism-related services. Atlanta is saturated with various therapeutic options; families can find behavioral, speech, occupational, and physical therapies along with equine, water, art, and music therapies. Kerala has significantly fewer options. Speech and behavioral-based therapies can be found in urban areas, however occupational and physical therapy, both considered in America to be hallmark services for autistic children, are unheard of. While most of the autistic children with whom I interacted in both locations attended school and received some level of services, be it special education or some type of weekly therapy,[59] children in Atlanta were far more likely to get private services outside of school.

Of the thirty-two families interviewed in Kerala, ten (31%) had tried or were doing some sort of therapy in the home or regularly attending a speech clinic.[60] The families who did in-home therapy usually did so by following suggestions from a therapist or pediatrician with whom they had consulted. Obtaining these recommendations, particularly on a regular basis, was difficult for families living in rural areas. Five of my caretaker informants in Kerala, all living in rural areas, reported traveling to a facility in a nearby town and staying for at least a month for assessments,

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[59] Some Keralan children did not attend school, however are more likely to attend school than disabled children in the rest of India. See the next chapter for more information on the school-based services in both locations.

[60] This number may be an inaccurate reflection of the larger Keralan population since I recruited from the therapeutic clinics in Trivandrum.

diagnosis, and suggestions of strategies to try in the home. Follow-up visits are difficult, expensive, and infeasible for many families. Occasionally, Block Resource Centers (BRCs)[61] sent special education teachers to the home to work with children who, because of physical or social barriers, are unable to attend school. These visits, which occur about once a month, focus on getting updates on the child's progress and showing the child's mother techniques she can work on in the coming weeks. Those living in urban areas who were able to attend therapeutic clinics did so about once a week. The parent who brought the child to the visits, usually the mother, sat in on the sessions. In this way, she learned strategies for increasing or encouraging language, teaching academic skills, or curbing difficult behaviors. However rural and urban mothers reported not being able to consistently follow these recommendations as they have neither the time nor training to fine-tune recommendations to meet their child's specific needs. Again, the daily routine of and time constraints at the home becomes an important driver of rehabilitative activities in the home.

Atlantan caretakers have much wider therapeutic options and so are far more likely to engage in services outside of the school or home. Private and public insurance can be used to access these services, however there are limits to the number of sessions covered per year. Also, as noted in the previous chapter, autism-related therapies were not covered in the state of Georgia at the time of data collection. Because of this, professionals provide documentation of another condition, such as a speech-related disorder, so that services can be reimbursed. Some services cannot start until this

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[61] Community based centers that provide certain services to families. See chapter five for a description of these facilities.

documentation process takes place and the insurance company agrees to cover them. This can often be a very frustrating and distracting process for families, who frequently fight with insurance companies to get retroactive coverage for services already accessed or approval for services the child should start immediately (Hogan, 2012). One occupational therapist described the complex process her clinic goes through:

> We have a social worker on our site and she's really good and she's always like, “It doesn't matter if he gets that diagnosis, it doesn't change how we'll treat him,” which is true. Which is going to give us something work to with and just give them [the family and child] better [services] to actually get more visits because if he just has a diagnosis of developmental delay, insurance isn't going to give you as many visits but if he has a secondary diagnosis, like a major diagnosis, they have clauses that they get more visits which is what one of my other kid's insurance did. They had a clause and then they got more visits.

Each insurance company has specific regulations regarding which conditions are covered, when they are covered, and how many sessions are allowed. Navigating these systems is complicated for families and professionals, compelling many facilities, such as the one this therapist was working at, to hire an individual dedicated to dealing with insurance companies.

Other therapists described instances in which they were seeing a child regularly and had to stop services because the child ran out of visits for that year. Usually, services would start up again during the next yearly insurance cycle. This kind of stop and start therapy is fairly common and frustrates parents, making them feel like the child loses critical progress and may even lose skills picked up in therapy. Sixteen Atlantan caretakers (94%) cited finances as part of their treatment decision making and ten (58%) specifically expressed frustration with insurance companies. Cost of services and, as discussed in the previous chapter, getting initial appointments are the most commonly cited difficulties among my Atlantan caretakers. One mother explained, “It starts all the way back with insurance, Medicaid and stuff you know. I mean, I feel it takes so long to get into any place that so much more damage is done in the amount of time that it takes. Three and a half months to get her into speech therapy. You know how much she could've learned in three and a half months!” Here, the idea of losing critical time is very upsetting to this parent. This is a common response throughout Atlanta as parents are always told that the earlier one can identify autism and begin services, the higher likelihood their child’s will improve in terms of a reduction in autistic characteristics.[62]

As is the case throughout the U.S., therapeutic services in Atlanta can be either in the home or in a clinic. Home-based services are provided by a trained behavior, occupational, or, sometimes, speech therapist who works on a variety of academic, developmental, and social skills. Outside services include behavior therapy as well as speech, occupational,[63] physical,[64] and alternative therapies. Floortime, which is an

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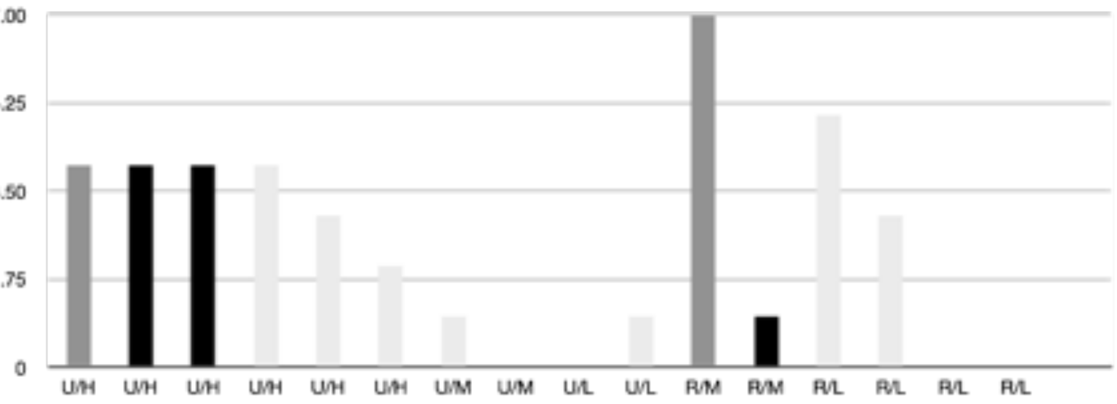
[62] For example, see the CDC’s “Learn the Signs, Act Early” campaign, which emphasizes the importance of parents’ ability to recognize children’s divergence from typical developmental paths. See the campaign details at: http://www.cdc.gov/ncbddd/actearly/index.html.

[63] Occupational therapy focuses on fine motor skills, such as holding a pencil or holding and picking up small items, as well as sensory integration types of activities that help streamline a child’s sensory processing abilities through activities such as brushing the skin and swinging.

[64] Physical therapy focuses on gross motor skills, such as jumping, running, and balancing.

approach similar to behavior therapy in the range of skills addressed but is characterized by the therapists getting ‘on the floor’ with kids and using what the child shows interest in to create teaching moments, is another popular approach that can occur either in the home or in a clinic. Social skills and sports groups are accessed to teach children how to interact with peers and adults. Alternative therapies include art, music, and water therapy as well as yoga and hippotherapy, which is the use of horse riding for motor and sensory input. All of these therapies were used by at least one of my Atlantan families and many families accessed more than one. Graph 1 shows the distribution of the number of therapeutic services accessed at any time by my Atlantan informants. It is split into rural and urban families and by SES and reflects the number of the child’s autistic characteristics, as reported by the caretaker.

Graph 1: Therapeutic Services Access by Urbanicity and SES



U: Urban; R: Rural
H: High SES; M: Middle SES; L: Low SES
Dark: 10 + autistic traits; Medium: 5-10 autistic traits; Light: Under 5 autistic traits

This chart shows that, with the exception of one family who lived in a fairly well-populated area outside of Atlanta, families in urban areas with higher incomes and access to resources use more services than those living in rural areas regardless of child characteristics. Families with low SES, even those with children with more significant and numerous autistic characteristics for whom professionals would suggest multiple interventions, are unable to access services outside of those offered through the school system. Even with insurance or Medicaid, many of these families do not have the time to bring children to services, do not live in an area where services are easily accessed, or have no access to information about the existence or need for these services.

As in the previous chapter regarding the number of clinic visits taken to get a diagnosis, we see that families with higher SES, and ostensibly higher financial and temporal resources, engage in more therapeutic options. Accessing these services serves to turn homes into therapeutic places of autism and the primary caretaker, the mother, into another professional. Even therapies that occur outside of the home, as most do, require scheduling, travel, waiting, and documentation. Interventions as seemingly simple as medication or diets contribute to the home becoming a therapeutic space.

Medication use, be it vitamins, herbal medicines, or biomedical pharmaceuticals, was the most commonly reported intervention in both locations—twenty-two (69%) Keralan caretakers and eleven (65%) Atlantan caretakers reported currently using medication to alleviate their child’s autistic characteristics. There are no medications designed to treat autism. Any medication is used addresses particular autism behaviors or traits. In Kerala, fourteen families were using Ayurvedic, homeopathic, or some other traditional medicine. Caretakers believed that these medicines have no side effects and so are safe.[65] Some of these caretakers used Western, biomedical medicines in the past but felt they were too strong. One mother described her son's reaction to these medicines and why she stopped them: "At the medical college the doctor had prescribed a tablet for his hyperactivity and he used to be very silent, sleepy, and such. Dr. P [the Ayurvedic physician] stopped us giving him the tablet and said not to stop his hyperactivity, that he should be hyperactive to grow. We think the [Ayurvedic] doctor was right." The notion that Western medicine was too powerful and made the child "dull" was a common sentiment among Keralan caretakers and professionals. Many traditional or Ayurvedic physicians requested that the child be taken off these medications. Western medication was most commonly prescribed and adopted when the child had "fits" (seizures) and, less frequently, aggressive or hyperactive behavior.

Overall, American autistic children have a high rate of medication usage, especially psychotropic medications such as anti-depressants, anti- anxiety medication, or neuroleptics. A 2008 study found that 56% of autistic children enrolled in Medicaid were on at least one medication, with 20% being on three or more (Mandell, Morales, Marcus, Stahmer, Doshi & Polsky, 2008), suggesting SES is negatively correlated with medications used. A 2010 study of over five thousand autistic children found that 35% used at least one medication. Children with private insurance or no insurance were far less likely to be on more than three medications than children on Medicaid (Rosenberg, Mandell, Farmer, Law, Marvin & Law, 2010). A recent report found that ASD patients are prescribed far fewer medications in the UK. Of the 5,651 patients studied, 29% were

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[65] Traditional medicines are not without side effects.

prescribed a psychotropic drug (Murray, Hsia, Glaser, Simonoff, Murphy, Aspersion, Elkhound, & Wong, 2013). Still another study found that Americans had higher rates of prescribing psychotropic medications for autistic children (108 of 10,000) than the UK (68 of 10,000), Germany (11 of 10,000), Italy (4 of 10,000), and France (4 of 10,000). The only countries with comparable rates of prescribing was Spain (100 of 10,000) and Canada (184 of 10,000; Hsia, Wong, Murphy, Simonoff, Buitelaar, & Wong, 2013). In this study, of the eleven (65%) Atlantan informants who were currently giving medication to their autistic child, five used psychotropic medications alone, four used both psychotropic medications and supplements (e.g. B-12), and two were using supplements alone.

When used to address autistic behaviors, daily pill regimes are usually more complicated than they at first appear. Because of the higher usage of psychotropic medications in the U.S. and general distrust and inaccessibility of Western medications in non-Western locations like Kerala, pill-related difficulties are primarily encountered by American families. Beginning a pill regime is a difficult and long process. Many children must cycle through several different medications before the proper dosage and medication is found. This means the caretaker must make several doctor visits and be particularly attuned to changes in behavior, perhaps even keeping a daily log. Additionally, medications must be given at certain times of day, with or without food, in certain combinations or not with other pills or foods.

The actual form of the medication must be taken into consideration. Some autistic children have sensitivities to food items that may be in the pill casings and so medications must be special ordered so they can be given in liquid form. If a child is not comfortable with taking pills or liquid medications, a skin patch can be tried. These patches, however, can cause skin irritation and for children who have particularly sensitive skin, their presence may be intolerable. All of these options must be considered before the perfect combination of form, timing, dosage, and type is found through a long process of trial and error. Even then, medications are adjusted throughout the child's life as her tolerance to them will change.

Side effects can be the most confusing and difficult aspect of giving psychotropic medications. One Atlantan mother reported going through five different medications over the course of several years. The first caused uncontrollable crying. The second gave her son "the shakes." The third soon led to aggression; during one aggressive episode, his father had to call emergency services. The fourth medication seemed to work for about a year, but then the boy "started having a problem with stiffness where he'd be like [shows me stiff arms]. And you'd call him and you wouldn't get a response." The fifth, and final, medication brought the aggression back. Although "his doctor had said it does not cause aggression. [Her husband] thinks he might not have liked the way it made him feel." This final statement highlights another concern medication gives families: children who do not communicate verbally have a difficult time alerting their parents to uncomfortable sensations from medications. While Keralan families attribute these side effects to the strength of the medication and stop using them, Atlantan families are more likely to persist.

Medications require attention to behavior, changes in regimen, and adherence to pill schedules. Dietary interventions, on the other hand, require changes in grocery shopping and cooking habits that effect the entire family. Nutritionally based interventions have been explored since the early 1970s and became popularized in the 1990s. The most common diet for autism, the GFCF diet (gluten free, casein free), removes all food items containing grains, especially wheat, or dairy proteins. It is built on the premise that defects in the intestinal barrier of autistic children lead to autistic behaviors when dietary peptides, particularly gluten and casein, permeate the intestinal linings through lesions and result in neurological and neurodevelopmental differences. Although the 'leaky gut hypothesis' has some supporting evidence, most scientists believe more research needs to be done to substantiate the evidence (Karl, Eeriness, Souders, & Pinto-Martin, 2013). Two of my Atlantan caretakers were currently using the GFCF diet with their child; one had tried it in the past but saw no changes, and stopped. While most Atlantan informants had heard of the GFCF diet, none of my Keralan caretakers were aware of it, although many did report trying to keep fried and sugary foods out of their child's diet. These families considered that diet and nutrition could be a cause of their child's differences or that diet could exacerbate their child's behavioral difficulties. Four Atlantan caretakers reported dietary changes similar to those Keralan families tried, including organic diets, healthier diets, or those based on the child's food selectivity, which is another frequently cited nutritional concern with strong influences on household routines.

Food selectivity occurs when children prefer to eat foods of certain textures, colors, temperatures, or types, and may entirely avoid other foods. Caretakers in both Atlanta and Kerala reported some food selectivities. One Keralan mother explained, “Food and all he is very particular about. He knows what he wants and other things he won't touch.” For example, one child would only eat items in small, single portions (e.g., one chip at a time); another child refused red foods; various other children had strong preferences for crunchy, ‘bready’, sweet, or spicy foods. Food preferences such as these can be concerning for caretakers in terms of a child’s nutritional intake and the added steps in creating meals readily eaten by their child.

In addition to food selectivity, some children need help physically eating the food either because of difficulty holding utensils, as is the case in Atlanta, or picking up food by hand, as in Kerala. In Atlanta, caretakers are able to access therapies directed at teaching self-feeding through private services or within school systems making the need to help a child eat is less common. Although Keralan caretakers and special education teachers readily hand-feed children, this was not an indication of accepting this trait as much as it was a lack of time and resources to devote to teaching independent eating. Although hand-feeding a child is a time consuming and distracting task, with young children it is common practice throughout the Indian culture. Teaching self-feeding is a more involved task on which Keralan mothers are simply unable to focus. Often hand-feeding continues beyond the usual age at which mothers hand-feed children. Developing and following a new diet and managing meal times when family members have different food preferences and consumption practices alters the home environment in noticeable and important ways.

Pills, food, and therapies are structures and practices that can turn a home into a therapeutic space. The uses of these interventions are closely tied to and mediated by urbanicity and socio-economic status. I would also argue that the use and awareness of multiple interventions delays caretaker acceptance of the permanency or stability of their child's autism. In other words, as long as there is another approach a caretaker can employ with their autistic child to reduce autistic traits, they are more likely to continue hoping for and expecting changes. Therapies and interventions for autism began to appear en masse in the late 1980s and early 1990s as awareness of autism was accompanied by fearful reports of sudden and dramatic rises in rates (Grinker, 2008; Offit, 2008; Feinstein, 2010). Researchers, clinicians, and entrepreneurs responded with numerous treatments and 'cures' for autism, particularly once people began believing a cause—vaccines—was identified. This occured in 1998 when British researcher and surgeon Andrew Wakefield claimed to have found a link between the measles, mumps, and rubella (MMR) vaccine and autism.[66] Caretakers, believing that autism could be avoided and possibly reversed, started looking for ways to prevent and cure autism. Although the vaccine link has since been debunked, most recently in a 2013 article in *The Journal of Pediatrics* (DeStefano, Price & Weintraub), this work continues to incite a fear of autism

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[66] There are two ways in which the MMR vaccine has been linked to autism. Wakefield's claim is related to the 'leaky gut' hypothesis and states that the measles part of the MMR vaccine causes infection and inflammation in the intestines, which allows harmful proteins to enter the bloodstream and brain. The other link claims that a mercury-based preservative found in vaccines, thimerosal, causes mercury poisoning which leads to serious damage to the nervous system. Both links have been discredited (Offit, 2008).

and vaccines as well as generating numerous treatments for autism, some valid and others false or even dangerous.

Paul Offit, who has written a book about the Wakefield controversy and events behind other dubious autism interventions, noted that “parents of children with autism—driven by a genuine desire to help their children—are desperate for a cure” (2008, p. xxx). Currently, there are myriad treatment and educational options available for children on the autism spectrum in the United States. Most are not likely to cause the children or families significant harm beyond financial and temporal strain, yet some treatments, like chelation (the process of removing then slowly reintroducing metals in the body) and MMS (Miracle Mineral Solution; a bleach solution), have been known to be harmful or even fatal. The plethora and range of intervention options are reliant on a Western biomedical model of autism that frames autism in negative, deficit-focused terms and so promotes the importance of reducing or eradicating autism. Individual caretakers, then, actively seek out rehabilitative options that are both affordable and geographically accessible.

Caretakers with access to the Internet can easily find information about treatments touted by marketers and other parents as cures for alleviating autism. Parents in America can spend years and hundreds of thousands of dollars trying out various therapies and treatments.[67] As noted above, most families in the Atlanta area tried multiple treatments. Although many Keralan families try Āyurvedic or homeopathic interventions, once these

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[67] A 2007 study from the Yale School of Medicine used information from private health insurance providers to estimate the average annual cost of health care expenditures for a child with an autism spectrum disorder to be $5,979, with a median of $3,368, in 2004 (Leslie & Martin). A 2012 article looked at families using Medicaid to access services for an autistic child and found that 78% of families had additional costs; 42% of the families reported spending over $500 and 34% reported spending over 3% of their income on autism-related services (Parish, Thomas, Rose, Kilany, & Shattuck).

resources are exhausted, the parent begins accepting their child's autistic behaviors as permanent. Fewer therapeutic options can facilitate an earlier caretaker acceptance.

In Kerala, I observed caretakers putting less effort into rehabilitative attempts and more effort into basic care and quality of life fairly early in their autistic child's life. Although it is difficult to find specific and clear data to support this, the study from Desai et al. (2012) noted in the previous chapter is useful here as well. The authors described a process in Goa that is similar to what I observed in Kerala. Talking to parents of children diagnosed with autism, they concluded there were four stages those parents experienced: beginning the parenting journey, interruptions from the path, roadblocks along the way, and here but not yet there. This final state is characterized by the parents accepting and addressing their child's differences by "aim[ing] to accept their child's limited capacities, to expand them as much as is possible in relation to the given social realities, and to attempt to change those social realities so that they would become more welcoming for their child" (p. 622). This stage was usually reached before the teen years, which the authors believe reflect when a parent's judgment about what their child should be doing shows stark contrasts with what their child is actually doing (Desai et al., 2012).

American research related to parental acceptance focuses on parental stress (Hayes & Watson, 2012). This research is closely related to work on parental coping styles and factors that mediate coping, such as religion, personal characteristics, and social support.[68] There is little research directly discussing parental acceptance of autism. This lacuna in research aligns with the medical model notion of autism: a state of being that is unwanted, broken, and in need of normalization. A 2012 article looked at how "child problem behaviors" (e.g., self-injury, hyperactivity, ritualistic behaviors) influenced parental acceptance. Here parental acceptance is defined as purposefully and actively embracing life events without making overt attempts to change these events. The study found that parental acceptance was related to fewer mental health concerns for the parents (Weiss, Cappadocia, Macmullin, Viecili, & Lunsky, 2012). It did not explore how or when this acceptance takes place. Unfortunately, the current study did not actively seek out data to reflect parental acceptance of their child's autism. However, by comparing caretaker perceptions and thoughts about their child's future, there is some indication that Keralan parents accept their child's autism earlier than Atlantan.

When asked what they want or see for their child's future, about half of the caretakers (50% Keralan, 59% Atlantan) discussed some iteration of normality, be it full recovery, cure, or changing to be more like neurotypical children. The average age of the children at the time of these statements was also similar (7 years for Keralan children, 7.6 years for Atlantan children). What differs between the two groups was the level of belief in the actuality of this future. Whereas only three Atlantan caretakers used a word like "hope" to describe this future, twelve Keralan parents did. Keralan families were more

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[68] For recent examples, see: Pozo P, Sarriá E, & Brioso A. (2013) Family quality of life and psychology well-being in parents of children with autism spectrum disorders: A double ABCX model. *J Intellect Disabil Res.* Apr 19. doi: 10.1111/jir.12042; Reiger, A. & McGail, JP (2013). Coping humor and family functioning in parents of children with disabilities. *Rehabil Psychol.* Feb;58(1):89-97. doi: 10.1037/a0031556; Zabolotsky, B, Bradshaw, CP, & Stuart EA. (2012). The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders. *J Autism Dev Disord.* Oct 26. [Epub ahead of print].

likely to match statements of a desire for cure with comments reflecting more pragmatic goals. For example, a parental pair in Wayanad expressed their desire that their eight-year-old with significant autistic features would become independent and able to care for himself. Later, however, they said, “We are worried if he will be able to speak the basic things.” They wanted full independence but are also aware that basic communication skills may be difficult for their child. Alternatively, Atlantan caretakers were more likely to make statements suggesting confidence in their child’s ability to recover. One Atlantan mother of two autistic children, a three-year-old girl with significant autistic traits and a six-year-old boy with moderate traits of autism, stated she “just want[s] them to experience life. The good and the bad. You know, getting married, having kids, making friends.” Keralan parents say they want improvement but expect their child to remain disabled throughout their lives, while Atlantan parents are more likely to expect their children to recover or experience dramatic reductions in autistic traits. Parental assessments of children’s prognoses are closely tied to the type of homes described above. One could imagine that parents who expect their child to eventually recover or normalize would foster a therapeutic home, while those who expect their child to maintain their autistic traits would foster a custodial home.

Parents in both locations made comments about wanting their child to learn basic, self-help types of skills. This includes activities that can increase the child’s independence, such as dressing, reading, or making food, but not to the same level of rehabilitation as the comments above from the American mother. Again, some caretakers made comments about both hoping their child will recover and also expecting them to learn basic, self-care skills. The rates of wanting a child to learn self-care skills were fairly similar (34% of Keralan caretakers and 47% of Atlantan caretakers), however the important difference here is the age of the kids. The Keralan parents who made these comments had children at an average age of 7.5 years. Atlantan caretakers had children at an average age of 9.1. This data suggests that, overall, Keralan parents changed their hopes to basic self-care needs earlier than the Atlantan parents. Three Keralan caretakers —with children ages fourteen, thirteen, and eight—commented that they do not expect their children to change; none of the Atlantan caretakers made such comments. Again, the current study did not purposefully seek out data related to parental acceptance, and so these findings should be considered preliminary. Replication with larger sample sizes would be necessary to more confidently claim differences in parental acceptance. Regardless, this data, along with the differences in approaches towards autistic children in the home (therapeutic vs. custodial), and differences in therapeutic options indicates that parental acceptance of autistic traits occurs earlier in Keralan homes than in Atlantan homes.

This data is consistent with the observations of science writer Lynn Payer who, in a chapter on American medical practices, noted the aggressive approach of American medicine. “[T]his ‘can-do’ attitude,” she writes, “is as much a characteristic of American medicine as it is of the American character in general” (1988, p. 131). She ties this attitude to an American penchant for tests, diagnoses, and quick results. Illness is seen as something invasive that is caused by an outside entity, and so should be able to be dealt with quickly (Payer, 1988). When it comes to ASD, it seems this attitude compels parents to continue to look for and use a variety of treatments and interventions in a search for a quick and permanent cure. My findings in Atlanta seem to mirror Payer's conclusions. The parents I encountered in Atlanta seemed disinclined to accept the presence and chronicity of their child's autistic characteristics as early as the parents I encountered in Kerala.

This variation in parental acceptance is an important consideration for understanding parental stress levels. Stress is also induced by social isolation, a frequent consideration in parental stress research. Studies from both America and India note that parents of autistic children often feel as though they lose friends and social support, sometimes from lack of time, but more often because others are unable to empathize with having an autistic child (Grindle, Kovshoff, Hastings, & Remington, 2009; Read, 2000; Carbone, Behl, Azor, & Murphy, 2010; Robertson, 2011; Divan et al., 2012; Hogan, 2012; Lutz, Patterson, & Klein, 2012). This social isolation is often the result of felt or enacted stigma[69] experienced by parents in public or even among existing social support systems, such as friends and families. Stigma is one reason caretakers in both Atlanta and Kerala reported difficulties spending much time outside the home.

Rachel Roberston (2011), a mother of an autistic boy, explains that the stigma of a presumed diminished personhood of disabled children is extended to their mothers: "Just as disabled children are considered less than non-disabled children, so, too, are their mothers" (p. 152). Public spaces are difficult for families of children with intellectual and behavioral differences. Unspoken rules regarding etiquette and 'appropriate' public

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[69] David E. Gray explored felt and enacted stigma among parents of children with high functioning autism, defining enacted stigma as "instances of overt rejection or discrimination experienced by stigmatised [sic] individuals" and felt stigma as "feelings of shame or the fear of rejection" (2002, p. 737).

behavior are made visible when children with autism and related differences breach these rules. Mothers must learn to negotiate and manage both her child's behavior and the responses to those in public scrutinizing her and her child (Ryan, 2008). Caretakers in both Kerala and Atlanta described instances in which they felt stigmatized and felt that others perceive them as bad parents. Caretakers are quick to relate what I call their 'grocery store story' in which they were in public with their child, often at the grocery store, and experienced stares or negative comments. However, stigma also comes from friends and family. One mother living outside of Atlanta described how this stigma affects her social life:

> No one really understands. You know they [friends] try, and them trying is great. But they don't...all of my family is in Miami. It's just me and my mother here. And she tries but this is foreign to her also. All of my friends don't really know. So then I try to bond or connect with people in the community, but unfortunately everybody's in Atlanta. In my area, it's not the type of area where everyone can kind of connect like that. So in order for me to even be able to find a place where I'm not in this by myself I have to drive 20 miles. So they try! They help. They try to help! But then they end up just staring or not knowing what to do, or asking me little questions like "So when is he going to talk?" Or "When is she going to start talking?" And it gets annoying. So more than anything I just kind of avoid it. I don't really take them out to parties with my family and friends we kind of just stay together. And I know it's unhealthy. And I know I'm

> supposed to kind of.... but I just don't want to because I don't think that anybody will really understand. They will just look at my kids like they're weird and I don't want to….

Research on illness-related stigma in India has looked at schizophrenia, depression (Lauber & Rössler, 2007; Nieuwsma, Pepper, Maack, & Birgenheir, 2011; Kumar, 2011), HIV (Thomas et al., 2007), leprosy (Barrett, 2005), and epilepsy (Andermann, 1995; Thomas & Nair, 2011) and various psychiatric and intellectual differences (Vaidya 2009; WHO 2010; Kumar, 2011; Nieuwsma et al., 2011). One of the frequently cited consequences of this stigma is an increased difficulty in arranging marriages for siblings, children, cousins, and other closely related family members. This is because the stigma affects the entire family who may in turn abandon the ill individuals. As stated above, family becomes both a source and a target of stigma (Lauber & Rössler, 2007).

Research that has looked at the effects of stigma on the lives of families with disabled children in India shows that mothers, who are usually the focus of this line of research, take these children out in public less frequently (Pal et al., 2002; Dhar, 2009), feel a lack of support or empathy from others, feel as though their child’s differences were a curse from god, fear for their child’s future, and avoid labeling or talking about their disabled children with others (Dhar, 2009). Illness labels are carefully applied or avoided to mitigate the level of stigma brought down on the child and the entire family (Grinker, 2008). Thus stigma influences the public presence of a disabled child as well as the ways household members talk about a child’s differences. Throughout India, the presence of chronic disease or disability threatens to negatively impact the family members of the ill person. This ‘bad blood’ stigma is pervasive throughout India and Kerala and is reflected in the ways families talked about and explained their child’s autistic traits.

Because the cause of autism is unknown, the explanatory models (EMs) parents employ reveal a range of information. An explanatory model is the way a person talks about the cause of a condition and one’s feelings about the presence of an illness or disability in the self and in one’s life (Kleinman, 1988). Everything from values of normalcy to the level of media exposure on certain autism related issues (e.g., the vaccine theory or savant skills) can be derived from a caretaker EM. In the absence of any definite causal connection, families can choose amongst culturally appropriate causal models in their EM, making this piece of information particularly revealing. EMs are indicative of a family’s appraisal of the autistic child, parental mental health and acceptance of the disability, and how the child is or is not integrated into the community (Herbert & Koulouglioti, 2010). A common way that families have been known to talk about developmental or intellectual disabilities in India is through spiritually based EMs (Daley, 2004; Dhar, 2009; Vaidya, 2009). This tactic is employed by families to avoid the application of the familial stigma discussed above (Andermann, 1995; Link & Phelan, 2001; Raguram, et al., 2004; Link, et al., 2004; Saxen, et al., 2007; Kumar, 2011). In other words, some families understand and discuss the causes of a child’s differences as resulting from karma, the evil eye, or a curse from God in order to communicate to outsiders that the condition is not carried by other family members (Kumar, 2011).

Interestingly, however, the families I interviewed in Kerala did not employ spiritually based EMs when talking about the cause or reason for their child's differences. Of the 32 parent, eight reported that their child's differences were the result of a negative event in pregnancy (e.g., injury, illness, taking Western medicine) and seven reported a negative event during the birth (e.g., drinking amniotic fluid, blue at birth, physician mistakes). Three families did not address the cause. Table 1 summarizes all explanatory models stated in the interviews.

Table 1: Explanatory Models for Autism used by Kerala Parents

Explanatory Model	Number of Parents
Negative event in pregnancy	8
Negative even in birth	7
Don't know/no guess	5
Seizures	3
Childhood accident	2
More than one language spoken at home	1
Television watching	1
Vaccine	1
Little interaction with parent at early age	1
TOTAL	**29**

The high utilization of pregnancy based EMs, accounting for roughly half of the given responses, is interesting in light of the complete absence of any spiritually based explanatory models. Although, when asked about the causes for autism more generally, a few families did mention genetics or heritability as a possible cause, they did not apply this explanation to their own child. It may be that families were not comfortable discussing spiritual EMs with a Western researcher, however these results indicate that non-spiritual EMs are available and accessible in even the most rural areas. This is likely the consequence of Kerala's high usage of Western, biomedical health care.

In Kerala, 95% of births occur in hospitals and mothers are more likely to receive antenatal care than other areas around India. Mothers often take their child to a Western doctor when they are experiencing serious illness or when traditional healing techniques are ineffective (Kutty, 2004). As discussed in the previous chapter, Western-style physicians were the first point of contact for caretakers in Kerala. Utilizing biomedical health care facilities influences not only treatment decision-making, but also the language used to talk about health, illness, and differences. The data presented here suggests that frequent interactions with medical facilities have influenced the local lexicon used in relation to illness and disability to such an extent that the lay public in Kerala are comfortable utilizing biomedically related terms and concepts. This does not seem to be the case in rest of India, where these resources are less ubiquitous. Again, the new diagnostic label of autism entered into the Keralan community with no definite cause, allowing parents to rely on these EMs to avoid 'bad blood' stigma. The medically based concepts caretakers have encountered in other healthcare interactions helped construct the ways families describe and explain their child's differences. The connection between home and clinic is evident not only in the creation of a therapeutic home, but also in caretaker understandings of their child's differences. Even though these EMs perpetuate some unlikely and unfounded causal theories about autism, they allow families to feel more comfortable in their home communities, thereby reducing familial and parental stress and enabling a higher quality of life for the entire family. Instead of calming autism-related stress and fear through the use of various therapeutic methods, which are largely unavailable, Keralan families deter stress and stigma by ensuring their child's differences are not constructed in a way that brings stigma onto themselves and other family members.

As noted above, most parents, either in interviews or in more casual conversations, made remarks suggesting a general distrust of Western medicine. The two findings seem in contrast: caretakers are reliant on a particular, non-spiritual and, thus, biomedical perspective to avoid 'bad blood' stigma, yet distrust the strength and use of biomedical treatments. This is an example of the "popularization" (Kleinman, 1980) of some biomedical concepts described in the third chapter. The concept that difference and disability is caused by something biological rather than spiritual is one aspect that families find useful. Medicines and diagnostic practices are aspects of modern medicine that are less germane or useful to Keralan parents of autistic children. Both the content of these EMs and the distrustful relationship families have with Western medicine are critical materials for those involved in international work on autism to explore, particularly since autism-related professionals tend to be trained in and supporters of a biomedical perspective.

Without knowing the presence and deployment of biomedical mistrust, professionals risk alienating the population they aim to help. Because of stigma, parents in Kerala would not accept a discussion that suggested their child's autism was genetically related. Explanations based on accidents or difficulties related to pregnancy that lead to a neurological or biological change are acceptable, yet medications as treatments are less likely to be readily accepted. At the same time, assuming the country-wide reliance on spiritually-based EMs is equally as present in Kerala is a potentially damaging mistake. Discussing spiritually based EMs with Keralan families could be offensive, particularly given the religious diversity of the state and the complexity of religious beliefs not aligned with one's own. A careful analysis of the type and influence of local healing techniques, including Western medicine, is critical in assessing the best way to talk about and describe autism to local caretakers.

In a location such as Kerala, where there is already mistrust of Western science, claiming that a child's autism was caused by negative events during pregnancy or birth, for example, places an emphasis on the stability of the condition that a spiritual causal model does not. It also implies an irreversibility that suggests intervention and education will not have a major impact, which may be another factor in earlier parental acceptance. Many families in Kerala were told that they should segregate their child in special schools or just 'care for' their physical needs. These suggestions were given by family members, doctors, and teachers who did not believe that the autistic child could progress, change, learn, or contribute anything to the general education facilities or wider community. While the EMs used by the families may deflect the stigma of 'bad blood,' it may also support notions of futility in treatment, another factor that contributes to earlier parental acceptance.

Further, these causal models imply to the community that the mother is somewhat culpable for the illness. This is particularly true in EMs that suggest that the mother, in deciding to use Western medicine during pregnancy, having an accident during pregnancy, or not providing appropriate early interactions, is responsible for the child's autistic characteristics. The cultural element of a reliance on the mother for the care and education of children (Kakar, 1981) intersects with the persistence of 'bad blood' stigma to develop this particularly unfortunate outcome for mothers of autistic children in Kerala: self blame and, often, blame from their families and community members. Families, especially mothers, must make decisions on where to place the stigma inherent in the presence of autistic characteristics in a young child—the family, the mother, or the child—to actively reduce or deflect experiences of discrimination. Unfortunately, as the presence and influence of Western medicine becomes more entrenched in locations like Kerala, the stigmas of biomedical causal models are sure to follow.

Conclusion

Homes in Kerala and Atlanta are influenced by autism in different ways. Previous work on care-taking in the home, conducted with Western homes and families, described the ways homes become custodial, particularly when caretakers' routine and mobility are limited (Power, 2012; Ryan, 2008). Here, I have altered the way homes are characterized by distinguishing between homes that have become custodial and those that become therapeutic spaces. The difference is the intent of daily activities: management and care in the former and rehabilitation in the latter.

The Keralan home is turned into a custodial space. Time and material resources, or lack thereof, dictate that autistic children are, as many Keralan informants put it, "managed." Daily needs are met and, while caretakers yearn for ways to help their child become self-reliant, learning and implementing techniques to teach the necessary skills is infeasible. Because of difficulties transporting children with behavioral differences on public transportation and because of the public stigma of differences, mothers and their autistic children are often confined to the home, leaving only when necessary. As is the case with clinical or educational institutions with few resources, basic needs are cared for but enrichment and education is difficult. The next chapter will describe how special education schools in Kerala are similarly constructed—being custodial rather than rehabilitative.

Atlantan homes, on the other hand, become therapeutic spaces where time and resources are largely dedicated to the instruction and rehabilitation of an autistic child. Rather than being an opposing approach, Atlantan homes differ in their focus as a result of resources and, to some extent, the composition of autism-related stigma. The therapeutic intent is visible throughout the home as visual aids and educational materials are scattered throughout to encourage and facilitate independence. The schedule is centered on ensuring the autistic child accesses his therapies and that an adult is always looking after him. Public and private merge as professionals regularly enter the home to provide services or assess a child's development. Parents closely monitor and record, mentally or physically, changes (or stagnation) in a child's behavior, looking for signs of progress or regression. Leaving the home regularly is difficult for many of these families as managing child behavior and public reactions is difficult and tiring. In this way, caretakers and their autistic children spend large amounts of time in the home, though, because of numerous physician and therapeutic visits outside the home, not as much as

Keralan families. Similar to Western clinics and schools, homes are places where the work of skill development pervades all time and space.

Custodial versus therapeutic homes influences parental perspectives of their children as much as it does the tangible and temporal structures of the home. For caretakers of children with sustained and stable differences, acceptance of the permanency of differences is assured, however the timing of this acceptance differs. In homes focused on rehabilitation, caretakers hope and strive for behavioral change longer than those in custodial homes. Although parental acceptance is associated with better parental coping and overall mental health (Weiss, Cappadocia, Macmullin, Viecili, & Lunacy, 2012) previous work has not identified how acceptance is generated. I have proposed here that it is accompanied by an exhaustion of the therapeutic resources a family is financially and geographically able to access, though this factor is not the sole influence. As stated above, more research is warranted to determine the precise mechanisms of parental acceptance in different cultural locations.

Although parental acceptance differs, social isolation is salient for both therapeutic and custodial homes and is partially the result of social stigmas of behavioral differences that are applied to the child and extended to the caretaker. This stigma compels parents to try to explain their child's differences in a way that both deflects stigma and fosters public understanding. A 2008 study in the Midlands of England described how mothers of younger children apologized for and explained their child's differences by relying on the increasingly socially acceptable label of autism. In contrast, mothers of older children had stopped apologizing for their child's behaviors and differences. These mothers were less concerned with “maintaining social order” (Ryan, 2008) and are perhaps more accepting of their child’s differences. Similarly, social stigma guides the ways Keralan caretakers discuss or explain their child’s differences. Here, the widespread use of Western medicine was useful for parents to rely on to discuss their children in non-stigmatizing ways. In Atlanta, as in the Midland mothers, autism is recognizable enough to enable social understanding in public and with family and friends, but this understanding does not always lead to acceptance or tolerance. Caretakers in both locations continue to struggle with private and public stigmas.

Overcoming stigma of behavioral and intellectual differences is a primary concern for families. The ways they approach negativity in public and private interactions is a rich source of information about how routines are created and maintained, needs are met, and acceptance is fostered. The WHO describes stigma as a primary barrier for person’s with disabilities to overcome in the community, which can be facilitated through public awareness and information (WHO, 2010). Public familiarity is key; the less individuals with disabilities are segregated, the more public acceptance can be fostered. Schools are one place where autism is located and where professionals, families, and autistic individuals can work towards increasing interaction between children with disabilities and those without. As autistic children in both Kerala and Atlanta regularly attend school, these are important places to study to learn how autism is constructed and approached within each culture. The next chapter focuses on schools as places of autism; it explores how educational practices differ between Atlanta and Kerala and how educational law impacts the construction of autism.

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Chapter 5: Schools, Segregation, Stigma

Introduction

In the previous chapter, I highlighted and analyzed the physical, temporal, and organizational structures of homes as places of autism in my two research sites. I differentiated between therapeutic homes, as observed in Atlanta, and institutional homes, as observed in Kerala. The difference between the two spaces relies on the frequency of educational and therapeutic activities occurring between caregivers and autistic children. Homes are unofficial educational spaces, conveying information about cultural norms and practical tasks or, as in the case of the therapeutic homes in Atlanta, a space where direct instruction can take place outside of official educational or clinical facilities (Holloway, Hubbard, Jöns, & Pimlott-Wilson, 2010). The focus of the current chapter is on these official places of education—particularly schools but also educational policy and teacher training. It will examine how "education is bounded into/and shapes wider social/economic/political processes" (Holloway, Hubbard, Jöns, & Pimlott-Wilson, 2010, p 595) for autistic students.

Despite this 'bounded'-ness, human geography has not yet taken a close look at educational spaces. Previous studies that look at schools' architecture see these structures as beneficial for academic training and rarely consider life inside these structures (Gulson, Kalevaro, & Symes, 2007). Canonical theoretical works on power, such as Foucault's thoughts on disciplinary systems (e.g., the Panopticon; Foucault, 1977) have been applied to education, yet few works describe a realistic application of how architectural structures impact and are used in contemporary educational practices. This chapter aims to take a critical look at these physical structures as well as certain conceptual structures (e.g., educational policy and teacher training) related to the education of autistic students in Atlanta and Kerala. I will give considerable attention to stigma within educational contexts.

First, common school designs will be described and analyzed in search of clues to a community's educational goals and practices for autistic students. Then, previous work on American educational policies and practices will be extended to discuss the impact of these policies in relation to autistic students in Atlanta, focusing on the creation and perpetuation of autism-related stigma and segregation. Finally, teacher training in Kerala is examined to trace the path to custodial educational environments that also replicate the segregation and devaluation of autistic individuals in Keralan communities.

There is some debate on how to explore the geographical implications of educational structures. Geographer Claudia Hanson Theim (2009) proposes moving away from inward looking research that explores how structures, physical and non, influence specific practices inside a school, in favor of outward looking analyses that explore the ways educational practices reflect and reinstate wider cultural, social, and political processes. "Rather than investigating the educational production of space," Theim contends, "such an approach would ask whether the geographies of education confirm or problematize state-of-the-art accounts of social reproduction, accumulation and state formation, among other processes" (p. 156). In this vein, the current chapter will explore the ways that educational policy in America reinstates historic practices of segregation of people of difference[70] while attempting to project an ethos of inclusiveness and progressive educational practices.

Somewhat differently, Holloway et al. (2010) argue for a combination of inward and outward looking approaches to the geography of education. While they agree with Theim’s (2009) emphasis of looking at schools as institutions firmly situated in and responsive to wider cultural and social structures, they call for a complementary analysis of the ways these practices and social relations are embedded into the formation of children’s and young adults’ identity formation (Holloway, Hubbard, Jöns, & Pimlott-Wilson, 2010). This approach is most informative for looking at special education practices in various cultural environments and allows for extensive analysis into related structures such as curriculum, special education teacher training, and educational policy. For example, while the curriculum for non-disabled students can be analyzed for practices that preserve and inscribe culture (Theim, 2009), the curriculum for students with disabilities can be examined for expectations of students with intellectual, behavioral, and communication differences. This is particularly true in places like Kerala where there is no policy obliging schools to implement uniform curricular goals to all students. Relatedly, the training of these students’ teachers is indicative of the generation of these culturally-sanctioned expectations.

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[70] This chapter will not make direct connections with the segregation of people of color, women, or sexual minorities however these are the histories to which I am referring. There is a deep similarities between these communities and people with disabilities, including the use of disabled metaphors to ensure the disenfranchisement of non-disabled minority communities (Bérubé, 2003; Davis, 1995; 1997; Garland-Thomson, 1997; Erevelles, 2011; Seibers, 2008).

One glaring structural similarity in the education of students with significant disabilities across the cultural environments explored here is the use of separate buildings or, at the very least, rooms in which to provide special education. Segregated schools and classrooms for particular populations serve to both shield and hide students similar to gated communities or historic walled-in cities (Gulson, Kalervo, & Symes, 2007). This arrangement has implications for both the outward looking focus called for by Theim (2009) and the ways Holloway et al. (2010) constructed a deeper inward looking analysis. Outwardly, keeping disabled students away from general education students reflects, and thus fails to problematize, historic societal preferences and practices that devalue the integration of people with disabilities into the general population[71] (Davis, 2010; Garland-Thomson, 1997; Shapiro, 1993). Inwardly, children internalize the message that their differences mean they should and always will be separated from their peers. The attitudes reflected in these practices are a concern for families. For example, an Atlantan mother interviewed for this project related a time when she found her son in the midst of an unexpected and unusual bout of crying. Her son, who does not communicate verbally, did not explain his crying, but she had her own hypothesis: “I think he doesn't like the way he is. He understands too well. I think he knows he's different. I think he wants to be

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[71] Joseph Shapiro powerfully described the implications of population-wide segregation of people with disabilities, including in education, in his 1993 book *No Pity: People with Disabilities Forging a New Civil Rights Movement*: “When a family chooses a segregated school, there is less pressure to integrate other school programs. When a parent enrolls a child in a private residential school that uses aversive therapy, it becomes harder to argue that such punishment is outmoded and should be abandoned. When disabled people are herded into sheltered workshops to earn below-minimum-wage salaries for piecework, employers lose the impetus to hire good workers, and taxpayers foot the bill. When separate recreation programs like Special Olympics exist, parents get turned away when they seek inclusion for their sons and daughters at neighborhood playgrounds. Disabled people remain segregated, and non-disabled people do not get to know them. The only force for overturning the status quo is a growingly militant generation of disabled people and their parents, whose anger and targets will surprise those who remain unaware of the growing frustration” (p 183).

like “other kids.” This boy, who was 15 at the time of the interview, had been educated in segregated classrooms since kindergarten. This separation of students with disabilities from those without, his mother believes, instilled in her son the message that he is different and less.

The primacy of segregation is reinforced beyond schools and classrooms, reaching into teacher training programs as well. The vast majority of higher education programs in education, including those in America and Kerala, have distinct departments and, frequently, distinct buildings for teachers interested in working in a general education environment and for those interested in working with children with disabilities. The separation of disabled and non-disabled students is so ingrained in education practices that it seems apparent that these groups would be differentiated in education training. The principle of segregation is perpetuated in the thoughts and attitudes of those trained to educate children (Young, 2008). In other words, the notion that the education of children with disabilities is so different from that of non-disabled students as to require distinct training topics and locations is fostered early in teacher’s career. Thus, teacher training practices are a critical site to explore in relation to cultural values related to autistic students. This issue is explored below in the context of Keralan special teacher training, which not only reflects segregation by ability but also sets up ineffectual, though thoughtful, instruction for significantly autistic students.

Beyond teacher training, educational policy is space outside of schools where one can learn how a community considers autistic children. On paper, Indian and Keralan policies appear to adequately address issues related to the education of students with disabilities, yet, as will be described later in the chapter, these policies are implemented unequally across the country and many fail to mention autism. Although Kerala is known for higher quality educational practices than most of the country, deep educational divides exist. The most obvious is between private and public schools that sets up a “dual system of education” (Ramachandran, 2009, p. 188) in which private schools offer high quality education to one sector of the community while the remainder, the less affluent sector, receives somewhat inferior education.

In Kerala, neither the public nor private schools had special education sections, meaning children with significant impairments who went to school did so in entirely separate facilities. Keralan scholar Anitha Ramachadran takes an outward look at the implication of this divide, stating “[t]he social and economic inequalities which are the legacy of the past get reflected in educational opportunities” in which the poorer communities “are invariably overtaken by the better off sections of society” (p. 189). One must consider what legacies are being reflected in Kerala with separate facilities for children with significant disabilities, many of which are non-governmental and require some fees to attend. Thus, children with significant disabilities are doubly separated from the “better off sections of society”—once by not being allowed into good private schools and again by not being allowed in to many public schools. This suggests that the government is not willing to provide appropriate facilities for children with physical or intellectual differences.[72]

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[72] Although some schools do have resource rooms and other resources of disabled students, these are also set apart from the general education students and primarily utilized by students with less significant forms of impairment.

Segregation of students, be it by race, class, caste, gender, or ability, can serve to represent and sanction social separation (Young, 2008) through physical structures, curricula, disciplinary practices, and national policies. A recent article reported both that American school administrators are threatened by students with disabilities reported and that these students are disproportionally suspended or expelled in public schools. This serves as a new, sanctioned segregation technique. According to this study, while only 11% to 14% of the American student population is being served in special education, these students comprise 20% to 24% of school suspensions and expulsions. Among the reasons administrators implicitly expressed feeling threatened was a belief that students with disabilities put an undue burden on teacher time and school resources. The authors argue that these practices were heightened in the wake of recent education policy, including the No Child Left Behind Act of 2002 (NCLB; Williams, Payee, Shelby, & Yates, 2013), a policy which will be more fully examined later in the chapter.

The educational spaces mentioned here are all systems that can provide detailed information on how a community evaluates intellectual and behavioral differences, including autism. Below, a detailed description of the architectural space in which the children included in this study are likely to attend school[73] is provided along with an analysis on how these places influence and reflect attitudes towards the education of this student population. Following this description, American educational policy is described in terms of the ways it sets up stigmatizing and stagnating educational environments for

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[73] As with the previous place descriptions, these are composites of the educational environments in which a child with a significant level of impairment would regularly take part.

autistic students. Finally, Keralan teacher education is looked at for the ways it generates a custodial approach to special education.

Kerala Schools

Along with the public-private school divide, there is a less discussed divide between the ‘normal’ schools—designed to teach non-disabled children—and the ‘special’ schools for children with disabilities. The normal schools are usually large, two-story structures that house hundreds of children, though rural schools can be much smaller. Classrooms in normal schools, including those for younger students, have an average student teacher ratio of 1:36, with Kerala fairing somewhat better at 1:27 (Ramachandran, 2009). Students wear uniforms and sit at wooden desks or at long tables with benches. The close proximity inherent in these classrooms (heightened when children share a table or desk), along with the uniforms and the frequent use of group recitation of facts and figures indicates a communal educational approach where individualism and atypicality is unrecognized or even discouraged. Special schools attempt to replicate this approach, though it is more difficult to implement.

According to Kerala’s statistics for 2010-2011, there are a total of 1,908 higher secondary schools (ages 17 to 18), 2,874 high schools (ages 13 to 15), 2,986 upper primary schools (ages 11 to 12), 6,784 lower primary schools (ages 6 to 10), and 44 ‘schools for the handicapped.’ In the district of Trivandrum, there were a total of 989 schools and three special schools for 385,464 students. The district of Wayanad, which had 123,740 students, had 292 schools and two special schools. Thirty-six percent of all schools are government schools, 57% are aided by the government but not fully funded, and 7% are unaided (General Education Department, 2012).

An interview with the Deputy Director of the Inclusive Education of Disabilities Scheme (IEDSS) in 2011 revealed there are actually 282 schools for children with disabilities throughout the state. Most are run by NGOs (non-governmental organizations) and so are not recognized in government statistics. The 44 reported special schools are ones for children with visual and hearing impairments working under the direction of the government. These are also the disability groups for which adapted curricula have been developed by the State Council for Education and Training (SCERT). Kerala has reportedly been working towards including children with disabilities into the so-called normal schools for at least thirty years, a project that is sponsored by the government of India. Most children with significant disabilities must yet attend special schools. There around 2,000 teachers trained in special education working in general education schools and about 63,000 students with disabilities in the general education environment, about 40% to 45% of which are labeled autistic or mentally retarded[74] (R. Rajan, personal communication, August, 16, 2011).

When it comes to children with significant impairments, however, schools are not yet able to ensure inclusion. The deputy director explained: “In the case of profound [impairment], it is very difficult to integrate because the percentage of disability will be up to 100.” For some of these children, teachers provide home based instruction “and

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[74] This is an official diagnostic term in Kerala for both education and general disability services. The rest of these students fall under one of the other 12 categories of disability, including learning disabilities, speech impairment, visual impairment, cerebral palsy, and loco-motor disability (Commission for RTE Act, 2011).

after two or three years, we are hoping to admit them into the school system." He admits that they are "at the starting point" and hopes that "in one to two years, Kerala will be a model to all states in India" in terms of disability education (R. Rajan, personal communication, August, 16, 2011). For now, though, autistic students are primarily educated in special schools. Again, this segregation suggests to families that the state is unwilling or, at the very least, unable to provide appropriate educational facilities for their children with significant disabilities; they must do so themselves. This responsibility continues throughout the child's life as, according to my informants, there are almost no programs or safe facilities for adults with disabilities. What follows is a description of a special school based primarily on the schools visited in the rural district of Wayanad. These are most reflective of the educational environments of autistic children around the state.

The school is located on a fairly empty road a few miles from the nearest town center. It can be reached by an auto-rickshaw or bus; the bus stop is a ten-minute walk away from the school. The building is two stories and is surrounded by an external, locked gate to ensure students stay within school grounds. In order to enter, a staff member must come and unlock the gate. Visitors are encouraged to alert staff of their arrival time so someone can be there to unlock the gate. According to staff, these gates, in addition to the distance from a town center, serves a dual purpose of keeping children safely in and outsiders safely out.

The school's interior hallways are enclosed by gates and wire barriers, allowing outside air to flow through while providing a secure encasement. These hallways lead to all parts of the school and overlook the interior courtyard, which contains well-worn, metal playground equipment. The principal's office is near the entrance and has a small exterior room for meetings or waiting, and an interior office with the principal's desk. Personal and school items decorate the walls and desk, including pictures of students at various events as well as general school information and achievements. Off the waiting area is a bathroom for teachers and other adults that is usually cleaner and more private than those used by students. Down the hall, there are several classrooms dedicated to students of different educational aptitudes. These rooms are labeled to reflect class levels in general education schools: pre-primary, primary, secondary, vocational, et cetera. However, as they are based on ability, these classrooms have children of various ages and disabilities. These designations are one feature indicating the desire for these schools to reflect the 'normal' schools; an obviously imperfect simulacrum that emulates 'normal' student life.

The classrooms are square or rectangular in shape. A teacher's desk sits near the door. The students sit facing the teacher either in rows or in a semi-circle at small tables and chairs, long tables and benches, or, rarely, at individual desks. Classrooms in the school vary in their seating arrangement based on the materials available to the school and the constitution of the children in the room. Seating arrangements in classrooms can be indicative of and even induce community values of sociality and individuality; sitting on shared furniture such as benches is suggestive of communal and collectivist experiences, whereas furniture for just one person, such as a chair, is individualistic (Tuan, 2012). Classrooms with shared tables and benches generate more interaction amongst the students in the form of sharing materials, conversations, joking, and occasional hitting or pushing. Students in lower level classrooms, who are seen as less mature, tend to be at communal tables, whereas those in upper level classes have individual desks. This advancement in furniture indicates a more perfect replica of 'normal' classrooms.

The communal nature of these classrooms influences teaching styles and practices such that students frequently work independently. In other words, teachers will set up a few students with puzzles or worksheets or an art activity then move onto the next small set of students (or individual student) to check on their progress or get them started on another activity. For group activities, the collective seating facilitates the teacher's ability to move around the room, and increases the likelihood that students will interact with each other. As there is no assigned seating, students may sit in different areas of the room; occasionally teachers use this to their advantage by insisting students sit apart or together to reduce distractions or facilitate sharing.

The classroom walls are decorated with various religious artifacts; pictures of Jesus or Hindu gods adorn the walls as appropriate to the school's religious culture. There is a calendar, student artwork, and colorful charts of the alphabet, animals, food, et cetera. The exterior and interior walls each have two windows with bars, but no glass. This allows for a natural breeze and light; electric lights are rarely used, even during the monsoon season. A blackboard has the date on it, often dictated to the teacher at the beginning of the day by the students, and notes reflecting the day's lessons (e.g., numbers, letters, days of the week, names).

Classrooms have one primary teacher and between eight and fifteen students, all of whom are about the same age or ability level. Younger and more significantly impaired children will be in classrooms with fewer students. The teachers are women, often nuns, and are occasionally assisted by a young woman, an *ayah*. *Ayahs* may spend the entire day with one class or traverse the schools, helping manage and care for students where and when needed. While the primary instructors have some kind of training or experience in special education, *ayahs* are generally local girls who recently finished or dropped out of school.

Classrooms are primarily located on the first floor, along with student bathrooms and the cafeteria. Upstairs there is a multi-purpose room where students do morning assembly,[75] daily yoga, and practice for local dance and marching band performances. The room has a small stage at one end where performances and graduations are showcased. Bamboo or coir mats are stacked in one corner to be brought out for yoga. Musical instruments, such as drums, chimes, triangles, and horns, are kept in a locked closet and are brought in for afternoon rehearsals.

At meal times, students go to the dining area and wash their hands in the communal sink before picking up their metal plates and sitting at long tables with benches. Eating is a communal and social act. Teachers and staff members circulate the room with large containers of rice, lentils, and vegetables. Most students eat the school's food, although some students come with a lunch from home. As is the custom in India, children eat with their hands. Teachers hand-feed students who have difficulty feeding

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[75] Morning assembly is a daily practice in all schools and consists of students lining up in rows and going through various recitations, such as the national anthem, and listening to daily announcements.

themselves, occasionally encouraging these students to feed themselves. When students are done eating, they return to the sink to wash their hands and go to the courtyard to play until it is time to go to the next class. At this time teachers sit down and eat their lunch and socialize.

Classes are 45 minutes long. A bell rings to signal the beginning and end of each class. In between classes, there is a 10-minute break during which time students congregate in the hallways to talk, play, and drink *chai* or water. As the hallways are fairly narrow, they are easily crowded and students and teachers stand in close proximity and contact. As with much of Kerala (and India), school is another place where people are physically close. Students may grab another student's or a teacher's hand while speaking or playing. Students with mobility impairments are often assisted in and out of classrooms for breaks by an older student who acts as a caretaker of younger and more impaired students. These breaks provide a time for students to use the bathroom, which is located at the end of a hallway and consists of several stalls with squat-style toilets and a few sinks for washing hands. *Ayahs* stand and monitor bathroom activity, helping when necessary. Often, these times are the most social time in a disabled child's days.

At the end of the day, students may be picked up by a caretaker, most often their mother, and taken home on the public bus, an auto-rickshaw, or personal vehicle. Other students are brought home on small buses owned by the school. As special schools serve children from large areas, travel to and from the school can be a long journey, taking an hour or two and involving bus transfers and long walks. The scattered nature of special schools in Kerala serve to make access more difficult, however their presence is comforting to many families. The schools provide respite during the day at which time mothers can take care of other household responsibilities which, as described in the previous chapter, are numerous and extensive.

Because of low teacher availability, Keralan special education practices are held in enclosed, separate facilities that are designed to keep children safely within the structure without constant monitoring. Although these schools house fewer children than the normal schools and class sizes are low, the student-teacher ratios are still higher than those typical of the United States. Teachers and administrative staff have no expectation of lower ratios; unsupervised students are common and go unremarked. I occasionally saw students sitting in hallways alone or wandering classrooms while the teacher was otherwise engaged. Older and less impaired students often assist other students. The social structure in these schools is reflective of typical Indian hierarchies in which older and male individuals have more power than younger and female individuals.

The physical structures of the special schools, including the gates, locked doors, and bars or fences on windows and open areas, are designed and used to enhance the teachers' ability to monitor students. Although similar in structure to that of Foucault's imaginary Panopticon (Foucault, 1977), the lack of oppressive intent suggests a more safety oriented purpose. Segregation is the most common educational approach; children with disabilities rarely spend the school day with non-disabled peers. This is particularly true for significantly autistic students, who, because of varying communication styles, may be less likely to conform to the collective instructional methods necessary for large and crowded classrooms. Yet, as will be described later, education for significantly autistic students is primarily custodial. This approach is largely as the result of the ways teachers are trained and a lack of the materials and resources necessary for a more directly instructional approach.

Atlanta Schools

In Atlanta, as is the case throughout the United States, children with disabilities are educated in local public schools. While the manner in which various schools and school districts implement the legal requirement to educate all students varies somewhat, children with disabilities are ensured a free and appropriate public education (FAPE) in the Least Restrictive Environment (LRE; Individuals with Disabilities Act, 2004). In some areas children with disabilities, especially those with significant disabilities, are sent to classrooms located in only certain schools or, less frequently, sent to a school dedicated to children with disabilities. However, recent changes in education policy and research encourage more inclusion in general education environments. Many more students with disabilities are being educated in their neighborhood schools than ever before. Students with disabilities will spend varying amounts of time in special education classrooms, where a teacher and a few aids instruct an unchanging student population, or in resource rooms, where special education teachers give specific instruction to a range of students who visit certain times each week. Children with the most significant levels of impairment are likely to spend most of the school day in special education classrooms. Resource rooms are generally used by students with learning disorders, speech disorders, and less significant behavioral, or intellectual differences. Official reports from 2009 indicate that 63% of Georgia’s special education students spent 80% or more of the day in regular education classrooms and 16% spent less than 40% of the day in these classrooms (Georgia Department of Education, 2012). Children with significant autistic characteristics fall into the latter category, while students with Asperger's Syndrome or less significant impairments will spend more time in classrooms.

The 6.5 million students with disabilities in the United States comprise 13% of the country's student population. In Georgia, 10.6% of students (176,962) are served in the state's special education program.[76] There are 112,460 teachers in the state, creating a total student teacher ratio of 14.9:1, slightly lower than the country's ratio of 16:1. Thus, Georgia shows slightly better averages in terms of overall teacher and staff availability than that of the rest of the country (U.S. Department of Education, Office of Special Education Programs, 2012; U.S. Department of Education, National Center for Education Statistics, 2012).

Regardless, Georgia Public Schools received a rating of "Needs Intervention" by the U.S Department of Education for the 2010-11 academic year.[77] This rating was determined by factors such as the high number of students spending less that 80% of the day in regular education; "disproportionate representation of racial and ethnic groups in specific disability categories that is the result of inappropriate identification" (p. 7); less than 100% compliance on the development, implementation, and assessments of Individualized Education Plans (IEPs); and low percentages of youths 16 and older with

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[76] The number presented here come from the U.S. Department of Educations's statistics from the Fall of 2010 or 2011 (depending on availability of data) and can be found at either http://www.ideadata.org/arc_toc13.asp#partCbC or http://nces.ed.gov/programs/digest/d12/tables/dt12_046.asp.

[77] This rating was also given previously but this was the most recent year in which the state received this rating.

appropriate plans and goals for after public school. This last factor was noted as a primary reasons for Georgia's rating for 2010-11. Unfortunately, Georgia is not unique in these indicators. For the 2010-2011 academic year, nine states were rated as "Needs Improvement" and thirteen were rated as "Needs Assistance" (U.S. Department of Education, Office of Special Education and Rehabilitative Services, 2012).

Georgia is required to provide services for disabled children from birth to 21 years and education to these students from 3 to 21 years. In order to do so, the state directs 6.9% of its education expenditures to special education services. The 2010-2011 special education report shows that a total of 3,004 (10.76%), students in special education are classified as autistic (Georgia Department of Education, 2012). This category includes children identified as having a developmental delay that "adversely affects a child's educational performance" (Individuals with Disabilities Act, 2004). Autism is generally considered to be a more significant and involved disability: many autistic students, such as the ones included in this study, are educated in special education classrooms. The description in this section will reflect the experience of an elementary school child with many autistic characteristics who spends much of the day in a special education classroom. It is important to note, however, that a student's school experience is mediated by level of impairment, school funding, and age, all of which come into consideration when developing the student's Individualized Education Program (IEP). What follows is a description of some of the more salient features of a typical special education experience for an older elementary aged child with moderate autistic characteristics. It does not include descriptions of all services and activities an autistic student may take part in, such as adapted physical education, physical therapy, sensory ‘diets’, or applied behavior analysis.

Students arrive either by bus or car. As many school districts do not have special education classrooms in every school, students may travel from all over the county. It is not uncommon for special education buses—outfitted with special seat belts, wheelchair access, and adult aides—to take up to two hours every morning and afternoon transporting students. For this reason, special education students sometimes arrive late and/or leave early from school. With this schedule, these students do not share the arrival and departure time with the remainder of the students in the school, which is a highly social time of day. Thus, from the very start of the school day segregation is in practice.

Special education rooms are located down a hallway located along the perimeter of the school. The hallway is accessible by either walking through the front door of the school and past other hallways containing regular education classrooms or by walking around the exterior of the school building to the rear or side of the school. If walking through the school during arrival or departure, the hallways are clogged with students and school staff, making this route sometimes difficult. Children with significant levels of impairment are escorted to their classrooms by an adult staff member, often a paraprofessional or teacher’s aide, who help them navigate through the other students. However, this assistance also serves as a barrier to interaction. Often, independently walking to a classroom is an educational goal that students work on with these adults on a daily basis.

The classroom has a large teacher's desk with a computer located at in the front of the room near the whiteboard and cabinet of materials. The main teacher does not spend much time sitting at this desk apart from daily breaks, as she is usually traversing the room interacting with students. Unlike general education classes, but similar to classrooms in Kerala, there may be students of various ages in one classroom depending on perceived level of ability or maturity. Students are either seated at an individual desk, with their own tabletop and chair, or at larger tables. Also similar to Kerala, individual desks are provided to the older and less impaired students, again reflecting a progression to a closer simulation of general education practices.

Classrooms have computers for the teachers and students to use and 'Smart Boards,' which are interactive white boards that use touch detection and have various computer programs and applications. In addition to classroom technologies, individual children may have their own technology. Students who do not communicate verbally often use iPads or other electronic voice output systems to communicate with teachers, staff, and students. Schools are required to provide these technologies if the child's IEP dictates the need for them. Because they are officially school property, many students are instructed to leave these technologies at the school, meaning communication techniques for home and school can vary drastically.

The classroom wall displays various educational charts and informational materials such as calendars, lunch menus, and daily schedules. Classrooms with autistic students rely on visual aids for most activities and so individual daily schedules are displayed. When a student arrives in the classroom, he is directed to his daily schedule that is hung on the wall alongside those of other students. Each event throughout the day (e.g., arrival, bathroom, art) is marked as completed by the student who, for example, moves a pictorial representation of the event into the completed folder or section, then determines his next activity. Additionally, items around the room are labeled with the written word of the item and a simple line drawing of the item, usually from the Picture Exchange Communication System (PECS) dictionary. These labels are designed to facilitate language and communication.

The visual aids are an indicator of the room's emphasis on both organization and increasing student independence and communication. Group activity areas, which are absent in regular education classrooms, indicate a focus on socialization, another practiced act meant to get students behaviorally closer to their non-disabled peers. Students with disabilities, particularly those with high levels of impairment, are segregated for much of their life and school day. Organized time and activities are dedicated to practicing social skills. Unlike special education settings in Kerala, which are more crowded and communal, special education classrooms in America, especially those with autistic students, combine individualized activities and areas (e.g., desks, separate student schedules, individual therapeutic sessions) with collective group areas. Isolation exists alongside teacher manufactured social times. Here, social abilities, or a seeming lack thereof, are considered to "adversely affect a child's educational performance" (Individuals with Disabilities Education Act, 2004) and so are taught in school. This is not so for non-disabled students. Recent efforts to include students with disabilities in regular education settings are primarily motivated by this focus on improved socialization.

Despite this social emphasis, much of a student's day is spent in the company of adults and other disabled students, particularly when compared to students not in special education. Resource and special education rooms have more adult professionals than regular education rooms. While some children have dedicated paraprofessionals to help them navigate the school, complete academic tasks, and communicate, most students 'share' a few paraprofessionals. These adults will circulate amongst children in special education rooms and often attend regular education classes with students to provide assistance there as well.

Aside from resource and special education classrooms, public schools have speech therapy and occupational therapy rooms to which students travel during the day. Speech therapy rooms are small, as activities are one-on-one and require only a desk or table on which to use materials such as puzzles, flash cards, books, or pictures. The therapist will sit on one side of the desk or table with the student across or adjacent to her. Various materials will be brought out to, in the case of autism, elicit language or to practice alternative communication systems. Speech therapists also visit classrooms to work with teachers on lessons or lead group activities. In this case, several children may be engaged in a speech-related activity to emphasize the social aspect of communication.

Occupational therapy rooms are much larger as the activities involved require large materials, such as swings, exercise balls, and trampolines. These activities are one-on-one and rarely involve groups of students. During a session, the student and therapist will navigate the room doing various activities as dictated in a child's IEP. These activities range from holding and using a pencil to swinging on a platform swing. Some children require special materials to use in the classroom as prescribed by an occupational therapist, such as pencil grips or weighted vests. Speech and occupational therapy sessions are once or twice a week for 30 minutes.

As noted above, the amount a student in special education interacts with the general education student population varies. For some autistic students, inclusion only occurs during meal times. The main mealtime during the day is lunch, which is served in a cafeteria. Students walk together to the cafeteria with at least one teacher and a few paraprofessionals or teacher's aides. With the aim at increasing the efficiency of lunch, special education students are fed earlier than the majority of the school's students. Inclusion at these times means that disabled students eat as their non-disabled peers get their lunches and sit nearby tables. The cafeteria is a large room with two sets of doors at the ends of the room. One set of doors is located close to the food line. Students who are eating the school lunch receive varying levels of adult support as they proceed through the lunch line.

After getting lunch, a student carries his disposable lunch tray to a long table with individual chairs where the students who bring their lunch are already seated. All classrooms are assigned a lunch table and so students do not have a choice in seating location other than their seat at a specified table. These tables are long and narrow, allowing several children to sit facing each other and in close proximity, which suggests that social interaction is encouraged. However, when students get too loud or boisterous, teachers will stop the interaction and sometimes separate the students. For children with disabilities, teachers determine where students sit based on the most efficient use of adult help. For example, a child with more involved feeding needs may be sat next to a student who feeds herself independently so an adult can constantly help the first student and only occasionally assist the second. As the special education students are eating, other children fill the room to eat their lunches.

Once all students have finished eating, the teachers prompt them to dispose of their lunch waste. This timing of lunch is often determined based on the likelihood that several of the autistic students are sound sensitive. This also means there they eat when the cafeteria is empty, leaving little opportunity for interaction or even visibility between special education students and general education students during this fairly unstructured and highly visible time. This arrangement is a good example of designated ‘inclusion’ times that ultimately and unintentionally ensure nothing beyond the sharing of physical space.

As noted above, some students spend part of the day in general education classrooms. Sometimes these are non-academic classes, such as music or art classes, and sometimes these are subjects in which a child is proficient, such as math. Often, a paraprofessional attends the class with the student. Decisions on which general education classes are taken are determined based on the student’s ability to attend (e.g., sit still and be quiet) and learn. While they do not promote much social interaction, these arrangements allow non-disabled students to experience learning alongside students with different learning styles and needs.

Because of these visits, in combination with frequent trips to therapy, special education students may leave their classroom several times a day. The transience of students and adults is a distinctive feature of special education rooms that contributes to the emphasis on maintaining a detailed schedule. Every activity is indicated on the classroom schedule, including bathroom breaks and visits from speech and occupational therapists. These schedules help teachers and aides coordinate their activities and roles but also are designed to help children on the autism spectrum who are comforted by and respond well to routines and schedules. The physical set up of the room is further designed to help students navigate their day and the classroom independently, as well as to reduce problem behaviors by, for example, creating small areas that impede running or jumping.

These features—the small areas, individual desks, separate activities and schedules—in combination with the isolated location of special education rooms promotes the segregation of students with disabilities. Yet, antithetically, these classrooms are spaces where social interaction is taught and encourage. The result of the arrangement described here is the acquisition of skills to interact with adults more so than peers. Although this description is of an elementary school setting, many features hold true for educational settings for autistic students in middle and high schools. While Keralan students are most often educated in entirely separate schools, and ones that parents may have to pay a fee for, Atlanta students are in the same geographic location, yet do not share much physical space. Even when physical space is shared, interactions with non-disabled peers are nearly impossible. These sets of students live different, yet parallel, lives in schools.

Creating these distinct school lives only serves to further stigma, which the World Health Organization's (WHO) report on mental health identified as is the biggest barrier to ensuring human rights for individuals with disabilities (The World Health Organization, 2001). As noted above, school environments are reflective of community values and both Atlanta and Kerala's reliance on segregation is indicative of wider community devaluation of people with disabilities. The next sections examine United States education law and Keralan teacher education practices. Both are conducive of generating stigmatizing practices in school environments.

NCLB, IDEA, Stigma

The American education system has been criticized for being a reflection of "white, middle-class-to-affluent American values" (Bejoian & Reid, 2005, p. 220). For many, this means the educational and developmental needs of minority children–including those of ethnic, ability, linguistic, and sexual minorities–are rarely met and the students regularly fall behind. Various fields—including medicine, rehabilitation, counseling, and psychology—guide the creation and regulation of educational expertise (Bejoian & Reid, 2005, p. 220). This disciplinary knowledge is reflected in major educational laws such as the Individuals with Disabilities Education Improvement Act (IDEA) and the No Child Left Behind Act (NCLB). In many ways, these laws aid in the stigmatization, segregation, and stagnation of children outside the 'norm' by deciding both the curriculum and the educational environment. As Nirmala Erevelles described in her 2012 chapter on education, race, and disability, often the very institutions set up to protect vulnerable populations are the ones that harm them the most.

IDEA.

In the wake of the Warren Court's dissolution of "separate but equal" education in *Brown v. Board of Education* (1954), parents and disability activists began fighting for the education of children with disabilities. By 1974, 48 cases on the segregation of students with disabilities were filed, many of which were upheld in federal court (Williams, Pazey, Shelby, & Yates, 2013). These cases led to Public Law 94-142, or the Education for all Handicapped Children's Act (EHA), which established free and appropriate education (FAPE) for children with disabilities throughout the country. This law had four main purposes: (1) "a free appropriate public education which emphasizes special education and related services designed to meet [student's] unique needs," (2) "to assure that the rights of children with disabilities and their parents [...] are protected," (3) "to assist States and localities to provide for the education for all children with disabilities," and (4) "to assess and assure the effectiveness of efforts to educate all children with disabilities" (Education for All Handicapped Children's Act of 1975, 1978). EHA mandated services for children ages 3 to 21 years, later extended to birth. The 1997 reauthorization named the bill the Individuals with Disabilities Education Act, or IDEA.

Reauthorized again in 2004, the Individuals with Disabilities Education Improvement Act includes autism and related disorders as one of the thirteen categories of recognized disabilities (Hill & Hill, 2012; Individuals with Disabilities Education Act, 2004) and provides FAPE in the Least Restrictive Environment (LRE) for 6.5 million students across the country (Moores, 2011). The public school system is required to provide these children a legal document, the IEP, outlining the specific educational goals and needs of each student. IEPs are created and updated yearly in a partnership between the school staff and students' caretakers.

The law states that children with disabilities are to be educated with children who are not disabled "to the maximum extent possible." Educational scholar Gregg Beratan (2006) argues that this provision could easily mean a self-contained setting, where, similar to the setting described above, the children have very little contact with their peers, and that "the onus is on disabled students who, given the necessary 'supplementary aids and services,' must find a way to fit into 'the regular educational environment'" (n. pag.). In other words, those students who cannot 'assimilate' into the existing system will be segregated from their peers (Beratan, 2006).

Students' placements are determined in the IEP, the creation of which is often problematic. Despite the fact that, by definition, they must be individualized, many IEPs share identical provisions, giving the impression they are simply cut and pasted from one IEP into another (Moore, 2011). Parents of children with autism have long complained of the similarity between their child's current IEP with the one they had the previous year or with another student's. This has led to several IDEA implementation-based court cases; in 2009, violations of IEPs in general were the issue of 73% of cases between school systems and parents of autistic children (Hill & Hill, 2012). In addition, the way the law defines disability is focused on a deficit model that conflates impairment with disability, leading to inequity in the education and treatment of this population (Beratan, 2006), a criticism that many also apply to NCLB.

Finally, Beratan (2006) noted how IDEA perpetuates and is somewhat built upon institutionalized racism and institutionalized ableism, which he defines as “uninterrogated beliefs about disability deeply ingrained within educational systems [that] subvert even the most well-intentioned policies by maintaining the substantive oppression of existing hierarchies”(n. pag.). He goes on to explain that IDEA uses racial and ability minorities to create socially acceptable discriminatory practices. In other words, because society is willing to discriminate against its disabled members, racism in education is more palatable as a disproportionate amount of minority students are relegated to special education and given disability labels. The institutionalized ableism and racism that focuses on individual differences to justify segregation and educational injustice is “camouflaged in the language of good intentions [and so] IDEA is protected against charges of either racism or ableism” (n. pag.). Here we see the how race and disability is exploited by policy makers and administrators to justify social hierarchies throughout the American education system and wider community. This is the basis on which disability education has been founded and on which with NCLB must contend.

NCLB.

NCLB was passed during the Bush administration as an attempt to bring all public education students up to a higher level of academic proficiency. The act was a reauthorization of the Elementary and Secondary Education Act of 1965 (ESEA) but extended the law’s reach. NCLB is based on four main pillars: (a) an increase in teacher and school accountability for student performance through frequent testing, (b) the use of scientifically-proven educational methods, (c) increased parental control and empowerment, and (d) increased local control through reduced bureaucracy and increased flexibility (Ryan, 2004; No Child Left Behind Act, 2002). The mandates set out in NCLB take precedence over those in IDEA (Moores, 2011).

NCLB, which is being systematically dismantled,[78] gave America's public schools twelve years to reach 100% proficiency in reading and math, and a series of consequences for little or no yearly progress (Ryan, 2004). Schools that are identified as failing, as reflected in standardized test scores, and have not improved after two years are given some government assistance. The students at these schools are given the option to transfer to higher performing schools. If after a third year, a school is still failing, 20% of Title 1 funds must be set aside for Supplementary Educational Services (free extra academic help to students; Bejoian & Reid, 2005; Ryan, 2004). After four consecutive years of failing scores, the school can replace either its staff or curriculum; after five years school officials must give up control of the school to the state who will then reopen it as a charter school or turn it over to a private management company (Ryan, 2004). Schools who are not failing and those that make the greatest progress are given bonuses (Bejoian & Reid, 2005). School progress is reflected in achievement targets met by the school as a whole and subgroups of children within the school, including students living

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[78] In 2011, the Obama administration began approving state waivers of NCLB, as long as these states agreed to certain concessions such as teacher evaluations. As of October of 2013, forty-two states had an approved NCLB waiver, one state had a pending waiver, and two states had their waivers reject. Georgia is one of the states that holds a NCLB waiver ("NCLB Waivers: A State-by-state breakdown," 2013).

in poverty, racial and ethnic minorities, English-language learners, and those in special education (Ryan, 2004).

Stigma and NCLB.

As an educator, I personally experienced the lack of individualization in the Individualized Education Plans (IEPs) and lack of funding for resources to access and benefit from the general education environment. One of my informants—a consultant for Georgia schools who focuses on creating optimal special education environments for autistic students—elucidated the considerable stigma inherent throughout NCLB. She explained that NCLB's focus on academics has made public education environments very difficult for autistic students. Teachers in general education classrooms see them as children with myriad needs beyond that of simple academic modifications. This, she said, creates resistance in the general education environment. She explained:

> No Child Left Behind has not helped with the acceptance of any child with a disability into a regular ed classroom because it may effect the test scores and test scores will reflect on the teachers and instruction and possibly reflect on her salary and job. So it's, you know, when you talk about No Child Left Behind, unfortunately, in many aspects the children with special needs are the ones who are left behind.

In her view, the provisions of IDEA "head butts" with the requirements of NCLB in practice, creating stigma and resistance among school personnel.

Similarly, special education scholars Ayres, Lowrey, Douglas, & Sievers (2011) explained that while IDEA created connections between both a student's educational needs and those that extend beyond the school environment, NCLB limits this connection by making functional skills a low priority for students who need them the most. They ask: “At what point does working toward fragmented, watered down academic standards become less important than working toward meaningful individualized curricula directly tied to increasing independence in identified current and future environments” (Ayers, et al., 2011, p. 12). The testing and accountability requirements of NCLB necessitate and reward education in which all students think, act, perform, and develop the same way (Bejoian & Reid, 2005).

When it comes to defining disability, NCLB again favors uniformity. Students are grouped together into a false binary of those who are ‘disadvantaged,’ (minority, disabled, poor) and the norm: the white, middle-class students to whom the rest of the school population must catch up. The states have the power to define disability and do so with the assumption that disability is an empirical fact. The power to decide who belongs in this group and how to educate them rests with the state and these decisions often made without the input of teachers, parents, or students (Bejoian & Reid, 2005). The deficit-based, medical model definitions of disability in the law (Beratan, 2006) rely on value-laden terminology that is reflective of politicized public policy and white, middle-class ableist norms to marginalize disabled students and even blame them for their failure and the consequent failure of American public schools (Bejoian & Reid, 2005). The language, regulations, and incentives in the NCLB and, to a lesser extent, IDEA serve to, at best, control the lives of disabled students in ways that parents and students often find unacceptable (Bejoian & Reid, 2005) and, at worst, push low-performing students, including those with autism, out of the school entirely, making it difficult to catch up or learn (Ryan, 2004).

Each of the four major pillars of NCLB are constructed in ways that stigmatize and fail students with disabilities. Writing for the Council for Exceptional Children's Division on Developmental Disabilities, Darlene Perner (2007) lays out these difficulties, saying that the main issues are varying assessments by state, the requirement to prove assessments are "technically sound" and can identify proficiency or non-proficiency, and little attention to the need to train teachers in how and when to use alternate assessments (p. 243). Parents and professionals I spoke with in Atlanta often referred of their distaste for the testing system and the low quality of their autistic children's teachers. One mother who lived in a rural town about 80 miles outside of Atlanta explained that, after her son passed the CRCT (Criterion-Referenced Competence Test; the standardized test used in Georgia public schools), he was placed in a general education classroom for second grade. At which point "he crashed and burned. In a fury." She attributed his failure to the removal of the support services he received the previous year. "They pulled the carpet out from under him," she continued, "But you know, they thought since he passed the CRCT he was fixed. He's not fixed...The problem is some of those teachers shouldn't be teachers at all." This comment addresses not only the over-reliance on standardized testing but the failure of NCLB to meet its goal of ensuring high-quality teachers as well.

As long as standardized testing is the primary benchmark for schools to assess their progress in order to gain additional government funding, instances like this will continue. In terms of students with disabilities, however, it is the law's accountability practices that are most criticized. Because it promotes conformity in learning and performance, schools disregard the diversity of learning styles and expression, thereby marginalizing those who do not meet this normative standard (Bejoian & Reid, 2005). The use of scientifically derived tests, which are considered to be objective (Bejoian & Reid, 2005), serve to increase the inequalities between poor and rich schools, simplify the curriculum as teachers begin to 'teach to the test,' and create school environments based on competition rather than equity and social progress (Ryan, 2005; Dudley-Marling & Baker, 2012).

As pointed out above, accountability requirements often lead teachers to reject autistic students in their general education classrooms. In a previous study on education reform's impact on disabled students, one teacher is quoted as saying: "Teachers don't want [difficult-to-educate students]. If my job depends on their test scores...I don't want those kids. I do because I am a teacher and went into teaching to help kids. But if my job depends on it...I don't want those kids" (Harley-Koelpin, 2006 as quoted in Dudley-Marling & Baker, 2012, p. 141). Similarly, a speech therapist working in a mid-sized town outside of Metro Atlanta said this is one of the reasons she has mixed feelings about NCLB: "Because I think a lot of teachers would get called out, they do get called out by administrators, like why are your children not performing, and that does reflect on the teachers in a way...it's not a good situation...In a way, I think the teachers must discriminate and at the end of the day it reflects on the teacher in the way it's written up, like if these children are not performing what are you doing wrong?" This stigma is one reason some argue that, especially for students with cognitive differences, schools should focus on rates of growth rather than overall achievement standards (Ryan, 2004).

Standardized testing, teacher accountability, and the incentive programs of NCLB are designed to serve the needs of policy-makers and those who profit from schooling, not the children themselves and certainly not students with disabilities (Dudley-Marling & Baker, 2012). For example, Ayres, et al. (2011) fear that the "wholesale adoption of modified general education standards" (p. 16) for all students will threaten FAPE for those with significant disabilities. And although 1% of the student population is allowed to be assessed using alternate assessments, such as portfolios, checklists, or teacher observations, these assessments still must be in line with grade level standards (Bouck, 2009) and, because of variability in teacher training and time, are rarely reliable or valid (Perner, 2007). The provisions of IDEA are being undermined by NCLB in many ways.

Parents are often dissatisfied with their child's education program and teachers. One affluent mother of an autistic child has gone through various school systems in Georgia and Florida only to sacrifice her and her husband's retirement money for a private school specializing in autism. Aside from the fact that she was never properly walked through the IEP process or, at first, really "completely understood what an IEP was or what it meant," she felt that the school was unresponsive to her child's needs. When she finally got her son in a classroom with what she considered a highly-qualified teacher, there were still problems: "He was in a room with 17 other kids, and it was a portable room, and it was probably 500 square feet. A portable 500-square-foot room with 18 screaming kids in there. For the kids with sensory issues!" For this family, the school's provision of FAPE in LRE was unsatisfactory. What is more, this setting is not only segregated but provisioned with lower quality resources, suggesting the children in this classroom did not merit access to the actual school.

There are charter and private school options for families looking for better educational options, or those in failing schools, yet these can be worse for disabled students, especially those with autism. Some states, Georgia included, have scholarship programs for disabled students to attend private special education schools, however these programs vastly underserve target populations and, as private schools are not required to report accountability data, the quality of the schools is unknown (Dudley-Marling & Baker, 2012). Yet none of the parents or professionals I spoke to either during my research or before have mentioned Georgia's Special Needs Scholarship Program, which is designed to assist students with disabilities to transfer to a more appropriate public or private school (Georgia Department of Education, 2013), suggesting that many people in the autism community are unaware of the program.

Charter school programs are perhaps more stigmatizing than voucher programs. Those that are for-profit avoid accepting students who will cost more money and nonprofit schools reject students who disproportionally impact the school's budget. For many charter schools, students are commodified and so disabled students are often barred under the guise of not having appropriate services, thus appearing to have the student's best interest in mind. It is possible that, for some students, the higher quality of charter school education decreases the need for excessive disability labeling (Dudley-Marking &

Baker, 2012), however this is not likely to be the case for students with significant autistic characteristics.

Finally, the ways in which school systems choose and implement the testing policies can be damaging to the education of a disabled student. States can create their own standards, tests, and proficiency criteria. This gives local educational authorities more control. This, however, means some school systems set lower initial expectations for improvement, thereby allowing the majority of students to quickly reach proficiency. The remaining students, including most disabled students, continue to be below proficiency and become an easy mark to blame for school failure (Ryan, 2004). The research-based assessments come from a one-size-fits-all approach that assumes there is one way to teach and learn (Bejoian & Reid, 2005). They may fulfill NCLB's requirement to implement scientifically-based practices, a stipulation mentioned over 100 times in the bill, but these tests neglect important and useful anecdotal and experiential based methods to teach students with disabilities (Bouck, 2009). It is these techniques that teachers in both Atlanta and Kerala reported find to be the most useful.

This practice also influences special education eligibility: "...the labeling and categorizing and subsequent placement (that is, tracking)–the very process of educational disabling–of students is based largely on standardized testing" (Bejoian & Reid, 2005, p. 225). A metro Atlanta public school occupational therapist concurred, explaining that "[i]n the school system they get an autism eligibility, and the things that are highlighted in that are their inability." NCLB encourages deficit-based labels that mark these children as the Other, which allows for students with disabilities to be marginalized and excluded (Bejoian & Reid, 2005).

Although IDEA aims to provide an acceptable education for students with disabilities, the requirements of NCLB take precedence and enhance the stigmatizing aspects of IDEA. Within the 10 titles of NCLB and hundreds of parts and subparts, the words "*special education, exceptional student education*, or *disabled students*"(Moores, 2011, p. 524) are never mentioned. In a 2011 editorial, Deaf scholar Donald F. Moores appropriately wonders:

> ...where was the United States Office of Special Education Programs was 10 years ago when NCLB was being developed. Why didn't the Office demand to be involved? Were the Congress and bureaucracy so out of touch that the needs of more than six million children never came to their attention? NCLB moved beyond 'benign neglect' to approach 'criminal neglect.' Clearly, NCLB is the 800 pound gorilla for special education." (p. 524)

Perhaps the only way to improve educational services is to stop transforming or reforming and to start from scratch (Moores, 2011). This is an especially salient issue in light of the numerous children diagnosed with autism and needing improved education in the public schools. In response to this increase, many schools are creating autism-specific programs that may be well intentioned but often serve to segregate autistic students from both their non-disabled peers and students with other disabilities. One answer is to move away from distinguishing between special and general education and towards the use of special education practices for all students, which would be beneficial to the entire student population. This, however, would require much more funding and dramatically different teacher training practices (Sarrett, 2012).

Education and Teacher Training in Kerala

On April 1, 2010, India's Right of Children to Free and Compulsory Education Act (RTE) came into practice. This bill was approved by parliament in August of 2009 and makes education a fundamental right to all children between the ages of six and fourteen. While it is the parents' responsibility to send their children to schools in America, RTE made this a government responsibility with the enactment of surveyors to monitor neighborhoods and villages to identify children in need of education and, when necessary, setting up facilities to do so (The Right of Children to Free and Compulsory Education Act, 2009). Since 2005, Pratham,[79] a NGO based in India that aims to ensure education to underprivileged children, has completed Annual Status of Education Reports (ASERs). The 2012 report, covering 567 districts, 16,166 villages, 331,881 households, and 596,846 children throughout India, found only 3.5 % of children 6-14 not being in school.[80] The percentage rises to 5.9% when looking at all children ages 7-16 and even higher to 17% when looking at 15-16 year olds. Rates are slight higher for females in all categories. When broken down by state, Kerala shows the lowest percentage of children out of school at 0.1% (Pratham Education Foundation, 2012). As noted in chapter two, Kerala's high access to education is one of the primary reasons the state was chosen as a research site as it indicates an area where children with disabilities are more visible and,

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[79] See http://www.pratham.org/ for details on this organization.

[80] Public schools, however, are generally for poorer children and the budget for primary-age children, which comprises ⅔ of the entire school population, is only about $6.50 a child a year. What's more, previous UNICEF reports indicate that only one in six schools in India has a toilet (Grinker, 2008). So children may be attending school but many are ill equipped.

thus, may be more frequently identified (e.g., by educators) and receive some sort of out-of-home support.

India’s Sarva Shiksha Abhiyan (SSA) program works to ensure the education for all by focusing on children with any kind of special need or disability. It works with all educational institutions, including non-formal and alternative schools as well as government schools. SSA provides up to Rs. 3,000 per child for the integration of a student with a disability, but these funds must be requested. It also aims to provide resources for identification, educational placement, teacher training, and improvement of school structures (Pratham Education Foundation, 2012). According to the director of special education programs at Kerala’s SCERT, SSA takes care of training general education teachers up to grade eight in teaching children with disabilities, including mental retardation (the category covering autism; S. Kumar, personal communication, July 22, 2011).

India’s Rashtriya Madhyamik Shiksha Abhiyan (RMSA) program focuses on secondary school, grades nine to twelve (R. Rajan, personal communication, August 16, 2011). It aims to make “all secondary schools conform to prescribed norms, removing gender, socio-economic and disability barriers, providing universal access to secondary level education by 2017” (Department of School Education & Literacy, Government of India, 2013). This group of students is also aided through the Inclusive Education for Disabled at Secondary Stage (IEDSS), which promotes and aids children with disabilities[81] to continue their school past grade eight at local government schools. There are various other programs and provisions for children with disabilities throughout the country. Most of these are new, especially those for autistic children, which is not a disability specifically listed in some acts. While the creation of committees are clearly laid out, some of the goals of these programs, such as yearly screening for all children, are difficult to implement.

In addition to these national policies and programs, Kerala has its own Right of Children to Free and Compulsory Education Act, 2012, which mirrors the regulations set out in RTE. The rules require the identification of children with disabilities and their completion of elementary education (Commission for RTE Act, 2011). Although no official statistics could be found, given the high percentage of children attending school in the state it can be assumed that the percentage of students with disabilities attending school or some other educational facility (e.g., regular visits to resource rooms or speech therapy clinics) is higher than that of the rest of the country. Of the families included in the current study, only three children attended no regular educational facility or activity (e.g., speech therapy). All live in Wayanad and were identified by educational staff members from the families' local Block Resource Centers (BRCs; described in chapter four). These mothers reported issues related to the cost of the special schools and transportation as barriers to access. However, according RTE and Kerala's Rules, "the

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[81] Children must have at least one disability listed under the Persons with Disabilities Act of 1995 or the National Trust Act of 1999. The former provides protection, employment regulations, identification efforts, and educational provisions for persons with at least "40% disability" however does not include autism in its list of disabilities. (The Persons with Disabilities, 1995). The latter is an autonomous organization under the Ministry of Social Justice and Empowerment which developed and implements The National Trust of Persons with Autism, Cerebral Palsy, Mental Retardation, and Multiple Disability Act of 1999. This act aims to empower people with disabilities, facilitate the establishment of guardians, and help people with disabilities who do not have family support (Ministry of Social Justice and Empowerment, 1999).

local authority shall make appropriate and safe transportation arrangements" or provide "home-based teaching" for "children with severe disabilities" (Commission for RTE Act, 2011). None of the Keralan informants mentioned this provision in the law; it was discovered in post-fieldwork research. Information of such provisions likely only reaches families with higher SES and education, thus generating another access barrier based socio-economic factors.

The regulations set out by RTE are another example of practices that look good on paper but are infrequently put into practice. Some autistic children in Wayanad had received some home-based teaching, however this was uncommon and, in the case of one child, abandoned due to the child's tendency to run away from the home when a teacher arrived and tried to begin instruction. While home-based education for children with significant disabilities appears to be a laudable goal, there are problems with both implementation and interpretation. A 2012 article in the *Times of India* chastised this provision, calling it "retrogressive," claiming it defeats the goal of the Act to promote social inclusion in all schools. Further, the author challenges the category of 'severe disability': "The very notion of what constitutes 'severe disability' is a contested term and the assumption that 'certain children' may be best educated at home rather than schools defeats the very premise of inclusive education that espouses the belief that every child, including those with differing abilities have an entitlement to study with their peers and not be excluded from mainstream education" (Singh, 2012, n.pag.). As noted above, this criticism has also been applied to the provision in IDEA that students be educated alongside non-disabled peers as much as possible. The *Times* article also questions the ability of local authorities to find the resources to provide such education.

This fear appears to be validated in educational practices for children with disabilities being education at home and those attempting to attend general education schools. A general education teacher in Wayanad confirmed the earlier comments of the deputy director on the inability to accommodate children with significant disabilities. When asked about the government's approach to include more children she said it should help, but "we haven't got any instructions so far how to do it in our own schools." In their small, 4-room school, there is one autistic student, the only student with a disability. "We don't get much time for him. There should be resource rooms in every school with all the facilities. We don't know how to give special training to [the autistic student], what we do is try to teach him with what we know." Although this school has a student with significant disabilities attending, the local government has offered no provision for his education.

This teacher's comment highlights another concern—that of teacher training. Several teachers and other professionals in Kerala noted the need for more information, more training, and more facilities for children with disabilities. Despite the existence and goals of the SSA, general education teachers get little to no information on how to teach students with disabilities from their training courses. The teacher quoted above confirmed this fact, stating that she learned from her autistic student's mother, who remains at the school all day to help with her child, but knows they cannot do much for him. Most special education teachers interviewed for this study reported taking a 1- to 1.5-year course in special education or mental retardation. These courses were often taken following the completion of a Bachelor's degree in education, but this was by no means necessary. These courses also did not provide much information on autism aside from stating it is different from mental retardation in some ways.[82] One teacher, a nun at a special school in Wayanad, took a one-year special teacher training course that focused on autism. Among the topics taught were: Autistic Nature and Nursing, Curriculum and Teaching, Human Development and Psychology, and Therapeutics. A small sample of teachers, all nuns from religious special education schools, had no formal training and reported learning how to teach autistic students from previous experience. It is important to note that this sample is not the case nation-wide. However, in Wayanad, the majority of the teachers of autistic students were learning on the job. They were there as either their chosen service to their religion or because they wanted to help what they considered to be the children in most need. The increasing presence and importance of these courses is an achievement for India and one that will, hopefully, not only continue but improve as recognition of ASD increases in throughout the nation.

Currently, however, only a few resources for training teachers how to identify disability and how to teach children with disabilities are available. One source is for workers and teachers at *anganwadis*—centers set up through India's Integrated Child Development Services (ICDS) that are designed to provide early child and maternal health care, including free preschools for all children. Childhood disability is a topic broached in the required thirty-day training course. On the fourteenth day, from 4 pm to

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[82] These ways ranged from autistic children being able to learn to autistic children forgetting everything and having to learn things more than once.

5:30 pm, future *anganwadi* workers learn about various childhood disabilities, how to identify possible disabilities, and what to do once a disability is identified. It is likely that the information provided on the morning of the fifth day about childhood development is useful to this discussion. There is also an hour and fifteen minute section on common behavior problems in childhood. The brevity of these sessions suggests there it little, if any, information on autism.

Although scant, this information is critical for *Anganwadi* staff as these women are often the only non-family support system with which a child and mother will interact. In addition, one of the responsibilities of *Anganwadi* teachers is to regularly collect information about the households the center serves—including which women are pregnant or lactating, the presence of all children under 5, which vaccinations these children received, and the presence of disability. A teacher at an *Anganwadi* center in Wayanad reported a 17-year-old with cerebral palsy, a four-year-old with an unspecified physical and intellectual disability, and a young girl with mobility differences among the 240 households her center services. Despite the minimal training *Anganwadi* teachers and workers receive on identifying disability, they learn on the job and from the families their center serves.

Beyond SSA efforts, there are plans to train teachers in inclusive education in Kerala. As of the time of this research, trainings on inclusive education were being developed at SCERT, however these focus on children with less significant disabilities. Information on autism is not included because it is still a new concept in Kerala (S. Kumar, personal communication, July 22, 2011). In-service trainings for general education teachers on providing inclusive education are available, however it is unclear how often these trainings are given or how many teachers attend. The materials for one of these trainings are available at SCERT and developed through the UNESCO PROAP Bangkok Project on the Promotion of Basic Education for Children with Special Needs. They broadly define inclusive education as education that consider situations related to poverty, child labor, and migrant families along with children with disabilities. It reminds teachers that most of the children with disabilities in their classrooms will have “mild to moderate” disabilities but that “[f]or children who have disabilities that seem very severe, it would be useful to get professional advice” (“Equity Among Diversity”, p. 34). In addition to lessons covering respecting differences and ensuring all children participate in the classroom, there is practical information on choosing appropriate learning experiences, breaking instructions down into specific steps, encouraging a range of communication methods (e.g., building things rather than speaking or writing), and using one activity to meet various goals (e.g., an activity that works on the math goals of one student and motor goals of another). Finally, the training helps teachers think through preparing their classroom for a diverse student group and they responsibilities of each special needs group (of which there are three: socio-economic needs, sensory and physical disabilities, mental and learning difficulties; “Equity Among Diversity”). It also helps prepare them for difficulties they may encounter even with this preparation. The information is useful and will hopefully be provided to all teachers in the state soon, particularly as Kerala continues to advance its inclusion goals.

For special education teachers who have completed their diploma, additional information and trainings are available at community centers such as local BRCs. Some of these are put on by NGOs and are likely available across India; but a centralized list of these courses is unavailable. Of the eight special educators included in this study, five reported attending at least one training on autism. Four of these were from Wayanad, where the Sulthan Bathery BRC was well known for providing services to children on the autism spectrum. A brochure available to teachers listed the symptoms of autism, most of which were taken from the DSM IV TR or ICD 10. A few items diverged from the diagnostic criteria, such as licking and smelling toys and disliking clothes, hugs, being touched, or cuddles. These items are somewhat representative of sensory differences in autistic children but are by no means characteristic of all. Perhaps more importantly, the brochure furthers misinformation by suggesting autistic children lack emotions or the ability to love. This information is filtering into the understanding of autistic individuals amongst professionals. More than half of the teachers interviewed in Kerala made comments that autistic children do not understand emotions, relate only to objects, do not recognize their family, or cannot connect with other people. These perceptions are inaccurate and dehumanizing.

Beyond trainings, teachers frequently reported gathering information about autism on the Internet and through previous experience. This was the experience for teachers and therapists in Atlanta as well. When asked, and sometimes on their own, these professionals uniformly reported that what they learned about autism through their higher education programs did not appropriately prepare them for teaching or interacting with autistic children. This is likely due to the variability in characteristics throughout the autistic population, which ensures any generalization about autism in inaccurate. If teacher training is going to be useful, the materials must avoid misrepresentations that perpetuate autistic stigma.

Given the relative paucity of information on techniques to educate autistic students, or, more broadly, students with intellectual differences, Kerala's aim at inclusive education remains a distant goal. Without widespread training and school provisions, students with significant behavioral and intellectual differences will, and probably should, continue to be educated in segregated school environments. In these facilities, teachers have some level of training in teaching special education students and perhaps some experience or information on teaching autistic children. Yet the material and informational resources available are unable to enact the intensity and specificity of education on which Western educators rely to work towards noticeable change in an autistic child's behavioral, communication, or social traits. Although this is not and should not be a universal goal, the resources needed to create educational environments that are beneficial and equitable are similar to those used in Western educational environments to reach these goals: lower student-teacher ratios; information on creative instructional techniques; material resources to provide visual, audible, or tactile learning experiences and training on how to use these materials; and student transportation. Without these resources, school systems have no choice but to segregate students and teachers have no choice but to rely on instinct to teach what they can and, beyond these limits, provide custodial care.

This result is by no means a result of low motivation or interest on the part of the teachers, many of whom have spent time and money finding resources on the Internet, books, or through other professionals. The differences in these educational practices are important to note for international autism work as they impact the trajectory of autistic populations and attitudes towards rehabilitative possibilities. While both environments are limited, they are so in distinctly different ways. Atlantan schools are limited by regulations while Keralan schools are limited by the unavailability of financial and training resources.

As noted, teacher training opportunities and resources support Kerala's largely custodial approach to the special education of significantly autistic students. Observations at various educational facilities revealed frequent reliance on limited and repetitive activities, such as beading, puzzles, looking at pictures, and sorting various items. One student was observed with an *ayah* who would dump a box of blocks on one side of the room and place the box on the other. The student, a large boy with significant autism who does not communicate verbally, was told to pick up the blocks one-by-one and return them the box, which was dumped again and the activity was repeated. This, and similar activities, are done to keep students active. While some engage fine motor skills, they are often non-functional (i.e., not useful in the world) and non-academic. Although the intentions of these teachers are benign and their actions express particular financial and training backgrounds, students often get frustrated and act out, thus seeming more disabled. The boy with the box and block activity became quite upset to the surprise of the *ayah* and his other teachers, whose training had never covered the benefits of varying activities.

Staff positions, like other educational resources, are limited, leading to lower student teacher ratios than is recommended in Western schools for optimal special education quality. Although this is a Western precept, it is clear from my observations that if more adults were available, many of the activities these students participated in could proceed with more focus and variety. Often a teacher would help a student get started on an activity only to find that, when she turn her back to help other students, the first student stopped his activity. Of course, these additional adults would require training in methods to engage with autistic students in ways that are educational and purposeful. As it stands, special education schools in Kerala are primarily safe, custodial places that provide parents some respite during the day. Those who work at these schools are well intentioned and dedicated to providing instruction on self-help and fine motor skills. However the tools and training necessary to facilitate changes in communication (e.g., the use of alternative communication techniques, the materials for which are unavailable), social interaction, or academic skills are unavailable. When a child shows significant behavioral or intellectual impairments, as is the case with many of the children I encountered, they are primarily kept out of danger. For example, one eighteen-year-old in rural Wayanad spent his day sitting on a windowsill, silently but vigorously rocking back and forth. The staff ties him to the window to keep him from falling off. Children prone to leave school grounds or harm other children are kept inside during outside and unstructured times. Although these practices may at first seem horrifying, in reality they are done with compassion and with the solitary aim of keeping everyone as safe as possible.

Conclusion

The education of children with significant intellectual and behavioral differences, such as those with autism, is a difficult and unpredictable enterprise. Even with extensive teacher training, as is available in America, it is still difficult to know which educational approaches are best for which children. Anecdotal and experiential information is thus critical, and yet undervalued. Professional educators in both Kerala and Atlanta reported dissatisfaction with the application of what was taught in trainings and higher education. One Atlantan teacher stated: "…[autism] wasn't really something we focused on. I didn't know how prevalent it was from my grad school training […] I didn't understand everything it entailed, so my training, overall did not prepare me. Because the book, what the book said were the characteristics but actually seeing a child doing these things, like live in a person, was a little bit different than the book knowledge."

This variability defines the uniqueness of autism. As is commonly said in the autism community, "If you know one person with autism, you know one person with autism" (Hacking, 2010, p. 265). Because of this, regardless of global location, on the ground experience should and could be a more integral aspect of training educators to work with children on the autism spectrum. This goes for general education teachers and special education teachers. Only with familiarity do people get comfortable including an autistic child outside of traditionally segregated environments. Training, segregation, public policy stigma, and the places autistic individuals are educated intertwined such that bolstering one area can enhance another. Providing training and experience to all educators, including administrators and other school staff, will reduce the fear of full inclusion. Reduction in segregation is the most effective way to reduce stigma of any group in any community. And when stigma is reduced among the lay public, this attitude can seep into appropriate and well defined public policy which will cycle back to generate even more acceptable and safe places for autistic individuals.

Taking a detailed look at the various educational structures described here—policy, teacher training, school architectures, school schedules, material and staff resources—can provide important information for those interested in school-based, international work on autism in a variety of ways. First, and most simply, areas of need can be identified. However, needs are only successfully addressed when their surrounding contexts are considered. For example, although teacher training is a need in Kerala, simply training teachers is not sufficient. One must determine how to make training suitable for a community by ensuring materials and ideas are both accurate and acceptable to those receiving the training. This analysis is a very straightforward inward analysis because it looks at effects on the internal processes and structures of education. Second, an outward analysis looking at how this information influences structures beyond education indicate cultural expectations about an autistic individuals. American educational policy makers expect autistic students to turn into adults with few functional skills who will likely remain segregated from society beyond school years. Keralan teacher practices suggest that educators do not expect autistic students to show vast changes in behavior or social-communicative abilities.

Finally, a deeper inward analysis can reveal how autistic children and their families have adapted to and internalized the attitudes implicitly revealed in educational structures. This is perhaps the most difficult, yet critical, information to be garnered here. Students are told they are different and less, though the effect of this message on autistic children is often difficult to ascertain. Families are a bit easier to read. As described in the previous chapter, parental acceptance is related to the availability of a variety of therapeutic options. It is also connected to all aspects of a child's education, from the approaches and attitudes of a child's educators to national policy. These factors can be encouraging, discouraging, or ambivalent for families.

Unfortunately, for both Kerala and Atlanta, schools are places of autism that produce adults without the tools to integrate into their communities. Perhaps more regrettable is that communities are not armed with the tools to facilitate this integration. This is one reason the community is not included in this project as a place of autism; there was not enough data because these children do not spend much time interacting with their communities. Schools serve as sites that both reflect community social structures and prepare children to enter and navigate them and so, currently, schools are places where children with significant autistic characteristics are treated as mysterious, stagnant, unpredictable persons who require specialized locations, instructors, careers, and materials. However, the rhetoric of professionals and caretakers in both Kerala and Atlanta is that of inclusion; hopefully these goals will work towards less segregation and, consequently, less autism-related stigma. If this occurs, the schools can then be the models for the community, generating a different student population, one that includes autistic students alongside non-autistic peers.

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Conclusion

In 2002, Tamara Daley laid out several benefits to comparisons of autism characteristics and structures across cultures. Considering at autism as “in-variant”(p. 537), or as similar in presentation around the world, can reveal which characteristics are seen as more or less symptomatic of deviance in particular cultures (i.e., bring to light implicit definitions of normality and abnormality); can illuminate help-seeking, diagnostic, and treatment practices and processes; can uncover family and community related issues (i.e., how disability affects the family and is defined through community policies); and can identify community-specific socialization practices and values. Cross-cultural variations, on the other hand, can highlight communication and socialization differences between cultures (e.g., values related to eye contact or preference for solitude), possible protective or risk factors,[83] and differences in the treatment needs of children and families (Daley, 2002). These possibilities result from a perspective similar to the outward looking analysis advocated by geographers Holloway et al. (2010) as described in Chapter Five. In his 2010 book on autism in different cultures, Grinker agrees with Daley: “As an anthropologist, I’ve learned that the best way to learn about the rules of any society is to see them broken. That’s why sickness, when it makes people unable to live up to the rules of social behavior, can teach us so much about ourselves” (p. 229).

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[83] Differences in prevalence rates would be one way to identify possible protective or risk factors. For example, a 2011 report by Kim, et. al claiming an autism prevalence rate of 2.64% (or 1 in every 38 children). The authors claim that the high rate is the result of their thorough search for and analysis of all children in the areas studied. Although these rates have not been widely questioned, they also are not commonly cited in studies as a reliable prevalence rate.

Many of the benefits of research on autism in different cultures listed by Daley were touched on in the present study and outlined in the preceding chapters. Perhaps one of the most revealing is the influence of cultural on the ways people understand ASD. As discussed in the first chapter, people can understand ASD as either an essentialist, biomedical fact or as a social construction, reliant on local beliefs of normality, abnormality, and child development. Although many people may be somewhere in the middle of these two perspectives, most Western trained professionals are more confident that ASD is a biological, neurologic, or genetic entity and one in which the person diagnosed is in need of extensive training, rehabilitation, and intervention (Sarrett, 2012). Advocates and individuals who are not familiar with biomedical perspectives are more likely to see the range of characteristics described as "autism" as a flexible, individual experience. As was the case in Kerala, a particular diagnosis may not be important, and so tracking and measuring specific traits is not necessary. The extent to which these different perspectives lead to categorical fallacies (Kleinman, 1977) and the consequences of inaccuracies from any categorical fallacies have yet to be seen. In part, this dissertation is designed to ensure future international work accounts for this fallacy by showing differences between cultures in the ways ASD is identified, understood, and treated. A consideration of varying perspectives on ASD is a common thread throughout the dissertation and the guidelines to follow. These perspectives were found to be important in clinics, schools, and homes.

Another important contribution of this work is its description and analysis of several distinct types of homes in which autistic children and young adults live. I described therapeutic homes, in which many of the home's resources are directed at rehabilitation and intervention efforts for the autistic person. This is contrasted with custodial homes, wherein an autistic person's physical and emotional needs are met, but there is a discernible lack of rehabilitative efforts and materials as compared to therapeutic homes. These homes seem to be partially responsible for a caregiver's level of acceptance of a child's autism. Although more research is needed to validate this finding, it appears that in places like Kerala, where there are few rehabilitative resources, parents accept the fact that their child will maintain autistic characteristics through his life earlier than Atlanta parents.

Finally, another critical focus of this work has been the enactment of stigmatizing practices towards autistic individuals. Here, the primary focus was on schools, which are the places autistic children are required to be and so should be where they are accepted and protected. The reality is that community-wide stigmas are enacted through school policies and practices, including teacher education. It is critical to identify the outcomes of disability-related stigma in order to more efficiently reduce this stigma. While the current work did not study autistic adults, there is much work on the ways employment practices reflect and generate autistic stigma in much the same ways as schools.[84]

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[84] For example, see: Hendricks, D. (2010). Employment and adults with Autism Spectrum Disorders: Challenges and strategies for success. *Journal of Vocational Rehabilitation, 32*(2): 125-134; Galarneau, D. & Radulescu, M. (2009). Employment among the disabled. *Perspectives on Labour and Income, 10*(5): 5-15; Lero, D., Pletsch, C., & Hilbrecht, M. (2012). Introduction to the Special Issue on Disability and Work: Toward re-conceptualizing the 'burden' of disability. *Disability Studies Quarterly, 32*(3); Taylor, J.L. & Seltzer, M.M. (2011). Employment and post-secondary educational activities for young adults with Autism Spectrum Disorders during transition to adulthood. *Journal of Autism and Developmental Disorders, 41*: 566-574; Torero, S.K. (2009). The right to work: A strategy for addressing the invisibility of persons with disability. *Disability Studies Quarterly, 29*(4); World Health Organization. (2011). *World Report on Disability.* Geneva, Switzerland: WHO Press.

Generating more accepting and diverse school environments will have long-lasting effects, as students become workers, friends, and community members.

There is much more to learn from looking at autism in different cultures. As global awareness spreads, research on autism is increasingly focusing on areas outside of the Global North. At the 2013 International Meeting for Autism Research (IMFAR), eighty-three papers and posters were marked as related to cultural diversity. However, the overwhelming majority were papers that explored a biological, etiological, or assessment issue in the Global South (e.g., a paper titled "Oxidative Stress Markers in Children with Autism Spectrum Disorders" was marked because the research occurred in Cuba). Most of this work was done by in-country researchers and, thus, did not include a deep cultural analysis by the research team. That these studies comprised the bulk of the cultural diversity research demonstrates the extent to which concepts and thoughts about autism are associated with the Global North and biomedicine. Explorations in issues related to how culture influences ASD and related disorders were unavailable, even in the selections purported to do just that.

As autism-related work becomes more common around the world, it is likely that more interventionists, consultants, and researchers will introduce practices and concepts of autism into new areas. This work will require a deep understanding of the culture of interest for which the guidelines presented below are designed to facilitate. Using the definition of culture in the introduction,[85] it is clear how important cultural influence is to

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[85] "...culture is a set of guidelines (both explicit and implicit) that individuals inherit as members of a particular society, and that tell them how to view the world, how to experience it emotionally, and how to behave in it in relation to other people, to supernatural forces or gods, and to the natural environment. It also provides them with a way of transmitting these guidelines to the next generation—by the use of symbols, language, art, and ritual." (Helman, 2000, p. 2).

current and future perceptions of ASD and how these perspectives are disseminated throughout a community. This definition also reminds us that culture guides our emotional reactions to our social and natural worlds; it is critical for understanding both emotional and practical reactions to differences, such as those seen with ASD. It is critical to keep these features of culture and Kleinman's notion of popularization[86] in mind when beginning to learn about a new culture in relation to ASD and related disorders. Kleinman's concept demonstrates the malleability and dynamic nature of culture as globalization brings in new ideas, like that of the diagnostic and conceptual category of Autism Spectrum Disorders. Taking steps to understand how communities will receive and utilize psychiatric, biomedical, and therapeutic information is paramount to successful international autism research and practice.

What follows are general guidelines or suggestions for people interested in doing autism-related work—specifically research, consultation, advocacy, and direct care—in a culture other than their own. Many of these recommendations are also useful for people who interact with culturally diverse families in their own communities. Most cross-cultural autism-related work is and should be done by individuals with academic or professional training in autism as well as training in the discipline guiding the work (e.g., anthropology, psychology, public health). However, I recognize that volunteers with organizations such as the Peace Corps send people to work with children in developing areas. Often this work will include disabled children as well as non-disabled children. Although these organizations may provide some level of training, volunteers do not

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[86] Whereby communities take certain aspects of outside concepts—here, biomedicine—and adapt them to fit into their existing structures (Kleinman, 1980).

usually come with the same level of training as researchers or clinicians. The guidelines presented here can still be a useful resource for these volunteers and for the organizations providing volunteers. After presenting the guidelines, I will discuss another critical consideration that outsiders will likely encounter: the ethical issues involved in this work.

The Guidelines

The chapters on the places of autism—the clinic, the home, and the school—began with a general physical and architectural description of each place in Atlanta and Kerala. The purpose of these detailed accounts was to demonstrate how these places can be ‘read’ for important information about how specific facilities and communities perceive and interact with children who demonstrate significant characteristics of autism. Human geography has taught us that the relationship between people, behavior, and the built environment is close, responsive, and informative. According to Arturo Escobar (2001), recent interest in globalization led to a decreased interested in locality. He argues this shift is detrimental, stating that place can be informative for learning about larger cultural and even global practices: “…[places] are historical and connected to the wider world through relations of power, and in many ways are determined by them” (p. 157). This work agrees with this perspective by basing the cross-cultural comparison between Kerala and Atlanta on the idea that looking closely at the specific places in which autism is found reveals a host of information about micro-level individual and community-wide held beliefs about ASD as well as macro-level, global attitudes that pervade a range of cultures.

Relatedly, disability scholars Snyder and Mitchell (2005) argue that practices and attitudes about disabled people establish and reinstate common and even trite cultural tropes (p. 21). The ways we see professionals and parents interacting with, for our purposes, autistic children, reveal community-wide beliefs about this population that are based on historic lineages of ability, disability, and power. This information can be seen and read at the facilities and within the structures autistic children and their families most often interact. This work argues that cultivating an awareness of these beliefs is useful to ensuring successful, efficient, and aware interactions with professionals and parents in different cultures or within various cultural backgrounds in one's own cultural location. It is also useful for identifying and reducing disability-related stigma. In this way, this dissertation is primarily about putting the theoretical notions about disability, place, and culture into useful and appropriate practices surrounding ASD and related disorders.

Among the guidelines below are those related to 'reading' the places in which autistic children and their families frequent, and those for gathering important information in initial interactions with professionals and families. After the guidelines are presented, this concluding chapter will discuss and review of some ethical issues encountered over the course of this research. Apart from recommending that these ethical issues be given more attention in discussions of global autism research, this section does not include direct suggestions for how to react to or solve these issues. A deep analysis of a wider range of experiences is needed for that work. Instead, this section is meant to provoke readers into deeper considerations on the issues associated with interacting with people related to intellectual, behavioral, and psychiatric differences in different cultures.

Research and cultural liaisons.

Before engaging a new cultural environment (or before interacting with a person or family from a different cultural background) it is essential to become familiar with its language, traditions, and familial and educational structures. These are basic issues that require more than a simple Internet search. An initial look into Kerala reveals that (a) the language, Malayalam, is a complicated Dravidian language, (b) although Hindu is the most prominent religion, Christianity is a close second and Islam the third, (c) Kerala's unique history and political structure led to the Kerala Development Model, and (d) Kerala has high rates of men who work for long periods of time in the Persian Gulf.[87] Knowing only this information is a useful start, but much more research is required for those who wish to engage with people impacted by autism or other learning, intellectual, or developmental disabilities. In terms of autism, the information listed above could connote that (a) linguistic features of autism, such as pronoun reversal, may not be present, (b) typical spiritual beliefs about illness and health associated with Hinduism may not be widely applicable in Kerala, (c) social services for education and health care are more accessible in this state than other areas of the country, and (d) many families are headed by women, at least temporarily, as many men are out of the country. This brief and incomplete background-cum-analysis demonstrates the value of cultural background information for guiding and contextualizing autism-related work. Much more useful and

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[87] This information was identified in my research on Kerala, but was also present on the Wikipedia page outlining the state. The page was accessed on July 10, 2013 and can be found at https://en.wikipedia.org/wiki/Kerala. I am not suggesting researchers only look at a new culture at this superficial level, however am demonstrating how even a small amount of research is useful.

critical information is gathered through direct interactions with individuals living in the culture of interest.

In addition to reading and gathering articles, books, and other materials, interacting with people from the culture of interest is paramount. For those interacting with families from a range of cultural backgrounds in their own communities, generating long-term relationships with individuals from the primary cultural backgrounds encountered is highly recommended. Beyond linguistic translations of necessary tools and materials or simple interpretation services, a liaison can provide context to certain comments and references and tips on fostering and maintaining collaborative and responsive relationships with autistic individuals and their families.

Those entering into a new culture to engage in autism-related work should establish a relationship with a cultural liaison within the community they will be working. This can be done by teaming up with professionals in the incoming culture or hiring a translator. It is critical to first ask these professionals if they would be comfortable providing cultural context and feedback on research or intervention practices that are and are not feasible or acceptable in the local culture. For this project, I hired a translator who was willing to provide this type of cultural context. Prior to and while working together, we had discussions about what autism is; the different educational and therapeutic options for autistic individuals in my culture and in his; my exact research goals and protocol; the concept of neurodiversity and the language of difference not deficit;[88] his expectations of the position; his prior experience with and attitudes about children with

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[88] We discussed this aspect of autism work because it was the perspective I take on autism. I wanted my translator to understand this perspective so we could discuss human rights and advocacy together.

autistic characteristics; and how one should react to specific situations, such as appointments being missed or delayed, comforting (or not) informants who became emotional in the interview, appropriate behavior in observations, and how to respond to individuals who were unwelcoming in some way. Obviously it was impossible to predict and discuss all possible research events, however we acted together to address unanticipated difficulties or situations needing context. Having these discussions from the very beginning allowed us to feel comfortable asking each other questions and to give each other advice throughout our work in Kerala. In this way, we were a collaborative research team.

‘Reading’ places for cues.

A close examination of the place of autism one enters into can provide rich insight into how to proceed with professionals and families in beneficial and comfortable ways. It is well known that developing and maintaining relationships during fieldwork is a delicate and often prolonged process. Being able to use architectural, temporal, and social cues can facilitate this process. Additionally, close readings of place reveal culturally inherent values about autism and individuals who demonstrate autistic characteristics. There are four primary areas in which information can be garnered through reading a place of autism: the purpose of the place, the approach taken in that place, what can be expected to occur in that place, and accepted and unaccepted behaviors for a place. As will be described below, these areas build on one another such that the information gathered about the purpose informs the approach, and so on. The preceding chapters demonstrate this practice in detail. This section is meant to be a broader overview of how to look for and infer useful information from the physical and temporal structures of the places in which autism is commonly found.

Purpose.

Discovering the purpose of the place means determining if it is dedicated to providing treatment, diagnosis, education, advocacy, et cetera. Many times it is obvious what the purpose of a place is before arriving (e.g., when going to a school the purpose is education), however, as noted throughout the dissertation, the details of a place's purpose may be clearer upon arrival. For instance, one primary purpose of clinics in Kerala is initial consultation, which often ends in a referral rather than a diagnosis. This is evident in the frequency with which families and patients enter and leave the physician's office. Clinics in which patients stay with professionals for prolonged periods are receiving treatment or more extensive assessments to develop clearer treatment plans.

Paying attention to the amount of documentation patients and providers are carrying can indicate the level of importance placed on diagnosis and creating a written history validating a person's medical or clinical history. This need for documentation indicates a higher importance placed on the validity of the patient's diagnosis (labeling) and treatment methods. This is more commonly associated with facilities using Western and biomedical practices. Similarly, educational facilities that gather and maintain detailed records are likely to focus more heavily on rehabilitation. Schools that neither produce nor require much documentation are more likely to have a custodial approach, ('custodial' refers to facilities that, because of few staff, material, or informational resources, keep children busy and safe but have few specified educational goals).

Homes can be similarly assessed with a quick appraisal of openly available child-directed resources. Homes that have toys and other child-specific materials are more likely to emphasize structured children's activities than those without. This is usually the case regardless of socio-economic status. Homes with low SES in cultures that value differentiating between child and adult spaces will have at least some child-specific materials around the home. Homes in areas that do not have this emphasis, such as those I visited in Kerala, often allow children to engage in more unstructured activities without any direct educational or social purpose.

Further, the presence of autism-specific materials indicates a therapeutic home rather than a custodial home. Materials such as visual aides, PECS, small trampolines or swings are used to alleviate or change autistic behaviors. These are present in homes where the child's autism is seen as something caregivers hope to fix or treat. Homes with access to many therapeutic options may also be places with less caregiver acceptance of the child's autism. As was described in chapter four, caregiver acceptance could be facilitated through fewer therapeutic options. Having access to fewer interventions may promote earlier parental acceptance of a child's autistic characteristics. Again, more research needs to be done to substantiate this correlation because it has vast implications —from understanding how to facilitate better mental health for caregivers to exploring the ways expressed emotion, or the amount of emotional reaction to differences,[89] impacts autistic children and adults.

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[89] Expressed emotion (EE) is the amount and type of emotional reaction that is demonstrated by people closely associated with an ill person (i.e. family members, psychiatrists, friends) in times of mental ill-health (King & Dixon, 1995; King & Dixon, 1999).

The purpose of a place of autism is gleaned through one's prior knowledge of the place (e.g., a school versus a home versus a clinic) and can be further established with a quick evaluation of materials and uses of time. With this information, people new to these places can begin to form an idea of what happens in these places and, thus, the beliefs and attitudes driving the formation and purpose of specific places of autism. Once the purpose of a place has been identified, the approach can be uncovered.

Approach.

The approach of a place refers to its institutional or theoretical background. It is at this level of information gathering that one can begin to see the influence of the perspectives described above (e.g., biomedical versus socially and culturally reliant). As with the purpose of a place, much of this is revealed by simply knowing what a place is—a school, a clinic, a healer, et cetera. Schools, for instance, can be custodial or rehabilitative. An educational facility with a custodial approach will be stocked with materials that keep children busy, but have unclear educational aims. For example, in both research sites I observed autistic children spending considerable time putting beads on a string. Although beading can improve fine motor skills, beading several times a day is more helpful for keeping a child occupied than teaching any functional or academic skills. Classrooms with a rehabilitative approach, on the other hand, will have multiple staff members who are constantly engaged with students as well as a wide variety of educational and therapeutic instructional materials. Overall, classroom and individual activities are more rehabilitative and educational. In these schools, the approach will be highly structured, organized, and purposeful.

Clinical approaches can range from biomedical to traditional holistic medicine. Western biomedical approaches are characterized by a clear distinction between professional and patient. A ‘gatekeeper’ (e.g., a clinic employee at a front desk) through whom patients access the professional is clearly present. Appointments are required and so patients are less likely to wait several hours to see the physician, healer, or related specialist. Additionally, professionals in more Western-style clinics wear distinctive clothing, such as white coats or scrubs to distinguish themselves from patients. These distinctions also indicate the competence and authority of the professionals.[90] Traditional healing clinics, on the other hand, do not establish such stark visual distinctions between the healers and patients. While this does not serve to diminish respect for the healers, is does suggest a more relaxed diagnostic and treatment atmosphere where labels are not as important and touch is more common.[91]

The approach in a home may be more or less child-directed and rehabilitative. As with the purpose, the materials indicate the approach. More autism- or child-specific materials indicate a therapeutic home, which can be a sign of a high level of supervision. Therapeutic homes are more likely to have caregivers who closely monitor the behavior of autistic children, consistently surveying a child’s progress and responses to interventions. In what I call custodial homes, the immediate needs of a child are monitored, however, the close scrutiny characteristic of therapeutic homes is either

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[90] Studies on the effect of physician attire show that patients’ perceive professionals wearing a white coat to be more authoritative and also more caring (Chung, Lee, Chang, Kim, Lee, Park, & Chae, 2012; Gerard, Cameron, West, & Crossley, 2009). However, there is also evidence of a “white-coat effect,” in which patients have higher anxiety and blood pressure during doctor’s visits (Hochberg, 2007; Jhalani, Goyal, Clew, Schwartz, Pickering, & Gerin, 2005).

[91] For more explanation on the use of touch, please see Chapter three.

unnecessary or infeasible. While most homes with autistic children have features of both custodial and therapeutic homes at various times, households in communities with more available therapeutic options are more frequently dedicated to rehabilitative efforts. Thus, the type of home is responsive to community resources and attitudes.

The approach of a place of autism can indicate how people in certain communities will talk about autism. Professionals at places relying on a biomedical, Western approach to autism—as in rehabilitative schools, therapeutic homes, and Western-style clinics—are likely to talk about autism in essentialist ways and in terms of problematic symptoms (things that are wrong) and how to fix or alleviate them. These facilities are focused on using approaches that are based on Western science, and thus are assumed to be more valid and effective. Facilities that use a more holistic, traditional, or custodial approaches may also discuss autism in terms of problematic symptoms, but are more likely to focus on difficulties with daily living skills rather than educational or rehabilitative goals. Here, ASD may not be a familiar or relied upon label; causal, educational, or therapeutic information is unknown and thus not applied. These places are also less likely to employ rigorous scientific or evidenced-based interventions. Traditional healers will also discuss cures or alleviation of symptoms, however the therapies used are more individualized and based less on a diagnosis than a set of behaviors or characteristics.

Similarly, professionals and caregivers at custodial homes and schools will more frequently talk about meeting the immediate physical needs of autistic children. They are more likely to focus on sleep disturbances and feeding difficulties than future recovery or full normalization. Understanding and attending to the approach towards autism employed in homes, clinics, and schools is not only useful for determining how to communicate about autism, but also leads to information about the expectations embedded in these places.

Expectations.

Here, expectations refer to what a patient, family member, or outside professional can predictably obtain from spending time at a particular place of autism, such as medication, advice, or documentation of a diagnosis. This is deduced from the purpose and approach from a place. Places that are more therapeutically oriented and ones that are based in biomedical perspectives of autism generate different outcomes than those that are more traditional and custodial. When entering into a biomedical or Western-style clinic, families expect to leave with answers and treatments. The professional nature of this type of clinic suggests the clinician has a specific kind of educational and clinical background and, thus, the authority and ability to assess a child, name the disorder, and inform parents about what steps to take next. In Kerala, patients do not expect much time with physicians in walk-in clinics, as is indicated by full waiting rooms and short doctor-patient interactions. They do, however, expect medication, a referral for more assessment, or to be sent to a specialized clinic where an appointment is required. The approach may be the same, but the outcome and expectations differ.

As was discussed in the third chapter, the types of answers families need or want varies. Families in Atlanta were more interested in discovering their child's diagnosis than those in Kerala, who primarily want to leave knowing either when the child would be "returned to normal" (a phrase I heard frequently from Keralan parents) or what they can do to fix their child. While Atlanta caregivers were also interested in prognosis and treatment, they value obtaining a diagnosis first. Generally, these parents believe that once a diagnosis is derived, the treatment program will become clear and available. This belief aligns with the reality in America that a diagnostic label is a valuable product that can qualify a child for services and get insurance coverage for these services. Meanwhile, clients and patients at traditional healing clinics in Kerala are less likely to expect a diagnosis but do expect to receive some sort of treatment or leave with a medication regimen to follow at home. Patients and caregivers expect interactions at any clinic to provide answers, however the types of answers vary based on approach and purpose.

At educational facilities, expectations differ based on cultural attitudes towards education in general as well as specific approaches towards autistic children. American, and thus Atlantan, caregivers are more commonly involved at schools, particularly for children in special education, for whom IEPs are, by law, generated in meetings that include a child's caregiver. Teachers and administrators in schools invested in rehabilitation or academic progress of autistic students are more likely to expect some level of parental involvement. Schools with a more custodial approach are less likely to provide reports abouts students or generate detailed educational programs, and so do not foster much interaction with caregivers. Similarly, caregivers with students in these facilities expect less contact and information from these types of schools. Thus, tracking and recording student progress is less emphasized in custodial than rehabilitative schools.

Similarly, expectations of outcomes and interactions differ in therapeutic versus custodial homes. Therapeutic homes are more likely to follow detailed schedules and expect all household members to be aware of, if not participate in, therapeutic activities for the autistic child. An outsider can expect to hear caregivers discuss treatment histories, successes, failures, and work within the household schedule. In this regard, Atlanta caregivers are focused on altering a child's autistic characteristics for a longer period than Kerala caregivers. Custodial homes, on the other hand, are more flexible with time[92] and schedules. The expectations about an autistic child's prognosis and future seem to differ between the types of homes. Family members in therapeutic homes seem to hold onto expectations of recovery or a lessening of autistic traits longer than those in custodial homes.

Knowing and understanding the expectations of a place can guide outsiders in initial interactions with families and professionals in other cultural environments by informing them on whether to talk about curing or caring for autistic children and even whether the label *autism* is useful. Additionally, it can help determine what one can and cannot expect in terms of intervention or participation in programs or research. All of this information can help one know how to behave in particular places of autism.

Behavior.

Once information regarding a place's purpose, approach, and expectations is gathered, acceptable behavior can be determined. This is critical for developing productive and sustainable relationships with families and professionals who spend time at these places. Clinics with more traditional and holistic approaches that provide

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[92] For example, it is common throughout India, and in Kerala, for people to make unannounced visits to friends and family. Women are expected to be able to get a snack together and men are expected to sit and chat with visitors. This is a less common event in America where visits are more often planned and anticipated.

treatment and have little expectation of formality allow patients, professionals, and visitors, including those from outside the culture, to behave in a more sociable manner. Asking questions and being asked questions unrelated to medicine or health is frequent, as is a less formal style of meeting. At this type of place, one may meet with a professional as they provide treatment or walk around the clinic. Privacy expectations are lower and so meeting in public spaces or in unsecure offices (e.g., open doors or walls that allow sound through) is common. Although announcing a visit is still recommended, there may be no expectation to make an appointment. For these visits, planning for time to wait to meet with professionals is recommended. This time can be useful. One can easily engage in the social atmosphere to observe and casually speak with patients and other professionals. However this should be done with an honest description of the professional reason for one's presence at the clinic. In any casual interactions, individuals must not be spoken to without them expressly understanding the purpose underlying the interaction.

Western-style clinics, on the other hand, are more likely to have an air of formality and will require some sort of official proposal or project plan before interacting with patients. When documentation is observed to be highly valued, it is likely that certain bureaucratic procedures are in place to allow interactions with patients and other professionals at the clinic. Here, spontaneous interactions should be avoided. Meetings with professionals will occur in offices and by appointment. However, as briefly mentioned in the third chapter on clinics, some cultures are less likely to ensure the level of privacy commonly seen in Western areas, such as America. Meetings may occur in private but may also overlap with patient consultations or be interrupted by other staff members.

When one has observed that an educational facility is highly structured and focused on academic and skill advancement, this usually means that observations should be done without much interaction with the students and that any meetings or discussions with teachers will have to occur at a specified time when students are otherwise engaged. Schools in Atlanta and throughout the U.S. require documentation, an application, and sometimes even a background check to visit for research, consultation, or some other purpose not related to the school. More casual custodial schools outside of Western communities are somewhat less strict about this level of formality. While one should call and arrange a time to visit, documentation may not be necessary. Additionally, interactions with students are encouraged and often professionals will take time to speak with you even during official instruction times.

Observing a school's materials and activities can also help one assess whether and how much to discuss instructional techniques or behavior management strategies. Researchers, advocates, or interventionists with knowledge, skills, and materials unknown to an inside culture may be tempted to advise teachers and other professionals on new techniques. While this may be welcome information, it must be provided with a deep consideration of the facility's time and material resources. For example, advising that teachers use some labor-intensive technique may prove more frustrating than helpful for groups without the staff to execute it appropriately.

Finally, homes that are well stocked with child-directed and, especially, autism-specific materials will likely follow a strict schedule and so it is more critical to be on time, to observe without interfering, and to clearly explain the purpose of the visit. Additionally, in homes and schools focused on rehabilitation and changing autistic behaviors, it is likely that autism is discussed in terms of deficits and prognostic goals. Language suggesting acceptance of current autistic behaviors or autism-related advocacy should be carefully considered. Alternatively, homes that are unable to focus heavily on autism rehabilitation are more likely to discuss and respond to discussions of autism as a life-long state of being, rather than a changeable or fixable one.

As is seen in this section, reading a place of autism can assist those interested in engaging in autism-related work in different cultural environments. Of course, before one can begin to read a place, extensive background research needs to be completed. This includes finding scholarly books and articles on the region that describe the culture, its history, and its norms. After one has had some time to discuss this work with a cultural liaison, to observe the places the work will occur, and after one has begun interactions, specific information can be gathered at each particular place of autism.

What to learn at clinics.

Whether one is doing research, setting up a clinical facility, providing or receiving training, or engaging in advocacy work, obtaining detailed information about diagnostic and therapeutic practices is important. Gaining a sense of how long assessments, consultations, or interventions last is helpful for determining time frames within which to work and for better understanding caregivers' journeys to diagnosis and treatment.

Understanding the importance invested in the validity of diagnosis, documentation practices, and use of specific assessments (e.g., questionnaires, observations, brain scans) indicates the types of language to use when interacting with individuals at specific clinics. Knowing if one can or should discuss, for example, an ADOS, the new DSM 5 diagnostic criteria, or use neurological and biological language, can make interactions smooth and efficient.

Learning about clinic diagnostic and assessment practices can also provide important information about what autism looks like in different cultures. Knowing which characteristics or traits are necessary for a diagnosis and which are ancillary leads to a picture of what children with the label may look like. For example, if professionals mention screaming, crying, self-abusive behavior, or frequent repetitive behaviors as critical to autism, they may not diagnose children who are quiet and calm or inactive—even if they exhibit other characteristics that would qualify them for an autism diagnosis in another culture. This was the case in Kerala, where the large majority of kids labeled autistic, or mentally retarded (the more common term in this area) expressed significant autistic characteristics. Gaining an understanding of the role of the family in the diagnostic or therapeutic practice will help incomers predict what family-provider interactions look like. Such understanding can lead to more efficient research or intervention models. For instance, many facilities in Kerala insisted that a caregiver attend therapeutic sessions with their child, whereas many American therapists insist on their presence at the clinic but not necessarily in the therapy room. This information can help researchers understand relationships between caregivers and providers, and also give them some insight into the information caregivers are receiving about autism and autistic rehabilitation.

What to learn at homes.

Families, especially caregivers, are rich sources of information. This is especially true when visits with and observations of families are not bounded by time and purpose. Open ended questionnaires and encouragements to tell their stories allow caregivers to provide information and details they feel are important. If it is possible to make sure time is not a concern, caregivers can relax and will often open up about their concerns and daily lives. However, when interacting with families with a cultural background different from one's own, it is important to understand familial and gender hierarchies so as not to alienate caregivers before beginning to work or interact with them. In Kerala, for example, men and fathers are considered heads of family, but mothers often have the most information and, as men are often away from the home due to work, are likely to be the first and only point of contact. Yet, if the father is present, it is important to direct questions to him as well as to the mother. Often, he will answer for both of them. However, even when it is clear the mother has more or better information, it is improper to ask her to also provide an answer. Information like this is critical and difficult to come by in texts but can be gleaned from a cultural liaison.

Allowing caregivers to speak freely at the beginning of an interaction can also help determine the ways in which the family considers a child's autism or the presence of traits considered to be part of the autism spectrum. Again, this relates to evaluating where a person is on the essentialist-socially-reliant spectrum of perspectives about autism. If autism is discussed as a biomedical condition, then using medically based language to describe autism or treatments, including genetics or neurology, may be the most appropriate way to discuss autism with that family. If caregivers suggest their child's differences are due to spiritual causes, such as karma or curses, then medical language should probably be avoided. Instead, focusing on characteristics and daily activities is more appropriate. Caregivers who frequently discuss their child's strengths or the benefits of having autism in the family can be related to through the language of neurodiveristy that does not highlight rehabilitative goals.

The ways families talk about autism or autistic characteristics can also provide insight into their expectations about the child's future. Some families expect their autistic children to grow up to hold jobs and have families, while others expect them to live at home or in an institution throughout their adult life. For most caregivers, the future of their child is a sensitive and stressful subject and so should be breached cautiously. However, once they express their expectations for an autistic child's future, discussions on how to reach their goals can proceed. Asking caregivers about their expectations is also important for ensuring one's own assumptions about a particular child's future do not seems offensive. This can easily occur if there are vast differences in a child's prognosis. These open conversations can also help determine how focused a family is on rehabilitation and at what point in acceptance of a child's autistic characteristics a caregiver currently is. For example, discussing lifelong interventions with a family who has ceased to expect any change in their child's autistic characteristics can create distance between the incoming individual and the caregiver. It may also provide additional stress for the caregiver who may feel as though they are being judged as not doing enough for their child. This is another area where more research to understand the process or parental acceptance would be helpful.

What to learn at schools.

As noted in the fifth chapter, the professionals, schedules, materials, and educational policies of schools reflect the attitudes of the wider society in regards to people with disabilities. In some ways, schools are perhaps a more accurate reflection of community attitudes towards autism than homes (because of the absence of familial connection between autistic and non-autistic individuals) or clinics (because of the longer interactions between people at schools). Speaking to teachers about their curriculum can reveal deep insights into community perceptions of disability. Curricula can reveal expectations for students' futures and abilities, values of normalization (and thus devaluation of differences), and the role of the family. For instance, American education policy currently prescribes that all students work towards and reach the same academic standards. Initially, this perspective may seem a thoughtful goal that does not discriminate based on expectations of ability or disregard the potential of students with disabilities. Yet speaking with teachers of students with disabilities reveals that this situation leads to unreasonable and infeasible curricula and more stigma.

Alternatively, when there is no curriculum or when curricular goals are not followed one can assume that educators have little to no expectations of students' abilities or progress. As autistic students are known to frequently have difficulties with fine motor skills (Frith, 1991), activities such as beading, putting together puzzles, and stacking blocks are employed to improve these skills. However, in the absence of educational goals, these activities become overused and directed toward keeping students busy. Overuse of these activities was seen in Atlanta, but was more frequent in Kerala, where training on educating autistic students is rare. Discussions with educators can reveal beliefs about their students' educational and developmental stagnation, which are present regardless of an educator's fondness for and dedication to autistic students. Thus, speaking with educators about what their curriculum looks like and how they develop it is a rich source of information for incoming researchers and practitioners about attitudes towards autism.

Finally, speaking with teachers about their temporal, material, and informational resources is critical to determine what can and cannot be expected from educational facilities as well as to explain why certain procedures and practices are being implemented. This will assist in informing practitioners on what ought and ought not be suggested as educational practices and how to best augment and culturally translate techniques from one community for another. Although there are myriad autism-specific strategies in Western educational facilities, this is not likely to be the case in areas that have more recently begun to use the diagnostic label. This means that when discussing educational techniques for children with intellectual impairment, using whatever term is most common in that area (e.g., in Kerala, the term most frequently used was mental retardation, though the term *autism* was familiar in to professionals at these special schools), will be more fruitful than asking about specific educational practices for autistic students.

Finally, speaking with educators about their educational or training backgrounds is useful for determining how much autism-specific information is known and how attitudes towards autism are developed. As noted in the previous chapter, teacher training programs that separate special and general education, as is the case for my informants in both research sites, implicitly suggest a need to segregate these groups in schools. Information about the structure of these programs can also help improve teacher-training programs. Educators and therapists in both regions noted that the information they received in higher education programs and other training programs or workshops did not prepare them for working with children on the autism spectrum. This is largely because of the behavioral and intellectual variability seen throughout the autism spectrum, which is difficult to reflect in textbooks, lectures, or on the Internet.

The suggestions presented here are critical for any international work related to autism. Many, if not all, of the recommendations may be useful for working with other childhood disabilities around the world, and for interacting with families from different cultural backgrounds in one's own community. Using these guidelines, one can efficiently and expertly find areas of need and address them with cultural sensitivity and understanding. Perhaps new approaches to interacting with autistic individuals can be identified that may be useful in one's home community. Most importantly, barriers related to stigma can be recognized and measures to reduce this stigma and consequent human rights violations of autistic individuals can be addressed. Without adequately preparing for this work or gathering the information suggested here, miscommunication between outsiders and in-country individuals will occur and important contextual information will be missed.

Although these suggestions are useful for beginning international work related to autism, they do not adequately prepare for most ethical issues that will be encountered in this line of work. As such, the next section discusses the ethical issues associated with interacting with autism-related populations in new cultures with the goal of beginning a conversation about these issues rather than solving problems.

The Ethics of Studying Autism Across Cultures

As described in the introduction, the field of anthropology has a history of coping with and preparing for ethical issues encountered in ethnographic fieldwork. In the aftermath of the accusations related to the research done by Napoleon Chagnon with the Yanomami tribe and an ensuing investigation, the Anthropological Association of America (AAA) reviewed its code of ethics through internal and public round tables and lectures (Borofsky, 2005). Currently, the AAA's code of ethics includes, among other guides, the injunction to obtain informed consent, respect for the privacy of informants, avoid exploiting a research site and participants, and, in general, do no harm. (American Anthropological Association, 2012). Along similar lines, the WHO's report recommends a respect for cultural traditions, informed consent, providing ongoing feedback, and engaging in ethical reviews of research protocols (Marshall, 2007). Comparatively, the field of bioethics promotes principles of autonomy, beneficence, nonmaleficence, and justice (Beauchamp & Childress, 1979; McGee, 2003).

As critical as these institutionally derived ethical guidelines and suggestions are, they remain ambiguous and Western-centric. However, researchers who engage in cross-cultural scholarship, particularly in the field of health and disability, are in a unique position to begin conversations about the ways these ethical guidelines are put into practice and identify areas where these principles fall short. In order to add to this discussion, I will discuss particular instances in my fieldwork in which I felt ethically challenged. Given the ambiguous and situation-specific nature of most of these issues, they are best discussed through storytelling. Stories of my ethical issues, or “moral breakdowns” (Zigon, 2010), will bring to the fore moments of cultural difference that challenge the universality of the enactment of ethical principles.

Jarrett Zigon defines a “moral breakdown” as moments that force a person to reflect on their embodied ethical stance. He argues that until we encounter events or persons who create these moral breakdowns, we are existing in a kind of ethical equilibrium during which we are not aware of or reflecting on our ingrained ethical beliefs (Zigon, 2010). Whereas morality is equated to action and events, ethics are based on the abstract principles guiding moral action (Zigon, 2010; Kleinman 1998) so a challenge to our ethical stance forces reflection and intentional action to preserve these principles. Moral breakdowns are usually called ethical dilemmas, however I prefer Zigon’s term as it demonstrates situations that, in the moment, feel like a shattering of ethical precepts previously considered to be indestructible.

Moral breakdowns are likely to occur when confronting new and different cultural practices because morality, and even guiding ethical principles, is rarely as universal as one assumes. This actuality is challenging for cultural outsiders to witness. Arthur Kleinman laid out these challenges in an 1998 Tanner Lecture: "…what morally defines a local world, may be, when viewed in comparative perspective, corrupt, grotesque, even down-right inhuman. That is to say, the moral may be unethical, just as the ethical may be irrelevant to moral experience" (Kleinman, 1998). Researchers must not rely on assumed universal ethical principles and moral actions; flexibility is a powerful and necessary tool that can and should be taught through example and reflection within an ethnographic account. This understanding is particularly essential in research in which the informants and the researchers are confronted with issues of stigma, non-normative development and embodiment; uncertain futures; urgent needs for resources and information; gender, familial, and childhood roles; and expectations of education, success, and productivity.

The flexibility needed to approach disparate ethical principles is challenging and requires leaving one's own cultural assumptions aside (Schweder, 1997). The scholars noted in the introduction—Biehl (2005), Grinker (2008), Radioman (1997), Kleinman (1988), Luhrmann (2000), Zigon (2010), and Throop (2010)[93]—have all described instances in which this challenge was faced. Grinker (2008), Fadiman (1998), and Biehl (2005) relate times they witnessed, to their discomfort, misuse of medications such as when families shared prescription medications, took powerful medications off schedule, refused medications, and dispensed medications past the expiration date. These situations

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[93] As a reminder, the works from these scholars are: *Vita: Life In A Zone of Social Abandonment*; *Unstrange Minds: Remapping the World of Autism*; *The Spirit Catches You and You Fall Down*; *Rethinking Psychiatry: From Cultural Category to Personal Experience*; *Of Two Minds: The Growing Disorder in American Psychiatry*; *"HIV is God's Blessing": Rehabilitating Morality in Neoliberal Russia*; and *Suffering and Sentiment: Exploring Vicissitudes of Experience of Pain in Yap.*

contrast with their own culturally sanctioned expectations about medication management. Similar to some of my own experiences in Kerala, Grinker (2008) mentioned that many of the parents he met wanted to know his opinion of their child, looking to him as a Western expert who could provide information and resources they could not get from their local pediatricians and psychiatrists. All of these scholars speak about witnessing some form of suffering or stigma, from a young patient in severe pain in Yap (Throop, 2010), to parents' confusion and frustration with Western medicine's approach (Fadiman, 1998), to professionals secretly mocking patients (Lurhmann, 2000), to the socially dispossessed (Zigon, 2010; Biehl 2005) and inappropriately incarcerated (Grinker, 2008). Witnessing another's suffering, Throop (2010) argues, is a moral breakdown that forces us to contemplate the sufferer as more than the subject of research, thereby generating an emotional connection to the research site and informant.

In discussing the ethics of studying autism in low- and middle-income countries, Daley and colleagues listed a range of possible issues. Among these is the negative consequences of applying disability label, which may enable schools to reject children based on a stated lack of resources and be futile and frustrating in areas without resources for that disability. Additionally, they list going beyond simple linguistic translations of assessment and diagnostic tools, ensuring control and power is balanced between an outside researcher and in-country partners who have considerably fewer resources, obtaining informed consent, and paying attention to the tendency of autism researchers to promote autism-related policies and provisions over other childhood diseases and disorders (Daley, Singhal, & Krishnamurthy, 2013). I encountered many of the issues described by these scholars during fieldwork in Atlanta, GA and Kerala, India. In Atlanta, I was challenged to develop appropriate recruitment materials in a way that clearly communicated the purpose of my work yet was also attractive to possible informants. I was also often unsure of when to give my opinion on controversial autism-related issues, such as the relationship between ASD and vaccines, or how to maintain my desire to use and model neurodiverse language without confusing or alienating informants.

In Kerala, my moral breakdowns were more frequent and informative because of cultural differences akin to those that Kleinman describes. The introduction of culture into this work compounds the complexity and ambiguity of research on intellectual and behavioral differences in childhood. This type of work is also where future scholars and professionals working in international settings and with diverse families will experience the most difficult ethical challenges. Thus, I will focus on here on the moral breakdowns I experienced in Kerala. Among the many, I chose three primary areas in which other professionals may experience difficulties in order to make this discussion valuable to as many readers as possible. Many of the issues presented here overlap and there are many I am unable to include because of space constraints and a lack of generalizability to other research. However I know it is critical to begin the discussion somewhere and so here I present issues related to navigating one's various roles, differing perspectives on health privacy, and the context of inappropriate situations.

Navigating Roles.

There were many instances in which I was unsure of what role to play—the researcher, the interventionist, or the advocate. I have a background in each area and, much like Grinker’s reported experience, as a Western researcher in India I was perceived to be more knowledgeable about autism and the various therapeutic approaches. As a researcher, I wanted to maintain the purity of my research site as much as possible. I knew I would account for the influence of my presence in my research but wanted to observe Kerala’s existing attitudes and structures related to the constellations of characteristics that comprise autism without tarnishing the data with my input. However, because of my assumed expertise, I was frequently asked for information and trainings. For example, a small special school I visited in Trivandrum asked for training in Picture Exchange Communication Systems (PECS), an alternative communication technique in which individuals use pictures to request items and express thoughts. I was unsure if it was ethical to withhold this information in the interest of preserving my data or if stepping outside my researcher role would be an appropriate message to send to my informants.

Although initially I was hesitant and fearful that this would perceptibly alter my research site, I decided that since the school’s director and teachers specifically asked for this information and were allowing me into their school on a regular basis, I would provide the training. I also hoped that doing so would enable some of the students to more effectively communicate with teachers and caregivers. To prepare, I spent about half a day searching for appropriate materials for a PECS folder and a few hundred rupees on the physical materials. I proudly brought these materials to the school, described them to the teachers, and demonstrated the techniques. Even with my preparation, I encountered unexpected issues during and after the actual training.

One of these issues was a difference in teaching technique. In Kerala, teachers are louder and rougher than those in America. They may shout or lightly flick a child’s face to get his attention. While my teaching experience taught me to wait several seconds for an autistic child to respond, these teachers were not trained to do so. Despite these differences, I thought the PECS training went well and would soon be implemented. Months later, however, I discovered that the teachers had not implemented PECS. What I didn’t consider and what was yet another issue with my approach was that the teachers had neither the time nor money to spend making and using these materials. While I found it an ethical project to provide the information because, unlike an Internet search, I could do so with a consideration of the cultural context, I was still unable to predict all the challenges and so did not appropriately modify this information. The AAA ethical code emphasizes the need to compensate informants in some way and so, without financial resources, I tried to do so with informational compensation. I used this experience as a guide through future instances in which I was asked to give talks or provide information. I did so, but was able to more appropriately apply the information I had gathered about the cultural context to these instances.

These talks and trainings were aided by my ability to rely on my previous experiences as a teacher and autism consultant. Although I arrived in Kerala with the notion that my primary role was that of a researcher, I quickly learned that I could navigate through my other roles to assist in the research process. For example, before I arrived at my first home visit in Kerala, both my translator and myself had explained to the family that I wanted to observe their usual Sunday activities. I arrived and, after the consent forms were signed, I found myself in the small front room with the entire family —including two grandmothers and an uncle—watching me watch the autistic child. It was not until I was able to fall back on my training as a special educator and began showing the family how to model and elicit some word attempts from the boy that the family relaxed and began to interact with each other. Soon, we were all playing in the front yard. Even though it wasn't their typical Sunday, I was at least able to observe some interaction and, more importantly, set the family at ease in my presence, thereby facilitating a trusting relationship between myself the family. As I noted in the guidelines, developing relationships is a difficult and complicated process and so being able to be fluid in my roles was a skill that could smooth this process and on which I frequently relied.

I also questioned my role as an advocate and preference to use and promote a language of difference not deficit. This moral breakdown occurred fairly early on in my fieldwork and arose from my wondering if my translator was truly mirroring the precise manner in which I was talking about autism and intellectual differences. I had discussed the importance of this perspective with him and he found it a bit confusing. I began to question whether my insistence on modeling the language of neurodiversity was yet another example of Western paternalism. After much thought and consideration, I decided that insisting on the use of this language or providing a description of this way of speaking unsolicited was inappropriate. However, demonstrating this way of thinking about autism as an alternative narrative to the traditional, biomedical perspective was, in my eyes, an ethical project. Whether my Keralan or Atlantan informants decided to apply it in their own lives or ask more about it was their decision.

The questions of when and how to give advice or advocate are issues that Daley, Singhal, and Krishnamurthy (2013), Grinker (2008), and Biehl (2005) have all experienced. Coming from a resource-rich setting into a resource-poor setting with specific goals related to one's own research or profession, questions of hierarchies of need are inherent. It is often unclear whether one should work towards empowerment or provide basic needs. This has been a criticism of many aid agencies from the Global North—that the provision of basic needs has disempowered communities in caring for themselves and, thus, perpetuates a neocolonial system of the Global South relying on the Global North (Petras, 1999; Reimann, 2005). In my work, I decided to provide information and perspectives when asked because I could do so with an awareness of the resources and perspectives of the individuals and groups with whom I was interacting. I did not have the resources to serve the needs of the community or vastly alter the perspectives of my informants, however I found that accepting the fact that one's primary role—be it as a researcher, consultant, advocate, or interventionist—is fluid and unstable can not only help further one's goals but also help ensure a project proceeds with an ethical consideration of the community and the individuals living in it.

Sanctity of health care.

One of the most persistent moral breakdowns I encountered throughout my time in Kerala was that of differing perspectives on health care privacy. In the US, we have vast privacy controls, such as the Health Insurance Portability and Accountability Act of

1996 (HIPAA) Privacy, Security and Breach Notification Rules,[94] and we rarely discuss private health matters with anyone other than our family and personal physician, whose code of ethics ensures confidentiality of all patient interactions. The American Medical Association's (AMA) Code of Medical Ethics includes a section on Confidentiality, which states: "The physician should not reveal confidential information without the express consent of the patient, subject to certain exceptions which are ethically justified because of overriding considerations" (American Medical Association, 2007). This privacy, and what is deemed as private, is part of the fabric of medical ethics in America however is not a universal code.

Around India, personal physical health is a frequent topic of conversation. In fact, in Kerala, the common greeting "*Sukkam anno?*" literally means, "Do you have health?" This is just one linguistic example of the normalized nature of knowing and sharing information about health and illness. During my fieldwork I was regularly invited to sit in on patient consultations and even asked to give my opinion on patients, a request I was always able to deflect. People feel free to discuss the health state of others as well. For example, when recruiting in schools, teachers or administrators would point at children saying, "That one is autistic. That one is MR. He has cerebral palsy. He is autistic. And probably that one…." Coming from a culture where this information is kept under legal lock and key, these events made me uncomfortable.

There was one event in particular that led me to a particularly difficult and memorable moral breakdown. This story does not involve an autistic child but is a good

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[94] For more detailed information about this act, please see the U.S. Department of Health and Human Service's HIPAA webpage at: http://www.hhs.gov/ocr/privacy/.

description of this issue and, when researching autism in different cultures, interactions with people with other disabilities is inevitable. I was observing at a traditional healer's clinic in rural Kerala. I found myself in the exercise room with a mother and her 14-year-old girl with an unknown skeletal and muscular condition. The girl was receiving treatment, which consisted of two practitioners moving her limbs in specific ways. I spoke with the practitioners and her mother through my translator then, once my questions were answered, watched the procedure quietly. My translator continued to converse with the practitioners as they provided treatment. A father came in with his son and two other practitioners, who all jumped into the lively conversation. All the while, the mother and daughter remained silent.

The last act of the girl's treatment was to straighten her knees, which were locked in a bent position. As the practitioners pressed on her knees, I could hear them pop. The girl began to whimper, then openly cry. Her mother comforted her while the men in the room continued their laughing and talking. I was horrified. Here was this girl, crying and in pain, yet no one but her mother and myself seemed to notice or respect her pain. I left feeling angry with the practitioners and my translator. When I later asked my translator about the event and expressed my discomfort, he suggested that perhaps hearing their laughter made the girl feel better; an answer that only served to make me angrier. Later, when reading about Jason Throop's own experience witnessing a young girl's painful healing session, I could relate to his reaction: "…her suffering, her cries, tears, and screams compelled a shift in my orientation to her. In those moments, she could no longer ever simply be a subject of my research, a token of a type of person who suffers pain" (2010, p. 282). This statement precisely reflects my experience, however it seemed that, aside from the girl's mother, I was alone in this reaction.

Eventually, however, I came to understand that the way Keralans respect health care and pain is by bringing it out into the open. As a physician later explained to me, hiding treatments or health-related conversations behind closed doors leads to gossip about the severity of the health issues and social exclusion from a fear of contagion. While I understand the practice, I still feel uncomfortable with it because of the stark contrast with the way my culture handles illness and pain. As medical anthropologist Arthur Kleinman says, "The ethnographer, no matter how successful she is in participant observation, is always an outsider" (1998, n. pg.). These interactions always left, and will always leave, me feeling like an outsider.

This experience also leads me to question the principle of autonomy laid out in the field of bioethics, which is the preeminent field guiding ethical practices of human subjects research and scholarship. Autonomy describes an individual's "self-rule that is free from both controlling interference by others and limitations that prevent meaningful choice" (Beauchamp & Childress, 2013, p. 101). In other words, it is an individual's self-governance that, in medicine, translates into a requirement of all physicians to respect a person's healthcare choices (Beauchamp & Childress, 2013; Downie & Macnaughton, 2007). This principle, which is closely related to issues of competence, informed consent, and refusing treatment (Beauchamp & Childress, 2013), is challenged by the fields of Disability Studies and cultural anthropology, both of which disagree with the notion that autonomy is a central and valued feature of humanness (Ouellette, 2011; Traphagan, 2013).

As in many non-Western societies, the Indian family is highly involved in medical decision-making. Physicians often meet with multiple family members to discuss an illness of one member; spouses or parents will stay in hospitals with ill individuals; social hierarchies often mean that the ultimate medical decision making is not up to the ill person, but is the decision of the head of the family (Kakar, 1991; Nunley, 1998). Here, autonomy of the patient is neither considered nor regarded as important to medical decision-making. In this context, pushing for the autonomy of a patient and, consequently, independent and private health care decision-making can easily generate higher levels of illness-related stigma and stress for that individual and her family. Although it may be uncomfortable, the sanctity provided for health care in America can and should be recognized as a localized value and set aside in cases involving cultures where openness and collective decision-making is valued.

Context of Abuse.

This is perhaps the most difficult realm of moral breakdowns I encountered and one that is somewhat unique to studying disabilities, particularly intellectual disability, in different cultural contexts. Grinker (2008) described visiting a residential home in South Africa that has bars on the windows and locks its residents inside. He asked a father of one of the residents why there was not a health care organization running the place that could put well-trained staff there. The father gave him a baffled look and explained that there was not enough money and that this house was much more humane than the state institutions.

Similarly, on more than one occasion I saw children being restrained either through the use of gates and barred windows or, more directly, being tied to furniture. One school had an 18-year-old boy who did not communicate verbally and who spent his day perched on a windowsill in the back of the classroom, silently, but vigorously, rocking back and forth. During my second visit to the school, I noticed that he was tied to this window by a strip of fabric. My first instinct was to insist that he be untied. However, as I thought through this interaction, I realized that I would be left without an answer to the inevitable question of “Well, then what should we do instead?” My only answers would have centered on more staff, money, and training, which was infeasible, or somehow going back in time to work with this young man to find a safer self-regulation technique. This boy’s teacher was kind and well intentioned and simply wanted to ensure this boy’s safety. What could have been interpreted as abusive restraint was, in that particular context, more humane than the alternative—leaving him untied until he fell and harmed himself.

The encasement of individuals with disabilities is a common security measure in resource-poor areas and one that, in many cases, leads to human rights violations. Physician and mental health advocate, Vikram Patel, has presented startling images of individuals with mental illness and intellectual disabilities from around the world chained and locked away with little clothing, food, or interactions (Patel, 2010). The instances of restraint I witnessed in Kerala did not indicate this level of abuse or harm and, upon close consideration, were clearly a reaction to the available resources. They reflected, however, a certain level of presumed lack of humanness of the autistic individuals I encountered.

Anthropologist João Biehl witnessed inhuman acts and living conditions at Vita, an institution in Brazil where individuals are abandoned because of health issues or simply because they are unwanted. “Vita,” he explains,” is a place for ex-humans.” He goes on to explain, “…when I say ex-human, I want to highlight the fact that these people’s efforts constitute their lives vis-à-vis institutions meant to confirm and advance humanness were deemed good for nothing and that their supposed inhumanness played an important role in justifying abandonment” (2005, p. 52). In other words, ex-humans are those who are rejected and demeaned within and by the institutions that are designed to promote and ensure their humanness. Although the individuals with intellectual and behavioral differences I met in both Kerala and Atlanta, while stigmatized and not quite considered as equals with non-autistic individuals, did not entirely fit into this category of ‘ex-human,’ there were overlaps. In particular, the facilities autistic children and adults frequented regularly fail these individuals and their families, a situation that occurs in both research sites. The important departure between the autistic individuals I encountered in my current and past work and Biehl’s ‘ex-humans’ is found in the fact that most of the adults in their immediate world interacted with them with loving and virtuous intentions. In other words, the caregivers I have interacted with have largely held good intentions towards the autistic individuals in their life. However, while there was no justified abandonment, there were clear times when the professionals and caregivers did not regard the children with the full consideration of an individual who is not regarded as intellectually or physically impaired. This includes being tied to chairs or not providing caretakers with enough resources to ensure high qualities of life.

Humanness, then, is not a binary category—individuals are not simply considered as fully human or not human. There is a range, and on this gradation of humanness, autistic individuals are considered to be somewhere in the middle–not fully human but not quite abandonable like Biehl's 'ex-humans.' I argue that autistic people are most often considered to be 'limited humans.' They are individuals who are considered to deserve love and care but are not bestowed the freedom, respect, or trust automatically granted to full, non-autistic humans. Not human enough to qualify for the negative rights[95] non-disabled individuals assume yet definitely not denied all human rights. By using the term 'limited humans,' I want to convey a public perception of people that are considered to be less than fully human because of a particular set of characteristics. The term is also meant to suggest the presence of an outside limiting force on autistic individuals because of this prejudice rather than devaluation derived from an internal, personal difference.

Just as Biehl (2005) saw individuals throughout Vita who qualified as ex-human —a characterization that is entirely appropriate for the discarded, forgotten, and dying individuals he met—throughout my research and professional experiences I have seen many autistic adults and children treated as limited humans. Caregivers and professionals in Atlanta are better equipped than those in areas with fewer autism resources to provide for their autistic family members, students, and clients, making these attitudes less

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[95] Negative rights are those that cannot be produced, such as the right to worship or the right to assembly; as opposed to positive rights like the right to health care or education (Carey, 2009).

obvious, but still subtly present in phrases of ‘Othering’. For example, the frequent use among my informants of the phrase “those children” or in reports of stares, segregation, and the endless search for who or what to blame and a way ‘fix’ a child. This is also seen in the disability-based segregation found in the workforce and in schools, as was described in the previous chapter. In the midst of Kerala’s nascent autism awareness and scarce material or instructional resources these attitudes become more obvious in actions, such as the restraint described above. When you look deeply at the context of (possible) abuse, often what you are seeing is the enactment of limited humanness. Identifying the type and source of negative acts towards individuals with intellectual, developmental, or psychiatric differences, such as ASD, can lead to more targeted practices to reduce inequality and improve qualities of life.

Final Summary

It is in moments of moral breakdown that the researcher becomes more than an observer. The witnessing of suffering, disenfranchisement, and inequity often humanizes a researcher and the researched. The ethical journey of the anthropologist is as informative as it is compelling. Throughout this dissertation and, most specifically, in the previous section, I have attempted to use my research experience to provide guidance for individuals intending to embark on some kind of cross-cultural work on ASD and similar disabilities. By comparing the experiences of parents and professionals in Atlanta, GA and Kerala, India, I aimed to highlight issues that will arise in most cultural contexts and will reveal how the culturally habituated notions about differences and childhood are perhaps less universal than often presumed to be.

I also aimed to provide a description of the cultural hybridization that occurs when notions of autism enter into a new cultural environment, and of how to identify critical areas of similarity and difference. By focusing on the places in which I found autistic children—the clinic, the home, and the school—I hope I have predicted where others will go to find autism in new communities. With the inclusion of schools, this work is more focused on autistic children than adults, which is the population on which I expect most international work on autism to focus. Research, intervention, and advocacy work on ASD is overly focused on children, as they are easy to locate at schools, despite autism being a life-long identity or disability. I would like to see future work on adults with intellectual and behavioral differences, however was unable to include this population in the current research.

Finally, I would like to emphasize that, in regards to the discussion on the ethics of this work, my stories and reflections are in no way meant to be a set of rules of how to work with and through moral breakdowns in the field. However, by allowing space and giving thought to these issues, I hope to generate and add to the much needed discussion of how to put guidelines such as “do no harm” into practice. As ethnographers move in the direction of more recognition of their influence on a variety of fields, I want to engage in conversations about the influence of the field on the researcher.

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Appendix 1

Behavior Checklist

Check the behaviors that describe your child exhibits:

During social interactions, my child has:

  __ poor eye-to-eye gaze
  __ inappropriate facial expressions
  __ inappropriate body postures
  __ inappropriate gestures

__ My child has a difficult time making friends of his/her own age
__ My child does not share his/her interests with others
__ My child does not attempt to share emotions with others
__ My child does not speak
__ My child's speech was/is delayed
__ My child has a hard time participating in a conversation
__ My child often repeats the same words or phrases frequently
__ My child uses his/her own language
__ My child does not participate in imaginative, make believe play
__ My child has one very specific topic or item of interest
__ My child always follows the same routine and is upset if this routine is not followed
__ My child sometimes has repetitive body movements, such as hand flapping or spinning
__ My child is often focused on specific parts of objects instead of the whole item

__ My child prefers to be alone

__ My child gets upset when people interfere with what he/she is doing

__ My child gets upset when the daily routine changes without notice

__ My child gets upset if his/her environment (i.e. bedroom, school desk, play area) changes without notice

__ My child has digestive problems

__ My child does not sleep through the night

Please list and describe any other unusual behaviors your child exhibits:

____

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*Most traits taken from:

American Psychiatric Association. (2000). Diagnostic and statistical manual of mental disorders (Revised 4th ed.). Washington, DC.

Appendix 2

Open-Ended Questionnaire

Global Autism: Parent/Guardian Questionnaire

The following questions are to be asked in an open-ended, conversation style format. Clarification and/or follow-up questions not specifically listed may be asked depending on the answers provided by the participant. Although the order is not crucial, all questions should be addressed within the interview. Interviews should last between 30 minutes and 1 hour.

Participant Code:
Date:
Interviewer:
Location:

- What is autism?
- What is the first sign of autism?
- What do you think causes autism?
- What do you know about autism? Where did you get this information?
- When do children normally begin speaking? acquiring social skills? making friends?
- What do you think causes autism? Do you think autism can be cured?
- What kinds of treatments and/or therapies are available for autism? How do you feel about the treatments/therapies you named (i.e. effectiveness, ethicality, etc)?
- Why did you first decide to have your child evaluated?
- Who was the first person to be concerned about your child's behavior?
- What do you take into consideration when making medial and/or treatment decisions for your child (i.e. cost, morals, invasiveness, accessibility, ease, recommendations)?
- What kind of playtime activities does your child enjoy?
- What have your experiences with doctors, educators, psychologists, etc. been like when consulting them about your child?

- What do you friends and family members think about your child?

- What methods have you tried to help you improve your child's behavior/development?

- What kinds of educational and treatment options are available for your child? What treatments do you expect to get?

(Levy, Mandell et al. 2003) questions:

- What did you call your child's problem before it was diagnosed?

- What do you think caused it?

- Why do you think it started when it did?

- What do you think autism does? How does it work?

- How severe is it? Will it have a short or long course?

- What are the chief problems you child's autism had caused?

- What do you fear most about it?

- What kind of treatments do you think your child should receive? What do you expect from this treatment?

- Is there any additional information or comments you would like to tell me?

- Do you have any questions for me?

Global Autism: Clinician/Practitioner/Therapist/Educator Questionnaire

The following questions are to be asked in an open-ended, conversation style format. Clarification and/or follow-up questions not specifically listed may be asked depending on the answers provided by the participant. Although the order is not crucial, all questions should be addressed within the interview. Interviews should last between 30 minutes and 1 hour.

Participant Code:
Date:
Interviewer:
Location:

- What is autism?

- What is the first sign of autism?

- What do you think causes autism?

- What do you know about autism? Where did you get this information?

- When do children normally begin speaking? acquiring social skills? making friends?

- What do you think causes autism? Do you think autism can be cured?

- What do you think autism does? How does it work?

- What kinds of treatments and/or therapies are available for autism? How do you feel about the treatments/therapies you named (i.e. effectiveness, ethicality, etc)?

- When did you first evaluate a child with autism?

- What kind of training or experience with autism do you have?

- How many cases of children with autism have you seen treated/diagnosed?

- What treatments/therapies are you familiar with in the community for children with autism? What do you recommend to families of children with autism?

- What do you think happens to children with autism as they grow up?

- Is there any additional information or comments you would like to tell me or do you have any questions for me?