

Caring for Star-Children: Autism, Families, and Ethics in Contemporary China

by

Emily Xi Lin

M.Sc.

University College London, 2008

B.A.

National University of Singapore, 2003

Submitted to the Program in Science, Technology, and Society
in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy in History, Anthropology, and Science, Technology and Society
at the
Massachusetts Institute of Technology

September, 2016

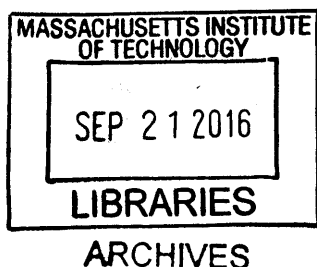
© Xi Lin 2016

© 2016: All Rights Reserved.

The author hereby grants to MIT permission to reproduce and distribute publicly paper
and electronic copies of this thesis document in whole or in part in any medium now
known or hereafter created.

Signature of Author: _____ **Signature redacted** _____
History, ~~Anthropology~~, and Science, Technology and Society
15 August 2016

Certified by: _____ **Signature redacted,** _____
Elting E. Morison Professor of Anthropology; Anthropology Program Head
Stefan Helmreich
Thesis Supervisor





77 Massachusetts Avenue
Cambridge, MA 02139
<http://libraries.mit.edu/ask>

DISCLAIMER NOTICE

The pagination in this thesis reflects how it was delivered to the Institute Archives and Special Collections.

- * The Table of Contents does not accurately represent the page numbering.

Pages 7-14 were not submitted

Signature redacted

Certified by: _____

Erica Caple James

Associate Professor of Anthropology
Thesis Committee Member

Signature redacted

Certified by: _____

Heather Paxson

William R. Kenan, Jr. Professor of Anthropology
Thesis Committee Member

Signature redacted

Certified by: _____

Susan Greenhalgh

John King and Wilma Cannon Fairbank Professor of Chinese Society
Social Anthropology Program Director, Harvard University
Thesis Committee Member

Signature redacted

Certified by: _____

David Shumway Jones

A. Bernard Ackerman Professor of the Culture of Medicine, Harvard University
Thesis Committee Member

Signature redacted

Accepted by: _____

Christine Walley

Professor of Anthropology
Director of Graduate Studies, History, Anthropology, and STS

Signature redacted

Accepted by: _____

Jennifer S. Light

Professor of Science, Technology, and Society
Professor of Urban Studies and Planning
Department Head, Program in Science, Technology, & Society

Caring for Star-Children: Autism, Families, and Ethics in Contemporary China

by

Emily Xi Lin

Submitted to the Program in Science, Technology, and Society on 30 August 2016 in

Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

Caring for Star-Children: Autism, Families, and Ethics in Contemporary China studies the emergence and development of family caregiving for autistic children after 1982, when autism was first diagnosed separately in two cities in China. Based on 18 months of ethnographic fieldwork at municipal specialist hospitals, community child-health clinics, autism rehabilitation centers, and homes of families with autistic children across six provinces, this study explores how social stratification and the turn towards self-governance not only made autism as an epistemic object, but has intersected with that category to create new forms of inequality. In the absence of thorough and consistent state initiatives, moral economies around the child's potential have sprung up. Such moral economies lead actors such as medical professionals, philanthropic and educational organizations, and elite parent-activists to prioritize the young autistic child's potential, and to urge parents to become behavioral therapists for their own children. Parents are urged to let go of the normative societal expectation of recompense in the form of elderly care.

I argue in this dissertation that the directives around these moral economies fail to take into account the local and gendered inequities that both produce, and constrain, parental diagnostic and therapeutic choices for their autistic children. Autism's spread as a diagnostic category has paralleled other spatial and economic disparities across the country. The economic reforms which began in 1978 and the devolution of many public functions to the purview of local governments have led to dramatic regional disparities with respect to economic opportunity and, the availability and quality of healthcare, education and social services. Where professional and parental elites in cities such as Beijing refer to autistic children through the valorized term "children of the stars" (a phrase chosen so as to reduce stigma), and are able to provide children in these locations with prompt diagnoses and early therapy, to date many healthcare workers and families responsible for nurturing children in less developed regions of China have not even heard of such a diagnostic category. Many families from rural or otherwise resource-scarce locations in China are not able to obtain a timely diagnosis, much less access therapy for their children. In managing care in landscapes of great disparity, families are turned into diagnostic and therapeutic internal migrants, as they travel across China in search of the appropriate doctors and therapy. I argue in this thesis that the post-socialist emphasis on choice, rather than care, in fact serves to legitimize neglect of the autistic adult and mother of the child. Autism advocacy rights which fail to take into account local forms of stratification thus serve to broaden the burden of care upon families.

Thesis Supervisor: Stefan Helmreich

Title: Elting E. Morison Professor of Anthropology; Anthropology Program Head

Table of Contents

Acknowledgements	7
Prologue	9
Chapter One Introduction	15
Chapter Two Producing Autism as an Epistemic Object in Landscapes of Inequality	50
Chapter Three Diagnostic and Therapeutic Internal Migrants	87
Chapter Four Tyranny of the Autistic Child's Tomorrow	122
Chapter Five "Truly Loving Your Child": The Autism Therapeutic Apparatus and the Making of Parent-Therapists in Contemporary China	163
Conclusion Care, Choice, Constraints and Capabilities	201
Bibliography	208



77 Massachusetts Avenue
Cambridge, MA 02139
<http://libraries.mit.edu/ask>

DISCLAIMER NOTICE

MISSING PAGE(S)

Pages 7-14 were not submitted

Chapter 1

Introduction

The past three decades have witnessed an intensification of pressures on families in contemporary China. As a result of wide-ranging social changes, including the state-enforced shrinking of the family size through the one-child policy and the dismantling of social and job security heralded by economic reform and liberalization, parents are directed by state, market, educational, and medical institutions alike to raise “quality” children and fewer of them (Greenhalgh and Wrincker 2005: 43), while children face the burden of being their forebears’ “only hope” for old-age security, and a better life (Fong 2004).

While the dramatic decline in patriarchy, the rising power of women, and marked shifts of power from senior to junior members and from parents-in-law to daughters-in-law might lead one to expect otherwise (Yan 2003, Fong 2004, To 2014), family life in China continues to be structured by the expectation of an intergenerational exchange of care across life spans. Parental sacrifices in turn, legitimize a moral demand for reciprocity on the part of children (Feuchtwang 2002), and such a moral logic is reinforced in schools where children are taught the importance of filial piety (Kipnis 2008).

What happens, however, when the cycle of reciprocity between parents and children is disrupted? Pulitzer Prize winning journalist Mei Fong shows with painstaking clarity in her 2015 book *One Child* some of the consequences for parents brought about by the unexpected and early demise of children. She observes how parents whose only children have died in the Sichuan earthquake of 2008 were ostracized by their neighbors who feared bereft parents would seek social and economic support from their neighbors and community. Known as *shidu* (meaning

those who have sustained the loss of an only child), these parents become social pariahs. Without guarantors, they have difficulties even getting a place in nursing homes or burial plots. Besides death, rifts and estrangements in parent-child relationships also disrupt the reciprocity that govern parent-child relationship (Ikels 1990; Zhang and Goza 2006).

The past four decades, however, have witnessed the making of another novel and complicated moral conundrum for families in post-socialist China—the growing albeit highly uneven recognition of developmental disorders such as autism in children. Unlike sudden and unexpected death or rifts in relationships, developmental disorders force parents to confront early on, in practical, moral, and affective ways, the reality that there might never be any reciprocity. Furthermore, most parents of autistic children come to this realization alone, unsupported by their family and immediate community who remain ignorant about autism. Autism leaves few traces on the physical body, making it difficult for the lay person to identify.

Identified by psychiatric and child development specialists as a developmental disorder that manifests itself through deficiencies in social communication, difficulties in reading nuances in social contexts, repetitive behaviors, and other global developmental delays, autism spectrum disorder renders it impossible for individuals to adhere to fundamental rules that govern sociality in contemporary China. Autism more often than not severely disrupts one's vital capacities to engage *guanxi*, the art of reciprocal social exchanges that determine one's social and economic success in life in China (Yang 2002; Qi 2013). Autistic children are unlikely to take on the practical and economic tasks of caregiving for their aging parents and grandparents, or even to acknowledge parental sacrifices.

Scholarly and Methodological Contributions

In this dissertation, I make five arguments. The first is that autism, as a condition and as a diagnosis, is a threat to the moral logic governing *entire families*, rather than simply a condition that is experienced by individuals alone in China. Autism, I argue, became particularly salient as a diagnostic category in China given the demographic shift and policy push toward having a quality singleton in urban areas, and two children in rural areas, and the loss of basic job security after the 1978 reforms. With the long-term strict implementation of the one-child-with-exceptions policy (changed to a two child for all policy but with all the mechanisms from the one child policy remaining in place), the quality singleton or developmentally normal children in rural areas have become particularly important, because they become a family's "only hope" for a better future. Essentially, autism threatens the moral logic undergirding the parent-child relationship in China, even as it presses new norms to come into place. By formally recognizing the existence of such a diagnostic category, Chinese medical and pedagogical professionals, influential parent-advocates and local government authorities legitimize the claim that autistic people have a special claim on family and social attention and resources on the basis of their disability status. Crucially, being labelled as autistic absolves individuals of their responsibility in undertaking economic, emotional, and practical acts signaling reciprocity.

In order to counter the threat that autistic children might be abandoned or neglected by desperate parents, and to solve the very real problem created by the state's neglect of public health, medical, educational professionals and parental activists in China insist on a novel moral claim. They argue that all parents should unreservedly nurture their autistic offspring's wellbeing and happiness and that they should let go of the normative societal expectation of recompense in the form of elder care. Such a novel moral claim thus contains the threat of autism to the existing

moral logic of reciprocity that governs Chinese family life, sociality, and cosmology (first, from parents to young children and then from grown children to aging parents) by insisting that true parental love involves continual sacrifice without hope of return. The terming of autistic children as *xingxing de haizi* (children of the stars) is, in part, a potent local adaption which seeks to remake parents into “moral pioneers” in China (Rapp 1987), and exemplifies how and why caregivers become diagnostic and therapeutic internal migrants or therapists for autistic children.

Two, the moral threat posed by autism to Chinese familial ethics reveal the limits of much anthropological and STS theorizations about autism. In studying autism in contexts such as China, I argue that anthropological and STS scholarship of autism must grapple more seriously with the materiality of autism’s disabling effects on entire families, rather than simply focusing on individuals or simply showing that disability is socially constructed. At present, much of the evidentiary base for anthropological and STS critiques of medical definitions of autism as a disability are grounded on experiences of individuals with Asperger’s or families living in the United States or Europe (see Davis 1997; Corker and Shakespeare 2002; Shakespeare 2006; Yergeau 2013). The U.S.-centric focus stems in part from the fact that autism has had a much richer history in the United States than other countries. Influenced by the theoretical insights of science studies scholar Ian Hacking, much of the emergent science, technology and society (STS) and anthropological scholarship on autism have either simplistically celebrated “neurodiversity” or has mined the derogatory metaphors used to stigmatize or denigrate persons with differences (see Nadesan 2005). Hacking has ignited productive conversations on how new biomedical categories “make up” people, because the existence of autism as a category allows both individuals (and others around them) to identify with such a category. A biomedical diagnosis, therefore, became “a way to be a person, to experience oneself, and to live in society”

(Hacking 2006). In effect, because people are “moving targets” who interact with “their friends, their families, their employers, and their counsellors” through the descriptions of diagnostic categories, they become kinds of people who did not exist in the same way they did before (Hacking 2006). Such a phenomenon Hacking terms “looping,” where he wants to focus on how the social environment, rather than a biological substrate, encourages individuals and people around them to classify either themselves or others as disabled.

Drawing on the voices of people with Asperger’s, or high functioning autism, many anthropologists and STS scholars critique the bio-medicalization of deviance and difference (as it pertains to autism). Anthropologist Nancy Bagatell, for instance, writes against “the biomedical discourses that casts symptoms of autism and their consequences for individuals and their families in a categorically deficit framework” by drawing upon her fieldwork with five high-functioning adults with autism in the United States (2010). She argues that “individuals with autism are challenging the widely accepted biomedical views of autism and forging an autistic community,” and thus, the articulation of their own identity strongly support the work of disability scholars who argue that disability is “socially constructed’ (2010). They do so because much of the public perception of autism has been shaped by biomedical perspectives that position autism as a neurological disorder. Autistic individuals belonging to the neuro-diversity movement within the United States have made a compelling case for self-representation. “Nothing about us without us” is the rallying cry of the Autistic Self-Advocacy Network (ASAN). For ASAN, and famous spokespersons such as Jim Sinclair, or Ari Ne’eman, autism is simply a different way of being, rather than a disorder that masks the real person. They make the case that autism should be represented by persons with autism, insisting that autism is better understood as representing a form of “neuro-diversity,” a natural variation in the human genome

resulting in neurological differences. Such arguments have found scholarly allies in disability studies, anthropology, and science studies

Important as it is to affirm the humanity of persons with autism, it is also important to recognize the material aspects of autism, ranging from the core characteristics, to the devastating effects it may have on family caregivers. Biomedical and family accounts of autism suggest that representation is no simple matter, and the question of who is left out of such representations is important both for autistic persons themselves, and their caregivers. For one, doctors and families will point to the huge variability in the way autism presents in different individuals — variation that is not apparent alone from the voices of those able to self-advocate. Some autistic persons like Jim Sinclair are highly articulate. Others are not only non-verbal, but may present as self-injurious even in adulthood. For these individuals, we know of their existence because of family and professional caregivers who take on the role of translators, that is, people who translate between autistic persons and other social worlds, as imperfect as their capacity to translate may be (Chew 2013). Neurodiversity and self-representation, then, are often championed by a small fraction of the entire population with the diagnosis of autism, whose voices are necessary but do not speak for the entire spectrum or elsewhere in the “manifold”, to use Hacking’s term. Neither does championing of neurodiversity speak to the concerns and challenges of families caring for those in the “manifold” who are unable effectively to make clear their own needs and desires. Focusing on the “highly functioning”, or those who require minimal social support neglects these families’ challenges and struggles.

While autism, as Chloe Silverman observes, is a “contested category” (2012: 6) in that there is no single known etiology or clear treatment model, current scientific research suggests that autism is formed from the complex interaction between genes and environment (and is not a

direct result of parenting styles). Rather, I suggest that the identifiably core aspects of autism, whether they have been formally and medically diagnosed or not, are experienced as an affliction that disrupts the practical and emotional heart of family relations in China. Focusing alone on normalizing neuro-diversity or highlighting the resistance to medical labels ignores the suffering that disability is a familial experience. We need to understand how forms of social stratification, such as race, class and education in various parts of the world constitute autism as a *bio-social disorder*. The difficulties that children with more severe forms of autism have in self-care and in enacting their autonomy without the help of familial translators or support makes it clear that we cannot lose sight of the debilitating aspects of autism in the push to normalize and valorize neurodiversity.

In many ways, neurodiversity is a claim that resonates in the United States because of its cultural specificity. In the United States, society's responsibility to ensure that all individuals, including those with disability, are provided with necessary accommodation to live, and its embrace of social diversity, in many forms, have deep-seated cultural and social salience. Different social contracts and imaginaries are in place in China, and the dramatic social and educational disparity amongst families with autistic children there makes it clear that "neurodiversity" is not, and cannot be, a universal ethical claim. To wit, neurodiversity, which holds within it a particularly Anglo-European assumption of personhood, has not been a tenable claim in societies such as China, where families are held legally, politically and culturally responsible for the care of their members. Anthropologists have suggested that what determines the perception of full personhood lies less in the person's autonomy than in a person's capacity to engage in social exchange (Guo and Kleinman 2011). In that sense, "personhood" is crafted and

legitimized in China through the capacity to reciprocate and engage in the give and take of social relations, even as this understanding of personhood has been transforming under post-socialism.

Third, I argue that what counts as good and appropriate care owed by parents to autistic children in China is a political, rather than a strictly moral, issue. Arguments that appear to be strictly moral or health-related around the child's potential do the political work of naturalizing parental responsibility for all aspects of their children's wellbeing. Such concerns have cultural salience, given the Chinese post-socialist turn towards self-reliance (*kao ziji*) and the existence of what I call gradated *citizens*. I argue that claims around what constitute moral duties of care are political claims since they render patients and families effectively responsible for their own health, and in the case of autism, the health, education and wellbeing of their children. Claims that parents must sacrifice all for their children naturalize the government's lack of provision of accessible, affordable, high quality medical care and educational services, while shifting the responsibility of caring for autistic persons entirely to families. Longstanding historical and social disparities determine the forms of care that families can provide to their autistic children. Autism's outcome—whether as a crushing disability that threatens to tear apart the fabric of a family, or as a condition that may simultaneously offer unique gifts—is shaped by unequal access to social and economic resources. Here, I critically interrogate how social class and privilege shapes experiences of autism for family caregivers. I include consideration of access and availability of diagnosis and the kinds of subjectivities and practices that are called into being in the name of ethical care. I argue that we need to pay close attention to the impact of local inequalities on how autism travels as a diagnostic category imported from elsewhere, and the lived experiences of families caring for autistic persons. Thus, I explore how the uneven travel of autism reflects longstanding historical and social inequalities in China, even as it

simultaneously engenders new norms of family care and novel forms of marginalization for families with autistic children.

In exploring the practical and moral issues related to care, I hope to move beyond theories of domination and power in biomedicine as well as simplistic critiques of biomedicine that treat biomedicine as an institution independent of larger social fractures as it pertains to autism. As science studies scholar Maria Puig de la Bellacasa note, it is important to also respect and care for the work of science and technology rather than abusing and reducing such endeavors as driven by “power and domination or a simple “lust for power” (2011: 88). In addressing the apparent rise of autism incidence rates worldwide, anthropologists and sociologists have sought to elucidate and complicate these questions by framing the critical issues around autism in the following ways. Some scholars seek to dampen the hysteria around the apparent “epidemic” of autism by critically challenging the assumption that incidence rates are indeed spiking. For instance, anthropologist Roy Grinker (2008) explores how social factors such as the changing diagnostic criteria across the various versions of the DSM and the need for specialized education and specific insurance coding and reimbursement drive autism diagnostic rates in the United States, while sociologist Gil Eyal and his colleagues (2010) explore how deinstitutionalization in the United States and the United Kingdom creates a space for autism. Other scholars seek to uncover syncretic understandings of autism as knowledge of the diagnostic category makes its way to regions outside Europe and the United States so as to show how local conditions powerfully shape the ways autism becomes understood or lived with in various societies, (Hart 2014, Sarrett 2015).

Following the lead of conversations initiated by disability scholars, or medical and psychiatric anthropologists who have hitherto studied disorders such as schizophrenia and

bipolar depression, other scholars challenge the presentation of autism either by arguing that the disabling aspects of autism are rooted in society rather than in genes, or by querying biomedical hegemony and authority. Inspired by a series of studies funded by World Health Organization, which suggested that persons with schizophrenia living in rural areas had better outcomes than persons living in developed urban areas,² scores of studies have explored how psychiatric conditions such as schizophrenia may be better understood as “idioms of distress” (Nichter 1988), or challenged the ways in which socio-cultural factors are deemed less relevant than biological or genetic factors (Kleinman and Good 1985). Though other anthropologists such as Alex Cohen have more recently debunked those studies (see Cohen et al 2008), there remains a strong preponderance towards critiquing biomedicine. From Jonathan Metzl’s powerful study of schizophrenia in *Protest Psychosis* published in 2010, to Tanya Luhrman’s sophisticated critique of the turn within psychiatry towards biological models (2000), anthropologists, historians and scholars in related disciplines continue to voice critiques of biomedicine, psychiatry, and psychology. In that respect, anthropologists who seek to challenge biomedical authority on autism come from a long established tradition. For instance, Nancy Bagatell and her coauthor, Olga Solomon, write against “the biomedical discourses that frame symptoms of autism and their consequences for individuals and their families in a categorically deficit framework” (2010). In their forward to a special issue of *Ethos*, Bagatell and Solomon argue that it is necessary to generate more complex understandings of autism in the face of biomedicine’s primary focus “on the challenges of affected individuals evinced in laboratory tasks” and “measurable clinical

² See the following: WHO. *Schizophrenia: An International Follow-up Study*. Chichester, UK: John Wiley and Sons; 1979. Jablensky A, Sartorius N, Ernberg G, et al. “Schizophrenia: manifestations, incidence and course in different cultures. A World Health Organization ten-country study”. *Psychol Med Monogr Suppl*. 1992;20:1–97. Harrison G, Hopper K, Craig T, et al. “Recovery from psy-chotic illness: a 15- and 25-year international follow-up study”. *Br J Psychiatry*. 2001;178:506–517. Though there are studies now debunking it, this study continues to be cited even more recently.

changes” in place of more profound ideals around a meaningful life. In writing about families’ experiences and perceptions of living with autism in contemporary China, I seek to honor the call by Bagatell and Solomon, and other anthropologists for scholars to develop more complex understandings of autism. I came to recognize that what was more pressing for families, and therefore for me as a scholar, was to explore how social inequality interacted with disability. In making the call for scholars and activists to wrestle more fully with how disability intersects with, and is mediated by, the systematic disparities that broadly shape how families experience the impact of a member’s need for care, I have also been influenced by the work of other medical anthropologists. To ignore these fault lines in society is to renege on our responsibility as scholars, and as *accompagneurs*, which as Paul Farmer (2013:238) reminds us, is a term that should recall its Latin roots of *ad cum panis*, which means breaking bread together — that is, sharing sustenance. In coining this term *accompagneurs*, Farmer argues that the work of engaging and serving an intended community is only completed when recognized as such by these communities. To be truly critical, for Farmer, we also need to understand how health is experienced and shaped for the socially marginalized. I suggest we need to pay close attention to the socio-economic rifts within such communities.

Fourth, I show that biosocial communities, especially those made up of families with autistic children in China, can have a darker side. Much analysis of bio-sociality has been inspired by Foucault’s analysis of the productive nature of power; and Paul Rabinow has been foremost in drawing attention to how the new genetics, or the ways in which individuals and families identify themselves through their biological make up have inspired the making of bio-social communities. Yet, my analysis shows that biosocial communities can be coercive, and the coercive power of such affiliations and communities are not necessarily exerted by the state or

biomedical professionals or even special education teachers, but by other parents themselves. Parent-advocates are pivotal to a moral discourse on parent-child relations that have it that good parents truly sacrifice and serve as their children's lifelong therapists, regardless of whether they can afford to do so. Many family members become impelled to travel for months to find a therapeutic option for their children, and lead lives of intense isolation, loneliness and stress even though they rent homes next to other families with autistic children; in part because many of the parents in turn critique their peers for not doing enough to help their children, and serve to shun and isolate some parents. These biosocial communities may actually be enacted in many rehabilitation centers, but do not necessary create a sense of community nor belonging for families.

Finally, I argue that the study of autism in China may also shed light on healthcare in China. At present, the state of healthcare in China has given rise to what some scholars call the "Rashomon effect", or very different interpretations of the state of China's healthcare by scholars studying the same time period (See Chen and Xu 2012). What underlies various studies have been a focus either on infectious diseases or mortality. I argue that an examination of autism, as exemplar of a complex disability, will reveal that China's healthcare reforms have in fact failed its populations in narrowly focusing on infectious diseases, while paying scarce attention to developmental disorders, and in assuming that it is parents, rather than doctors, who are responsible for finding the appropriate specialist.

Autism's development as a psychiatric concept

What then is autism? Autism as a psychiatric concept and childhood developmental disorder was first developed by Leo Kanner in Baltimore, where he worked as the head of a child psychiatric

department in Johns Hopkins Hospital. In 1943 Kanner published a paper entitled “Autistic Disturbances of Affective Contact,” in which he drew upon his observations of three girls and eight boys in order to characterize the condition as one typified by children displaying an “inability to relate themselves in the ordinary way to people and situations from the beginning of life,” or what he calls “an extreme autistic aloneness,” “repetitiousness [and] an obsessively anxious desire for the maintenance of sameness that nobody but the child himself may disrupt on rare occasions” (1943: 242-245). Leo Kanner adopted the term “autism” — which was developed from the Greek *autos*— from Eugen Bleuler’s (1950) descriptions of schizophrenia. Influenced as he was by Austrian psychiatrist August Homburger’s textbook on childhood schizophrenia and other developmental disorders, Kanner hypothesized that autism could be understood as a biologically rooted developmental disorder, where children are born with an innate handicap to build affective relationships (Hacking 2006). Lorna Wing was also crucial in translating Asperger’s work from German into English (Wing 1981). Though Asperger believed that his syndrome and Leo Kanner’s category were distinct disorders (see Wing 1981), autism spectrum disorders became a broad category that encapsulated both definitions.

Journalist Steve Silberman (2015) argues, however, that Leo Kanner committed intellectual theft, as he stole the Austrian Hans Asperger’s clinical insights. Silberman argues that Leo Kanner learnt of Hans Asperger’s observations from Georg Frankl, the chief diagnostician in Asperger’s clinic and that Asperger had been lecturing about children with autism from as early as 1938. At the same time, Ian Hacking has argued that it would be inevitable that Hans Asperger and Leo Kanner would both develop a keen interest in developmental disorders. Asperger had been trained by August Homburger and so developed; he was to share Kanner’s interest in childhood developmental disorders. With Leo Kanner’s

preeminent reputation as the first ever child psychiatrist in the United States, Kanner's conception of autism as a developmental disorder was to land on fertile soil. Chloe Silverman observes the "explosion in referrals for parents, mainly mothers of children diagnosed with autism" in the United States (2011: 75); a fact which only points to the entrenchment of the concept of autism in the popular imagination in the United States and parts of Western Europe, as can be seen by the term "refrigerators mothers," a term developed by psychoanalyst Bruno Bettelheim to reference the cold and detached parenting style he saw as responsible for causing children to withdraw into their autistic aloneness (Silverman 2011: 38)

At present, prevalence rates for autism in the United States have been estimated to occur at the rate of one in 68 persons, which is significantly higher than the global incidence rate of 1 percent. These high rates have sparked concerns among North American parents that vaccination and environmental pollution cause autism. For instance, there are beliefs that the combination measles-mumps-rubella vaccine damages the intestinal lining, and the central nervous system, and having multiple shots for infants and toddlers weakens the immune system (Gerber and Offit 2009).

Nowadays, in the twenty-first century, psychiatrists and other biomedical professionals in the United States (and China) define autism as a neurological and developmental disorder and as a disability characterized primarily by social communication deficits and restricted behavioral patterns and interests. For instance, the standard classification manual used in practice by mental health professionals in the United States (and in many parts of the world such as China), the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition, calls this condition the Autism Spectrum Disorder. The nomenclature is a nod to the complex range of abilities and disabilities that manifest in a person with this diagnosis. Currently, data emerging from clinical

and genetic studies suggest that there is no single presentation of autism. The current director of the United States National Institute of Mental Health, Dr. Thomas Insel, has proposed that “autisms” might be a more apt term in place of the singular, because of the broad spectrum of traits (2013). Such recognition, however, has not quite caught on in China, where autism continues to be referred to as a singular condition, even if clinicians and families alike use degrees of severity to denote a person’s condition.

This call to recognize autism as a complex, rather than a singular disorder, is not made by Thomas Insel alone; scholars of science studies have insisted on this point as well. Hacking has proposed his own term, “autism manifold,” as a way of recognizing the complex range of abilities and disabilities encapsulated by autism, rather than the more linear continuum encapsulated by “spectrum” (Hacking 2006). For Hacking, the term “manifold” is intended to highlight that autism is not a linear condition where one suffers from higher or lower degrees of autism, but refers to a multi-dimensional condition bearing abilities and limitations, which exist at the same time, rather than simply denoting a singular form of disability.

In referring to autism in my dissertation, I draw upon these biomedical and social perspectives, different though they may be in their intention and epistemological starting points, because they converge on one shared point—that autism is not a singular condition, but a loose and rough term that encapsulates a range of expressions, strengths, and limitations as well as the fact that how these strengths and limitations are perceived have also changed over time. I argue we need to situate autism in the life worlds of families across different social positions, while also understanding it as an “epistemic space” in generating novel ways of thinking and practices of care (Rheinberger and Müller-Wille 2012).

Research Questions and Initial Field sites

In developing my initial research questions, I had triangulated between related anthropological research showing the pre-eminence of Traditional Chinese Medicine in managing disorders and illnesses of the body and mind (Farquhar 2002) and my preliminary fieldwork in the summer of 2009 and 2011, the winter of 2012. Much of this research positions such frameworks as alternatives to the atomistic aspects of biomedicine, or as ways to allay the iatrogenic aspects

introduced by the psychotropic drugs within Western biomedicine (see for instance Farquhar 1994; Good 1993; Lou 2014). I planned to explore the following questions: What are local adaptations of the biomedical category of autism? I wanted to study how local categories have fused with, and refigured imported Western biomedical classifications. I knew that some families were using Traditional Chinese Medicine and wondered if their therapeutic choice was out of a resistance, or distrust of biomedicine, especially since the anthropological study of illness and health in China typically touched on the ubiquity of Traditional Chinese Medicine in China. What are the social-cultural conditions that permit the growing acceptance of the category in a society which has no indigenous category of autism prior to the early 1980s? Did urban settings make autism less stigmatizing than rural settings as I have heard suggested by some parents and doctors? Many parents and doctors argue that superstition made intellectual disability less acceptable to many rural families, while urban families are more informed about developmental disorders.

I set out to study local translations of autism by spending most of my time in Beijing by parceling out my time equally between the oldest autism rehabilitation center in China and one of the top outpatient child hospitals. Housed in a small and shabby building, Sunflower Autism Center's physical appearance does not do any justice to the school's history and importance in autism services within China. Sunflower is an autism rehabilitation center that is targeted at parents of three to six-year-old children; it runs 3 month long semesters for parents to learn how to become therapists for their own children. It also holds the distinction of being simultaneously the first autism rehabilitation center, and the first nongovernmental organization within China.

I also spent time at Beihe, a one of the top outpatient child psychiatric units in the capital, which was also one of two places within China during the 1980s where children might receive

the autism diagnosis. Sunflower Center's teachers and staff told me that it might be more fruitful for me to stay in Beijing since the families they served came from all of China, and I would have a diverse set of respondents. That seemed true. Some of the families I saw in Sunflower were so well-to-do they drove Mercedes Benzes and owned multiple properties in Beijing, while other families borrowed money from their colleagues, which they worried constantly about returning, and tried to live under 30 yuan (USD\$5). Some of them were grandmothers from Xinjiang, parents from urban Mongolia, and others from Hunan, Hubei and other provinces across China and they all came to Sunflower Center because they said there were no therapy centers nor training programs in their province.

Although I knew that the urban/rural distinction was important in understanding family experiences in China, many doctors and teachers discouraged me from exploring rural sites, or talking with rural families in China. Shaking his head because he said that these resource-poor settings would not provide services for autism to begin with Dr. Gao Jinfeng, one of the few autism experts in China simply said, "there is no point going out to low end hospitals, many of the doctors will not have even heard of autism. What you see here in Beijing would be representative since most parents will have to come here for a diagnosis." Dr. Gao and other doctors had told me that there were few, if any, autism centers that specifically catered to lower income families, and there were no doctors competent to diagnose autism that primarily served rural or lower-income urban families because of the poor quality training that doctors in rural areas received.

I nonetheless pressed Dr. Gao to suggest schools or hospitals that served low-income parents. He put me in touch with Hong Li, a friend of his who had recently set up a rehabilitation center for autistic children in the outskirts of a third-tier city in the Hebei region, between

Shijiazhuang and Zhangjiakou, which means that most of the children would be parents of the “floating population” (or low-skilled internal migrants). In my brief visit to Hong Li’s organization, I was told that I would meet plenty of migrant laborer parents. Unlike the other organizations that I contacted or visited in Shanghai, Beijing or other cities, the parents who made use of their services, I was told, would mostly have graduated only from primary or lower secondary school. They chose to put their children in the school set up by Hong Li because they could not afford to live away from their families, and the breadwinner was mostly engaged in construction work around the vicinity. We made plans to keep in touch. I decided to focus my efforts on Beijing, Hebei and Shandong, since they are all in the North, while taking side trips to Shenzhen, located as it was at the edges of Guangdong Province next to Hong Kong.

The one-and-a-half years of conducting extended, multi-phased, multi-sited fieldwork from 2013 to 2014, however, was to drastically change my plans, while forcing me to reconsider my research questions. During the first few months of fieldwork in Beijing, both at the Sunflower Autism Center and in the top psychiatric outpatient specialist clinic, I became increasingly haunted by my observations of families in search of a diagnosis or therapy for their children, and of the impossibly chaotic hospital grounds and crowded waiting rooms and schedules of the doctors. In the hospitals, many families barged their way into a doctor’s room demanding to be seen. Whenever I left the doctor’s room for errands during my observations, many families would mob me, pleading that I get them a queue number with the doctor. I also experienced, vicariously, how tired the doctors were after having to insist that other families who have barged in without queue numbers must leave the room. Whenever I alluded to the great number of parents who were turned away, these specialists simply waved their hand, saying that there were not enough doctors trained to diagnose autism across China. For a while, I was

satisfied by that explanation of a general lack of doctors.

It was not until after many months into the research that I came to see that I had been blindsided by the apparent chaos in the waiting room of these hospitals. I saw that the story that doctors, nongovernmental organizations, parent-advocates and the local media were telling others and themselves about the lack of specialists or bad luck was only partially correct. Such an explanatory model failed to explore who had access to a doctor and why, and how this impacted the way entire families experience autism and other developmental disorders. Such a story ignores how the adoption of technological means to improve the ease of making appointments might in fact further contribute to the marginalization of some patients and their caregivers.

The general lack of trained doctors in China was not experienced equally by all families with autistic children. As I discovered during my fieldwork, there were broad patterns in who would obtain a diagnosis fairly quickly, while others might receive a diagnosis after many years of false turns, or in fact, never receive a diagnostic label. More often than not, it was rural families (evident from their accents, weather-beaten faces and hands and well-worn clothes) who would end up pleading for the doctors to take pity on them to see their child since they had travelled for days on the slowest and cheapest train tickets across provinces, and they would be the ones who would be turned away when doctors simply could not add another queue number as their clinical hours stretched impossibly thin. Since they did not know how to access the online booking system that opened months in advance, they would then come early, wait for days, and then plead with the doctor to add a queue number for them (which was up to the discretion of the doctor since any extra numbers that might be added to the caseload would take place after the patients with pre-booked appointments would be seen). This contrasted sharply with the other

families who had made their booking online (and who would have to be fairly literate to begin with). These were the parents who were, in fact, actively encouraged by doctors to make repeat or follow-up appointments online to ensure they would not travel to the hospital in vain; during my fieldwork, I was to observe doctors telling families who did manage to make an appointment with them to remember to book an appointment online, lest they make a long trip to the hospital in vain.

I also came to realize that the advocacy of therapy in fact, exemplified what Jane Duckett terms as “the state’s retreat from health” (2011), since it pushed all responsibility onto parents, while masking post-socialist China’s neglect and systematic marginalization of parents from poorer provinces, or rural areas. By the time I left Sunflower Autism Center and the other rehabilitation centers, I came to see that the model they, and other practitioners were offering was unrealistic for families with insecure economic means, since they required a full-time commitment: at least one parent would need to bring the child to different classes for the three-month semester at the Sunflower Autism Center or for up to a year in others. Getting a coveted place at any of these schools would mean a significant financial outlay of school fees, accommodation, and living costs for the child and the accompanying adult(s), for a couple of months, including the transportation costs. It might mean that husbands and wives would not see each other for months or years, as the entire family depended on the sole breadwinner.

I came to see that “what really mattered,” to borrow physician-anthropologist Arthur Kleinman’s phrase, to families was not resistance to or critiques of biomedicine, but rather, how they might best enact care for their children within China. As Kleinman says in writing about the importance of “local [moral] worlds” (1998: 358), I saw that family, professional, and para-professional care for autistic children in China was shaped by deep moral valences. I came to

understand that what shaped the experiences of caring for an autistic child who would grow up into an adult was as much related to autism as a bio-social condition, as it was to the social, economic, and political position of each family within their community and country. Furthermore, experiences of care are always imbued with moral expectations, by family caregivers themselves and Chinese society. These moral expectations take it for granted that parents, rather than the state or society, are responsible for providing high quality behavioral therapy for autistic children; they also justify in moral terms placing a higher value on the child's future than on parents' existing psychosocial and financial concerns.

Yet, local worlds in China are split by gender and other distinctions, including those who are local and those who are internal migrants. They vary between urban and rural areas from various Chinese provinces. These worlds are profoundly unequal and shape the course and experience of disabilities for families. Furthermore, social and economic capital influenced how early a child might have a diagnosis or access to early intervention, and whether a family would have the social and living arrangements to permit a child's unique strengths to shine through. The lack of such forms of capital would therefore make it likely that the child's needs for accommodation would rip apart a rural or less educated and less well-to-do family's fragile social compact, given the tenuous subsistence of such families.

Developing Methods

Finding rural families, or families with limited social power to understand how they experience autism when I was in the field, however, proved to be one of the most difficult pursuits of my fieldwork, as it mirrored in reverse the difficulties many rural families had in finding the right diagnostician, or rehabilitation center. Staying put in any one autism rehabilitation center, even

one as well-known as Sunflower (which charged lower rates than many other private autism rehabilitation centers, as of 2013-2014) would not be enough, for the following reasons. Teachers of Sunflower Autism Center were vehemently against all forms of Traditional Chinese Medicine (TCM), and actively discouraged families from spending time and money pursuing alternative treatments. It was thus difficult to ascertain whether the low levels of interest in TCM I encountered in Sunflower was reflective of families caring for children with autism, which seemed surprising given the rich literature on medical plurality, or the blending of TCM and medical treatment in maintaining health and medical wellness, within China (see for instance, Farquhar 1994; Kleinman et al 1995; Ma 2012; Zhan 2009). Demographically, Sunflower Autism Center's families seem to be mostly urban middle class parents, even if they came from a wide variety of provinces, with a few peasant families (who might have become recently well-to-do) and other families whose main breadwinners were migrant laborers. While it is true that many of the families visiting Beihe were poor peasant families, many of them were only in Beijing for a few days, and were rushing to return home, lest they lose their jobs; they also had no personal relationships with the child psychiatrists and had no incentive to help me with my research. I also observed that there were few, if any, parents from the Pearl Delta area (even though there were urban middle class parents from Shanghai and other provinces). Since Sunflower did not keep track of the demographics of their parents, I asked the 50 or so parents enrolled in the beginning of each semester to tell me where they came from, and it seemed that in the year 2013 at least, urban middle class parents from the Pearl Delta Area did not come to Sunflower. Yet, I could not simply go to any village or any rural hospital to study how rural families cared for their autistic children, given that many rural clinicians may not have heard of autism to begin with.

I therefore shifted my research methodology in order to navigate the complex terrain that shapes the patterns of family caregiving for autistic individuals in China. I moved a total of 14 times during close to one and a half years. While I did not follow the same group of informants as they made their journeys, as did Seth Holmes in his ethnographic study of Triqui migrant farmworkers in California (2013), I elected to move independently along the same circuits and paths as my informants. Having served as a translator for organizations (whenever their teachers were hosting English speaking visitors, or trying to read autism pedagogical materials written in English), my networks begin to enlarge, and I found myself travelling to diverse organizations so as to ensure that the families I studied would be more representative of the diversity of backgrounds of families with autistic children in China.

And so it was that I conducted research in another school that served 40 families with children of various intellectual disabilities. These families all had registration papers in Hebei region, which meant that their province paid the costs of their tuition fees. I also followed a nongovernmental organization that was providing free TCM concoctions to rural families, and travelled with them on jeeps over barely functional roads to villages where we interviewed rural families who lived a minimum of 5-6 hours by jeep from the nearest hospital outpost. I also developed my own network of doctors who knew rural child health providers in Hainan Island, and I also re-established contact with Shenzhen Autistic Advocacy Centers. Finally, I also developed new contacts that allowed me to move to the Pearl Delta Region, where I conducted research in Guangzhou and Shenzhen. In conducting fieldwork in Sunflower Autism Center (and other centers such as Friendship Autism Center in Beijing), I came to notice that there were few parents from Guangzhou or Shenzhen. Meanwhile, some parents suggested to Guangzhou offered even better quality services for autism than Beijing. Both Dr. Zhu, a university professor

from Yunnan, and Liu Xi Zhen, well-educated and well-to-do librarian born and bred in Beijing, had suggested I take at least a short trip to Guangdong Province (including Shenzhen City), in addition to Qingdao, so that I would have a fuller picture of where parents would travel to for high quality autism services. Liu Xi Zhen had in fact moved to Guangzhou by the beginning of 2014 for two reasons. She concluded that the quality of autism service in Guangzhou were at least equal to, if not better than that which is offered in Beijing (as of 2014), and she also feared the long-term effects of air pollution in Beijing. I had also developed close relationships with professionals working in the One Foundation (thanks to Sunflower Autism Center, which had made the introduction). One Foundation was located in Shenzhen, and both Guangzhou and Shenzhen were part of the Pearl River Delta. Having developed asthma after eight months of living in Beijing, I was more than happy to take Liu Xi Zhen's friendly recommendation to move at least for a month or so to the Pearl River Delta to give myself some respite from the horrific smog that encased Beijing on a daily basis. Both Dr. Zhu and Liu had struck me as highly knowledgeable, and judicious in their evaluation of the quality of doctors and therapeutic options alike. They both suggested I also look up another well-known pediatrician in Guangzhou: Dr. Cai, since they had done copious research online and said that he was highly recommended as a doctor from other online parent groups.

In the end, between 2013 and 2014, I undertook research in seven autism rehabilitation centers, two municipal specialized hospitals, three district level hospitals, and seven community and village child-health clinics. I conducted semi-structured and informal interviews with 80 family caregivers attending these schools who were seeking diagnoses for their children, and also managed to continue keeping in touch with 25 parents for a year after the families and I left Sunflower Autism Center. Volunteering to translate for parents and organizations and sharing

meals with families, I observed daily routines of parental care. I used snowball sampling, tapping into networks of parent-informants, to locate parents who had chosen not to attend these centers to conduct interviews with them. I observed the diagnostic process of three highly regarded child psychiatrists in Beijing, two child psychologists in Guangzhou, three psychiatrists in city hospitals, and fifteen healthcare practitioners working in community and village child-health clinics. Finally, I conducted anonymous surveys at the two of the most reputable autism rehabilitation centers in China, so as to confirm the prevalence of families on the move for therapy.

Fieldwork and Ethical Responsibility

How should I ethically conduct my fieldwork, and represent my informants? What are the duties of care I owe to the communities I found myself embedded in China, as well as an anthropologist? These questions troubled me from the time I began conceptualizing this research, to the actual fieldwork itself and even now, as I represent the families and professionals I studied for this dissertation and beyond.

Initially, I went into the field planning to be an observer. I thought I would be predominantly amongst families with sufficient means to enroll their children into autism rehabilitation centers in China. While I was sympathetic to anthropologist Nancy Scheper-Hughes' call for a militant anthropology, a call she voices in several places such as her 1992 "Hungry Bodies, Medicine, and the State: toward a critical psychological anthropology," where she argues that the aim is to "speak truth to power and domination, both in individuals and submerged social groups or class" (1992: 22), I was uncomfortably aware of the danger in her

sweeping critique of all modern institutions as means of “continuing oppression.” For instance, Scheper-Hughes makes the point that:

Increasingly in modern bureaucratic states technicians and laboratory scientists, doctors, psychologists, teachers, social workers, sociologists, criminologists and so forth-come to play the role of the “traditional intellectuals” in sustaining “commonsense” definitions of reality through their highly specialized and validating forms of discourse. Gramsci anticipated (see Foucault 1972) in his understanding of the diffuse power circuits in modern states and the role of the “expert” forms of power/knowledge sustaining the “common sense” order of things. (1992: 230)

While she is right in that medical, educational and scientific professionals often sustain the power of the state, such an analysis is highly limited because it reduces all efforts and encounters either initiated or conducted by any of these professionals into sustaining state power. Such a framework misses out that many of the professionals may simultaneously be critical of the way their intellectual labor may go on to support the existing order, but want the best possible outcome for an individual in the immediate future. While I was sympathetic to the recognition that the medicalization of deviant behavior was problematic (Foucault 1965; Illich 1976; Parsons 1951; Conrad and Schneider 1980), I also saw that such a framework also failed to capture other complex affects and desires that involve wanting a positive outcome for patients in the case of medical professionals, and also did not always grapple with the reality that systems of power may also lead to the flourishing of particular humans in particular places in the present. I knew prior to beginning my research that I did not want to engage in covert research (see Scheper-Hughes 2004), and I did not want to mislead my participants into thinking that my research would directly benefit them or that I was a professional expert. I figured that I would have conducted myself professionally and ethically as long as I chose to emphasize that I was still a student and not misrepresent the extent I knew.

Things turned out to be more complex. I found myself struggling with the impulse to contribute to easing an individual or family's difficulties *right now*, though I knew I might be inadvertently contributing to unforeseen and unwelcomed consequences. Furthermore, my relationships with some of my informants were tangled; it was hard to know where research began, and where daily life and friendships began.

Like anthropologist Seth Holmes "my body offered important field notes on social suffering" (2013: 34), and I came to appreciate for a limited time the difficulties particularly of family caregivers from rural and less well-resourced urban areas, knowing of course, I could always walk away from this situation. Without extra-mural funding for the first six months of the fieldwork, I was living in migrant-laborer quality housing, and came to appreciate the difficulties that many low-income rural families face if they were to even take a few months away from home to become their children's therapists. By migrant-laborer quality housing, I mean just that: my landlord stored her construction materials, bricks and steel rods in my room and often came in and out to take her materials. At night, winter winds whistled into various cracks into my room. Wearing six layers of clothing and my thickest parka to sleep did little, while a chorus of dogs howled right on schedule at 12 am sharp to 5am daily outside my door. If I conducted interviews during the time parents were able to spare the time, I more likely than not would go hungry that night, since the little village where Sunflower Autism Center was located in had only a few food stores which closed early, as room conditions made it impossible for me to do necessary functions such as cooking or washing up. These are the same issues that made many families fall behind in their homework when they were in Sunflower or other schools; many of them might be rushing to do chores before it got dark. By the time they were done with chores, they would be too exhausted to practice.

For these reasons, my plans to simply be an observer were unsustainable in the face of the needs I witnessed at times for families from rural and illiterate backgrounds. No one asked me for money or any form of financial assistance or tried to subtly hint that I should help them (it was actually organizations who insisted on donations). But I found it impossible to see families struggle with the cold, or with hunger when I could relieve a little of that misery. I gave money to families to purchase warm clothing and food, sometimes via other third parties and these never knew I was the donor. In other situations, third parties gave away my identity, as with Feng Ma, whom I discuss in Chapter Three.

Living in conditions that were more similar to those experienced by families from the lowest socioeconomic strata, however, also had unexpected upsides. It went a long way towards fostering relationships with informants who quickly took me into the fold. Feng Ma, for instance, brought her leftovers to share with me. Other parents living in better quality housing in the little village asked if I was sleeping enough or delicately asked if I would like them to wash my winter clothing; they had toured these temporary accommodations before renting elsewhere.

What I had not anticipated was that I would be seen as a someone who could provide advice as a “lay expert” — not in the way of being a patient myself, as are the AIDS activists in Steve Epstein’s 1998 *Impure Science, AIDS, Activism and the Politics of Knowledge*, which makes it clear that their source of credibility lies in their intimate knowledge of the effects of the HIV virus and their willingness to risk their bodies — but as someone who has experienced caring for an autistic family member, and who saw first-hand how families in other cultures and societies understood and experienced autism.

Since these expectations of me as a lay expert also differed according to these families’ social positions (and their social power relative to me), I had to develop different sets of

responses. Parents who were well-educated, and economically well-off simply wanted to find out if I knew any autistic adult and to tell them whether these young adults were gainfully employed, in what fields, and whether they were able to make friends of their own, or create a family unit of their own through marriage; they wanted to garner some kind of prognosis for their child by hearing about the developmental journeys of other autistic young adults in other contexts. Some would ask me what therapeutic techniques families in other social contexts used. On the other hand, families who were either from rural areas or who left school after high school might ask if autism could be cured abroad. Many might ask me what they should do for their children, and where they should seek for help. Or they might ask if parents from Southeast Asia or the United States used drugs or cures. Even the way these parents ask questions would be different. With the former group of parents and grandparents, questions might be asked at times in a disinterested tone, or my response will be met with a statement where they would sigh, shake their heads and sometimes make statements such as “autism is autism, what else can you expect?” (in reference to my cousin) or “Your friend is lucky he’s got such a mild variant of autism” (in reference to my friend). In our interaction, these parents were simultaneously garnering new information but were establishing that we here to relate as equals since they were no less well informed. Answering their queries was a relatively uncomplicated process that allowed us to establish rapport. If they asked for advice, I often turned the question back at them, and asked them what options they preferred, and why. I preferred offering them a space to come to a decision on their own.

What was probably more common, and more difficult for me to deal with were the questions many families who were barely literate or low-income were to throw my way. Many were to ask me directly what forms of therapy their child should undertake and where they

should enroll their children, and what they should do for their child. I feared becoming a meddling outsider who, despite good intentions, served to reinforce the hegemony of biomedicine or reproduce unequal relations of power by offering unasked for advice. But I also wearied of hearing that families were 20,000 RMB (3060 USD) — a staggering debt for low-income rural families— in debt from sending their children for brain surgery to cure autism, or that they had spent that same amount traveling to various provinces over the past years in search of a doctor who might recognize autism. There was no easy answer. Directing them to autism rehabilitation centers also brought up difficult issues; how were any of these parents or grandparents ever to serve as their children's sole and unpaid therapists for the rest of their lives, and to make that difficult decision to give up their insecure employment for a therapy that did not promise a cure? I had to formulate an answer on a case-by-case basis, knowing any answer I provided was inadequate at best. I did choose, however, to sometimes direct them to other parents or teachers I trusted, where in the case of Xiaoxi, I asked other parents I had grown close to provide emotional support and long term advice for them.

After leaving the field, I had tried to keep my *wechat* account (a kind of mobile application with similar functions to *WhatsApp* which draws upon the internet to allow individuals to make phone calls or leave text messages for each other) open, so that families, teachers, nongovernmental organization employees were free to contact me if they should choose to do so.

In writing up my research, I have also chosen to give pseudonyms to all the centers, doctors and parents I write about and have not included photographs. Readers familiar with autism services in China will have little trouble identifying the real identity of Mother Zheng or Sunflower Autism Center, or the doctors such as Dr. Chu. While they have all given me

permission to use the data I collected with them, some of the vignettes I present might put them, at first glance, in less than flattering light (unlike the laudatory evaluation of them by other authors in print). To protect them, and to ensure that my readers focus less on allocating blame or criticism to individual actors and more on the way parents of autistic children are failed through local advocacy of the rights of autistic children, I have also chosen not to use any photos. I was unable to gain consent from the autistic children themselves, and I decided not to perpetuate a disparity between families who willing to allow me to take photos (usually those from rural or lower income families) and those who were not (usually those from upper middle class families).

Organization of the Dissertation

In “Chapter Two: Producing Autism as an Epistemic Object in Landscapes of Inequality,” I argue that autism, as a psychiatric category, is an epistemic object made possible by the increasing and changing pressures placed upon families through the one-child policy, the post-socialist state’s move toward self-governance, and the post-socialist state’s abrupt withdrawal from healthcare and the social provision of education during the last two decades of the twentieth century. In making this argument, I draw upon and adapt Hans-Jörg Rheinberger’s concept of epistemic things, which he develops in describing how novelty is produced in the scientific process. I argue that epistemic objects are also *produced by, and constitutive of*, local forms of social and political inequalities. I develop this argument by examining autism’s uneven travel across China. Regional and other forms of inequalities also ensure that autism as a biomedical category has travelled in fits and starts across China. Autism as an epistemic object in China has been shaped by local forms of inequality, which have hardened since 1949. As an epistemic object, autism is determined by interlocking factors such as regional economic and social

disparities and the household registration system. In contextualizing how epistemic objects such as autism are also shaped by local inequalities, I show how diagnostic categories, not just infections or diseases, travel along “gradient[s] of social inequality” (Farmer 2001; Marmot 2005). I am indebted to Paul Farmer’s term “immodest claims of causality” (2003): Farmer warns social scientists of the dangers of narrowly focusing on “culture,” rather than the complex political and economic structures that render communities more susceptible to HIV infections.

In “Chapter Three: Diagnostic and Therapeutic Internal Migrants”, I explore the experiences of families who move in search of *professional* medical care and therapeutic services for their autistic children. I argue that family caregivers who travel in search of care, diagnosis and therapy for their autistic family members should be characterized as medical or therapeutic internal migrants. Grounded on ethnographic fieldwork with 20 farmer families with autistic persons and 60 urban families caring for autistic children, and interviews with 18 rural healthcare practitioners, my 18-month fieldwork suggests the importance of disaggregating types of families who might “go on the run” (as Mother Zheng calls it) in search of diagnosis and therapy. Not all families are equally likely to “go on the run”; parents with *hukous* outside of advanced provinces such as Beijing and Guangdong Province are more likely to do so. Furthermore, this group of family caregivers who have to travel in search of diagnosis, therapy and care can be divided broadly into two: rural, impoverished and barely literate families who are more likely to travel in search of diagnoses, and urban and well-educated families who are more likely to travel in search of high quality therapy. I show how factors which impact one’s experiences in the search for a diagnosis or therapy such as a family caregiver’s literacy levels, and the capacity to search the Chinese World Wide Web are powerfully linked to the structural inequalities in China. I settle on medical and therapeutic internal migration because existing

terms used to conceptualize travel in search of care such as “medical tourists,” “pilgrims,” and “exiles” are less useful in understanding the experiences of the families I study, and do not capture the sense of unsettledness which the families I study experience.

In Chapter Four, I draw attention to the value and emphasis placed upon an autistic child’s “golden period of development” so as to explore how the concept of the autistic child’s potential anchors multiple moral economies of care around the family and person grappling with autism. I argue that the autistic child’s potential functions as an ethical imperative upon doctors, humanitarian organizations and family caregivers alike, galvanizing doctors and humanitarian organizations to exhort and advise family caregivers to provide therapy for their autistic children in China. Such a concept determines how doctors may choose to allocate their scarce clinical time or even humanitarian funding, while serving as an arbiter of which families with autistic children in China are more deserving of care, and which are not.

At the same time, I propose that the framing of the autistic child’s potential for change and intervention as one restricted to “the golden period of child development” also serves to limit the possible claims that can be made on the state and Chinese society at large, legitimizing the neglect of autistic adults while exacerbating gendered divisions of labor. While “framing something in terms of potential is a political act,” (Taussig, Hoeyer and Helmreich 2013: S6), the framing of a child’s developmental needs through potential not only depoliticizes the lack of institutional and state support in China, but renders thinkable the neglect of family caregivers and the autistic adult.

In Chapter Five, I explore the transformation of parents into therapists for their children through Applied Behavioral Analysis, and show how such a call is an attempt by doctors and

nongovernmental organizations to reverse the intergenerational contract between parents and children. I argue how such a call by what I call the autism therapeutic apparatus, made up of doctors, elite parents advocates, and other advocates, give rise to coercive biosocial communities which disproportionately marginalize rural or poor families who are unable to provide therapy for their children. In conducting a close reading of how behavioral analysis is taught to parents, the chapter illustrates not only the novel skills and attitudes parents need to take on, but also the social and economic capital they must have to successfully turn into therapists for their children. I seek to illuminate how moral categories, exemplified through discourse on the “good” parent or the parent with low *suzhi* (quality), are imbricated in legitimizing the uneven quality of care families with autistic children receive. This chapter brings the matter of disability into focus for scholars of contemporary China by exploring how the “intergenerational contract,” a relational ethics that assumes that children will grow into caregivers for their parents, is being rewritten by autism advocates for families with autistic persons.

Chapter Two

Producing Autism as an Epistemic Object in Landscapes of Inequality

Until 1981 autism, now typically translated as the “loneliness disorder” (*zibizheng*) or “self-enclosure disorder” (*guduzheng*), was not a category known in China. Now, *zibizheng* and *guduzheng* are ubiquitous terms in modern metropolises such as Beijing, Guangzhou, and Shenzhen, but they remain unknown in rural areas and many less developed urban areas. The travel of the diagnostic category of autism to and across China is often narrated as a “just-so” story of China “catching up” with the developed world. For instance, journalist Adam Feinstein writes that the translation of autism into *zibizheng* or *guduzheng* is not “particularly enlightened” (2010: 234), while the Chinese Web of Science, which is supported by the Chinese Academy of Sciences, Chinese Academy of Engineering, and the National Natural Science Foundation, bemoans how “backward” (*luohou*) China is compared with “the West” as far as how autism is understood (see *kexue shibao* 科学时报 2011). Such an interpretation is consonant with broader trends in scholarship which assume China is finally adopting more sophisticated approaches to mental illness after the long and dark night of Communist repression from 1949 to 1978 (see Yip 2004; Pearson 1995; Munro 2002).

Such a “just-so” interpretation, however, is particularly problematic given it is based on the following assumptions: (1) that the travel of psychiatric and biomedical categories from the United States to China is inevitable; (2) that psychiatric categories such as autism are biomedical universals (see Kleinman and Good 1985); (3) that China’s understanding of psychiatric illnesses or mental disorders was sorely lacking until the end

of the twentieth century; and (4) that biomedical and psychiatric knowledge necessarily leads to improved attitudes toward disability. In fact, ancient Chinese medical texts and the Chinese imperial state bureaucracy paid close attention to madness and disability. For instance, the Yellow Emperor's Classic of Internal Medicine, an ancient Chinese manual of medicine that has been around for at least two millennia, offers sophisticated conceptualizations of insanity (*kuang*) and madness (*dian*) (see Henry Lu's translation in 1978; Ng 2009), while eminent historian Derk Bodde argues the Tang imperial state displays a fine-grained recognition of different forms of disability from the Tang dynasty onward, offering special consideration to law-breakers who meet the criteria for disability.

The seeming lack of interest in intellectual disability or developmental disorders, in contrast to the close attention paid to conditions of madness and insanity, requires another interpretation. In this chapter, I argue that autism, as a psychiatric category, is an epistemic object made possible by the reform and opening up of China after the 1970s. I trace how local conditions specific to China facilitated the making of autism as an epistemic object in China. In making this argument, I draw upon and adapt theoretical insights from Hans-Jörg Rheinberger's concept of epistemic things, which he develops in describing how novelty is produced in the scientific process. I explore how autism has been produced, and how it in turn generates new apparatuses that would reshape parental behaviors.

Epistemic things, according to Rheinberger, can refer to material objects or processes and are "question-generating machines" (1997: 26); they make *thinkable* conceptual frameworks which drive scientific priorities, practices, professions, and

scientific objects of study. In short, epistemic things *exert* material effects. Epistemic objects such as autism, I show, are produced by specific conditions such as the increased pressures placed upon families through the one-child policy, the post-socialist state's abrupt withdrawal from healthcare and the social provision of education during the last two decades of the twentieth century, and the pressures on families to take over responsibility for their own welfare. These conditions impel a sense of urgency in parent advocates, doctors and nongovernmental organizations. As an epistemic object, autism mobilizes attention and actions on the part of families, doctors, and humanitarian organizations toward the necessary nurturance of persons who meet the criteria for autism.

Indebted as I am to Rheinberger's formulation of epistemic objects, I argue that epistemic objects are also *produced by, and constitutive of*, local forms of social and political inequalities in practice. I develop this argument by examining autism's uneven travel across China. Regional and other forms of inequalities also ensure that autism as a biomedical category has travelled in fits and starts across China. Autism as an epistemic object in China has been shaped by local forms of inequality, which have hardened since 1949. As an epistemic object, autism is determined by interlocking factors such as regional economic and social disparities and the household registration system.

Chinese epidemiologists writing in the Shanghai Archives of Psychiatry have observed a wide disparity between rural and urban prevalence rates of autism in China (see Wan et al 2013). At present, there seem to be three times as many urban persons who have been diagnosed with autism as rural persons. Such disparities in incidence rates is in keeping with other high income countries. Prominent child psychiatrists have suggested

to me that the prevalence rates in China might either reflect an actual disparity in the prevalence of autism or denote the increase of autism prevalence in China (one doctor insists that rapid industrialization and pollution are responsible for the increased prevalence). On the difficulties that rural families have in obtaining diagnosis, these epidemiological articles remain silent. Scarce attention has been paid to the social factors influencing the disparity in diagnosis between rural and urban areas or the barriers to diagnosis for families in rural areas. Even scholars who do recognize that rural families may experience barriers to accessing diagnosis, however, still frame it as a problem in the users of services, rather than how accessible these services are. For instance, a study has stated that families in rural areas need “family support” because of their low educational attainment and economic status (Zhang and Ji 2005: 340), rather than suggesting changes in the delivery of services.

In contextualizing how epistemic objects such as autism are also shaped by local inequalities, I show how diagnostic categories, not just infections or diseases, travel along “gradient[s] of social inequality” (Farmer 2001; Marmot 2005). In studying the travel of autism in practice for families across China, I show how autism is experienced for what I call gradated citizens in China. While political scientist Sun (2009) first developed this term in relation to maids and the use of civilizing discourse to differentiate types of urban citizens, I use this term to highlight the differential access citizens have as a result of the intersection of their household registration system, and regional disparities.

I begin with a discussion of how disability has been understood prior to the twentieth century in China. I then show how the understanding of disability has been shaped by broader political struggles for the control of China and Chinese territories by

imperial powers during the nineteenth and twentieth century, and the long decades of civil war within China during the twentieth century. I suggest the large-scale political strife repeatedly inflicted upon the Chinese national body throughout the 20th century made an unfavorable home for autism, a psychiatric category with core characteristics that seem more about inwardness, repetitiousness, and social ineptness, rather than about dramatic social disruption. Therefore, autism was unlikely to garner much attention in China until the tail end of the 20th century. Political contingencies such as the open-door policy, reforms in psychiatry, and educational policies and the one child policy are thus crucial in facilitating the acceptance of autism as a biomedical category.

Management of Disability and Mental Illnesses in Pre-Reform Era China

Disability as a social category certainly existed from the Tang dynasty (618–907 AD) to the Qing dynasty (1644 to 1912). So did the recognition that disabled persons needed to be offered special consideration on account of their differences from *quan*, *zheng*, and *ding*, three classifications that denote wholeness, perfection, completeness and orderliness (see Huang 1964; Stone 1998). Even prior to the Han dynasty, the second imperial dynasty ruling China (206 BC – 220 AD), medical seals of authority attest to the existence of specialists who treated speech impediments. From the Tang dynasty onward (AD 618-907), disability not only excluded individuals from participating in social and public affairs, but was to also grant them exemption from military conscription, taxation, while offering them greater clemency in the case of wrongdoing (see Stone 1998 94; Twichett 1970: 212; Pearson 1995: 31). For instance, the Tang (Legal and Imperial) Codes through to the Qing dynasty codes recognized three grades of impairment: *can ji*

(minor impairments), *fei ji* (moderate) and *du ji* (severe impairments). For instance, blindness in one eye and deafness would correspond to *can ji*, persons who are seen as dumb would be classified as *fei ji*, while insanity and total blindness might be classified as *du ji* (Twitchett 1970). While there was no distinction made between intellectual and physical disability in these three grades, the legal codes nonetheless were intended to show clemency, in terms of culpability for crime and for conscription, especially for the young, the old, and the disabled. Sinologist Derk Bodde argues that the Tang codes embodied Confucian humanitarianism, where “compassion (*chin*) and love (*ai*)” governed the logic of clemency which was to be shown to lawbreakers and offenders who were either very young, old or infirm. The Tang Codes, for instance, included “feeble-mindedness (*ch’ik*) under infirmity, and insanity (*tien-kuang*) under incapacity” and the feeble-minded and the insane were not deemed to be legally responsible for their actions (Bodde 1973: 454). Feeble-mindedness and insanity, however, were to disappear as relevant terms within infirmity, and Qing legal codes collapsed both feeble-mindedness and insanity into mental illness, or *feng ping* (Bodde 1973; Bünger 1950), leaving only physical infirmities under Ming and Qing legal codes. It is still evident there was clemency shown toward infirmity from the Tang to the Qing dynasty.

While these classificatory systems for the infirm also afforded some level of protection from legal punishment, they also increased the burden of care on family members, particularly during the Qing dynasty. Qing codes stipulated that relatives had to report insane family members, and they were expected to keep them in confinement so that they could not hurt either themselves or others; only when the insane lacked family

were neighbors or local leaders placed in charge (Chiu 1981; Hsueh 1970). Neglect of duties was punishable. Impairment, as historian Emma Stone argues in her dissertation spanning imperial China to post-Mao China, is “a family affair and a lineage tragedy rather than an individual tragedy” (1998: 71). Beyond the responsibilities which family members had toward insane family members, anyone who is recognized as having impairments are likely not to be seen as eligible marriage material (which thus threatens the capacity to bear children who can continue the family lineage), or even un-filial since they are unable to take on their roles in ancestral worship and to carry out their duties in caring for aging parents or in contributing to household funds. The classifications of mental impairments as either *chi* (slow), *dian* (mad), *sha* (foolish) were only useful in obtaining clemency in the area of state punishment or taxes (Stone 1998), but not in obtaining benefits or special rights and protection.

The Uneven Travel of “Western” Psychiatric Categories during the 19th to the 20th Century

The advent of Western imperialism during the 19th century brought, at least to parts of China, “Western” biomedical and psychiatric categories vis-à-vis disability and mental illness and alternative ways of managing mental illnesses and disability. Western psychiatry made limited forays into China from the 19th to the 20th century, its progression hampered for multiple reasons, including the particular ways in which imperialism and colonialism was enacted in China, and the Communist takeover of China. Western imperialism in China was far more limited than in many parts of Asia such as India. The carving of the Chinese watermelon, as the imperial ambitions by Great

Britain, Germany, France, and Japan during the 19th century has been termed (see Fairbank 1978), was primarily focused on gaining economic spheres of influence in China (where they were to receive trade benefits) than in dominating China as a colony or territory. Colonial ambitions in China never involved the complete dominance of one colonial power (Mommsen and Osterhammel 1986). Parts of Shanghai, for instance, were controlled by France until 1943, while Germany controlled Shandong Province, and the British had primary influence over Hong Kong and trade rights in Guangdong Province (then known as Canton). Imperial powers, however, never sought to reform the state, medical, or bureaucratic structure in China (see Fairbank 1992).

With multiple imperial powers jostling for economic, rather than territorial, control over parts of China, Western-style psychiatry only had a presence in Chinese cities where there were significant numbers of foreigners, such as Beijing, Shanghai, Nanjing, Guangzhou, Chengdu, Changsha, and Harbin, but not in others. By 1949 there were only five psychiatric hospitals and a small cadre of psychiatrists to be found only in these cities (Pearson 1995). In areas with a heavy foreign presence, institutions and educational resources for mental illnesses and special education centers were set up, while academic and research disciplines such as psychiatry, psychology, sociology and anthropology were also introduced. Medical missionary John Kerr for instance is known for establishing China's first mental asylum in 1891 in Guangdong (and that hospital was known as Kerr's Refuge for the Insane) because he was already working in Canton. Canton, however, was the exception rather than the rule. There was no state or medical institutionalization of persons with mental or developmental disorders in the rest of China. Other missionaries established schools for the blind in Guangzhou, Fuzhou,

Hankou, Shanghai, Beijing, Hong Kong, and Taiwan (Lautourette 1966), but there were no such schools outside these areas.

Western psychiatry also suffered from the stigma attached to mental illness within China. Qing codes held families (or in rarer cases, neighbors or community leaders) responsible for locking up insane persons and keeping them from killing or hurting themselves or others. Mental illnesses and conditions were thus stigmatizing, since they necessarily entailed hefty responsibility on the part of families (and in some cases, neighbors) to keep both the person with insanity and the larger community safe from harm. While Western style psychiatry succeeded in making inroads in some areas of China, it was never as well integrated or socially accepted as other biomedical disciplines such as surgery, even if there were diagnostic categories that did make their way into China, such as neurasthenia (Kleinman 1982). According to Tsung-Yi Lin, the first honorary advisor to China on matters pertaining to mental health during the 1980s and the director of mental health at the World Health Organization then, psychiatry was too culture-bound to teach and learn easily in China during the early part of the 20th century (see Pearson 1995: 12).

The Chinese Communist Party's takeover of China by 1949 was to make it difficult for western psychiatry and psychiatric categories to survive, much less develop or spread. The communist takeover stifled whatever nascent psychiatry and psychological study budding in China, in part because the Chinese Communist Party insisted that mental illnesses or disabilities resulted from faulty political ideology. Socialist psychiatry in China promulgated the belief that mental illnesses were the product of the "failure of the old political system" and argued that Mao's writings would heal mental illnesses

(Pearson 1995: 23). The disciplines of anthropology and sociology were banned and social workers and other professionals had to put aside their professional and disciplinary training to favor the party line (Pearson 1995: 23). Western psychiatry became a target for political repression and control, even as it became a political tool used to repress dissidents and intellectuals. Child psychiatry units were attached to Shanghai, Beijing, Changsha (in Hunan Province), Chengdu (in Sichuan), Guangzhou (in Guangdong province), and Shashi (Hubei province) but mainly focused on children with major psychoses, or mental retardation. Some psychiatric wards were shut down, or co-opted for the purposes of political repression. Novelist Jung Chung of *Wild Swans* fame has written of her mother's careful concealment of depression, because depression was seen as a manifestation of excessive individualism, while other forms of mental illnesses were seen as the result of capitalism and the past political system (Sing Lee 1999: 359-360). Treatments included thought reform and physical labor. In such a climate, it is easy enough to understand why French child psychiatrist Georges Heuyer, who visited China during the 1960s, was told that there had been no cases of autism in China since Mao came to power (Feinstein 2011: 234). Following Ian Hacking, it might be argued that there were no autistic persons to be found in China because the category itself did not exist in China.

China's reversal of state policy after 1978 and its impact on autism

Political and social changes during the 1970s made it possible for autism to emerge as an epistemic object in selected parts of China. The self-evident failure of socialist economic and political reforms became easier to acknowledge after Mao Zedong's death in 1976 and after Deng Xiaoping managed to dislodge the Gang of Four, composed of Jiang Qing

(Mao's wife) and other top ranking Communist Party officials (MacFarquhar 1997). Deng Xiaoping, now the premier of China, was able to implement economic, social, and educational reforms beginning in 1978. Such reforms spurred the development of academic psychiatry, provided unparalleled opportunities for the elite students sent abroad by the Chinese government, reduced family sizes through the one-child-with-exceptions policy, and forced individuals and families to move toward "self-reliance" because of the state's withdrawal of support for social and healthcare services.

Chinese academic psychiatry began to develop, especially in urban areas (though much less in rural areas) because of China's open-door policy and American psychiatry's move toward a standardized diagnostic system in the form of the DSM-3. For the past thirty years, psychiatry had been wielded as a political tool of repression by the Communist Party against dissidents and intellectuals (see Munro 2002); psychiatric units had been forced to shut down (Pearson 1995) and had been required to use thought-reform in approaching mental illnesses (Ho 1974; Yan 2010). After the opening of China during the late 1970s, academic psychiatry in areas such as Beijing and other places where it had already established a presence was eager to make up for lost ground (Kleinman and Mechanic 1980). The open-door policy spurred psychiatrists to catch up as quickly as possible.

Internationally, American psychiatrists were concerned with making psychiatry more of a science by establishing the reliability of psychiatric diagnoses. They published the DSM-3 as an attempt to standardize diagnoses across different psychiatric categories (Kirk and Kutchins 1992; Wilson 1993). With the publication of the DSM-3, American psychiatry turned away from the psychoanalytical approach which dominated from the

1960s to the 1970s and gained greater respectability as a medical science (Kirk and Kutchin 1992). Such shifts within American psychiatry suited Chinese psychiatry well. Prominent psychiatrist Sing Lee argues that “the scientism [within the DSM-3] readily harmonized with the epochal discourse of post-Mao China, according to which science and technology should overcome the nation’s backwardness and alienation” (1999: 354). These two changes were to make possible autism’s travel to China.

The open-door policy also enabled highly educated Chinese citizens to become active players in driving reforms related to learning disabilities, as I will show later. In 1978 the Chinese government began sending elite students abroad. Between 1978 and 1979 alone the Chinese government sent at least 3000 students, or *liuxuesheng*, to countries such as the United States, Canada, Germany, Great Britain and others (Zweig 2002). The students who were sent abroad during the 1970s and 1980s were to take the lead in China’s higher education. One of them, as I will discuss later, set up an autism rehabilitation center, which would also serve as China’s first non-governmental organization.

The one-child policy and what political scientist Jane Duckett terms as the “Chinese state’s retreat from health” (2011) restructured families in ways that rendered closer attention to a child’s developmental milestones. Believing that China’s rapid population growth would prove a threat to national security and the country’s dreams of modernization (Greenhalgh 2005), Chinese state leaders implemented the one-child policy, which would restrict urban families to one child, and rural families, if their first child was a girl, to two children. This draconian policy was enforced unevenly, but often harshly. The net effect of this policy was to focus parental gaze ever more closely on

their child's developmental milestones since the family's "only hope" for the future of the family was to depend heavily on that urban singleton, or urban two children (Fong 2004). The state's dismantling of healthcare and other social policies (Huang 2012), made families more responsible than ever for their family members' wellbeing. These diverse factors helped make it possible for autism to be diagnosed beginning in the 1980s.

Autism's Travel into Nanjing and Beijing

Ever since Deng Xiaoping instituted the new policy of "reform and opening up" (*gaige kaifang*) in 1978, a psychiatrist in Nanjing and a psychiatrist in Beijing both began diagnosing cases of infantile autism in China (Sun et al 2012; Feinstein 2010; McCabe 2003). During the period of time before the communists took control of China, Dr. Tao Kuo-tai had been sponsored by the World Health Organization in 1948 to spend a year at the Institute of Psychiatry at the University of California, and he had returned to China a year later in 1949 (Sun et al 2012). While it is unclear what directions Dr Tao's career took between his return in 1949 until the opening of China in 1978, what is definitively known is that Dr. Tao was instrumental in setting up the Nanjing Child Mental Health Research Center in June 1984, and was the first to offer a formal diagnosis with his report of four cases of autism in mainland China in the *Journal of Chinese Neuropsychiatry* in 1982. After "collect[ing] another 11 cases" (see Sun et al 2013; Tao 1982), Dr. Tao published a paper (in English) in *The Journal of Autism and Developmental Disorders* in 1987. In his reports, Tao draws correlations between a family's social class and a diagnosis of autism for the children within that family applies to China as well (Tao

1987: 290), while asserting that Chinese psychiatrists and pediatricians have misdiagnosed autism as mental retardation, infantile dementia, and childhood schizophrenia (see Tao 1987: 290-295). Tao refutes the assertion oft-told by other Chinese psychiatrists to Western psychiatrists that “China has no infantile autism” (Tao 1987: 290), with his own case studies and by reporting that upper-class families in Hong Kong had children diagnosed with autism. Tao claimed that a significant number of mothers of autistic children in mainland China had “a college and above education” (Tao 1987: 290).

While Nanjing may have first taken the lead where autism diagnoses are concerned, Beijing quickly gained ascendancy in leading psychiatric reform in China. Because of their location in the capital, hospitals in Beijing were expected to take the lead in medical and psychiatric reform. In 1980 the Institute of Mental Health of Beijing Medical College was set up under the directorship of Professor Shen Yucun, who served from 1980 to 1997 and who had survived attacks by the Red Guards during the Cultural Revolution (see Munro 2002: 76). That institute was designated as the World Health Organization/Beijing Mental Health Collaborating Center for Research and Training, and was subsequently renamed as Institute for Mental Health in 1982¹. Through such global collaborations, Beijing became the model for the rest of the country where medicine and psychiatry are concerned.

Thus, Beijing’s Dr. Yang Xiaoling and her students became well known as autism experts during the 1980s. Interviews with senior psychiatrists such as Dr. Jia Meixiang and parents of adult aged children with autism in Beijing, as well as searches into Beijing

¹ see Wacp Newsletter January 2006 – Vol. 2, N. 1: 23-25

Association for Rehabilitation of Autistic Children (BARAC)'s loose and incomplete archives of its own newsletters and yearly reports (which are to be distributed among the members of BARAC) reveal that there was another psychiatrist in Beijing known for providing an autism diagnosis during the 1980s: then-president and one of the early founders of BARAC, Beijing psychiatrist Dr. Yang Xiaoling. ²Dr. Yang had published a follow-up article in 1990, reporting on another 30 cases of children who met the criteria for autism (see Volkmar et al 2007:1203).

BARAC's headquarters are in a small, dusty, and run-down storeroom at the back of Peking University's Sixth Hospital. It is manned by an unpaid volunteer, Teacher Li (the "Teacher" being a term of respect for his age and efforts), during clinic hours, and he not only holds the keys to the cupboards which store old publications by BARAC, but carefully guards the few reports they have (most are missing). The earliest yearly report they have in their own collection is from 2003, even though the cover states clearly that this is the fifth year they have been publishing quarterly reports. Nonetheless, BARAC remains an important source in piecing together the history of autism's travel across China. These quarterly reports not only list Dr. Yang Xiaoling's name as founding president and chief psychiatrist, while recounting her efforts to offer rehabilitation for their patients but also comprise of articles on autism by Beijing psychiatrists. Other articles are penned by parents, who write gratefully of the efforts put in by the Beijing child psychiatrists in offering a diagnosis and in teaching them how to use behavioral analysis in relation to their children (see 2006's yearly reports for instance which had a parent writing a note of gratitude because Dr. Gao, then a young doctor, had gone to

² (see <http://www.autism.com.cn/tag/9>).

considerable personal expense to give her extra coaching on how to use ABA in her interaction with her children, and had, as a result, gotten caught in the rain and injured himself).

Designated as one of the partners of World Health Organization for China, Beijing not only became the *de facto* location for diagnosis of autism, but for autism therapy, because of Sunflower Autism Center (which was set up by a parent), and to a smaller degree, BARAC. Sunflower Autism Center is widely recognized as the first autism rehabilitation center in China. BARAC disputes such a claim, because Dr. Yang Xiaoling's former trainees felt that the founder of Sunflower Autism Center, Zheng, had not given enough official recognition to Dr. Yang and other doctors for introducing Zheng to other parents with autistic children, and believe that BARAC rightfully came first, but most academic accounts consider Sunflower as the first center (see McCabe 2003; Sun et al 2012).

Descended from a line of intellectuals, Zheng was one of the few students earmarked to be a leader in 'Chongqing's Technical Institute'³. Zheng, as she herself would say in her interviews and lectures to parents, led a privileged life for the first two decades of her life: she came from a happy and well-to-do family and married an ambitious classmate. During the 1980s the central government began sending the best and the brightest students abroad. These students were few and far between, numbering 3000 per year (Zweig and Rosen 2003), a small figure in light of China's population which grew from 0.962 billion to 1.12 billion between 1978 to 1988. These students were sent in the hopes that they would return to modernize Chinese universities, research centers,

³ (<http://gongyi.qq.com/a/20130122/000003.htm>; ??Zhang 2013)

and hospitals and the like. Zheng had given birth to a young boy shortly before she was selected for the study abroad program. She was informed that she was provided a scholarship to study in Germany for two years, and she had to decide whether to go immediately—if she turned it down, the scholarship would be given to someone else. Her five-month-old son was hurriedly entrusted to his maternal grandmother, while Zheng went to Germany to study for two years, from 1986 to 1988. Weekly letters she exchanged with her parents did not suggest there was anything for her to worry about: her parents spoke of Taotao as growing well and the pictures they showed a beautiful toddler (from interviews in April 2013 and newspaper accounts). She believed that she could make up for her two-year absence once she returned from Germany.

It was not until she went back to her parents' home after completing her advanced training in Germany that she finally saw her then two-year-old son again. She was struck by her son's lack of affective responses to her, his refusal to be carried by her, and that he felt "moshen" (or distant and strange to her). But everyone around her dismissed her concern, saying that "boys learn to speak later, geniuses speak late"⁴

Over the next year or so she confronted the difficult reality that her son was markedly different from other children. After her husband left for his own studies in Germany and increasingly distanced himself from her and their son, Zheng discovered that her son seemed only capable of repeating her questions (a characteristic that would now be recognized as *echolalia*). For instance, he would say "happy or not happy" in response to her questions "were [you] happy or not happy at the kindergarten?" or "eat"? in response to her query "what did you eat in kindergarten?" (see Liu 2010). Zheng:

⁴ (translated and referenced from Liu 2010 http://paper.people.com.cn/jksb/html/2010-07/15/content_573292.htm).

discovered that her son never seemed to display interest in other people's activities, nor did he initiate conversations with others, while his speech was restricted to repeating parts of other people's questions to him.

By then, she was desperate. She knew that Chongqing did not have the trained doctors she needed and she was not willing to delay any further. She made her own inquiries and headed to the Institute of Mental Health in Beijing for a diagnosis in 1989 (see Peng 2009). There, she was to receive a diagnosis for her son of autism, and the bleak prognosis that there was nothing to be done except apply for an exception to the one-child policy and to try for a second child, especially since she was a government employee and would be subject to the one-child policy. A year later, her husband decided to divorce her, as he did not want to be responsible for Taotao. This time was the darkest time for her. In despair, she crushed a lethal amount of sleeping pills in the porridge that she had cooked for her son and herself, but at the last minute, was not able to go through with her plan.

Zheng travelled back to Beijing in hopes of connecting with other parents with autistic children. At Peking University's Sixth Hospital (psychiatry), Zheng met fourteen other parents, came across a photocopy of an instruction manual called "Behavioral Training for Autistic children" (*zibizheng ertong de xingwei xunlian*) at the hospital, and decided to start a school for autistic children. In the beginning of 1993 she quit her very secure employment as a lecturer, and moved alone with her son to Beijing. She then founded Sunflower Autism Center.

The school's first few years were not promising. Zheng, with the help of other parents only managed to recruit six students. Within a month, she had to move to a

location within a school for the deaf, which they were asked to leave when the neighbors claimed that they were afraid of these children. Zheng had only two parent volunteers and they hired pre-school teachers. They moved from one location to another (wherever they were able to rent places at a low enough cost), before finally purchasing a house in a village in Tongzhou, a village within Chaoyang District, with the help of donations from the German Embassy and other donors (see Stars and Rain). Zheng was funded to travel to Eden Services in New Jersey in 1997 and was able to teach the special teachers she employed how to use ABA (Applied Behavioral Analysis). Here it is worth noting that the school she set up has been pivotal in making Zheng a powerful spokesperson for parents of autistic children and in shaping expectations around the parenting of autistic children.

With the development of this school (even as autism rehabilitation groups or centers remain steadfastly absent in the rest of China, including Nanjing, until the end of the 20th century), Beijing became a place where families went in search of a diagnosis and therapy. It also became a place to learn new parenting styles. Over the next few decades, the school Zheng set up directly and indirectly, influenced other wealthy or educated parents to set up other schools, as has been acknowledged by other key figures in autism advocacy within China. During a closed-door meeting in April 2013, for instance, key autism advocates such as Shen Jin (founder of a school in Qingdao which is widely recognized as one of the best possible autism rehabilitation centers in China), Liu Li (chairperson for autistic persons' rights in Beijing's China Disabled Persons Federation) publicly acknowledged Zheng's role in galvanizing attention and efforts toward the needs of autistic persons. Years ago, Shen had brought her son to Zheng's

school. With Zheng's encouragement, Shen set up her own school in Qingdao, and her school is now the other highly popular school, with waiting lists over a year long for autism rehabilitation. I was allowed to attend this meeting because I had served as a translator for Zheng's school.

It is worth noting that Shen's school is located in Qingdao, a port city which was once under German colonial rule, but was designated a "coastal open city" (*yanhai kangfai chengshi*), along with 13 other coastal cities. Such a status offered various economic and political privileges that served to attract foreign investment. The investment had the result not only of increasing the coffers of the local government, but also the quality of healthcare and other public services in these provinces (Blumenthal and Hsiao 2005; Sheng 2010: 61; Schiere 2009; Wei and Fan 2000). From the 1990s to the first two decades of the 21st century, Guangzhou has gained ascendancy regarding autism. Other urban provinces are beginning to have more doctors trained to diagnose autism, even as autism remains an unheard-of diagnostic category in many rural and less prosperous urban areas. Many parents continue to travel to Beijing either for an initial diagnosis, or for a confirmatory diagnosis.

Other provinces besides Beijing, however, have also begun providing more extensive services. Guangdong Province is one of them. Earmarked for economic development, Guangdong is one of the first places where Western biomedicine and psychiatry put down roots. Unsurprisingly, mental health and child psychiatry services were poised to grow more rapidly in Guangzhou than other areas, and Sun Yatsen University set up its child development unit in the mid 1990s, a fact I had discovered through interviews with the child psychiatrists and child psychologists there, and by

talking to parents who have compared and contrasted the different services offered across various provinces. While there are numerous well-regarded autism rehabilitation centers in Beijing and increasingly, in other metropolises such as Shanghai, there is at present, only one public full-time special school that is run for autistic children under the age of 14 in the whole of China and it is located in Guangzhou (Guangzhou News Center 2010). Rather than the model of short-term intensive rehabilitation, this school takes the place of other forms of compulsory education, which means that autistic children under the age of 14 will enter a different grade, along with their classmates, every academic year. Set up in 2008, at the time of writing the school is able to take in 300 pupils.

Urban centers such as Beijing or Guangzhou, drawing upon longstanding linkages with overseas partners or the foundations laid during the 19th century were able to quickly bring their medical professionals up to speed. In that sense, the economic and social reforms from the late 1970s to the 1980s vastly improved the quality of urban mental health care in coastal and eastern provinces, as well as Beijing, since it was the capital of China. In Shanghai, Guangzhou, Shenzhen, and other cities campaigns for autism awareness are now frequent and highly visible.

At the same time, this awareness has been achieved through the efforts of elite parents, such as Zheng, who has been lauded as an “extremely strong and courageous” mother by various news sources (Su Jiaqiu 2015), and has been featured in talk shows and interviews repeatedly. While her perseverance and resourcefulness in cobbling together resources for her son are indeed impressive, framing her difficulties and triumphs as simply reflective of her individual strength of character is far too simplistic. Zheng was a member of a highly elite group of students who were provided a quality of

education that many other families in China could never imagine possible. A close examination of all the key pioneers in driving autism advocacy, all mothers whose children are in their twenties, reveal that these mothers are indeed strong and resilient, but they also had significant economic and social advantages that helped them know what questions to ask, which doctors to trust or mistrust, and how to gather the information they need; Shen for example, was married to a lecturer in a university. Other families in China have struggled for years to obtain a diagnosis.

Though few social science scholars pay extended attention to the intersections between class and autism, the links are certainly there. Asperger was to notice that the majority of his young patients' parents came from scientific and technical backgrounds. Kanner speculated that over-educated parents' emotional coldness nurtured autism in children. Ian Hacking argued that that the rise of American psychologist, pediatrician and Yale professor Arnold Gesell ensured that middle-class families would expect their children to develop on a schedule, and the parents would therefore be prompted to visit Kanner's clinic, the very first child psychiatry clinic in the United States (2006). Even the depiction by Chloe Silverman of the emergence of parents as "expert amateurs", I suggest, is notably a middle-class phenomenon, staffed by parents who are teachers, engineers and the like. Roy Grinker has debunked the theory that well-educated parents' coldness is responsible for their children's autistic behaviors: he suggests this idea might exemplify a referral bias, where parents with higher socioeconomic status are more likely to utilize medical intervention (Grinker 2008: 73).

As an epistemic object, it is evident that autism has been produced by the confluence of factors such as the rise of the urban singleton (Fong 2004) and the open

door policy which also helped legitimize psychiatry as a medical and scientific discipline. The diagnosis of autism in Nanjing and Beijing in the early 1980s, however, did not trigger a rapid spread of autism as a diagnostic category across the country. Outside of these economic powerhouses, autism remains unheard of in some urban areas, and for most of rural China. Many doctors in much of rural China and many parts of urban China are not trained to diagnose autism. Rural families have to travel into specific provinces in order to get a much-needed diagnosis to explain their child's symptoms, and it is to the other structures of inequality I now turn.

Structures of Inequality in China

China has consistently been marked by inequality and the widening inequality post-1978 has influenced the making of autism as an epistemic object. In thinking about the relevance of social divisions, China's complex and tumultuous political history render class, or *jieji*, a less useful term, because the term is strongly imbued with notions of class warfare and antagonism in China since 1949 when Mao's Chinese Communist Party took over the reins in governing China. Other terms that have emerged as a substitute such as social strata or *shehui jiecheng* (Anagnost 2008: 298) remain unsatisfying, because these terms are ill-defined and use crude measures such as income to determine class while failing to take into account the great disparity in income and living costs between highly developed cities and other less developed cities (see Fewsmith 2007: 2; Zhang 2010: 6). For all these reasons, I show how social stratification plays out along three axes: the household registration system, urban/rural differences as it pertains to access to healthcare and social services, and being from a less economically advanced city,

province or region to create what I call graduated citizens. For some scholars, post-socialist Chinese governmentality, or how state and non-state actors encourage Chinese subjects to act in ways to achieve optimal outcomes for themselves as individuals, is characterized by a shift from “‘relying on the state’ (*kao guojia*) to ‘relying on yourself’ (*kao ziji*),” where subjects are left “free to govern on their own behalf” (Zhang and Ong 2008: 3). For others, post-socialist governance tightly maintains gradations of citizens through the *hukou* (household) registration system (see Solinger 1999).

In this section, I will explore how the Chinese Communist Party’s successful take-over of China from the then ruling Kuomintang Party in 1949 was to formalize a strict hierarchy between urban and rural residents for three decades. I argue that the structural marginality some families experience is created by three interlocking factors — one’s household registration, rural versus urban, and the central government’s preferential policies towards coastal areas. I will discuss how each of these factors, ranging from the policy of selective social and economic growth for some cities, provinces and regions over others, the deliberate cultivation of a modernized biomedical healthcare system in many urban centers along with the collapse of rural healthcare and the central government’s devolution of responsibility of social services and economic growth to local authorities are all integral to determining the travel of autism as a diagnostic category across China.

Then I explore how various post-1978 policy reforms, such as the as interlocking factors, work in concert to make the diagnostic category of autism in China during the last two decades of the 20th century a particularly elite and limited category. I draw upon Pierre Bourdieu’s multifaceted treatment of class distinctions where he distinguished

between the control over economic resources, social capital or resources based on group memberships and networks of influences as well as cultural capital which refers to education and other forms of knowledge which will generate status (Bourdieu 1986).

I. Household Registration System

Disparities certainly existed between urban and rural areas in imperial China. Legal scholar Derk Bodde, for instance, argues that Confucianism has enabled imperial law to “legalize inequality” (1973: 437). Yet for centuries, internal migration was the route undertaken to escape famines, or poverty in rural areas. This changed radically by the middle of the 20th century. After the Qing dynasty collapsed in 1912, the Kuomintang Party was to govern China, tenuously, while engaging in civil war with the Chinese Community Party. When the Chinese Communist Party took over in 1949, The Communist takeover of China in 1949 was in fact to put in place formal structures of inequality between urban and rural areas. The Chinese Communist Party instituted a tight control over the movement of peoples through the household registration system otherwise known as *hukou* system (see Chan and Zhang 1999; Cheng and Selden 1994; Solinger 1999; Zhang 2001a, 2001b, 2001c). Instituted in 1958 during the Great Leap Forward (a disastrous economic and social campaign that sought to move the country beyond an agrarian economy into an industrialized and collectivized society and which led to the Great Chinese Famine 1959 -1961), the *hukou* system originally divided citizens into two categories: rural or urban. Intended originally to weaken the Kuomintang’s power bases in the cities, the *hukou* policies also served to show preferential treatment toward the cities, in part because Mao wanted to promote

industrialization. Those fortunate enough to be registered with household papers in these places were the main beneficiaries. In order to power industrial production within the cities, rural areas were to serve as low-cost agricultural producing centers; citizens of these areas became effectively second-class citizens. This preferential treatment toward the city created a stratified citizenry—urban residents with *hukou* papers were guaranteed jobs, assisted public housing near their workplace, the right to education in the urban area to which they are registered, rationed allotment of goods, as well as benefits which have been termed the “urban public goods regime” (Whyte 2010: 11). It was likely during this time that the saying “iron rice bowl” (*tie fan wan*), which refers to job security and the importance of rice consumption to people living in China was popularized during this time as it privileged the urban *hukou* owners (by protecting their grain supplies).

In contrast, the bulk of citizenry who lived in rural areas did not have these social benefits except for the very basic healthcare provided by the Commune-based Cooperative Medical Scheme and low quality education. Instead, they had to meet grain procurement targets, and supply grain at artificially lowered prices. They might have an “iron rice bowl” where job security is concerned, but the food that was placed in these bowls during these three decades would likely be sweet potato and watery rice gruel that barely fed them (Watson 2010: 39; see also Siu 1989: 184). Rural communities were forced into deep poverty created by Maoist policies (the most notable example being the Great Leap Forward from 1958-1961, which brought about cataclysmic famine in many rural areas). Rumors of child cannibalism during those years continue to swirl today, as I have been informed by psychiatrists I met during my research who grew up in these rural areas themselves). Rural people had no way of escape: it was impossible to engage in

outmigration since there were no private markets for housing, nor access to schools or any of the other public amenities necessary for survival; rural citizens were essentially forced to stay in the places they were born and registered in.

The Reform Era brought about a loosening of restrictions around the movement of peoples from rural to urban areas, but continued to divide Chinese citizens into what Martin Whyte terms the two caste system, with “sharply different rights and opportunities in life” (2010: 13). The reforms allowed for greater mobility between rural and urban areas, but forced rural citizens to live under the restrictions that come with their *hukou*. That is to say that rural citizens and their children who moved to urban areas did not gain access to the social, educational, and healthcare services in these urban areas. Because most of them had limited access to education and other employment opportunities, these once-rural citizens would now take on work that was “dirty, difficult, and dangerous” in urban areas (Whyte 2010: 14). Moving one’s *hukou* status to an urban area was all but impossible except for those who somehow gained admittance to the most prestigious universities such as Tsinghua or Beijing or those who managed to land highly coveted jobs in highly ranked companies, and were able to use these statuses to transfer their *hukou* to a specific urban area. Even children of rural migrants who may have spent their entire lives in urban areas are subject to the same *hukou* restrictions---they can only attend schools in the provinces where their family’s household registrations give them access. Rural citizens had to make a difficult choice between staying in a rural area where jobs may not be plentiful and their children would have the rights only to poor quality education and other social services or moving to an urban area where they might not be allowed to access the social services available to all those with *hukou* to that particular

urban area. In spite of these restrictions, many rural migrants have continued to make the journey to urban areas, because of how poorly compensated they are in rural areas. The *hukou* system thus serves to restrict the life chances of many citizens, depending on where their *hukou* is registered.

Geographer Kam Wing Chan and his colleague Will Buckingham note that the reforms to the *hukou* system served only to devolve administrative power to local governments, while maintaining the rural-urban divide because these reforms made it harder for rural *hukou* holders to move out of their rural provinces. Political scientist Wang Fei Ling argues that the *hukou* policy serves the interests of elites, by ensuring that institutional inequality will always allow elites to amass more economic, cultural and social capital (2005). Yet, other scholars such as Zeuthen Jesper and Michael Griffiths (2011) make the argument that the *hukou* policy does not create such a large rural-urban divide in contemporary China, but instead institutionalizes larger inequalities between different localities and different tiers of *hukou* offered by the same city or province, since some categories of *hukou* are more desirable and offer greater privileges than other categories even within the same province. Even the more recent *hukou* reforms announced in 2014-2015, groundbreaking as they may sound, are not intended to abolish a system that institutionalizes inequality. These reforms fail to systematically overhaul the system since they only allow a small percentage of rural *hukou* holders to move to smaller and less desirable cities, while not providing social and educational rights and services for the existing migrant labor who have settled into cities. Even if they disagree about the nature of social stratification, all of these scholars recognize the deep embedding of social inequality through the *hukou* system. Along with the well-known

disparity of economic growth and provision of medical services between different provinces, these forms of institutionalized social inequality thus ensure that many families will experience developmental disorders such as autism as a disabling condition, because of the complex intersection between *hukou* status, the widening disparities between provinces, the family's social, economic, and educational capital. Pre-existing stratification of rights means that all citizens, regardless of disability, already do not enjoy equal rights.

II. Healthcare Provision and Reforms in Urban/Rural Areas

Right from the outset in 1949, healthcare provision, access and quality was better in urban, rather than rural areas, even if access was uneven, since the Ministry of Health had inherited a healthcare system that favored urban residents. There were 4.6 hospital beds and 2.7 doctors per thousand for urban residents, as compared to 1.2 hospital beds and 0.7 doctors per thousand for rural residents (Ministry of Health 2000); urban areas had 74.8 percent of hospital beds and 62 percent of senior physicians (Huang 2013: 24), while urban per capita healthcare expenditure was three times as much as rural per capita healthcare spending (Liu et al 1995). Military, state, and public institutions offered access to healthcare for their employees. Healthcare was also largely funded by the Ministry of Health and insurance systems paid by the workplace (*danwei*), while rural citizens paid a small fraction out of pocket (Duckett 2011: 31; Nehru et al 1997). Political elites in urban areas had easy access to top tier drugs, or reimbursement for their medical bills because they had final say over the hiring of “barefoot doctors”, or doctors with very rudimentary healthcare training (Zhang Zikuan 1993: 16).

Rural healthcare lagged behind urban healthcare from 1949 to 1978, but were to exacerbate post-1978, though the recent healthcare reforms during the early 2000s have given rise to strikingly different interpretations of China's healthcare provision, as discussed in the introduction. From 1949 to the mid 1980s, though the quality of rural healthcare was poor and the state's coffers were low, the state did provide some level of low-cost healthcare access. During the three decades immediately after 1948, the Chinese Communist Party initiated a rural healthcare system called the Commune-based Cooperative Medical Scheme (CCMS) that covered the medical expenses of everyone living in these rural communes. The CCMS ensured that medical fees were within the reach of rural citizens. While socialist healthcare paid little attention to mental health, as I laid out earlier in the section of socialist psychiatry, socialist healthcare was forced to pay some attention to rural preventive healthcare, because of Mao's insistence. Mao Zedong had in fact criticized the Ministry of Health for its urban elite bias. Mao had argued:

tell the people in the Ministry of public health [sic] . . . They are providing healthcare to only 15 percent of the people of this nation. Of these 15 percent, it's those lords in the national and local governments who receive the best care. The ministry thinks that as long as those lords are happy, its work is being done well. But the vast percentage of people in the countryside has no healthcare at all . . . The ministry pays attention only to city residents, to those masters [sic]. Let's give it a new name—the Ministry of Urban Health, the Ministry for the Health of the Lords (Li Zhisui 1994: 419-20).

With sustained political will, China came to offer a much better quality and availability of healthcare both to rural and urban areas than other countries with similar economic statuses (Whyte and Parish 1984), thus seeing dramatic declines in mortality rates and improvements in life expectancy (see Huang 2013: 51)

Rural healthcare was offered through a three-tiered system: a county general

hospital, maternal and child health (MCH) hospital and anti-epidemic clinic (Duckett 2011: 27). The county general hospital was intended to be a referral hospital for the entire county, staffed by high school graduates with four to five years of training, the MCH managed disease control and preventive care, while anti-epidemic clinics would be staffed by a doctor with three year of medical supervision. The majority of villages--85 percent--had health stations managed by barefoot doctors, or farmers with basic hygiene training (see Bloom and Gu 1997). Prior to the reform, the Ministry of Health had a three-tiered system that was funded jointly by the CCMS and the central government. The first tier was staffed by barefoot doctors, or high school graduates who were mostly trained in TCM and very basic medical training, followed by the second tier of assistant doctors (whose training was at a very limited level). Then, patients would be referred to the third tier where they might be able to access doctors with more than five years' training, and the third tier was financed by the central government. This system kept costs low both for the central government and patients alike, even if it had shortcomings as the system provided very rudimentary healthcare systems that did not usually include mental healthcare for persons in rural areas. Some results were clear: for example, schistosomiasis (snail fever), which plagued rural areas, was eradicated.

After the inauguration of the economic reforms, districts and municipal hospitals in designated centers modernized rapidly, leaving the rest lagging behind. Structural inequalities in the area of healthcare dramatically increased between different urban centers as well as between urban and rural areas after 1978, after the state abandoned its responsibility for healthcare provision. The first reason is that some of these centers already housed the few psychiatric hospitals begun by imperial powers prior to the

takeover by the Communist Party. Though psychiatry was controlled as a handmaiden of political control (since mental illness was supposed to be the outcome of incorrect ideological beliefs and thoughts), some of the mental hospitals had survived during those difficult years between 1949 and 1978. Rather than building from nothing, these selected urban centers could build and improve upon existing infrastructure. The second reason is that many urban centers, especially if they are designated Special Economic Zones such as Shenzhen, or coastal cities such as Shanghai, or important provinces such as Beijing received much needed funding and support as they were charged with the mandate of serving as healthcare models for the rest of China. Mental health services begin to grow exponentially in these areas that were supposed to model good quality care for the rest of China. Urban residents of centers that are designated as coastal areas, or special economic ones with special economic rights, then, benefited from access to rapidly improving education and healthcare and mental health services. Urban residents of urban centers that have been less favored were provided less adequate mental and physical healthcare.

Healthcare provision and funding, however, significantly declined after 1978, a state of affairs which Huang Yanzhong attributes to “buck-passing” (2013: 8), or the bureaucratic behavior where no one is responsible for either implementing a policy or for holding anyone accountable. Jane Duckett attributes this pattern to the state’s “retreat” or retrenchment from health. The 1978 reforms decimated the healthcare that rural residents had access to during the previous thirty years (Dunford and Li 2010), while ensuring that all citizens would now bear the risks of ill health. During the devolution of power from central to local forms of government, the government placed price controls on essential

and basic level of services, but forced local health systems to make up their shortfalls by either increasing local taxation, or to price their own non-essential health services (see Ge and Wang 2005; Duckett 2013: 52). All hospitals had to suddenly operate as commercial enterprises in making up their own income streams, subject to the very low levels of prices that can be charged for basic services. These hospitals were thus serving low-income families while bereft of funding from the central government or even from the local government, since local governments were more focused on promoting economic growth than ensuring healthcare provision (Edin 2003). Since provinces with vast agricultural areas tended to be landlocked (example Anhui), and would have been passed over by imperial powers during the 19th century, provincial coffers were also low. In insisting that individual provinces bear the responsibility for funding the modernization of social services and healthcare and that individuals are responsible for paying for healthcare, these reforms fundamentally left rural citizens with little or no access to healthcare. CCMS also collapsed, because it also lacked strong institutional and bureaucratic backing when Mao died, and in part because poorer villages were unable to financially support the costs of healthcare. The CCMS fees were initially collected from the village funds, rather than via household subscriptions (see Han and Luo 2007). Now that farmers earned their own incomes directly, the CCMS was unable to collect funds, and doctors begin charging patients directly (see Xu and Chen 1981; Duckett 2011: 63). Healthcare systems in provinces that were not designated as special economic zones or coastal areas lagged behind.

III. The Selective Economic Liberalization of Eastern and Coastal Areas

The open door policy was to accomplish two changes: first, it liberalized trade, and loosened up restrictions for citizens in selected provinces, while it also deepening macro-territorial inequalities. Deng Xiaoping promoted economic growth in eastern and coastal areas of China by explicitly claiming that wealth is glorious and exhorting selected provinces and individuals to “get rich first,” letting other provinces and individuals catch up later (Naughton 1993:501). Within the policy of selective devolution of political and economic power, some cities that were designated as Special Economic Zones (such as Shenzhen) and 14 coastal cities (including Guangzhou and Shanghai) were subject to different sets of political and economic rules (Gupta 1996). Many of these eastern and coastal areas are, not by coincidence, Treaty Ports that already had significant foreign investment and presence at the turn of the 20th century (Cheung *et al* 1998). The coastal development strategy, whose official name was the Outward Orientation Development strategy, was broadened to include provinces of special interest to the central government; these include Beijing, Shandong, Guangdong, and Shanghai. Within these provinces, foreign investors were given more flexibility and tax breaks to invest in areas such as Special Economic Zones (SEZ). Since many of the provinces already enjoyed much better quality of infrastructure because of contact with Western powers, for instance, infrastructure in the forms of banks, Western-style streets, and streetcars were introduced by the French to Shanghai (see Leo 1999), these coastal and eastern provinces already had a much earlier head start. The new policies designed to encourage dramatic economic gains in southeastern coastal areas as opposed to the west, inland hinterlands, or northern areas further exacerbated macro-territorial inequalities (see Fan 2002; Yao 1999).

Conclusion

Economic and healthcare reforms made it possible for autism to spread as a diagnostic order, first by delinking psychiatry from its reputation as a handmaiden of political thought, and by developing closer links to international health bodies. Yet, these reforms also gave rise to widening social disparities between urban and residents, while instilling an assumption of self-governance, which render all families as solely responsible for their children's wellbeing. These reforms thus naturalized social disparities into the diagnosis, and social services, as well as outcomes for families caring for autistic children. The diagnostic category's travel across China not only reflects the complexity of China's social concerns, political upheavals, and economic reforms, but illustrate how epistemic objects are constituted by economic and political fractures within any country. Such a logic of self-reliance, as we shall see in the next chapter, creates diagnostic and therapeutic internal migrants out of parents. It also enables urban doctors to remain blind to why autism prevalence rates appear to be lower in rural areas, and why rural families may seem to come "too late" to obtain a diagnosis for their child. In some ways, urban families, and rural and urban doctors do not experience the vast gap in resources, and are able to write off the difficulties of other families as individual failures.

At the same time, this chapter shows the limitations of theoretical models of autism developed by studies grounded in the United States or Europe. Anthropologist Roy Grinker (2007) argues that the increase in the rates of diagnoses in the United States follows from the framing of more inclusive criteria, and sees the rise of diagnoses as arising from greater scientific literacy, more expansive services, and a public more willing to embrace and nurture disability in the United States. Sociologist Gil Eyal and

his colleagues (2010), drawing on the work of philosopher of science Ian Hacking, postulate that the de-institutionalization of mental retardation is a cause for rising diagnostic rates in the United States and Europe. They argue that mental retardation was undifferentiated prior to deinstitutionalization, and the movement of the mentally retarded from institutions to homes forced caregivers to seek greater diagnostic and educational services. Other anthropologists and sociologists consider autism of interest for what it can illustrate about the processes of knowledge making. Chloe Silverman (2011) for instance examines how parental love shapes and drives the scientific research behind autism in contemporary American society. Studying how parental organizations have partnered with scientists to create autism gene banks, raise funds for research, and augment scientific research, Silverman highlights the importance of love in driving autism research and the awareness of the diagnostic condition. Others have productively explored how autism might be translated as reactive attachment disorder in South Korea (Grinker and Cho 2013) or how Israeli mothers seek to make the personhood of autistic persons (see Shaked 2005). While these perspectives are valuable, they privilege a focus on cross-cultural differences at the expense of paying close attention to how novel diagnostic categories are imprinted by social inequalities.

The public discourse in China on what needs to be done for an autistic child generally converges on the need to obtain a diagnosis and to enroll a child in schools which favor Applied Behavioral Analysis and other variants of behavioral analysis. The little recognition of the psychiatric concept also meant that there was a persistent absence of centers and provisions for persons with autism from the late 1980s till the early 2000s. It must be remembered that the economic reforms inaugurated in 1978 after Deng

Xiaoping and his reformist colleagues took over control of the Chinese Communist Party were cautious in nature, and were intended mostly to revitalize the economy (though not to liberalize social control), especially since food production was so low by the 1970s that China was in danger of re-creating the disastrous Great Leap forward which led to millions starving to death (Brandt and Rawski 2008). With the overwhelming focus on developing the economy (and the lack of disposable income for many families) for several decades after the economic reforms inaugurated in 1978, neither the Chinese state nor the private sector paid much attention to psychiatry or children with special needs for that matter. This stands in sharp contrast to the United States and other countries such as Brazil, where the management of autism is a highly contested affair with parents and self-advocates publicly debating with medical and pedagogical professionals as to what constitutes appropriate intervention (Orsini 2009; Silverman 2012; Rios and Costa Andrade 2015).

I therefore urge epidemiologists, medical anthropologists and science, technology and society scholars to pay close attention to the historic and local roots of inequality in our accounts of the transnational travel of psychiatric categories, and in characterizing patterns of family care for autism, In paying close attention to local forms of inequality, we avoid re-creation of “immodest” typologies of societies, particularly ones as complex as China in accounts of how psychiatric categories travel, given that the very ubiquity of autism in Beijing, Guangzhou and Shenzhen exist side by side with the wide-spread lack of knowledge about autism among pediatricians and families in the rest of China.

Chapter Three

Diagnostic and Therapeutic Internal Migrants

I have been on the road for 30 months with my child, first, travelling across the country just to get a diagnosis, then going to different rehabilitation centers across the country. There are no proficient doctors or good schools for us who live in backward areas like Yunnan. I am so exhausted being constantly away from home, but I am also afraid for my son if we return. What if he regresses [since there are no schools or other social services]?

Dr. Zhu Xiaoling said this to me amid exhausted sobs as we talked in her blustery, poorly furnished rented room in the outer rings of Beijing. Suspecting her young son had a learning disability, Dr. Zhu let her promising career as a university professor grind to a halt when she decided to leave Yunnan with her young son in tow. Like many other parents living outside of China's economic powerhouses such as Beijing or Guangzhou, Dr. Zhu brought her son to various reputable hospitals in Guangzhou and Beijing in search of a doctor who could make an accurate diagnosis. After she obtained a diagnosis for her son, her travels did not end. The diagnosis led to another arduous search, this time for a high quality center that might provide necessary therapy.

Thin and gaunt Wang Lijun is a lecturer in a community college; she completed her bachelor's in accounting. Her husband is a poorly paid policeman back home in Ulan Bator. Lijun is a Han Chinese from Mongolia, and has been travelling between Mongolia and Beijing for the past two years, initially when she was seeking a diagnosis for four-year-old Xiaoniu (or little cow, a nickname based on her horoscope year). Lijun blamed herself for Xiaoniu's pre-mature delivery and autism, saying, "My pitiful child has to suffer because we are too poor. The nurse urged me to eat more, telling me I was one of the thinnest mothers around, but we had so little money. Xiaoniu was a premature

delivery and she was slow in her development for everything. Look at her, she's much smaller than her own age group. If only I was able to nourish her when I was pregnant with her." When Xiaoniui remained non-verbal at close to three years of age, Lijun and her husband began to suspect that there was more to Xiaoniui's developmental delays than her premature birth. Lijun went first to doctors in Mongolia, who could not provide a diagnosis for Xiaoniui. She decided to make her way directly to Beijing. After visiting two hospitals, Lijun brought Xiaoniui to the child psychiatry unit of the top psychiatric hospital of Beijing and discovered that Xiaoniui had autism. Devastated and frantically determined to "save" her child, Lijun then spent about six months in one of Beijing's autism rehabilitation centers (whose name is very similar to the most famous one in Beijing), before returning home to Mongolia, unsatisfied with Xiaoniui's progress. When she returned home, she began doing more research, and realized that she should have taken her daughter to the other center, but she had already spent whatever savings and loans she and her husband had taken from family members. Hearing of their plight, colleagues of Xiaoniui's father raised funds to send Xiaoniui and her mother back to Beijing for one semester at Sunflower Autism Center. Thus Lijun and Xiaoniui were to be separated from Xiaoniui's father yet again.

Chubby and weather-beaten Feng Ma is from rural Hebei. She has travelled repeatedly between Beijing and Hebei for three years because of nine-year-old Dudu. Driven to desperation by Dudu's aggressive treatment toward other boys his age in his home village and his inability to cope with loud noises, Feng Ma first travelled in search of a doctor who could diagnose autism and later in search of appropriate therapy for Dudu. The wife of a recently disabled construction worker, Feng Ma stopped schooling

after high school, and until recently, was working as a school cleaner back in Hebei. She has borrowed 20,000 RMB from family and friends over these three years. Finally, the family received a diagnosis of autism last year, and were urged to leave their name with Sunflower Autism Center, so that they can get on the waiting list. They returned a year later and Feng Ma frets every day about the tuition, fees, and their living expenses while they are in Sunflower Autism Center.

The tales I heard from Dr. Zhu Xiaoling, Wang Lijun, and Feng Ma about travelling around China in search of diagnosis and therapy for months on end became depressingly familiar to me by the time I left the field in 2014. By my estimation, there are between 8.4 and 13.7 million families who, irrespective of their socioeconomic backgrounds, might have to make the same journey.¹ Some of the reasons for the travel include the dearth of clinicians sufficiently trained to recognize autism in many provinces (Huang, Jia, and Wheeler 2013), the lack of rehabilitation centers for autism in their home region,¹ and their recognition and mistrust of the poor quality of services available

¹ I have arrived at these figures by considering the following factors. Researchers in Cambridge University and Chinese University of Hong Kong have estimated that the incidence rate of autism is at least one percent in China by drawing upon global incidence rates which hover around one to three percent (University of Cambridge 2013; CDC 2014). Two epidemiological studies, one conducted by Cambridge University and CUHK, and the other by Shanghai University in collaboration with *Autism Speaks*, are currently underway to determine this rate. Second, there are very small-scale studies conducted in Anhui, suggesting that 11.7% of the population might have autism, while another study conducted in Changzhou suggests a much lower rate of less than one percent (Clark 2005: 287; Ren and Duan 2002). 14 million persons in China then might meet the criteria for autism. Since few rural clinicians have even heard of autism, it has been argued that epidemiological rates in mainland China are lower than they should be due to the degree of under-reporting and under-diagnosis (Sun *et al* 2013). Given that 62% of people have rural household registration status (The Economist, 22 March 2014) and estimated incidence rate of one percent, it stands to reason that 8.4 million rural persons might have autism. If that is the case, then their families will have to travel with them.

to them in their home region.

Their medically and therapeutically motivated travel within the country, however, has attracted little attention in the academic literature, and by autism advocates in China. Because autism is a relatively novel diagnostic category in China and is still understudied by social scientists,ⁱⁱ it is unsurprising that most remain silent on the fact that parents are traveling around for months or years on end in search of diagnostic and therapeutic services. There are only a few references to this problem. They state that parents in China experience difficulties with “a lack of information and services,” attribute difficulties to “stigmas regarding disabilities” (McCabe 2007: 40), or they allude briefly to the disparities in healthcare provision between urban and rural areas in China (Sun *et al* 2012), but do not mention that parents are indeed moving across China for both diagnosis and therapy. For instance, special education expert Helen McCabe observes that “there are still many doctors in smaller, more remote locations who are not aware of the disability. In many cases this delays diagnosis as parents search for a doctor who can help them” (2017: 40). She argues that stigma is to blame for such a state of affairs in Hong Kong and mainland China, drawing upon the rich literature on stigma regarding mental illness and intellectual disability in China. In many ways, McCabe’s claim that stigma is to blame is well-supported (see Fong and Hung 2002; Holroyd 2003; Liu 2003: 95, Tsang, Tam, Chan, and Cheung, 2003; Yang and Pearson 2002). These studies predominantly focus on the role of “stigma” as one of cultural barriers which families face whether in dealing with autism or epilepsy or other mental illnesses or disabilities.

At the same time, much of the existing scholarship on internal migration in China focuses on issues related to flows of surplus labor, in part because of the sheer numbers

(155 million) of internal rural-to-urban migrants in search of work outside of their hometowns (see Cai et al 2011: 18). Scholars of migratory patterns in China have been concerned with characterizing and understanding the experiences of rural laborers who migrate to urban centers in search of work and have framed the migratory movement of people as one mainly motivated by employment and higher wages (Jacka 2004; Yan 2008; Zhang 2001). Others have explored how the household registration system, known as the *hukou* restricts the mobility of citizens (Zhao 2006; Wang *et al* 2010; Wong *et al* 2007). Even those scholars who choose to examine the intersection between healthcare and migration ignore concerns around the quality of healthcare and social services as an issue for low-skilled rural-to-urban migrants. They mostly study low skilled migrants working in provinces other than their hometowns to analyze the restrictive effects of the *hukou* (Zhang 2001; Hong *et al* 2006; Guang and Zheng 2005). So it is that the pull of professional and high quality healthcare as a factor in drawing people from many rural and less developed urban areas has been dismissed as unimportant, even by public health scholars (Gong *et al* 2012).

Perhaps the fact that many public health scholars concentrate on diseases with more straightforward etiologies or symptomology such as tuberculosis, rather than neurological disorders that require the skilled gaze of a clinician for a diagnosis such as autism might also lead to the systematic overlooking of migration in search of healthcare. Quality of medical advice and diagnosis is difficult to measure, so it is no wonder that many scholars focus on metrics such as expenditure or geographical distance in measuring access (see Akin *et al* 2005; Das *et al* 2008).

Even prominent parent advocates such as Mother Zheng, the prominent parent-activist whom I introduced in the last chapter, may over-simplify the nature of the problem by only highlighting the travel parents undertake for therapy, rather than focusing on diagnosis as well. About the parents who travel seeking therapy for their children, Mother Zheng hypothesizes that it is the inability of families to accept that their child will have a lifelong disability and the strength of community stigma that would lead parents to live the unstable lifestyle of an internal migrant. Every semester, Mother Zheng kicks off the semester at Sunflower Autism Center by scolding mothers in this way:

Which autism organization are you going next in your search for some miraculous intervention or medical treatment that will make your child normal? How healthy is it for you and your child?

Mother Zheng would then ask for a show of hands indicating which parents “plan to run” or be “on the run”— phrases she uses to refer to parents who leave home for years on end so as to accompany their children to rehabilitation centers across the country. In her view, parents travel across China because they do not want to deal with the humiliation and social stigma of having a child with autism. In an interview I conducted with her and in her lectures to parents, Mother Zheng criticized Chinese parents as “superstitious” (*mixing*) as they kept hoping for a miracle (*qiji*), rather than being willing to put in the effort and time to train their children at home.

It is likely that Mother Zheng focuses on what parents can do and on their own responsibility not to be “superstitious” because she wants parents to focus on what is within their control. To journalist Adam Feinstein, for instance, Mother Zheng said:

Here in China, everyone believes that, if a child is disabled, it is the child's fault, not the fault of the system or society. Our government is the luckiest government in the world. Nobody expects them to help. But it is their job to help! (quoted in Feinstein 2010: 236)

From her conversation with Feinstein, it is clear that Mother Zheng believes the care for autistic persons should rest not entirely on parents, but on the state as well. Yet, her public lectures in Chinese have lumped parents into a homogeneous group and seem based on the assumption that all parents face the same barriers and share the same beliefs or “superstitions.”

In this chapter, I explore the experiences of families who move in search of *professional (zhuanye)* medical care and therapeutic services. Based on how family caregivers characterize their own experiences by using either the terms “float” (*piao*) or “internal migrant” (*liulang*), I argue that family caregivers who travel in search of care, diagnosis, and therapy for their autistic family members should be characterized as medical or therapeutic internal migrants. Grounded on ethnographic fieldwork with 20 farmer families with autistic persons and 60 urban families caring for autistic children, and interviews with 18 rural healthcare practitioners, my 18-month fieldwork suggests the importance of disaggregating types of families who might “go on the run” (as Mother Zheng calls it) in search of diagnosis and therapy. Not all families are equally likely to “go on the run”; parents with *hukous* outside of advanced provinces such as Beijing and Guangdong Province are more likely to do so. Furthermore, this group of family caregivers who travel in search of diagnosis, therapy, and care can be divided broadly into two: rural, impoverished and barely literate families who are more likely to travel in search of diagnoses and urban and well-educated families who are more likely to travel in

search of high quality therapy.

Rethinking Care-Seeking Behaviors, Medical Tourism, and Travel

Anthropologists have long been concerned with travel in search of healthcare and have variously framed it as either medical tourism, a quest, or a pilgrimage (see Kleinman 1978; Janzen and Akinfall 1982; Inhorn 1994; Song 2010). In using these concepts to describe the phenomenon of individuals from more developed countries travelling to less developed settings to seek medical care at lower costs or with less restrictive legal regulation (Inhorn and Patrizio 2009; Scheper-Hughes, 2002; Sobo 2009; Whittaker 2008), anthropologists have paid close attention to the global inequalities which allow healthcare consumers from more developed countries to exploit services available in less developed host countries, with the corresponding reduction of services available for citizens within the host nations (Smith-Morrison and Manderson 2010). Anthropologists have also considered how pleasure is sought along with medical treatment (Weisz 2011; Ackerman 2010).

In attending to the subjective sufferings of those who travel for medical care and the frivolity implied by medical tourism, anthropologists have offered alternative terms to describe the practice. China scholar Priscilla Song offers the term “biotech pilgrims” (2010) so as to capture the element of difficulty, the faith in biotechnology in healing intractable medical problems, and the focus on the higher purpose in describing the experiences of patients who travel transnationally in search of experimental stem-cell procedures, while Beth Kangas argues for “transnational medical/therapeutic journeys” because of the ubiquity of transnational travel in search for medical/therapeutic

procedures in the lives of Yemenis across different social strata (2010). Anthropologist Marcia Inhorn, on the other hand, has offered “reproductive exiles” in capturing the involuntary nature of transnational travel in search of reproductive services abroad (2011).

While all of these terms that already have been offered are productive and helpful in framing the nature of transnational travel in search of care, they are less useful in understanding the experiences of the families I study. All of the individuals studied by Inhorn (2011), Kangas (2010) and Song (2010) travel transnationally, while the Chinese parental caregivers I study travel within the borders of their own country. The experience of engaging in travel for medical and therapeutic reasons as part of caregiving is a burdensome and painful experience and one which comes at tremendously high cost to the caregiver. While the experience of providing therapy for one’s child, as I show in Chapter Five, can be understood as personally rewarding and may transform the caregiver’s subjectivity and being in the world in positive ways, this experience of travelling with no permanent home or abode is rarely experienced positively. Many of the families have described themselves with metaphors that signify aimlessness and vulnerability: they use terms such as “float” (*piao*) to describe their actions or “internal migrants” (*liulang*) to describe themselves. To describe their endeavors in terms associated with pleasure, vacations, or religious fulfillment would be inappropriate.

Many of the families, experience exclusion from healthcare, education, and other social opportunities and services; they are denied access to the same quality of healthcare and rehabilitation options offered to other citizens because of state classificatory practices. Like the individuals whom anthropologist Susan Greenhalgh calls “unplanned”

persons (2003), these families I observed in my fieldwork are omitted in state accounting. Drawing attention to children who had to be birthed surreptitiously under the regime of the one-child policy, Greenhalgh's study illuminates the ways in which being omitted from state accounting creates persons who lack full rights to social services such as schools, healthcare, and other provisions (see also Eckholm 1999; Solinger 1999; Zhang 2001). Similarly, these diagnostic and therapeutic vagrants lack full and equal access to social services because of the household registration system, which restricts them to accessing services only in their home province, regardless of whether their home province has any doctors trained to diagnose autism, or whether their home provinces offers any high-quality autism rehabilitation centers.

I urge scholars working in public health and migration to also pay attention to the flows of people in search of diagnosis and healthcare, and to further explore what access means for subsets within a national population. As Sean *et al* (2014) point out in their examination of rural healthcare in China through the study of two diseases, namely dysentery and angina, less attention has been paid to the quality of rural healthcare in the urgent work done to broaden access through making rural healthcare more affordable. They point out that it is unlikely that village clinicians are able to serve as “effective primary first point of contact for ill patients” (Sean et al 2014: 22). Likewise, my observations of village clinicians and specialists in top hospitals reveal that that many village and urban clinicians fail to provide a diagnosis or refer family caregivers to appropriate or specific hospitals. For the vast majority of parents with household registration outside of economically advanced provinces such as Beijing, Guangdong, and Shanghai, the variability of access also means that many of these parents feel they

need to travel to these provinces in order to make rational decisions with respect to therapy for their child, even if it means they might end up living lives of precarity for the rest of their lives. This means that families from less developed areas not only struggle to cobble together care, but will risk their marriages, their economic job security, and their psychosocial health since they will be cut off from their social networks for long periods of time. Likewise, my observations of village clinicians and specialists in top hospitals reveal that that many village and urban clinicians fail to provide a diagnosis, and do not know which other hospitals to refer the family to.

Yet, as I show in this chapter, access indexes multiple issues for families: the ability to seamlessly receive a diagnosis as well as the necessary social support so that a family will be able to put in place care for their autistic members. The lack of access to a diagnosis and therapy thus create patterns of displacement for families.

I have settled on the term medical internal migrants to describe the family caregivers who move from place to place in search of doctors who have been trained appropriately to diagnose autism. I use this term internal migrants over the term “nomads,” which has been used briefly, and loosely, in the context of patient rights and responsibility to name the practice of patients doctor-hopping (Batifoulier et al 2011: Laur 2013: 121); such a term appears unduly pejorative and critical of patients.

Rural Diagnostic Internal migrants

I got to know Feng Ma, Dr. Zhu, and Wang Lijun at the Sunflower Autism Center, the center briefly introduced in chapter two as having been started by Mother Zheng as the first autism rehabilitation center in China. This school itself is housed in an old and

somewhat decrepit building located in an area of Beijing seemingly forgotten by land and state developers alike, with only one bus route serving this suburban area in a metropolis generally well served by modern subways, and multiple bus routes. This area, located at the extremes of Chaoyang District, in the southeastern regions of Beijing, where the school is located has also been nicknamed, half in jest, half earnestly, as “an autism village” by parents. The nickname came about not only because of its remote location, but also because of the relative acceptance and tolerance of what might otherwise appear bad behavior on the part of the children. Most of the residents depend on the informal economy that has developed around the sale of daily necessities and the rental of somewhat basic housing to the constant flow of new itinerant parental caregivers (as well as to the “floating population” of migrant laborers who find temporary housing while undertaking construction work in Beijing). No one stares or yells when a child is having a “melt-down,” or when a child damages an item in a shop or grabs candy or a *baozi* (bun) that has not been paid for. Shopkeepers know the embarrassed parent will soon follow up with an apology and some compensation; they see this scene with every new batch of parents and children on the three-month training course. Parents, after all, come to learn to become therapists for their children; parents, rather than their autistic children, are the students here and they are expected to learn the principles of Applied Behavioral Analysis so that they can return home to serve as their children’s therapists.

Having volunteered briefly in Sunflower Autism Center in 2009 and 2011 and having secured permission to begin my fieldwork properly there, I began my 18-month fieldwork at Sunflower in February 2013. Running up to me as I was leaving the school one day, Feng Ma introduced herself to me, with words of gratitude tumbling out rapidly

as she urged her son to greet me. Earlier, I had heard from the cleaning ladies in the center about a mother and son who were not only struggling to pay for their school fees, but who had been seen shivering in their threadbare winter jackets. Their winter jackets provided few defenses against the unusually harsh winds in the Beijing winter of 2013. I had given money to one of the cleaning ladies, asking her to purchase warm jackets for the mother-son pair. The cleaning lady had done so, but went against my wishes by telling Feng Ma that I had paid for their warm winter clothing. Clothed at times in hand-me-downs seemed either too tight or too big for her, chubby Feng Ma cut an anomalous figure in her bright green jacket. Her weatherbeaten face and rough red hands spoke of physical labor. She stood out from the sea of mothers who may have been no more than five years younger than she, but whose fair and smooth skins and fashionable attire attested to their quite different social stations. Feng Ma had made her way to Beijing from neighboring Hebei. A less developed landlocked province whose labor force mostly works in iron and steel manufacturing, along with agriculture and animal husbandry (see *China Perspective*), Hebei is in fact one of the chief sources of air pollution for Northern China due to coal burning (which supplies much of the energy for iron and steel manufacture).

Over the course of the three-month long semester, I was to hear Feng Ma's story and got to know Dudu well enough that he would tightly take hold of my hands whenever we would spend time together. With alert eyes, rosy cheeks, and a bright smile, Dudu was minimally verbal. His vocabulary rarely ranged beyond "mother" (mama), or "older sister" (jiejie), which he was trained by his mother to call me as a mark of respect. Yet

Dudu was very quick and he was always the first in a group to grasp concepts taught by his mother or teacher. Even Feng Ma's homeroom teacher in Sunflower Autism Center spoke of Dudu's intelligence. Nine years old, Dudu was also older than the other children.

Feng Ma had been driven to desperation by Dudu's increasingly abrasive interactions with boys his age back home in their poor village in Hebei. She told me about the situation during our repeated encounters during school lunch breaks, or when she shyly invited me to have dinner with her parents-in-law who were also living as migrant laborers in Beijing. From an interview:

EXL: How did you find out about Dudu's condition?

Feng Ma: Dudu has always been smart. His teacher also said the same thing. Sure, he can't talk, but he's always the first one to learn things in school. But when he was about six, the teacher called me up and told me they couldn't let him stay in school. Whenever the bell buzzed to signal a new class lesson, Dudu would become very angry and violent. He would start throwing tables and chairs around. The teacher and school could not tolerate his behavior, and told me they could not keep him in school. And then there was this other incident, when Dudu got into a fight with other boys from the villages. He apparently hit another boy very hard. My neighbors witnessed the altercation, and came running to get me. The other parents of the other boy were very angry, and wanted to call the police. I got on my knees to beg them to let him off. I told them that there's something wrong with my boy and not to report to the police. The neighbors also helped by saying that my child was not normal, they told the father that this child had something wrong in his head. After showing me the bruises on the boy, the father told me angrily I should do something about Dudu, because he could kill someone one day. He didn't go to the police, but he kept saying that Dudu could injure someone one day, and I had to do something soon. I felt that he was right. I was shocked that Dudu could be so violent. Now with his father's condition, his sister and I don't have the physical strength to restrain him anymore. I knew I had to get help.

EXL: When was it that Dudu hit someone?

Feng Ma: Over three years ago.

EXL: So what did you do?

Feng Ma: I travelled with Dudu to the nearest hospital in my village in Hebei. But the doctors said that his hearing seemed fine, and that there was nothing wrong with his hearing or anything else. In fact, his previous teachers used to say he was the smartest boy in the class. We tried going to other hospitals. They all claimed that he was fine, just developmentally slow. A few months later, I tried going to several of the children's hospitals in Beijing, but test results didn't yield anything. They all said he seemed normal. We paid hundreds of dollars to do different brain tests, but his hearing tests and everything all came back normal. So we went home again. Meanwhile, my sister-in-law is a village doctor in Hebei. She also asked around with her friends and colleagues. She said I should try going to Beijing's top psychiatric hospital, and we waited outside the doors of the hospital from 5 am just to get an appointment number. Then the doctor said Dudu had autism. I still did not know what autism means, so I just went back. After Dudu's teacher said he couldn't stay in school, I came back to Beijing for another diagnosis, in the hopes of finding a doctor who could suggest something. Meanwhile, I had run into someone else who said that we had to come and talk to Sunflower Autism School as they knew what to do with autism. So I came here last year and registered on the wait list, and went back home. We got the phone call, and I felt we really had to come here. I'm so afraid Dudu will hurt someone else as he's getting so strong.

EXL: Have you ever been worried about Dudu at home before?

Feng Ma: No. Dudu gets along great with his older sister, and with us. But he did hit the other child very hard. I'm afraid he cannot control his strength. His teacher actually praised him though, for being the smartest boy. I cannot "waste" the potential of this child! I cannot give up on this child! So we ran here even though we have no money, and even though I already owe a few thousands! Even (as she started weeping) if I have to borrow tens of thousands so as to pay for these school fees, I think it's necessary!

EXL: So you came here to Sunflower Autism Center?

Feng Ma: Yes, I was so terrified when I first came, and I was crying everyday. I already owed 20,000 RMB, how can I pay off these loans? And we didn't have money to pay for the school fees at Sunflower Autism Center. How can we afford the 10,000 RMB school fees, and living expenses for Sunflower Autism Center? My sister-in-law and other relatives loaned us the money in the past. Then some teachers saw me crying, and brought me to see Huimin [the grants coordinator] who told me that she will contact organizations to help raise funds for Dudu's schooling here during these few months. They told me not to be afraid of being interviewed by the press, and just tell my story. If we do, maybe there will be goodhearted people who will want to help us!

Knowing the inadequacy of the medical and educational services in rural Hebei, as do many rural dwellers (Blumenthal and Hsiao 2005; Shi 1993), Feng Ma made the decision to travel to Beijing's top child and maternity hospitals.

The Pursuit of a Diagnosis in the Midst of Social Precarity

Deciding to travel for a diagnosis is not an easy or a one-time decision, especially for families struggling with precarity, or the condition of insecurity and dispossession.

Writing about the social precarity experienced by the urban poor in Kinshaala, anthropologist Filip De Boeck observes that social precarity “syncopates” and suspends the rhythms of life (De Boeck 2015), while anthropologists Veena Das and Shalini Randeria argue that “the poor are not passive spectators in everyday life . . . in fact, they have to struggle within the given economic and political structures to ensure that they have access to housing, water, work and medical assistance” (2015: S5).

In many ways, the life rhythms of Feng Ma's household is punctuated and ordered by complicated calculations and struggles for the present and future. Even prior to them suspecting that Dudu was not simply experiencing normal developmental delays—it was a common saying that boys, or geniuses, would speak late, as I discussed briefly in chapter two—the family unit, which consisted of Dudu's paternal grandparents, parents, sister, and himself, lived a life of deep social uncertainty. Dudu's grandmother suffered from multiple chronic illnesses ranging from heart disease, hypertension, diabetes and other forms of pulmonary diseases, and Dudu's father's salary had largely gone toward

medical bills and the financial support of his family. Nonetheless, they scraped by, and were able to send Dudu's older sister (she was older by two years) to school. Then tragedy struck. Dudu's father's legs were crushed by an on-coming truck when he was undertaking road repairs as a construction worker and he had to quit his job. The paltry compensation they received has long been spent on medical bills. Faced with mounting medical bills for the grandmother's chronic illnesses, and the need to now pay for the daily bills of the entire family, Dudu's grandfather decided to work as a construction laborer, and thus took on migrant laborer work in the sixth ring of Beijing. His grandfather's co-workers and immediate supervisor were kind. Recognizing the difficulties experienced by the family, the supervisor allocated the grandfather (and the accompanying grandmother) a spare loft on top of the construction materials to afford them some level of privacy; in normal circumstances, the grandfather would have to share sleeping quarters in a dormitory full of his co-workers. His meagre earnings went toward family support and Feng Ma's travels with Dudu in search of a doctor. As Feng Ma spent thousands of RMB only to receive no diagnosis from doctors over the past few years, her in-laws begin pleading with her to "give up" on the boy.

These thousands, however did not simply come alone from her in-laws, or Dudu's father. They also came from her own sister, and maternal family, since such loans were acts of kindness, relatedness, and love, as is common among the urban poor as reported by Clara Han (2012). Such loans, however, are also replete with what Clara Han calls "an active waiting, [or] the hope that relations could change with time" (2012: 31), and in their case, a hope that Dudu's condition might improve. By the time we met in Beijing during the winter of 2013, Feng Ma's family was already knee-deep in 20,000 RMB debt.

Feng Ma had not known for sure that the tuition fee remission and stipend would be available. As she remarked, she took a big chance in coming to Sunflower without any tuition, but this was a gamble she took because she feared this would be her only chance to rehabilitate her son. After the torturous route she took to obtain a diagnosis, she feared finding the wrong school and again and had multiple sources tell her that Sunflower Autism Center was one of the best schools in China. Thus she landed there. The first two weeks were agonizing; she avoided the grants administrator daily, knowing she did not have the money, but wanting desperately to stay. Grappling with limited finances is not a simple issue of simply living hand-to-mouth. As the work of economists Daryl Collins, Jonathan Murdoch, and their collaborators Stuart Rutherford and Orlanda Ruthven who study the “financial diaries” of the poor in Bangladesh, India, and South Africa in *Portfolios of the Poor: How the World’s Poor Live on \$2A Day* (2010), many of whom would be classified as poor today grapple with complex financial transactions, where borrowing takes place involves complex and finely-tuned transactions between the present and the future.

It was only when a senior teacher found her crying in a corner that she explained her dilemma, and the senior teacher assured her they would find funding for her. Then, it became clear to the teachers and administrators why it was that the mother-son pair would disappear every time the grants coordinator came around, or why the mother-son pair always seemed to scramble to make it in time for school, or scramble to leave once school was dismissed during the first two weeks of school. They did not rent housing near the school, opting to rent a place near Dudu’s grandfather’s workplace, where the rent was approximately 350 RMB (54 USD), even though there were low-cost rentals

near the school itself. Located at the edges of Chaoyang District, the rental housing around the village where Sunflower Autism Center was located in ranged from 850 to 3000 RMB (127 to 450 USD), since it mostly housed either villagers who lived there for many generations, migrant laborers, or parental caregivers who came to attend Sunflower Autism Center.

Yet, that three hundred and fifty RMB per month represented a princely sum for Feng Ma. Dudu's sister had to miss school the previous semester because they weren't able to pay the 200 RMB school fees (30 USD). Feng Ma also had to give up her job as a school cleaner when Dudu was expelled from school. Feng Ma and her son would take three bus transfers from 5:30 in the morning to make to school on time. They napped during the lunch hour on classroom floors and tables, then took the two-to-three-hour bus journey after the school day was over, just in time to have dinner at 7:00 pm. Regardless of how bitterly winter winds might blow, there would be no running hot water. Showering or clothes washing would be out of the question.

In exchange for Feng Ma's agreement to do a media interview, the school coordinator managed to arrange for a philanthropic organization to cover the family's tuition fees (about 10,000 RMB) while providing the mother-son pair a small stipend to cover their expenses during the semester. Such a decision, however, would prove to be one that would make the family vulnerable to criticism, as I show in chapter five, of trying to "earn" money and sympathy.

Deficiencies in the Medical System

It is evident that one of Feng Ma's difficulties in obtaining a diagnosis is very much the

result of the poor medical and healthcare services available in rural Hebei. In some ways, Feng Ma was lucky—she did at least meet psychiatrists who were able to diagnose autism. Geographers Julia Vedom and Huhua Cao (2011) make the case that geographic factors, rather than healthcare insurance, shape access to healthcare. Drawing upon publicly available longitudinal data from the UNC Carolina Population Center and the China Statistical Yearbook 2005, they show that the time needed to travel to these healthcare facilities, and the costs charged by these centers have in fact increased the barriers for many rural users. They also point out that epidemiologists have had difficulties determining quality of healthcare in understanding disparity in China. To understand the difficulties Feng Ma and other rural families experience, we need to understand the existing healthcare system in China.

The Hospital and Child Health System in China

As with many other institutions in China, the hospital system, known as the *sanjishideng* system (or 3 grades and 10 levels) is organized in a tiered system. Urban areas are served by street clinics, district hospitals and city hospitals, while rural areas are served by village clinics, township health centers and county hospitals. Provincial and central hospitals serve as the referral points for complex cases (see Eggleston *et al* 2008). Hospitals are organized hierarchically, where grade 1 refers to primary hospitals, while grade 3 refers to tertiary hospitals. These grades are further subdivided into three levels: A, B, and C, which means that 3AAA is a status reserved for hospitals which house specialists trained to treat the most complex diseases in the entire country, while the 1C hospitals will be capable of offering only minimal services and preventive education

since they are staffed by medical personnel with rudimentary training. Tertiary hospitals are not only responsible for offering the most comprehensive medical services, but for overseeing the quality of medical education and medical research for the particular region and provinces they are located in. Top medical specialists are thus clustered in tertiary hospitals, and these hospitals are generally located in important cities, provinces or municipalities (such as the center of Beijing). Hospitals at the primary level are generally found in small towns, while secondary hospitals are mostly located in cities, county or districts. Hospitals are tasked with the responsibility to provide training for medical professionals in other hospitals under their chain of command, so the lowest ranked hospitals will be also responsible for ensuring the training for rural clinics. Outpatient community clinics and smaller hospitals are then expected to serve as gatekeepers, while medical specialists will serve the most complex cases.

While China's healthcare provision, especially in rural areas, was to languish between 1980s to the early 2000s (as I have discussed in Chapter Two), China's healthcare reforms, costing RMB 850 billion (USD\$125 billion) that were launched in 2009 were to reverse much of the damage during the last two decades of the 20th century (see articles in Lancet by Yip et al (2012). Such a design is also evident in the provision of mandatory child health services, and the Chinese National Children Health Standard, which has been set by the Ministry of Health. World Bank Reports written by Kin Bing Wu, Mary Eming Young and Jianhua Cai suggest that all newborns should receive two home visits, four checkups during the first year of their lives, two check ups in a year for one to two years old, and one check up once a year for three to six-year-old children under the 2:4:2:1 schedule (Wu *et al* 2012: 41). During these check ups, child health

professionals provide free immunizations, monitor the child's development, while providing guidance to parents on how to feed their children, or to maintain good hygiene. Many provinces also provide free dental care and hearing tests (see Wu et al 2012: 41). After the age of six, children are expected to attend school and to receive their checkups in school. Many rural children under the age of 6 will receive these checkups at community and rural healthcare clinics in the provinces in which they are registered. Increasingly, many urban children will receive their annual check ups and mandatory vaccinations either from doctors attached to kindergartens, or by teams of community doctors sent by the local public health division to these kindergartens.

While there have been some strides made in the management of infectious and fatal diseases for children after the first decade of the 21st century, China's healthcare reforms remain inadequate, as evidenced by the lack of attention to developmental disorders particularly in rural areas. Many of these rural providers continue to provide health services in rural China are not well-trained themselves. Over seventy percent of village doctors have no more than a high school education and receive no more than twenty months of medical training (Wang et al 2003), while a study of four township health centers and eight village clinics in Wuxi County of Chongqing and Min County of Gansu showed that less than two percent of the drug prescriptions in these clinics were due to sound medical reasons (Zhang et al 2003). The quality of medical training remains highly variable (Eggleston 2012; Sean et al 2014; Yip and Hsiao 2009).

In much the same way, the doctors who staffed these clinics are not sufficiently trained to identify developmental disorders. This was further confirmed by my research in Hainan province in April 2014, when I went there to attend a parent-training seminar.

There, I met doctors who were part of the public health division within the hospital. These doctors were responsible for ensuring the quality of training which doctors in community and rural clinics were provided, as well as the kinds of care they were providing to the patients attending these clinics. Some of these public health doctors told me that many rural and community clinicians are not conversant with child developmental milestones beyond knowing the normal height/weight schedules for children. Nonetheless, they allowed me to accompany them as they conducted their annual inspections of the public health records held in the clinics or also kindly sent other personnel to ferry me via a motorcycle to these clinics.

My study, while very small and certainly not representative, suggests that the poor quality training provided to rural clinicians and poorly constructed referral systems made it difficult for rural families to find the appropriate clinician. While I have not yet been able to conduct a systematic study of rural healthcare professionals and plan to do so in the future, I had the opportunity to interview 15 rural healthcare professionals in April 2014. During my interviews with healthcare practitioners spread across ten different rural and community clinics, I was to discover that only two nurses had heard of autism. Of the two who heard of autism, one had found out by watching the news on television, while the other had found out during her employment in a private clinic. She had worked in a private clinic before she saw a child being diagnosed with autism. As she was on warm and friendly terms with the child's mother, she was able to observe the child for long periods of time, and was thereby able to identify the striking characteristics of autism.

The other 12 clinicians had never heard of autism, and some in fact were to ask me, "isn't it a loneliness disorder? How can rural children be lonely? They are unlike city

children! In fact, I'll tell their parents to bring them out to play!" While their interpretation certainly encodes a critique of urban life, their interpretations reveal the quality of professional training medical and professional training rural and community practitioners are provided, in that they have not even heard of autism. The doctors who expressed surprise that rural children should suffer from a loneliness disorder in fact tried to guess that autism must refer to an emotional state of loneliness because of its name. The quality of training rural clinicians is provided determines whether a doctor or nurse is trained to diagnose autism and recognize symptoms. Those who have heard of autism, or know more about it can direct these families to specific doctors in certain specialized hospitals who will be able to diagnose the condition. Those who cannot, then leave their patients to do all the necessary work. In this way, while scholars such as Winnie Yip and William Hsiao are indeed right that China's healthcare reforms have indeed brought about significant strides, but the failure of governance which Yanzhong Huang has pointed to in his work are not to be underestimated.

In fact, the lack of follow through or a referral system might be more at fault for why rural families might spend years on the road. 14 out of 15 of the rural nurses and doctors I interviewed said that they would tell the parents to bring a child to what they call a "large hospital" (or how many rural families and rural clinicians referred to specialist hospitals, rather than by medical specialization) if a child seemed developmentally slow, only one said they would directly offer the name of a large hospital. But not all doctors at large hospitals are able to diagnose autism. As Feng Ma's story reveals, it is not that families do not visit big hospitals, but that they do not know which one to go to. It is not good enough to visit a maternal and child health hospital in

the case of autism; it was necessary to visit a psychiatric hospital instead. My interviews with rural healthcare providers bear out many families' complaint of rural healthcare.

In that sense, inadequate services at Hebei and lack of follow through by the other doctors in Beijing trigger a larger chain of systematic failures. Feng Ma did know of the disparity in the quality of healthcare between rural and urban areas, but thought as long as she brought her son to a “large hospital”, she would obtain an appropriate diagnosis. The maternity and child-health hospitals she visited failed her— they all told her that there was nothing wrong, even though Dudu was highly non-verbal by the age of 6 when he was first brought to the hospitals. After her sister-in-law, who was a village clinician, managed to ask her extended network for recommendations, Feng Ma decided to go back to Beijing, but this time was directed to a psychiatric hospital for another diagnosis. It was at the psychiatric hospital visit in 2012 that she had heard of Sunflower Autism Center from another parent, and left her name and contact number on the year-long waiting list. By that time, Dudu was 8 years old.

Capabilities of Rural Families

Coming from a poor village in Hebei, Feng Ma had eight years of compulsory education. How was she to know that the doctors who are trained to diagnose autism in China are psychiatrists, rather than child health doctors, if she was not told? Just as Paul Farmer argues that poverty and access to health care determine the ravages of tuberculosis and HIV (2001), Feng Ma's long and arduous journey in obtaining a diagnosis for her autistic son illustrates how rural policies that emerge through accidents of birth and history are writ large into the personal history and ability of family

caregivers, which more than often leads them to become diagnostic and therapeutic nomads for their autistic children. Feng Ma had to spend three years just to obtain a diagnosis for Dudu, who she knew was “different,” from other children. Feng Ma’s search for a diagnostician with sufficient training and skills was one with many false turns, and severe delays of several years and it illustrates how dependent rural families are on happenstance of a social tie to extended families or other mothers who can direct their search.

I argue that mothers like Feng Ma become diagnostic internal migrants because they lack social, cultural and economic capital. Only eight percent of rural junior secondary graduates, for instance, will enter senior secondary school, as compared to sixty-two percent of urban junior secondary graduates (Qian and Smythe 2007). The effects of educational underachievement are not restricted to income — it is strongly correlated with poorer health outcomes in countries such as the United States (Dewalt *et al* 2004). Neither could Feng Ma easily leave Hebei to access better educational and career opportunities. As I have established in Chapter Two, household registration for citizens in China not transferrable; but it is directly correlated to access to medical care, educational opportunities and other life chances (Wu and Treiman 2004). Being born in rural areas means a greater likelihood of poor educational attainment.

In the case of disorders such as autism, finding the right rehabilitation center in contemporary China is dependent either on families knowing where to search for the appropriate information, or on well-connected others in the form of family, friends, acquaintances, who know which hospitals might have the expertise to diagnose autism. While the families I followed did in fact succeed eventually in obtaining a diagnosis

years later (or else I would not have been able to interview them), what is particularly striking is that they finally met the right specialist because of an accidental meeting with another mother in a waiting room who gave them recommendations, or one of their relatives or friends might happen to be able to find out the information for them. Without social connections who might be able to obtain the necessary information, they will not be able to navigate contemporary China's vastly unequal access to healthcare, and rehabilitation options. There are many who will never be able to find the appropriate medical care without the right social connections.

Therapeutic Internal migrants from Poorly-Resourced Urban Areas

While therapeutic internal migrants share similarities with diagnostic internal migrants, there remain some key differences between these two categories. Long-term therapeutic internal migrants, who travel for close to a year or more in search of therapy tend to be at least college-educated, but may come from poorly resourced urban areas. At the same time, they are driven by a sense of an emergency, and this sense of an emergency surrounding a child's potential I discuss further in Chapter Four.

Take Wang Lijun and her daughter for instance, the pair I begun this chapter with. I met the painfully thin mother-daughter pair in Sunflower Autism Center as well. Wang and her husband had struggled to scrap together the funds for Sunflower Autism Center. As a policeman in Mongolia, her husband earned little; the couple had in fact married despite Lijun's parents' fierce objections because they feared Lijun would be condemned to a lifetime of poverty. Unfortunately, as her parents feared, Lijun and her husband were to struggle financially from the time they married, to the present. In fact, Lijun and her

five-year-old daughter, Xiaoxin, were only able to attend Sunflower Autism Center because of her husband's ex-colleagues, who kindly held a donation drive to fund their attendance.

Initially, Lijun stood out to me because she seemed to be a disinterested attendee. She was constantly dozing off in class, and never completed any of the assignments at Sunflower Autism Center. She always had a worried and hassled look on her thin face, running into class late, and leaving early. When I approached her to explain my project, Lijun would hurriedly say she has no time for a formal interview. She offered to talk to me as she completed her chores during the day. Over the course of the semester, I came to see that it was true, as we spent a lot of time together during the bitterly cold Beijing winter after school. Lijun was either cooking or cleaning for Xiaoxin. When Xiaoxin finally fell asleep, Lijun would quietly work on her laptop, creating teaching packages to help ease the financial burden carried by her husband. Lijun knew I was conducting my research and was willing for me to write down everything as we spoke. I saw how exhausted she was, given Xiaoxin's condition. Xiaoxin was not only non-verbal, she was developmentally behind---she never seemed to hear any instruction or anyone attempting to interact with her. Yet, her hearing was perfectly normal, which we knew from her predilection for musical toys. Xiaoxin only responded to those toys, screaming every time her mother or someone else would remove the toys so as to ensure that she would not disrupt the class or the neighbors who shared the rental accommodation. Xiaoxin could not focus her gaze on anything, so it sometimes appeared as if she was visually impaired. Conversations with Lijun took place in snatches, when she was cooking or feeding her daughter, or when Xiaoxin was asleep and she was working on her computer. She had no

choice but to work. They had taken on 30,000 RMB (USD5000) in loans last year as they had brought Xiaoxin from Mongolia to Beijing, seeking for first a diagnosis, then a therapy.

EXL: What made you decide to come to Beijing?

Lijun: I knew something was wrong with my poor daughter when she was born. I was too thin for a pregnant woman, and she was severely underweight when she came out. The first year of her life, we were in and out of the hospital, because she was constantly sick. I knew she would be slower [in her development]. She had all these tubes running through her veins when she was a baby. She looked so pitiful! When she didn't talk at the age of three, I knew then we have to go to a hospital. But our hospitals [in Mongolia] weren't good. I went straight to hospitals in Beijing, and they said she had autism. That's the problem, we didn't know which schools were good, and so spent a lot of money travelling from one school to another. We did so for a year, travelling from one autism rehabilitation center to another, where they all promised to cure Xiaoxin. All of these were empty promises! The other schools were terrible, they are so poor quality! We also got ripped off. These Beijingers know that foreigners like us are easy to cheat and bully: I paid three times as much as other people for the housing as they said I was an outsider who is not from Beijing. We then met this other mother who had been enrolled in Sunflower Autism Center before, and who advised us to go to Sunflower rather than visiting other schools.

Lijun said all this as she simultaneously washed Xiaoxin's clothes while watching over the food she was preparing for Xiaoxin. All in all, Lijun and Xiaoxin had spent close to two years travelling in search of a therapy, because there were few, or non-existent services in Mongolia.

In many ways, Lijun's story illustrates the structural inequalities built within a country's social system that determines which parents, together with their autistic children, will take on a lifestyle of medical nomadism in search of diagnosis, and which others will do so in search of the most appropriate rehabilitation. Here, I follow in the footsteps of medical anthropologists who examine how the burden of infectious diseases is unevenly distributed owing to the forces of structural violence (Farmer 1996, 2001),

inequality (Fassin 2003; Nguyen and Peshard 2003), socioeconomic conditions and political economy (Singer 1998).

Their experiences, I argue, have been precipitated because of the post-socialist logic of “kao ziji” or self-governance, where all individuals are expected to depend on themselves rather than the state (Zhang and Ong 2008: 3). For the vast majority of parents like Lijun, with household registration outside of economically advanced provinces such as Beijing, Guangdong, and Shanghai, the variability of access also means that many of these parents feel they need to travel to these provinces in order to make rational decisions for their child. It is important to note that mothers like Lijun are not entirely putting their faith in a procedure that will produce the miracle of a changed child. They are acting less out of a simple faith in the wonders of the rehabilitation therapies currently available. But faced either with the disquiet that there is something wrong with a fast-growing child who might be violent and aggressive but whose condition cannot be diagnosed by the doctors available in one’s province, or the knowledge that their child is fast-developing and that the existing available interventions are targeted at younger children, the parents feel they have no choice but to move repeatedly across the country.

Dr. Zhu Xiao Ling

I began this chapter with Dr. Zhu Xiaoling’s story. I came to know her because other parents kept insisting I speak to her, given that she appeared to be the most knowledgeable about all the different existing therapies that exist in China today. When I first met her, Dr. Zhu immediately asked me, “Which do you think is the best? Is it PCI, or RDI, or ABA?” I had to admit shamefacedly that I had no idea what she was talking

about (and found out to my relief later than PCI was well-known only in Taiwan and in Southeastern China. I explore what PCI is in Chapter 5). Dr. Zhu was a font of knowledge for all the latest therapies for autism---she had travelled, as I mentioned at the beginning of this chapter, from Yunnan to Guangdong Province (as she had done her research, and found out that one of the best diagnosticians was there), and that there were competing schools that integrated ABA with PCI (which stood for Play, Culture, Therapy, a form of therapy developed by a Taiwanese Professor who studied in the US). She had also spent more than six months in Qingdao, which housed the other highly regarded private school set up by a mother of a now adult son with Asperger's. Her son, Kaijin, had borderline autism, and would have been diagnosed under DSM-IV as having some level of Asperger's. He was communicative, but not particularly strong at taking turns in a social conversation. As we talked, she told me that Sunflower Autism Center was probably best at teaching families how to care for their autistic children.

After leaving Sunflower Autism Center, however, Dr Zhu continued to travel to different provinces---she even went to Henan, and Hubei. Close to two years after we both left Sunflower Autism Center, Dr. Zhu would sometimes send me frantic texts over QQ or short messages, saying how she felt she was afraid of returning to Yunnan because of the dearth of quality private autism centers back home. This was, as she echoed what other doctors said (and which I discuss in the next chapter), "the golden period for training a child"---what if she did not seize this moment?

Wang Lijun's and Dr. Zhu Xiao Ling's story of travelling frantically throughout China in search of therapeutic services outside their home province are not unique. Data from my small-scale survey suggests that families feel extremely driven to search for

high quality professional therapy, or what they refer to *zhuanye*. During my fieldwork, I conducted a survey at the two most highly regarded rehabilitation centers in China. Of the 150 parent-respondents, 65% claimed that they had been to at least 2 schools prior to coming either to Sunflower Autism Center to Good Hope Autism Center (with 5 informants choosing not to answer this particular question saying that they had been to at least 2 other schools prior to the schools they were currently at). And even though these parents are already at the top schools, at least 30% want to continue travelling to other schools. Reasons mainly centered on the anxiety of returning home to either non-existent or what they characterize as poor quality rehabilitation centers. 81 respondents out of 150 had already spent at least 2 years travelling with their child with no income.

In designing my survey which was completed by parents anonymously (and who were not the same 80 informants I had interviewed or stayed in contact with), I considered the following factors. Due to the fact that autism rehabilitation centers are unevenly distributed across different provinces, with at least a hundred in Beijing, and perhaps only one or two in other provinces such as Henan, conducting a survey in any province would not be representative of how Chinese family caregivers access therapy for autistic persons. At the same time, since the quality of therapy was a consistent factor which families mentioned during the open-ended interviews, it would be more productive to gather responses from schools that are well regarded within China. There are, of course, limitations to my survey design. In choosing these two schools, I am well aware that the families who choose to come to this schools are likely to be reasonably well-educated, and the most driven to obtain the best therapy for their children, and have at least middle-class incomes. Yet, quality is such a big factor in driving these anonymous

respondents to undertake a life style of nomadism. That many of the parents I have interviewed who have wept upon recounting how long they have been away from home, while insisting that this is what they have to do for their child's future is indicative of the importance of quality therapy to these families.

Dr Zhu's story has a happy ending. In January 2015, she decided to return back home to Yunnan. She said that her son was now showing so much improvement that she had decided to go home to Yunnan, and in an emoticon sent on QQ, she also alluded to the fact that her son's future school fees will need to be accounted for, and it was time for her to provide a stable home and community life for him.

Conclusion

I began this chapter by exploring how the care-seeking behaviors of what I call diagnostic and therapeutic internal migrants require a fresh examination of travel due to medical or therapeutic reasons. Though there have been other terms aplenty to describe medically motivated travel such as medical tourism, biotech pilgrims or medical nomads, none of them evoke the reality that many s parents, particularly those from rural areas or urban areas with poorer quality social services, become diagnostic and therapeutic internal migrants because of structural inequalities between provinces in China.

At the same time, I urge scholars working in public health and migration to also pay attention to the flows of people in search of diagnosis and healthcare, and to further explore what access means for subsets within a national population. My observations of village clinicians and specialists in top hospitals reveal that that many village and urban clinicians fail to provide a diagnosis or refer family caregivers to appropriate or specific

hospitals. For the vast majority of parents with household registration outside of economically advanced provinces such as Beijing, Guangdong, and Shanghai, the variability of access also means that many of these parents feel they need to travel to these provinces in order to make rational decisions with respect to therapy for their child, even if it means they might end up living lives of precarity for the rest of their lives. This means that families from less developed areas not only struggle to cobble together care, but will risk their marriages, their economic job security, and their psychosocial health since they will be cut off from their social networks for long periods of time. Likewise, my observations of village clinicians and specialists in top hospitals reveal that that many village and urban clinicians fail to provide a diagnosis, and do not know which other hospitals to refer the family to.

As I show in this chapter, access indexes multiple issues for families: the ability to seamlessly receive a diagnosis as well as the necessary social support so that a family will be able to put in place care for their autistic members. The lack of access to a diagnosis and therapy thus create patterns of displacement for families.

ⁱⁱ Apart from epidemiological studies (which are few in and of themselves), there are only a few social studies of autism in China, written mainly by four academics, a student, and a journalist. The four academics consist of Elaine Clark, a professor at the University of Utah's Educational Psychology Department, who has written a short review article with Zheng Zhou, a psychology professor at St John's University. The article they have written is titled "Autism in China: From acupuncture to applied behavior analysis", is primarily a review of some publications, rather than a qualitative study of what families actually employ in caring for autistic persons. Helen McCabe, formerly an associate professor at Hobart and William Smith College's Education department, now a research at the Hussmann Institute, is one of the few reliable sources, since she is fluent in Mandarin (we both translated on 1 April 2013 for some of the organizations and know each other briefly), and has been off and on in China since 1992. McCabe has published a few informative articles based on her qualitative research in Stars and Rain (see McCabe

2001, 2003, 2008. 2011) Sophia Xiang Sun has published articles on autism therapy in China. Sun completed her PhD in Cambridge under the supervision of Simon Baron-Cohen (see Sun et al 2010 and Sun 2013). Cindy De Clerck's unpublished dissertation, based primarily on a few months' stint in Stars and Rain Autism Institute, is also available; it is unclear if this is for a bachelor's or master's dissertation (see: <https://soc.kuleuven.be/web/files/11/69/Tekst%20Cindy%20De%20Clerck.pdf>). The other account is written by journalist Adam Feinstein.

Chapter Four

Tyranny of the Autistic Child's Tomorrow

“There is hope, during the golden period of child development [*huangjin fayu shiqi*]. Who says there is no hope [*mei xiwang*]? Choose to exchange your today for your child's tomorrow,” exhorted Dr. Cai, one chilly Saturday morning in one of Guangzhou's child development hospitals. Dr. Cai, a tall and wiry pediatrician with salt-and-pepper hair, made that statement during an informational session for about two hundred family caregivers of children he had recently diagnosed as autistic. The family caregivers diligently took notes. Some of these caregivers, like the internal migrants I discussed in the previous chapter, travelled to Guangzhou months previously to obtain a diagnosis from Dr. Cai, returned to their home province, and then travelled back to Guangzhou to attend the session. With so many families waiting in line for him to diagnose their child's developmental delays that he had to maintain a six-month-long waitlist, Dr. Cai restricts appointments to twenty or thirty minutes. After he arrives at a diagnosis sometime toward the end of the session, he signals the end of the appointment by handing these families a slip of paper listing the dates of a free half-day informational session he runs every one to two months, depending on his availability and extensive travel schedule. A child development expert who is well regarded within his country and by international collaborators such as the U.S.-based Autism Speaks, Dr. Cai not only offers diagnoses, but serves as a key advisor to the Ministry of Education on how to run studies of autism incidence rates in China.

During the informational session which took place in January 2014 in a small

lecture hall attached to one of the top pediatric hospitals in Guangzhou, Dr. Cai first lectured on the history of the diagnostic category of autism, before moving on to emphasize the urgency of providing consistent and intensive therapeutic regimes for children diagnosed with autism. Insisting that there is “hope” and that parents should make the choice to “exchange [their] today for [their] child’s tomorrow,” Dr. Cai instructs the listening audience that the child with autism needs at least six to eight hours daily of interaction and engagement, and the parent or adult who is responsible for ensuring the daily dose of interaction must actively draw upon the principles of behavioral therapy. Dr. Cai insists that parents are the child’s first teachers. So, it befalls parents to actively play and engage with a child so as to prevent the child from escaping into “his autistic aloneness” for now and in the future. Parents are reminded that any sacrifice they make now will secure their child’s future so that their child will lead lives, as Dr. Cai puts it, that are akin to normal (or *xiang zhengchang*). Dr. Cai bolsters his claim by alluding to his travels to the United States, where he claims that the most successful autistic young adults have had parents who have taken on the role of their child’s therapists. Though there is always a risk that the child does not improve even with intensive therapy, Dr. Cai and other doctors rarely allude to the possibility of failure. Instead, they focus on warning parents that if they do not do anything, the child will grow up to be very “frightening” (*hen ke pa*), and caring for an autistic adult who did not undergo therapy at an early age would be “unimaginable” (*buke xiangxiang*). With therapy, however, the child can lead a life that is close to “normal”; that is, the child may be able to attend school, and in a few cases, may be able to marry and start his own family. In fact, Dr. Cai spoke glowingly of the few cases he knew personally who

completed university.

Dr. Cai is not alone in warning parents of the dangers of missing the period of time when the child's brain is apparently most malleable; during my fieldwork I heard medical professionals in Beijing and Hainan either scolding parents for "coming too late," or exhorting parents that "there is hope," and they can "save" their child. Such a sense of urgency around that "golden period of child development" is shared by parents, medical professionals, special education teachers, and humanitarian organizations such as the One Foundation (which primarily funds rehabilitation centers and autism advocacy events).

In some ways, Dr. Cai's public exhortation to family caregivers to give up their "today" for their child's "tomorrow" is nothing new for urban middle-class parents in postsocialist China. Drawing on Gayatri Spivak's interpretation of Karl Marx's notion of value, Ann Anagnost argues that the middle-class child in post-socialist China is the subject of capital accumulation, since both child and parents labor to accumulate value in the body of the child through educational distinction (see Anagnost 2004:191; see also Anagnost 2004: 141-142). With China's strict enforcement of the one-child policy in urban areas and the concomitant loss of social security in the form of state-assigned employment and housing for urban citizens, the demand for parents to prioritize their children's developmental needs appears consistent with a parenting landscape in which urban middle-class parents anxiously chauffeur their children to endless enrichment classes and fervently study the latest parenting guide on how to nurture their children so that their singletons are able to grow up into flexible adults who can compete in a fiercely competitive postsocialist education system and economy (Fong 2004; Kuan 2015, Naftali

2014). Anthropologist Vanessa Fong (2004: 40) writes movingly about low-income parents foregoing hospitalization and meals so they can spend buy tonics or treats for their children when they prepare for their examinations. Greenhalgh and Wrinckler make the argument that the pursuit of the quality child is exemplified by the eugenics campaign (termed as *yousheng youyu*) of the 1970s, which focused on quality healthcare and education for the young, and the use of environmental and educational factors to encourage *youjiao*, or superior education (2005: 234-235). The pursuit of the quality child, Greenhalgh and Wrinckler argue, puts “a benign face on the one child policy, presenting the party-state as a caring parent whose heart lay first and foremost with the young” (2004: 235).

Yet, there are vital differences between the children Dr. Cai and other doctors and parents are concerned about, and the children of urban middle-class parents who have been extensively studied by anthropologists of China. The families who have enthusiastically embraced the state’s call for the quality child of their one (or two) children are by and large urban middle-class parents with a developmentally normal child, from whom they can expect future support. This is true of parents and children in Vanessa Fong’s study (2004), Orna Naftali’s work (2014) and Teresa Kuan’s ethnography (2015), and the kind of parents Anagnost analyzes. Such a child is a “precious commodity” used to secure one’s future, but is one presumably able to compete on a national stage (see Greenhalgh and Wrinckler 2005: 243). The parents Dr. Cai is exhorting, however, are nurturing children with autism. These children, Dr. Cai makes clear, can live almost “normal” lives according to him, but only with age-appropriate intervention at an early age; otherwise they are likely to have problems leading

independent lives. Here, the potential and future of the child anchors two imagined futures, one which promises that an autistic child left without therapy would pose a frightening and unimaginable burden on the family for the rest of the parents' lives, and another more hopeful vision which promises that the autistic child who has been provided early and sustained intervention when the child is sufficiently young can be "saved" from the nightmarish future outlined earlier. The hope which Dr. Cai invokes is therefore qualitatively unlike the hope (even if it is accompanied by tremendous insecurity) which drives urban middle-class parents with developmental normal singletons. The parents of Dr. Cai's patients are not envisioning their children growing up to be highly successful and able to compete in the national and global educational and work arena; even the rosier vision is simply focused on getting the child to be "normal" and indistinguishable from his or her age-appropriate peers. Moreover, their sense of urgency and emergency cannot be understated. If the child fails to develop in a way that might prove to be more akin to his "normal" peers, then families are likely to face the frightening prospect of managing an uncontrollable autistic adult. That much has often been conveyed by Dr. Cai and other doctors. These differences render the insistence of Dr. Cai's plea for parents to sacrifice their present for their child's future and the urgency experienced by Dr. Zhu markedly different from urban middle-class parents' frantic efforts to educate and nurture their middle-class singletons from an early age.

The emphasis placed on an autistic child's "golden period of development" anchors multiple, and very different, moral economies of care around the family and person grappling with autism. In the context of autism in China, the child's "golden period of child development" (*huangjin fayu shiqi*) falls between the ages of

approximately three and eight. The colloquial term conveys urgency and value through the metaphor of yellow gold, a color which conjures up associations with royalty and value in Chinese mythology, history, and now in contemporary culture. Yellow and gold were colors reserved for emperors when China was ruled by imperial dynasties (He 2011). Even after the overthrow of the last Qing emperor, yellow and gold continued to evoke good luck, value, wealth, and power and are colors used by marketing teams in advertising. Framed this way, the preciousness and inestimable value of the ages of three to eight are highlighted through these metaphors, which demand in turn a moral response not to waste the child's potential, and for parents to obtain a diagnosis and send their child for therapy as quickly as possible. As anthropologists Karen Sue Taussig, Klaus Hoeyer, and Stefan Helmreich argue, "articulations of potential typically enact politics by working on and through morality, by making claims on us to do something" (2013: S6); the concept of the autistic child's potential in China is thus a short period of time which needs to be quickly exploited.

I argue that the autistic child's potential functions as an ethical imperative among doctors, humanitarian organizations, and family caregivers alike, galvanizing doctors and humanitarian organizations to exhort and advise family caregivers to provide therapy for their autistic children in China; such a concept also determines how doctors may choose to allocate their scarce clinical time or even humanitarian funding, while serving as an arbiter of who is more deserving of care as it pertains to families with autistic children in China. At the same time, I propose that the framing of the autistic child's potential for change and intervention as one restricted to "the golden period of child development" also serves to limit the possible claims that can be made on the state and Chinese society

at large, while legitimizing the neglect of people with autism and. It can also strengthen gendered divisions of labor. While “framing something in terms of potential is a political act” (Taussig, Hoeyer and Helmreich 2013: S6), the framing of a child’s developmental needs through potential not only depoliticizes the lack of institutional and state support in China, but renders thinkable the neglect of the autistic adult and the mother of the autistic child.

In exploring how the autistic child’s potential serves such potent moral and political claims through the term “moral economy,” I draw on the elaboration offered by the physician-anthropologist Didier Fassin, who defines the moral economy as “the production, distribution, circulation, and utilization of moral sentiments, emotions, values, norms and obligations in the social space” (2013: 112). Fassin builds upon the work of historian E. P. Thompson and political scientist James Scott, both of whom argue that peasants and proletariats in Europe and Southeast Asia staged protests when local norms of justice were ignored and violated, rather than out of a material concern with everyday subsistence. Fassin argues that the concept of moral economy can be broadened to include social concerns such as violence and poverty; he also makes the case that the study of the moral economies of the suffering child reveals the kinds of suffering that are deemed to be morally impermissible and those that continue to be legitimized and ignored within the logic of humanitarian aid.

The autistic child’s potential has been deployed in different arenas, ranging from the diagnostic process to the way it governs priorities within autism advocacy, justifying the neglect of the autistic adult, who is figured as having no further potential for intervention. The autistic child’s “golden period of child development” may lead

clinicians, in situations of few resources, to make decisions that may at first glance appear uncaring and unsympathetic. Here I will draw on ethnographic data I gathered from research conducted at Beijing's top psychiatric hospital (where two of the country's most well-known child psychiatrists are located), with Dr. Cai in Guangzhou, and from visiting rural and community clinics. Though my intent is to show how doctors are caught in double binds of their own, I will show how their decisions have unwittingly exacerbated the plight of diagnostic internal migrants. However, as I will report from my fieldwork, influential parent-activists have resisted the dominance of the "golden period" concept and have sought to wrestle back social attention for their autistic children.

Allocating Time and Attention During Diagnosis

If you are one of the few experts in autism at Beijing's top psychiatric hospital, offering diagnoses must be an extremely stressful experience since there are always crowds of families waiting for your attention. Doctors have to make complex decisions about how to allocate scarce clinical time and attention. The way they do so, sometimes it is unclear who they are serving: the idea of the child whose potential they seek to safeguard or the actual child and parents who stand before them. Consider Dr. Chu, one of China's most eminent child psychiatrists where autism is concerned. Dr. Chu, now in her sixties, was trained in the 1980s by one of only two doctors able to diagnose autism at the time, Dr. Yang Xiaoling, whom Dr. Chu still respectfully refers to as Yang Laoshi (Teacher Yang). Dr. Chu is often recommended on Chinese websites¹ where middle-to-upper- middle-class families look for suggestions about where to bring their child.

At the beginning of each consultation, Dr. Chu asks parents what they think is

wrong with their child. She then asks the child directly his or her name. If the parent or family caregiver reports that the child seems to ignore everyone at home (despite numerous hearing tests that show the child is not hearing impaired), Dr. Chu will then either wave a toy police car (with its sirens blaring), or a tin of sweets at the child. As part of her diagnostic practice, Dr. Chu will ask the parents to leave the room as the child is playing with one of the toys (typically a police car with loud blaring sirens, or some candy). She uses the child's reaction as a litmus test for whether the child displays a lack of attachment to his or her caregiver. If the child is above the age of three or four and is not fully ambulatory, Dr. Chu will often scold the parents or other caregivers for not allowing them to walk or stand on their own. The diagnostic encounter reported below is typical of how she offers parents a diagnosis:

"Your child is so obviously autistic", snaps Dr. Chu without looking at the parents, nor at the six-year-child, as her pen moves speedily across the page of the little booklet issued by the hospital; each patient or family must buy one of these booklets in order to obtain diagnostic and treatment services.

"Can it be because we work full-time, and he is with old people all the time?"

"No."

"Maybe it's because the old people, like my parents, don't talk to him so he doesn't know how to interact," says the father, his eyes brimming with tears. The young mother, probably in her late twenties, was crying too hard to speak.

"No."

"How serious is his autism?"

"If I tell you it's not serious, you won't take it seriously!" barks the doctor. Apart from a

hastily wolfed down lunch at 1:20 pm, and a quick visit to the toilet, the doctor has been sitting in this stiflingly warm and cramped room since 8:00 am. It is now two in the afternoon. There are two other doctors who are here shadowing her, and they are furiously taking notes; they are here only for about three months and then they will return as newly minted experts on child psychiatric disorders in their municipal hospital. She continues, "If I tell you he is not that serious, will you see his condition as serious? How can you neglect him till now?"

"I didn't know there was something wrong," said the young mother haltingly, still crying. "Don't you go to the playground? Or watch how other toddlers interact with their parents or other children? What kind of parents are you to not pay attention to how your child is interacting?" the doctor responds impatiently as she continues writing down her diagnosis. She has repeated herself at least twenty times in the course of the day and might do so at least 15 more times till 5:30 pm in that office, long after the neighboring doctors have finished seeing their last patient at 4:45 pm.

"Did you notice your child has no fear of strangers, nor seems attached to you? Most children would at least display fear or curiosity when their parents are not nearby. Autistic children don't have such reactions. How is it that you could have missed this all these years? Don't you see any difference between your child and the children around your neighborhood? Autistic children are so obviously different from other developmentally normal children."

"What is your cultural and educational level?"

"I finished high school, while his mother finished lower secondary school," says the father, his voice cracking.

“Are you from Beijing?”

“No.”

“Look out of the window, and I’ve written down the address, and the teacher you must see. I’ve also written down the name of organizations you might visit. You can try spending a few months in this school I’m suggesting as their waiting list isn’t that long. It is a good school.”

“Doctor, what do I do for my child? Please understand, this child is precious to me. We want to do everything we can for my child.”

“Go and get some tips from the teacher I’ve telling you to see. They have recommendations that would be useful for you.”

“Is there anything else I can do?” asks the father. “We are not from Beijing, and there’s no one we can ask where we are.”

“What can I do now that you’ve come so late? Training is the best at the age of three, the golden period of child development. You’ve missed that. This is all I can do for you. I have to see the next parent and patient now. I can’t do anything for you now that you come so late!”

“Thank you, Doctor,” says the father, as he cuddles their son lovingly, and his wife walks out with tears streaming down her face.

As can be seen from the above exchange, Dr. Chu clearly delineates her role as that restricted to providing a confirmatory diagnosis in support of parents’ suspicions. She expects parents to already know what autism is, or to be able to do their own research once they have the diagnostic label. She is sparing with her words and is intent on offering the diagnostic label as quickly as possible.

On average, Dr Chu. sees between 62 and 65 patients in a day. Most of the children she sees are children suspected to be autistic since she is known to be one of the few experts in China who can diagnose autism. Few of these patient appointments run uninterrupted. Every ten minutes or so, the door to her small room will be opened by a parent or grandparent pleading, “Please, doctor, we have travelled for many days on the slow train here from another province, and this is the last day we can afford to stay in Beijing as we need to go back to take on contractual work.” Dr. Chu will barely look at the supplicant, though she will sign off on a slip stating, “add one,” before instructing the grateful parents or grandparents to first pay for their appointment fees and wait until all the other patients with prior appointments have been seen. Even so, she always has to turn away some parents, despite their desperate pleas that they have travelled for three days just to get a diagnosis. Doctors have the authority to provide additional appointment slots after all the scheduled appointments for the day are seen. Typically, the maximum additional slots that can be added would be 3-5 a day. Many of these families will return to their hometown empty-handed. Allocating each patient approximately 10 minutes of her time (unless parents have booked and paid for a premium consultation which will run about 20 minutes), Dr. Chu typically suggests one of two autism rehabilitation centers in Beijing she is familiar with. As she dismisses each family, Dr. Chu will order someone—the family whose consultation has just ended, or a junior doctor observing her, or me—to call in the next family.

Dr. Chu makes the decision to restrict patients to a few minutes each on the basis that she wants to “save” each child’s potential, and that she empathizes with the parents of these children, since she is a parent herself. During one of our numerous interviews,

the well-respected child psychiatrist sighs as she turns to me, “What can I do? I’m a human, and even I stay in here diagnosing the whole day, I will die before I finish diagnosing! You go back and tell your foreign doctors that they have it so lucky they never see so many patients in a day! I would love to see about ten patients a day. Do I have the time to explain what autism is to them? I have no time. I have so many patients. I just want them to send their child for rehabilitation as soon as possible.”

For Dr. Chu, protecting the child’s potential thus means cramming as many patients as possible into her work hours and giving them the label of autism in the hopes that someone else, perhaps an autism rehabilitation center, will explain what autism is. Thus, guarding her work hours is driven by the ethical imperative to “save” as many children as possible by giving their parents the diagnosis. She does not bother to assuage family caregivers’ guilt and self-blame; many of these rural and migrant breadwinners, such as the one in the vignette above, leave their hometowns in search of employment; their young children are left in the care of grandparents. In recent decades “left-behind” children, as they are popularly known in China, have become a source of concern, with scholars and the general public fearing that these children experience mostly negative consequences as a result of being separated from their parents (Ye and Pan 2011; Wen and Lin 2012). The parents are expressing a kind of guilt and anxiety very common to rural migrant parents, who worry that their child’s development is hindered by the sporadic care provided by their *nongmin* (farming) grandparents in the countryside. Dr. Chu addresses these concerns only with a curt “no,” while emphasizing that the child needs to be enrolled in an autism rehabilitation center. For her, responding sternly and scolding parents for not noticing that the child is unlike children of the same age is her

way of reminding the parents to take parenting more seriously.

During countless conversations, Dr. Chu often says “I am a parent too, I feel bad for them [that they have a child like this] so I know they need a diagnosis!” She believes her time is better spent giving an authoritative diagnostic label, leaving the job of explaining what autism is—or describing the implications for the child of a life with autism, or stressing what developmental gains might be achieved if the child enrolls in a rehabilitation center—to volunteers at advocacy organizations. Dr. Chu is most concerned with “saving” the child’s potential with a clear diagnosis, as she wants parents to recognize how “serious” autism is, a word she uses repeatedly. Consequently, Dr. Chu often sends parents directly to a volunteer associated with the hospital (Teacher Li, the volunteer whom I mentioned in chapter two as guarding the archives of BARAC’s collection of old newsletters), who collects all the names and addresses of autism rehabilitation centers around the country. Teacher Li will look up addresses and centers nearest to a family’s home province.

Alternatively, Dr. Chu might direct parents to autism rehabilitation centers such as Friendship Autism Center or the autism center she set up early in 2013. She does not recommend Sunflower Autism Center for several reasons, including a long running feud with Mother Zheng. Dr. Chu bitterly faults Mother Zheng for not giving enough credit to Dr. Yang Xiaoling and the doctors then in raising funds to help Mother Zheng survive during those difficult early months in the early 1990s and for helping her network with parents who set up Sunflower Autism Center. I have never been able to confirm the source of conflict between that hospital and Sunflower Autism Center. Mother Zheng’s face darkened visibly when I asked her whether she went to that hospital when she was

seeking a diagnosis for her child in the early 1990s.

Dr. Chu, however, recommends Friendship Autism Center because of her close ties with the founder, Dr. Mu, and because Dr. Mu often takes on the job of explaining to parents who have been referred to her center by Dr. Chu. Dr. Mu is a protégé of Dr. Yang's close friend. Dr. Mu was trained in TCM by a famous TCM expert who was wooed by the Japanese government to set up a TCM Unit in a hospital in Japan. Dr. Mu went abroad with him as his trainee, and then stayed on to guide the Japanese doctors studying TCM for close to a decade after her teacher passed on. It was during her stay in Japan that Dr. Mu learned of autism; she had a personal interest in autism because of her deceased brother, whom she suspected had autism but he was never diagnosed. Their grief-stricken mother died a year after her brother killed himself. Dr. Yang, who had been in close contact with Dr. Mu, urged Dr. Mu to return to China to serve Chinese families by setting up an autism rehabilitation center in Beijing. Dr. Mu enthusiastically agreed, taking advantage of the currency exchange between Japan and China to earn the necessary start-up capital. Dr. Yang also helped by raising funds. Thus it was that Friendship Autism Center, a center which blended Dr. Mu's specialty in acupuncture and applied behavioral analysis, was born in 2010. Dr. Mu often gently sits down the bewildered parents referred to her by Dr. Chu and explains to them what autism is.

Rural Families: Technological Divide and Computer Literacy

While Dr. Chu appears harsh, she has good reason to prioritize seeing as many patients as possible. Many diagnostic vagabonds from rural areas are not aware of the developmental

milestones a child should reach. In the bid to modernize and to introduce greater efficiency into the health system, many of the top specialist hospitals in China have moved to an online booking system. While many urban families are able to make online appointments, many rural families, or even families living in urban areas with low levels of educational attainment, are not able to do so. I observed that many rural families were frequently turned away because they had not made a prior appointment online, and the appointment slots for the days ahead were full by the time they arrived.

Take Xiaoxi, for instance, a parent who received a diagnosis from Dr. Chu and who narrated the process to me. I met Xiaoxi in a state-run disability school in Hebei province.¹ The school in a city that was well known for its skies being constantly smoggy and chalky colored from the year round air pollution.

Xiaoxi came up to me shyly to ask if I were a teacher while I was in the rehabilitation center's playground observing lessons. As her then four-year-old son clung tightly to her thin hand, Xiaoxi narrated her story in her heavily Hebei accented Chinese. Jinyun had been diagnosed with autism three months ago in Beijing; she and her father had made the journey there because none of the doctors in her vicinity knew what was wrong with him. Xiaoxi and her father had travelled intermittently for a year or so in search of a doctor able to diagnose Jingyun. One day, a mother who was also in a waiting room in a hospital in Hebei and leaned over and told her to bring her son to a particular psychiatric hospital in Beijing. She told Xiaoxi of her suspicions that Jingyu had autism, and insisted that Xiaoxi must bring Jingyu to that particular psychiatric hospital as

¹ This school would be too easily identifiable if I were to state its precise location, so I have identified only the province.

quickly as possible. Xiaoxi and her father then made yet another trip back to Beijing, on a slow but inexpensive train. They took turns holding Jingyu as there was no place to sit on the crowded train (most likely full of migrant laborers). When they arrived in Beijing, they could not afford to rent a room, but desperately needed an appointment with one of the few child psychiatry specialists trained to diagnose autism. Outpatient diagnostic services for autism were not offered every day in the hospital, since the three physicians recognized as autism experts were also teaching fellows. Xiaoxi and her father then took turns carrying Jingyu as they spent three sleepless days in the overcrowded waiting room of the hospital. Like many other peasant families I encountered in the waiting room, and whom I encountered while observing specialists run outpatient clinics, Xiaoxi had not known of the online appointment system. Luckily for her, Dr. Chu had given her an additional slot, and she was able to receive a relatively prompt diagnosis. The kindly gentleman, Teacher Lee, had done some research and found that Jingyu would be eligible to attend the school at no charge. In that way, Xiaoxi avoided becoming a diagnostic nomad, as did Feng Ma, even though both of them were from villages in Hebei. Xiaoxi did not accrue a lot of debt in search of a diagnosis for Jingyu; even if she did for the first two children who died before they reached their second birthday. Her first two children had died before they each reached their second birthday, and she never knew why. We speculated it was malnutrition, since Xiaoxi had been warned by doctors repeatedly that she and her children were malnourished.

Though Dr. Chu's interactions with the family caregivers appear brusque (and her explanatory process is so curt that it seems pointless), her cramming so many patients in a day provided a lifeline for Xiaoxi, who could barely write her name, much less search

electronically for information or set up appointments in Beijing. An examination of computer ownership and digital literacy shows the gulf between families from middle-to-upper-middle socioeconomic strata, and those from below, with 47.2 computer ownership per 100 urban households versus 2.7 computer ownership per 100 rural households (Fong 2009:6). At the same time, rural families also lack the capacity to navigate and evaluate online sources so as to locate relevant information, is also necessary in navigating such uneven quality of medical care and services in China. Given that at least 2/3 of rural populations stop schooling past the 9 years of compulsory education (Fong 2009:6), it is not surprising that parents like Feng Ma, Xiaoxi, and the parents being scolded by Dr. Chu are unable to identify their child's puzzling symptoms, and need a diagnosis from Dr. Chu.

Every morning, long lines snaked around the psychiatric hospital, since slots are allocated supposedly on a first-come-first-served basis electronically, but which then effectively cuts out rural or less literate families. If these families fail to make a slot, they might have to wait at least a week or even a month, since none of the senior psychiatrists or clinicians familiar with autism either in Beijing or Guangdong hold outpatient clinics every day and many of these clinicians would often travel to other provinces to train other doctors.

Yet, Dr. Chu's harsh scolding of parents in the name of "saving the child's potential" failed to take into account the difficulties which parents from less well-resourced provinces or from rural areas faced. She is not alone in doing so; I have observed doctors in other provinces such as Hainan similarly scold parents, if their children are over five or six years old, for not bringing in their children earlier. That she

harshly berates parents is well known; parents and other doctors, such as Dr. Li, used to wink at me knowingly and asked me whether I had heard Dr. Chu yelling at parents. In privileging the child's potential and blaming the parents for missing out on the child's golden period of development or as she puts it, "not observing their child's development in the playground," Dr. Chu essentially limits her area of concern to the child, while ignoring the families responsible for the child, especially the families who lack social capital to make informal diagnoses on their own.

Consider Mother Xing, a prominent parent-advocate, who expressed such a sentiment to me one day. "Does having a doctor who can diagnose autism matter?" asked Mother Xing dismissively as we walked up Baiwang Mountain, huffing as she tried to catch her breath. We were on a hike organized by a nongovernmental organization, seeking to take full advantage of the all too rare clear skies after weeks of unremitting smog. She continued, "Don't families need long-term therapy and care more than a diagnosis? As long as you [the parent] find a diagnosis on the Internet, that's all we need! What else can the doctor do but give you a label?" From the perspective of many well educated and comfortably well off parents, a diagnosis from a doctor is useless and pointless, as they believe that they can serve as diagnosticians themselves. Unlike well-educated families in the United States who typically obtain a diagnosis for insurance purposes, well-educated parents in China often told me they did not even bother to visit a doctor to obtain a diagnosis, since they had already observed that their child displayed a number of traits that could be seen as autistic. These parents were able to find an appropriate diagnostic label because they are able to go on the Internet, sieve out the appropriate information, and go straight to the appropriately trained doctor. Neither Dr.

Chu nor Mother Xing are unique in not recognizing the difficulties rural families have in identifying a child's autism; so too do other nongovernmental organizations funding autism advocacy in China. During my fieldwork, I volunteered with the One Foundation, an organization funding virtually all the autism rehabilitation centers in China as well as the publicity for World Autism Day in most major cities in China. Invariably, officials in the One Foundation will ask me how parents in China with autistic children could be better supported. While officials often nodded in assent to the suggestions I offered regarding meeting the psychosocial and material needs of families caring for autistic children beyond the age of 12, my observation that families also need access to trained medical professionals who could provide a diagnosis would be met at first with surprise and shock, especially when I provided rough figures of how much money some families were spending on obtaining a diagnosis.

Some other specialists make other choices than Dr. Chu and see fewer patients in their practice in favor of providing longer and more comprehensive consultations, but they do so by refusing to add last-minute patients. Dr. Li Hanwei, in Beijing, and Dr. Cai, in Guangzhou, typically spend 20 minutes on each patient, taking time to explain what autism is and to ensure that parents do not blame themselves for their child's autism. Having interned in urban hospitals on the East Coast of the United States. First he asks them to describe their child's syndrome, then he patiently tries to work with the families to consider their next steps within the 20 minutes he can give. He is careful to explain that autism is not caused by any caregiver's actions.

"You don't pay attention to our son! I'm always the one who has to take care of him!"
says the woman furiously.

“You shut up! I want to talk to the doctor! Is it because his mother doesn’t talk to him enough? Or doesn’t show enough love? I bet it’s from her side.”

“You are never home! You see the child twice a year! You’ve never fed him or cared for him! You hit the boy! You hit me too! All the time!”

Dr. Li often calmly intervenes at this point in time. “Please don’t bring in your quarrels here. Autism is a congenital disorder, not an acquired one. It is caused by genetics, but there’s no point in blaming each other now. Please focus on how you can bring up your child. Autism is a disorder where children have difficulties with communication. But you need to spend time with your child. Please don’t hit your child. Just ignore him when he is misbehaving, but reward him with attention and toys when he is behaving well. What’s your educational level?”

“Secondary.”

“Okay, so you can read? Please just go to my website, which I’ve written down for you. You can find information on techniques as to how you can raise your child.”

“Is there anything I can do? Are there any schools I can send our children?”

“I don’t know enough about organizations to recommend something to you--you have to spend time to figure out which organization is best for you.”

Dr. Li only has outpatient clinic hours twice a week, for half a day. Thus, he can only see on average fifteen patients a day. Dr. Li sees fewer patients because he wants to spend time quelling any anxiety on the parents’ part that they caused the child’s autism. To the grandparents or parents who barge into his office begging for him to add another appointment, Dr Li always has this to say: “ I’m sorry, but I really cannot see you because there are just too many patients. Please come tomorrow or find another doctor.”

Dr. Li knows that some of the parents or grandparents he turns away will never receive a diagnosis. But as he points out, what is the point of providing these parents with a label they cannot understand?

Double Binds of Diagnosing Novel Conditions in Settings of inequalities

Is it better to see fewer patients and provide each one more time or see as many patients as possible? How can the doctor impress upon the parent the importance of exploiting the time when their child is most malleable? These are the double binds that each specialist of childhood autism must navigate. A concept originally developed by Gregory Bateson, anthropologist Kim Fortun defines a double bind as “not simply a situation of difficult choice, resolvable through reference to available explanatory narratives. ‘Double binds’ denote situations in which individuals are confronted with dual or multiple obligations that are related and equally valued, but incongruent” (Fortun 2001: 13). The moral economies that have emerged around the value of the autistic child’s “golden period of child development,” place injunctions on doctors to provide a diagnostic label and to impress upon parents of young autistic children the importance of providing early enough intervention. At the same time, the sheer number of families outside their office, some of whom will never obtain a diagnosis, also place upon the doctors the injunction to give as many diagnoses as possible. As parents themselves, both Dr. Chu and Dr. Li understand that parents are naturally frantic and may blame themselves. But quelling these parents’ anxiety will take away time from the next parent; even if they skip their meals, as Dr. Chu (and Dr. Cai) have done many times, they will never finish seeing the long line of families who line up in front of their office. In many ways, Dr. Chu and Dr. Li have to

confront such difficult decisions owing to the poor quality of medical care provided by rural or community clinics. It is understandable why specialists like Dr. Chu might come across as impatient and angry with the parents they see on a regular basis and why Dr. Li chooses to turn away parents instead.

In many ways, their allocation of time raises other questions as to what constitutes care by doctors for children with autism. While Dr. Chu may privilege the provision of a label to as many parents as possible, and Dr. Li chooses to see fewer patients so that he can allocate more time to each family and their questions, both of them similarly privilege the language of choice in limiting the scope of their responsibility. Dr. Chu, for instance, insists that parents must have chosen not to prioritize their child's wellbeing, which is why they only brought their child for a diagnosis now, when the child is too old to be accepted by any therapeutic center. Dr. Li and Dr. Cai on the other hand, steadfastly refuse to recommend any therapeutic centers; both of them insist that parents have to do the research and make that decision themselves. When I asked both of them why they refuse to offer any recommendations, both of them explained they wanted families to make the choice themselves, since they did not want to be held responsible if the parents end up being dissatisfied by the therapeutic centers they have chosen.

Anthropologist Annemarie Mol reminds us that the logic of choice, which appears to be a unilateral good because "it offers individuals autonomy," often means in practice patients are neglected or abandoned (see 2008: 85). Care, on the other hand, "reacts forgivingly to failures" even when families may appear not to give adequate care (see 2008: 96). Seen in this light, the privileging of "choice" and the autistic child's potential, both of which inform doctors' allocation of time, represent an abandonment of

families to their own devices.

I suggest that the well-meaning focus on the child's potential also allows doctors to avoid being blamed; it allows them to dictate how parents need to respond to their child, while limiting the services they might provide. Such a pattern of doctor-patient interaction in fact mirrors what anthropologist Katherine Mason terms "the bifurcation of service and governance," which in turn fuels social mistrust on the part of doctors and patients (2016: 27). Fearing that families will blame them for making wrong recommendations, Dr. Li and Dr. Cai refuse to make any recommendation. In some ways, they are right to harbor such fears. During my fieldwork, many parents asked me for recommendations. As one parent poignantly said to me, "I don't trust the doctors who may suggest therapies that would line their own pockets, so I'd rather trust you because you are a foreigner!" In such a social climate, it is difficult for parents and doctors alike to collaborate or to recognize the human limitations upon each party.

Neglect of the Autistic Teenager and Young Adult

The focus on the autistic child's potential leads to neglect of the autistic adult. In so narrowly focusing on the potential of *xingxing de haizi* (children of the stars) during childhood, autism advocates effectively neglect the adult with autism, even if said adult was diagnosed late. During my fieldwork, I met parents who spoke of having to lock their adult sons behind closed doors. The reason is that their child was diagnosed only after the age of 16 and doctors said that there was nothing to be done for them. The parents could not afford one-to-one tutors and these adult sons sometimes touched themselves inappropriately in the company of female neighbors. The parents resorted to locking up

their sons out of desperation. There are few, if any, organizations willing to care for autistic teenagers and adults (with the exception of the teenager section of Sunflower Autism Center, which accepted teenagers until the age of 18, and one center in Shenzhen). Explaining the lack of service provision for teenagers and young adults with autism, an organization in Shenzhen told me that it was widely perceived that there was “no hope” once the child grew past elementary-school age. Their teenage section was only able to charge about 800 RMB (120 USD) per month for the daycare of an autistic teenager or young adult, while the children’s section was able to charge about 4000 to 5000 RMB (600 to 750 USD) per month for the day care of an autistic child. Organizations explained to me that parents were unwilling to pay more for the care of autistic teenagers and adults, while they were willing to pay more for an autistic young child.

In response to the nation-wide neglect of autistic teenagers and young adults, a group of parents in Beijing have banded together to set up Golden Leaves Autism Center. Golden Leaves was registered as an independent nongovernmental organization in October 2012 by six fairly well-to-do parents (with children ranging from the ages of 15 to 24), some of which were either trained at Sunflower Autism Center, or knew each other because of the extremely small number of educated parents with young autistic children in the late 1980s and early 1990s then living in Beijing. This center integrates behavioral therapies in the daily routines of teenagers and young adults with autism. It is the only autism center in Beijing catering solely for older teenagers and young adults (mostly of upper-middle-class backgrounds), whose families can afford to hire one-on-one tutors and import materials and syllabuses from the United States while providing

additional training to special education teachers. It is important to note that this center is funded mostly by the parents, who work as directors or upper-level management in multinational corporations, and thus, can afford to fund such specialized attention.

Due to high rental costs, this training center is located far away from the city center in Beijing. The large bungalow located a few bus stops away from the last stop on the Chang Ping District subway line in the northern Beijing was carefully chosen so that it feels more like a home than a training center. On an unpolluted Beijing day, the sunlight often streams in through the bungalow's wide glass panels as the autistic teenagers and young adults in this center bake their own cookies for sale and take computing classes on equipment donated by the companies where some of the parent founders work as directors or managers; there are tiny plots of land which showcase the crops grown by the autistic teenagers and young adults enrolled in the center. All these features are not necessarily typical of autism rehabilitation centers. Many I have visited have small or practically no windows. The teachers and parents often video-record, or invite the media to record baking classes and so on so that the public will be able to see that these children can enter the workforce given the right social support. As Mother Xing, one of the parents responsible for Golden Leaves, told me during an interview

Our children are our guinea pigs. We want to ensure that there will be quality services at every stage of the autistic individual's development, and the only way to motivate the nation is by showing how [applied behavioral analysis] works through the use of our own children If our children are able to have their own careers and take on jobs suited to their abilities as they grow older, the nation will see that autistic young adults have a future, and see the need to invest in this industry.

Golden Leaves is the exception rather than the rule when it comes to the services for autistic teenagers and adults; it is also available only to these affluent families.

Gender Disparities

The focus on the autistic child's potential also exacerbates gender disparities. Though pediatricians, clinicians, special education teachers and parents alike insist that “jiazhang” (a gender-neutral term which translates as the head of the household) are to exchange their present for their child's future, it is mostly mothers who end up making sacrifices for their children's developmental needs, but they also receive little recognition for the sacrifices they make. I was able to obtain a breakdown of the profile of family caregivers at Sunflower Autism Center, even though the school did not keep track of the demographic profile of parents. Since the school only ran five classes (of not more than ten parents) per class in each three-month long semester, it was easy for me to rotate to each class after every few weeks and get a profile of the family caregivers who had brought their children for the three-month rehabilitation course. Out of 48 family caregivers there, only four were fathers, the rest were mothers (with one exception, a grandmother). The demographic breakdown in terms of gender was to remain similar for the next two semesters (though there might sometimes be a few aunts and uncles who took on the role as primary caregivers). This was not unique to Sunflower Autism Center. I counted 25 mothers out of 30 parents in another school in Beijing. These percentages were similar in schools I observed in Changsha, Guangzhou, and Shenzhen; teachers in these schools also confirmed such a gendered division of labor. Mothers constitute eighty to ninety percent of the long-term attendees, not only of one-day seminars, but also in the residential semester-long autism rehabilitation centers in Beijing, Guangzhou, Shenzhen, Qingdao or Changsha. Fathers were still a rarity in these centers. When asked about how they made their decision, mothers (and sometimes aunts) explained that it made better

sense economically for them to give up their jobs, while fathers were responsible for ensuring the upkeep of the family. Furthermore, the risks and rewards for parents serving as primary caregivers of autistic children also differ according to gender. Fathers are recognized and praised by the local communities while mothers' dramatic sacrifices go unremarked and are taken as the basic duty of parenting an autistic child in China.

In some ways, such a gendered division of labor reflects broader patterns in gender disparities in child rearing and rising gender inequalities. Mothers have come to bear the responsibility for nurturing the quality child. As Greenhalgh and Wrinkler show, the raising of the quality child became a woman's project for several reasons: the reform era gave rise to a gender ideology that prized the "virtuous wife and good mother (*xianqi liangmu*)" (2005: 238-239), while the loss of retirement pensions also has meant mothers came to more deeply depend on their child serving as their source of old age support. Such a remaking required that mothers drew upon "scientific methods" as they raise the quality child (see Greenhalgh and Wrinkler 2005: 237 on Susan Champagne's 1992 dissertation). The subject of much scrutiny, as anthropologist Teresa Kuan shows, is "no longer the immature child but rather the problematic parent" (2015: 6). Of course, the effects of the shift towards the affective, and pedagogical nurturance of the singleton are not always experienced in negative and stressful ways for the parent. Harriet Evans, for instance, shows that mothers and daughters increasingly move toward an affective style of discourse, emphasizing communication (*guotong*) (see 2008: 97).

Yet, it must be emphasized that the mothers to whom Dr. Cai is speaking cannot hold such expectations. Through the analytical framework of moral economies, we can see that the value of a child's potential as it pertains to autism intensifies patriarchal

norms of childrearing in postsocialist China, placing mothers in far more vulnerable positions than fathers or their counterparts raising children who are reaching their developmental milestones in a timely manner. What is even more problematic is that doctors themselves expect mothers to observe their children's developmental milestones and to also essentially give up all opportunities for their own economic security both in the present and the future.

This was brought home to me one evening. I had become a familiar face to doctors such as Dr. Cai and Dr. Li, who were presenting at a seminar, and I was invited to join them for the banquet to celebrate the seminar's successful conclusion. The seminar, which was run with the intent of explaining the principles of psychological techniques relevant to autism, was attended by both doctors (whose attendance was made mandatory by their workplace or *danwei*) and mothers of young autistic children. As with other such seminars, most of the free spots were filled by mothers who came because they were eager to learn as much as possible about techniques they can use with their autistic children. The banquet, which praised the doctors who presented as having "established the field of autism itself within China," followed the typical format of most banquets in China, in which each toast honoring each guest becomes ever more extravagant. Each of the doctors praised Mr. Wu, a director in a prominent state-funded nongovernmental organization, for his work in organizing a successful conference. They claimed that he had raised the standards for autism treatment in the whole of China.

Shaking his head in reply, Mr. Wu jumped into an explanation of why the conference was necessary. Mr. Wu complained, "If I didn't organize a workshop [run by qualified people like you all], there will be only the conferences organized by those

mothers [with adult autistic children]! All the young mothers hold on tightly to those mothers with grown up autistic sons as if they are Buddhas, but look at their autistic adult children! They are hardly success cases. The children absolutely can't cut it. No way."

Dr Zhu chimed in quickly to say, "That generation of adult autistic children is lost For some, their mothers have spent too much time running an autistic rehabilitation school. These mothers should just stay at home to focus on training their autistic children, and not do anything. They should not be allowed to set up schools for autism training. In fact, we should just sponsor parents to come for training [by us] so they don't train under those mothers."

The rest of the banquet ended with the doctors and Mr. Wu proposing a new school, which would be run and governed by the doctors. Tuition would be completely subsidized for all parental attendees, but parents would have to sign an agreement that they cannot set up autism rehabilitation centers to train other parents with autistic children.

In complaining that that "generation of adult autistic children were lost," Mr. Wu and Dr. Zhu (as well as the other doctors who were all vigorously nodding their heads in agreement), the doctors and Mr. Wu seemed especially myopic, given that they themselves were raising children who are all well on their way to academic and career success. The mothers they have criticized have in fact achieved tremendous success in the face of a complete absence of services during the 1980s to the 1990s. As I suggested in chapter two, it was the sole efforts of such mothers as Mother Zheng who, without any help from doctors or other trained professionals, helped other mothers see that autism was not a death sentence for the child or the entire family. These mothers fought to provide

therapy for their by-now adult autistic children at a time when the two to three doctors in the whole of China trained to diagnose autism were strongly advising them that there is no hope and all they can do is to go home and manage as best as they can. The reason why they are looked up to, or (as I will demonstrate in chapter five) are seen as exemplary mothers by younger mothers today, is because they filled a vital role at a time when there was no state or societal provision for autism care.

In blaming the mothers for their adult sons' apparently bleak fate, the doctors and Mr. Wu had forgotten that the "lost generation," as Dr. Zhu puts it, was lost also because the state had failed to provide other forms of care for them. And the adult children's fate, in effect, foretells the fate of the young autistic children whose parents still today lack the means to become full-time therapists. It is clear that Mr. Wu and the doctors, influential actors who hold the purse strings for tuition subsidies and bursaries, never accounted for mothers' loss of livelihood, independence, identities, or relationships with spouses and other family members during these years. More perniciously, however, they were not only blaming the mothers for not doing more to train their autistic children, but were expecting mothers to give up any means of supporting themselves in the present or the future.

Such expectations are unreasonable, especially for mothers from lower socioeconomic strata. Qingling, a young mother with long burn scars on her hands and legs in Friendship Autism Rehabilitation Center, told me she had been extremely entrepreneurial in selling food in carts along the streets and was able to save money for her two children, while her husband roamed the informal and illegal gambling dens in her hometown. She gave up her thriving street food business (which had also given her those

scars along her limbs) when she came to suspect her son was mute. After Dr. Chu gave her a diagnosis and a recommendation to come to Friendship Autism Center, Qingling signed up the next day at Friendship. She had hoped that both she and her son could live off her savings while they were in Friendship Autism Center, but it was not to be. Her husband absconded with her savings, and Qingling had to draw upon her maternal relatives for loans (again, she was fortunate that the founder of Friendship Autism Center, Dr. Mu, was an unusually generous middle-aged doctor who empathized with her and other mothers' plight, in part because of her deceased autistic brother).

While Qingling's decision to stop her entrepreneurial activities made sense in terms of the urgency of her son's needs, such a choice to give up her source of employment would put her at greater risk in the present and future. These patterns of maternal sacrifice had devastating effects on many of the mothers (though less so the fathers or uncles). Many mothers I met in Sunflower and in other autism rehabilitation centers told me their husbands were having affairs, but they were staying in their marriages because they had no way of re-entering the job market quickly, and their child's expensive tuition at these autism rehabilitation centers still had to be paid for. They cannot afford to wait until they get a job, since it is only during this golden period of time they can "save" their child. Others, especially those who used to be white-collar professionals such as accountants and office managers, spoke of pretending not to notice their husbands' secret expenditures and fast-depleting bank accounts, and the sudden increase in their husbands' out-of-town business trips. While they knew (and some had proof) that their husbands had an extramarital relationship, their loss of an equal standing within what were once fairly egalitarian marriages (by their standards) meant that

confronting their husbands was risky business. Because high-quality autism rehabilitation centers were located only in a few regions such as Beijing, Qingdao, and Guangzhou, these mothers who were once white-collar professionals had to make difficult decision as to whether they should focus on keeping their jobs and to maintain the strength of their family relationships or to prioritize their children's developmental potential by leaving their home provinces, while risking all else. It is mothers, rather than fathers, who bear the brunt of exchanging their jobs, the risk of losing their relationships with their spouses and other family members.

“Exceptional” Caregiving Fathers

The asymmetry of such a moral economy becomes even more evident when we trace how fathers are feted when they become primary caregivers for their children, while mothers' work remains by and large unmarked and taken for granted. Over and over again, I was to hear these fathers hailed as “great” (*weida*) or “outstanding” (*youxiu*) or “wonderful” (*bang*) for their willingness to travel from their hometowns to autism rehabilitation centers in Beijing, Guangzhou, and Qingdao. I was to hear parents and teachers alike complimenting these fathers to their faces or pointing them out as exemplars to me or to other parents. Some parents and teachers told me enthusiastically that they had to introduce a particularly “outstanding” father to me since it would be so relevant to my research. When I asked why they considered that particular father “outstanding” or “great,” answers ranged from “this father is not like other fathers, he does not leave parenting duties to the mother of the child” to “mothers are naturally more suited for

childrearing, and the fact he is willing to do this is really amazing” or “he is patient with his child, not like other fathers.” Such understandings play into the essentialisms around gender which anthropologists of China have observed continue to haunt postsocialist Chinese discourse (Lee 1998; Rofel 1999; Woo 1994). Significantly, none of the fathers who were praised in this manner were single parents, or at risk of losing their livelihoods. Several ran their own businesses and many came accompanied by their wives, although it was the father who would accompany the child to classes at the autism centers. The gender disparities was not the effect of a skewed sample size in Beijing’s Sunflower Autism Center, but was something I observed too in Friendship Autism Center, and even in Shenzhen, where enthusiastic teachers insisted I meet fathers who took on the primary responsibility for their autistic teenaged sons.

The fathers were applauded in many ways, but what was noticeable is that these fathers (and their wives) were overwhelmingly from the middle-to-upper strata of society, their wives were fully supportive of their endeavors, and their wives were professionals in their own rights. All of them had entered a love-marriage freely and met their wives during their university years; in many ways, their relationships represent what anthropologist Yunxiang Yan terms as “the triumph of conjugality” (1997), or the shift toward a language suffused with affection between husbands and wives. Five out of eight fathers who took on the long-term responsibility for their autistic children were running their own businesses while married to doctors. With their wives effectively guaranteed steady employment with decent benefits, even if their salaries were not terribly high, these fathers were able to decide to scale down their involvement in their businesses since they were in no danger of being fired by disgruntled employers. As a father told me, “I

can easily restart my business again after this child is better, but this way, we can still have more income and job security for the two of us so that we can provide for the child.”

At the same time, many of their wives expressed their admiration for their husbands’ devotion to their child, and willingly took on additional household chores so that these husbands could take charge of their son’s therapy needs. Like the American mothers whom Arlie Hochschild studies, the mothers of autistic children often took on a “second” shift (1989). While fathers assumed primary responsibility for the child during the school week in bringing the child to classes and attending to the child’s daily needs, their wives, who had stayed behind in their home provinces to take care of in-laws and to go to work daily, visited every weekend. Their weekend visits were not leisurely ones: the wives washed piles of dirty clothes and bed linens and cleaned and mopped floors. It was almost impossible for me to find time to talk to these wives because they would always be doing some neglected household chore or other. And some of the fathers I studied had also made it clear that they planned to go back to work and leave their wives as the primary caregivers. The fathers felt they would, as one put it to me, “go crazy just facing the child alone, day in and day out.” Some of the mothers had in fact expressed exactly the same sentiment to me, but all the mothers took it for granted that it was ethically imperative they sacrifice for their children (no matter how they felt about it personally). It was far easier for me to meet with the fathers who had come to visit their children in all of these autism rehabilitation centers. Even the weekend activities engaged by these families who are temporarily living far away from home in search of therapy were revealing of the gendered nature of the moral economy. Fathers who came to visit their children in places such as Friendship Autism Center or Sunflower Autism Centers

during the weekends often requested to tour Beijing (or Guangzhou), and the whole family would troop out to have a mini excursion (chores had been done during the week in preparation for the father's impending weekend visit).

And yet, many of the wives whose husbands took a lead in providing therapy to their child often expressed deep gratitude. Hochschild's (2003) perceptive questions around who is grateful to whom, and who is seen as responsible for which tasks sheds light on "the economy of gratitude" evident even in these well-educated middle-class families. Such an economy of gratitude, in that sense, reveals the gendered nature of the economy around a child's potential; a mother's present and future is seen as less valuable than a father's and the autistic child's. Anthropological research has revealed the increasing power of urban daughters and rural daughters-in-law relative to parents as a result of shrinking family sizes (see Fong 2003; Yan 2004), yet the shift of power to the females of a younger generation is not necessarily indicative of a power parity between spouses, or what local communities deem as the responsibilities of husbands and wives. Instead, gender relations, especially in the arena of marital relationships, have in fact become tremendously unequal in postsocialist China, with what several scholars observe as "the sexualization and commodification of women's bodies in China" (Hanser 2005: 584; see also Brownell 2001; Schein 2000; Zheng 2009). Geographer Cindy Fan has argued that postsocialist employment patterns in the form of rural-urban migration only have only given women short-lived opportunities for employment, and marriage relegates rural women back to childcare and household responsibilities within the village because of the enduring persistence of the stereotype that women are "the nurturing family members ...[and] primary caregivers" (Fan 2003: 28; Yu and Chau 1997; McDowell

1999). Fan's study reveals that rural families' household strategies position women as the primary caregivers and men as the primary breadwinners. In many ways, both rural and urban households' management of the care of autistic children replicate the return of women to the care of domestic matters, while men take on the work of breadwinners.

Conclusion

In this chapter, I have paid close attention to the value placed upon the child's potential and the different moral economies that have sprung up around it. The concept of a child's potential drives the ethical decisions by doctors in allocating clinical care, while justifying the neglect of the autistic adult and the unequal sacrifices made by women. Such a value placed upon a child's potential appears to make particular sense to generations raised under the one-child-with-exceptions policy, but has had terrible repercussions on family caregivers, particularly ones from rural or marginalized areas (where they might also leave the other sibling at home). As Fassin points out in his work on the moral economy of humanitarianism, children "encapsulates the future of the population [and] embody both innocence and vulnerability" (2013: 128). In China, however, children do not only embody the two qualities he identified. While children without developmental disorders may embody the potential for the nation to compete on a global stage, children with autism embody a terrifying future, and the best that may be hoped for them is that they will turn out to lead lives that may approximate others.

At the same time, the moral exchange normalized in Dr. Cai's call to exchange "your today for your child's tomorrow," effectively weighs more effectively on mothers. It is after all, mothers, rather than fathers, who bear the brunt of exchanging their jobs,

and risk of losing their relationships with their spouses and other family members; even the diagnostic and therapeutic vagabonds in chapter three are predominantly women. The asymmetry of such a moral economy becomes even more evident when we trace how fathers are feted when they become primary caregivers for their children, while mothers' work remains by and large taken for granted.

In many ways, the case of autism offers another perspective on the sometimes celebratory responses of scholars in the fields of anthropology, women studies, science studies, and disability studies to ultrasound, amniocentesis and other reproductive technologies. In her examination of how technologies open up new terrains for ethical and moral decision-making for mothers, anthropologist Rayna Rapp hails mothers who grapple with whether to use amniocentesis as “moral pioneers.” She argues that these mothers essentially become the gatekeepers in deciding who is allowed entry into the human community as they decide whether to carry a child with congenital disorders. If mothers are “keepers of technologically assisted health” (Rapp 1999:198), they are also held morally responsible for fetal health, whether by themselves, or with other family members (Rapp 1998: 98). This is true especially of mothers of infants and toddlers with disabilities, as Gail Landsman found. Herself a mother of a daughter with cerebral palsy, Landsman observed that most of the mothers “hold themselves accountable, or feel that they are held accountable by others, for the failure to produce a perfect child despite their access to expert medical knowledge” (1998: 85). What these anthropologists have shown is that knowledge about maternal and fetal healthcare practices have simultaneously empowered women, but also placed women under approbation for failing to make

effective health and lifestyles decisions or for not being good mothers.

The “tyranny of the child’s potential,” as I describe the situation, thus intensifies maternal blame for families with disabled children. Having in the past (and among some, still today) been held responsible for childrearing practices that resulted in autism, mothers are now expected to devote their entire energies and time in training their autistic children, even if it endangers their own livelihoods. As anthropologist Jianfeng Zhu observes, the state attempts to “promote national health in economic terms and to free itself of responsibility for public health, insisting that the individual make personal but ‘rational’ choices about his/her own future” (2013: S37). These “rational” choices which Dr. Cai and others insist the mother should make all but allow the state to free itself of responsibility for the plight of families.

ⁱ She is highly recommended on Chinese website such as www.haodf.com and <http://health.sohu.com>.

Chapter Five

“Truly Loving Your Child”: The Autism Therapeutic Apparatus and the Making of Parent-Therapists in Contemporary China

With autism diagnosis and therapy (for school-age children) available in Beijing and Guangzhou but remaining absent in other provinces well into 21st century, both doctors and parent advocates alike urge that a child should be provided early and intensive autism rehabilitation, since there are no alternatives once the child grows into a young adult. Over the past few years, autism rehabilitation centers, autism support groups and autism parent-training seminars have mushroomed across many economically advanced centers such as Beijing, Guangdong, and Qingdao, though remaining completely absent in China’s less economically developed provinces and rural areas. These diverse centers, support groups and seminars have these features in common: they serve as the main channel through which financial aid from philanthropic organizations and the state flows to families with autism, they take as central the tasks of reforming parental practices, as I show in Chapter Five. Organizations such as Shenzhen’s One Foundation primarily fund rehabilitation centers for autistic children under the age of eight or so, and municipal governments in Beijing and Guangzhou similarly fund rehabilitation for school-going children, but lack services for autistic adults. Other provinces may not have any rehabilitation centers, much less offer any tuition subsidy. For these reasons, much of autism advocacy circles, including parents, doctors and nongovernmental organization focus on exhorting families to provide their children with rehabilitation as quickly as possible, or else they will hit the age when no rehabilitation can be provided.

Zheng Huifeng,¹ the parent-advocate whom I have already introduced in the previous chapters, is giving a lecture, as she usually does, at the beginning of the semester in Sunflower Autism Center. She reminds parents “you are here to learn scientific principles in parenting and caregiving [through Applied Behavioral Analysis, or ABA], and indeed, how to love and respect your child.” Zheng’s lectures are always delivered to a packed audience made up mostly by mothers, as well as a few fathers and grandparents. She emphasized, “in order to help our (autistic) children, you will have to unlearn expectations about parent-child relations prevalent in China, ...and we are here to teach you how. You have to learn how to respect and treasure life for itself, and not see a child as a form of old-age insurance as so many of us do in China.” Through her lectures, Zheng has articulated how the advocacy of behavioral therapy training in China today is motivated by more ambitious aims than simply teaching autistic children; the advocacy is aimed at remaking parental practices and dispositions, and not least, they make claims of re-making Chinese parental ethics with the help of behavioral therapies. In this chapter, I show how the advocacy and insistence on behavioral therapy is an attempt by elite parent-advocates, nongovernmental organizations and doctors to rewrite the intergenerational contract, or the often unspoken, yet taken for granted assumption that children will constitute old-age security for parents and grandparents for families with autistic children. I argue that the call for all parents to become *parent therapists* for their autistic child(ren) makes a new kind of parent. In a startling reversal, the moral worth of parents, rather than the autistic children, is measured by their capacity to nurture the potential of their children to its fullness, irrespective of the capacity of these children to reciprocate economically or practically over their life courses.

Speaking on behalf of all autistic children, doctors, philanthropic organizations, and other

¹ All interviewees have been given pseudonyms to protect their privacy.

autism child experts in China claim that “true parental love” is marked by i) the unstinting willingness to nurture a child’s potential without expectations for future recompense in the form of elderly care, and ii) the implementation of round-the-clock therapeutic behavioral regimes tailored by the parent for the child. In this discourse around parenting, truly loving parents, or “great, self-sacrificial” parents, are those who become highly regulated, self-monitoring, *life-long* therapists for their autistic children. It is not enough simply to feed and clothe autistic children. They parent through the consistent deployment of intensive and round-the-clock behavioral therapies so as to free the child as much as possible from his or her autistic tendencies. Conversely — as I was to hear over sixteen months of fieldwork in outpatient child psychiatry and child psychology clinics, autism rehabilitation schools, as well as autism training seminars for parents — selfish parents “give up” on their children by not putting in the effort to institute these intensive behavioral therapies at home. Such moral judgments that good parents must unceasingly nurture their children make it self-evident that the onus of care should lie on the shoulders of families, regardless of their access to educational, social, medical, and economic resources, to serve as their children’s therapists.

At present, comprehensive nation-wide provisions for autistic persons remain absent within the nation, even as autism diagnoses rise in urban China. Though autism has been diagnosed first in the 1980s in Nanjing and Beijing, the central government, in fact, was to only formally recognize autism, by including it within the rubric of mental disorder in 2006, and in 23 July 2010 when the Ministry of Health issued a directive to doctors nationwide on how to diagnose autism, and what to suggest to parents. Yet, the central government has not funded autism diagnosis or therapy consistently across the country; it is left to municipal and local governments to decide whether they will subsidize the therapeutic needs of the autistic children

in their municipalities, such that Guangzhou and Beijing have decided to offer tuition subsidies to children under the age of ten or so, while other municipals do not. The lack of consistent support by the central government thus sends a message that families are fully responsible for their children's therapeutic needs; even the tuition subsidies offered by local governments is restricted to young children. As such, non-state actors such as medical professionals, philanthropic and educational organizations, and parent-activists have spoken, remarkably, with one voice in urging parents to become behavioral therapists for their children. Holding Chinese culture responsible for normalizing the expectation that children should serve as a form of old-age insurance, parent-advocates such as Zheng and child psychiatrists seek to reform parental behavioral practices and ethics. In their vision, children's autistic strengths and limitations should not be made to bend to the wishes of their parents. During my fieldwork in Zheng's school, I heard Zheng and the other teachers employed in the school repeatedly preface their correction of parents with the claim that parents must learn to "respect their child." Such an exhortation applied to any aspect of parenting behavior these teachers found problematic — from using corporal punishment when the autistic child failed to obey a command, to a parent's inability to read a child's unhappy face; they equated the use of ABA with the respect for the child and life itself.

As I show in the previous chapter, autism is charged with contradictory affects: that of hope but also with tremendous anxiety; these affects in turn impel parents and doctors alike to insist that autistic children must be provided therapy at an early point, or else it would be too late for them. Drawing upon anthropologist Erica James' "aid apparatus" (2010: 81), which she defines as "networks of international, national, and local governmental and governmental agencies and agents that have a common 'principled issue'" (2010: 85), I identify a similar

apparatus as it pertains to autism in China, and term all of these non-state actors and their efforts the “autism therapeutic apparatus,” because all of their initiatives focus on encouraging parents to provide round the clock therapy to their children, in part because of the lack of state-run and funded social services. Doctors who not only diagnose, but urge therapy (as we see from Chapter Four), parent advocates who encourage the setting of such a therapy, humanitarian organizations who fund endeavors related to therapy and the families who use autism rehabilitation centers all constitute this apparatus.

On other possible forms of social assistance for families with autistic children, the autism therapeutic apparatus and the state have remained largely silent. By framing the therapeutic care of autistic children as the rightful duty of parents, the autism therapeutic apparatus attempts to upends the intergenerational contract by taking the willingness and capacity to deploy behavioral therapies as a barometer for the *quality and ethics* of the individual parent and Chinese culture writ large. I show how the exhortations of the autism therapeutic apparatus give rise to a coercive form of biosociality which occludes the structural inequalities that either foster, or hinder, the making of individual parents into therapists, while encouraging the stigmatization of those who are unable to provide therapy for their children.

Autism’s Significance for the Intergenerational Contract

The autism therapeutic apparatus’s directives, I suggest, shed light on a drastically changing “intergenerational contract”, or the norms of parent-child relations in Chinese family life. Since imperial times, Chinese family life has been structured around norms of filial piety in parent-child relations, where parents instruct their children that the moral worth of an individual is measured by how they treat their elders (Whyte 2004: 106). Anthropologist Susan Greenhalgh

(1988) argues that parent-child relationships are governed by the intergenerational contract, a term she developed in analyzing Taiwanese childrearing practices, where parents invest more heavily in male children's education and nurturance (while exploiting their female children) in the expectation that male children will be more economically able to repay back their parents' investment. Charlotte Ikels also uses this term in discussing the strategies which parents take in order to guarantee old age (1993: 307). Even as the balance of power has shifted from parents to children in post-reform China (Yan 2003; Ikels 1993), the moral presupposition that parent-child relationships are governed by generational exchanges in caregiving labor remains prevalent for Chinese families (Chou 2010, Liu 2008, Hui and Scott 2014, To 2014, Yeh 2013).

This is also evident from anthropologist Vanessa Fong's ethnographic studies in Dalian where she reports moving exchanges of daughters protesting that they will take care of their fathers and mothers once they grow up, revealing that the moral basis of high expectations for future repayment of parental care in the form of caregiving responsibilities for aging parents and grandparents are implicitly accepted and internalized by many singletons (2004: 151-152).

Recent scholarship has paid close attention to the development of middle class parental subjectivity as a result of a rising interest in children's psychological health (Greenhalgh and Wrinckler 2005), and observed the tension that mothers experience as they seek to raise quality children, yet these studies, like the *suzhi jiaoyu* (quality education) movement, a wide-ranging education reform by state and private actors in the drive to develop quality citizenry, assumes that all children have the capacity to grow up into autonomous citizens. As a developmental condition primarily characterized by difficulties in reading and responding appropriately to subtle emotional cues in social communication and interaction, however, being autistic makes it more difficult for many children to be able to attend school, much less take on the work of caring

for aging parents and grandparents. With autistic children's known difficulties in taking part in the necessary dance of give and take in social exchanges, autistic children in China particularly struggle with the "deep [Chinese] cultural logic that defines personhood in terms of reciprocity" (Kuan 2015: 20). As such, the autism therapeutic apparatus's directives attempt to rewrite the intergenerational contract such that it is now parents, rather than children, under societal pressure.

Such pressures, of course, are exacerbated through the one child policy. The policy was heavily enforced particularly in urban areas, in that government employees, or anyone employed in social and medical services, would lose their employment, their allocated housing and all other benefits that make life possible should they flout the one-child policy; rural parents on the other hand, would be forcibly sterilized if they have more than two children (see Greenhalgh 2008). One the one child policy has been replaced most in 2015 by a two-child for all policy; the restrictions that were put in place during the one child policy remain in place. Unsurprisingly, the enforcement of such a policy has created a strong emphasis on providing quality education (or *suzhi jiaoyu*), by which outstanding and high quality individuals and populations might be nurtured (Anagnost 2004; Greenhalgh and Wrinckler 2005; Kipnis 2006). Part of quality education increasingly includes a keen attention to children's psychological health. As anthropologist Teresa Kuan observes, "China's response to childhood and adolescent distress was more pedagogical than medical" (2015: 5). By that, Kuan is making the observation that parents tended to focus on pedagogical approaches to manage children's and adolescents' psychological distress rather than trying to manage it clinically through psychiatric drugs; middle class parents preferred to focus on learning pedagogical techniques to nurture children's psychological health. The call for parents to use Applied Behavioral Analysis for their children's

autism is thus one that falls on willing ears.

For these reasons, the autism therapeutic apparatus's attempt to remake the intergenerational contract, I propose, also exemplifies how seemingly contradictory aspects of Chinese post-socialist governance are but different sides of the same coin: on the one hand, a strict control over citizens' movement and on the other, the state's active encouragement of self-governance in China. Here, I show how both aspects work in concert to naturalize the assumption that good parents serve as parent-therapists for their autistic children. For some scholars, post-socialist Chinese governmentality, or how state and non-state actors encourage Chinese subjects to act in ways to achieve optimal outcomes for themselves as individuals, is characterized by a shift from "relying on the state" (*kao guojia*) to "relying on yourself" (*kao ziji*)," where subjects are left "free to govern on their own behalf" (Zhang and Ong 2008: 3). For others, post-socialist governance tightly maintains gradations of citizens through the *hukou* (household) registration system (see Solinger 1999).

Bringing scholarship on gender and kinship, labor, China scholars' work on *suzhi* (quality) discourse, and my fieldwork on labor, China scholars' work on *suzhi* (quality) discourse, and my fieldwork to bear on the reformation of parenting, this chapter also examines how these moral distinctions — which turn on the adept parental use of behavioral therapies — come to determine how aid, care, and attention are directed to families with autism in China. I argue that the advocacy of behavioral therapies in China has failed to take seriously the structural inequalities that foster, and inhibit, the way parents from varying backgrounds may enact therapeutic care for their autistic children and in fact, further exacerbates stratification based on gender and the household amongst families with autistic children. I pay close attention to *how* parents are turned into therapists for their autistic children while parents of low socioeconomic

status are automatically denigrated as having low *suzhi*, thus allowing the autism therapeutic apparatus to ignore the structural constraints placed upon these families. I explore how the successful learning and deployment of ABA in Chinese parenting is tightly linked to social capital.

Governing parental care-giving through moral categories is not unique to China, as the work of feminist scholars has shown. From decisions about breast-feeding (Jackson and Mannix 2004), to the occurrence of medically unassisted childbirth (Tsing 1990), to the neglect of caregiving duties in favor of compulsive gambling (Schull 2002), scholars have shown how moral categories have been used to govern parenting practices in North America. Scholars rooted in the traditions of science studies and medical anthropology have also drawn attention to the way scientific innovations and information have shaped the self-identity of parents (see Faircloth 2010 on breastfeeding and maternal identity, as well as Rapp 1999 on parental use of moral reasoning in making sense of amniocentesis, for example). Much less attention, however, has been paid to how parenting becomes an object of moral reform through behavioral therapies outside of Euro-America. In this chapter, I examine how the technical mastery of tenets from behavioral sciences serves as a means by which biomedicine, and forms of humanitarianism both local and international, determine which families are more deserving than others of receiving care, attention, and aid in contemporary China.

In analyzing how these distinctions between “great” and “unloving” parents come to have such performative power in justifying the Chinese state’s abdication of responsibilities for the lives of rural families with autistic persons, I also pay attention to the inequalities that foster, and inhibit, the way parents from varying backgrounds may enact therapeutic care. I draw attention to the unpaid labor inherent in becoming “self-sacrificial, good parents” home-based behavioral

therapists and the social-economic capital required to understand the tenets behind behavioral sciences. For families with autism, having *hukou* registered in Beijing opens up access to tuition subsidies for their child, and themselves to attend autism rehabilitation centers located in Beijing. Having *hukou* papers from other provinces, however, renders these families ineligible to the tuition subsidies offered by local provincial authorities. This remains the case even in the absence of any autism rehabilitation centers located in the child's natal province. For families who cannot afford the tuition charged by these centers and seminars, philanthropic organizations, such as the Shenzhen-based *One Foundation*, have offered tuition subsidies on a case-by-case basis to selected families on the following conditions: these families must have already begun attending these autism rehabilitation centers, and they must be willing to publicly circulate their photos and personal stories.

At the same time, I introduce the term *the autism therapeutic apparatus* to characterize the experts and institutions who define the moral categories that determine which families with autism are worthy of receiving aid, financial and otherwise. Given the shared focus on behavioral therapies in the context of autism in China, I develop the term "rehabilitation apparatuses" to highlight the fact that aid for families with autistic children is forthcoming solely on the basis of the use of behavioral therapies. At present, families with *hukous* from selected provinces will enjoy tuition subsidies if they enroll their child in autism rehabilitation centers recognized by the state. Impoverished families with autistic children who have travelled across provinces so as to enroll in autism rehabilitation centers might, if they are lucky, have their school fees paid by anonymous donors. Other than short-term tuition subsidies for autistic children under the age of 7, there are no state, or private programs to assist with the long-term needs of impoverished families with autistic children.

In making the argument that the autism therapeutic apparatus's conflation of good parenting with becoming an adept therapist for an autistic child is in fact an attempt to remake the moral basis of the parent-child contract and has taken for granted the presumption that all parents should provide therapeutic care, regardless of their social positions in China, I turn my attention to *how* parents are being turned into therapists for their own children, illustrating through examples from my fieldwork in Sunflower Autism Institute and other centers the emotional labor that go into becoming a parental therapist for an autistic children. Through the story of Feng Ma, I illustrate that parents' ability to become good or bad therapists is inextricable from their social position as gradated citizens in contemporary China, and show the coercive aspects of biosociality. Towards the end of the chapter, I comment on the double-binds — of contradictory injunctions — placed upon parents with autistic children who are managing the need to care for other family members, enjoined to display filial piety to their elderly parents in matters of child-rearing on the one hand, and the need to care for their own autistic children. I conclude the chapter by suggesting that these categories of good and bad parents serve to divest the state of responsibility for the care of families with autistic persons.

Approaches towards Autism Therapy

At present, legal and state institutions and professional organizations in North America generally advocate behavioral therapies, rather than pharmaceutical or surgical interventions, as the most appropriate form of therapy for autism. While the United States' Federal Drug Administration has approved pharmaceutical interventions such as risperidone and aripiprazole for autistic persons, these drugs are understood as only used to manage disruptive symptom such as the irritability that many autistic persons may experience, rather than addressing the underlying causes. For instance, the National Institute of Child Health and Human Development, the U.S.

Surgeon General, the American Academy of Pediatrics, the American Academy of and the influential autism advocacy group Autism Speaks endorse Applied Behavioral Analysis (ABA) as the primary means to manage symptoms rather than the underlying condition.

As a therapeutic option most widely recommended by medical and special education professionals to families in North America, ABA has its roots in the behaviorist tenets of the American psychologist B. F. Skinner, and was further developed by child psychologist Ivar Lovaas at the University of California, Los Angeles. In 1962, Lovaas published articles arguing that ABA was an efficacious mode of intervention for children with autism. As its name implies, ABA utilizes behaviorist principles in modifying the social environment as well as the use of consequences so as to stimulate desirable behaviors while also reducing problematic ones, a practice they call operant conditioning. The therapist must learn to systematically break down behavior into different components with the help of the sequence Antecedent-Behavior-Consequence (ABC). The therapist must first identify the antecedent, or a stimulus, which prompts a behavior in the child, before tracking the outcomes of the behavior in question. Identifying this sequence is crucial to reshaping future behaviors. The use of whatever the child finds pleasurable, otherwise known as social reinforcers, are intended to encourage the child to adopt behaviors desired by parents and external caregivers. For instance, a parent might be vexed by his child's refusal and inability to clean himself. A parent who is competent in ABA might break down the desired sequence of behavior into several steps, for instance, turning the tap, soaping oneself, and then rinsing off the soap. In short, parents need to break down the desired activity into a sequence, setting the bar high enough to promote new learning, but not enough to discourage the child. Finally, ABA entails the use of one-on-one training by a teacher in a distraction free environment, known as Discrete Trial Training (DTT). With its reliance on

pedagogical methods as a way of intervening in autism, it is no wonder that ABA would be seen as a widely acceptable therapeutic option in China by parents and medical professionals alike

Applied Behavioral Analysis and Elite Urban Parents in China

As I discussed in previous chapters, autism's spread as a diagnostic category across China in fact parallels other spatial and economic disparities across the country, where professional and parental elites in Beijing refer to autistic children through the valorized term "children of the stars" (a phrase chosen so as to reduce stigma), and are able to provide children in these locations with prompt diagnoses and early therapy, while healthcare workers and families in less developed regions of China to date have not even heard of such a diagnostic category. I show all these in the previous chapters.

Through her efforts in promoting the use of ABA in Beijing, Zheng facilitated the creation of a small network of "pioneering mothers" who are also seen as experts in China because of their mastery of ABA. In fact, a key representative for autistic parents in Beijing's China Disabled Persons Federation was to publicly acknowledge Zheng's importance on 1 April 2013 during a celebration of Autism Day in Beijing. Twenty years after the opening of the Sunflower Autism Institute, ABA has become the *de facto* therapy of choice in Northern China. From 2011 onwards, free parent-training seminars have begun proliferating in Beijing (so special education teachers and parents from surrounding regions will travel in to attend). These seminars, led either by child psychiatrists, or parents who are employed as university professors or professional speechwriters, teach parents how to integrate ABA in daily life. Furthermore, as I discovered from my fieldwork in Henan and Hebei, families and social services for autistic persons in other provinces invariably use the models created in Beijing or similar provinces as

standards to aspire towards.

The early users of ABA — all urban professionals who happen to be parents or grandparents of autistic children — have likewise gained cult status as exceptionally good parents among parents, and the early friendships between elite urban parents with young autistic children in the late 1980s and early 1990s have continued to shape the direction of autism therapy in China. (Some doctors may perceive things differently because they are positioning themselves, rather than these mothers, as experts as I show in Chapter Four). As I observed in Beijing in 2013, mothers with autistic children of school-going age refer to Zheng with the honorific “Mother”, rather than the more distant “Teacher” to indicate their profound respect. In the local Chinese world of autism care, Zheng’s riches-to-rags story as she cared for a son who was abandoned by his father and biomedical authorities alike, and Shen Jin, another well-respected mother advocate, have all become urban legends; these two mothers run the most well-regarded autism rehabilitation centers in China today. Zheng’s Sunflower Autism Institute wields a powerful influence (with year-long waitlist of parents hoping to obtain admission to the school), particularly because many of the parents who have trained at this institution have gone on to set up autism support groups or schools of their own. Some of these schools are now equally famous in their own right for their success in training other parents of autistic children to become therapists of their own children. For these reasons, autism services in Beijing (and Guangdong) have remained ahead of the curve in China. While there are more than 40 rehabilitation centers in Beijing, the same cannot be said of rural China, where few, if any, autism rehabilitation centers exist, as the narratives I recount in Chapter Three show.

The advantages of being in Beijing can also be seen in the one and only school set up for teenagers and young adults. Just four years ago, six affluent parents (with children ranging from

the ages of 15 to 24) decided to set up Golden Leaves Autism School, a school for teenagers and young adults with autism in China. These parents, all employed as directors or upper level management in multi-national corporations, were able to pool together approximately 300,000 RMB (USD\$47,000). Unsurprisingly, many of these parents were originally trained at Sunflower Institute. Golden Leaves Autism Institute is intended to showcase why applied behavioral analysis remain useful for autistic teenagers and young adults, and to persuade the state to expand the range of services for autistic adults in China. Xing (the very same mother we met in Chapter Four who dismissed the value of a diagnosis), one of the founders, said: “We want to set up this center and use our children as experiments to showcase that ABA is useful. We want Chinese society to see that our teenagers and young adults can be helped through ABA”. The school invites the media to run presentations and interviews featuring their autistic teenagers and young adults engaging in bake and pottery sales.

It is important to highlight that parents like Xing perceive ABA as a bridge between their children and wider Chinese society, in ways that parallel Moroccan parents’ use of ABA to create a “prosthetic environment” (Hart 2014). Rather than a simple-minded attempt to change their autistic children, as autism self-advocates in the United States see it (see Sinclair 2005; Orsini 2009), elite Chinese parents use ABA to help their children enter into the wider social world. To this end, the parent-founders of Golden Leaves Autism Center have hired a personal tutor conversant with ABA principles for each of their children. It is also important to note that these teenagers and young adults with autism have well-to-do parents who are able to hire a personal tutor to reinforce the principles of ABA round the clock.

As the brief historical sketch I have offered in Chapter Two shows, white-collared urban parents have been pivotal in pushing for the adoption of ABA in China. The parents crucial to

the adoption of ABA in China are from the upper echelons of society. Even Zheng, the single mother who gave up her career and marriage for her son, was one of the few students to be sent abroad by the Chinese State for further studies during *gaigekaiifang* (the economic reform). While it may be true that she came to Beijing with her son without any economic security in the early 1980s, what is less well known is that her comfortably well-off parents had purchased a home for her in Beijing because they could not bear to see their daughter and grandson homeless. She is mostly silent on this fact (except once, fleetingly, in a public interview), and usually frames her experience during those difficult initial years of Sunflower Autism School as one when she had nothing but was able to push on due to her perseverance and love for her son. The silence on social class, while public emphasis on how these parents struggled on for the sake of their children thus gives credence to the autism therapeutic apparatus's claim that true parental love is all that is needed for parents to enfold ABA in their daily childrearing practice; their role also serves to mask the effects of the lack of institutional support, as well as the historical configuration of healthcare and educational access over the past four decades which makes it likely for some parents to integrate ABA successfully, and others to fail.

Making Parent-Therapists

How social position shapes the capacity for parents to integrate ABA is evident in the way ABA is taught in China. Here, I draw upon my ethnographic material from Sunflower Autism Center. Over eleven weeks in this school, parents will be taught to use ABA to teach their young children a range of skills and dispositions, from learning how to wait patiently for something they want, to identifying colors. Celebrated for its success in training parents to become therapists for their own children, Sunflower Autism Institute runs on the slogan that they are in the business of teaching parents how to be parents. Over 11 weeks, parents will learn how

to use ABA in teaching their young children anything from learning to wait patiently for something they want, to identifying colors. They will also learn to use ABA to reduce problematic behaviors. Here, I was to meet parents who had lived as therapeutic vagabonds — I detail this in Chapter Three — in moving across China in search for the best autism rehabilitation center for their child. An anonymous survey I conducted there showed that easily three quarters out of the fifty or so families who enroll Sunflower Autism Institute would have been to at least two other autism rehabilitation centers prior to Sunflower, while my long term follow up with some families likewise reveal that they will go onto to enroll in at least two other autism rehabilitation centers. Many of them, however, came because of Mother Zheng's reputation. At least three-quarters of them have monthly incomes of at least 8000 -12000 RMB (1200 to 1800 USD) that put them in the range of urban professionals, and will have gone to college. In fact, many of the parents were well-to-do, owning multiple properties in Beijing, and driving Mercedes-Benz sedans. Other families, however, had borrowed money from colleagues. But none I met there were illiterate. Most were able to use the web, and we used Wechat, China's mobile version of web-messaging applications such as WhatsApp, to stay in touch long after the 3-month semester ended.

Over the course of the semester that I spent at Sunflower Autism Institute, I was to watch variations of the following scene. I reproduce below a classroom scene that illustrates how Teacher Li, a kind and charismatic woman in her thirties who has taught at Sunflower Autism Institute for twelve years, runs a class for parents. Or, in fact, how the other teachers in the school train the parents under their care. I reproduce below a typical classroom scene featuring Teacher Li, who has taught at Sunflower for twelve years:

“You must learn how to truly love your child!” commanded Teacher Li as she blew into

the face of the giggling toddler she was cuddling and tickling. That toddler, just fifteen minutes ago, had been wailing so loudly that her cries dwarfed all the other verbal instructions taking place in the small room where the teacher, eight parents, children ranging from three to eight years old, and I were jammed behind ten child-sized tables. The toddler's mother had tears in her eyes. She had been attempting to teach her child how to identify a banana with the use of a bright yellow toy banana. Glaring at her child, that mother raised her hand halfway to hit her, before catching herself in time. Her hand fell to her side.

The brief moment of tension was palpable in the air, as other mothers awkwardly looked away, knowing that they too have often stifled an instinct to hit their children out of frustration. The silence was quickly broken by a child who started screaming and throwing things on the floor. Another child wriggled free. Climbing onto the tables, he hopped up and down on the small table he was sharing with his mother. His mother was too busy trying to take down notes on a pad of paper resting on her knee to take notice, while other mothers were holding down their children's hands and legs in case they tried to take off. Some mothers were whispering frantically to their children, "Keep quiet! Stop babbling senselessly!" As she continued eliciting cries of delight and laughter from the child in her lap, Teacher Li said:

To love your child is to know how to appreciate (*xinshang*) your child. If I saw your facial expression, I too, would not want to look at you, if I were your child, and had to see your sour expression. You show no delight, no appreciation, and no pleasure in interacting with your child. Being a good parent and an ABA practitioner would entail learning how to control one's facial expressions. Show joy during your interactions. Express your praise louder in a more exaggerated fashion. You might feel like you are faking it, but if you don't learn to praise your child from your heart in a bright, clear

voice, your child will not know that he or she has done the right thing. Praise him, yes, even if he does pick up the right item because of your help. Then he will know he has done the right thing. Has it occurred to you how many responses are wrong, and how difficult it is to pick the right response to please you?

When the class ended, Teacher Li turned to me and sighed, “I feel like I’m just teaching China’s parents how to be parents! China’s parents just don’t know how to parent!” In her complaint, Teacher Li uses the word *zhongguo*, or China, to create the noun phrase. Her tone and word choice made it clear that she was criticizing parents in China for their poor parenting.

In delineating that the love of a child entails the modulation of their own behavior to encourage the kinds of behavior they want to see in their own children, for instance, to smile at their children brightly even if they do not necessarily feel happy, Teacher Li is encouraging what philosopher Michel Foucault terms “technologies of the self” (1988). In his study of modern governance, Foucault argues that modern governance is “pastoral” in nature as it is focused on nurturing the capabilities and the potential of individuals so that they can pursue optimal outcomes for themselves. And yet, these “technologies of the self” advocate a narrow vision of ethical parenting which does not take into consideration the very high level of economic and social capital necessary for parents to serve as their children’s therapists.

Self-Governing Technologies and Behavioral Styles

For Sunflower’s teachers such as Teacher Li, to *xinshang* is a skill that family caregivers will have to learn so that they can become home therapists. *Xinshang* means to appreciate, but as a verb, it signifies admiration (of someone with significant accomplishments and attributes) and denotes the enjoyment of pleasurable company. Being able to appreciate a child, the logic goes,

would enable parents to more easily integrate ABA in their daily practice. For this reason, the school requires parents to write weekly reflective essays on topics such as “Describe ten positive traits about your child and/or yourself”. Despite parents complaining that they have nothing to write, the teachers will insist on the assignment’s completion. Parents were expected to put up positive notes about their children or their aspirations on a public notice board (see below). These private and public forums were intended to chart parents’ transformation into self-reflexive parents able to give unconditional love to their children, and pasted on the walls of Sunflower Autism Center to inspire other parents.



fig 1: Board covered with notes detailing parental aspirations

Why is appreciating one’s child so important? Sociologists and historians of science have examined how behavioral norms such as objectivity and detachment enable professionals to identify themselves as scientists (see Daston and Galison 2007). For special education teachers in

China, ABA therapists need to embody qualities of being simultaneously detached and optimistic, so that they can look past the child's faults while playing up their strengths. Parent-therapists must be able to take note of all the variables that affect a child's learning, such as whether they are causing the child to be confused by giving long or unclear instructions. They need to also consider the timing and quantity when they reward the child — too much, and the child is satiated and has no incentive to repeat the desired behavior; not given at the right moment, the child is unable to understand that the reward is given for the right response. Every day in Sunflower, each caregiver has ten minutes to demonstrate to the other eight to ten parents how they plan to use ABA in daily routines, or lessons. Sometimes the lesson falls apart mid-way. The child might start flinging things off the table (indicating either a lack of interest or frustration). The teacher will then step in to demonstrate that the parent had placed the toy apple two inches too close to the toy banana on that rickety child-sized table where the lesson took place. This had confused the child, leading to a meltdown. At other times, other parents or the teacher will break in and insist that the parent reward the child through a snack or a cuddle without delay.

Furthermore, by insisting that parents need to empathize with the difficulties their children have in “picking the right response to please” them, Teacher Li is making a claim that ethical parental care is one which enables their children to find acceptance while not allowing them to stay in their autistic “loneliness.” Doctors, philanthropic organizations, and other autism child experts in China constantly remind parents that they need to “learn how to parent” because “true parenting” is marked by the unstinting willingness to nurture a child's potential without expectations for recompense in the form of elderly care, and the implementation of round-the-clock therapeutic behavioral regimes tailored by the parent for the child. In this discourse around

parenting, “great, self- sacrificial” parents, are those who serve as self-monitoring, *life-long* therapists. During the semester, both Zheng Huifeng and teachers will remind parents to accept the reality of their children’s autism, and to celebrate what little successes their children might have, rather than seeing their children as Zheng claims “old-age insurance”. Parents, as I listed at the beginning of this chapter, are reminded that their children will always be autistic, and not to expect more.

Unrecognized Emotional Labor of Serving as a Parent-Therapist

Parent-therapists, after all, must engage in *emotional work*, a concept developed by Erickson (1993) and Hoschchild (2013). To control one’s facial expressions, to “show joy,” even if one is not truly pleased, and to “express praise...in a more exaggerated fashion” are forms of emotional labor that typify work in public service, as observed by sociologist Arlie Hoschchild in *Managed Hearts* (1983). Yet from its inception, ABA depended heavily on the unpaid labor of parents. Writing about the importance of parental involvement, Lovaas proclaimed, “we have been unable to help a child meaningfully in language development without the parent’s active involvement” (1977: 3). In moving the therapeutic site for autistic children from the clinic to the home, and in enrolling parents in his therapeutic experiments during the 1960s, Lovaas legitimized parents as “co-therapists” for autistic children (Silverman 2011: 113), and I argue, developed new behavioral norms and standards for parenting. Yet, it is important to note that many parents in North America do have the support of professionals in state-funded specialized schools; they serve as co-therapists. That is not the case in China, where upper middle class families have served as the *sole* therapists for autistic children. Yet, this emotional work is not recognized as actual work, but is framed by the autism therapeutic apparatus as springing naturally from “true parental love” which all parents of autistic children should have. This is not

surprising: feminist scholars have often observed that women's kinwork has rarely been recognized as labor (Lionardo 1987; Tom 1993). But the misrecognition — and here I draw upon Pierre Bourdieu's notion (1984) where the powerful fail to recognize disparities because of their social position — of the social capital and labor necessary to using ABA make possible the conflation of parental ethics with the grasp of ABA. Fundamentally, the consistent implementation of ABA requires the capacity to take on self-governing technologies of behavior that would be easier to enact for individuals who have high social capital such as many years of education or those from households with stable incomes.

The project of “teaching China's parents how to parent” glosses over the high income levels and social capital necessary for parents to serve as full-time therapists, and how the *hukou* system necessarily make it all but impossible for many families to meet such requirements. Such social stratification is evident not only from the misrecognition of the labor that goes into serving as a parent-therapist for one's autistic children, but also the status of highly lauded parent-advocates, and the backgrounds of families who are able to attend schools such as Sunflower Autism Center. The impact of the *hukou* system on families' life chances, socioeconomic status, and capacity to turn into parent-therapists cannot be under-estimated. Writing about the phenomenon of unregistered children (under the *hukou* system), anthropologist Susan Greenhalgh points out that these children are, effectively “unmodern unplanned persons” with few opportunities for schooling, employment, access to healthcare and the like (2003:198). So too, are families without household papers to certain cities in China. Such structural inequalities determine which parents have had the opportunity to obtain a diagnosis, or to become the early pioneers in autism therapy during the 1980s to the 1990s. All the parents valorized as “great mothers” in China are all educated professionals and have household registrations (*hukou*) in

Beijing or Qingdao, with the exception of Zheng (who was already highly educated herself and came from a family of literati).

The stratification of chances for families with autistic children is not specific to the last two decades of the 20th century. Even today, a family's *hukou* continues to shape access to therapeutic options. For families with autism, having *hukou* registered in Beijing opens up access to tuition subsidies for the family to attend autism rehabilitation centers located in Beijing (no small detail, since Sunflower, the one and only autism rehabilitation center in the whole of China during the 1990s was in Beijing). Having *hukou* papers from other provinces makes these families ineligible for the tuition subsidies offered by local Beijing authorities. This remains the case even in the absence of any autism rehabilitation centers located in the child's natal province or the lack of tuition subsidies by their home province. For families who cannot afford the tuition charged by these centers and seminars, philanthropic organizations like the Shenzhen-based *One Foundation* have offered tuition subsidies on a case-by-case basis to selected families. These subsidies are conditional on the families having already begun attending the autism rehabilitation centers, and are willing to publicly circulate their photos and personal stories. Given that few rural medical providers recognize autism, and that low levels of awareness of autism persist outside of highly developed urban areas in China today, it is clear that being registered in resource-poor provinces significantly diminishes a family's opportunities to receive a diagnosis, much less find their ways into specialized schools to learn therapeutic skills.

Coerciveness of Biosocial Therapeutic Communities

In many ways, the community of families who are gathered in many of these schools for therapy might be seen as biosocial therapeutic communities, since they are all gathered into

these settings because of their child's autism. At present, much of the anthropological literature on autism have also celebrated the capacity for novel social affiliations and communities through "biosociality" or "biological citizenship"; my dissertation seeks to provide a corrective by showing the dark side of such forms of affiliation in the way that many are left out of such affiliations and especially who is policed through such communities. Biosociality has been playfully developed by Paul Rabinow in 1999 in the following ways:

If sociobiology is culture constructed on the basis of a metaphor of nature, then in biosociality nature will be modelled on culture understood as practice. Nature will be known and remade through technique and will finally become artificial, just as culture becomes natural [...] This remark involves a large number of issues, but the only one I will underline here is the likely formation of new group and individual identities and practices arising out of these new truths. There already are, for example, neurofibromatosis groups who meet to share their experiences, lobby for their disease, educate their children, redo their home environment, and so on. That is what I mean by biosociality. I am not discussing some hypothetical gene for aggression or altruism. Rather, it is not hard to imagine groups form around the chromosome 17, locus 16,256, site 654,376 allele variant with a guanine substitution. Such groups will have medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene, and "understand" their fate. (Rabinow 1999:413)

Through this term, Rabinow suggests that the new genetics can give rise to new identities as well as communities of persons identified with such a condition. At the same time, anthropologist Adrian Petryna (2002) has developed the term "biological citizenship" to describe how Ukraine Chernobyl survivors are able to use their wounds and injuries to obligate the state to recognize their rights, and this term was further taken up by sociologist Nikolas Rose (2007) to show how the state is able to hold citizens' responsible for their own wellbeing. Even more recent writing by Vinh-Kim Nguyen interprets biosociality positively. In his 2010 *The Republic of Therapy*, Nguyen explores how local and international communities respond to the HIV/AIDS epidemic in Francophone West Africa, which harshly critiques the way therapy has been conjoined to citizenship. Even as he critiques therapeutic citizenship, or how citizenship has been

mediated through one's willingness to comply with therapeutic regimes, he nevertheless claims that "it is possible to see in therapeutic citizenship the rudiments of a new form of "biosociality" (Rabinow 1992). This suggests the possibility that a shared biological condition may foster new forms of belonging, however fragile" (Nguyen 2010: 186). In his view, biosociality appears to foster a healthy and positive community.

In the next section, however, I argue that biosociality has darker and coercive aspect. Here, I illustrate how biosocial therapeutic communities reinforce stigma, the loss of identity, and the problems with double-binds through three cases. In conceiving of the community in Sunflower Autism Center as a biosocial community, I have been inspired by the work of Paul Rabinow and other scholars, whom I already discussed in the introduction.

Suzhi, Charity and Control

At first the object of much pity and sympathy, Feng Ma (one of the diagnostic vagabonds we have met in Chapter Three) became the target of much appropriation. Feng Ma could often be seen with her eight-year-old son, hand in tow, both clad in thin attire, which did little to fend off the harsh wintry winds in Beijing. Her eight-year-old son, Dudu, only obtained diagnosis after three years of visiting various doctors. Dudu responded strongly to unexpected sounds, and was known to destroy school furniture whenever the school bell buzzed. That was why he was expelled from school. Initially, mothers and teachers alike felt sorry for Feng Ma and wanted to help her pay for food and other daily necessities. They wanted her to focus on learning ABA so that she could serve as a therapist for her son. But over the semester, people turned against her. Instead of developing ingenious lessons that would encourage her son to manage his anxiety whenever the school bell buzzed, Feng Ma was observed to either scold or bribe her son with

sweets. Where other mothers created elaborate picture aids drawn painstakingly by hand, which they used to guide their children in taking on some behaviors over another in settings such as supermarkets or other public setting, Feng Ma never turned in homework; her exercise books remained empty.

Over the course of the semester, gossip about how she was seen pocketing donations from other more well to do parents spread like wildfire; other teachers cynically interpreted the fact she and her son were constantly wearing the same clothes over and over again as evidence that she was planning to use this opportunity to earn money. One teacher said to me, “Can’t you notice she and the boy are always wearing the same bedraggled clothes everyday? She’s obviously trying to present them as so poor that they can’t afford other clothes! But they have the weekends to wash clothes! There’s no excuse for her!” Others pointed to the fact that some parents were buying her food, or that she barely used ABA in her caregiving routines. She was observed to barely consult her notes (as do other mothers there), or devise learning opportunities for her son. Where many other parents were observed to use ABA in devising little tasks for their children in the form of paying for groceries in the supermarket as the semester progressed, Feng Ma had shown no progress in this area. In the words of parents and mothers, she had “given up” on her son, and was treating him as a cash cow to solicit donations from other parents. Max Gluckman has argued that gossip is a powerful mechanism for policing moral norms of the group (1963: 308); Feng Ma’s seeming lack of complete devotion to learning ABA made her an obvious target for gossip. By the end of the term, I also saw other mothers sniff in disapproval, stepping aside whenever they saw Feng Ma and her son coming across. She just wants money, they said. For the teachers in Sunflower Autism Center, Feng Ma had internalized the lesson of what it meant to be comfortable with asking for aid far too well. While many of the teachers at

Sunflower Autism Center were initially sympathetic to her, they all turned against her when they saw other parents giving her money. Shaking their heads, they all said she should be focused on learning Applied Behavioral Analysis techniques, as she needed to be the main therapist for her son.

Yet, becoming a fulltime parent-therapist was an impossible task for Feng Ma and her son rented temporary lodgings near where Dudu's grandparents were, which meant two to three hours of bus rides each way from their rented home to Sunflower Autism Center. Dudu's grandfather and grandmother had found a temporary room for Dudu and his mother to stay, since the rent around Dudu's grandparents' temporary lodgings averaged 350 RMB (USD\$50) per month, and was significantly cheaper than 800 RMB (USD\$130) monthly rent charged by the villagers with homes around Sunflower Autism Center. Because bus fares are only 1 RMB for an adult (and free for a child), and as there is only one feeder bus that shuttles from the nearest bus-stop to Sunflower Autism Center, bus drivers know that many of the families who board that particular route at specific times of the day are likely to be very poor and are willing to wave them on the bus for free (and as I did notice with Feng Ma and her son).

Not only did they spend four hours daily travelling between their accommodation and the school, Feng Ma's rented accommodation in construction zones located at the edge of Beijing's Sixth Ring, had no heating. Any washing of clothes had to take place where the cold water public taps were shared by other tenants. Washing typically took place during the daytime, when the sun brought some level of warmth to the cold and blustery Beijing days. In addition, Feng Ma was busy trying to scrap together money for their bus-fares and the months ahead. The entire family was in dire financial straits, as I outlined earlier in Chapter Three. In addition, Fengma had spent approximately three years and 20,000 RMB (3000 USD) seeking for a diagnosis (this is in

contrast to some well-educated mothers, particularly those from Beijing, who spent approximately 400 RMB (60 USD) obtaining a diagnosis (because they were able to go directly to the appropriate specialist).

After getting to know Feng Ma, I visited her rented accommodation to have dinner with her in-laws (who were living in the same construction premises; Feng Ma's in-laws had found her the accommodation). Cardboard boxes littered the floor of their small room bare of all else except a bed and a few plastic bags full of clothes. Outside of her rented accommodation were dusty machines and giant slabs of concrete on floors thick with sand, and dust. Smiling embarrassedly, Feng Ma explained that she spent her weekends collecting and sorting out cardboard boxes to make a few dollars. After all, the money they received for their living experiences from philanthropic organizations via Sunflower Autism Center was enough only for the duration of the three-month course at Sunflower Autism Center. She worried: what would they do after they returned to Hebei, and when Feng Ma would be expected to be the sole therapist for her son? Where would their income come from, now that her husband was crippled? She could not take on new work as a school cleaner since Dudu required full time care, and she was asked to leave her last job because of Dudu. Since she stopped schooling past lower secondary school, the only kind of work she could take on would be blue-collared work. Yet, she fretted constantly about the 20,000 RMB (3050USD) they had borrowed to travel to hospitals across the country. And she worried about their future bills—where would they find the money for their living expenses? She also battled with her in-laws over Dudu. While Dudu's grandparents loved Dudu dearly, they had fiercely opposed her plan to send him to Sunflower or to go to any other autism rehabilitation for that matter. They insisted that she give up, pleading, “he's not normal and will never be normal.” Dependent as she was on her in-laws to pay the

bills, it was difficult for her to focus on learning ABA. It was imperative that Feng Ma should try and contribute to the household expenses, so that the family would be less opposed to Dudu being in the school. In some ways, the whispered accusations around Feng Ma, I argue, might rightly be understood as instantiation of what Paul Farmer identifies in *AIDS and Accusation* as the moral logic where it is the poor who are the target of suspicion, especially in contexts of great competition for scarce resources (see Farmer 1992: 204).

In contrast, the mothers gossiping about Feng Ma had an in-law, another parent, a sibling, or even a paid nanny to help with the daily chores. Many of the parents who attend Sunflower, are clearly affluent as they travel to school in Mercedes Benz sedans. Some parents have mentioned to me in passing that they own multiple properties in Beijing. While I did not explicitly ask families how much they were earning, I used other indirect measures to assess their socioeconomic status, for instance, by asking them how they were able to find out about Sunflower Autism Center. Out of a sample of 48 attendees during a semester at Sunflower Autism Center, 45 family caregivers consented to be interviewed. All of them, with the exception of three, found out about Sunflower Autism Center by searching the internet. It is clear that the vast majority of families attending Sunflower or Golden Leaves are at the very least urban and educated households. With Sunflower Autism Center and Golden Leaves Autism Center serving as the pioneers in social services for autism in China. Behavioral therapies remain the province of families with high social and economic capital, especially in a highly stratified society such as China. But it remains the case the insistence that parents are solely responsible for their children's therapists now formalizes an insistence that parents must unceasingly devote themselves to their children; such a demand is made in a society which provides little in the way of social support for these families.

Few of them were trying to scrap together living expenses for the months ahead. Many of them rented very well-kept housing (around 4000 RMB), or (600 USD), which I myself was unable to afford since my grant funding were only successful after the first six months of my fieldwork). Still, some other parents and teachers were to complain about Feng Ma's low *suzhi* (quality). In fact, I was to repeatedly hear doctors, teachers and other parents explain away Feng Ma, or other mothers' lack of proficient adoption of ABA as a reflection of their low *suzhi* (quality). Such explanations, as Andrew Kipnis (2006), Jacka Tamara (2009) and Li Zhang (2008) remind us about *suzhi*, is often used to denote lack as it pertains to migrant workers, or marginalized communities within China. In the case of autism therapy, low *suzhi* then, enables the autism rehabilitation apparatus to blame families of low socioeconomic status or from rural areas for not being able to successfully turn into therapists for their children.

B. Losing one's identity as wife and woman

Beyond stigma for rural families, however, biosocial therapeutic communities also seem to discourage parents to give up their individual identities. Hongli was a young mother from Henan whom I met in Sunflower Autism Center in Beijing, a school that prioritized teaching parents how to use ABA to interact with their autistic children over the short span of three months. In her early twenties, Hongli seemed vivacious, with eyes that creased over when she laughed. She appeared to be a snappy dresser, with clothes that not only fitted her well but also showed her keen sense of aesthetics. Over the course of the semester, however, I was to notice that she started putting in a lot less effort into her appearance. She moved towards simple t-shirts and athletic pants and seemed to have lost her easy smile.

These changes were not surprising; Hongli had also become the subject of vicious gossip

when she had applied for a bursary for her child's tuition at Sunflower Autism Center. Sunflower Autism Center was well connected to the One Foundation, a philanthropic organization based in Shenzhen (and set up by the well-known Hong Kong actor Jet Li, who came to be interested in the wellbeing of autistic children and their families after he starred in a 2010 local movie called *Ocean's Heaven* which written and directed by a long term friend of Mother Zheng; that movie has been often praised by Chinese parents and doctors alike for realistically portraying the difficulties of parenting an autistic young adult). The One Foundation provided tuition subsidy and a living stipend to selected families. The award of these bursaries was administered directly by these selected autism rehabilitation centers. One condition of the bursary offered by the One Foundation and administered via Sunflower, however, was that parents had to be willing to write out their personal narratives of their financial hardships and to consent for their personal narratives (along with their photographs) to be pasted along the walls of the school. In short, who applied for, and received these tuition subsidies would be public knowledge. The reasoning behind this condition was that it would deter persons who did not really need these tuition subsidies to apply for these subsidies since their application would be publicly vetted by many eyes, including the administrators and teachers, and also the other parents (who might know of them from their hometowns and so on). The insistence on allowing the entire community to scrutinize all applicants made logical sense since China has a strong and thriving underground economy which escapes the attention of the state through various means such as fake receipts (Barboza 2013; Tsai 2002), but the effects on applicants, whether they are successful or not, can be pernicious. Refusing to go public with one's story would not only render one ineligible for the aid, but might then subject the parent to the suspicious eyes of the teachers and administrators in Sunflower Autism Center and the families currently enrolled in the school. Hongli had asked

about the application process, but declined upon finding out that she would have to make public her narrative which involved her detailing the name of her family members including her father and spouse and pictures of herself and her child, and why she was applying for a tuition bursary.

It was then Hongli also became the second scapegoat in Sunflower. Parents complained that she clearly was more concerned about her appearance and took it as evidence that she did not really care about her child. They gossiped viciously about her, speculating that her clothing must have cost several hundred dollars and the time she spent dressing up would have made it difficult for her to focus on practicing ABA. Much like the way witchcraft accusations exploded with the bureaucratization of aid in Haiti, a phenomenon which anthropologist Erica James identifies as “bureaucraft” (2012), the rumors around Hongli proliferated once it was made known that Hongli had initiated the process for a tuition aid subsidy application, but had aborted the rest of the application process. I was to witness other parents sneering at her in front of other parents and teachers, saying, “let’s not pretend to be broke, shall we? You are so well dressed all the time. Or is it because you place more value on yourself than your child?” The deafening silence that met the accusation was not just fueled by awkwardness; many of the parents were rolling their eyes in agreement with Hongli’s accuser.

After a few weeks of being cold-shouldered by other parents, I noticed that Hongli began biting her lips nervously. She nonetheless agreed to participate in my interviews. Initially, she answered mechanically, but as we moved onto questions related to how her family created everyday routines of care for her son, she began to cry.

“I have forgotten how to be a woman. I have forgotten how to be a wife. I have forgotten how to act coquettishly (*sajiao*) for my husband, and I no longer have myself. You see these

clothes? They are all imitation goods that cost less than 40 RMB (7 USD). None of them are expensive. I need the tuition subsidy for my son, but we cannot ask my father for money, because he is old and I don't want to worry him. I am not pretending, why don't they believe me? I just want my son to be fine! ” cried Hongli, with tears streaking down her face. I did not have to ask who “they” were; I knew she was referring to other parents who turned upon her after she visibly balked at having to reveal her family's names and details, and the accusation that she was far too well groomed (at least in the early weeks of the semester) to truly need a tuition waiver for her son.

Putting aside questions as to whether Hongli's clothes were indeed “imitation goods” (a plausible claim as China is rife with counterfeits of branded goods), what is of interest here is how the other parents tried to curtail Hongli's expression of her own identity. Parents' gossip and concern with Hongli's dressing as a marker of an apparent lack of concern for her child is indicative of the moral norms of parenting autistic children. Through the gossip around Hongli, these parents are articulating a moral norm that parents were supposed to sacrifice everything for their autistic children during that age. Her fine dressing became grounds for suspicion that she wanted the tuition waivers so that she could continue spending money on herself.

What is perhaps important here, however, is that Hongli herself accepted the logic of such a moral norm. During the time I knew her, I never heard her make the argument that she had the right to enact self-care, or that how she chose to dress was none of the other parents' business; rather, she implicitly agreed that parents should prioritize their children above all else in her insistence that her clothes were worth only 40 RMB (7 USD). She also tried to accommodate these norms by dressing down, and became more subdued. She even said she was no longer able to converse with her husband, and her world had shrunk to an obsessive concern

with the child's progress, or lack thereof. Her husband had become increasingly frustrated with her, stating that she was "going crazy" worrying fruitlessly about their son. I soon came to dread her ringtone whenever we were together, as Hongli would hastily instruct me to give her a few minutes as she had to pick up her husband's call, since every single phone conversation between the husband and wife would end up in one or the other slamming down the line, threatening a divorce, or an affair. With her adopted father on the other hand, Hongli kept up a cheerful façade, lying that the child was simply going for enrichment classes, and was doing very well. She feared her father would die of a broken heart if he knew that his one and only grandson had a developmental disorder. And as the semester went on, she grew somber and timid in her demeanor. Hongli was fortunate in that her husband eventually came to share her concerns after he came to visit his wife and son at the school (and sat in for some of the classes), and I was to watch her incandescent smile return by the end of the semester as her husband began to share the burden of using ABA to nurture their son.

C. Duties to Other Family Members

Chen Ping is a mother who grew up in the *nongcun* (farming community) but who has since married a man with an urban *hukou* in a developed city in northern China. She was one of my first informants to agree to being studied, but always had to break up an interview as soon as her child became restive and indicated he wanted to be carried. She finally invited me to interview her one afternoon in her rented room. I watched her as she nursed the beautiful and plump four and a half year old suckling happily by her side in a cramped, damp and musty rented room, where the family had brought over all their electric appliances and even some furniture to these rented digs for the next few months.

We went to many diagnosticians who were not able to diagnose the child, but then finally decided to come to Beijing's psychiatric hospital. I still did not understand autism then

[during the process of diagnosis], but after coming here, I know that the old way I used to treat my child is wrong. It's just really hard, when I see my precious son, I feel bad that he has autism and he has such a disability. He must be very lonely and he must be suffering because he is unable to communicate his frustration. Can you imagine how lonely it must feel to be unable to communicate and tell someone whatever you want or are feeling? But now, I understand [after these weeks of classes at Sunflower Autism Center] that real love is not to do things for my child [but to allow him to do things for himself].

She said this as she continued helping her child nurse out of long years of habit before catching herself, giving me a sheepish look, and half-heartedly asked her son to express what he wanted before she acceded to his desire for more milk.

Chen Ping was a mother who was a source of fascination to all of us because we rarely saw her son in the first few weeks of the short course. Unlike the other parents who would bring their children to class, we rarely saw the son who was apparently either sleeping, or upset, or playing at home and would be taken care of by Chen Ping's sister, even while Chen Ping turned up herself every day for class. Her son seemed to walk only a few steps before he would either reach out his arms to Chen Ping, or Chen Ping would scoop down and quickly cuddle him, even when he showed no indication of exhaustion after taking a few steps. Teacher Zhou, on the other hand, grew increasingly worried and insisted that he really needed to be in class like the other children. Over multiple weeks, Teacher Zhou was to carefully pry her son away from Chen Ping for a one-to-one demonstration in front of the entire class. But after a particular session when Teacher Zhou was able to teach her son how to distinguish between colors, despite Chen Ping's initial protestations that her son could not possibly learn such difficult skills, Chen Ping noticeably changed her parenting style. She looked up with tears in her eyes and admitted, "I never knew my son was capable of so much, I guess I hadn't truly made sufficient demands on him before". By the end of the semester, Chen Ping was to tell me of how proud she was that her son could do little things such as feeding himself. Teacher Zhou would sigh with relief and pride

that Chen Ping was no longer taking on all the tasks for her son. But that was not the end of the story. As elated as Chen Ping was in the new-found abilities of her son, she was worried. Her son was the first grandchild for her in-laws. Her mother-in-law had berated her every time Chen Ping attempted to make her son learn to eat by himself, and scolded her for being a negligent mother. Being filial to her parents-in-law would obliged her to fulfill her son's every desire, but being a good mother in ABA terms would mean that she could not do so. Now that the semester was coming to a close, what would she do?

Conclusion

Throughout this chapter, I have shown how the advocacy for behavioral therapies have placed the parent under tremendous pressure. In demanding that parents give up everything to serve as their children's therapists, the autism therapeutic apparatus is an attempt to rewrite the intergenerational contract for families with autistic children. At the same time, I show that the autism therapeutic apparatus's categories of the good and bad caregiver (based on whether the parent is able to successfully serve as a parent-therapist) ignore the deep economic, social and educational chasm between families caring for autistic children, while giving rise to other forms of surveillance by other community members. Such blindness to these structural inequalities is not necessarily the fault of any individual actors within the autism rehabilitation apparatus; many of the special education teachers and parent-advocates in Sunflower and other autism rehabilitation centers work incredibly hard to raise funds and provide other forms of support for mothers like Fengma. Yet, these biosocial therapeutic communities also serve to encourage parents such as Hongli to strip away their individual identities, while also putting them at odds with their in-laws. By not addressing the everyday struggles of low-income families (who

struggle to balance the needs of other family members) while insisting that all parents have to “learn how to love” their autistic child, the autism therapeutic apparatus reinforces the marginality of parents like Fengma and more troublingly, children like Dudu whose already precarious futures now hang upon the slim hope that their parents can successfully make the transition into their personal therapists.

Conclusion

Care, Choice, Constraints and Capabilities

Suspicious of biomedicine's hegemony, anthropologists who study medical or psychiatric conditions often use ethnography to show how medicine, psychiatry, and psychology support dominant social economic political structures, whether it comes in the form of colonialism, neoliberalism, or post-socialism. Many draw upon medical pluralism, or alternative forms of medical practices and theories, in order to highlight the resistance of the patients, or caregivers to biomedicine (Ma 2012).

What I observe in my study of family caregivers, however, is that the critiques of biomedicine are most strongly voiced by affluent parents such as Wei Ting, who has a Beijing *hukou*, is married to a well-to-do businessman and has a postgraduate degree in library science. Wei Ting, one of my closest informants turned friend is financially well off enough that she can afford to have multiple homes in Beijing and the Pearl Delta Area; for now, she has chosen to move her family to the Pearl Delta Area to escape the relentless smog that envelops Beijing. Other individuals who are most critical of biomedicine include a retired engineer who developed a regime involving acupuncture and practices which he claims to have derived from Buddhist monasteries for his autistic grandson. Apart from these two or three families, however, the majority of the eighty or so families in China I studied rarely expressed criticisms of biomedicine; this was to hold true in Friendship Autism Center (the center in Beijing which offered acupuncture in conjunction with behavioral therapy) and other autism rehabilitation centers in the Pearl Delta area. In fact, many behaved like the parents in Morocco observed by anthropologist Brendan Hart. Hart argues that parents tend to be "therapy omnivores" in that they

are willing to try anything that works (2014). In that sense, parents care less about resisting biomedicine, than to use anything that works for their children as it pertains to autism.

In her fierce critique of what she calls the “romance of resistance”, anthropologist Lila Abu-Lughod makes the case that anthropologists tend to “romanticize resistance, to read all forms of resistance as signs of the ineffectiveness of systems of power and of the resilience and creativity of the human spirit in its refusal to be dominated (1990: 42). Abu-Lughod suggests that young Awlad Ali Bedouin women’s resistance of their elders’ traditions in marriage customs and so on in fact “bind them irrevocably to the Egyptian economy, itself tied to the global economy, and to the Egyptian state, many of whose powers depend on separating kin groups and regulating individuals (1990: 52). I extend her critique that anthropologist should not narrowly focus on the apparent “resistance” families display towards biomedicine by playing up the importance of Traditional Chinese Medicine. Though TCM may be employed as a form of resistance against biomedicine in bodily ailments or episodic illnesses such as schizophrenia, it is rarely of great interest to many families grappling with the care of autistic children.

Instead, we should be more attentive towards social disparities and who are blamed for not caring appropriately for their children. The wide disparity I find in the access to diagnosis and therapy for families with autistic children thus point to other more pertinent concerns. The debate between cure and diversity is overplayed in the literatures because parents are not necessarily aligned with one philosophical view of how humans should be over another, they are trying to negotiate their children’s interest amidst structural conditions. Writing about Triqui farm migrant laborers, anthropologist Seth Holmes speaks about his conviction that it was necessary to “portray marginalized peoples as full human beings, showing up the odds and prejudices they are up against” (2013: 28). In similar ways, I hoped to also bring about broader

questions as to how we understand disability, and how we artificially restrict its impact to the person diagnosed with such a condition. This was brought home to me over and over again by mothers such as Xiaoxi.

Xiaoxi, a mother I met in Hebei, had left her village on an arranged marriage to her husband, who had since then been working as a migrant laborer, and in this school, she was the only one who was not here with the rest of the family. The other families were not very well to do either, since many of them were also migrant laborers, but they moved to that city as a family. In addition to struggling to pay for rent, and food, Xiaoxi was barely literate. She had been too ashamed to admit it; many of the teachers in that state-funded school were in fact to complain of the low “suzhi” of the families who attended the school. She often pleaded with me to translate what the teachers said to her (in Mandarin), and only finally disclosed that she had difficulties even reading the books on autism that another mother had gifted her. Her position as a poor peasant from Hebei did her little favors in other aspects. She also had few personal networks she could turn to. When I left, she cried that she had only three friends—one was the other mother she met by chance and who told her to bring Jinyun to a psychiatric hospital in Beijing, and myself, and another young mother who seemed to have taken her under her wing. So, I would call her periodically, send her gifts of toys for Jinyun, or small amounts of money to buy winter clothing. Every phone call would find Xiaoxi in tears. She never asked me for money, but talked about how lonely and overwhelmed she felt being Jinyun’s sole care-giver, and her longing to have a normal child. Xiaoxi shot down my every suggestion, such as organizing playdates with other parents, where they can rotate care for each other child, saying that other parents never provided adequate care while she cared for their children like her own. Xiaoxi was very fatalistic. At this time of writing, Xiaoxi was unsure what she would do with Jinyun the next

year. Once Jinyu was seven, he would have no place in this school. She had nowhere to go, and could only look forward to being Jinyu's main therapist. Yet, as she cried, she could not even stop Jinyu from biting her when he was angry. What kind of therapist would she be for him? How was she to obey the call to choose to be a better parent?

The Problem with Choice and Care

Speaking of the impact of autism upon whole families, Wen Hong, an influential speechwriter for the Chinese Communist Party and the chairperson for autism advocacy in Beijing Disabled Persons' Federation, had this to say:

The burden of care inevitably and always falls on the family [in China], 4 [grandparents] 2 [parents] 1 [autistic child] there are six plus one (autistic child) now suffering because of autism. Who will bear the economic burden? We are talking about seven individuals' misery...Our parents need their *shengming*, *shenghuo*, their own *jingcai*.

One of the oldest amongst the founders of Golden Leaves Autism Center as she is now in her sixties, having given birth to her 27 year old autistic daughter at the relatively old age of 37, at a time when her peers had their first babies in their early and mid twenties (though there are older parents at the center). As a parent, and as the head of the mental disability section in China Disabled Persons Federation, Wen Hong speaks as the representative of these parents to the state and the general public alike, not to mention as a mentor to younger cohorts of parents.

Wen Hong makes clear the anguish of the family unit with an autistic child through *shenghuo*, *shengming*, and *jingcai*. *Shenghuo* is often glossed as i) ways and means to live, ii) livelihood, and iii) existence while *shengming* would best be glossed through the greek *bios*; it is often used to refer to a life that is imbued with meaning invested by the individual, and with worth and value by others around that individual,. *Jingcai*, which is synonymous with wonderful, brilliant, excellent, and amazing. *Jingcai* is used in reference to performances or shows, but Wen

Hong uses it to make the case that parents need their own sources of happiness that is distinct from the child. By calling upon *shengming* (life/bios), Wen Hong is staking claims on the nation and the Chinese public to recognize the rights of the parents of autistic children to also pursue a meaningful life as defined by psychological health. For that, financial support and social services must be created because at the moment, all of the hopes, expectations, and emotional energies of these four grandparents and two parents are all expanded on a child who is disabled, and will remain so because of the lack of social security. In using the image of an upside down pyramid of four grandparents, two parents, and one child, she is drawing upon a common trope of the 4-2-1 “ticking time bomb” used by population scientists and the local Chinese to castigate the one-child policy for causing only children to become spoilt and/or stressed out by future caregiving burdens. She uses it now to highlight the financial tragedy and emotional pain experienced by six adults who have placed their entire energies around a single child.

In many ways, her critique of the burden of care is in fact a criticism of the one child policy, because such a phenomenon did not exist on such a large scale prior to the introduction of the one-child policy. I suggest that the significance, and efficacy of the trope here comes from the normalization of the plight of autistic families in China---everyone in China is familiar with this family structure and the stresses such a reverse pyramid causes, either because they are in such a family structure themselves or their family or friends would be in such a structure; the incidence rate of autism makes it likely that someone will at the least know of a family whose suffering would be exacerbated by the confluence of autism and the social norm of having only one child in urban centers. The sole focus on the child, as I show on Chapter Four, has meant that parents such as Wen Hong and Mother Zheng simply become targets for criticism by doctor and increasingly, humanitarian organizations. Thus, their claims on the Chinese state remain

ineffectual ones.

The Logic of Care

In many ways, the diagnostic process, both in specialist outpatient clinics as well as rural and community care shows the problem with “the logic of choice” (as embodied by the call for parents to choose to love their child or to give up their present for their child’s future), a concern that takes on greater significance in post-socialist China, as it is also haunted by powerful memories of lack of choices barely three decades ago, especially under a regime of socialism from 1959 to 1978 (Yan 2010). Such a moral logic, however, as anthropologist Annemarie Mol reminds us, bespeaks a way of uncaring. In her fierce critique of the logic of choice, Annemarie Mol argues that “the logic of choice” mistakenly figures patients as active agents since they are able to make choices. She argues that such a logic misplaces the burden entirely on patients, and pleads for a logic of care, which sees patients as doers of activities, and takes “fragility as a part of life” (2006: 25). Building upon her argument, it is evident that the logic of care needs to take into account the wellbeing and needs of caregivers in the family.

In her study of China’s public health professionals, Katherine Mason writes of the “bifurcation of service and governance” (see 2016: 182), where local health officials in China serve the global common, while governing the migrant population, and excluding these migrant population as legitimate objects of care. In similar ways, the doctors, professionals and humanitarian organizations belonging to autism therapeutic apparatus prize the idea of the potential of the child, but ignore the family caregivers who have to provide much of the actual work of care. Such an increased burden of care on families cannot be understood as an issue which only concerns families in China; neo-liberal forms of governance in many countries means that families are also made to bear the burden of care themselves. The focus on the child’s

potential, in the end, though well-meaning in some way, becomes yet another way to limit the claim some families might be able to make on the state, and thus shows the problems when autism advocacy travels to states where not all citizens enjoy the same rights and access to healthcare and social services.

Bibliography

- Abu-Lughod, Lila. 1990. "The Romance of Resistance: Tracing Transformations of Power through Bedouin Women." *American Ethnologist* 17 (1): 41–55. doi:10.1525/ae.1990.17.1.02a00030.
- Ackerman, S.L. 2010. "Plastic Paradise: Transforming Bodies and Selves in Costa Rica's Cosmetic Surgery Tourism Industry." In *Medical Anthropology: Cross-Cultural Studies in Health and Illness*, 29:403–23.
- Akin, J.S., W.H. Dow, P.M. Lance, and C.P. n.d. "Loh 2005. 'Changes in Access to Health Care in China, 1989-1997.'" *Health Policy Plan* 20 (2): 80–90.
- Alpermann, Björn. 2012. *Politics and Markets in Rural China*. London and New York: Routledge.
- Anagnost, Ann. 1997. *National Past-Times: Narrative, Representation, and Power in Modern China*. Durham, NC: Duke University Press Books.
- . 2008. "From 'Class' to 'Social Strata': Grasping the Social Totality in Reform-Era China." *Third World Quarterly* 29 (3): 497–519. doi:10.1080/01436590801931488.
- Bagatell, Nancy. 2010. "From Cure to Community: Transforming Notions of Autism." *Ethos* 38 (1): 33–55. doi:10.1111/j.1548-1352.2009.01080.x.
- Barboza, David. 2013. "Coin of Realm in China Graft: Phony Receipts." *The New York Times*, August 3. <http://www.nytimes.com/2013/08/04/business/global/coin-of-realm-in-china-graft-phony-receipts.html>.
- Bartocci, Goffredo. 2006. "Editorial - jan060305.pdf." *World Cultural Psychiatry Research Review*, January. <http://www.wcpr.org/wp-content/uploads/2013/09/jan060305.pdf>.
- Bautifoulier, Philippe, and Jean-Paul Dmin and Maryse Gadreau. 2011. "Market Empowerment of the Patient: The French Experience." *Review of Social Economy* 69 (2): 143–62.
- Bellacasa, Maria Puig de la. 2011. "Matters of Care in Technoscience: Assembling Neglected Things." *Social Studies of Science* 41 (1): 85–106. doi:10.1177/0306312710380301.
- Bleuler, Eugen. 1950. *Dementia Praecox; Or, The Group of Schizophrenias*. International Universities Press.
- Bloom, Gerald, and Xingyuan Gu. 1997. "Health Sector Reform: Lessons from China." *Social Science & Medicine* 45 (3): 351–60. doi:10.1016/S0277-9536(96)00350-4.
- Blumenthal, David, and William Hsiao. 2005. "Privatization and Its Discontents — The Evolving Chinese Health Care System." *New England Journal of Medicine* 353 (11): 1165–70. doi:10.1056/NEJMhpr051133.

- Bodde, Derk. 1973. *Law in Imperial China*. 1st Pennsylvania edition. Pennsylvania: University of Pennsylvania Press
- Bourdieu, Pierre. 1984. *Distinction: A Social Critique of the Judgement of Taste*. Translated by Richard Nice. Cambridge, Mass.: Harvard University Press.
- . 1986. “The Forms of Capital.” In *Handbook of Theory and Research for the Sociology of Education*. New York: Greenwood.
<https://www.marxists.org/reference/subject/philosophy/works/fr/bourdieu-forms-capital.htm>.
- Brandt, Loren, and Thomas G. Rawski, eds. 2008. *China’s Great Economic Transformation*. 1 edition. Cambridge; New York: Cambridge University Press: Cambridge University Press.
- Bunger. “The Punishment of Chinese Lunatics and Negligents according to the Chinese Classical Law.” *Studia Serica* 9: 1–16.
- Burchell, Graham, Colin Gordon, and Peter Miller. 1991. *The Foucault Effect: Studies in Governmentality*. Chicago: University of Chicago Press.
- Cai, Fang, Dewen Wang, and Yang Du. 2011. *Zhongguo renkou yu laodong wenti baogao No.12 (Report on China’s Population and Labour)*, Beijing: Shehui kexue wenxian chubanshe.
- Cambridge University. 2016. “Prevalence of Autism in Mainland China, Hong Kong and Taiwan: A Systematic Review and Meta-Analysis | Molecular Autism | Full Text.” Accessed July 29.
<https://molecularautism.biomedcentral.com/articles/10.1186/2040-2392-4-7>.
- Centers for Disease Control and Prevention. 2016. “CDC Estimates 1 in 68 Children Has Been Identified with Autism Spectrum Disorder.” *CDC*. January 1.
<http://www.cdc.gov/media/releases/2014/p0327-autism-spectrum-disorder.html>.
- Chan, Kam Wing, and Li Zhang. 1999. “The Hukou System and Rural-Urban Migration in China: Processes and Changes.” *The China Quarterly* 160 (December): 818–55.
doi:10.1017/S0305741000001351.
- Cheng, Tiejun, and Mark Selden. 1994. “The Origins and Social Consequences of China’s Hukou System.” *The China Quarterly* 139 (September): 644–68. doi:10.1017/S0305741000043083.
- Chen, Lincoln, and Dong Xu. 2012. “Trends in China’s Reforms: The Rashomon Effect.” *The Lancet* 379 (9818): 782–83. doi:10.1016/S0140-6736(12)60285-2.
- Cheung, Peter T. Y., Chae-ho Chōng, and Zhimin Lin. 1998. *Provincial Strategies of Economic Reform in Post-Mao China: Leadership, Politics, and Implementation*. Armonk, NY: M.E. Sharpe.
- Chew, Kristina. 2013. “Autism and the Task of the Translator.” In *Worlds of Autism: Across the Spectrum of Neurological Difference*, edited by Joyce Davidson and David Orsini.

- Chiu, Martha. 1980. "Insanity in Imperial China: A Legal Case Study." In *Normal and Abnormal Behavior in Chinese Culture*, edited by A. Kleinman and T. Y. Lin. Springer Science and Business Media, BV.
- Chong, Siow-Ann, Mythily, Alvin Lum, Yiong Huak Chan, and Patrick McGorry. 2005. "Determinants of Duration of Untreated Psychosis and the Pathway to Care in Singapore." *International Journal of Social Psychiatry* 51 (1): 55–62. doi:10.1177/0020764005053278.
- Chou, Rita Jing-Ann. 2010. "Filial Piety by Contract? The Emergence, Implementation, and Implications of the 'Family Support Agreement' in China." *The Gerontologist*, August, gnq059. doi:10.1093/geront/gnq059.
- Cindy, Fan. 2002. "The Elite, the Natives, and the Outsiders: Migration and Labor Market Segmentation in Urban China." *Annals of the Association of American Geographers* 92 (1): 103–24.
- Clark, Elaine, and Zheng Zhou. 2005. "Autism in China: From Acupuncture to Applied Behavior Analysis." *Psychology in the Schools* 42 (3): 285–95. doi:10.1002/pits.20079.
- Cohen, Alex, Vikram Patel, R. Thara, and Oye Gureje. 2008. "Questioning an Axiom: Better Prognosis for Schizophrenia in the Developing World?" *Schizophrenia Bulletin* 34 (2): 229–44. doi:10.1093/schbul/sbm105.
- Collins, Daryl, Jonathan Morduch, Stuart Rutherford, and Orlanda Ruthven. 2010. *Portfolios of the Poor: How the World's Poor Live on \$2 a Day*. Princeton, NJ: Princeton University Press.
- Conrad, Peter, and Joseph W. Schneider. 2010. *Deviance and Medicalization: From Badness to Sickness*. Temple University Press.
- Corker, Mairian, and Tom Shakespeare. 2002. *Disability/postmodernity: Embodying Disability Theory*. London: Bloomsbury Continuum.
- Das, Jishnu, Jeffrey Hammer, and Kenneth Leonard. 2008. "The Quality of Medical Advice in Low Income Countries." *Journal of Economic Perspectives* 22 (2): 93–114.
- Daston, Lorraine J., and Peter Galison. 2010. *Objectivity*. New York; Cambridge, Mass.: Zone Books.
- Das, Veena, and Shalini Randeria. 2015. "Politics of the Urban Poor: Aesthetics, Ethics, Volatility, Precarity: An Introduction to Supplement 11." *Current Anthropology* 56 (S11): S3–14. doi:10.1086/682353.
- Davidson, Joyce, and David Orsini. 2013. *Worlds of Autism: Across the Spectrum of Neurological Difference*. Minneapolis, MN: University of Minnesota. <https://www.upress.umn.edu/book-division/books/worlds-of-autism>.
- Davis, Lennard J. 1997. *The Disability Studies Reader*. London: Psychology Press.

- De Boeck, Filip. 2015. "'Poverty' and the Politics of Syncopation: Urban Examples from Kinshasa (DR Congo)." *Current Anthropology* 56 (S11): S146–58. doi:10.1086/682392.
- Demurger, Sylvie, and Hui Xu. 2015. "Left-behind Children and Return Migration in China." *Journal of Migration* 4 (10): 1–21.
- Dewalt, Darren, Nancy Berkman, Stacey Sheridan, Kathleen N. Lohr, and Michael P. Pignone. n.d. "Literacy and Health Outcomes: A Systematic Review of the Literature." *Journal of General Internal Medicine* 19 (12): 1228–39.
- di Leonardo, Micaela. 1987. "The Female World of Cards and Holidays: Women, Families, and the Work of Kinship." *Signs* 12 (3): 440–53.
- Duckett, Jane. 2013. *The Chinese State's Retreat from Health*. London and New York: Routledge.
- Dunford, Michael, and Li Li. 2010. "Chinese Spatial Inequalities and Spatial Policies." *Geography Compass* 4 (8): 1039–54. doi:10.1111/j.1749-8198.2010.00359.x.
- Dyer, Caroline. 2014. *Livelihoods and Learning: Education For All and the Marginalisation of Mobile Pastoralists*. London and New York: Routledge.
- Eckholm, Erik. 1999. "For China's Rural Migrants, an Education Wall." *New York Times* 23 (December): 1–8.
- Edin, Maria. 2003. "State Capacity and Local Agent Control in China: CCP Cadre Management from a Township Perspective." *The China Quarterly* 173 (March): 35–52. doi:10.1017/S0009443903000044.
- Eggleston, Karen. 2012. "'Health Care for 1.3 Billion: An Overview of China's Health System.' Stanford Asia Health Policy Program Working." *Paper* 28. <http://papers.ssrn.com/sol3/papers.cfm>.
- Epstein, Steven. 1996. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press.
- Erickson, Rebecca J. 1993. "Reconceptualizing Family Work: The Effect of Emotion Work on Perceptions of Marital Quality." *Journal of Marriage and Family* 55 (4): 888–900. doi:10.2307/352770.
- Evans, Harriet. 2008. *The Subject of Gender: Daughters and Mothers in Urban China*. MD, USA: Rowman & Littlefield.
- Eyal, Gil, Brendan Hart, Emine Onculer, Neta Oren, and Natahsa Rossi. 2010. *The Autism Matrix*. 1 edition. Cambridge, UK ; Malden, MA: Polity.

- Fairbank, John K. 1978. *The Cambridge History of China: Volume 10, Late Ch'ing 1800-1911*. Cambridge: Cambridge University Press.
- Fairbank, John King. 1870. *China: A New History by John King Fairbank*. New York: Belknap Press.
- Faircloth, Charlotte. 2009. "Mothering as Identity-Work: Long-Term Breastfeeding and Intensive Motherhood." *Anthropology News* 50 (2): 15–17. doi:10.1111/j.1556-3502.2009.50215.x.
- Fan, C. Cindy. 2003. "Rural-Urban Migration and Gender Division of Labor in Transitional China." *International Journal of Urban and Regional Research* 27 (1): 24–47. doi:10.1111/1468-2427.00429.
- Farmer, Paul. 1996. "Social Inequalities and Emerging Infectious Diseases." *Emerging Infectious Diseases* 2 (4): 259–69.
- . 2001a. *Infections and Inequalities: The Modern Plagues*. Berkeley: University of California Press.
- . 2001b. *Infections and Inequalities: The Modern Plagues, Updated with a New Preface*. Updated edition. Berkeley: University of California Press.
- . 2013. *To Repair the World: Paul Farmer Speaks to the Next Generation*. Edited by Jonathan Weigel. 1 edition. Berkeley: University of California Press.
- Farquhar, Judith. 1994. "Eating Chinese Medicine." *Cultural Anthropology* 9 (4): 471–97. doi:10.1525/can.1994.9.4.02a00020.
- . 2002. *Appetites: Food and Sex in Post-Socialist China*. Durham, NC: Duke University Press Books.
- Fassin, Didier. 2003. "The Embodiment of Inequality." *EMBO Reports*. Jun 4. doi:1): S4–S9. doi: 10.1038/sj.embor.embor856.
- . 2013. "Children as Victims: The Moral Economy of Childhood in the Times of AIDS." In *When People Come First: Critical Studies in Global Health*, edited by João Biehl and Adriana Petryna. New Jersey: Princeton University Press.
- Feinstein, Adam. 2010. *A History of Autism: Conversations with the Pioneers*. 1 edition. Chichester, West Sussex, U.K. ; Malden, MA: Wiley-Blackwell.
- Feuchtwang, Stephan. 2002. "Remnants of Revolution in China." In *Postsocialism: Ideals, Ideologies, and Practices in Eurasia*, edited by C. Hann, 196–215. London: Routledge. <http://www.routledgeanthropology.com>.

- Fewsmith, Joseph. 2016. "The Political Implications of China's Growing Middle Class - CLM21JF.pdf." *China Leadership Monitor* 21. Accessed July 29. <http://media.hoover.org/sites/default/files/documents/CLM21JF.pdf>.
- Fong, Chung-yan Gardian, and Anchor Hung. 2002. "Public Awareness, Attitude, and Understanding of Epilepsy in Hong Kong Special Administrative Region, China." *Epilepsia* 43 (3): 311–16.
- Fong, Mei. 2016. *One Child: The Story of China's Most Radical Experiment*. Boston: Houghton Mifflin Harcourt.
- Fong, Michelle. 2009. "Digital Divide Between Urban and Rural Regions of China." *EJISDC* 36 (6): 1–12.
- Fong, Vanessa L. 2006. *Only Hope: Coming of Age Under China's One-Child Policy*. Stanford University Press.
- Fortun, Kim. 2001. *Advocacy after Bhopal: Environmentalism, Disaster, New Global Orders*. 1 edition. Chicago: University Of Chicago Press.
- Foucault, Michel. 1965. *Madness and Civilization; a History of Insanity in the Age of Reason*. New York: Pantheon Books.
- Fu, D. Y. 1974. "Prevention and Treatment of Mental Illness in the People's Republic of China." *American Journal of Orthopsychiatry* 44 (4): 620–36. doi:10.1111/j.1939-0025.1974.tb00917.x.
- Gerber, Jeffrey S., and Paul A. Offit. 2009. "Vaccines and Autism: A Tale of Shifting Hypotheses." *Clinical Infectious Diseases: An Official Publication of the Infectious Diseases Society of America* 48 (4): 456–61. doi:10.1086/596476.
- Gluckman, Max. 1963. "Gossip and Scandal,." *Current Anthropology* 4 (3): 307–16.
- Gong, Peng, Song Liang, Elizabeth J. Carlton, Qingwu Jiang, Jianyong Wu, Lei Wang, and Justin V. Remais. 2012. "Urbanisation and Health in China." *Lancet* 3 (May): 843–52. doi:doi:10.1016/S0140-6736(11)61878-3.
- Good, Byron J. 1994. *Medicine, Rationality and Experience: An Anthropological Perspective*. Cambridge: Cambridge University Press.
- Greenhalgh, Susan. 1988. "Intergenerational Contracts: Familial Roots of Sexual Stratification in Taiwan." In *A Home Divided: Women and Income in the Third World*, by Daisy Dwyer and Judith Bruce, 39–70. Palo Alto: Stanford University Press.
- . 2003. "Planned Births, Unplanned Persons: 'Populations' in the Making of Chinese Modernity." *American Ethnologist* 30: 195–215.
- Greenhalgh, Susan, and Edwin A. Winckler. 2005. *Governing China's Population: From Leninist to Neoliberal Biopolitics*. Stanford California: Stanford University Press. <http://www.sup.org/books/title/?id=5558>.

- Grinker, Roy Richard. 2007. *Unstrange Minds: Remapping the World of Autism*. New York: Basic Books.
- Grinker, Roy Richard, and Kyungjin Cho. 2013. "Border Children: Interpreting Autism Spectrum Disorder in South Korea." *Ethos* 41 (1): 46–74. doi:10.1111/etho.12002.
- Guang, Lei, and Lu Zheng. 2005. "Migration as the Second-Best Option: Local Power and Off-Farm Employment." *China Quarterly* 181: 22–45.
- Guo, Jinhua, and Arthur Kleinman. 2011. "Stigma: HIV/AIDS, Mental Illness, and China's Nonpersons." In *Deep China*, edited by Arthur Kleinman, Yunxiang Yan, Jing Jun, Sing Lee, and Everett Zhang. Berkeley: University of California Press.
- Gupta, Dr S. P. 1996. *China's Economic Reforms: The Role of Special Economic Zones and Economic and Technological Development Zones*. Allied Publishers.
- Gu, X, Gerald Bloom, and S Tang. 1993. "Financing Health Care in Rural China: Preliminary Report of a Nationwide Study." *Social Science & Medicine* 36: 385–91.
- Hacking, Ian. 2006. "Making Up People." *London Review of Books*, August 17.
- Han, Clara. 2012. *Life in Debt: Times of Care and Violence in Neoliberal Chile*. Berkeley: University of California Press.
- Hanser, Amy. 2005. "The Gendered Rice Bowl The Sexual Politics of Service Work in Urban China." *Gender & Society* 19 (5): 581–600. doi:10.1177/0891243205276794.
- Harrison, Glynn, Kim Hopper, Thomas Craig, Eugene Laska, Carol Siegel, Joe Wanderling, K. C. Dube, 2001. "Recovery from Psychotic Illness: A 15- and 25-Year International Follow-up Study." *The British Journal of Psychiatry* 178 (6): 506–17. doi:10.1192/bjp.178.6.506.
- Hart, Brendan. 2014. "Autism Parents & Neurodiversity: Radical Translation, Joint Embodiment and the Prosthetic Environment." *BioSocieties* 9 (3): 284–303. doi:10.1057/biosoc.2014.20.
- Hochschild, Arlie, and Anne Machung. 2003. *The Second Shift*. New York: Penguin Books.
- Hochschild, Arlie Russell. 2013. *So How's the Family?: And Other Essays*. Berkeley: University of California Press.
- Ho, David Yau-fai. 1976. "On the Concept of Face." *American Journal of Sociology* 81 (4): 867–84.
- Holmes, Seth. 2013. *Fresh Fruit, Broken Bodies: Migrant Farmworkers in the United States*. 1st Edition edition. Berkeley: University of California Press.
- Holroyd, Eleanor E. 2003. "Chinese Cultural Influences on Parental Caregiving Obligations toward Children with Disabilities." *Qualitative Health Research* 13 (1): 4–19.

- Hong, Y., B. Stanton, X. Li, H. Yang, D. Lin, X. Fang, J. Wang, and R. Mao. 2006. "Rural-to-urban Migrants and the HIV epidemic in China." *AIDS behavior* 10: 421–30.
- Hu. 2012. "China's Young Rural-to-Urban Migrants: In Search of Fortune, Happiness, and Independence." *Migrationpolicy.org*. January 4. <http://www.migrationpolicy.org/article/chinas-young-rural-urban-migrants-search-fortune-happiness-and-independence>.
- Republic of China: Diagnosis, Legal Issues, and Educational Services." *Journal of Autism and Developmental Disorders* 1 (May): 43. doi:doi: 10.1007/s10803-012-1722-6.
- Huang, Yanzhong. 2012. "The Sick Man of Asia." *Foreign Affairs*, May. <https://www.foreignaffairs.com/articles/china/2011-11-01/sick-man-asia>.
- Huang, Yanzhong. 2013. *Governing Health in Contemporary China*. London and New York: Routledge.
- Hu, Yi. 2013. "Cooperative Medical Services in Rural Areas." In *Rural Health Care Delivery*, 157–67. Springer Berlin Heidelberg. http://link.springer.com/chapter/10.1007/978-3-642-39982-4_15.
- Ikels, Charlotte. 1990. "The Resolution of Intergenerational Conflict: Perspectives of Elders and Their Family Members." *Modern China* 16 (4): 379–406.
- . 1993. "Settling Accounts: The Intergenerational Contract in an Age of Reform." In *Chinese Families in the Post-Mao Era*, by Deborah Davis and Steve Harrell, 307–33. Berkeley: University of California Press.
- Illich, Ivan. 1976. *Limits to Medicine; Medical Nemesis: The Expropriation of Health*. London: Marion Boyars Publishers.
- Inhorn, Marcia C. 1994. *Quest for Conception: Gender, Infertility and Egyptian Medical Traditions*. First Edition edition. Philadelphia: University of Pennsylvania Press.
- Inhorn, Marcia, and Patricia Patrizio. 2009. "'Rethinking Reproductive "tourism" as Reproductive "exile".' Fertility Sterility." *Journal* 92 (3): 904–6. doi:doi: 10.1016/j.fertnstert.2009.01.055.
- Insel, Thomas. 2013. "The Four Kingdoms of Autism." <http://www.nimh.nih.gov/about/director/2013/the-four-kingdoms-of-autism.shtml>.
- Jablensky, A., N. Sartorius, G. Ernberg, M. Anker, A. Korten, J. E. Cooper, R. Day, and A. Bertelsen. 1992. "Schizophrenia: Manifestations, Incidence and Course in Different Cultures. A World Health Organization Ten-Country Study." *Psychological Medicine. Monograph Supplement* 20: 1–97.
- Jacka, Tamara. 2006. *Rural Women in Urban China: Gender, Migration, and Social Change*. New York: and.

- Jackson, D., and J. Mannix. 2001. "Clinical Nurses as Teachers: Insights from Students of Nursing in Their First Semester of Study." *Journal of Clinical Nursing* 10 (2): 270–77.
- James, Erica. 2010. *Democratic Insecurities*. California: University of California Press.
<http://www.ucpress.edu/book.php?isbn=9780520260542>.
- Janzen, John M., and William Arkininstall. 1982. *The Quest for Therapy: Medical Pluralism in Lower Zaire*. University of California Press.
- Jianfeng, Zhu. 2013. "Projecting Potentiality: Understanding Maternal Serum Screening in Contemporary China." *Current Anthropology* 54 (7).
- Jingzhong, Ye, and Pan Lu. 2011. "Differentiated Childhoods: Impacts of Rural Labor Migration on Left-behind Children in China." *The Journal of Peasant Studies* 38 (2): 355–77.
doi:10.1080/03066150.2011.559012.
- Kanbur, Ravi, and Xiaobo Zhang. 2005. "Fifty Years of Regional Inequality in China: A Journey Through Central Planning, Reform, and Openness." *Review of Developmental Economics* 9 (1): 87–106.
- Kangas, B. 2010. "Travelling for Medical Care in a Global World." *Medical Anthropology* 29 (4): 344–62. doi:doi: 10.1080/01459740.2010.501315.
- Kanner, Leo. 1943. "Autistic Disturbances of Affective Contact. | Research Autism Publications." *Nervous Child*, 217–50.
- Kipnis, Andrew. 2006a. "Change in Rural China: American Scholars' Research on Zouping County, Shandong,." In . <https://researchers.anu.edu.au/publications/25302>.
- . 2006b. "Suzhi: A Keyword Approach." *The China Quarterly* 186 (June): 295–313.
doi:10.1017/S0305741006000166.
- . 2012. *Chinese Modernity and the Individual Psyche*. Palgrave Macmillan.
- Kirk, Stuart A., and Herb Kutchins. 1992. *The Selling of DSM: The Rhetoric of Science in Psychiatry*. New Jersey: Transaction Publishers.
- Kleinman, A. 1982. "Neurasthenia and Depression: A Study of Somatization and Culture in China." *Culture, Medicine and Psychiatry* 6 (2): 117–90.
- Kleinman, Arthur. 1998. "Experience and Its Moral Modes: Culture, Human Conditions, and Disorder." In . Vol. 1998. Stanford California.
- Kleinman, Arthur, and Byron J. Good. 1985. *Culture and Depression: Studies in the Anthropology and Cross-Cultural Psychiatry of Affect and Disorder*. University of California Press.

- Kleinman, Arthur, and Jinhua Guo. 2011. "Stigma: HIV/AIDS, Mental Illness, and China's Nonpersons." In *Deep China: The Moral Life of the Person*, edited by Yunxiang Yan, Jing Jun, Sing Lee, Everett Zhang, Pan Tianshu, Wu Fei, Jinhua Guo, and Arthur Kleinman, 1 edition. Berkeley: University of California Press.
- Kleinman, Arthur, Yunxiang Yan, Jing Jun, Sing Lee, Everett Zhang, Pan Tianshu, Wu Fei, and Jinhua Guo. 2011. *Deep China: The Moral Life of the Person*. 1 edition. Berkeley: University of California Press.
- Kleinman, A., W. Z. Wang, S. C. Li, X. M. Cheng, X. Y. Dai, K. T. Li, and J. Kleinman. 1995. "The Social Course of Epilepsy: Chronic Illness as Social Experience in Interior China." *Social Science & Medicine (1982)* 40 (10): 1319–30.
- Kuan, Teresa. 2015. *Love's Uncertainty: The Politics and Ethics of Child Rearing in Contemporary China*. Oakland, California: University of California Press.
- Landsman, Gail H. 1998. "Reconstructing Motherhood in an Age of 'Perfect' Babies: Mothers of Infants and Toddlers with Disabilities." *Signs* 24 (1): 69–99.
- Latourette, Kenneth Scott. 1966. "Missionaries Abroad." *The ANNALS of the American Academy of Political and Social Science* 368 (1): 21–30. doi:10.1177/000271626636800104.
- Laur, Audrey. 2013. "Patients' Responsibilities for Their Health." *Medico-Legal Journal* 81 (3): 119–23.
- Lee, Ching Kwan. 2016. *Gender and the South China Miracle*. California: University of California Press. Accessed August 30. <http://www.ucpress.edu/book.php?isbn=9780520211278>.
- Lee, Leo Ou-Fan. 1999. "Shanghai Modern: Reflections on Urban Culture in China in the 1930s." <http://publicculture.dukejournals.org/content/11/1/75.full.pdf>.
- Lee, Sing. 1999. "Diagnosis Postponed: Shenjing Shuairuo and the Transformation of Psychiatry in Post-Mao China." *Culture, Medicine and Psychiatry* 23 (3): 349–80. doi:10.1023/A:1005586301895.
- Li, Zhi-Sui 1994. *The Private Life of Chairman Mao*. New York:Random House Publishing Group.
- Liu, Fengshu. 2008. "Negotiating the Filial Self Young-adult Only-children and Intergenerational Relationships in China." *Young* 16 (4): 409–30. doi:10.1177/110330880801600404.
- Liu, Hongjie, Zhi Hu, Xiaoming Li, Bonita Stanton, Sylvie Naar-King, and Hongmei Yang. 2006. "Understanding Interrelationships Among HIV-Related Stigma, Concern About HIV Infection, and Intent to Disclose HIV Serostatus: A Pretest-Posttest Study in a Rural Area of Eastern China." *AIDS Patient Care and STDs* 20 (2): 133–42. doi:10.1089/apc.2006.20.133.

- Liu, Yuanli, William C. L. Hsiao, Qing Li, Xingzhu Liu, and Minghui Ren. 1995. "Aspects of the Medical Care System in the People's of China Transformation of China's Rural Health Care Financing." *Social Science & Medicine* 41 (8): 1085–93. doi:10.1016/0277-9536(95)00428-A.
- Li, Zhang. 2001. "Migration and Privatization of Space and Power in Late Socialist China." *American Ethnologist* 28 (1): 179–205.
- Li, Zhisui. n.d. *The Private Life of Chairman Mao*. New York: Random House Publishing Group.
- Lou, Loretta. 2016. "Beyond Miracles: How Traditional Chinese Medicine Establishes Professional Legitimacy in Post-Colonial Macau." Accessed July 28.
[http://www.academia.edu/8104348/Beyond Miracles How traditional Chinese medicine establishes professional legitimacy in post-colonial Macau](http://www.academia.edu/8104348/Beyond_Miracles_How_traditional_Chinese_medicine_establishes_professional_legitimacy_in_post-colonial_Macau).
- Lu, Henry C. 1985. *A Complete Translation of The Yellow Emperor's Classic of Internal Medicine and the Difficult Classic. (A Complete Translation of Nei Ching and Nan Ching) Vol 1 2 3 4 5 Complete. Chinese Medicine Study Series Text 301,302,303,304,305*. First Edition edition. Academy of Oriental Heritage.
- . 1999. *Chinese Natural Cures: Traditional Methods for Remedies and Prevention*. New York, NY: Black Dog & Leventhal.
- Luhrmann, T. M. 2000. *Of Two Minds: The Growing Disorder in American Psychiatry*. 1 edition. New York: Knopf.
- MacFarquhar, Roderick. 1997. *The Politics of China: The Eras of Mao and Deng*. Cambridge University Press.
- Maria Puig de la Bellacasa. 2011. "Matters of Care in Technoscience: Assembling Neglected Things." *Social Studies of Science*, February. <http://sss.sagepub.com/content/41/1/85.full.pdf>.
- Marmot, Michael. 2005. "Social Determinants of Health Inequalities." *The Lancet* 365 (9464): 1099–1104. doi:10.1016/S0140-6736(05)71146-6.
- Mason, Katherine. 2016. *Infectious Change: Reinventing Chinese Public Health After an Epidemic*. Palo Alto: Stanford University Press.
- Ma, Zhiying. 2012. "Psychiatric Subjectivity and Cultural Resistance: Experience and Explanations of Schizophrenia in Contemporary China." In *Chinese Modernity and the Individual Psyche*, edited by Andrew Kipnis. Basingstoke, UK: Palgrave Macmillan.
<https://humdev.uchicago.edu/news/ma-zhiying-2012-psychiatric-subjectivity-and-cultural-resistance>.
- McCabe, Helen. 2007. "Parent Advocacy in the Face of Adversity Autism and Families in the People's Republic of China." *Focus on Autism and Other Developmental Disabilities* 22 (1): 39–50. doi:10.1177/10883576070220010501.

- . 2008. “Autism and Family in the People’s Republic of China: Learning from Parents’ Perspectives.” *Research and Practice for Persons with Severe Disabilities* 33 (1-2): 37–47. doi:10.2511/rpsd.33.1-2.37.
- McDowell, Linda. 1999. *Gender, Identity and Place: Understanding Feminist Geographies*. 1 edition. Minneapolis: University of Minnesota Press.
- Mechanic, D, and A Kleinman. 1980. “Ambulatory Medical Care in the People’s Republic of China: An Exploratory Study.” *American Journal of Public Health* 70 (1): 62–66. doi:10.2105/AJPH.70.1.62.
- Meng, Qun, Ling Xu, Yaoguang Zhang, Juncheng Qian, Min Cai, Ying Xin, Jun Gao, Ke Xu, J Ties Boerma, and Sarah L Barber. 2012. “Trends in Access to Health Services and Financial Protection in China between 2003 and 2011: A Cross-Sectional Study.” *The Lancet* 379 (9818): 805–14. doi:10.1016/S0140-6736(12)60278-5.
- Metzl, Jonathan. 2011. *The Protest Psychosis: How Schizophrenia Became a Black Disease*. Boston: Beacon Press.
- Ministry of Health, State Bureau for Medical Management, and Ministry of Finance and State Planning Commission. n.d. “Implementing Opinions Concerning the Management of Different Types of Urban Medical Institution (Guanyu Chengzhen Yiliao Jigou Fenlei Guanli de Shishi Yijian).”
- Mol, Annemarie. 2008. *The Logic of Care: Health and the Problem of Patient Choice*. 1 edition. London ; New York: Routledge.
- Mommsen, Wolfgang J., and Jürgen Osterhammel. 1986. *Imperialism and After: Continuities and Discontinuities*. German Historical Institute.
- Müller-Wille, Staffan, and Hans-Jörg Rheinberger. 2012a. *A Cultural History of Heredity*. Chicago: University Of Chicago Press. <http://www.press.uchicago.edu/ucp/books/book/chicago/C/bo8787518.html>.
- . 2012b. *A Cultural History of Heredity*. Chicago: University of Chicago Press.
- Munro, Robin. 2002. *Dangerous Minds: Political Psychiatry in China Today and Its Origins in the Mao Era*. Human Rights Watch.
- Nadesan, Majia Holmer. 2005. *Constructing Autism: Unravelling the “Truth” and Understanding the Social*. 1 edition. London and New York: Routledge.
- Naftali, O. 2014. *Children, Rights and Modernity in China: Raising Self-Governing Citizens*. 2014 edition. Houndmills, Basingstoke, Hampshire: Palgrave Macmillan.

- Naughton, Barry. 1996. *Growing Out of the Plan: Chinese Economic Reform, 1978-1993*. Cambridge (England); New York: Cambridge University Press.
- Nehru, Vikram, Aart Kraay, and Xiaoqing Yu. 1997. "China 2020 : Development Challenges in the New Century." 17087. The World Bank.
<http://documents.worldbank.org/curated/en/1997/09/694610/china-2020-development-challenges-new-century>.
- Ng, Emily. 2009. "Heartache of the State, Enemy of the Self: Bipolar Disorder and Cultural Change in Urban China." *Culture, Medicine and Psychiatry* 33 (3): 421–50. doi:10.1007/s11013-009-9144-4.
- Nguyen, Vinh-Kim. 2010. *The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS*. 1 edition. Durham, NC: Duke University Press Books.
- Nguyen, Vinh-Kim, and Karine Peschard. 2003. "Anthropology, Inequality, and Disease: A Review." *Annual Review of Anthropology* 32: 447–74.
- Ng, V.W. 1991. *Madness in Late Imperial China*. Norman, Oklahoma: University of Oklahoma Press.
- Ng, V.W. 1980. "Ching Laws Concerning the Insane: An Historical Survey." *Ching Shi Wen Ti*, no. 4: 55–89.
- Nichter, Mark. 1981. "Idioms of Distress: Alternatives in the Expression of Psychosocial Distress: A Case Study from South India." *Culture, Medicine and Psychiatry* 5 (4): 379–408. doi:10.1007/BF00054782.
- Noble, Barnes &. 2016. "NeuroTribes: The Legacy of Autism and the Future of Neurodiversity." *Barnes & Noble*. Accessed July 28. <http://www.barnesandnoble.com/w/neurotribes-steve-silberman/1121099414?ean=9781504615907>.
- Orsini, Michele. 2009. "Contesting the Autistic Subject : Biological Citizenship and the Autism/Autistic Movement." In *Political Interventions in the Ethics of Health Care*, edited by Stuart Murray and Dave Holmes, 115–30. London: Ashgate Publishing.
- Parsons, Talcott. 1951. *The Social System*. Glencoe, Ill: The Free Press.
- Pearson, Veronica. 1995. *Mental Health Care in China: State Policies, Professional Services, and Family Responsibilities*. London: Gaskell.
- Qian, Xiaolei, and Russell Smyth. 2007. "Measuring Regional Inequality of Education in China: Widening Coast–Unland Gap or Widening Rural–Urban Gap?" *Journal of International Development* 20: 132–44.
- Qi, Xiaoying. 2013. "Guanxi, Social Capital Theory and beyond: Toward a Globalized Social Science." *The British Journal of Sociology* 64 (2): 308–24. doi:10.1111/1468-4446.12019.

- Rabinow, Paul. 1996. "Artificiality and Enlightenment: From Sociobiology to Biosociality." In *Essays on the Anthropology of Reason.*, 91–111. Princeton: Princeton University Press.
- Rapp, Rayna. 1999. *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America.* Psychology Press.
- Ren, L., Z. Duan, and J. Xu. 2003. "An Analysis on Positive Rate of Autism among Preschool Children in Tonglingcity." *Chinese Journal of Child Healthcare* 11: 105–7.
- Rheinberger, Hans-Jörg. 1997. *Toward a History of Epistemic Things: Synthesizing Proteins in the Test Tube* |. Palo Alto: Stanford University Press. <http://www.sup.org/books/title/?id=794>.
- Rios, Clarice, and Barbara Costa Andrada. 2015. "The Changing Face of Autism in Brazil." *Culture, Medicine, and Psychiatry* 39 (2): 213–34. doi:10.1007/s11013-015-9448-5.
- Rofel, Lisa. 1999. *Other Modernities: Gendered Yearnings in China after Socialism.* Berkeley: University of California Press.
- Sarrett, Jennifer C. 2015. "Custodial Homes, Therapeutic Homes, and Parental Acceptance: Parental Experiences of Autism in Kerala, India and Atlanta, GA USA." *Culture, Medicine, and Psychiatry* 39 (2): 254–76.
- Schein, Louisa. 2016. *Minority Rules.* Duke University Press. Accessed August 30. https://books.google.com/books/about/Minority_Rules.html?id=GomyOthrHjUC.
- Scheper-Hughes, Nancy. 2002. "The Ends of the Body: Commodity Fetishism and the Global Traffic in Organs." *SAIS Review* 22 (1): 61–80.
- . 2004. "Parts Unknown Undercover Ethnography of the Organs-Trafficking Underworld." *Ethnography* 5 (1): 29–73. doi:10.1177/1466138104041588.
- Scheper-Hughes, Nancy, and Geoffrey White. 1993. "Hungry Bodies, Medicine, and the State: Toward a Critical Psychological Anthropology." In *New Directions in Psychological Anthropology*, edited by Theodore Schwartz and Catherine Lutz. Publications of the Society for Psychological Anthropology. <http://dx.doi.org/10.1017/CBO9780511621857.012>.
- Schiere, Richard. 2009. *China's Development Challenges: Economic Vulnerability and Public Sector Reform.* London and New York: Routledge.
- Schull, Natasha. 2002. "Escape Mechanism: Women, Caretaking, and Compulsive Machine Gambling." Working Paper, No 41. Last Access: 29 August 2016. Available on: <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.124.3163&rep=rep1&type=pdf>
- Science Times (kexue shibao). 2011. "Current State of Autism Research (Gudu Zheng Yanjiu Xianzhuang Ji Qianyan Wenti)." *Kexue Wang (Science Portral)*.

- Sean, Sylvia, Yaojiang Shi, Xue Hao, Tian Xin, Wang Huan, Qingmei Liu, Alexis Medini, and Rozelle Scott. 2015. "Survey using Incognito Standardized Patients Shows Poor Quality Care in China's Rural Clinics." *Health Policy Plan* 30 (May): 322–33. doi:doi:10.1093/heapol/czu014.
- Sen, Amartya. 1999. *Development as Freedom*. New York: Oxford University Press.
- Shaked, Michal. 2005. "The Social Trajectory of Illness: Autism in the Ultraorthodox Community in Israel." *Social Science & Medicine* (1982) 61 (10): 2190–2200. doi:10.1016/j.socscimed.2005.04.022.
- Shakespeare, Tom. 2006. *Disability Rights and Wrongs*. Taylor & Francis.
- Shao, Jing. 2006. "Labor and Blood Money: The Economy of HIV/AIDS in Rural Central China." In *Cultural Anthropology*, 21.
- Shi, L. 1993. "Health Care in China: a Rural-Urban Comparison after the Socioeconomic Reforms." *Bulletin of World Health Organization* 71 (6): 36.
- Silberman, Steve. 2016. *Neurotribes: The Legacy of Autism and the Future of Neurodiversity*. Penguin Publishing Group.
- Silverman, Chloe. 2011. *Understanding Autism: Parents, Doctors, and the History of a Disorder*. Princeton, NJ: Princeton: Princeton University Press. <http://press.princeton.edu/titles/9611.html>.
- Singer, Merrill. 1998. "Drugs, Violence, and Moral Panic in Urban America." *American Anthropologist* 100 (1): 186–88.
- Siu, Helen F. 1989. *Agents and Victims in South China: Accomplices in Rural Revolution*. New Haven: Yale University Press.
- Smith-Morris, Carolyn, and Lenore Manderson. 2010. "The Baggage of Health Travelers." *Medical Anthropology* 29 (4): 331–35.
- Sobo, E.L. n.d. "2009. 'Medical Travel: What It Means, Why It Matters.'" *Medical Anthropology* 28 (4): 326–35. doi:Last Accessed: doi: 10.1080/01459740903303894.
- Solinger, Dorothy J. 1999a. *Contesting Citizenship in Urban China: Peasant Migrants, the State, and the Logic of the Market*. Berkeley: University of California Press.
- . 1999b. "Citizenship Issues in China's Internal Migration: Comparisons with Germany and Japan." *Political Science Quarterly* 114 (3): 455–78. doi:10.2307/2658206.
- Solomon, Olga, and Nancy Bagatell. 2010. *Autism: Rethinking the Possibilities Introduction*. *Ethos*. 38(1):1-7. doi:10.1111/j.1548-1352.2009.01078.x

- Song, Priscilla. 2010. "Biotech Pilgrims and the Transnational Quest for Stem Cell Cures." *Medical Anthropology: Cross-Cultural Studies in Health and Illness* 29 (4): 384–402.
- Stone, Emma Victoria. 1998. "Reforming Disability in China." UK: University of Leeds.
- Sun, Wanning. 2009. *Maid in China: Media, Morality, and the Cultural Politics of Boundaries* London ; New York: Routledge.
- Sun, Xiang, Carrie Allison, Bonnie Auyeung, Simon Baron-Cohen, and Carol Brayne. 2013. "A Review of Healthcare Service and Education Provision of Autism Spectrum Condition in Mainland China." *Research in Developmental Disabilities* 34 (1): 469–79. doi:10.1016/j.ridd.2012.08.013.
- Sun, Xiang, Carrie Allison, Bonnie Auyeung, Fiona E. Matthews, Simon Baron-Cohen, and Carol Brayne. 2013. "What Is Available for Case Identification in Autism Research in Mainland China?" *Research in Autism Spectrum Disorders* 7 (5): 579–90. doi:10.1016/j.rasd.2012.11.003.
- Sun, Xiang, Carrie Allison, Bonnie Auyeung, Fiona E. Matthews, Stuart Murray, Simon Baron-Cohen, and Carol Brayne. 2013. "Service Provision for Autism in Mainland China: A Service Providers' Perspective." *Research in Developmental Disabilities* 34 (1): 440–51. doi:10.1016/j.ridd.2012.08.010.
- Sun, Xiang, Carrie Allison, Fiona E. Matthews, Stephen J. Sharp, Bonnie Auyeung, Simon Baron-Cohen, and Brayne, and Carol. 2013. "Prevalence of Autism in Mainland China, Hong Kong and Taiwan: a Systematic Review and Meta-analysis." *Molecular*. Vol. 1.
- Tait, Alan. 1979. "Schizophrenia: An International Followup Study." *Journal of Neurology, Neurosurgery, and Psychiatry* 42 (11): 1072.
- Tao, Kuo-Tai. 1987. "Brief Report: Infantile Autism in China." *Journal of Autism and Developmental Disorders* 17 (2): 289–96. doi:10.1007/BF01495062.
- Taussig, Karen-Sue, Klaus Hoeyer, and Stefan Helmreich. 2013. "The Anthropology of Potentiality in Biomedicine: An Introduction to Supplement 7." *Current Anthropology* 54 (S7): S3–14. doi:10.1086/671401.
- The Economist. 2014. "Moving on up." *The Economist*. March 22. <http://www.economist.com/news/china/21599397-government-unveils-new-people-centred-plan-urbanisation-moving-up>.
- Tom, Allison. 1993. In *Women, Work, and Coping: A Multidisciplinary Approach to Workplace Stress*, by Bonita C. Long and Sharon E. Kahn. Montreal: McGill-Queen's Press - MQUP.
- To, Wai Chun Clara 杜維真. 2014. "Economic Reforms, Changing Intergenerational Transfers, and Women's Labor in Contemporary Rural South China." <http://repository.lib.ied.edu.hk/jspui/handle/2260.2/19733>.

- Tsai, Kellee S. 2004. *Back-Alley Banking: Private Entrepreneurs in China*. Ithaca, NY: Cornell University Press.
- Tsang, Hector W.H., Phidias K.C. Tam, Fong Chan, and W.m. Cheung. 2003. "Stigmatizing Attitudes towards Individuals with Mental Illness in Hong Kong: Implications for Their Recovery." *Journal of Community Psychology* 31 (4): 383–96. doi:10.1002/jcop.10055.
- Tsing, Anna. 1990. "Monster Stories: Women Charged with Perinatal Endangerment." In *Uncertain Terms: Negotiating Gender in American Culture.*, edited by Faye Ginsburg and Anna Tsing. Boston: Beacon Press.
- Twitchett, D.C. n.d. *Financial Administration under the T'ang Dynasty*. UK: Cambridge University Press.
- University of Cambridge. 2013. "Autism Prevalence in China." *Accessed 1 (May)*. <https://www.cam.ac.uk/news/autism-prevalence-in-china-0>.
- Urla, Jacqueline. 1993. "Cultural Politics in an Age of Statistics: Numbers, Nations, and the Making of Basque Identity." *American Ethnologist* 20: 818–43.
- Vedom, Julia, and Huhua Cao. 2011. "Health Care Access and Regional Disparities in China." *Espace populations sociétés*, no. 2011/1 (March): 63–78. doi:10.4000/eps.4345.
- Volkmar, Fred R., ed. 2007. *Autism and Pervasive Developmental Disorders*. 2 edition. Cambridge ; New York: Cambridge University Press.
- Wang, Fei-Ling. 2005. "Preservation, Prosperity and Power: What Motivates China's Foreign Policy?" *Journal of Contemporary China* 14 (45): 669–94. doi:10.1080/10670560500206033.
- Wang, Feng, Zuo, and Xuejin. 2007. In *"Inside China's Cities: Institutional Barriers*.
- Wang, Xiaolu, Wan, and Guanghua. 2014. "China's Urban Employment and Urbanization Rate: A Re-Estimation." *China and World Economy*/ 22: 30–44.
- Wang, Y.P., Y.L. Wang, and J.S. Wu. 2010. "Housing Migrant Workers in Rapidly Urbanizing Regions: A Study of the Chinese Model in Shenzhen." *Housing Stud* 25: 83–100.
- Wan, Yumei, Qiang Hu, Ting Li, Lijuan Jiang, Yasong Du, Lei Feng, John Chee-Meng Wong, and Chunbo Li. 2013. "Prevalence of Autism Spectrum Disorders among Children in China: A Systematic Review." *Shanghai Archives of Psychiatry* 25 (2): 70–80. doi:10.3969/j.issn.1002-0829.2013.02.003.
- Watson, James L. 2010. *Class and Social Stratification in Post-Revolution China*. Cambridge University Press.
- Weisz, George. 2011. "Afterword: Historical Reflections on Medical." *Medicine* 18: 137–44.

- Wei, Yehua. 1999. "Regional Inequality in China." In *Progress in Human Geography*, 23:48–58. 1.
- Wei, Yehua Dennis, and C. Cindy Fan. 2000. "Regional Inequality in China: A Case Study of Jiangsu Province." *The Professional Geographer* 52 (3): 455–69. doi:10.1111/0033-0124.00238.
- Wen, Ming, and Danhua Lin. 2012. "Child Development in Rural China: Children Left behind by Their Migrant Parents and Children of Nonmigrant Families." *Child Development* 83 (1): 120–36. doi:10.1111/j.1467-8624.2011.01698.x.
- Whittaker, A. 2008. "Pleasure and Pain: Medical Travel in Asia. Global Public Health: An International." *Journal for Research. Policy and Practice* 3: 271–90.
- Whyte, Martin. 2004. *Filial Piety: Practice and Discourse in Contemporary East Asia*. Stanford: Stanford University Press.
- . 2010. *Myth of the Social Volcano: Perceptions of Inequality and Distributive Injustice in Contemporary China*. Stanford University Press.
- Whyte, Martin, and William Parish. 1984. *Urban Life in Contemporary China*. Chicago: University Of Chicago Press. <http://www.press.uchicago.edu/ucp/books/book/chicago/U/bo5960741.html>.
- Wilson, M. 1993. "DSM-III and the Transformation of American Psychiatry: A History." *The American Journal of Psychiatry* 150 (3): 399–410. doi:10.1176/ajp.150.3.399.
- Wing, L. 1981. "Asperger's Syndrome: A Clinical Account." *Psychological Medicine* 11 (1): 115–29.
- Wong, D.F.K.W., Y.L. Chang, and X.S. He. 2007. "Rural migrant workers in urban China: Living a marginalized life." *International Journal of Social Welfare* 16 (2): 32–40.
- Wong, Virginia C. N., and Stella L. H. Hui. 2007. "Epidemiological Study of Autism Spectrum Disorder in China." *Journal of Child Neurology*, December. doi:10.1177/0883073807308702.
- World Health Organization, World Health. 1979. *Schizophrenia: An International Follow Up Study*. Chichester Eng. ; New York: John Wiley & Sons Ltd.
- Wu, Kin Bing. 2002. *Early Child Development in China*. Washington, DC: The World Bank. <https://openknowledge.worldbank.org/bitstream/handle/10986/9383/709830PUB0EPI0067926B09780821395646.pdf?sequence=1>.
- Wu, Xiaogang, and and Donald J. Treiman. 2004. "The Household Registration System and Social Stratification in China: 1955-1996." *Demography* 41 (2): 384.
- Yang, Lawrence Hsin, and Veronica J. Pearson. 2002. "Understanding Families in Their Own Context: Schizophrenia and Structural Family Therapy in Beijing." *Journal of Family Therapy* 24 (3): 233–57. doi:10.1111/1467-6427.00214.

- Yang, Mayfair Mei-hui. 2002. "The Resilience of Guanxi and Its New Deployments: A Critique of Some New Guanxi Scholarship." *The China Quarterly* 170 (June): 459–76. doi:10.1017/S000944390200027X.
- Yan, Hairong. 2008. *Servants: Migration, Development, and Women Workers in China*. New Masters, New: Duke University Press.
- Yan, Yunxiang. 2003. *Private Life under Socialism: Love, Intimacy, and Family Change in a Chinese Village, 1949-1999*. Stanford California: Stanford University Press. <http://www.sup.org/books/title/?id=1030>.
- Yao, Shujie. 1999. "Economic Growth, Income Inequality and Poverty in China under Economic Reforms." *The Journal of Development Studies* 35 (6): 104–30. doi:10.1080/00220389908422604.
- Yeh, Kuang-Hui, Chin-Chun Yi, Wei-Chun Tsao, and Po-San Wan. 2013. "Filial Piety in Contemporary Chinese Societies: A Comparative Study of Taiwan, Hong Kong, and China." *International Sociology* 28 (3): 277–96. doi:10.1177/0268580913484345.
- Yergeau, Melanie. 2013. "Clinically Significant Disturbance: On Theorists Who Theorize Theory of Mind." *Disability Studies Quarterly* 33 (4). <http://dsq-sds.org/article/view/3876>.
- Yi, Bin, Li Wu, Hong Liu, Fang Weimin, and Wang Youjie HuYang. 2011. "Rural-Urban Differences of Neonatal Mortality in a Poorly Developed Province of." *China* 11 (477).
- Yip. 2005. "Family Caregiving of Clients With Mental Illness In The People's Republic Of China (Part 1 - Historical Background)." *International Journal of Psychosocial Rehabilitation* 10 (1): 27–33.
- Yip, Winnie Chi-Man, William C Hsiao, Wen Chen, Shanlian Hu, Jin Ma, and Alan Maynard. 2012. "Early Appraisal of China's Huge and Complex Health-Care Reforms." *The Lancet* 379 (9818): 833–42. doi:10.1016/S0140-6736(11)61880-1.
- Yip, Winnie, and Hsiao, and William. 2009. "China's Healthcare Reform: A Tentative Assessment." *China Economic Review*, 613–19.
- Yu, Sam Wai Kam, and Ruby Chui Man Chau. 1997. "The Sexual Division of Care in Mainland China and Hong Kong." *International Journal of Urban and Regional Research* 21 (4): 607–19. doi:10.1111/1468-2427.00104.
- Zhang, Hong. 2006. "Family Care or Residential Care? The Moral and Practical Dilemmas Facing the Elderly in Urban China." *Asian Anthropology* 5 (1): 57–83. doi:10.1080/1683478X.2006.10552560.
- Zhang, Li. 2001a. "Contesting Crime, Order, and Migrant Spaces in Beijing" In *China Urban: Ethnographies of Contemporary Culture*. Edited by Nancy N. Chen, Constance D. Clark, Suzanne Z. Gottschange, and Lyn Jeffery. North Carolina, Duke U Press.

- . 2001b. *Strangers in the City: Reconfigurations of Space, Power, and Social Networks Within China's Floating Population*. Stanford University Press.
- . 2001c. "Migration and Privatization of Space and Power in Late Socialist China." *American Ethnologist* 28 (1): 179–205. doi:10.1525/ae.2001.28.1.179.
- . 2010. *In Search of Paradise: Middle-Class Living in a Chinese Metropolis*. Cornell University Press.
- Zhang, Li, and Aihwa Ong, eds. 2008. *Privatizing China: Socialism from Afar*. Vol. 2008. Ithaca, NY: Cornell University Press.
- Zhang, Xiaobo, and Ravi Kanbur. 2005. "Spatial Inequality in Education and Health Care in China." *China Economic Review* 16 (2): 189–204. doi:10.1016/j.chieco.2005.02.002.
- Zhang, Xin, and Cheng-Ye Ji. 2005. "Autism and Mental Retardation of Young Children in China." *Biomedical and Environmental Sciences: BES* 18 (5): 334–40.
- Zhang, Yuanting, and Franklin W. Goza. 2006. "Who Will Care for the Elderly in China?: A Review of the Problems Caused by China's One-Child Policy and Their Potential Solutions." *Journal of Aging Studies* 20 (2): 151–64. doi:10.1016/j.jaging.2005.07.002.
- Zhan, Mei. 2009. *Other-Worldly: Making Chinese Medicine through Transnational Frames*. Durham, NC: Duke University Press Books.
- Zhao, Zhongwei. 2006. "Income Inequality, Unequal Health Care Access, and Mortality in China." *Population and Development Review* 32: 461–83.
- Zheng, Tiantian. 2009. *Red Lights: The Lives of Sex Workers in Postsocialist China*. University of Minnesota Press.
- Zhu, Jianfeng. 2013. "Projecting Potentiality: Understanding Maternal Serum Screening in Contemporary China." *Current Anthropology* 54 (S7): S36–44. doi:10.1086/670969.