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Interpreting and Treating Autism in Javanese Indonesia

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in Culture and Performance

by

Anne Currier Tucker

2013

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ABSTRACT OF THE DISSERTATION

Interpreting and Treating Autism in Javanese Indonesia

by

Anne Currier Tucker

Doctor of Philosophy in Culture and Performance

University of California, Los Angeles, 2013

Professor Irma Dosamantes-Beaudry and Professor Michael Owen Jones, Co-chairs

Autism is a complex developmental disorder affecting communication, social interaction, and behavior. As interest in this disorder has increased worldwide, clinical and social science researchers have begun to ponder how autism might be configured and understood in different parts of the world.

There may be as many as one million people with autism in Indonesia, yet little information is available regarding the implications for affected individuals, families, and communities. My dissertation takes a sociocultural perspective in addressing how autism is recognized, interpreted, and responded to in Javanese Indonesia. Based on 12 months of multi-sited ethnographic fieldwork in Yogyakarta and Jakarta, I have a) documented how autism is being introduced to and taken up by Javanese families, b) addressed the benefits and challenges of using autism as an interpretive framework for developmental difference, and c) considered the reactions to and implications for some of the interventions that have been attempted thus far.

In doing so I make a number of key observations and claims. First, Javanese reactions to individuals with autism are deeply influenced by local models of personhood and sociality as well as socio-economic status. Second, introducing the concept of autism to Javanese families and attempting to make it useful for them is a complex process, and those who would do so call upon a number of variably successful strategies including a) making autism visible in the popular media, b) re-signifying autism in order to reduce stigma, c) building supportive networks, d) translating unfamiliar concepts associated with autism into familiar idioms, and e) teaching parents how to recognize the signs of autism and adjust their behavior accordingly. These strategies seem to be least successful when dissonant with local values and practices. I describe a promising experimental treatment that incorporates therapeutic gamelan practice and performance, which provides benefits for individuals with autism within an inclusive social environment that is framed as a Javanese tradition.

My dissertation thus a) contributes to the growing cross-disciplinary scholarship on global autism by providing descriptive and qualitative data from Java, b) documents and analyzes the role of performance in the cultural construction of autism and c) proposes a framework for identifying interventions that might simultaneously meet the needs of autistic individuals and incorporate locally-prized activities and models of healthy development.

The dissertation of Anne Currier Tucker is approved.

Victoria Marks

Thomas Weisner

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DEDICATION PAGE

I would like to dedicate this dissertation to all the students on the spectrum I have worked with in various capacities over the course of this past decade as I have learned about the world of autism. My experiences with them shaped my professional trajectory in unexpected ways and catalyzed this research; but more importantly they have enriched my life with their generosity of spirit, keen sense of humor, and unique insights and ways of seeing the world.

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for Robert Lemelson, I never would have realized that the topic I wanted to explore was a viable one. His body of work in Indonesia has been a unique and outstanding model, and the opportunity to work with him has been instrumental in shaping my research trajectory and approach. Tom Weisner's teaching and writing has inspired me to think pragmatically about research that might prove useful on the ground and was invaluable in the design of this project. And finally a big thank you to Victoria Marks, whose input has helped me probably more than she realizes; it has been a privilege to think through these issues with you.

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Chapter One

Introduction

Autism is most commonly known as a developmental disorder that affects language, communication, and behavior. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), the standard used by mental health professionals in the United States and many other countries, the major diagnostic criteria for autism are “qualitative impairment in social interaction,” “qualitative impairments in communication,” typically characterized by both verbal deficits and lack of nonverbal communication skills such as eye contact, affect expression, and body postures, and “restricted repetitive and stereotyped patterns of behavior, interests and activities” (APA, 2000). However, the recognition, interpretation, and treatment of autism and autistic symptoms has gone through major shifts since its “discovery” as a new, rare, and obscure condition in the early 1940’s to its current contested status as a global epidemic. While a definitive cause or cure for autism remains elusive, various etiological theories have emerged and various interventions have been proposed. These theories have tended to reflect contemporary social concerns and concepts of personhood, and the interventions they have given rise to reflect what is considered to be normative or appropriate social behavior in the culture. Meanwhile, representations and interpretations of autism made by the media, the arts, popular culture, and vernacular discourse interact with psychological and medical models and serve to further shape its meaning for families directly affected by the condition.

As the autism diagnosis has been popularized and globalized, autism has emerged as a meaningful category of developmental difference in Indonesia. While the diagnosis is primarily known among upper-middle class urban dwellers, information about the condition has also

reached some in less affluent and more rural communities. Some in the field believe there might be as many as one million children and adolescents with autism in the country (Diniah, 2010). But what does it mean to have autism in Indonesia? Guided by a socio-cultural approach, which suggests that the meaning and experience of any disability will be shaped not just by individual deficits but also by the responses of caregivers and family members who avail themselves of the treatments, services and frameworks of meaning available (Skinner & Weisner, 2007) my dissertation addresses how autism is recognized, interpreted, and treated in Indonesia. I contend that autism's meaning is shaped by the responses of primary caregivers and family members and their social interactions with the autistic person, the treatments and interventions available for families and individuals, and a variety of media that influences the popular conception of what autism is and how people with autism should be responded to. My dissertation aims to gain a basic understanding of all three of these dimensions that frame autism and autistic symptoms across Indonesia. In building this understanding, I document some of the ways in which the comparatively new and often unfamiliar diagnosis of autism is introduced to and understood by Indonesian families. My analysis further addresses the benefits and challenges of using autism as an interpretive framework for developmental difference and considers the benefits and challenges of some of the interventions that have been proposed and attempted thus far in Indonesia.

Literature Review

Autism was first identified in 1943 by child psychologist Leo Kanner and pediatrician Hans Asperger who worked separately, in America and Austria respectively, on studies with only a handful of children. Both borrowed the term "autistic" from part of a pre-existing childhood schizophrenia diagnosis, which indicated a patient's preference for their own internal

world rather than shared interests or realities. Kanner noticed similar symptoms of speech disturbances and rote behaviors in his different patients while Asperger studied children who despite their precocious speech, interests, and intelligence were highly socially impaired by their restricted behaviors, sensory needs, and desire to be alone (Kanner, 1943; Asperger, 1944).¹ Over the next two decades both the interest in autistic symptoms and the influence of psychoanalysis grew. Bruno Bettelheim and other psychoanalysts in the 1960's and 1970's considered autistic behavior to be the result of severe emotional trauma due to poor parenting where children sensed they were not wanted in the world and had therefore withdrawn from it (Bettelheim, 1967). This hypothesis was later disproven and de-popularized through the work of parents and educators, including the influential Eric Schopler who argued for a spectrum of organic brain differences and pioneered many successful teaching strategies and encouraged parents to become his "co-therapists" (Rutter & Schopler, 1978). Influential British researchers Simon Baron-Cohen and Uta Frith posited autism is a neurological deficit affecting "theory of mind," or the ability to take others' perspectives (Baron-Cohen, Leslie & Frith, 1985; Baron-Cohen, 1997), a popular idea that nonetheless has been critiqued as, among other things, being culturally biased by failing to account for the cross-cultural diversity of neurological activity engaged during mentalizing tasks as illustrated in experiments comparing Euro-American and Japanese subjects (Kobayashi et al., 2006).

Due to parental activism, the disability rights movement and increasing diagnoses of autism in the '80's and '90s through the present, there is now many active autism research projects being conducted and a plethora of intervention techniques available in the United States.

¹ In the current version of the DSM-IV, Aspergers remains distinct from Autism. Although it is considered as one of the spectrum disorders, it has quite a different profile, often categorized by above-average verbal ability. As the new edition of the DSM-5 is currently being written, it has been proposed that Aspergers be eliminated/ subsumed into Autism, spurring strong opposition and much dialogue. For the purposes of my research I will be focusing on those Indonesians who are classified as having Autism, not Aspergers.

Autism is now understood as an organic biological difference resulting from a complex cluster of factors that may include genetic influence (Eapen, 2011), atypical neurological activity (Dapretto et al., 2006), adverse reaction to environmental toxins (Landrigan, 2010), and sensory processing integration difficulties (Watling et al., 2001). The multiple pathways to autism are further complicated by its conceptualization as a “spectrum” which can encompass many different kinds of people with many different symptoms, presentations, strengths, and deficits, and often compounded by an additional diagnosis such as intellectual disability or anxiety (Kim et al., 2000; White et al., 2009; Matson & Shoemaker, 2009).

In the past decade, the prevalence of autism spectrum disorder (ASD) diagnoses have risen dramatically such that autism has become one of the most pressing concerns in child development in America today. By some accounts the rate of autism has risen to 1 in 88 children, although it is debated whether these radically increased numbers in diagnosis suggest a true increase in prevalence of the disorder (Gernsbacher, Dawson & Goldsmith, 2005; Grinker, 2007). Increasing amounts of funding are being directed towards autism research and treatment. In the United States, certain treatments for autism are officially endorsed by state and federal agencies, primarily Applied Behavioral Analysis (ABA) and pharmacotherapy to reduce symptoms. Other common educational and therapeutic programs include speech therapy and occupational therapy. Complementary and alternative treatments for autism used in the United States include acupuncture, massage, yoga, restricted diets such as the gluten-free-casein free diet, nutritional supplements, and the creative arts therapies, among others (Barnett & Shale, 2013).

In addition to an increasingly significant presence in biomedical research and the fields of psychology and education, autism has gained currency in media and popular culture with the

development of an ever-growing autism niche: autism memoirs by those on the spectrum and their family members (Park, 1967; Williams, 1998; Grandin, 2006), autistic characters in films and novels (Haddon, 2003) and documentaries about autism (Regan, 2007; Drezner, 2011). This cultural production is informed by medical discourses and contributes to shaping the vernacular view of what autism is and means (Murray, 2008). Of particular note in the last decade, activist groups such as the Autistic Self-Advocacy Network (ASAN) have begun to advocate for “neurodiversity” and promote representations of autism that do not pathologize autistic difference but celebrate the strengths and potentials of a newly self-conscious minority group to advocate for autism as a valuable “way of being” (Schwartz, 2009; Bagatell, 2010).

Many in academia have argued for autism research that complements biomedical and neurological findings. With the advent of fMRI machines and brain imaging techniques and an increasing push to locate developmental difference and mental illness within the brain, “hard” science has taken the lead. However, simultaneous advances in the field of transcultural psychiatry have emphasized the impact culture has on the interpretation, and treatment of even neuropsychiatric disorders such as Tourette's, which may have strikingly similar symptomatology regardless of cultural context (Lemelson, 2010). This impact necessitates qualitative, person-centered, eco-cultural and ethnographic methods of research on autism that moves beyond merely testing “elicited behaviors in structured experimental settings” (Ochs, 2005, p. 143), a need which has been recently recognized in the special autism-themed issue of *Disability Studies Quarterly* (2010) and the recent *Ethos* issue “Rethinking Autism, Rethinking Anthropology” (2010).

Outside the United States and Europe, and more markedly so over the past ten years, there has been a steady increase in global awareness and concern about autism, along with

increased diagnoses of the disorder. Recent scholarship suggests that autism is both biologically based and culturally inflected; in other words, while there are organic or biological components to autism and common symptoms, behaviors, deficits, and strengths that are recognizable cross-culturally, autism may yet have various presentations depending on cultural context (Mandell & Novak, 2005); as autism researcher Tamara Daley states it, "the most accurate view of autism is a biological condition that is culturally shaped in symptoms and course" (Daley, 2002, p. 543). Furthermore, various symptoms of autism may be interpreted and treated differently depending on the values and beliefs of the different cultures within which they emerge (Danesco, 1997; Levy et al., 2003; Grinker, 2007). Finally, while the biological condition we now call autism may have always existed, autism as a recognizable category of developmental disability itself is a cultural phenomenon that is enabled by particular social and historical developments (Nadesan, 2005; MacDonagh, 2008). Therefore, scholars working in diverse fields from applied anthropology to critical disability studies are calling for comprehensive, culturally comparative research on autism. As Stuart Murray has stated, "autism is configured, understood, and discussed in vastly different ways in different parts of the world, and to know the condition properly we will have to work through many examples of its various manifestations" (Murray, 2008, p. 16). An understanding of the diverse cultural places in which people with autism grow and develop is also crucial to the development and provision of appropriate services and supports. And yet, it is still lamented that "unfortunately, there are to date only a few data-driven studies of how, in the context of the global influence of psychiatric knowledge, culture shapes the understanding and management of autism" and "researchers are just beginning to study the extent to which factors such as race, ethnicity, and poverty influence the recognition and treatment of ASD, not only across but also within cultures" (Grinker & Choo, 2011, p. 47).

In the growing effort to work through these manifestations and understand these influences and factors, there have been a number of studies of autism in various cultural groups within the United States and in other countries, including studies that focus on parental beliefs and behaviors, the interpretation and treatment of autism and autistic symptoms, and the efficacy of various interventions in different cultural settings (Ohta, Hara & Sasaki, 1987; Garcia et al., 2000; Daley, 2002; Daley, 2004; Grinker, 2007; McCabe, 2007; Humphrey & Lewis, 2008; Pajareya & Nopmaneejumruslers, 2011; Kim 2012). This growing body of literature demonstrates that cultural beliefs and cultural histories do indeed influence the interpretation of autistic symptoms and the preferred treatments for them. For example, folk beliefs about development and spirituality may frame autistic symptoms as indication of spiritual power or divine connection and pre-existing popular practices of folk healing already in use for other ailments, such as herbal treatment, divination, or energy work, may become options in addressing developmental or behavioral challenges associated with autism (Shaked & Bilu, 2006; Daley, 2002). In addition historical events, national identities, and generational trauma also impact the interpretation and treatment of autism. For example in the Navajo nation, a lack of indigenous conception of “disability” combined with history of forced removal of children from families’ homes on the part of white government workers made families less likely to seek “official” diagnosis or treatment and consider their child as in a “constant state of becoming” (Connors & Donnellan, 1995) rather than autistic. In South Korea, some viewed autistic children as “ghosts in the nursery,” the fruit of parents and grandparents still struggling with repressed depression and anger over Japanese colonization and the effects of the Korean War (Grinker, 2007).

Despite the range of treatments and interpretations of autism, the diagnosis is gaining international visibility and credence and is increasingly de-stigmatized, easing some of the suffering caused by previous attribution to parental, and particularly maternal, failure. In the global context, folk models of transmission such as parent-to-parent information sharing and internet resources, are often important in spreading up-to-date and accurate information about the diagnosis which local doctors, though formally educated, may not have (Grinker, 2007).

Biomedical treatment and locally coherent interventions may be quite complementary and can be integrated or used simultaneously. For example, in Israel, Shaked & Bilu (2006) conducted open-ended interviews with Orthodox Jewish mothers to find that mother's perspectives are "flexibly accommodating" to both biomedical and spiritual models of difference and suggest that different cultural groups access their own "cultural toolkits" to help them understand, frame, and cope with autism and developmental difference.

In this nascent phase of global comparative autism studies, the phenomenon of autism remains under-studied in Indonesia. While there has been one epidemiological study in Yogyakarta that is already certainly outdated (Wignyo Sumarto et al., 1992), some publications on detection and treatment (Wijayakusuma, 2004; Waruwu, 2006), proposals for public awareness campaigns (Puspasari, 2005) and as yet unpublished graduate and undergraduate research on suggestions for improved services (Hardiansyah, 2009), scarce qualitative research on the interpretation or treatment of autism has been published. Yet within the country there is increasing development of both biomedical and alternative treatment and education centers, stretched across the archipelago from Bali to Bukittinggi. There is a proliferation of autism education and awareness organizations, as well as a flowering of Indonesian-language web resources, such as Facebook groups and parenting blogs. This growing public awareness of

autism has been reflected by a steady stream of autism-themed articles in popular national newspapers such as *Kompas* and *Tempo* (Triyono, 2008; Triyono, 2009), memoirs by parents of autistic children (Sarasvati, 2004; Puspita, 2005) and an increased presence of autistic characters in recent Indonesian films and novels (Utami, 1998; Idris & Tobing-Rony, 2007; Suryadi, 2011; Nadia, 2011). Clearly autism is emerging as a culturally salient category of developmental difference in Indonesia, yet there is still very little scholarly understanding of this phenomenon. There is almost no literature that deals with autism in Indonesia from a qualitative perspective including explanatory models or theories of etiology, experiences of intervention or treatment, and the effect on the everyday life of families. There is also almost no literature that explains how and why over the past decade or two autism has been able to take root as a useful label for, or category of, developmental difference in Indonesia.

Despite the gap in the literature on autism in particular, anthropological research in Indonesia shows a long-standing interest in development and folk psychology as well as a historical focus on the topics of family, social structure, child rearing, and healing that informs my own work. The ethnographic corpus of Clifford and Hildred Geertz provides a comprehensive background of knowledge on Javanese family, spirituality, and socialization (C. Geertz, 1960, 1973, 1977, 1984; H. Geertz 1961, 1974), while Ward Keeler's work illuminates how the values of Javanese personhood are inculcated through childrearing practices (1975, 1983). I will revisit these in some detail throughout the dissertation, particularly in Chapter Three, and hence will not delve into them here. Though some of the conclusions these scholars drew about the Indonesian "character" and Indonesian culture have been contested, their works provide valuable ethnographic data the bulk of which resonates today.

An equally impressive body of work describes local logics of health, development, and

traditional healing throughout Indonesia (Connor, Asch & Asch, 1986; Salan & Maretzki, 1983; Hobart, 2003). Sketched most broadly, those works underscore the conceptualization of “health” in Indonesian cultures to be in many ways inseparable from conceptions of spirituality, emotion, social ties, communal responsibility, and artistic practice. Fear and frustration may weaken vital life force, and anger may directly endanger it (Wikan, 1989; Hay, 2003; Hollan, 1988, 1992) while the arts help cultivate and strengthen it (Holt, 1967; Foley, 1984; Hughes Freeland, 2008). Situating illness within the context of the community, entire kin networks may share responsibility for determining the cause and participating in the cure for any one person’s illness, disturbance, or distress. Throughout Indonesia there is a well-developed, well-researched, and persistent landscape of traditional healing that ascribes various meanings to developmental and health disturbances and incorporates various models of community (Salan & Maretzki, 1983; Suryani & Jensen, 1992; Connor & Samuel, 2001). Yet Lemelson’s work on Tourette’s (2004, 2010) makes the important point that if there is no folk model for a particular illness, patients may experience their symptoms as existing outside the realm of social meaning and traditional methods of treatment may not succeed in alleviating symptoms. In this case non-indigenous biological models of illness may be more effective in providing treatment that can reach the neurological bedrock of the condition, even as family and community might either serve to exacerbate symptoms or act as a protective guiding buffer (Lemelson, 2010, 2011).

Meanwhile, increasing Indonesian encounters with globalized diagnoses and intervention models have introduced new labels for and categories of illness and disturbance (Ferzacca, 2001; Lemelson, 2010, 2011) as well as new concerns regarding how to maintain personal and communal health in the context of significant historical change and cultural shift. Scholars such as Steve Ferzacca have explored pluralistic health care for “modern” ailments such as diabetes

and high blood pressure seen by locals as coming from an increasingly Westernized lifestyle that could be cured by a hybridity of “traditional” or Javanese health practices and biomedical knowledge (Ferzacca, 2001). Work in medical anthropology, transcultural psychiatry, and folk medicine have illustrated that in negotiating “western” and “traditional” models of diagnosis and treatment, available labels, interventions, and family responses may have significant impacts on wellbeing and long term outcomes; a common challenge often addressed is how to retain the benefits of traditional or indigenous models of individual and collective wellbeing while also incorporating the benefits of biomedical treatments and globalized identity discourses. These dialectics are in evidence in the interpretation and treatment of autistic symptoms as well.

Critical Concepts Underlying Study

Multiple and Dynamic Pathways of Child Development

Super and Harkness (1996) write that in all circumstances cultures develop folk theories, or ethnotheories of development, which include local socialization practices, goals of development, and ways of understanding child behavior. These pathways are various, adaptive, and meaningful, made up of everyday routines that themselves constitute cultural activities which crystallize important aspects of shared cultural life such as goals, resources, important figures, tasks, emotions, and scripts (Quinn, 2005; Weisner, 2005). The “culture” learned by a child is both internal (as beliefs and ideas) and external (as practices), both of which are often transferred nonverbally during infancy and early childhood by the primary care giver(s) (Dosamantes-Beaudry, 1997; Gottlieb, 2004). Culture enacted and imparted through particular practices over time influence individual development through shaping patterns of cognition, motivation, and emotion, worldviews and self-construals, and interactions with others. The

ecocultural approach to comparative developmental pathways also acknowledges the geopolitical context of childrearing, as factors such as deprivation and globalization all powerfully influence adaptive goals and practices (Weisner & Lowe, 2008; Scheper-Hughes, 1990; Howard & Millard, 1997). Globalization processes may influence local ideas about development, for example through the spread of the period of “adolescence”; the changing role of women (Seymour, 1999); the gradual easing of stigma and increasing acceptance and social integration of children with disabilities (Ingstad & Whyte, 1995); and the variable spread of new labels and pathologies (Watters, 2010). Globalized and globalizing institutions may restructure the provision of health care and education, sometimes giving rise to problems of cultural “fit” and cultural “coherence” as people contend with local and international models of personhood (Weisner & Lowe, 2005).

Cultural Models of Illness, Healing, and Disability

Local ideas about human development in turn influence the structure, expression, and recognition of developmental difference and atypical experience such as mental illness or disability. Arthur Kleinman famously argued that there is disease, that which is physically and/or symptomatically wrong with the patient, and then there is illness, which encompasses a much more complex explanation of what is “wrong” in terms of personal history, social concerns, religious significance, and etc., in the life course of the ill person. He proposed medical anthropologists determine the “explanatory model” to take all this into account, and underscored the importance of the “illness narrative” (Kleinman, 1980, 1989). His and others’ theories of illness narratives suggest the stories we tell about our illnesses may impact prognosis and the efficacy of cure (Jones, 1976; Mattingly & Garro, 2000).

Amidst this diverse landscape of illness theory and response, the solution of health care tends to be pluralistic, with people often seeking care from biomedical, spiritual, folk and alternative modalities of healing. “Hierarchies of resort” may determine what genres of medicine are used in what sequence to cure different illnesses (Schwartz, 1969). Ultimately, integrative medicine that includes both biomedicine and folk models of health and folk healers tends to be most efficacious, a finding increasingly recognized by biomedical and folk practitioners who, in Indonesia and elsewhere often mutually refer patients (Myers, 1999). Indeed, folk medicine is still frequently utilized across the globe, not least because it has its own distinct logics of healing (O’Connor & Hufford, 2001) that address aspects of the illness experience that biomedicine cannot, such as spiritual or supernatural etiologies, and may provide other aspects of care that the biomedical approach cannot, such as sensory-rich and aesthetic forms of healing or intersubjective work towards cure (Jones et al., 2001). Folk medicine, faith healing, or alternative treatments informed by folk models of illness and health may be successful dynamic agents of change at the intersection of the sacred and the secular because they derive from, draw upon, and perform or embody cultural values, symbols, and beliefs (Santino, 1985; Toelken, 2001; Csdordas, 2002).

Implicated in and informed by cultural models of development, illness, and healing, disability is a sociocultural phenomenon (Skinner & Weisner, 2007), a category that is contested and forever fluctuating. Ethnographic and historical research has shown that categories of disability are locally and culturally specific and determined by historical and socio-cultural conditions (Ingstad & Whyte, 1995; Ariotti, 1999) and folk theories of etiology and pathology, or “explanatory models” develop in the context of disability (Daley & Weisner, 2003). Autism is considered by many to be a developmental disability, a social and communicative disorder,

which might be ameliorated but which cannot be “cured.” There are often significant physical symptoms for some people with autism—such as gastrointestinal and digestive issues, sleep disturbances, and seizures—which can be ameliorated with appropriate treatment, but even if these physical aspects of the condition are ameliorated, other differences and/or challenges may remain. Therefore autism is not a primarily physical sickness that can be recovered from, nor can it temporarily abate or go into remission like certain major mental illnesses. Therefore I propose that “development” is a more apt paradigm for thinking about interventions for autism than ideas of healing or cure. While families can achieve healing in terms of their approach or perspective—where healing is understood to mean a state of wellbeing, acceptance, and sense of coherence and purpose despite the presence of illness or disability—the better paradigm for autism is that of encouraging or promoting a more normative or adaptable development, which incorporates communication, interaction, and participation in culturally meaningful shared activities. In analyzing the treatments and interventions designed to respond to people with autism, it is therefore fruitful to ask: what are the cultural practices that support healthy development? What are the signals that such development is occurring or has occurred? What qualities are cultivated or prized in development, and what abilities—corporeal, behavioral, sensory, interpersonal, etc.—are exercised? All of these ideas about and expectations for development are informed by and inform the way autism is treated and understood in any cultural place and penetrate many aspects of autism intervention and the socialization efforts to educate and inform the wider public about autism and its significance.

Critical Disability Studies

While in many ways harmonizing with sociocultural studies of disability, critical disability studies argues against the medical or deficiency model of biological determinism,

which locates disability within an individual body that needs to be fixed or cured, and instead acknowledges various impairments and ways of being in the world as naturally occurring aspects of human diversity (Garland-Thompson, 2005). While various impairments may prevent typical functioning, the level of disability is in part created through the interpretation of and response to that impairment (which abilities are prized, which limitations accommodated, which differences are stigmatized). As such, attitudes towards disability are always created in the context of social relationships and changing socio-cultural conditions, which may pathologize or integrate people with certain kinds of disabilities and forge new labels, group identities, and interventions (MacDonagh, 2008).

Critical disability studies also argues that disability is also always, implicitly or explicitly, about norms (Davis, 1995; Michalko & Titchkosky, 2009) and attitudes regarding disabilities and their treatment allow us to reconsider issues of normalcy and embodiment, as well as independence, interdependence, and more. As medical anthropologist Steve Ferzacca says about his work on chronic illness in Central Java:

clinical encounters not only reveal the presence of disease, but also tropes of development, conceptual frameworks of health, cultural constructions of place and time, navigations of social life, and measures of hegemonies (Ferzacca, 2001, p. 111).

In my discussion of autism interpretation and treatment, it becomes apparent that the way the needs of Indonesian people with autism are being negotiated are in effect negotiations of normative Indonesian identity and the kinds of practices that support this identity and foster it's healthy development.

Disability studies have also placed an emphasis on deconstructing the previously naturalized or reified negative aspects of the experience of disability by looking at how negative reactions have been shaped by different social and political practices which have been influenced

by histories of colonialism and racism (Bell, 2006; Baynton, 2001; Ariotti, 1999), gender discrimination (Wendell, 2000; Bumiller, 2008), class prejudice (Schweik, 2009), and given rise to socially and legally instituted oppressive discourses of disability (e.g., associating disability with misfortune, deficiency, indigence, deviance, and spectacle). However, in part thanks to disability activism and disability studies, over the past few decades a new discourse about disability has arisen. There is now a developing focus on enablement, empowerment, participation, identity politics, and a model of community based rehabilitation, which envisions that people should be helped within their own communities, using inexpensive and locally appropriate means, and mobilizing families and neighbors (Ingstad & Whyte, 2005). Coming from her practice in the field of community arts practice, Petra Koppers has convincingly advocated for the emergence of disability “cultures,” which emerge around disability and develop unique values, aesthetics, and practices (Koppers, 2003, 2007, 2011) that generate new shared beliefs, expectations and understandings about physical and developmental differences. The neurodiveristy movement, which celebrates autism as a way of being and even as conferring “extraordinary gifts,” has played an active role in the burgeoning of this new disability culture (Broderick & Ne’eman, 2008).

Performing Autism and Disability

Much of the work in critical autism studies has argued that autism itself can in some ways be considered a metaphor. Psychological, neurological, and genetic research in the field tends to search for an objective thing that could be identified as “autism” or its cause—a genetic sequence or epigenetic sequelae, certain patterns of brain activity, an auto-immune response—and support this view with the similarity of many symptoms of autism present across-cultures.

By contrast, disability-studies informed autism scholars believe that autism is more elusive and adaptable than that, a term or concept that can be used to group together a diverse range of people whose social, expressive and/or behavioral practices significantly deviate from the norm (Nadesan, 2005; Murray, 2010). According to this view, autism is metaphoric in that it draws parallels or connections between individuals that previously, or in other contexts, would have been seen as unrelated.

As such, its meaning, salience, and recognition change over time and place. This view is supported by historical studies of autism in Euro-America, where interpretations have varied significantly over the seven decades since its first articulation, and prevalence rates have skyrocketed. Arguably, it could also be supported by recent research outside of such a cultural context; a recent groundbreaking study of the prevalence of autism in a South Korean school (Kim et al., 2011) showed that 2.64% of students in a South Korean community aged 7-12 fell on the “autism spectrum” according to Western diagnostic criteria, and yet two thirds of these students had not been recognized as different, let alone diagnosed as “autistic,” by their communities, nor were they receiving services of any kind. Autism was a label, or an idea, that didn’t yet hold weight within the local South Korean community. Some global autism researchers have had to become “cultural brokers” in order to promote the notion of autism (Grinker et. al, 2012) in the local places they are seeking to study it. Indeed, scholars have suggested that the lack of prevalence data about autism is due not only to lack of infrastructure but to the fact that autism is socially constructed differently in different cultures and that what is most needed is a better understanding of how diverse cultures understand all kinds of social and behavioral differences (Kim, 2012).

Autism doesn't have to be "just" a social construct or "purely" neurobiological; it clearly is both, and an understanding of each aspect of autism requires its own methodology. Disability studies and performance studies provide one analytical framework with which to track the dynamic social construction of any particular disability, which is the framework of performance (Sandhal & Auslander, 2005; Koppers, 2003). This has a number of key aspects. One of these is the idea of performativity (Austin, 1975), which argues that one constructs identity categories through the use of labels, descriptions, narrative or symbolic associations, tone, and bodily expressions. Therefore one is never only discussing or representing or referring to autism, but also helping to create and instantiate it. Repetitions and shared evaluations of certain kinds of constructions and representations therefore solidify or reify the understanding of an identity (Butler, 1988) including a disability identity.

Such performances occur in a variety of situations and across genres of cultural production. Therefore, an analysis of the performance of autism or disability also includes paying close attention to the way autism is constructed via an array of performance genres, from vernacular speech and the "performance of everyday life" in routine relationships (Goffman, 1959) to popular media to fictional narrative. Any discourse or individual that seeks to talk about or represent autism is also, therefore, helping to construct or produce the meaning of autism. This process is sometimes highly self-conscious, as individuals or organizations specifically choose frameworks or symbols to impart a particular meaning, or highlight particular aspects of the disability experience for a particular audience (Nadesan, 2005; Sandhal & Auslander, 2005). Examples of these self-conscious performances of autism would include choosing to use a rainbow rather than a puzzle piece symbol to de-stigmatize autism, or highlighting difficulties or "deficits" of autism during an evaluative interview in order to obtain

supportive services. Often performances are enacted unconsciously, as in folk speech or casual conversation. Groups holding different perspectives can contest the different meanings of autism created through such varied performances.

Using performance as a framework also calls attention to the role of performance genres in spreading new ideas and teaching new vocabulary and behaviors about disability. Through modeling and instruction, performances such as speeches, public awareness campaigns, books, films, and journalism seek to influence others' interpretations of and reactions to autism. As the diagnosis of autism is comparatively new in Indonesia, emerging over the last ten years, such performance genres may be the primary way people learn about the disorder, which subsequently may create preconceptions about autism that shape the way Indonesians treat autistic people in real-world encounters. As Diane Goldstein has noted in her study of AIDS narratives, media and fictional narratives create a "vast body of shared non-personal narratives about health that encode associative meanings linking illness and health to fundamental cultural values, explanatory models, and social relations" (2004, p. 76).

This is not to discount the significant contributions of neuroscientific or sociocultural research into autism and spectrum disorders, rather to acknowledge that the meaning and significance of autism is in part produced and shared through multiple vectors of performance and cultural production, from vernacular personal narrative to state policy to therapeutic interactions to didactic presentations of intervention pedagogy to cinematic and fictional portrayals; and therefore, a disability studies approach informed by performance studies can serve as a complementary approach to autism studies which will glean its own unique and additive insights.

Ethnographic Approach of Study

Ethnography is the descriptive and systematic study of a particular society, based on immersion in every-day life, language and culture. Ethnography uses qualitative research methodology to explore various cultural phenomena and has been extensively applied in anthropology, social science, and communication studies in order to understand an emic, or insider, perspective on the systems of meaning and facets of lived experience within a culture (Bernard, 2011; Georges & Jones, 1980; Lau, 2002; Rosaldo, 1989).

It has been suggested that ethnography should be a key method in the research of development, disability, and neuropsychiatric disorders because it helps describe the cultural place within which development and developmental difference occurs and is interpreted and can therefore help construct an account of autism that is phenomenologically accurate to local experience (Weisner, 1996; Kleinman, 1988; Hopper et al., 2007). My study is based primarily on data collected during ethnographic fieldwork carried out over the course of two stays in Indonesia, the first between July and November of 2010 and the second between September 2011 and June 2012, utilizing the qualitative ethnographic research methods of participant observation, direct observation, and guided open-ended interviewing (Bernard, 2011). As I asserted that based on a socio-cultural model of autism the interpretation of and response to autism and people with autism would be shaped by the interactions of family members with autistic people, treatments and interventions available, and representations in popular media, my research was designed to address each of these multiple dimensions.

In order to do so, my study was multi-sited. Rather than selecting one particular clinic or therapy center or community, I chose to investigate a range of sites providing services to individuals and families affected by autism and conducted interviews with families living in

different regions. The benefit of this approach is that it can address cultural formations that are produced across a certain set of locales rather than focusing on a totalizing world system of one particular locale (Marcus, 1998). This is an appropriate approach to take for the study of autism in Indonesia, as my research will show that national networks of support and gatherings which educate and link people from across the archipelago play a significant role in shaping the encounter with and experience of autism for Indonesian families.

However, within these multiple sites my research remained focused on Javanese Indonesia, considering Java both as a bounded geographical area and a cultural milieu. Indonesia is a large and staggeringly diverse archipelago home to many different ethnic and cultural groups. The largest of these groups is the Javanese people, who make up over half of the Indonesian population and in fact comprise the largest ethnic group in Southeast Asia (Sutarto, 2007). For better or for worse, the Javanese have historically played and continue to play a dominating role in Indonesia's national development. While historically associated with the kingdoms of Central Java, the Javanese now live across the archipelago, no longer confined by these boundaries, and frequently intermarry with those from other islands and cultural groups, meaning their cultural influence has spread (Suryadinata, 2002). Furthermore Java, home to the megalopolis and capital city of Jakarta, is the nation's center of government services and administration, industry and business management, institutions of higher education, and media production. People from all over the archipelago come to Java seeking work and educational opportunities. Hence Java provides a setting for cultural influence that then may variably migrate to other islands, as temporary dwellers become "Javanized" (Suryadinata, 2002). Java is deeply influential in broader national trends; some of the effects I have documented, or variations of them, are certain to be at least partially transmitted throughout the rest of the

archipelago. Therefore, as both the home to a majority of Indonesia's population, a center of influence, and as an engine of social and economic change, Java is a good place to start to study the emergence and rooting of autism as a globalized clinical and vernacular diagnostic category.

Autism as Experienced Within Families

In order to gain an understanding of the experience and interpretation of autism within Javanese families I conducted semi-structured, open-ended, and in-depth interviews with mothers, fathers, siblings, and other family members of people diagnosed with autism. It is probable that the majority of cases of autism in Indonesia are in fact undetected or at least not labeled or reported as such, the reasons for which I will explore in the following chapters. For this initial research I chose to interview families whose children had already received the diagnosis of autism by a health care professional, such as a pediatrician or a child specialist. Families were recruited through service provider and clinician networks, in collaboration with service providers, and contacted initially either via introductory flier or in-person at place of service. Those families with children diagnosed with autism who were recommended and willing to be interviewed and/or observed were entered into my study. I was able to interview thirty families, living in Western, Central, and East Java. For list of families interviewed, and further details about them, see Appendix A.

During interviews I used open-ended questions to elicit responses from interviewees about their experiences (Charmaz, 2006). Interviews took place in the location(s) of interviewees choosing, either at their home or at their child's school or therapy center, or both, as is common in medical and psychological anthropology in Indonesia (Lemelson, 2010; Good, 2007; Browne, 2001). Interviews incorporated one or more family members and lasted from one

to four hours. All interviews were audio recorded (as permitted) and transcribed verbatim. Field notes were taken during and following all interviews. Research protocol and all instruments used in these interviews and all following research described below were approved by UCLA's Institutional Review Board (IRB) as study number 10-000680. All instruments were translated into Bahasa Indonesia and verified with the assistance of a professional language instructor and interpreter who is a native Indonesian speaker and fluent in English. In order to protect respondents' privacy according to IRB standards and due to the still somewhat sensitive nature of having a family member with a developmental disability in Indonesia, I use first-name pseudonyms for those parents I interviewed and quoted who are not public figures explicitly involved in autism awareness, or who have not already chosen to share their stories or certain aspects of their stories in public venues.²

These interviews allowed me to gather information on the direct interactions of caregivers with children with autism, personal experience narratives and an understanding of how caregivers interpret and respond to their children's symptoms, and the cultural influences guiding these. The in-depth interviews incorporated aspects of the explanatory model interview (Kleinman, 1980), which helped determine local labels for autistic symptoms as well as theories of etiology and onset, severity, and course of autism and the nature of treatments pursued. They also included elements of the ecocultural interview (Weisner, 2002), which looks at the places, practices, and activities important to families of children with autism. Taking into account child characteristics, the physical and social context of child and family, and family values and goals, as grounded and expressed in everyday family routines, an ecocultural approach targets behaviors and practices that are both meaningful for families and children and useful for cross-cultural comparison (Weisner, 2002). I also gathered personal narratives about the experience of

² For those who volunteered their real names, please note that some Indonesians only go by one single name.

having an autistic child, and what autism means to family members personally. For question and observation guides used in these family observation and interviews, see Appendix B. Through these strategies, I was able to gather data on “information-rich” cases, or “cases from which one can learn a great deal about matters of great importance and are therefore worthy of in-depth study” (Patton, 1990, p. 242) which can identify areas of focus for follow-up research.

My research into the experience and significance of autistic difference within the family was supplemented in two ways:

(A) Informally spending time with families during extended periods of participant-observation, what has been called “deep hanging out” (Desjarlais, 1997), and can both support the development of rapport (Bernard, 2011) and garner additional data that cannot emerge during one single interview session. This participant observation included time spent with families during unstructured periods at home, excursions out, attending religious events, and etc. This allowed me to conduct observations of verbal and non-verbal transacted interactions between caregivers and child to assess child-rearing practices of caregivers and the emotional attitudes they expressed. Here I was looking at how caregivers or other significant family members interact with child when engaged in everyday life activities and how the child behaves in relationship with caregivers, others, and the environment. Observing families across various domains of experience also provided a sense of some of the broader frameworks and discourses within which autism is situated. I also spent unstructured time with service providers during a similar range of activities to a similar purpose. When not spending time with families affected by autism I was further immersed in Javanese family life by living in a family compound in the outskirts of Yogyakarta with two typically developing children and a host of neighboring families with children of all ages.

(B) Collecting data via online Facebook focus groups and online group “chatting” sessions in order to reach a wider range of respondents than those I could interview or observe directly. While participation in each group session varied, some sessions had up to forty participants. I developed the questions asked during these sessions in collaboration with the founder and moderator of this group, which were based off of the questions used in in-person family interviews and addressed similar themes and concerns. For a list of questions asked to spur discussions, see Appendix C.

Range of Treatments Available

The second dimension affecting the interpretation and meaning of autism and the lives of those with autism in any cultural place is the treatments and services available, e.g. schools, clinics, and therapy centers. I garnered a representative sample of treatments available by snowball or referral sampling (Bernard, 2011)—identifying key contacts who are active and respected in the field (including Dr. Rina Adeline, child specialist based in the Jakarta metro area and providing treatment to over 1,000 children across the archipelago in a “mobile clinic,” Dr. Herini, a pediatric neurologist based at Sardjito hospital in Yogyakarta, involved in her own research on autism, and Any Sonata activist and organizer) and visiting further sites they referred me to. Any site identified had to have local credibility and be willing to have a foreign researcher observe treatment or educational practices and interview participants and practitioners. Through this process I was able to identify and visit a range of sites offering different treatments, including schools, alternative healers, private clinics, and therapy centers. At each site I conducted observations and interviews. I determined their model of autism in terms of what causes autism; what they believed the key symptoms and needs of children with

autism are; what constitutes treatment as per their modality; the key activities of the site and the rationale for those activities; the characteristics of the therapeutic actions and interactions at the site, such as number of participants, length of treatment, quality of relationship, attitudes and “roles” of participants; and the idiom of communication (e.g. bodily-expressive, sensory, verbal, etc.). When possible and appropriate, I also became a participant in the healing modality, as group member, intern, or client, paying attention to the key theories in treatment, the approach used, and my own reactions and experiences (Sklar, 1994). For a list and brief description of all sites visited, see Appendix D. For question and observation guides at these sites, see Appendix E.

Analysis of these observations and interviews provided information about what is entailed in Indonesian treatments for autism—their logic and rationale, the cultural models of health, and/or education and human development at play, and the key activities, qualities, or values to be instilled. In reviewing the data I analyzed verbal responses (narrative analysis) and non-verbally expressed attitudes. In my observation and analysis of treatments I used tools provided by Arthur Kleinman (1980) for comparing treatments across traditions and paradigms, such as looking at the clinical reality established during treatments, as well as considering treatments as dynamic events that can be analyzed using the parameters of folk performance where roles of participants, setting, symbolic healing, elements of belief, cultural frames, etc. may be key components (Santino, 1985). It should be noted here that all treatments observed are used because they are believed to have a specifically therapeutic effect for children with autistic symptoms although their paradigms and techniques differ (for example, one intensive set of treatments in the case of dolphin therapy or an ongoing therapeutic practice in the case of the

gamelan). Question and observation guides were modified to particular situations as deemed necessary.

My fieldwork revealed that another key component in autism response on the island of Java was education, training, and awareness events. While not clinical or educational centers per se, these temporary events became sites of information exchange and community building, many of which explicitly addressed various aspects of autism intervention, treatment, services, or response, providing information about these and/or direct instruction in how to carry them out. Falling under this category are seminars, conferences, small-group workshops, weekend retreats, expos, and fairs. For a list and all such events visited, please see Appendix F. Visiting all of these different sites provided me an overview on the range of treatments, attitudes, and approaches available to people with autism in Yogyakarta and Jakarta.

Autism in the Popular Media

My ethnographic methodologies of observation, participant observation, and interviewing of key informants in family and service settings was enhanced by my accumulation and textual analysis (McKee, 2003) of an archive of autism-themed materials. I conducted close readings of popular media such as films, novels, and memoirs, as well as surveying Indonesian-language journalism about autism, social networking sites, and the blogosphere and analyzed this media for the kinds of information represented, in order to identify any emerging themes or key associations that help shape the popular meaning of autism. This aspect of my research sought to understand how different media define autism and its causes, key symptoms, treatments, how autistic persons and their families are being represented by the media, and what other concerns or biases are reflected in the way that autism is described and autistic people are represented.

Addressing these three dimensions of autism in data collection—autism as experienced within families, the range of treatments available, and the construction of autism in the popular media—has allowed me to provide an exploratory, descriptive, and qualitative ethnographic report of autism in Indonesia, and more specifically on the island of Java, addressing its construction and significance in families’ daily lives, therapeutic and educational settings, and the broader worlds of popular media. My analysis of the data collected has allowed me to highlight some of the key tasks and difficulties in introducing autism and associated concepts into the Javanese family.

Outline of Chapters

Following this introductory first chapter, Chapters Two and Three will provide a primarily explanatory and descriptive report on the status of autism awareness and treatment in Javanese Indonesia. Chapter Two, “Autism in Indonesia: An Overview of a ‘New Phenomenon,’” provides a brief introduction to Indonesian and Javanese cultural and political history and the emergence of the autism diagnosis there. I sketch an account of the diagnosis in the country over the past decade or so, addressing the multiple factors that contribute to its local significance and interpretation including therapeutic and educational opportunities, activism, and representations of autism generated by Indonesian media and popular culture.

Chapter Three, “Autism in the Javanese Family,” addresses autism as experienced within the context of the Javanese family. In this chapter I apply Ingstad and Whyte’s “local moral worlds” theory of comparative disability (1995) to show how local Javanese interpretations and treatments of autism are deeply influenced by pre-existing Javanese models of personhood, family structure, and the related goals and practices of childrearing. Using data gleaned from my

own ethnographic work and strengthening my own perspectives with support from the existing ethnographic corpus on Java, I sketch a picture of how this local moral world affects the response to people with autism—the labels and explanatory models used, community response, noted symptoms, perceived etiology, treatments pursued, and issues surrounding education, family response and coping mechanisms, local concerns, and hopes and fears for the future.

Chapter Four, “Performing, Teaching, and Learning New Autism Cultures,” and Chapter Five, “On Food, Love, and Bad Behavior: Family Interventions and Conventions of Care,” address what I term “new autism cultures.” Here I address the apparent fact that learning about autism to a certain extent involves processes of enculturation, or acquiring new norms of this culture, and acculturation, or adapting behaviors or traits from another culture different from one’s own original culture. I focus on workshops, seminars, and memoirs, referring to these as “performances” of autism as described above. In these performances, actors in the autism awareness and education movement, influenced by best-practices of autism intervention developed outside of Indonesia and particularly in Western countries, seek to re-train parents out of aspects of their familiar models of personhood, child-rearing, and developmental difference. I identify and interpret strategies of re-signifying autism and developmental difference, or giving these categories new meaning, significance, and associations, in order to de-stigmatize the condition and build community around shared experience. I also identify and interpret strategies of cultural translation, which involve translating new concepts and vocabularies associated with autism diagnosis into more familiar local concepts; teaching parents how to re-interpret signs in their child’s behavior; and promoting new behaviors, practices, and sentiments of childrearing. These strategies are sometimes successful, but they are also often unsuccessful, encountering

difficulties and resistance because of their poor fit with local models of childrearing and development that are meaningful to families.

Finally Chapter Six, “Therapeutic Gamelan: Fostering a Javanese Development and Embodying Javanese Inclusion,” is devoted to work being done at Bina Anggita, a small school for autism spectrum children in the Central Javanese city of Yogyakarta that has a therapeutic gamelan troupe. I explore how social and pro-social skills are fostered through the accrual of musical and sensory-motor skills. Gamelan appears to be a particularly effective tool for supporting personal and social development in the context of a cultural tradition that emphasizes the power of the Javanese arts to improve the self and connect with others. Within Java, there is a well-researched and persistent philosophy of arts practice as holistically linking art, self-regulation, spirituality, and morality, and therefore, fostering personal and collective wellbeing and interpersonal connection (Holt, 1967; Foley, 1984; Keeler, 1975; Freeland, 2008; Prijosusilo, 2011). Perhaps not surprisingly, a number of experimental autism interventions in Indonesia incorporate collective arts practice such as music or dance. Addressing therapy as a dynamic event that incorporates elements of ritual, performance, and belief (Santino, 1985; Dosamantes-Beaudry, 1998) I contend that gamelan’s perceived efficacy may be attributed to the elements of its practice, including core activities, structure, symbolism, and bodily-felt experiences of the participants during rehearsal and performance. I describe how the participants’ senses are mobilized for adaptive development in ways that are congruent with locally coherent cultural logics of self and personhood. I argue that gamelan practice and performance not only address the developmental needs of the participants but also act as a catalyst for social change, becoming an embodied mnemonic for an inclusive and mixed-abilities-based citizenship, one that is framed as a Javanese tradition. This select local arts-based model of collectivity and inclusive

citizenship represents an intriguing and promising multi-faceted therapeutic activity that both provides potential benefits for individuals with autism but also advocates for social change that creates a more inclusive environment using ideals and practices that feel familiar and authentically “Indonesian” and therefore speak to some of the anxieties both about disability and personhood in a contemporary context.

Chapter Seven, “Autism In and Outside the Archive,” my concluding chapter, will summarize and synthesize my findings, suggest the potential implications or applications of my preliminary work, and make recommendations for future research.

Chapter Two

Autism in Indonesia: An Overview of a “New Phenomenon”

Indonesian History in Brief

Indonesia, the fourth most populous country in the world, is an archipelago nation made up of more than 17,000 islands scattered across an area as large as the United States located in between mainland Asia and Australia. Of these islands approximately 6,000 are inhabited; the largest and most populous are Java, Bali, Kalimantan, Sumatra, Sulawesi, and Irian Jaya. It is a staggeringly diverse country; Indonesia’s total of approximately 250 million inhabitants can be divided into over 200 indigenous language and cultural groups, each with their own local beliefs, practices, and politics. Many of these groups have long interacted with other nations and cultures, as the Indonesian islands have for centuries been a key trade destination as a producer of tea, cocoa, coffee, spices, rubber, palm oil, and other natural resources. Traders from India, the Middle East, Portugal, and China have come to Indonesia bringing their religion and customs with them, leading to a syncretism of ideas and practices originating both locally and abroad.

Java is Indonesia’s most densely populated island, with fertile soil and deeply established and far-reaching royal authorities, historically home to a number of powerful sultanates and empires over the centuries, including the Majapahit (late 13th-early 16th century) and Mataram (late 16th-early 18th century) kingdoms. By the late 17th century, Dutch colonizers were a powerful occupying presence on the island, at times working as allies with local Javanese leaders. Over the next two centuries, many Javanese worked as tenant farmers for a small number of Dutch and Javanese landholding elites. The influence of the Netherlands stretched beyond Java across what is now the Indonesian archipelago, from Aceh to the Moluccas. Under colonial rule, a nationalist sentiment began to grow amongst the occupied peoples, including on

the island of Java, in opposition to the ongoing military skirmishes and economic exploitation of occupation. The movement for independence gained force in the early 20th century, as Islamist, communist, and nationalist groups explored a wide range of political ideas and strategies in order to determine what kind of progress they wanted and how that progress might be achieved in the face of Dutch resistance. Then, the Japanese occupation and wider events of World War II weakened the Dutch powers and paved the way for Indonesian autonomy (Cribb, 2000).

The Republic of Indonesia proclaimed independence in 1945 and, after a number of years of anti-colonialist struggle, was established in 1949. The country's founders, including its first president Sukarno, shaped the nation based on five fundamental principles known as "Pancasila." These are: (1) "Faithfulness to God Almighty," as declared religious faith is a requirement of citizenship, (2) "Consensus Democracy" (as opposed to parliamentary "majority rules" democracy), where ideally democracy is achieved by a process loosely based on traditional village models of consensus through discussion, (3) "Social Justice," (4), "Social Prosperity" or social welfare, which, like consensus democracy, was based on indigenous models of communal work for the good of all, which in Javanese is known as *gotong-royong* (Bowen 1986). Finally, perhaps the most oft-quoted principle of Pancasila is (5) that of "Unity in Diversity," which celebrates the plurality of the nation's peoples and defends the right of everyone to live in peace. While nationalist efforts to draw together disparate groups to overthrow colonizing forces and institute unifying practices have promoted and attempted to solidify that unity post-independence, negotiating that diversity has often proved a challenge (Vickers, 2005).

As a comparatively new nation, Indonesia has gone through dramatic and sweeping change over the past three quarters of a century. Since gaining independence, two key concerns that have guided the trajectory of the nation and informed much of scholarship on the region are

those of “development” and “modernity.” First efforts towards “development” came from Dutch colonial powers as they sought to move inhabitants out of the interior towards coastal areas in order to better control them, established infrastructure, and provided education for a limited ruling class. But since independence, Indonesian politicians and thinkers themselves have prioritized development and modernity while pondering how Indonesia can establish its own unique form of modernity that might be an alternative to a “Western” modernity (Vickers, 2005).

Early nationalist movements leading up to independence associated “development” with nation building and modernizing the way of life of a society that had been formerly colonized (Heryanto, 1988). The first president, Sukarno, wanted Indonesians to be cosmopolitan participants in a new world and yet firmly rooted in their own traditions. He was staunchly anti-imperialist, criticized what he saw as the neocolonialism of Western powers, and envisioned an Asian alliance that could be based on more socialist policies, within which Indonesia might stay true to what he saw as traditional village values. While this was appealing and exciting to the Indonesian populace who was proud of its new independent identity, by the end of Sukarno’s rule the country was suffering economically and many were living in poverty (Vickers, 2005). Then in 1965, only twenty years after Indonesia gained its independence, it was wracked by political unrest and anti-communist mass killings that remain shrouded in mystery and little discussed up until the present (see Roosa, 2006; Robinson, 1995). In the aftermath of this violence and amidst the instability it caused, Suharto seized power from Sukarno.

Suharto’s rule over the country, which lasted for thirty years, was known as the “New Order.” Similar to the nation’s founders, the New Order regime was also concerned with shaping a “modern” Indonesia (B.I. *modernisasi*) and the impact of “development” reached its peak force during this time; President Suharto was named the “Father of Development” and New

Order was also known as the “Development Order” (Heryanto, 1988, 1990; Evers & Gerke, 1997; Li, 1999). This focus on development entailed much physical labor towards tangible results; Suharto improved infrastructure for industrialization, built offices, factories, highways, parks and monuments, telecommunications networks, and military weaponry. He was able to obtain funds to support this development by changing Indonesia’s foreign and economic policy; while Sukarno had kept the country for the most part closed to the West, Suharto opened up the country to international investment and trade, capitalizing on Indonesia’s rich natural resources via logging, mining, oil drilling, and other resource extraction. The late 1980’s in particular witnessed an economic boom as the end of the cold war helped usher in a new era of openness to foreign trade and markets eroded subsistence production and the moral economy of agriculture and petty trade (Evers & Shrader, 1994). The era was marked by a growing impact of globalization, expert-oriented industrialization, the extension of mass consumption, and the beginning of deregulation.

The New Order also sought to “modernize” and “develop” Indonesian citizens themselves by designing and implementing educational initiatives and other government programs geared towards improving public health. One priority was the construction of elementary schools to meet the needs of large numbers of uneducated youth (Suryadarma, Suryahadi, Sumarto & Rodgers, 2006). Suharto’s leadership also oversaw enhanced medical services and public health did significantly improve, thanks in part to dengue fever, malaria, and infectious disease prevention programs, while advancements in health care meant if such diseases were acquired they were not as dangerous (Ferzacca, 2002). The New Order also sought to curb population growth through the Family Planning Program (B.I. *Keluarga Berencana*, or KB), which aimed to remake the Indonesian family through the promotion of

contraceptives and through public service campaigns that aimed to transform people's concept of an ideal family from "many children, much good fortune" to "two children is enough" (Warwick, 1986). These policies all significantly affected families and family life, enacting a transition within the Indonesian family; by the 1980's, infant mortality rates drastically decreased, population growth slowed, family size shrank, the country had achieved universal primary education, the populace had access to more years of formal education and higher levels of literacy (Suryadarma et. al., 2006), and there was a rise in the proportion of those Indonesians living in nuclear rather than extended families. Women increasingly joined the "official" workforce, and families became increasingly mobile, with many relocating to urban centers (Blackburn, 2004).

However, while many Indonesian citizens enjoyed the benefits of Suharto's policies and the middle class grew, the changes the New Order brought to Indonesia were part of an ambivalent development which was in many ways forced upon the nation and relied on tactics of censorship, intimidation, and at times violence, to ensure that differences of opinion with regard to both the means and the ends of the New Order were silenced. Some political prisoners from the events of 1965 were held for over a decade, and ongoing "cleansing" of local communities and stigmatization of alleged communists continued well into the nineties. The New Order regime silenced dissenting voices, jailing or at times "disappearing" particularly inspiring or outspoken artists and activists. The main political party associated with the New Order, Golkar, kept their power by holding what came to be known as "festivals of democracy," regular elections with predetermined results ensured through bribery and intimidation at the polls (Pemberton, 1994). Similar tactics of intimidation and violence were also used to enforce contested strategies of economic development (Li, 1999).

Many scholars have interpreted the New Order's heavy-handed regulations to be part of a national homogenization project with the goal of a "modern," cohesive, and globally competitive nation; to that end it promoted a nuclear family, enforced one national language at the expense of local dialects, and continued to suppress various local cultural and spiritual practices. In the Suharto era, therefore, "development" was an overriding theme and anyone who did not want to participate was to a certain extent framed as "backwards"; there was a clearly stated incompatibility between being a "modern Indonesian citizen" and holding certain beliefs, engaging in certain practices, often those framed as "traditional" (Heryanto, 1988).

Meanwhile economic disparities between provinces and cultures within Indonesia were established and reinforced by corruption and uneven distribution of resources. The benefits of national development were uneven, with the provinces of Yogyakarta, East Java, Jakarta, Bali, and Northern Sulawesi becoming ever more affluent. Urban areas in particular grew prosperous and ushered in a new era of consumerism. Meanwhile, many rural areas stayed poor and suffered the ill effects of corporate activities in the forms of pollution, natural resource decimation, and financial drain. Indonesians began to grow increasingly frustrated at the restrictions on their freedoms and the rampant corruption of the Suharto regime (McGlynn & Sulistyono, 2005). This dissatisfaction came to a head in 1997, when Indonesia was one of the hardest-hit during the pan-Asian monetary crisis and experiencing an intense drought. Suharto's re-election to a new term by parliament sparked widespread protests and riots throughout the country.

Suharto was forced to step down and gave power to his vice-president Jusuf Habibie in 21 May 1998, ushering in the age known as *Reformasi*, or "Reform." During this period, Indonesia emerged from decades of authoritarian rule and entered into a more open and liberal

political and socio-cultural environment, which to a much greater extent enabled a passionate national discussion about equality and difference within its re-claimed democracy. Solid leadership of the country remained somewhat turbulent for the next decade, seeing four different presidents. In 1999 the country had its first real free election since 1955, and the number of recognized political parties ballooned from three to over forty. Long-held political prisoners were released, and initial steps towards an honest discussion of the events of 1965 were begun. Local separatist movements that had objected to nationalist policies from the start now resisted with greater confidence and momentum. Demands were made for the nation to reconsider the meaning of “diversity” and to accommodate multiple personal and cultural trajectories and choices within the pattern of national development. There was a surge of vocal feminist, queer, and minority voices in the media and popular culture (Aveling, 2007; Oetomo, 2008; Turner, 2003). Overall, this period can be classified by the enthusiastic, if not always smooth, widespread engagement in a new political and civic life that has arguably led to successful democratization and tempered political inclusion (Rosser, Roesad & Edwin, 2005) and continues to the present.

The sociopolitical changes of *Reformasi* were simultaneous with the influx of communication technologies which brought many Indonesians in ever more frequent contact with globalized media. These new technologies united the emergence of local identity politics with global social movements and grassroots strategies of advocacy and activism, even as they signaled the increasing rise and growth of the Indonesian middle class for which these technologies were now accessible (Slama, 2010; Hill & Sen, 1997, 2010). While Indonesia has always been a dynamic ground for intercultural contact and influence, the processes of globalization have increased the pace and extended the range of access to experiences outside

those immediately geographically available, as ever-increasing number of Indonesians now leave the country for education and work purposes, amplifying the interactions with foreign cultures (Lamoureux, 2003).

Amidst this technological and social change, “modernization” has remained a fascination and a goal for national and vernacular projects of self-fashioning for Indonesia and Indonesians, and there has been a strong interest in a thematic exploration of the traditional/modern dialectic and the processes of modernization in much scholarly work on Indonesia, from the field of development studies (Heryanto, 2008, 2005) to education (Lukens-Bull, 2001) to performance studies (Peacock, 1968; Shrauwers, 2000; Bodden, 2010) and medical anthropology (Ferzacca, 2001). Contemporary modernization is perhaps increasingly associated with access to higher education and a corollary affluence and access to technology and consumer goods (Connor, 1995). Indonesia, along with other countries in Southeast Asia, has transitioned to become an increasingly market-driven economy, the kind of economy which is thought to be “the automatic guarantor of progress, civil rights, democracy, and of course, modernity” as “the visions of the political leaders of Indonesia are of ‘catching up development’ following the paths [...] of the industrial countries of Japan, the European Union, and the United States” (Evers & Gerke, 1997, p. 7). As such, the new heterogeneous wealthy and middle-class social groups in Indonesia, made up of civil servants, business people, and professionals are increasingly concerned with consumption, particularly of Western products available in food, fashion, technology, entertainment, and leisure or “lifestyle” products as “indispensable markers” of modern urban ways (Mulder, 1994, p. 112).

While the constructs of “modern” and “traditional” in Indonesia have been rightly critiqued (Hawkins, 1995), scholars still assert that the conflict of “old”/“tradition” versus

“new”/“modern” which was one of the dominant themes pre-independence and became so central under Suharto, still colors discussions among “Indonesian intelligentsia” (Heryanto, 1988, 2005) and, I would argue, is still powerfully salient for Indonesians in general, an organizing principle that many people use to make sense of their lives. And yet despite the desire for an affluent modernity and perhaps particularly since the new freedoms of *Reformasi*, as Indonesians strive to reclaim aspects of their local cultures silenced by the New Order, the modernity many strive for is one that might feel more self-consciously “authentically” Indonesian and that preserves, protects, and promotes “traditional” Indonesian values and practices. In public discourse this investment is evident in various heated debates frequently discussed during my fieldwork stays over such issues as the preservation of regional languages and anxious beliefs that aspects of cultural heritage are being “stolen” (Hanggarini, 2012) or eroded. There is, from some, a rueful mourning of the loss of a local or national soul or essence, which after decades of Suharto’s enforced amnesia and homogenization has been leached of all force, turning Indonesia into a postmodern nation, or “*negara posmo*” (Evers & Gerke, 1997) characterized by rapid change, dislocation, a fragmented culture, and the loss of meaningful meta-narratives that have been replaced by consumerism and increasingly appealing and powerful world religions (Mulder, 1994; Anderson, 2008).

It is certainly beyond my scope to provide a comprehensive account of Indonesia before delving into my particular area of focus; however a basic understanding of the Indonesian national history I have loosely outlined above has affected local families in ways that I believe prove significant for the emergence of the autism diagnosis in Java and therefore will serve as a useful reference for discussions in the following chapters, which each return to various themes related to historical development and national change and in greater detail link them to trends in

autism interpretation and treatment. In some ways the effects of these changes may be quite concrete: when we look at comparative histories of autism in the United States, for example, decrease in family size, increasing isolation of mothers in nuclear family homes, and increased access to primary education similar to that which was heralded by New Order policies may have paved the way for the recognition of autistic difference (Nadesan, 2005; Grinker, 2007). Other effects of these changes may be more conceptual, however, as key ideas about “development” and “tradition” and shifting understandings of the requirements and sentiments of an authentic Indonesian modernity may influence the interpretation of autistic difference as well as preferred treatment and intervention methods. Furthermore, one could argue that encountering and negotiating the globalizing diagnosis of autism is yet another aspect of Indonesia’s broader cultural, political, and economic histories of contact, colonialism, and development wherein indigenous models have been challenged and local people must accommodate, adapt to, or reject new ideas and practices.

Jakarta and Yogyakarta: Alternative Modernities in Urban Java

Some of Indonesia’s broader national histories can be read from and read into the cities of Jakarta and Yogyakarta, in some ways two of the most iconic cities on the island of Java, which is the most populous island in Indonesia with 130 million people. These two cities have played a significant role in the development and governance of the nation, and were home to most of the families I interviewed and many of the sites I visited during my fieldwork. It can also be argued that both cities illustrate different approaches towards instantiating a contemporary Indonesian identity.

Located on the northwest coast of the island, at the mouth of the Ciliwung River on

Jakarta Bay, Jakarta is the economic and political center of Indonesia. Previously known as Batavia, the area used to be the capital of the Dutch East Indies and, as Jakarta, remained the capital post-independence. Sukarno imagined Jakarta as a great international city, and used government funds to build monuments, modernist architecture, shopping centers and Parliament buildings, and constructed a system of highways and major boulevards. In 1966, Jakarta was declared a "special capital city district" (*daerah khusus ibukota*), thus gaining a status approximately equivalent to that of a state or province. In the 1970's and 80's foreign investment contributed to a real estate boom that triggered massive building and development. In the late nineties Jakarta witnessed violence and riots as Suharto's regime began to crumble, and in the following decades it was rattled by terrorist bombings of the Australian embassy in 2004 and luxury hotel bombings in 2009. Still, after the New Order fell, the city has remained the focal point of democratic change in Indonesia.

Over the last decade the city has grown faster than either Beijing or Kuala Lumpur. It is currently the most populous city not only in Indonesia but in all of Southeast Asia, with the city proper containing over 10 million inhabitants and the wider metropolitan area (known as "Jabodetabek" for Jakarta, Bogor, Depok, Tangerang, and Bekasi) swelling to approximately 28 million. Jakarta's economy depends heavily on financial service, trade, and manufacturing. It also serves as Indonesia's media center for major national newspapers, national television channels, and the film industry. Inside the cafes and malls of many affluent neighborhoods of Jakarta, one could be in almost any well-off metropolitan city across the globe, shopping at luxury brand stores or H&M and Ace Hardware, eating at Starbucks or grabbing sushi, and brushing shoulders with people from London, Hong Kong, Nigeria, or New Delhi as well as many domestic immigrants from all over the archipelago. Minted "the Big Durian" akin to New

York's "Big Apple," Jakarta is home to museums, movie theaters, art galleries, cultural centers, and restaurants, as well as hosting annual arts and culture festivals and events. As a megalopolis it also exhibits mind-boggling traffic jams, constant flooding, high levels of pollution, and radical socioeconomic disparity, with many people just scraping by working as motorized rickshaw drivers or peddling wares.

While in Jakarta, I spent much of my time based in Bintaro, an upper-middle class residential community in South Jakarta. Bintaro is filled with gated housing complexes with calm quiet streets, private schools, car dealerships, malls packed with international food courts, cafes, salons and day spas, after-school tutoring centers and book stores. McDonald's is a popular hangout. Most parents are professionals or full time homemakers with full-time household servants. Teenaged children, many of whom plan to pursue higher education abroad in Australia, Europe, Japan, or the U.S., lounge in coffee shops conversing in English and Jakarta slang sipping boba tea while blockbuster films play on TV screens in the background. Their younger siblings, dressed in cute matching school uniforms, are shuttled from soccer practice to music lessons to karate to after-school tutoring at Kumon by private family drivers. In many ways Bintaro resembles an American suburban idyll (and, as other new neighborhoods in Jakarta, has directly borrowed from US suburban design), segregated from the ills that plague much of the rest of the city and by design a world away from that inhabited by the urban poor (Kusno, 2001). While certainly not the only domestic or urban reality in Jakarta's sprawling megalopolis, Bintaro and other developments like it can be seen as a realization of a contemporary urban environment that is not seeking to reference indigenous or "traditional" architecture or physical worlds, rather hoping to achieve a "universal modernism" (Hogan & Houston, 2002); a fitting setting for families who hope to prepare their children to compete in a

competitive globalized consumerist marketplace where they very well might end up in another far-flung city, such as Los Angeles or Sydney, with a similar orientation.

Yogyakarta, the other Javanese city where I carried out much of my fieldwork, is a much smaller city located about sixteen miles from the Indian Ocean on the southern coast of Central Java. It is the capital of the Yogyakarta Special Region, with a population of not quite three and a half million people. The majority of people living in Yogyakarta are Javanese but the city also has attracted a large population of domestic immigrants and is one of the most ethnically heterogeneous cities in Indonesia. This is in part because Yogyakarta is famously a “city of students” who enroll at one of over one hundred available universities including the prestigious Gadjah Mada University, Indonesia State University, and the Indonesian Institute for the Arts.

The city has played a noted role in Indonesian history and government. The area is rich with archeological and historical sites, the most famous of which are the centuries-old Borobudur and Prambanan temples. In more recent history, the city was significant during the war for independence, when it became the temporary capital of the nation after Jakarta fell to the Dutch. Yogyakarta has a legacy of powerful and revered Sultans who were influential in the earlier Mataram kingdom going back as far as the 8th century, and retains a unique status as the only remaining Indonesian region governed by a monarchy. The sultanate still commands a mystical, spiritual, and admiring reverence from many Yogyakarta subjects even as they acknowledge that it holds little actual political power today. For many, dedication to the sultan means dedication and attention to ancient Javanese spiritual mandates and wisdoms that pre-existed Indonesia as a nation.

Yogyakarta is known the world over for being the center of Javanese culture and traditional arts including gamelan, dance, *wayang* puppet theater, poetry, and other music and

performance genres as well as silver and leather work, batik, and wood carving. In the eyes of many, the city's continuing dedication to a heritage of performing arts is directly related to the persistence of other less tangible cultural values and practices, such as the continued use of "proper" Javanese language with its exquisite structural etiquette. The city also has a thriving contemporary arts scene, with many city venues and private galleries showcasing the works of artists from all over the archipelago. Both traditional and contemporary arts continue to be identified with Yogyakarta and are central to the city's self-definition and economic success; due to its vibrant creative life, historical riches, and international savvy, Yogyakarta has become the second most well-known domestic and international tourist destination in Indonesia after Bali and its primary industries are education, tourism, the arts, and craft exports.

Yogyakarta's built environment reflects its dedication to a local identity; in the old city, densely packed narrow streets wind through walled sections of palace dwellings, and the town square still serves as a festive gathering place, especially on Saturday nights. Traditional wooden Joglo houses and open-air structures, known as *pendopo*, grace many civic and educational institutions as well as tourist lodgings and art centers. Huts with woven bamboo walls exist on the same city blocks with sleek new contemporary buildings. The perimeter of the city quickly gives way to lush rice paddies where many people supplement their incomes farming family land. Yogyakarta thus far embodies different priorities in urban development than those seen in Jakarta, in that the city strives to be both cosmopolitan and deeply invested in local identity and culture. While Jakarta-style luxury malls, such as Ambarukmo Plaza, and affluent housing developments are making inroads here, especially on the north side of the city, many residents feel strongly that preserving an indigenous flavor needs to remain one of the city's top priorities into the future, for economic reasons so that they may continue to benefit

from the tourist industry, but also out of a genuine pride in local identity.

Autism In Indonesia: A “New Phenomenon”

So where do autism, autism awareness, and autistic Indonesians fit into this sweeping history and sketched-out geography? Little is known about this topic, because even by those active in the field, autism is considered a “new phenomenon” (Diniah, 2010) that seems to have emerged in Indonesia approximately concurrently with the fall of the New Order. As such the autism diagnosis is unfamiliar to many and yet, as has been the case in other countries, this unfamiliarity is paradoxically coupled with a dramatic rise in the rates of diagnosis. According to one source, in 1989 there were only two reported cases of autism in the entire nation. By 2004 there were 40,000, by 2007 there were 100,000, and by 2010 there were estimated as many as one million people across the archipelago with autism (Diniah, 2010), comparable to current numbers in the United States (Center for Disease Control and Prevention, 2012), and one suggested prevalence rate of autism in Indonesia is eight cases of autism per 10,000 births (Radius, 2011).

The public history of autism in Indonesia seems to have begun in the late 1990’s. According to Agus Haryanto, who has been working in the special education field in Central Java and Jakarta since he was a recent college graduate in the early nineties, it was the “extraordinary effort” of parents during the key years of 1997-1999 that brought autism into public awareness in Indonesia. Individual parents with developmentally different children and little resources available to them to help interpret their behavior or support their learning began to conduct independent Internet research, travel abroad to study psychology and special education, and compile libraries of relevant materials that they could share with others. Those

with or working with children gained access to influential published works; Haryanto remembers being influenced by Stanley Greenspan's *The Child With Special Needs: Encouraging Intellectual and Emotional Growth*; *Behavioral Intervention for Young Children with Autism* and *Let Me Hear Your Voice: A Family's Triumph Over Autism* by Catherine Maurice; and *A Work In Progress* by Ron Leaf and John McEachin, among others. Parents also pooled their resources to invite autism and special education experts from abroad to come teach, consult, and work one-on-one with Indonesian families with "special needs"³ children. Pak Agus believes that autism at that point was still very much seen as a family shame (B.I. *aib keluarga*) "so it was hidden, causing a situation where such things were covered up, which for individual families was quite sensitive and quite a burden" (Haryanto, 2012).⁴ Therefore, the work of individual parents in the late nineties was important in both spreading information about the label, criteria, and treatment of autism and inaugurating a public discussion about children with special needs. In this, the history of autism in Indonesia mirrors a broader global history where the impetus for autism response has initially come from individual parents and budding support services have been provided through grassroots organizations before national governmental, educational, or health care institutions assumed greater responsibility, if they have assumed such responsibility at all (Feinstein, 2010; Grinker, 2007).

Agus describes the significant change he has seen in his own practice over the years, as more and more parents availed themselves of services as they learned about autism and other special needs. He says,

I have felt and experienced the increase myself. I have experienced the numbers of children who come, the numbers of centers that have been built—there are now an extraordinary number of therapy centers. In general, [autism] is very visible.

³ While in the United States this terminology is felt by some to be an at best outdated and at worst paternalistic way to describe children with various disabilities, it is still frequently used in Indonesia.

⁴ Haryanto, Agus. Interviewed by Annie Tucker. Bintaro, 26 January 2012.

Maybe that's due to a number of factors ... I can say for sure that the number has really risen from the numbers of people coming to therapy, the numbers of people seeking consultation (Haryanto, 2012).⁵

If there are in indeed now one million or more Indonesians with autism, it is important to have an understanding of certain key areas of concern for those affected and the key actors within those areas in order to begin to address the growing presence of autism awareness and people diagnosed as autistic in contemporary Indonesian society.

Treatment

The cause for autism remains unclear in Indonesia, as around the world. However, some formal literature provided in Indonesia, such as informative brochures provided by special education schools or non-governmental organizations, list the potential causes of autism as psychosocial trauma, biological factors such as genetics and neuroanatomical differences, immunological factors, perinatal TORCH infections, heavy metal poisoning through vaccines or environmental pollution, and digestive problems (for example, see The Department of Education, 2011). At this time autism is not “curable,” and the very idea of cure is controversial; while global research pursues knowledge leading to autism prevention and cure, a growing global neurodiversity movement actively rejects such a pursuit, arguing that autism is a part of inherent human diversity and as such deserves respect and recognition (Bagatell, 2010; Broderick & Ne'eman, 2008). Regardless of one's stance on cause or cure, there are complex constellations of symptoms of autism that many people, including within the context of Indonesian families, hope to ameliorate, ranging from socialization and communication challenges such as the delay

⁵ Haryanto, Agus. Interviewed by Annie Tucker. Bintaro, 26 January 2012.

or lack of verbal communication to seemingly out of control emotions to physical issues such as sensory sensitivities, digestive problems, and sleep disturbances.

Therefore, perhaps of primary importance to families with autistic members is treatment. However, for many Indonesian parents, seeking treatment may at first pose a challenge.

Throughout the country there are still no standardized methods for early detection of autism, a dearth of Indonesian-language information about autism in both academic and general interest circles, very few centers for psycho-educational intervention, and limited networking between assessment centers and health care centers or educational centers (Adinugroho, 2010).

Recognizing the growing need for more widely available facilities, at the 2008 “Autism Awareness Expo” in Jakarta the Department of Health publicly promised therapy centers for people with autism to be established in all public hospitals (Damanik, 2008). These centers would be accessible to all and provide free therapy for those families unable to privately afford it; however, five years later it is unclear what specific steps have been taken to begin this monumental task and the logistics of funding and implementation are overwhelming.

Furthermore, even if these centers were built, there remains a lack of specialists to staff them in order to serve the particular needs of autistic children; for example, as of 2006 there were only 35 child psychiatrists to serve a nation of 220 million people (Pols, 2006), a number which is sure to have risen in the past six years but certainly not nearly enough to fill the growing need.

Despite these limitations, there have been a few key figures who have catalyzed the provision of specialized care to autistic children and their families. Most are based in Jakarta, but have traveled extensively throughout the country and have counseled therapists, educators, and families with the means to come to Jakarta to consult with them. These figures have been crucial not only in the provision of treatment for people with autism, but in the dissemination of

knowledge about the condition. Perhaps unsurprisingly, many have received training and support from organizations outside Indonesia.

Dr. Rudy Sutadi is primarily associated with the spread of Applied Behavioral Analysis (ABA), and has named himself “The Indonesian Father of ABA.”⁶ ABA, formerly known as behavior modification, shapes behavior by assessing the relationship of behavior to the environment. In ABA tasks, skills, or desired behaviors are taught and undesired behaviors discouraged or replaced through systematic trials using positive and negative reinforcement. Using such a method of repetitive training, children can be taught how to complete basic daily and self-care tasks such as getting dressed, learn academic skills such as sight-word recognition, and develop skills to self-soothe, ask for help, or avoid problem behaviors such as self-injury and aggression. ABA is frequently endorsed by behavioral therapists and service providers as the most effective treatment for autism and is the most commonly used therapy for autism in the United States, despite debates over its methodology and how helpful it is in addressing the core deficits of autism. Dr. Rudy discovered ABA while searching for information regarding how to best serve his own son, who was diagnosed at an early age. He pursued his studies in autism intervention at the Lovaas Institute for Early Intervention in Los Angeles and at Integrated Services for Autism and Developmental Delay in Perth. He found ABA methods to be successful with his son, who was ultimately able to join a playgroup, attended mainstream schools, and is now currently a pre-med student (Sutadi, 2011, 2012). Since 1997 Dr. Rudy has made it his mission to popularize, standardize, and spread ABA methods to parents and therapists across Indonesia. He is the founder of Klinik Intervensi Dini Autis (Early Intervention Autism Clinic) known as KID-Autis, which is no longer operational, and Kid ABA, which

⁶ As can be seen on the website of his therapy organization, Kid ABA. <http://www.kidaba.com/index.php>, retrieved 28 December 2012.

provides therapy and trains and supervises aspiring ABA therapists in its Bekasi location. Dr. Rudy facilitated the First National Congress on Autism, held in Jakarta in 2003, has organized and led national workshops and autism events, and has a thriving practice counseling parents and therapists.⁷

Dr. Melly Budiman, a psychiatrist with a highly successful private practice, is the founder of The Autism Foundation of Indonesia, which provides symposia, seminars, and workshops, and is one of the pre-eminent autism experts in Indonesia. Along with Dr. Rina Adeline, who runs *Klinik Intervensi Biomedis* (The Clinic For Biomedical Intervention, known as KIBM), Dr. Melly is most closely associated with what is known as “biomedical treatment.” Biomedical treatment is based on the premise that autism is a disorder caused by a combination of lowered immune response, external toxins from vaccines and other sources, and problems caused by certain foods. Its treatment protocol thus combines high daily doses of various vitamin and mineral nutritional supplements and a restricted diet.⁸ The biomedical approach is most vocally supported by the Defeat Autism Now! (DAN!) project, which is part of the Autism Research Institute founded by the late Dr. Bernard Rimland.⁹ Much of the global autism research

⁷ In a bizarre turn of events, Dr. Rudy has faced a number of charges, including falsifying papers and sexual harassment of minors, and has been imprisoned in Cipinang prison since 2004, serving a thirteen-year sentence. Supporters say these allegations are false, brought by his rich and powerful ex-wife who is bribing those in the legal system to keep Dr. Rudy in jail as revenge for infidelity; detractors believe that Dr. Rudy is a dangerous psychopath. Yet, perhaps because of his personal charisma or significant influence in the field, Dr. Rudy maintains a robust practice from inside prison walls and continues to supervise Kid ABA together with his second wife, Liza Sutadi, who manages all of his activities outside the prison. Dr. Rudy reviews notes and videotape from every client, provides supervision, and holds team meetings inside prison walls. I interviewed Dr. Sutadi inside the prison. It was a surreal experience, to say the least, to be talking about autism treatment while sitting next to women in full purdah who were visiting their husbands, who according to Liza were being held for their involvement in the 2009 Jakarta Marriott terrorist bombing.

⁸ Biomedical treatment is usually part of an integrated therapeutic plan that includes behavior therapy, but not in all cases.

⁹ For those unfamiliar with restricted diet, a more detailed explanation follows. The most typical form of this restriction is the Gluten Free Casein Free (GFCF) diet. GFCF is also sometimes also known as the Wheat Free Milk Free Diet, since gluten is a protein most commonly found in wheat products and casein is a protein most commonly found in milk, although these proteins are also found in a wide range of foods. Followed by others outside the autism community with gastrointestinal problems such as celiac disease, the application of the GFCF diet to autism treatment evolved as researchers noted a much higher prevalence of GI problems in people on the autism spectrum,

community on the whole feels that the efficacy of the biomedical approach remains as yet unproven and its benefits remain controversial and primarily anecdotal.

In Indonesia, Dr. Melly's services are in high demand and she has been featured in countless articles and interviews, writes the introduction to the majority of books about autism published in the country, and frequently serves as a guest speaker at conferences, workshops, and events nationwide. Dr. Rina has been featured in women's magazines since her Bogor-based clinic was founded in 2000, and her office estimates that it serves 800-1000 families every year both locally and across Indonesia; recognizing the fact that not everyone can afford to fly to Jakarta for diagnosis or treatment, KIBM provides regular mobile lab tests and clinical services in outposts in the major cities of Surabaya, Medan, and Makassar, as well as in Bali and parts of Malaysia (Reiny, 2010).¹⁰ These two women are highly influential figures for families seeking treatment for their children.

In addition to ABA and biomedical treatment, there is a diverse range of treatment options available for people with autism in Indonesia, depending on personal preference and geographical availability. Some schools, therapy centers, and private practices offer individually tailored child-guided psycho-educational programs such as Floortime and TEACHH (Treatment and Education of Autistic and related Communication Handicapped Children). There are also a number of highly popular Sensory Integration clinics and some speech and occupational

such as constipation, diarrhea, colitis, and food allergies. The theory behind GFCF is also related to the "leaky gut" theory of autism, which proposes that some people on the spectrum have permeable intestinal tracts, weakened due to overgrowth of yeast, high levels of heavy metals, viral infections, or other causes. In a "leaky gut," when proteins such as gluten and casein are being digested they are broken down into peptides gliadinomorphin and caseimorphin which then pass through the permeable tract into the blood, causing an opiate reaction similar to that caused by the drug morphine, altering a person's behavior and perception of the environment and/or triggering an unusual or overactive immune response (White, 2003). Further dietary restrictions that often accompany the GFCF diet is the elimination of sugar and caffeine, particularly with those children who are prone to sleeplessness, hyperactivity, or poor impulse control, and in Indonesia, many parents further restrict seafood intake and forbid all processed foods, such as instant noodles, with the belief that these contain high levels of metal, such as mercury, and other harmful chemicals.

¹⁰ Yulia, Reni. Interviewed by Annie Tucker. Jakarta, 14 July 2010.

therapists in private practice. Many family physicians provide pharmacological therapy, including sedatives and anti-psychotics (Herini, 2010).¹¹ It is not uncommon for parents to pursue bodywork such as reflexology and traditional Javanese massage, *prana* (breath) and energy work, yoga, acupuncture and/or Chinese medicine for their children. There are also additional therapies available such music therapy, dance therapy, and animal therapy including dolphin therapy, which is offered at university and private clinics and is gaining in popularity. Many parents also avail themselves of “traditional” or “alternative” healers, also commonly known as *dukuns* or *tabibs*, who make up a vibrant sector of health care in contemporary Indonesia and are frequently consulted for a whole host of ills and troubles.

In Indonesia public knowledge about autism remains uneven, pluralistic health care practices are the norm, disparities in socio-economic background are vast, cultural backgrounds are diverse, and individual belief systems, life histories, and geographical location all impact the experience of seeking treatment. This results in disparate trajectories; I have talked to families that have tried almost every single one of the treatments listed above and more, and I have talked to families that have tried almost none.¹² In the following chapters I will present family perspectives on treatment seeking and family assessments regarding the experience and efficacy of those treatments they did pursue.

¹¹ Herini, Siti. Interviewed by Annie Tucker. Yogyakarta, 31 August 2010 and 27 October 2010.

¹² While no one I interviewed said they themselves had done so and I myself did not witness these practices, I was also told stories of families tying up their autistic family members (B. Indonesia *pasung*) in situations of aggression or wandering or having autistic people injected with strong sedatives where “with one shot, they sleep for a week,” (Adinugroho, 2010). Similarly, while none of the families I interviewed had attempted it, I was told that a small number of wealthy Indonesian families are investigating the possibility of stem cell injections for their autistic children, hearing of some successes in treating cerebral palsy.

Education

Almost as important to treatment, if not equally so, in the minds of families with autistic members is their education. In addition to providing special needs children with similar opportunities it provides their peers—such as opportunities for personal development and social interaction, learning about the world, preparing the child for future education and employment, and a form of childcare—school may also be the place where children with autism and other developmental differences or learning difficulties might receive beneficial treatments and therapies as part of their education plan. Yet while children with various special needs or disabilities may make up 5% or more of the school-aged population, there is as of yet no national programs efficiently in place to ensure or maximize their education (Adinugroho, 2010).

Because of the common experience of either having their child be rejected or refused from their local public school and with limited access to special education schools, most of the parents and families I spoke with believed that students with autism and other special needs have no legal right to education, with no governmental protection or support. One founder of a private school for autistic children said to me that in a country where many typical children don't have access to education, education for disabled or autistic children "is not even seen as a responsibility, let alone a right" (Puspita, 2010).¹³

Despite the disappointment and pessimism of many families based on their personal experiences, this perception is not technically correct. Original constitutional legislation ensures every child the right to education, including economically disadvantaged children, those living in remote areas, and those with special needs (Steff, Mudzakir & Andayani, 2010). Despite what could be considered slow progress, legislation regarding special education has evolved over the

¹³ Puspita, Diyah. Interviewed by Annie Tucker. Jakarta 13 July 2010.

years. As of 1989, according the law, “citizens with physical and/or mental differences have a right to exceptional education,” meaning they have a right to education in a SLB, short for *Sekolah Luar Biasa*, or a segregated “exceptional school.” In 2008, in Article 5 (2) of Law 20, the category of those students guaranteed special education was refined to indicate those who are blind, deaf, intellectually disabled or slow learners, physically disabled, or with emotional and behavioral disturbances (Yuswan, 2010). Such students are enrolled either in schools specialized for each category of disability, or in general special education schools serving a mixed disabled population. The law further limits the number of students in the classroom, determines the curriculum, requires that teachers have a degree either in special education or the topic they are teaching, and mandates access to special education at all levels, from pre-school through high school (this actually means that students with special needs have a right to more years of formal education than their non-disabled peers, who are only required to attend school through the equivalent of sixth grade).

In addition to laws providing for and governing special schools, there are also evolving standards on inclusion in general education classrooms. Indonesia has put considerable effort into achieving the Millennium Development Goals including the goal of “achieve[ing] universal primary education” (United Nations, 2000) and in 2007 signed the UN Convention on the Rights of Persons with Disabilities, Article 24 of which states that persons with disabilities should be guaranteed the right to inclusive education at all levels, regardless of age, without discrimination and on the basis of equal opportunity (United Nations, 2007).¹⁴ The ultimate goal is that eventually every public school will be inclusion ready; as a preliminary step, in 2009 it was decreed that every Sub-district must have at least one inclusion school at the elementary, middle, and high school level. The Department of Education offers incentives to inclusion schools by

¹⁴ The United States failed to ratify this convention in late 2012.

providing scholarships for children with disabilities, subsidizing school fees, and training teachers on special education topics. The responsibility for implementing these laws is designated to the Districts, each of which is supposed to have one Supervisor of Special Education (Yuswan, 2010).

However, as parents of autistic children discover, despite these laws that are officially in place, in reality a number of obstacles remain to providing education for children with special needs in general and children with autism in particular, and as of the present it is estimated that 95% of school-age students with disabilities in Indonesia are not yet receiving a formal education (Helen Keller International, 2010). As with the proposal of therapy centers in every hospital, part of the issue is the difficulties of implementation when faced with unclear responsibility in administration and lack of a skilled workforce; with many public school class sizes swelling to forty or more students, there are simply not enough teachers, and in particular not enough trained teachers—even those teachers who do have degrees in special education or child psychology may have never heard of autism, let alone received training on how to educate autistic students (Field notes, various interviews, 2010-2012). Further resistance is met in various local communities as yet unaccustomed to the idea that educating children with special needs is a normative and expected aspect of education. There is particularly strong opposition to inclusion education, which many parents of typical students worry will negatively impact their children's educational progress.

Local resistance combined with administrative confusion means that whether special education will be available, and what kind of special education will be available, is often in the hand of local districts, or even local schools or specific principals or teachers who decide

whether or not they are able to serve special needs students in their schools or classrooms.¹⁵

Perhaps it is not surprising then that a significant number of children with disabilities, including those with autism, are not enrolled in school or receiving any kind of formal education. Many parents are turned away, and many parents are not even aware that such education is an option for their child.

These local-level school readiness issues are being addressed by the National Department of Education and local and international NGO's. For example, Arbeiter-Samariter-Bund (ASB) from Germany has supported local community workers on the ground in Yogyakarta educating parents with special needs students about their options and partnering with local schools that might be willing or interested to accept such students. They also have funded public awareness campaigns; for example pamphlets and posters spread across the city during my field stay in 2011-2012 alerted parents, students, and schools, about the option of inclusive education and shared helpful tips about how to make inclusive education a successful reality (see Appendix I, Figure 2.1). Despite these difficulties, it can thus be argued that students with disabilities now have greater access to formal education than ever. Part of this access is due to the increasing numbers of private schools geared towards students with autism and other learning difficulties and part of it is due to the growing number of alternative schools beginning to pay more attention to the cause of disability rights and coming to understand these rights as part of broader ideas such as social justice and sustainable communities. Often an inclusion school's decision to welcome students with special needs is part of a school's larger mission and their ideas about educational reform, the role of education in influencing or redefining core national and community values, and the strategies required to shape future Indonesian citizens who will live

¹⁵ Findings for higher education, still out of reach for many non-disabled Indonesians, show that disabled students face significant discrimination and lack access to reasonable accommodations if they choose to pursue a university degree (Steff, Mudzakir & Andayani, 2010).

within them. Interestingly, schools with disparate missions are starting to recognize accessible education for people of all abilities as an important part of their platform.

For example, *Sanggar Anak Alam*, or “The School for Nature’s Children” located literally in the middle of rice fields in the Nitiprayan neighborhood of Yogyakarta, is part of a group of alternative schools and educational centers whose first effort began in 1988 in Banjarnegara, Central Java with the goal of supporting sustainable local health and prosperity. It was founded in 2008 and now serves a total of 125 children, from pre-K through middle school. The quiet and thoughtful founder Sri Wahyaningsih told me that she founded the school because she felt the state curriculum and methods were unaccommodating of diverse learning skills and needs. Her curriculum focuses on rebuilding a connection to nature through learning about sustainable agriculture; the development of imagination, individuality, and social conscience within students; and the integration with and respect of local culture, through traditional arts and experiential learning. A fundamental part of the school’s humanitarian mission and vision is that they turn away no one, regardless of financial status or individual ability (Wahyaningsih, 2010).¹⁶ At the time of my fieldwork the school had two students that fell on the autism spectrum and one with Down syndrome. The faculty was very dedicated to these boys, consulting with specialists, including them in group activities whenever possible, and providing them with individualized instruction via a dedicated instructor whose sole charge was to adapt and develop lessons for them and work with them one-on-one.

On the other side of the city in Yogyakarta, the inclusion of autistic and other disabled children is being carried out with dedication by SD Muhamaddiyah Bangutapan.

Muhammadiyah is a reformist Indonesian Islamic organization that has been providing elementary through college education and health services across the nation since the early 20th

¹⁶ Wahyaningsih, Sri. Interviewed by Annie Tucker. Nitiprayan, Yogyakarta. 7 October 2010.

century. It has over 25 million supporters and has built thousands of schools, hospitals, and social programs, primarily in urban areas. As a part of this larger organization, SD Muhammadiyah Banguntapan is a bright and cheerful school where all children wear a standard uniform, the girls in *jilbabs* (head-coverings) and ankle-length skirts and the boys in long sleeves and long pants. Students receive instruction in basic subjects as well as computer, music, art, and English, Arabic, and Javanese.

The charismatic school principal, Heriyanto, is passionate about education and has included children with special needs on his own initiative; he estimates he has about one child with special needs per classroom (see Appendix I, Figure 2.2), some of who have their own privately hired assistants or “shadows.” He sees his “experiment” with inclusive education as one of many experiments in learning he encourages in his classrooms, such as grouping desks together into collaborative teams, moving students from individual study at these desks to group sessions on the rug, and etc. His interests lie in the praxis and “ethics” of learning, and he was upset that so many of the children in his school district were being denied an education. He believes that not only could special-needs children learn successfully, but also that early integration of children with disabilities would foster citizenship and cooperation and the successful long-term development of mixed ability communities (Heryanto, 2010).¹⁷ Heryanto’s attitudes towards education harmonize well with Muhammadiyah’s broader platform, which seeks to empower Muslim Indonesians and effect positive change through education. In order to keep Islam relevant in the contemporary world, Muhammadiyah feels it must be able to show that “Islam can be an objective basis on which justice for everybody can be established” (Faud, 2004, p. 408).

¹⁷ Heryanto. Interviewed by Annie Tucker. Yogyakarta. 29 October 2010.

In these cases it is evident that certain individuals and schools are folding educational equality and inclusion for people with disabilities into their broader missions. Still, due to the significant challenges to procuring an education for autistic children, and due to what they see as a poor fit between the established curriculum and the needs of these children, many parents choose to enroll their autistic children in small private schools for children with disabilities, many of which are run and staffed by parents of autistic children themselves. As with autism treatment, there have been a number of influential figures who have blazed the trail for private autism education. Diyah Puspita has an autistic son and is one of the first autism activists in Indonesia; with Dr. Melly Budiman she helped found The Autism Foundation of Indonesia, has written two memoirs on the topic of raising an autistic child, and has travelled all over Indonesia leading workshops and promoting autism awareness. She also founded Mandiga School in an upscale Southern Jakarta neighborhood in the year 2000, when it was one of the first of schools of its kind.

Christened with a name combining the Indonesian words for “independent” and “happy” (B.I. *mandiri* and *bahagia*, respectively), Mandiga grew out of Diyah’s desire to educate and train her own child, Ikhsan, and others like him. As of 2010 the school was at capacity with 24 students, and there is a long waiting list. The school meets Monday through Friday, from 8-12 and its facilities include classrooms, a kitchen for cooking class, a music room, a computer room, a courtyard, and a large common room. Diyah defines her approach as “eclectic,” but emphasizes behavior training and life skills, saying that without these skills the autistic person will remain unable to do anything for themselves so that without them “social skills, communication, whatever, I don’t care!”¹⁸ Aside from such training, students do additional work in areas of communication, academic skills, and the children’s’ own interests. Since a majority

¹⁸ Puspita, Diyah. Interviewed by Annie Tucker. Jakarta 13 July 2010.

of the students, including Diah's son, remain non-verbal, many students are taught to communicate via PECS (Picture Exchange Communication System), typing, or even through text messaging (see Appendix I, Figure 2.3). Diah prefers to work with children whose parents truly no longer are invested in the curriculum or benchmarks of mainstream schooling, and she does not use any part of the state curriculum at all, which she feels is rigid and disconnected from actual life experience. While Diah likes the freedom of being able to determine what methods of learning and evaluation will be best for each student, she believes that the lack of standardizations in special-needs curriculum means that the many different schools serving autistic students scattered across Indonesia are in a sense each individually starting from scratch when they could be pooling their experiences and resources.

There may in fact be hundreds of such private schools cum therapy centers spread out across the island of Java and beyond—I was able to visit a handful including private schools Sekolah Lanjut Autis Fredofios (“Fredofios Autistic School”) and Sekolah Autis Bina Anggita (“Independent Thinker Autism School”) in Yogyakarta, Wila Kertia in Bintaro, Putera/Puteri Mandiri (“Independent Sons and Daughters”) in Tangerang, Citra Anandiya in South Jakarta, Special School Al Ishan and Yayasan Anak Mandiri (“Independent Child Foundation”) in Serang, West Java, and the A Plus Center for Integrated Therapy in Malang, East Java. These schools have all received formal recognition from the Department of Education, although there are many smaller informal schools and therapy centers that serve just a handful of children at a time. Some of these schools are quite modest and others are state of the art. As with Mandiga School, most of these facilities were almost entirely privately funded by parents who had themselves faced a lack of satisfying educational options for their autistic child and their child's peers, and so built a school and opened its doors to others. In such cases, as described by Agus

above, it is not uncommon for a group of well-off parents to pool their resources to bring experts from outside the country, either to stay on staff or act as an ongoing consultant for these private schools. And just as Diyah suggested, each school does in fact often have its own curriculum, focus, and approach. For example Yayasan Anak Mandiri begins new students with an academically and therapeutically intensive one-on-one method at its facility and gradually introduces them into group and classroom settings with individualized support and then fades that support, with the hopes that certain students will eventually be able to be integrated into mainstream classrooms. Meanwhile Fredofios, serving primarily teens on the spectrum, focuses on group training of life skills and basic job readiness with the hopes the students will soon be able to be employed.

Autism Awareness and Networks of Advocacy and Support

Many parents and professionals in the autism field in Indonesia have lamented what is perceived as a lack of cohesion or coordination of isolated efforts so at this point in Indonesia to provide education, treatment, and care for children with autism, each parent or family has to struggle alone to figure out their own way, and the chances of success for each individual person with autism are totally dependent on the efforts of the individuals and individual circumstances surrounding them. However, there is a small but vibrant community of people, spread out across the nation, who are involved in explicit and targeted autism awareness and education with the hopes of linking parents and others in the field to share best practices and support a more equitable future for autistic and disabled people. As with treatment and private schooling, the autism awareness and education field is primarily spearheaded by the parents of children with autism, particularly those with offspring who are now in their late teens. These parents faced

what they felt was a significant dearth of information when they were raising their own children, and have therefore made it their mission to collect and disseminate as much as they can for the benefit of other families. As Any Sonata, founder of the LRD newsletter and Facebook group discussed below, described:

My inspiration for the Newsletter was my own bitter experience raising my son Adi, who is now 17.5 years old. At that time, Adi was 3.5 when he was diagnosed with Autism and ADHD. The available information was so minimal, and there was no literature, no friends with a similar fate, not even professionals who could help. It turned out that even the doctors who handled it didn't give me very much information. Since then I made a promise inside my heart, if I could find a way, I would share with others (Sonata, personal communication, 2010).

This work of sharing is carried out on a person-to-person basis over coffee, phone calls, chat rooms, and support group meetings, as well as at large-scale events such as workshops, seminars, and “talk shows” about autism, and through online and print media such as newsletters, blogs, and memoirs. Such activities seek not only to address gaps in knowledge about autism but also to build networks between parents, therapists, and teachers, to prepare a work force to work with autistic children, and to begin to strategize and advocate for services and support. Below I will introduce some significant figures and efforts, which I will then revisit in later chapters as I analyze how these genres seek to inform and influence parental behavior and family life.

One group active in the field is the non-profit organization The Autism Society of Indonesia, or *Masyarakat Peduli Autisme Indonesia* commonly known by its acronym Mpati, pronounced as “*empati*,” the Indonesian word for empathy.¹⁹ Mpati was founded by Gayatri Pramoeji, an elegant and charming woman who was a successful hotelier before she dedicated herself full time to the care of her autistic son and the cause of autism awareness. Mpati is comprised of a small group of volunteers who work out of borrowed office space using private donations. The organization publishes informative books, runs a website that provides treatment

¹⁹ See www.autismeindonesia.org.

recommendations, produces and distributes a series of DVD's about the early signs and symptoms of autism and interventions that can be carried out at home. The first of such DVD's focuses on early detection and intervention by illustrating the basic signs of autism as described in the M-CHAT (e.g. does your child point, is your child interested in other children, does your child hold eye contact?) as well as some basic principles of ABA. Mpati plans a whole series of such DVD's, addressing additional behavior interventions, speech therapy, occupational therapy, school preparation, social skills, and vocational skills training. Gayatri targets her efforts towards women, by partnering with *Femina*, the largest women's magazine in Indonesia, the RCTV television channel, which has women in leadership positions, and women-owned radio stations. She is particularly driven to reach middle and lower class women with the reasoning that wealthy mothers can go to Singapore, Europe, or Australia to pursue intervention and treatment, as she herself did—and as many wealthy Indonesians choose to do for a variety of health care services (Smith, 2013)—but the average Indonesian women will have much more limited options. She sees her job as “changing misconceptions” about the diagnosis and empowering parents in raising their autistic children on their own with minimal resources (Pramoedji, 2010).²⁰

As one last activity in part of this mission, Gayatri also gives “talk shows” and workshops for parents, therapists, and educators. She has thus far visited twelve cities, including Jakarta, Yogyakarta, and Solo in Java and Palembang in Southern Sumatra. With an estimated 200 audience members at each show, she has already reached approximately 2,400 people and her goal is to reach all the major cities in every province in Indonesia. She is certainly not alone in providing events of this nature. I attended a number of these as part of my fieldwork including “Talk Show All About Autism,” one of Gayatri's events held at the Muhammadiyah

²⁰ Pamoeji, Gayatri. Interviewed by Annie Tucker. Jakarta, 13 July 2010.

Public Hospital in Solo on 17 July 2010; the “Regional Seminar and Workshop To Get a Handle on Autism” offered by Talented Kids Autism School in Salatiga 1 August 2010; “Identifying and Educating Special Needs Children (Autism and ADHD)” held August 2, 2010 at Satya Wacana Christian University also in Salatiga; and “The Prospect of Empowerment of Autistic Persons For Their Future” organized by Fredofios Advanced School for Autism and held at Gadjra Madah University 19-20 November 2011. These events all involve a similar roster of activities: live performances by children or adolescents with autism, video clips of autistic people and their families from across the world, power-point presentations providing information on particular aspects of autism such as symptoms, interventions, or educational strategies, personal testimonies, a question and answer period, break-out sessions in small groups involving role playing or hands-on problem solving, and booths selling merchandise and accessories related to autism such as books, organic and dietary foods, T-shirts and bumper stickers, and etc.

Another significant source of information is parent newsletters. Perhaps the longest-running newsletter, *LRD*, has been published by Any Sonata since 1994. It started as a simple photocopied pamphlet that Any would photocopy herself then put in envelopes and send to parents scattered across the archipelago. *LRD* combines original content and information combed from other research sources: inspirational vignettes and quotes; interviews; personal experience narratives and reflections from Any, her husband, and other readers; encouragement and prayers; explanations of key terms and concepts in autism and child development; practical suggestions, exercises and activities; diet and supplement information and recipes; professional and school recommendations; book and film reviews; news photos and updates from long-time members and their families; and general news from the world of autism and disability. As such *LRD* is a cornucopia of autism-related material that provides an almost dizzying amount of

information, guidance, and support. The newsletter continues up until the present, now with a number of employees who assist with its production. It has recently been supplemented by an *LRD* Facebook group where parents from across the archipelago can “chat” with one another directly to ask for help, vent, or share their experiences in real time. Parent support groups occurring face-to-face occasionally supplement such virtual support groups and newsletters. Other websites and local groups offer similar activities; for example *Putera Kembara* (trans. “Wandering Son”) provides a significant online destination for the Indonesian autism community,²¹ offering information but also regular support group meetings and large-scale annual “Family Gatherings.”

Further efforts towards autism awareness are channeled into the writing of memoirs, of which there are a number including *Meniti Pelangi* (trans. *Waiting for Rainbows*) by Gayatri Pramodji (2004), *Untaian Duka, Taburan Mutiara* (trans. *Strands of Sorrow, Pearls of Wisdom*) by Diah Puspita (2004), *Faisal Sayang Mama Sampai Tua: Perjuangan Ibunda Dengan Banyak Keterbatasan Membesarkan Putranya Yang Autis* (Trans. *Faisal Loves Mama For Life: The Struggle of One Mother with Many Limitations to Raise Her Autistic Son*) by Sri Murni (2010), *Tumbuh Di Tengah Badai* (trans. *Growing Up In The Middle of a Storm*) by Herniwatty Moechaim (2009), *Indahnya Bersama Mereka* (trans. *So Beautiful To Be With Them*) by Umiyati Imaculata (2010), and still others (see Appendix I, Figure 2.4). These memoirs are all broadly considered “inspirational,” and could be enjoyed and appreciated by a wide range of readers for the way they depict maternal devotion and inspire strength, faith, and hope amidst challenging circumstances. But they also prove informative and instructional, as parent authors share lists of symptoms that they saw in their children, detail interventions that worked or did not work, and

²¹ See www.puterakembara.org

provide advice for how other parents should tackle such problems in their own life and best support their own children.

A Growing Presence: Autism in the Media and Popular Culture

Autism has received a fair amount of coverage in the two significant national Indonesian-language newspapers, *Tempo* and *Kompas* as well in various women's magazines such as the aforementioned *Femina*, and other online and print family-interest publications known locally as "tabloids." Different aspects are discussed in a range of articles, from those describing what autism is and its visible symptoms (Ferdianto, 2012), its increasing prevalence (Dewanto, 2003), suspected causes and risk factors (Desyana, 2012; Hadi, 2012), personal experience stories (Sari, 2011), to intervention methods and treatments (Rahman, 2009; Triyono, 2008) as well as event coverage (Damanik, 2008).

These articles have played a significant role for some families with autism, providing them with their first contact with the idea of autism as well as a description of its symptoms. In some of my interviews parents described to me encountering descriptions of autism in news publications and having it be an "aha" moment for them in framing their children's challenges and behavior. For the most part these articles are balanced and use primarily positive or neutral language to discuss the disorder; this is actually quite heartening, compared to the often-negative rhetoric in autism coverage that has been critiqued by autism scholars and neurodiversity advocates in US and Europe (Murray, 2011; Broderick & Ne'eman, 2008), and stands in interesting, and perhaps self-conscious, contrast to a perception many families have that the general public views autism as something embarrassing or worse, as Agus quoted above and many others phrased it, a "family shame" where parents either feel, or perceive they are

expected to feel, mortified by their child's condition. A number of blogs have also been authored, some with the intention of combatting negative stereotypes about autism, informing other parents, or just providing a day-to-day account of family life.²²

Beyond being relevant solely to people with autistic family members, autism has entered into the public imaginary, and increasingly autistic characters and references to autism can be found in Indonesian literature and film (see Appendix I, Figure 2.5). Autism might function as an incidental or symbolic plot point, as in the locally critically acclaimed horror flick *Perfect House* (2011), in which the main character is a young female private tutor who has just finished working with an autistic student before arriving at a her new job at a house where everything turns out to be more sinister than it seems. Alternatively, autistic characters may be used to further spiritual or religious themes of forgiveness, gratitude, and the importance of caring for others, as in the best-selling "inspirational" novel and now popular feature film *Rumah Tanpa Jendela* (Trans. *House Without Windows*, 2011) by Asma Nadia, a popular and prolific author of Muslim inspirational books. Other film plots incorporate autistic characters to more critical purposes. For example, the short film *Cerita Pulau*, or "Island Story," from the omnibus feature *Perempuan Punya Cerita* (2007) (trans. "Women Have Their Stories," international title *Chants of the Lotus*) tells the story of Sumantri, a community midwife, and her friendship with Wulan, a young woman with autism. In the film, Wulan's brutal gang rape and her village's reaction to it serves to critique Indonesia's entrenched patriarchy and development policies.²³

Additional film efforts speak to social issues surrounding autism and disability more directly. The blockbuster *Simfoni Luar Biasa* (2011), (Trans. "Extraordinary Symphony,"

²² For example, see "My Child is Autistic" by Mama Frieda <http://anakkuautis.blogspot.com>, or "The Art Blog of Hari Ihsan, An Autistic Man" <http://harizihsan.blogspot.com>.

²³ I have elsewhere presented my work on the rhetorical use of autistic and developmentally disabled characters in Indonesian film and literature as feminist critique (Tucker, 2010).

international title *Jayden's Choir*) specifically seeks to promote positive inclusion of people with disabilities. In the film, a frustrated rock star—played by real-life pop idol Christian Bautista—takes a job teaching music to a class of special-needs children. Led by an autistic “savant” singer with an angelic voice and an unusual attachment to rolls of toilet paper, the talented group ultimately performs at a prestigious regional concert, singing John Lennon’s “Imagine.” This film portrays its disabled and autistic characters in a positive light as cute, genuinely talented, and being given a chance that is well deserved. Furthermore, in the film Bautista’s character defends and supports disabled people, in one scene passionately chastising the lead singer’s parents, who have rejected him, and by extension chastising viewers’ own discriminatory attitudes. This movie was quite successful and as such it could be quite powerful in changing the public’s perception and treatment of children with disabilities. In his work on autism in South Korea, Roy Grinker asserts that the influential 2005 film *Marathon*, a movie about a young autistic man that includes a similar scene where his devoted mother chastises an insensitive stranger, helped change the atmosphere of acceptance, and in turn even available services, for families in South Korea (Grinker, 2007). Some film promotion events had Bautista viewing and discussing the film alongside people with disabilities, increasing visibility for the issue and providing a platform for their opinions and experiences to be heard. This film—albeit somewhat clichéd—thus contributes to the growing popular conversation about autism, disability and equal rights within the country. Taking a similar approach but from a non-fiction perspective, at this writing there is at least one documentary film about autistic Indonesians currently in production; *Love Me As I Am* is the pet project of well-known actress Christine Hakim and will feature interviews with families and local autism experts (Purwoko, 2011).²⁴

²⁴ Trailer for this film can be viewed at <http://vimeo.com/40800430>.

Perhaps in part because of this increasing visibility in the media, autism has also caught on as a form of slang or folk speech for young people. During the course of my fieldwork I encountered the term “autistic” or “autism” used in a casual, light way to call attention to lapses in pro-social behavior and as an idiom for isolation or stunted development. This usage appears to stretch at least across the island of Java. For example, a young professional woman in Jakarta explained to me that if someone invites you to join a group of friends out on a Friday night and you feel like staying in you might say, “No thanks. I’m feeling autistic right now” (B.I. *lagi autis*) (Field Notes, 27 June 2010). In the small Central Javanese city of Salatiga a college student declined an after-lunch cup of coffee, indicating that it would make it difficult for her to focus in her afternoon classes, saying, “If I drink coffee, I become autistic” (B.I. *menjadi autis*) (Field Notes, 24 July 2010). In one final example, in the East Javanese city of Malang I was visiting my old campus where I studied as an undergraduate. I joined my other alumni friends at a meeting for a university music collective where alternative and rock bands share studio space and plan events. The meeting of about 30 students packed into a practice room turned into a fairly serious self-critiquing session, in which members were voicing their concerns about the group. One member believed the problem was that people weren’t pushing themselves and instead staying in their comfort zone, saying “Some kids are too involved in their own world, they don’t want to develop and grow” (B.I. *Anak terlalu asyik dengan dunia sendiri, tidak mau berkembang*) and someone else called out from a corner of the room, joking, “You mean they’re autistic!” (B.I. *Berarti, autis*) (Field Notes, 24 September 2010). Some Indonesian parents of autistic children strongly oppose these kinds of casual usages of the word and worry about the ensuing slippage of meaning. For example in a Facebook forum one parent said,

I wish people understood the what and how of autism. Autism is not a condition where people are busy with their cell phones or blackberries. But until the present

time I still see, hear, and read comments like, “*dasar autis loe*” (that’s totally autistic) when someone sees someone else absorbed in their gadgets (Soviany, 2012).²⁵

Yet despite the fact that in some (young, urban, college educated) circles autism is so familiar as to have entered slang in a form of satirical usage that indicates a basic albeit stereotyped understanding of its symptoms (see Appendix I, Figure 2.6), I just as frequently encountered a confusion of categories regarding developmental difference, so that some people used autism and Down Syndrome or autism and schizophrenia interchangeably. For example, I attended an “outsider art” exhibit in Yogyakarta entitled “Schizophrenia’s Paintings,” featuring the work of Dwi Putro. The Indonesian friend who invited me to attend the exhibit, as well as the gallery representative who provided me with a tour of the exhibition and introduced me to the artist, both described him as autistic. Even well-meaning efforts that resist derogatory or misled representations of developmental difference may similarly blur distinctive categories of these differences, such as an inspirational card that proclaims, “‘Autistic’ is not an insult (B.I, *bukan olokan*), God loves you and so do I” which seems to illustrate autism with a picture of a young boy with Down Syndrome.

Finally, increasing efforts to recognize—in both senses of the word, to accurately identify and to acknowledge—autistic citizens in the face of lingering confusion or derision comes from autistic people who are beginning to speak for themselves; following the example of Temple Grandin, Donna Williams, and others, Oscar Dompas has written the first memoir from the perspective of an autistic Indonesian young adult, *Autistic Journey* (2008). Clearly, in Indonesia as in the United States and Europe, autism has been a highly productive idea (Murray, 2011) as it is incorporated into existing genres of creativity and catalyzes new expression.

²⁵ Soviany, Ade. Online Facebook forum facilitated by Annie Tucker and Any Sonata Bagwanto. Opened 18 January 2012.

Autism, Disability Rights, and National Development

As Ingstad and Whyte point out in their *Disability and Culture* (1995), outside the Euro-American context, the unifying word or idea of “disability” may not carry much weight, because the way of categorizing people with physical, intellectual, or developmental characteristics that differ from the norm may vary from culture to culture. In Indonesia, while the boundaries between autism and other forms of developmental difference are blurred, there is not a common-sense affinity between people with autism and people with physical or other disabilities—in fact, I found that many parents of autistic children felt comforted, or even asserted their autistic child’s relative normalcy, by underscoring their physical health or typical appearance. However, it may be relevant to state here that in contemporary Indonesia there is currently a growing self-advocacy movement for and by people with physical disabilities—alternately called *cacat* (trans. wounded, injured), *difabel*, disabled, or differently-abled. Such self-advocacy groups are increasingly demanding equal access to public transportation and other facilities, jobs and educational opportunities, and voting rights (Winarti, 2012; Stephani, 2012; Rachman & Haryanto, 2012) and often work in concert with governmental organizations and NGO’s. Autism groups share some of these strategies of advocacy, such as the aforementioned Autism Foundation of Indonesia, whose most publicized event is their annual Autism Walk.

Finally, there are a number of regional and national events that aim to effect social change by promoting positive views of people with autism and other disabilities while simultaneously arguing for their rights to access and inclusion. For example in 2010 Surabaya hosted the “Java-Wide Festival of Autism: Art and Sports,” highlighting the works and accomplishments of autistic children. That same year “Serving Everyone with A Sense of Duty,” an expo held in Yogyakarta, featured booths and performances from special needs

schools from across the entire nation while the following year in November of 2011 there was a national Youth Special Olympics held in Solo. These and other events present the public with the various abilities and accomplishments of autistic and disabled people while working to further instantiate a model of autism and disability that is defined by equal opportunity, accomplishment, and success.

Interestingly, some key national and health organizations relate the growing presence of autism and disability rights demands and provisions to Indonesia's increasing national stability and economic growth. Politicians and service providers have begun to acknowledge Indonesia's responsibility for the country's disabled citizens while explaining the heretofore failure to do so through narratives of national development. Some scholars have suggested that the overall increasing democratization and transparency of Indonesian social and political life since the fall of the New Order regime has included increasing transparency about mental illness and developmental disability (Baines, 2013). The National Department of Health explains its lack of attention to the issues of people with disabilities by explaining that Indonesia has only now just begun to get a handle on the more pressing health problems, in terms of broad impact and fatality, such as infectious diseases (Harjono, 2011). Mpati, the autism awareness group described above, tells a similar story on their website, which explains,

During the past seven years, the Indonesian government has faced a number of challenges in their efforts to stabilize the economy and secure national, social, and political stability and public safety, which were marked by the events of the monetary crisis in 1998, the first and second Bali bombs, the bomb at the Australian embassy, the Tsunami and Nias disasters, the bird flu, and other such occurrences.

One effect of this political and economic instability is that the attention the government towards education for children with special needs has not been a top priority, despite the fact that during this time reporting on the topic of Autism in

the mass media has been seen ever more frequently.²⁶

In such narratives the comparatively recent focus on autism and disability awareness and treatment becomes a sign of Indonesia's successful national development. In other words, now that Indonesia has been able to achieve political peace, economic stability, infrastructural functionality, and a generally high level of public health, it is finally ready to turn its energy to those with disabilities. In this context, autism intervention literature in essence asserts that Indonesia itself has been "developmentally delayed," but now it has caught up and finally "arrived." However, the attention paid to autism, and the stability and resources required to do so may be more available in some Javanese Indonesian communities than others, noticeably present in those areas that have high socioeconomic status and are more familiar with globalized medicine and global identity discourses and have more access to the therapy and services that do exist, and noticeably absent in others.

The lack of equally available basic infrastructure and health and human resources often means that the experience of autism diagnosis and treatment and the education of children will be significantly different for families who are monetarily wealthy and/or living in urban areas from those who are in poorer or more rural circumstances. Wealthy families will have access to the few private schools, clinics, and cutting edge treatment centers based in large metropolitan areas such as Jakarta the quality of which rivals those in other countries. Meanwhile poorer families, or even those of average wealth, may have access to none of these. Reni Yulia, from the aforementioned KIBM went so far as to say, "In Indonesia, having autism is the same thing as being rich." She went on to explain that for one thing, having access to a doctor or specialist who can provide the diagnosis itself most often means living in a wealthier urban area or having

²⁶ www.mpati.org. Accessed May 7 2010.

the means to travel to procure such a diagnosis. Beyond this, private schools for children with autism that have been founded to fill in the gaps left by the public education system are expensive, often costing from Rp 400,000 to as much as Rp 1,300,000 per month, which for most Indonesians is prohibitively expensive (for example a public school teacher's salary might only be Rp 1,000,000 a month or less). Similarly, most consultation sessions, therapies, and prescribed medications or supplements are expensive and must be paid for out of pocket. For example, simply an initial evaluation at a Kids ABA might start at the price of one million rupiah, with the cost of follow-up therapies many times that. Lab tests used to determine metabolic profiles and levels of mercury or other metals in the body, which are considered significant indicators of autism in Indonesia, must be sent to America to be evaluated, at a cost of approximately \$500 US dollars (5 million rupiah) per test. Because of this, Reiny estimates that about 80% of families who have a child diagnosed with autism are "*mampu*," or of financial means (Yulia, 2010).²⁷

A similar dynamic has been identified in the United States as well, where autism centers and treatment facilities tend to be clustered in affluent urban areas and there is a high correlation between being educated, richer (and living in Los Angeles) and having a child diagnosed with autism. Of course, this doesn't mean that Indonesians or Americans from wealthier socio-economic classes are actually four times more likely to have autism than those less well off, and in fact it may be exactly the opposite (Grinker et al., 2011). As in the United States, where socio-economic disparities in prevalence rates have also been debated, the diagnosis of autism often depends on access to resources, community influence, and referral bias (Liu et al., 2010; Begeer et al., 2009). Therefore, one could rephrase Reni's words, from "having autism is the

²⁷ Yulia, Reni. Interviewed by Annie Tucker. 14 July 2010, Jakarta. A variation on this theme that I came across in my research is the rumor that "In Indonesia, most people who have autism are Chinese." This may be similar in that it is widely believed by non-Chinese Indonesians that all Chinese people are all rich.

same thing as being rich” to “primarily it is people of means who get the diagnosis of autism, and such a diagnosis is most relevant to those with the means to treat it in the way that is envisioned as optimal and appropriate.” In an interesting turn, autism has in some ways even come to be a high-status diagnosis in certain parts of urban Indonesia. Dr. Mahar Agusno, a psychologist, medical anthropologist and professor at Gadjah Mada University in Yogyakarta, believed part of the reason why autism is becoming a more popular diagnosis in the country is because it is now seen as “prestigious.” For example, if after a period of observation and assessment he diagnoses a patient with childhood schizophrenia, the patient’s mother might ask him to change the diagnosis to autism because there is less social stigma associated with that label (Agusno, 2010).²⁸ Agus Haryanto, the child and family therapist, echoed this experience saying that despite the fact that autism was mostly unknown when he entered the field in the late 1990’s, now it is a preferred diagnosis for parents of special needs children, saying “Autism is the word that is the most *halus* (trans. polite, cultured, high class). It’s more respectful, more wise, than other disabilities” (Haryanto, 2012).²⁹

As socioeconomic factors seem to be significant determinants of autism response, then, in certain Javanese communities the label of autism may remain little understood or irrelevant, while in other communities the label of autism is actively preferred, even ‘prestigious,’ as it indicates an understanding and participation in globalized discourses of equality, health, and education, and signals affluence and access to specialized services. Clearly, the practices and institutions that have enabled the diagnosis and salience of autism in Indonesia are historically specific, variably salient and available, and yet ultimately gaining force.

²⁸ Agusno, Mahar. Personal communication. Yogyakarta. 28 August 2010.

²⁹ Agus. Interviewed by Annie Tucker. Bintaro, 27 January 2012.

Toward an Analysis of This New Phenomenon

Indonesia has a complex and fascinating history, the most recent chapter of which has witnessed rapid change and been in many ways defined by aforementioned self-conscious concerns with development and identity. Meanwhile, autism awareness in Indonesia is a recent historical phenomenon made possible by immense personal effort, shifting national concerns, and global change alike. It has become part of recent Indonesian history due to national discourses of inclusion, democracy, and equal rights since *Reformasi*, as well as ever-increasing access to resources and networks via the Internet and other avenues. Such awareness is also strengthened and extended by the hard work of additional key figures, the organizations they have built, and the works they have produced. These efforts and this work can be traced historically over time and space such that in a little more than a decade autism awareness and the autism field have grown exponentially into a national force; still, much additional investigative, ethnographic, and critical work is required in order to understand the underpinnings, significance, and implications of this history as nestled within and intertwined with broader Javanese and Indonesian history and culture, particularly ongoing negotiations of development, modernity, and tradition. The rest of this dissertation comprises initial steps in that direction.

Chapter Three

Autism in the Javanese Family

Approaching Autism in Javanese Indonesia: Entering “Local Moral Worlds”

Ingstad and Whyte in their seminal *Disability and Culture* (1995) emphasize the fact that conducting comparative ethnographic global disability studies requires a particular framework for understanding impairment or developmental difference and its interpretation. Since the meaning of disability is in part created by the environment within which it exists, and since we cannot assume that the history of disability, institutional infrastructure, or categorizations of difference that exist within one culture will exist in another, before we address disability or difference directly we must first get to know the “local moral world” within which it arises. Ingstad and Whyte suggest taking into account beliefs and practices regarding cosmology, personhood, and the social; for example do certain kinds of difference carry a particular meaning or send a particular message about people’s behavior and their place in the world? How do people gain a sense of personhood, that is, how do they live in a way that is thought to be valuable and meaningful, and what characteristics or behaviors enhance this value and meaning? How does the society interpret (inter) dependence and what additional social contexts influence evaluations and possibilities for personhood? Further factors such as gender, age, economic status, or the resources, accommodations and occupations available to those with impairments can potentially all be influential in the construction of a particular disability or difference in any particular cultural context.

To understand Javanese models of autism, we first must understand Javanese local moral worlds and local models of personhood. This chapter will thus focus more closely on autism as

it is experienced within Javanese Indonesian families in order to explore the way Javanese families inculcate, embody, and encourage culturally specific models of personhood and how they cope with those autistic children who do not fit the expected or normative model. To do so, I will first sketch some of the most significant aspects of Javanese personhood in terms of cultivated personal values and expectations for social comportment. Then, using data primarily collected from in-depth interviews and observations of 30 Javanese families with autistic children, who ranged in age from 3-19 years old, along with additional interviews and observations with therapists, focus groups with instructors and parents, and guided online forums with parents, I will report and summarize accounts of autism within the Javanese family, primarily from the perspective of parents and siblings.³⁰ I will address explanatory models including labels for autistic difference; perceived etiology; treatments pursued; community response; coping mechanisms; as well as personal narratives and descriptions of the subjective experience of having an autistic family member. I will then synthesize these bodies of information in order to offer some preliminary ideas about how Javanese culture, family structure, and child-rearing goals and practices might affect the interpretation, treatment of, and response to autistic people and autistic symptoms.

Javanese Personhood and the Javanese Family: Values, Goals, Practices, and Norms

There is ample evidence suggesting that from the earliest moments of existence within the family unit children are involved in processes of cultural learning through their relationships with primary caregivers, who impart a worldview, core beliefs, values, expressive style, and the

³⁰ During fieldwork I encountered and interviewed families from a variety of Indonesian backgrounds, including Batak (ethnic group from Sumatra), and Balinese. In this chapter I am focusing solely on ethnic Javanese families.

structure of social relationships (Keller, 2007; Quinn, 2005; Gottlieb, 2004; Dosamantes-Beaudry, 1997). The ethnographic corpus shows an early and enduring interest in the Javanese family, which therefore provides a good foundation from which to begin understand Javanese personhood. In her classic ethnography, *The Javanese Family: A Study of Kinship and Socialization* (1961) Hildred Geertz suggests that the family environment and the interactions with primary caregivers and siblings provide the first instructions into Javanese cultural values, priming the child for interpersonal relationships with others and inculcating the Javanese value system. She posits that there are two “distinctly Javanese” values that characterize interpersonal relations in Central Java, which are those of *hormat* (etiquette and respect) and *rukun* (harmony). Etiquette and respect is a key aspect of Javanese society, which has historically been hierarchically structured and remains somewhat so to the present.³¹ Within this hierarchy, those with more power and those with less are bound together in relationships of respect which are stable and mutually supportive: those higher up on the hierarchy are entitled to service, loyalty, and obedience while those on the lower ends of the hierarchy are entitled to support, protection, and beneficence. The expectation or ideal is that those in power know best and will act in everyone’s best interest, and therefore those lower down trust those in power and are grateful to them.

Historically, when Sultans ruled basically feudal agrarian states, these roles were sharply delineated. Now Javanese society is no longer as rigidly hierarchical and while there are some guidelines—for example, a younger person will almost always subordinate themselves to an

³¹ While there is not room for an extended discussion of contemporary Javanese sociopolitical life here, it should be acknowledged that political networks of power, from the national to the most local levels, are still very important in getting anything done in Indonesia. Often these networks overlap with leaders in local custom and religious authorities, all carrying out ongoing surveillance of various activities. A variety of personal, civic, professional, and other activities require obtaining multiple levels of permission and showing a significant degree of deference and respect. However at the same time in Indonesia there is a powerful and ongoing move towards democratization in socio-political power and everyday speech and interaction.

elder, and a lower-level employee may position themselves humbly in comparison to their higher-up or boss—this respect and relative hierarchy is flexible and constituted in the moment through the use of language levels, tones of voice, body posture and gesture. Language is especially important in the performance of respect in Java: it has at base three speech levels (although some speakers are masters of even further refinement), with *ngoko* being the low level of speech and *krama*, or *krama nggil*, being the highest level; so for example “eat” in Javanese may be said as *ma’am*, *mangan*, *madang*, or *dahar*, depending on who is speaking to whom. The more respectful one tries to be, an ever softer and slower tone of voice will be used and a gentle bowing posture will be adapted.

Rukun, or harmony, means that people come to decisions based on what is good for the collective over any personal interest. People are supposed to work together for the common goal, and so identify with their group that their individual desires become irrelevant. Geertz argues that maintaining the appearance of *rukun* is almost as important as actual feelings of *rukun*; but in order to achieve either actual *rukun* or the appearance of *rukun*, and in order to work together without seeming to make bids for personal gain, people must know how to passively avoid conflict and how to make their wishes known and perceive the wishes of others without having to engage in heated—or perhaps even evident—negotiation. This value of collective harmony determines behaviors within families, villages, and work communities. It goes hand-in-hand with what is felt by many to be a defining quality of Javanese and broader Indonesian culture, which is *gotong-royong*, or collective work that is done by all for the common good without any expectation of personal reward.

Writing more than thirty years after Geertz, Niels Mulder in his *Inside Indonesian Society* (1994) saw a stability and continuity within these Javanese values, but articulated a key third component, “*utang budi*,” which is literally translated to mean “a debt of gratitude.”

This debt is relevant to the hierarchical relationships of respect discussed above; part of the reason those lower on age and power totem poles are able to defer to those with more power is that they feel indebted to them. This sentiment is first instilled within the family system, where the young (est) child is positioned as being on the receiving end of generosity and selfless giving. The indulgence a child so positioned benefits from is not just an expression of love but also serves a didactic purpose. Mulder posits,

[T]he child appears to be on the receiving end, as the one who benefits from nurture and care, attention and teaching. This lays the basis of one of the most important attributes of personhood; the sense of gratitude, of obligation, of dependence and origin, or identity. Alone, nobody can survive; as social beings, people depend on each other, first of all on morally superior parents; this in turn gives rise to obligations of respect, submission, and especially the recognition of sacrifice, and thus of gratitude. In a general sense, to be in the care of somebody places the recipient under a moral obligation (*utang budi*), a debt of gratitude. Not to acknowledge such a debt is more than despicable; it is to be morally defective (Mulder, 1994, p. 106).

The *utang budi* suggests an awareness of interdependence and origins, and Mulder sees the *utang budi* as the key to Javanese moral personhood.³² Furthermore as part of this indebted interdependence, he described ego boundaries dissolving into the family unit through physical proximity and emotional intimacy. In this family intimacy (B.I. *keakraban keluarga*), people identify so strongly with the other members of their family group that they experience themselves as a part of that group rather than an individual, and hence are acutely aware of needing each other. In parent-child interactions this need is reciprocal; the children, in receiving

³² During my fieldwork stay I was struck by how many of my peers and acquaintances used the phrase “my mother is my God,” or the common maxim “heaven is found at your mother’s feet,” perhaps attesting to these persistently salient feelings of deep reverence, obligation and gratitude.

nurture, care and in having their needs anticipated are aware of emotionally and instrumentally needing their parents. If they are young enough, they will be carried in a sling or a constant embrace of a family member even well after they can walk, almost literally enveloped into their being. However, in many ways the identity of the parents, and in particular the mother, also gets subsumed into the identity of their child. To illustrate, a new mother may no longer be called by her own name, but will assume her child's name, so that a hypothetical Ibu Supartini, or Mrs. Supartini upon having a son named Joko may be called Ibu Joko (which can be translated either as Mrs. Joko or Joko's mother) or Mama Joko, and sometimes then will even called by her child's name for short (Field Notes, 2010). Having a family, in particular having children, is a central aspect of adult Javanese and Indonesian life from which few are exempted (Boellstorff, 2005), but it could be said that a woman is particularly dependent on her child for the accordance of full adult personhood. During my fieldwork I heard many people say that a woman is not "truly" a woman until she "enjoys" the suffering and sacrifice of labor pains and being a mother (Field Notes, 2011-2012).

Being able to meet the requirements of Central Javanese interpersonal conduct demands certain skills of individuals in order to manage their own emotions and appearances. In his two works "Shame and Stage Fright in Java" (1983) and *Javanese Shadow Plays, Javanese Selves* (1987) Ward Keeler identifies two key aspects of comportment, the emergence of which signals increasing maturity in a growing Javanese child or adolescent. The first is to "know *isin*" and the second is to "*ngalah*." "*Isin*" can be translated as "shame" or "embarrassment," but at its core it indicates a self-consciousness in encounter, the acknowledgement that interpersonal relationships have the power to support or question each individual's status, role, personal power, and self-respect. *Isin* acknowledges an intersubjective vulnerability; since status is constructed in

encounter a misstep on your part will reflect badly on you but also your interlocutor whose status is insufficient to inspire or evoke the correct response in you, and vice versa, so that another's gaffe is also your own fault and your own gaffe embarrasses not only you but your conversation partner. This awareness breeds some level of anxiety in all people when interacting with anyone who is outside the immediate family, or anyone who is unknown and therefore whose status might be ambiguous; what Euro-Americans might classify as shy awkwardness is valued in Javanese self-presentation, seen as crucial to laying the foundation for thoughtful, aware, and appropriate interpersonal relationships;

by exerting self-control one can behave humbly, a quality embodied in terms like *rikuh* (unwilling to assert oneself), *ewuh-pekuwuh* (ill at ease, awkward), and *isin* (embarrassed, shy, self-effacing). Such attitudes are believed to create harmony, respect and empathy (Sutarto, 2007, p. 45).

While sometimes Javanese people might tease one another that an awkwardness can be carried too far and they need to "loosen up," a proper demeanor and the use of proper and fully-expressed Javanese etiquette brings great pleasure to all involved parties when carried out correctly.

Keeler also discusses the importance of *ngalah*, or voluntarily acquiescing to another's wants or desires. Other cultural variants on the same sentiment or practice include cultural concepts of surrender (B.I. *pasrah*), sincere submission, often to greater cause or for a greater good (B.I. *ikhlas*), and especially acceptance (B.I. *menerima*, B.J. *nrima*), all of which contain an element of acquiescing to others or submitting to forces outside of one's control. It is assumed that much of what happens to an individual over the life course is the result of God's will, fate, or karma, and therefore not under individual control, as encapsulated in the folk wisdom "Accept the lot given you by God" (B.J. *Nrima ing pandum, pandume sing kuasa Gusti Allah*) (Sutarto,

2007, p. 46). The implied belief is that not much can be done to change external circumstances, governed by larger and invisible forces such as they are, so that the most important and effective response to adverse conditions is emotion work on the self; if one fully accepts a situation, she will not suffer further nor will she cause others to suffer. The orientation and practice and of *ikhlas*, *pasrah*, and *nrimo*, is highly praised in Javanese culture, and it is assumed to be genuine when internally motivated, not prompted or forced. It is seen as a sign of emerging maturity and civility, an ability that is sought and cultivated by many throughout the life course through ascetic practices such as fasting and meditation.

Another practice that enables the individual to comport themselves in a proper manner is the development of intuition (B.I. *rasa*, B.J. *roso*) and the maintenance of awareness (B.I. *sadar*, B.J. *eling*). *Rasa*, often glossed as “intuition” or directly translated as “feeling,” can indicate both a state and a process, both what you are aware of feeling and the sense you use to develop this awareness (Stange, 1984). *Rasa* allows an individual to be attuned to his or her total environment. Maintaining *eling*, or awareness, ensures that an individual will always be conscious of themselves and their position in that total environment, and therefore like *rasa* is an orientation to the world, a way of knowing. As a psycho-spiritual goal, maintaining *eling* will prevent offense and preclude bad behavior (Browne, 2003). A well-developed *rasa* or well-preserved *eling* means that in encounter or decision-making, an agent can sense or know another’s desires or motivation and anticipate their needs as well as modulate their own, ensuring collective harmony.

Finally, people constantly work to maintain personal balance, avoid harmful extremes of emotion such as anger, frustration (B.I. *frustrasi*), and disappointment (B.I. *kecewa*), which is seen to weaken and endanger the life force and make one prone to both physical and mental

illness (Browne, 2001a, 2001b; Ferzacca, 2001). Surrendering to fate is one way dampen the response to, and hence mitigate the systemic dangers of these negative emotions. Another key to maintaining this balance is avoiding shock or startle, which has a destabilizing effect that is deeply disturbing to physical and emotional health and according to some leaves one vulnerable to the possession by evil spirits. As Heider put it in his linguistic ethnography *Landscape of Emotions*, “there are no good surprises in Java,” as all word associations with “surprise” are negative (1991). Individuals may try to cultivate and fortify their resistance to such shock or startle, again turning to ascetic practices believed to acclimate the body and mind to discomfort as well as condense personal power.

On the whole, Central Javanese communities have been characterized as tolerant of minor inter-personal transgressions, difference, or deviance. This is partly because of the awareness of *isin*: another’s transgression reflects badly back on the person transgressed against, so it’s better to overlook such deviance whenever possible. Furthermore, as it is important for overall well being to maintain emotional balance and avoid negative feelings, tolerance is crucial. Therefore in Java, similar to what Hollan and Wellenkamp note in their work in Indonesian Toraja (1994), a harsh response to an infraction of social etiquette may be judged more critically by others than the infraction itself. Shows of negative emotions or visible attempts to bend others to your will are frowned upon: the Javanese view power as an “attractive rather than coercive force” (Keeler, 1987), and the person who can spontaneously and effortlessly inspire obedience and accord is the one who has true power.

Associating the mastery of cultural requirements with an ever-increasing sophistication of behavior and maturity, those who fail to behave with proper etiquette or who violate *rukun* may be diagnosed with a kind of cultural developmental disorder, termed “not yet Javanese” (B.I.

belum jawa) or “not yet understanding” (B.I. ”*belum ngerti*”) (Sutarto, 2007). These terms are often used to excuse little children or explain inappropriate or “immature” behavior in others. It is implied that all people are in a constant state of becoming, ever approaching a pinnacle of Javanese-ness which is the result of an inner process of self-cultivation and growth; a state that if it is not achieved, must be met with patience, and understanding, not force. Another way to put it might be that Javanese-ness, much like autism, is a “spectrum condition” and some Javanese people are much more “Javanese” than others.

Autism in the Javanese Family

Some families embedded within these cultural patterns of practice have autistic children who as such may evidence disturbances in speech (no spoken language, language delay, seemingly non-communicative speech such as echolalia or idiosyncratic word choice), socialization and communication (eye contact, affect regulation or matching, body language), and stereotyped behaviors (“odd play,” perseveration, resistance to deviation from routine). They may also experience sensory disruptions and have specific sensory needs (sensory integration problems, proprioceptive dis-regulation), and may have other physical issues, such as sleep disruption, food allergies, digestive problems and/or cognitive and behavioral issues such as learning disabilities or disruptive, self-injurious, or aggressive behavior. Despite the common underlying deficits or challenges, the expression of autism will depend heavily on the individual’s particular profile.

On the whole, based on the psychocultural environment of Javanese families and communities, it might be that people with autism spectrum disorders may be particularly challenged by the requirements of early elaborate social, emotional and empathic awareness,

control, and response, the very skills that many argue are impacted or impaired in ASD. And yet, an observer might also surmise that people with autism might find themselves in a particularly socially forgiving environment in Javanese Indonesia, where social development is considered to a certain extent to come at its own pace and family and community members are motivated to overlook at least minor social infractions in order to preserve their own sense of proper comportment and to maintain interpersonal harmony. Below is a more detailed summary of how some Javanese families respond to and cope with their children's difference, based on my interviews and observations.

Labeling and Mislabeled

Historically in some cultures, before the label of autism existed, there have been folk models or vernacular concepts of developmental difference that could arguably be analogous to the contemporary understanding of American autism. For example, in folk and fairy tales from the British Isles, Scandinavia, and Germany, there is the figure of “the changeling,” or a young child who exhibits remarkable sudden changes in behavior characterized by unresponsiveness, resistance to physical affection, inability to express emotion, unexplained crying, and the loss of language, attributed in these tales to human child's soul being stolen by supernatural beings and replaced by that of an otherworldly fairy or goblin child (Frith, 2003; Leask, Leask & Silove, 2005). In Russia from the 16th to 18th centuries, there were people known as “blessed fools,” who were mute or echolalic, wandered, and engaged in repetitive behaviors; in contemporary Senegal there are the *Nit-ku-bon* or “marvelous children” who exhibit lack of speech and social un-responsiveness; and in rural Laos there are those termed Samqyng-Uan, who are known to experience social difficulty and adhere to strict routines (Grinker, 2007).

My research in Java revealed no folk ideas or folk terms directly correlating to autism such as these.³³ However all the families I spoke with, although they ultimately obtained the diagnosis of autism for their child, experienced that at one time or another others in their families or communities labeled their children with certain folk terms or grouped them into certain folk categories that encompassed various indigenous beliefs about behavior, developmental and intellectual differences, or disabilities. Some commonly heard terms were *bodoh*, meaning stupid, *nakal*, meaning naughty or misbehaved, *terlambat*, meaning slow, late, or delayed, *keterbelakang*, meaning left behind, and *gila*, *kenthil* (Javanese), or *edan* (Javanese), all meaning crazy. *Bodoh* and *nakal* are terms that are frequently applied to typically developing children and adults and often indicate a temporary lapse in expected or acceptable behavior—*bodoh* may be used to characterize a lack of knowledge and poor choices or judgment, and *nakal* is perhaps most indicated when someone is not following rules and making trouble for others. *Gila* or *edan* is a term that can frequently be used affectionately, similarly to English usage of the word crazy to indicate behavior that is wild, excessive, exciting, silly or unexpected. However, when it is not being used in such familiar or joking context, these words are most often applied to people who are visibly and severely disturbed, and who according to Javanese have lost touch with reality. People labeled as *gila* may wander, disregard personal hygiene or disrobe, talk to themselves or be unable to carry on a sensible conversation, seem to forget their roles, duties, or identities, and/or seem to be existing in an alternate reality and may be used in Indonesia for

³³ Past research has described and analyzed cultural syndromes or folk illness present in Indonesia, some of which indicates symptomatology that overlaps with autism symptoms in intriguing ways. These include for example *latah*, the echolalic startle response (Geertz, 1968), *bebainan* or temporary “fits” (Suryani, 1984) and soul loss, often characterized by a seeming unresponsiveness to the environment (Wikan, 1989). Yet these symptoms and syndromes were not associated with autism by any of my respondents; while perhaps descriptively similar, these terms are often quite specific to certain groups (e.g. in the case of *bebainan*, young Balinese women of marriageable age experiencing increasing restriction in their daily lives), and according to some are fading out of common usage (Lemelson, 2009). ASD has a much more complex profile and a much broader range of associated developmental problems.

those exhibiting symptoms of major mental illness such as bi-polar disorder and schizophrenia (Lemelson, 2011a, 2011b). *Terlambat* and *keterbelakang* are terms that seem to refer most specifically to people with developmental delays, such as those that Americans might label as intellectually or cognitively disabled or mentally retarded, and are infrequently heard outside of such a labeling context.

The term selected to refer to an individual with autism is most probably contingent on the profile of the autistic individual it is being applied to; some autistic people are noticeably “hyperactive,” needing to move their bodies and having difficulty controlling their impulses while others are seemingly non-responsive, sitting very still or appearing to take little notice of their surroundings. *Nakal* or *gila* is most likely to be applied to those former children who are more active, perhaps grabbing or touching things inappropriately, vigorously stimming or running away, engaging in echolalia or seemingly nonsensical speech. Meanwhile *keterbelakang*, *terlambat*, or *bodoh*, or sometimes *idiot* might more frequently be applied to those children who tend towards passivity, engage in activities that seem to lag developmentally behind their physical age, or have difficulty with self-care or self-protective activities. Slippage between vernacular understandings of being “left behind” and being “crazy” occurs somewhat frequently.³⁴

Finally, some people with autism are occasionally labeled as being possessed by spirits, with terms such as *kesurupan* or *kesambet*. This may be because particular behavior certain people with autism might engage in at times, such as repetitive movements, self-injury, absence of direct eye contact, or seeming obliviousness to the immediate surroundings--what can be

³⁴ One illustrative example comes from an unlikely place, the popular and campy Yogyakarta restaurant “House of Raminten” owned by an infamous eponymous cross-dresser, where patrons wait for a table sitting on rows of plastic chairs facing a blasting television and a sign proclaiming, “We all are “Exceptional School” graduates (B.I. *lulusan SLB*, [indicative of cognitive or developmental disability]) so if it’s seems to be taking a long time, we hope you understand we’re completely crazy (B. J. *kenthir*).”

termed a loss of *eling* or awareness (Browne, 2003)—might seem to resemble the behavior of those people who are possessed by spirits. I had an interesting experience in Salatiga, Central Java that illuminated this connection for me:

I had attended an autism seminar and in the last session of the day, the speaker was suggesting the power of Islamic prayer as an effective intervention for certain behaviors. She showed a video of a young boy sitting cross-legged, rocking repeatedly and biting his own forearms. A therapist instructed the boy, “Prayer hands!” (B.I, *tangan sholat*). The boy responded by wrapping his hands around his waist, a standard position in the Islamic prayer ritual many Muslim Indonesians engage in 5 times a day, and the therapist and the boy prayed together. This “replacement behavior” seemed to immediately calm him. The presenter then showed a video of a teenaged autistic girl in pajamas yelling and flapping her hands. Again the instruction “prayer hands!” was heard, and again the subject’s hands went to her waist and she immediately calmed.

When the seminar was over, I went walking with a number of new acquaintances. We passed through the center of town, which was in the middle of a festival celebrating Salatiga’s anniversary. I could hear lively music, drumming and singing, and one of the attendees accompanying me shouted out with excitement, “*Reog!*” I joined her to watch as men performed a popular folk dance where participants dance and “ride” rattan horses until they go into trance and engage in a pantomime of fighting. They engaged in repetitive movements of circling, stamping, rocking, and moving their heads back and forth before the trance took hold and the spirits entered them. Once they were in trance they charged at one another, their bodies stiff and eyes unfocused. They ate strange foods, like flowers and candles, interacted with objects in unusual ways, such as being transfixed by the smoke of incense, and continued in this affectless performance of affect: their faces blank yet their bodies stiff with aggression, their eyes unfocused yet their bodies honed in on a certain perception, seeming compelled by a possessing spirit to pursue these bizarre and unusual activities.³⁵ The men emerged from trance when the *pawang*, or spiritual leader of the performance, recited a prayers: once he whispered the holy words to bring them out of their possessed state and to halt their self-injurious behavior, their bodies immediately relaxed into positions of submission and they were led off the performance grass to a backstage area where they could rest, and return to their normal selves and typical behavior.

³⁵ *Reog*, incorporating dance, hobbyhorse riding, and spirit possession, is one variation of a popular performance genre found throughout Indonesia. In Central Java another common variant is known as *jathilan*, while in East Java it is known as *kuda lumping*. This practice has been linked to ancient animist ritual and spirituality, where dancers are entered by ancestor and animal spirits who may engage in wild behaviors, including various acts of self-mortification. For further information on *jathilan* see Lemelson, 2012; Browne, 2003; Hughes-Freeland, 2008.

At the time I was struck by the similarities of the experiences of watching the video of the autistic teenagers and the possessed performers. Certain outward expressions of trance or possession behavior (Ward, 1984) did in fact seem to mimic certain physical expressions of autism, including shaking of limbs, which might mimic the “flapping” or rocking associated with self-stimulation, changes in speech and facial expression and glazed eyes, which might mimic the non-normative verbal communication and aversion some autistic people have to eye contact, and a muscular rigidity and spatial disorientation similar to that which some people with autism may exhibit. There were further similarities in the seemingly causeless aggression both groups of people displayed, as well as a seeming imperviousness to pain.

Certainly the internal experience of an autistic person engaged in self-injury and a “possessed” performer is not the same. The more we come to know about autism, the more it seems that the observable behaviors described above stem from sensory processing and regulation issues and dyskinesia (Biklen, 2005; Bogdashina, 2003; Williams, 1998). However to an onlooker, especially one who may have never come in contact with an autistic person or the concept of autism before but who is familiar with genres of folk performance where such trance is observable and for whom such a framework is both meaningful and readily available, the experiences might appear somewhat analogous.³⁶

Despite how commonly these various, and variously derogatory, terms were applied, most parents and siblings of autistic children I spoke to all felt certain that these terms were a wrong fit for their family member. Such labels were understandably experienced as a hurtful

³⁶ I developed this analysis after the fact, so I am currently unable to confirm whether Javanese themselves are making these kinds of comparisons when calling someone with autism “possessed,” however, some symptoms noted by parents and others, such as an “empty gaze” (B.I. *pandangan kosong*) are also descriptors commonly used for people who are possessed or in trance.

misrecognition of who their children were and what they were like. For example, Warno³⁷ was born in Salatiga. He has three sons the youngest of who, Bayu, has been diagnosed with autism.

Bayu is now a well-mannered and academically successful teenager, but Warno remembers

There were people around us, even friends, and even let's say family...they would say that my child is crazy. But [...] that's my child. My son. I know precisely that my child is not crazy (Warno, 2011).³⁸

Warno felt sure that Bayu wasn't crazy; indeed in some ways he seemed quite precocious, even brilliant—for example he had memorized the entire contents of his father's record collection and his own karaoke video collection, and had even seemingly taught himself to read both Indonesian and English through the songs lyrics that accompanied these videos. Warno was excited to have a chance to prove that his son was actually quite intelligent. For example, in one gratifying circumstance,

a friend who had said my child was crazy came over to the house. So I called him, "Yu, come here Yu!" There was an English-language magazine, written in English. "Read that!" So he read it...come on, crazy?! [My friend said,] "Hey, *my* kid can't read a magazine in English!!" And yet he had said my child was crazy (*ibid.*).

As Ingstad and Whyte rightly remind us, there may be multiple interpretations of a disability within one culture or "local moral world," and in this case many Javanese parents, like Warno, certainly contested what they perceived as a mainstream view of their children, which socially marginalized and undervalued them by classifying them as "crazy."

Another common label, albeit less hurtful, suggested by well meaning neighbors and friends is that of deafness. Because of apparent non-responsiveness, even to their names being called, some autistic children are mistaken for deaf; in fact, it is such a familiar symptom of

³⁷ As previously noted in most instances in this dissertation, except for those of outspoken activists who speak openly about their experiences (indicated as such), all names have been changed.

³⁸ Warno. Interviewed by Annie Tucker. Bantul. 20 October 2011.

autism that the M-CHAT one of the most commonly used screening instruments worldwide, asks, “Have you ever wondered if your child is deaf?” (Robins, Fein & Barton, 1999). However, despite occasional unresponsiveness, many parents felt sure that their children were not deaf based on their empirical experiences. Warno was just as sure that Bayu wasn’t deaf as he was that he wasn’t crazy.

Early on, even if you called his name he wouldn’t turn his head. Even if you got right into his ear, you shouted the name Bayu, he still wouldn’t look. So many people said it seems like he’s deaf and dumb. They already judged him that way, friends came to that conclusion. Because if you tried to get him to talk, he stayed quiet. If you called his name he just remained still (Warno, 2011).³⁹

Warno knew there was no way that Bayu could be deaf, because one of his main pleasures was listening to and memorizing music, so he figured he just needed extra tutelage about names and came up with his own system to teach him through repetition.

I’ll give an example of how I followed through on my principle that my child was not deaf and dumb. I would call him, point at him, and pull his hand towards his own chest, “Bayu! Bayu!” In his ear. Then I would go in front of him, and I would pull his hand towards me, “Dad, Dad!” Then I switch back, “Bayu.” He was confused, but I just kept on going like that. “Bayu! Dad!” Until he learned (*ibid.*).

Another parent, Woro, had a similar experience with her daughter Dian. Woro has a steady calm demeanor, is a devout Muslim who wears a *jilbab*, or headscarf, and is the mother of three daughters, of whom Dian is the youngest. Dian is a pleasantly chubby nine-year old with curly bangs who loves to sing and dance. When Dian was one and a half Woro became concerned that she had not yet begun to speak like her older sisters had at that age. She took Dila to get diagnosed, and the doctor told Woro that Dila was deaf, and advised her to use hearing aids.

³⁹ Warno. Interviewed by Annie Tucker. Bantul. 20 October 2011.

The first time I had a consultation, Dila was called “deaf and dumb.” [The doctor said] she couldn’t hear, she was deaf and dumb, and she was told to use hearing aids. I was still too nervous to put those hearing aids in, because she was so little you know, just one and a half. I was worried that actually wearing them would destroy her ears! I asked if we could wait to put in the hearing aids until the next check-up. So we were given six months. After six months I went for another check-up, she was tested, and it was all just like the first time... at the second check-up, Dila could hear 15 decibels.⁴⁰ But the doctor still advised the use of hearing aids.

I felt hesitant, that it wasn’t right. I wasn’t really sure that she was deaf. Because at home, if the TV was on, even if the sound was muted, if we turned it off she would hear it, she would cry. So we left the TV on 24 hours a day, even if she was asleep [...] she would wake up and cry. She knew if we had turned it off! (Woro, 2011).⁴¹

With the ability to observe their children in a continuous fashion, these parents were able to notice that seeming deaf was just one in an array of perplexing symptoms their children exhibited.

Symptoms Noted

There were other symptoms that parents noticed in their child that gave them pause, many of which are considered “classic” symptoms of autism. Indeed, while some scholars question the coherence of autism as a diagnostic category, saying that it is in fact quite broad and subjective (Nadesan, 2005; Murray, 2011), other autism experts have asserted that “there is no other psychiatric disorder of children (or, perhaps, of persons of any age) for which such well-grounded and internationally accepted criteria exists” (Cohen & Volkmar, 1997) and that such an intercultural consistency of symptoms, suggests an as yet not fully understood organic or biologically-based etiology (Daley, 2002).

⁴⁰ The normal range for children with no hearing impairment is 0-25 decibels (Moeller, 2000), so this means that Dian did not technically qualify as being hearing impaired.

⁴¹ Woro. Interviewed by Annie Tucker. Bantul. 13 October 2011.

In the Javanese families I interviewed, one primary symptom among many that drew their attention was that their child was late to speak or lost the language that they had acquired, usually between the ages of two and three but in some cases later. Others noticed unusual vigor and hyperactivity in their children, often including a disrupted sleep schedule and impulsivity, such as throwing or breaking household items. Still others noticed that their children did not make eye contact with them or seemed unresponsive to their environment—their children didn't react when their name was called, didn't seem to bond with or even notice their family members or what was going on around them, avoided hugs or touch and seemed to prefer to be alone or be “in their own world” (B.I., *dalam dunianya sendiri, asyik dengan dunia sendiri*). Other parents interpreted their children's behavior as a form of egotistical behavior, a kind of cultural-developmental delay (Tucker & Lemelson, 2011) where the child was not yet able to consider other people's feelings and modulate their own behavior accordingly; so outbursts of emotion, impulsive behaviors, lack of communication, and non-compliance might all be considered evidence of egotistical self-centeredness or an individualistic will (B.I. *keegoisnya*). Other symptoms parents noted included walking on tiptoes, systemic digestive and/or skin problems, laughing or crying by themselves with no apparent cause, “flapping” or repetitively moving their hands, and sensory irregularities including sensory sensitivity indicated by the child becoming afraid or covering his or her ears at loud noises or having an acute awareness of faint noises such as Woro describes in her daughter above, and hyposensitivity, including a seeming imperviousness to pain.

Parents often also noticed other behavioral quirks in their children that they did not interpret as a signal of difference or disturbance until they had received the diagnosis and become well versed in the behavioral aspects of autism. So, while initially such practices as

playing with or gazing at things that spin, like a fan or toy car wheels, lining toys up in neat rows, being obsessed with all kinds of bottles, or adhering to a strict dietary regimen of the child's own making seemed innocuous or just unique aspects of the child's character, in retrospect they were reinterpreted by the family as being part of the larger picture of autism. Interestingly, some families noticed an affiliation with computers and machines in their children, which has also become prevalent in the American discourse on autism, particularly in folk models of so-called "high-functioning" autism (Nadesan, 2005; Silberman, 2001). In Javanese reports this affiliation included noticing an affinity for machines, so that children were precociously talented with electronics or notably adept at working, playing with, or fixing computers, and a perceived resemblance to machines, so that one parent said he felt his son "acted like a robot."

However, since as I mentioned above there does not appear to be a local folk model of developmental difference that is analogous to autism, parents for the most part felt mystified by their child's developmental differences. The most common response to their symptoms was the feeling that there was no existing label sufficient to explain their child's difference, no familiar category that seemed appropriate. Therefore many parents asked themselves, "What's wrong with my child?" and asked their children, "What's going on with you, sweetheart?" They found themselves searching for words or concepts to help them understand their children. As one mother put it,

Before we got the diagnosis we didn't know about autism... It was just like there was something different... I didn't know how exactly... I just felt like there must be something delayed with my child (Roro, 2010).⁴²

⁴² Roro. Interviewed by Annie Tucker. Bogor. 15 July 2010.

In this atmosphere of confusion, for some family the news media played an important role in interpreting their children's behavior, or at the very least, putting a label on it. A number of parents reported that they considered that their child might have autism only after reading a number of articles describing the condition in popular national newspapers, *Tempo* and *Kompas*. Those parents who spent periods of time living outside of Java in more remote regions of the country such as rural Kalimantan, with spotty internet connections and almost nonexistent public health services, stated that in the late 1990's and early 2000's, news publications were the only source of information on autism that they could find. These parents describe reading these articles as a revelatory moment for them as they considered their children and thought to themselves, "Oh, so this is called autism!"

Perceived Etiology

My research revealed a variety of etiological theories of autism. As mentioned above, some parents I interviewed have come to believe in autism as a neurodevelopmental disorder present since birth, and while they perhaps didn't notice anything unusual about their child until they were older, in retrospect they felt that signs of difference may have been there all along if only they had known how to recognize them. For others, it was the experience of birth or labor itself that seemed to be a precipitating factor; two families had children who were "born blue" due to oxygen deprivation during a complicated labor. Other mothers believed that a physical illness or infection they experienced while pregnant, such as typhus or herpes, contributed to their child's autism; still others believed it was due to emotional stress during pregnancy. In other cases parents pinpointed an occurrence during childhood that caused their child's behavior to change remarkably, to stop speaking or to withdraw from friends and family, for example.

These occurrences included major illness during which the child experienced high fevers (typhus, food-borne illness, etc.), physical shock, or emotional trauma.

Such occurrences perceived as the cause of autism also include vaccinations, which a number of mothers mentioned; interestingly, perhaps because the vaccination schedule is not as strictly monitored in Indonesia as in the United States, at least one parent noted the effect when her son was vaccinated at age 7 (Norma, 2010).⁴³ Another mother, who believed vaccinations had caused her son's autism, shared with me a rumor that could explain this despite her knowledge that current scientific and medical opinion has stated that there is no causal effect between vaccinations and autism. I heard this rumor from other mothers and therapists and various events. Paraphrased, the rumor is as follows:

Due to the lobbying of mothers, heavy metals in vaccines that were causing autism in American and European children were removed and new vaccines were made. Once health officials and pharmaceutical companies had decided to protect American and European children, there was still a lot of leftover stock of the old, harmful immunization shots. Pharmaceutical companies didn't want this stock to go to waste, so it was sent off to Indonesia and other third world countries. The international health community was willing to take that risk because, as a poor developing nation, the lives of Indonesian children are seen as less valuable than the lives of those children in Western nations.

She finished telling me this rumor loudly proclaiming, "So you tell them back at home with your research: we don't want any more of these vaccinations!!"⁴⁴

Others believed their child had food allergies or had been exposed to mercury and other harmful chemicals in processed foods, either consumed by the child directly or consumed by the mother while the child was in utero. Some parents believed that autism was caused or exacerbated by environmental poisoning through pollution, especially vehicle emissions and industrial waste. Some family members identified other psychological or associational triggers;

⁴³ Norma. Interviewed by Annie Tucker. Lovina. 15 September 2010.

⁴⁴ Heni. Interviewed by Annie Tucker. Tangerang. 1 February 2012.

one father, influenced by an article that subscribed to a psychoanalytic explanation for autism that is now considered outdated and widely unpopular, believed that his son's autism was the result of a lack of love and attention.

Many of these etiological theories were not mutually exclusive and many parents took into account an intersectional or multiple pathway model of causality. For example, one mother's narrative of her son's autism pointed to causal factors of a traumatic birth where he was born deprived of oxygen, her own illness with typhus while breastfeeding, marital friction between herself and her husband during her son's infancy which she believed impacted their child negatively emotionally at an early critical stage, and her son's allergic and immunological responses to various irritants, which she attempted to mitigate through restricted diet. Another father suggested that his son was autistic due to a combination of biological and karmic inheritance. His wife was prone to allergies, and he believes this contributed to his son's autism, he further supported the "leaky gut" theory of ASD in his son's case, but he also believed that an "inherited weakness" in his family line, the same one that led his younger brother to become a gambling addict, may have also contributed to autism, suggesting that his wife's biological vulnerability and his family's "character" vulnerability combined to contribute to his son's autism.⁴⁵⁴⁶

Belief in the supernatural world and black magic is quite vital in Java, and accordingly some I spoke with suggested that children could be possessed by spirits (B.I. *jinn*, *roh jahat*) that were either themselves mute or were preventing the children from speaking, or that their condition was the result of being struck by black magic. Some parents pursued courses of

⁴⁵ Alfred. Interviewed by Annie Tucker. Denpasar. 18 September 2010.

⁴⁶ For a similar "family inheritance" or karmic explanation for behavioral problems and/or mental illness, see the Lemelson 2010 film *Family Victim*.

treatment based on this idea, as I will describe below; yet others were miffed or peeved by such a proposal. As two mothers shared,

Because the public's understanding about autistic children is still lacking... there are stiiilll [sic] people who advise me to take my child to a "wise person" alias a *dukun*... but along the same lines as a parent I never get bored of explaining to all of them that autistic children have been created by God, and it's not work of evil people who have bothered my child (Ratih, 2012).⁴⁷

Where I am there are still autistic children that are thought to have been struck by black magic. The way of responding to them is then minimal because there's the idea that if it really has happened like that, there's nothing else that can be done (Mila, 2012).⁴⁸

Family Response and Coping Mechanisms

Upon first receiving the diagnosis for their child, many families are confused and upset. A common sentiment is succinctly captured by one mother, Ayu, who told me, "After we got the diagnosis of autism, at first we were shocked because we had had no idea what autism was or what causes it" (Ayu, 2012).⁴⁹ In this atmosphere of unfamiliarity, some parents may be blamed by other family or community members for their children's challenges, or be accused of not adequately teaching their children, or not raising them correctly. This can lead parents to experience feelings of shame, depression, and despair. Warno told me that certain parents in his situation might even think of how they could "get rid" of their autistic child.

If all I did was listen to what other people were saying, maybe I would have had—I could have had—terrible intentions. When he was little, it could have all been over in an instant. And I'd be free, right? We would go out to the middle of the road together, I would go back, and he would be in the middle of the street, and he would get hit. That would be possible. So that I wouldn't have to be ashamed.

But I didn't think like that. I have a principle that he is from God. Meaning that however, wherever, in any way possible, I have to educate this child. You could

⁴⁷Ratih. Online Facebook forum facilitated by Annie Tucker and Any Sonata Bagwanto. Opened 18 January 2012.

⁴⁸Mila. Online Facebook forum facilitated by Annie Tucker and Any Sonata Bagwanto. Opened 18 January 2012.

⁴⁹Ayu. Interviewed by Annie Tucker. Ciputat. 20 January 2012.

say, in this world, to solve the problem of this autistic child, it's easy. When he's three you just put him out on the Ring Road [a major thoroughfare in Yogyakarta], and it's done! There's no longer a crazy child in my house. We cross, I run behind, he gets hit, it's over. But then, what about my responsibility to God? (Warno, 2011).⁵⁰

One mother confessed that at times she had considered not harming her child, but killing herself. This same mother, who works tirelessly for the cause of autism awareness and has counseled hundreds of families and is kind to and encouraging of her autistic son, did not wish to celebrate or even be reminded of his nineteenth birthday. I was with her on that day; every well-meaning text or phone call that she received made her wince or sigh, bespeaking a deep wound that despite her pro-active and humanitarian response seemed to remain quite fresh. Another mother I interviewed in her home seemed to become increasingly upset while discussing her autistic son; she ultimately excused herself, saying she was ill, and never re-emerged from her bedroom. While it is possible she in fact was merely struck with a sudden flu, I felt guilty that the pain or negative emotions I had stirred up with my questions were overwhelming for her.

While I heard rumors that this shame or grief caused some families to neglect or ignore or even nutritionally deprive their autistic family members, there is no reason to assume that feeling embarrassed or ashamed because of social stigma accorded to disabled child means that the family members find their children in and of themselves shameful. Many expressed the desire to protect their child from being made to feel embarrassed, or becoming the target of negative attention. As one mother of a child with mild autism explained,

We keep the situation from all our family. There's nothing about shyness, or that we don't want to open it [*sic*], but we care about Peter and psychologists think that if everybody thinks he's a strange one... we don't want like that. We still want him to be normal, and we keep telling him that he's a normal kid (Nana, 2010).⁵¹

⁵⁰ Warno. Interviewed by Annie Tucker. Bantul. 20 October 2011.

⁵¹ Nana. Interviewed by Annie Tucker. Solo. 15 July 2010.

Various families employed different coping strategies depending on their personal preferences and resources as well as the needs and profiles of their particular children. A number of common responses involving “emotion work” (Wikan, 1990) on the self to adjust one’s mindset, outlook, and emotional and interpersonal response appeared to be deeply informed by normative beliefs about Javanese personhood and the shaping of that personhood within the guidance of the family system. Shaked and Bilu (2006) call such a pre-existing framework a “cultural toolkit” which can be called upon in responding to developmental difference. Indeed, many of the cultural values and expectations of personal development and interpersonal comportment previously delineated above became relevant in family responses to autism and coping strategies that they preferred or enacted. These responses emerged in interviews through the use of overdetermined terms, concepts, and practices, both explicitly referenced and implied. The aforementioned acceptance and submission (B.I. *menerima*, *pasrah*, B.J. *nrimo*), patience (B.I. *sabar*), and intimacy (B.I. *keakraban*), were all recurring themes in expressing strategies of coping used by Javanese families.

Every person I interviewed told me that the most important thing for parents to do was to accept their children: “the first thing is to accept the child” or “the most important thing is to accept the situation” was a universal refrain. This makes sense perhaps in any cultural context, and of course acceptance is the final step in the well-known Kubler-Ross “stages of grief,”⁵² the end of a mourning process that many parents who learn of their child’s autism diagnosis may go through after planning for or expecting a typically-developing child (Sinclair, 1993). However, in the Javanese context, *menerima* or *nrimo* is already a culturally laden term, a concept that is what psychological anthropologists would call “hypercognized,” or given a great deal of

⁵²These five stages are denial, anger, bargaining, depression, and acceptance (Kulber-Ross 1969).

emphasis in many areas of Javanese and Indonesian social and psychological experience (Lemelson, 2011). A fundamental aspect of *nrimo* is the assumption that a true understanding of the reason for the affliction, as well as any effect on its long-term outcome, will remain outside the individual or family's control, and that instead their condition is controlled by divine beings and the vagaries of fate and karma. With this worldview it is possible that current difficulties or suffering—from illness to financial challenges to interpersonal discord—is the result of misdeeds of long-deceased ancestors, the interference of local place spirits, or a test from God (Geertz, 1970; Lemelson, 2010). *Nrimo* or *pasrah* is therefore found to be a common response by family members of people with serious mental illness or other intractable health or developmental issues in Java (Lemelson, 2011; Ferzacca, 2001). As has been found in the case of mental illness, it seems that beliefs about acceptance can have meaningful implications for long-term outcomes. This acceptance is not always easy, however and neither is it straightforward; indeed, families debated what exactly is meant by “acceptance” of an autistic child and what the “right” kind of acceptance should entail, negotiated what kinds of actions and responses embody acceptance, and worried about how models of acceptance influence preferred treatments and responses to autistic children.

In addition to acceptance, *sabar*, or patience, was highlighted by all parents as a very important skill to call on and develop when interacting with their autistic child. Even with typically developing children, in order to avoid the dangerous emotions of shock, frustration, or disappointment in the growing baby as described above, the Javanese approach to child development may be fairly “self-guided,” in that practices such as weaning, toilet training, speaking, emotional control, etc. are expected to come when the child him- or herself is ready as

opposed to on a developmental “schedule.”⁵³ For this reason, even for typically developing children, Javanese parenting can be classified by patience and low affect, with minimal scolding or demands for compliance, and an emphasis on calm repetition (Geertz, 1967). Those parents I interviewed who had already raised typically developing children felt that having an autistic child required more patience (B.I. *kesabaran yang ekstra, kesabaran yang tinggi*) for various reasons: because their autistic child often had difficulties learning concepts and tasks, because they needed more monitoring or oversight, because they had to be frequently re-directed from doing things that were forbidden or unsafe, because they have difficulty expressing themselves, and because parents were constantly waiting for their child’s strengths, gifts, or capabilities to become evident and trying a variety of activities and approaches to elicit these. Some Javanese parents with autistic children believe that unflagging patience is key to their healthy development.

Similar to acceptance, it might be safe to assume that in any cultural context a majority of parents with autistic or other disabled children would report that patience would be highly relevant to their experience; but again as in the case of acceptance, *sabar* may be particularly salient to Javanese parents, as *sabar* can be considered a “core personal virtue” in Javanese, Indonesian, and broader Southeast Asian Malay cultures (Sutarto, 2007; Goddard, 2001). Furthermore, the meaning of *sabar* is more complex than its common English gloss of patience in a temporal sense; while also encompassing a temporal meaning, *sabar* involves additional emotional self-regulation and requires one to have the self-control to stay calm in the face of

⁵³ As has been noticed in other cultural and historical contexts (Nadesan, 2005; Grinker, 2007), those parents who are not used to frequent “expert surveillance” that comes from widespread access to public education and a utilization or faith in professionals such developmental psychologists may use other children or relatives as reference points for development rather than such schedules. So, outside of Euro-American context there may be a much broader range of “normalcy” and a different set of markers for abnormality such that parents might only their child’s speech delay when they pass the age their older siblings began speaking, as Woro described above.

suffering or affliction, so that an angry or grieving person will be frequently be counseled “patience,” and in this be encouraged not to lose heart. *Sabar* can thus also be interpreted as a core aspect of faith, in which difficulties will be rewarded or acknowledged by God in time (Goddard, 2001).

Acceptance and patience seem to work in concert, as sentiments and active emotion work that are as much directed towards the parent him- or her-self as towards the child. In many of these parent’s descriptions of their responses to autism, their reaction or approach highlights Javanese cultural norms, expectations, and ideals of comportment: remaining patient in any situation, being sensitive to and aware of the needs of others, and protecting the self and others from negative emotions or shocks. In some ways then, an autistic child seems to further elicit and shape a parent’s Javanese moral personhood. Another mother described,

My life has become way more focused, directed, and with the goal of doing only the best for others around me. [My son] has taught me the true meaning of the words “process,” “patience” (B.I. *sabar*) and “submission to God’s will” (B.I. *pasrah*) (Puspita, 2010).⁵⁴

These cultural values mean that in the context of interpersonal difficulty and in relationship with a developmentally delayed child, the focus of emotional work is inward. Accordingly, the desired change will be experienced in the self and not necessarily in the child; or rather, parents seemed to feel that by becoming more patient and accepting themselves, and not by imposing rules on the child or demanding that the autistic child change, ultimately an adaptive development would take shape both within themselves and within their autistic child.⁵⁵

⁵⁴ Puspita, Diyah. Interviewed by Annie Tucker. Jakarta 13 July 2010.

⁵⁵ This is quite different when compared to the responses of contemporary Californian-American mothers to a diagnosis of autism. As described in Lappe (2013), the experience of these mothers was colored by perceptions of risk and prevention. These mothers actively engaged in work on the self, but this work required active *anticipation* of future developments in order to plan timely or urgent early intervention, and a sense of vigilance in decision making via informed consumption practices and a *pre-emptive modulation* of the environment rather than a patient acceptance or receptivity. The overarching sentiment here was that time was constantly running out, and therefore the earlier and more intensive the response, the better.

In seeking such patience and submission, many Javanese parents derived strength, comfort, and sense of peace from their faith and spiritual beliefs. As mentioned in the previous chapter, as a key element of citizenship religion plays a significant role in the lives of most Indonesians, and both the Christian and Muslim religious faith practiced by the families I interviewed emphasize the equal sanctity of all human life, a framework that many parents from various cultural backgrounds and religious faiths are able to apply in the context of autism (Jeegatheesan et. al., 2010; Grinker, 2007; Shaked & Bilu, 2006). Many of the parents I spoke to emphasized that no matter their challenges, their children could still be considered a “blessing from God.” As one mother put it,

It turns out, that with all the products of the All Powerful, not one of them is a failure. It turns out that with whatever weaknesses or deficiencies, be they small or large, anyone can succeed. Meaning, no one is a failure” (Redno, 2011).⁵⁶

Others shared the belief that their children had been entrusted to them by God (B.I. *titipan dari Allah*) in order to help them grow spiritually, and that through their children they had been able to embody and practice values that made their lives more spiritually meaningful.

Having Peter in our family even teach us a lot. We are more patient, more knowledge-able, and also willingness (*sic*) to share with others. We don’t really think that he gives us problems, but I think God give Peter to us to help us, so we thank God for it (Nana, 2010).⁵⁷

Religious faith led some parents to believe that if they were patient, God would ultimately intervene to help their child’s condition improve, for example one mother proclaimed

If Allah has not yet deigned to grant our prayers and effort and the child still shows no change, sometimes as parents we lose all hope and are at a loss about what else can be done so that the child can be like other children, but my advice to parents of children in this situation, even if their chest feels tight, is “Be patient and steadfast in your efforts and ask God for guidance because that child is God’s

⁵⁶ Redno. Interview by Annie Tucker. Muga-Mugu, 14 October 2011.

⁵⁷ Nana. Interviewed by Annie Tucker. Solo, 15 July 2010.

creation, a blessing that has been entrusted to you by God and hopefully, at some point in the future, you will see the results (Dian, 2012).^{58 59}

Such an attitude, almost word for word, was also reportedly used by some doctors in counseling parents being faced with the diagnosis of autism for the first time (Various interviews, Field Notes, 2011-2012).

In this way, parents were able to call upon Javanese core values to both cope and find meaning in their children's difference by mobilizing cultural understandings of moral and spiritual personhood and striving to achieve these with their own behavior. However, while not denying the benefits of these coping mechanisms and the very real strength parents certainly derive from them, I do want to introduce the caveat that these coping mechanisms and emotion work described might represent an idealized version of autism response, or perhaps just one part of an ongoing and complex daily reality of living with an autistic child. While conducting my interviews, I frequently had the experience that parents were reticent to discuss the more difficult parts of raising an autistic child on record. Often it was only after I had formally ended the interview, thanked the participants, and turned the tape recorder off that parents or siblings would share with me the more difficult aspects of living with their autistic family member; the ongoing disruptions, occasional physical aggression, and exhaustion. Java is not a "confessional" society, and perhaps the area which is most protected is that of family life. Niels Mulder has explained that in Java

family members should *mendem jero*, meaning "to bury deeply" i.e. anything that might betray disharmony, aggressive feelings, or whatever else is felt to be

⁵⁸ Even as religion served as a source of strength and provided a framework of meaning for many families, it also acted as a source of concern in that parents were unsure how to ensure their children developed a religious identity, so important both for their spiritual and their civic development, religion being a key component to Indonesian citizenship. Common questions or concerns were how to teach the abstract concept of God, and whether it was right to circumcise autistic boys (Javanese Muslims hold a circumcision ceremony for boys in puberty) and if so, how to explain to them what was being done and why.

⁵⁹ Dian. Online Facebook forum facilitated by Annie Tucker and Any Sonata Bagwanto. Opened 18 January 2012.

negative about family life, especially in the relationship between parents and children. Conflicts should be kept concealed inside and are not for public display. [...] Insiders should observe *rukun*, that is, cultivate harmonious relations and practice the art of give-and-take, of compromise, while also spontaneously sacrificing ego drives (*pamrih*) in order to be able to enjoy the well-being (*slamet*) that ensues from harmonious relations (Mulder, 1983, p. 264).

Again, while both challenges and coping mechanisms will depend on the personality and profile of both the child and the family, in some cases it seemed that a child's behavior does overwhelm Javanese models of patience, understanding, and emotion work but there are few available frameworks to discuss this openly. Only one of the mothers I interviewed was willing to frankly lament on record, "The situation at home has become totally chaotic because every single member of the family is constantly busy screaming out "Don't! Don't!" to our special needs kid" (Kasih, 2012).⁶⁰ The perceived limits and challenges of Javanese models of childrearing, family life, and coping mechanisms in the context of autism will be discussed further in the following two chapters.

Autism, Intimacy, and Family Dynamics

The Javanese family as described in the ethnographic literature uses various child-rearing strategies that arguably train for interdependence and foster a sense of intimacy, both physically, through practices such as constant physical proximity via carrying and co-sleeping well beyond infancy, and emotionally, through the symbiotic identity of mother and child and the mutually supportive relationship of older and younger siblings. Some families I interviewed felt that their family member's autism has had a positive influence on the family as a whole, rendering even more clearly the Javanese values of intimacy, togetherness, and cooperation. One mother said

⁶⁰ Kasih. Interviewed by Annie Tucker. Tangerang, 1 February 2012.

Our family has really changed. Every member of the family has become more patient and caring. His older siblings have become more mature, and not spoiled even though before they were somewhat spoiled and egotistical (Eliana, 2012).⁶¹

An older brother of a sibling with autism said of his experience,

The benefit is that as a family we are more close-knit, we can be more unified, more solid. We understand each other, we get one another. So that part of it is not negatively affected by [my younger brother's developmental] disturbance (Jerry, 2011).⁶²

However, within the Javanese family unit it seems there are particular demands and dynamics of intimacy and closeness. One common theme that emerged in my in-depth interviews and observations (of which only four out of thirty involved a father's participation), is that the mother often takes the primary role in attending to a family's autistic child, while the father's primary role is to work to financially support the family. This appears to be based on economic and gender role distinctions; in middle and upper-middle class Javanese families the husband often has an official steady job while the mother stays at home. The mother is also seen as being inherently closer to her children, more patient and understanding.⁶³ One mother described her experience this way:

Usually, my child's father would just get angry all the time, because he couldn't understand an autistic child. And at the same time, his work was quite demanding. Of course, I admit the fact that my husband's work was not easy, it was hard, because he was stationed in the field. It was just that at that time, even I didn't yet fully understand what autism was. So for that to happen, it would require everything I had: meaning time, energy, thoughts, and of course finances.

⁶¹ Eliana. Interviewed by Annie Tucker. Pamulang, 31 January 2012.

⁶² Jerry. Interviewed by Annie Tucker. Wonocatur, 19 October 2011.

⁶³ This is a gendered family dynamic that was actively promoted by New Order policies and the Indonesian Family Welfare Network (PKK) delimiting the roles and duties of women as wives and mothers which has come to be known as "state ibuism" (*ibu* being the Indonesian word for mother or a respectful term for a woman of marriageable age). While the space and scope of my argument prevents too lengthy a discussion of "state ibuism" here, quite succinctly this policy exhorted women to assume their primary duties as faithful wives and dutiful mothers, in essence, as housewives (Blackburn, 2004). However, Javanese women have historically had freedom and fair amount of power as breadwinners working outside the home; this is a role many continue to play in families of lower socio-economic status (Brenner, 1995).

So finally I made a decision about that problem. I spoke with my husband, and we decided that I had to stop doing all of the activities that I enjoyed. From social activities to everything else, all my other duties. Ultimately, I just focused on our child. My husband was focused on his work, to find money to pay for all of this (Redno, 2011).⁶⁴

If, as described above, a Javanese mother's identity and attention is normatively invested in and focused on her child, the case of an autism, wherein the child often requires much more attention, may act as a lens that magnifies these normative expectations. This dynamic, in which the presence of an autistic child seems to require an amplified performance of traditional women's roles, can be found cross-culturally (for example, see Cumberland, 2008).

What may be more particular to the experience of autism in the Javanese family is the role of older siblings in their younger sibling's care (Ambarini, 2006). Ethnographers have highlighted sibling relationships as being of particular importance in Javanese families. Ward Keeler has described the practice of indulgence and assistance among older siblings on behalf of younger siblings as a key aspect of socializing Javanese values (Keeler, 1983, 1987). As described previously in this chapter, this indulgence plays an important role in strengthening the self and developing Javanese maturity. For the older sibling, it builds an understanding of the roles and responsibilities required in healthy hierarchical relationships; if the older sibling learns how to fear and obey the father figure, he also learns that beneficence and indulgence is the responsibility of those in more power and rehearses this symbiotic relationship with the little sibling. Meanwhile the younger sibling is ideally learning a debt of gratitude and modeling practices of interdependence. Young Javanese elder siblings are thus teachers in addition to caretakers and playmates (Farver & Wimbarti, 1995). Javanese sibling relationships tend to remain intimate into adulthood, with comparatively high levels of both material and emotional

⁶⁴ Redno. Interviewed by Annie Tucker. Muga-Mugu, 7 October 2011.

support (French, Rianarsi, Pidada, Nelwan & Buhrmester, 2001) and in the role of mental illness or developmental challenges, siblings may be expected to maintain high levels of involvement (Lemelson, 2010; Browne, 2001).

A number of the autistic children in my sample had an older sibling, and in some cases this sibling did play a significant care-taking role and was quite influential in their younger sibling's life. Take for example the two brothers Jerry and Bima, originally from Yogyakarta. Jerry is 21 years old, and now in his senior year of college in Yogyakarta. A number of years ago Jerry's parents relocated to Jakarta for his father's work. Unwilling to disrupt Bima's education at a special school for those on the autism spectrum, the family made the decision that Jerry would stay behind. Since then, Jerry has been caring for his brother alone in the house with the help of a servant; their mother comes home for one or two visits a month, and his uncle who lives locally also occasionally checks in on them. Jerry is used to taking care of Bima and he is an advocate, protector, and companion for his brother. In his discussions with me Jerry seemed to see his role as a sibling caretaker not just as a personal or family decision, but also as his part of his cultural identity, explaining,

Sometimes, my uncle doesn't act like he cares about my younger brother, so I don't respect him. Because I don't like that. He's individualistic, not like a real Indonesian, who cares and works together. So it's like he's from a different culture. So if I'm at home, if my mom and dad are not there, it's me. I'm the one who protects [my brother] (Jerry, 2010).⁶⁵

He feels like he plays an important role for Bima and he is prepared to keep playing this role and to take care of Bima for life.

Autistic people need someone by their side. Psychologically, they feel comfortable if there is someone they care about, who is close. Like me and my younger brother. Even though he can't speak, his behavior shows that he is definitely happy if he has my company. His feelings are comfortable and there's a sense of satisfaction....

⁶⁵ Jerry. Interviewed by Annie Tucker. Wonocatur, 19 October 2011.

Maybe in the future, if I graduate, my plans are to work and I will definitely keep working hard. Not just for my work but also to provide for my younger brother. Because in the future, if I don't do it who else will care for my younger brother? My parents will of course ultimately pass away. And automatically I will be responsible for my younger brother. And in my case, since high school, since I was little, I have accepted my younger brother so I don't feel a sense of burden (*ibid.*).

Other older siblings I met exhibited similar responsibility and care; there were even those who had chosen to pursue special education, a small but growing field in Indonesia, in order to learn how to interact better with their siblings and provide for others like them. Like many of the other culturally informed coping mechanisms addressed above, elder sibling care and indulgence was also a contentious issue in the autism community, because it was feared to exacerbate or create a sense of "learned helplessness" on the part of people with autism. This will be further discussed in the following chapter.

Treatment

Of course, an additional form of coping is seeking out treatment that will ameliorate troubling symptoms, promote adaptive maturation within the autistic person, and facilitate positive attitudes and relationships among family members. The Javanese families I interviewed exhibited a wide range of treatments and treatment-seeking behavior. Treatments sought fall into a number of general categories.

The first of these categories is prescription medications. A number of families reported that their child was currently using pharmacotherapy or had taken medication at one time. Some could not remember the name of the medication their child was taking or had taken, but those mentioned by name included Ritalin, and the anti-psychotics Risperdal and Abilify. There were mixed responses to these medications. While some families felt that medications helped their

children focus and behave, others had a number of negative responses to medications, the general theme of which was there was little productive change noted but there were side effects—one mother believed that the drugs her son was taking made him incontinent, while another mother felt that the medications sapped her child of her personality. Other parents were reluctant to continue a long course of prescription medications for their child for health reasons; one mother terminated her son’s medication after only a few weeks because she worried about the long-term effect the medicine would have on his kidneys and liver. She also felt like it was restrictive for the family to have to consistently follow the schedule of taking the medications throughout the day (Lia, 2012).⁶⁶ There are a variety of medications prescribed for ASD, the many side effects of which have been reported on in clinical trials; commonly reported side effects for Risperdone, prescribed to curb aggression, include weight gain and fatigue (Troost et al., 2005), while reported side effects of stimulants such as methylphenidate, prescribed to reduce hyperactivity, include depressed mood, anxiety, and excessive drowsiness (Handen, Johnson & Lubetsky, 2000).

Another course of treatment very popular in Indonesia is a restricted diet and biomedical treatment, which also often entails high doses of vitamins and supplements, as explained in the previous chapter. Many who were following some form of this diet endorsed it because of positive effects they saw in their children; some believed that since beginning biomedical treatment their children began to be able to speak, and others noted a decrease in hyperactivity and better sleeping regulation. However, other families who had tried a biomedical approach viewed restricted diets less positively. Some believed that it didn’t make a difference for their child, one mother observed that the more restricted the food she allowed her child to eat, the more sensitive he seemed to become to eating varied foods, and many found the diet difficult to

⁶⁶ Lia. Interviewed by Annie Tucker. Yogyakarta, 16 January 2012.

follow. This was in part because purchasing and preparing special foods was expensive and felt like a lot of work, but perhaps more importantly restricting food ran counter-intuitive to local beliefs about developmental health and eating habits, seemed to distance the child from the rest of the family, and for many it felt almost unbearable to deny their child the particular foods they enjoyed or desired. Like the debates over “acceptance,” and “intimacy,” debates about whether or not to follow a restricted diet was a particularly charged issue among families and educators, and will be discussed in greater detail in Chapter Five.

A third category of treatments is behavioral and physiological treatments, eclectic in themselves but unified in that they entail some form of training abroad or from those who have studied abroad. Many parents had tried ABA and other families had tried or were still using Floortime, Sonrise, and TEACCH methods. Many children were receiving or had received Sensory Integration therapy, occupational therapy, or speech therapy. While ABA seemed to be a poor cultural fit, to be addressed in Chapter Five, the main problem with all of these therapies is that for most Indonesian families they are prohibitively expensive and thus cannot be pursued for very long, in some cases for only a handful of meetings, not nearly long enough to have a significant or lasting effect.

Beyond the specific context of autism, various forms of traditional healing and alternative medicine are popular in Indonesia, and these can be grouped into a loose fourth category of treatment sought. Families utilized these “alternative” therapies in various combinations to varying degrees with autistic members. Some families pursued Chinese medicine for their children including reflexology, acupressure (B.I. *totok darah*), and acupuncture. Other families sought treatment amidst the landscape of Javanese folk healing. This included buying and drinking specially prepared herbal remedies and tonics known as *jamu*. Others took their

children to receive traditional Javanese massage, known as *pijat* or *urut*, or “*ngerokin*,” a Javanese folk practice of coining used for flu-like symptoms, intestinal discomfort, and mood disturbances. Some parents reported this had a calming effect on their children, with no negative effects reported. One family in my sample reported they had tried *bekam*, which is a form of cupping.

There are additional contemporary innovations or variations on traditional bodywork. One of these reported to me was “electricity” therapy; an alternative healer has electricity “in their hands” or transfers electricity via acupuncture needles into the body of the autistic child with a logic of stimulating the nerves. Another therapy, *balur*, combines traditional Javanese massage with processes of “detoxification,” purporting to integrate the best of contemporary “science” and Indonesian “tradition” by using Nano therapy to remove mercury, amalgamate heavy metals, and free radicals from the body through the skin. In a typical *balur* session the patient will have a number of substances massaged into their body and/or inserted as an enema including ground aspirin, coffee, vitamin C, and garlic paste. After this massage they lie on a copper table designed to help leech out toxins and have smoke blown on their bodies. After this treatment a dark liquid will then be washed off their body, proof of the toxic metals and chemicals that have been removed.⁶⁷ Some parents believed that this process was effective because they observed that their children’s behavior and speech improved after the sessions; other parents had a very negative reaction to the therapy, saying that their child was traumatized by the treatment process (Sinta, 2012).⁶⁸ An underlying logic that unifies many of these traditional and alternative therapies is the Javanese conception of health wherein the body is made up of channels (B.I. *aliran*)—of energy, temperature, humors, or bodily fluids—that must

⁶⁷ The same nanotechnology treatment is also purported to help prevent and cure cancer and AIDS (Field Notes 2011-2012).

⁶⁸ Sinta. Interviewed by Annie Tucker. Tangerang. 25 January, 2012.

flow freely or remain open in order to ensure health. Illness, then, may be caused by the blockage of such flows, and the buildup of “dirty” or “poisonous” detritus. Health may be restored by breaking down these blockages and re-opening these channels (Ferzacca, 2001). The release of gas, mucous, or other dirty fluids indicates that these channels are being flushed out and health may soon return. This indigenous philosophy of health may logically combine with a theory of autism that posits its etiology to be the buildup of mercury, heavy metals, chemicals, or other poisons inside the body that need to be removed.⁶⁹

Many families may also seek out the assistance of a traditional healer, known as a *dukun*, wise man (B.I. *orang pintar*) or *tabib*, who can diagnose and treat both physical and spiritual ills and promote well-being using their expertise in ritual and spiritual matters, including communicating with and channeling those deceased and other spirits. As with other interventions, families had varying success with these alternative healers. For example, Woro brought her daughter Dian to a *dukun* who said the young girl was possessed by a spirit who was holding her captive and preventing her development. He recommended a ritual wherein the possessing spirit would be transferred onto a goat, which could then be slaughtered. When that proved unsuccessful, Woro visited another *dukun* who proscribed a ritual sacrifice of a chicken. A third recommended that Dian sleep each night with her feet submerged in cold water. Woro was dissatisfied with these interventions because they were not efficacious, did not seem logical to her, and the last intervention made it even more difficult for her wakeful daughter to sleep at night (Woro, 2011). However, another mother, Redno brought her daughter Cindy to a traditional healer who told them that Cindy in fact had special powers of insight which needed to be fostered, which Redno did not seem to mind. She explained,

⁶⁹ A similar theory has also been applied in chelation therapy in the United States and Europe, which is a therapy designed to remove heavy metals from the body approved in certain circumstances but not approved for the treatment of autism (Davis et. al., 2013).

It turns out that according to a, what would you call it, an alternative healer or whatever, Cindy has a gift. Who knows whether that is for real or not, because at that time I didn't believe in it either. But something had been revealed to Cindy, like a sixth sense, that she has now had for these fifteen years. The way I look at it is, for her development it's really a positive thing... so for her sake I don't question it (Redno, 2011).⁷⁰

Still other families visited a *kyai* or *ustad*, respected elders within the Muslim community. The *kyai* may provide a number of services, from counseling the family spiritually, to providing generalized advice and support, to praying over a glass of water to be then drunk by the child or family member. As one parent explained it, this is not necessarily to seek immediate cure for the child per se, but rather to connect the family with a divine power who can provide them with guidance and strength, saying, "This activity just factors in our Supporter On High" (Devi, 2012).⁷¹ One family reported having held a *ruqyah* for their son. *Ruqyah* is a form of Indonesian Muslim faith healing by means of which people, usually those classified as mentally ill or suffering from spiritual disturbances, may be protected, strengthened, or even healed when family and friends gather to chant koranic verses.⁷²

In the child's early stages of development folk practices used to stimulate development may also be used, such as the practice of feeding a late talking child chopped up chicken anus mixed with porridge to stimulate speech, splashing cold water on the lower back to stimulate muscle tone and active movement, or changing the child's name with the logic that the one it has been given is unsuitable, making the child unhappy or ill (Sari, 2011).⁷³ Some parents also use their own strategies of giving child extra attention, trying to understanding the child, and intentionally treating the child as if it were just any other child with no differences or challenges.

⁷⁰ Redno. Interviewed by Annie Tucker. Muga-Mugu. 7 October 2011.

⁷¹ Ayu. Interviewed by Annie Tucker. Ciputat. 30 January 2012.

⁷² As described earlier in this chapter, prayer may also be believed to have a calming effect on people with autism who appear to be in an agitated state.

⁷³ Sari. Interviewed by Annie Tucker. Yogyakarta, 29 November 2011.

Many parents have tried a combination or succession of such treatments. As one mother told me with an air of fatigue,

I've already tried it all. I don't know what else I could do. I started when he was two years old. We have already tried all kinds of methods. He has joined ABA, sensory integration, then occupational, hydro, biomedical treatment, then reflexology, cranium, supplements, alternative... *everything* (Roro, 2010).⁷⁴

Parents are guided and influenced in deciding which or how many treatments to pursue by a number of factors; cost was frequently mentioned as significant, as parents often couldn't afford behavioral, sensory, or speech therapies, or if they could afford them they couldn't afford to pay for a full course of therapy. Influential figures in the field often convinced parents to try certain therapies, while perceived efficacy or inefficacy and child comfort or discomfort often led parents to continue or terminate certain treatments.⁷⁵

Education

As described in the previous chapter, in theory parents of autistic children in Java have a variety of choices for schooling—regular schools, inclusion schools, public special education schools, and private schools—but the realities of the situation are complicated. Both treatment and education were challenging for many Javanese families due to a combination of the scarcity of available facilities, local prejudices, their own personal preferences in what they were looking for in schooling and therapies for their children, and the vagaries of life.

Judging from my sample, it is not uncommon for parents and children to try out a range of schools before one “clicks.” While a local public school might be the first option, many parents reported that in public school their child was ostracized; one remembered it was because

⁷⁴ Roro. Interviewed by Annie Tucker. Bogor, 15 July 2010.

⁷⁵ One problem in such pluralism in therapies, both in Indonesia and elsewhere, is that advocates of various programs rarely offer criteria to families that might help them decide which therapies to do first, how long to participate in them, and so forth (Thomas Weisner, personal communication.)

her child's peers and their parents feared that autism was contagious (Roro, 2010).⁷⁶ Some parents who can afford to may hire a private "shadow," therapeutic companion, or a one-on-one instructor to accompany the child in a mainstream classroom protecting the child from such potentialities and providing the child with necessary supports so that they might continue to access a mainstream academic curriculum and social environment. Others may choose to move their child to a private school. One mother reported,

At this time we have chosen a special school for special needs children because our son Mahfud is not yet able to join a public school like other normal children. And it's certain that if Mahfud was put in a public school he would just become a mockery and an entertainment for his peers, because they think that Mahfud is a kid who acts really strange (Ayu, 2012).⁷⁷

Another mother said she chose a special school for her child because "he is not yet able to follow the kinds of lessons at an inclusion or public school, and he really needs special and intensive treatment from an expert" (Eliana, 2012).⁷⁸ For similar reasons, other parents choose home schooling programs tailored to their children's needs and capabilities.

Logistical problems in procuring education emerged as a significant theme in many parents' experience; many mothers and children endured long commutes, and some even lived apart from the rest of their family, or lived in between two different cities in order to meet their child's needs for therapy and education. Other challenges emerged when husbands were relocated for work. As mentioned above, due to gendered socio-economic norms, upper middle class women are often the full-time caretakers of their autistic children and financially dependent on their husbands, who if they are working in business or government may be re-stationed or

⁷⁶ Roro. Interviewed by Annie Tucker. Bogor, 15 July 2010.

⁷⁷ Ayu. Interviewed by Annie Tucker. Ciputat. 30 January 2012.

⁷⁸ Eliana. Interviewed by Annie Tucker. Pamulang, 31 January 2012.

appointed to a position in a new city. Here is one story to illustrate what may be a quite common situation.

Redno and her husband are originally from Yogyakarta. Redno's husband works for Pertamina, a state-owned oil and natural gas corporation conducting extraction operations across the archipelago. When Redno first suspected that her toddler daughter was autistic, her husband was stationed in the field and the family was living in a remote area of Kalimantan, where drilling was taking place. She took their daughter to Jakarta for testing to confirm her suspicions. When her husband had the opportunity to take a position back on Java the family jumped at the chance, in the hopes that they would be able to get better education and services for their daughter. However, these services were only available in Jakarta and they were stationed in Cirebon, a port city on the north coast of Java about 200 miles away from Jakarta. Wanting to do the best for her daughter but also wanting to be able to be there for her two sons, who were older than Cindy but still young (in fourth and fifth grades), Redno spent seven years moving back and forth between Jakarta, where she and Cindy lived with relatives and pursued therapy, and Cirebon, where her husband and sons were, spending one week at a time in each location. Redno says this was incredibly hard on her, especially in circumstances where she felt her sons needed her—she described one particularly harrowing occasion where her eldest was gravely ill with typhus and she had to rush back to Cirebon. But if she wanted to provide the best she could for Cindy, she felt she had no other options.

After these seven years her husband was reassigned again, this time to Palembang, in South Sumatra. At this juncture, the rest of the family chose to relocate to Yogyakarta, where Redno was born, to be closer to her family. Cindy first tried a local public school with private class for autistic children in the morning, and attended a special school for autistic students in the afternoon. However Redno felt that teachers didn't truly accept her child and had some altercations with parents of other students. After an incident where Cindy was physically harmed by another student, they withdrew and switched over to full time autistic school. Cindy graduated middle school with good academic marks, and Redno sought a school where her daughter could be pushed and develop to her utmost capacity. At an autism seminar she met a supportive and enthusiastic principal from an inclusion public school in Semarang, (about a six hours' drive to the North of Yogyakarta), and decided to enroll Cindy there. She and Cindy now spend their weekends in Yogyakarta with her husband and sons and their weekdays in Semarang, where they rent a house with another mother from Yogyakarta, who is doing the same to support the education and growth of her own son.⁷⁹

⁷⁹ Redno. Interviewed by Annie Tucker. Muga-Mugu. 7 October 2011. Paraphrased here.

Redno was not alone in sustaining what seems like an unsustainable commute routine; Woro, who was also originally from Yogyakarta and whose husband also works for the government and was for a number of years stationed in rural Sumatra, regularly took a fifteen hour bus trip with her daughter Dian home to Java from Sumatra for therapy. She said she chose this overnight ride rather than a much shorter flight in part for financial reasons, but primarily because her daughter could not bear the long waits in the airport and would frequently become unmanageably upset, whereas she could tolerate sitting in the bus for long stretches, as long as the bus itself was moving. Woro described, “The whole process took a whole day and my legs were stiff, but I just couldn’t stand those two hours waiting in the airport” (Woro, 2011).⁸⁰

Difficult on typically developing children (and adults), relocation and disruptions in familiar patterns may be particularly distressing for those with autism--a deep investment in sameness is one significant aspect of the condition. More often than not, such relocation meant stumbles and drawbacks in their child’s progress. Another mother, whose husband also works for the government, told me her story.

Ningsih, originally from Yogyakarta, was living in Jakarta with her husband, originally from East Java, when her first child, Pando, was diagnosed with autism and started receiving treatment. Then, when Pando was three, Ningsih’s husband was relocated to Semarang, a city on the Northern coast of Java, and his family joined him. This was a difficult situation for everyone; Semarang was hot and boring, Ningsih didn’t know anyone, and there were few activities for a young child. Ningsih’s own asthma acted up, and Pando was often sick. She felt that in these stressful conditions her son regressed. So when her husband was re-stationed again, this time being offered a position in Magelang, a smaller city in the mountains, the family jumped at the opportunity to move.

There was one school for autistic children in Magelang, but it was already at capacity, so at first Ningsih had to put Pando on the waiting list and make do at home. Then, a slot opened up in the afternoon but it was during Pando’s usual naptime. They enrolled him anyway, but it disturbed his (and hence everyone else’s) sleep, as he would fall asleep after he came home from school, sleep from about 5 in the afternoon until 7 in the evening, and then be unable to fall asleep

⁸⁰ Woro. Interviewed by Annie Tucker. Bantul. 13 October 2011.

again until two or three in the morning. The family was finally able to switch Pando to morning hours at school. Once Pando settled into his morning routine, Ningsih noticed a great deal of improvement; he began to speak and mastered toilet training. After a year and a half at the school, he began to communicate spontaneously, using one or two words to indicate what he wanted or what he was thinking about, and developed a love for the computer.

Things were going well until 2006, when there was a large earthquake in Yogyakarta, about one hour away. Ningsih's husband was relocated once again to help with the rehabilitation efforts. The family at first stayed behind in Magelang, but Pando was distressed; he frequently cried and asked for his father, so the family decided to once again relocate. They settled in Yogyakarta, close to Ningsih's family, and were able to enroll Pando in a special school for autistic students, but the transition was difficult for Pando. Ningsih remembers, "It was a new atmosphere and everything new took him back to square one. So once again he was confused, angry. When we would get school reports they would say he didn't want to coordinate with the teachers, he still wanted to be alone, didn't want to be with his peers."

Since this last move about five years ago the family has not had to further uproot their lives, and Ningsih believes that this continuity has been good for her son. After working with the same teachers in a familiar environment and getting to know his peers, "Up until this point, praise God, it's still good. In our eyes, Pando has advanced a lot. Even though maybe he can't write yet, in his book it's still just scribbles and his pictures don't match, the teacher draws a star and he draws a circle, he doesn't know... but he can sit nicely and follow the teacher's instructions. For me, that's progress" (Ningsih, 2011).⁸¹

From these and other similar personal histories it seemed to me that a cluster of factors were uniting to make stable and effective education difficult for Javanese families; in particular a lack of evenly distributed resources in place to support autistic children, combined with a lack of familiarity with autism and a lack of legal enforcement which meant that local schools could choose to be inhospitable to children with autism, made finding a nearby school quite challenging. Limited options became even more trying when factoring the particular needs of autistic schoolchildren. Parents often stressed themselves and the entire family unit by moving or travelling long distances in order to obtain education or therapy for their children, but the

⁸¹ Ningsih. Interviewed by Annie Tucker. Yogyakarta, 15 October 2011.

purported gains from these services may well be outweighed in certain circumstances due to the stresses of specifically these kinds of stressors and disruptions.

Community Response

Parents I spoke to overwhelmingly felt like the general public has not accepted and still does not accept their children. Many believe that people have negative perceptions about those with autism and developmental disabilities and many base this belief on negative reactions to their children that they have encountered out in the world. Parents may frequently become nervous or uncomfortable in public because their child's behavior is at times unpredictable and they fear they may be blamed for their child's behavior or accused of not educating their child correctly.

Ningsih described an incident at a public playground where, while playing, her son accidentally scratched a young girl of about his age. The girl's parents were upset, refused to accept her explanation that Pando was autistic and had probably not hurt their child on purpose, and demanded an official apology and acknowledgement of guilt. Ningsih gave in because she felt she had no choice, but years later the event still stung as she recounted, "It truly hurt me to say that my child was naughty (B.I. *nakal*). He wasn't being naughty!!" (Ningsih, 2011).⁸²

One of the most humiliating things that can happen to a Javanese parent is to be accused of not teaching one's child properly; insults to the family can be more stinging than insults to an individual and a reprimand of an individual is seen as a reproach to the whole family, a reflection of the "environment" the child was raised in (Lemelson, 2010). As one mother, Yogi, described her experience,

⁸² Ningsih. Interviewed by Annie Tucker. Yogyakarta, 15 October 2011.

I am always apologizing if we're in a public area because sometimes my child's behavior bothers other people's comfort and I really have to be tolerant if people get mad. This is the *haaaaarddest* part... this makes me want to cry, if only they knew that I have already taught my child and educated him every day, and it's not that my child has not been raised right. But on the other hand if I meet someone who understands, I feel like everyone on earth is *reaaaally* nice (Yogi, 2012).⁸³

In response to such upsetting situations, parents may feel frequently on edge, internalize feelings of stigma, or restrict their activities as a family. One mother explained,

At home or outside the home we have a special child, who must constantly be extra-protected. So our life could be considered not normal like other families, who can freely go wherever they want without being extra-cautious of their children to protect them from hurting themselves or other people (Sinta, 2012).⁸⁴

While feelings of stigma still remain part of the reality of having an autistic child in Indonesia, many families are able to enjoy their children and counteract these experiences by focusing on the pleasures of being together as a family. Mahfud, an autistic eleven-year-old boy, loves to swim, play ball, and jam on the drums with his Dad. His mother told me, "It is especially pleasing when Mahfud interacts with his older sister, his dad, and me. Sometimes he can joke around with the family and we all laugh together" (Devi, 2012).⁸⁵ Another mother said,

The happiest times are when he hugs us and kisses us and looks at us for a long time, when he calls for us and his older brother, when he jokes and laughs out loud, when he rides his bike, when he swims with his own special style, when we can take him to eat with us in a restaurant and go shopping as a family, and etcetera and etcetera and etcetera! (Eliana, 2012).⁸⁶

During my home visits and observations I myself spent many happy moments with families and their children, talking about favorite soccer teams and bands, singing together, admiring and creating drawings and paintings, playing ball or other games, or simply sitting and watching DVD's together.

⁸³Yogi. Online Facebook forum facilitated by Annie Tucker and Any Sonata Bagwanto. Opened 18 January 2012.

⁸⁴Sinta. Interviewed by Annie Tucker. Tangerang. 25 January 2012.

⁸⁵Ayu. Interviewed by Annie Tucker. Ciputat. 30 January 2012.

⁸⁶Eliana. Interviewed by Annie Tucker. Pamulang, 31 January 2012.

Many families seek out the company of other families with autistic, disabled, or special needs children in order to avoid feelings of judgment and stigma and be able to freely share these many pleasures that they do experience; I will further discuss these new communities in the following chapter. Other families have come up with unique strategies to integrate their children and support positive interaction with the community. One family created an art studio in their home and offered classes to neighborhood children so that their twelve year-old son Fajar could be with children his own age.

So that he could get together with normal kids we started a dance and painting studio in our home, so that our house would always be lively and he could hang out while working and we could still keep an eye on him. It's because of him that we had the initiative to open the studio for the children, to provide a place where Fajar could just generally socialize with the other kids, but it built our self-confidence, it made us more active and full of initiative. [Since then] our lives have become more colorful, we're very grateful, and it has brought us closer to God (Eliana, 2012).⁸⁷

Here the family created something of value to draw the community in that allowed Fajar to be safely included and ended up being a positive experience not just for the family but also for the neighborhood kids.

Meanwhile on the other end of the spectrum one parent, Heni, living in a rougher neighborhood in the Tangerang region of Jakarta, was happy that her seventeen-year-old son Haryo was not involved with their neighborhood teens because it helped keep him out of trouble. She said,

It's pleasing to me because he's not influenced by a social environment that's not great, like defying parents, hanging out with bad kids. He's not influenced by the world of globalization (Heni, 2012).⁸⁸

⁸⁷ Eliana. Interviewed by Annie Tucker. Pamulang, 31 January 2012.

⁸⁸ Heni. Interviewed by Annie Tucker. Tangerang. 1 February 2012.

Hopes and Fears for the Future

Because autism is a spectrum disorder and despite unifying criteria each child will be quite different in terms of profile and ability, not to mention the range of ages of their children, each family I interviewed had their own set of short-term goals that they were working on with their child from self-care skills, to communication skills, to academic skills. Similarly, long-term hopes for their children varied from parent to parent, although with the youngest child in my sample barely out of toddlerhood and the oldest person in my sample nearing his twenties, most parents did still have some hope for improvement or recovery over the course of their child's development. Some optimistic parents hoped that ultimately their children would lead "normal lives." As Ayu, mother of a twelve-year-old son who was as yet non-verbal said, "My biggest hope is that I hope Mahfud can live independently, live normally, socialize with his community and have a family in the future. Pretty much just like other people" (Ayu, 2012).⁸⁹ In working towards as "normal" a life as possible, some parents were actively preparing their children for work. A select few had even been successful in securing internships for their children, a rare and coveted experience in Indonesia where unemployment remains high and many typically-developing teens and young people are at a loss to find jobs or job training.⁹⁰

Still others hoped that their teens might meet their "*jodoh*," the Indonesian word for soul mate or destined match. For example, Cindy is a bright and beautiful sixteen-year-old and her mother Redno hoped that she would find a husband who would truly love her for who she is, not out of pity, and who could become her lifelong companion. Other families are more modest in their expectations—they hope their children will ultimately be able to take care of themselves

⁸⁹ Ayu. Interviewed by Annie Tucker. Ciputat. 30 January 2012.

⁹⁰ Indonesia actually has a work quota wherein companies are obliged by law to provide job opportunities for people with disabilities. Technically, if 1% of employees are not disabled, companies can face fines, but this is rarely enforced (Krishanti, 2012).

within the home on a daily basis, find something that they are good at and that they enjoy.

Ultimately, most hoped that their child would be independent (B.I. *mandiri*) with almost every family stating this as their most important long-term goal. Alongside the hopes for a child who is as independent as possible, many parents were prepared to financially and otherwise support their child for their life course. As one mother said,

In my case, the family will definitely protect her, make a safety net for her. For example, we'll give her money... because in Indonesia we can't rely on the government, so our family will take care of her (Intan, 2010).⁹¹

Of course, as parents were encouraged and guided by their hopes for their children, so were they plagued by a number of fears. Some fear that there will be no change in their child's condition, particularly that they might never learn to verbally communicate or take care of themselves. Parents of non-verbal children worried that they were unable to communicate the pain or duress they might be experiencing. Many were afraid that others might harm or abuse their child, and their child would be unable to defend him- or her-self or tell their parents.

Warno had remarried, only to discover that his new wife was physically abusing his autistic son, and so he ended that marriage. If the possibility for such treatment exists within the extended family unit, it seemed even more possible in contexts where extended families must share care, send children to a private school sometimes even in a different city or in a different province to obtain therapy or education that is locally unavailable, and entrust their children to others for treatment in a world where certain techniques or approaches might seem foreign and confusing.

During my 2011-2012 fieldwork stay there was an ongoing case, frequently talked about in the autism community, of a young autistic boy who had been abducted. I heard a number of versions of Ilham's story, which I have condensed here.

⁹¹ Intan Interviewed by Annie Tucker. Bogor, 15 July 2010.

Ilham was born into a middle-class family in the Wirobrajan neighborhood of Yogyakarta. His parents were both slightly overwhelmed by his condition, but willing to try anything that might help him. They hired a married couple, who seemingly had a pre-existing practice south of the city, to help take care of their son. First the husband and his wife cared for Ilham in his home, but then they suggested to Ilham's parents that they take him to Jakarta to undergo a battery of tests to better understand his condition. They also said he would be able to receive more sophisticated treatment in Jakarta than what was available in Yogya. The family agreed, giving the therapists a large sum of money to pay for the trip and medical visits. At first they were sent results of brain scans, EEG's and MRI's, purportedly belonging to Ilham, with the therapists themselves providing an explanation of results. After each of these tests the therapists would ask the parents for more money, saying they needed to conduct additional tests. They did not allow the parents to speak directly with their son. After a number of weeks of this, Ilham's mother became suspicious, stopped sending money, and tried to contact the man to demand he return her son, but at this point he had deactivated his cell phone and vanished along with Ilham.

After six months, a police investigation had gleaned nothing. Meanwhile the autism community mobilized to help find Ilham or the people who had taken him; amateur investigation revealed the fact that the husband in the team was not in fact a therapist and had a past history of theft. By February of 2012 Ilham had been missing for almost a year, and some feared that he had been murdered and his organs stolen (rumors about children, getting stolen for their organs are somewhat common in Indonesia at this time).

At the time of this writing, why exactly Ilham was taken, his present whereabouts, and his fate remain unclear. However this case is a sobering tale for parents who might entrust their autistic children to the care of others, especially in distant cities. Parents are forced to make difficult choices as they weigh the desire to help their children with such worst-case scenario fears.

Even if their children stay within their care, some parents remained worried that their children will be receiving fraudulent therapy or that they might go missing. The parents of adolescents I interviewed often had terrifying experiences where they temporarily lost their children; for example one then-nonverbal child boarded public transportation when she was eight years old and was noticed by a well-meaning stranger who took her to a police station in a distant neighborhood, and was ultimately reunited with her family because she had memorized her

address that she was able to type on the station computer. Missing signs featuring developmentally disabled family members, posted on telephone poles or in public squares, are not an uncommon sight in Yogyakarta. Some solutions that local families and schools have developed are shirts that read, “I’m autistic, handle with love,” in an awareness-cum-protective measure. Other parents, in considering their options, wondered about the ethics of tattooing a non-verbal autistic person’s identifying information and home address on their wrist. Because there is little legal recognition of autism, family members worry that their sibling or child, without the protection or mediation, could be held criminally responsible for doing something they don’t understand is wrong, including taking things that don’t belong to them or inappropriately touching others. If the family member is present, most problems can be immediately remediated. As Jerry explained,

Whenever I meet someone new, I explain that [my younger brother] is autistic, so that he can quickly be understood and there isn’t any--how should I say--so that nobody gets the wrong idea or something like that. Sometimes if Bima is out, he’ll take something from someone’s house, or from a food stall or a store. [I explain], “My younger brother is autistic,” so that it’s clear, so that people know (Jerry, 2011).⁹²

However, if the autistic person is out on their own, family members worry about imprisonment or immediate “vigilante” justice, which does occasionally happen to those with mental illness or other not immediately visible developmental disturbances (Lemelson, 2010).

A final fear that some parents have is that a sense of sibling responsibility and family intimacy will not bear out, or their siblings will marry someone who doesn’t want the responsibility of caring for a disabled family member. Citing a common worry about her son, one mother told me, “I am afraid he will become a burden to his siblings. Can they take care of Taufik with a sincere dedication and a fullness of affection? And will their husbands be willing

⁹² Jerry. Interviewed by Annie Tucker. Wonocatur, 19 October 2011.

to accept Taufik?”(Kasih, 2012).⁹³ The ultimate fear is that if parents are elderly or have passed on and siblings are unavailable, there will be no one to care for their child. Another mother (Andi, 2012) of a child with no siblings asked plaintively, “When we, his parents, are already old, who will take care of him, with the fullness of care and patience?”⁹⁴ Some parents have begun to seek allies in their community who might agree to share care if loved ones have passed or family members cannot take care of their child; a few have looked into religious orphanages and Islamic boarding schools (B.I. *panti asuhan*, *pesantren*) to see whether they would take an adult with autism in such a situation.

Conclusion

Based upon my interviews with Javanese parents of children with autism, some experiences and concerns could be considered universal, such as many of the symptoms noticed, social stigma and the difficulties encountered in explaining autistic difference and integrating an autistic child into mainstream surrounding environment, and the personal challenges of reaching a point of acceptance, practicing ongoing patience, and discovering approaches for teaching, communicating with, and enjoying a child with autism. Other concerns that emerged are mainly due to a lack of resources—such as a pervasive lack of information about what autism is and how to treat it and limited access to schooling and therapy centers.

Finally, some aspects of autism response within the Javanese family are culturally quite specific. A panoply of “traditional” and “alternative” treatments available in the vibrant health care landscape in Java are often applied in the context of autism, to mixed effect. A Javanese family structure that emphasizes sibling intimacy, and in particular the role of elder siblings in

⁹³ Kasih. Interviewed by Annie Tucker. South Tangerang, 1 February 2012.

⁹⁴ Andi. Interviewed by Annie Tucker. Depok. 28 January 2012.

caring for their younger siblings throughout the life course, can provide a safety net that benefits autistic Indonesians, although families worry whether such relationships will bear out under the stress of disability. Meanwhile cultural models of comportment, interpersonal interactions, and “emotion work” affect reactions to autistic family members, in particular mobilizing concepts and sentiments of submission, acceptance, and patience, which provide access to spiritual encouragement and contextualize the experience of having an autistic child within the ongoing work required to develop a Javanese moral personhood and within a framework of religious faith and (sometimes obscure) divine intention. As indicated above, many of these Javanese models of response are subject to debate within the world of autism awareness and intervention, calling into question their efficacy or appropriateness both in the case of autism or developmental delay and simultaneously subjecting the Javanese family itself to a broader critique. It is these latter findings in particular that I will focus on as I move forward in the next two chapters.

As a final note, in discussing autism in “the Javanese family,” it is important to acknowledge how much the family has changed over the past forty years, and in many cases this cultural bedrock, while enduring, has been modulated and shifted both by decades of purposeful New Order interventions into the family and the effects of globalization. In some families, these changes have led to changes in expectation for personal comportment and child development. For example, increasingly smaller family size means a greater focus can be placed on each individual child within the family. Widespread access to early and public education means children are increasingly subject to expert scrutiny and their development increasingly measured by developmental benchmarks and schedules, increasing opportunities for developmental difference to be noticed and interpreted in particular ways. Furthermore, models of self-hood required for success in new socio-economic environments mean parents might hope for different

qualities in their children or value different attitudes in themselves. The following three chapters, while revisiting some of the culturally-specific coping strategies and illustrating how they become points of contention in the world of autism response, interpretation, and intervention will also specifically address how these changes, and the debates and anxieties they provoke, are enacted through autism intervention and interpreted through understandings of autistic and developmental difference.

Chapter Four

Performing, Teaching, and Learning New Cultures of Autism

As mentioned in the previous chapter, for many Javanese and Indonesians, autism as a concept is a very new idea. Partly because there is very little in the ways of an established local concept of autism (although there are other local concepts of developmental difference), and partly because the idea of using specific and specialized intervention targeting people with autism and developmental disabilities is comparatively new, the experience of parenting an autistic child at times can seem overwhelming, exhausting, isolating, and even perilous. As one mother, Nefrijanti Sutikno, described her situation in a forum on Facebook,

The biggest problem for me... is... I don't know what has happened to my child... starting from how I can help him... what I will have to face in order to bring him "out" of this situation and what I will find at the end of my entire journey with my child. To put it briefly... everything about children with special needs... is still in the "dark"... in the world of education ... the medical world and even the social world...

People that I meet... can't help me very much... because they themselves don't have any clear outlines... about kids with special needs... I have to try on my own... pummeled from the left and right... accepting the risks of blame and failure... (Nefrijanti, 2011).⁹⁵

Here Nefrijanti's ellipses evoke and perform her feelings of caution and confusion. In this perceived "darkness," where so much is at stake, there is clearly a desire and a need for guidance from trustworthy mentors and others who have successfully navigated a similar situation. People with special needs children, and those who either suspect their child might be autistic or have had their child officially diagnosed, have a lot of questions that span a wide range of issues and

⁹⁵Nefrijanti. Online Facebook forum facilitated by Annie Tucker and Any Sonata Bagwanto. Opened 18 January 2012.

concerns, ranging from prevention, to the definition and recognition of autism, to generalized intervention strategies to particular case-specific challenges.

Those active in the autism awareness and education field are able to answer many of these questions, and they strive to do so through live events such as talk shows, workshops, and seminars, on the internet via Facebook and Yahoo groups and blogs, and in print via self-published and self-distributed newsletters and instructive memoirs published by major presses and available at events and in popular bookstores. But they face a complex task. Much of information these would-be interventionists have about the signs and symptoms of autism as well as best practices in autism treatment were gained abroad in Australia, Singapore, the United States, or the Netherlands, or from specialists trained in these countries. This information lends a particular perspective on child-rearing methods and goals, socialization and behavior, and etc., that might be different from, or perhaps even at odds with, the various local models with which the parents they are aiming to help feel more familiar or more comfortable. Therefore a common mission these awareness efforts share is not only to problem solve, direct parents to resources, or educate them about autism as a neurodevelopmental disorder, but also to guide parents in their interpretation of their children and their children's behavior, provide them with the vocabulary and concepts that those experienced in the field feel are necessary for parents and teachers to understand for autism treatment and intervention, and encourage parents to reshape their own beliefs, attitudes, behaviors, and family practices in order to produce autistic adults who might be successfully independent and included members of society.

I want to suggest that the work being done under these auspices can be considered cultural work, and propose that in a sense those active in the nascent autism field are inducting parents into a new disability culture. While definitions of culture more broadly and disability

culture specifically have been proposed and opposed,⁹⁶ when I suggest that there is a new disability culture emerging around autism awareness in Indonesia, I am referring to some of the significant aspects of the culture concept that have been shared by many of the definitions put forth, incorporating aspects of culture as historical, linguistic, social, political, and aesthetic (Peters, 2000): this includes a common language or vocabulary; specialized knowledge, beliefs, and customs; a historical lineage that can be traced textually or through a body of oral narratives or performances; evidence of a cohesive social community and rituals and events where people come together as a group; shared values, norms, and worldview; the development of group solidarity, identity, and pride; and engagement in public symbolic action, all of which I believe are operant to a certain extent in this culture I will begin to trace and elaborate on in this chapter.

The formation of such a disability culture often involves concurrent processes of enculturation, or acquiring new norms of this culture, and acculturation, or adapting behaviors or traits from another culture different from one's own original culture (Rogers-Adkinson et al., 2003). Based on his fieldwork with Australian Aboriginal populations, Ariotti (1999) has argued that local "disability culture" is often shaped by processes of intercultural contact, and societies or cultures may follow a similar trajectory in coming to adopt or apply it. In the first phase of this process, those with impairments or differences are taken as individuals, perhaps being labeled in certain ways, perhaps playing meaningful roles in their communities or being subject to exclusion and stigma, but on a case-by-case basis without a conceptual connection to others with impairments. In the second phase, categories of disability or developmental difference are introduced by outside forces. These new categories draw certain groups of people together as

⁹⁶ This idea of a culture of disability, and the use of the phrase "disability culture" was already quite prevalent in the United States and Europe by the mid-1990's; as such it was already being debated, both with respect to disciplinary definitions of culture and with respect to whether what was being called disability culture could even be considered as such, or whether it was not better understood as a subculture, counterculture, or just a growing consciousness (Peters, 2000; Barnartt, 1996).

sweeping change enables new configurations and conceptualizations of people with various impairments or differences. These changes are cognitive, wherein societies develop new words and concepts to address people with disabilities or developmental difference, and behavioral and social, where people learn to internalize and apply these new conceptual categories in order to build coalitions, advocate for or create new methods and institutions of service, inclusion, and support. Further scholarship conducted in various immigrant populations in the United States has outlined some of the potential difficulties encountered in processes of being enculturated into disability culture: families may feel pushed to reject the traditions or values of their own culture as they explore appropriate services for their child, or may have to navigate changes in language preference and use, role identification and behavior, and even foodways (Rogers-Adkinson et al., 2003; Jegatheesan et al., 2010). While this sweeping change may not come without some pain as people experiment with new labels and work to avail themselves of services without internalizing new stigmas, in Ariotti's model these changes can ultimately lead to empowerment and an incorporation of those positive aspects of disability culture, such as a worldview where people with disabilities are better honored and included in aspects of community life. Local groups can then work to develop indigenous labels and models of inclusion that preserve these positives while establishing culturally preferred methods of thinking about disability and difference.

The following three chapters will illustrate some of these processes of enculturation, acculturation, and change as they occur within the Indonesian context. I will first show how this new culture being shaped in Indonesia at workshops and other autism events is synchronized in part with globalized disability culture and as such offers positive and supportive alternatives to parents in helping them think through and respond to their children's difference; in other words, I

will argue that the new globalized culture of autism confers some very real benefits to Javanese and Indonesian families. However, I will also draw attention to the opportunity for careful choices to be made, and illustrate some of the complications that arise and tensions that emerge in this process as participants in this new culture take up and disseminate a vision of childrearing goals and practices and family structure and behavior that is heavily influenced by values culled from sources extending beyond the locally-specific.

While exploring the benefits and challenges of autism education, awareness, and culture, I will also pay particular attention to how this culture is being spread through performance, as I have defined in my introduction to refer to constructions of autism via strategies of representation. In these chapters the performances I am referring to come in a number of formats including live performances such as dance, music, monologue, informal re-enactments, personal narratives, as well as performances in other genres such as video sharing and written memoirs. These performances are often either explicitly or implicitly didactic, in that they are hoping to teach particular lessons to their intended audience, which include parents, teachers, and others unfamiliar with autism, and seek to ultimately influence their beliefs and behaviors.

It can be argued that these performances are performative. Disability studies scholars have theorized various forms of autism and disability as performative, and thought through the connections between disability and performance, from issues of heightened visibility and the dynamics of gaze such that disability becomes a “performance in everyday life” (Garland-Thompson, 2005; Sandhal & Auslander, 2005), to the various framings of disability and difference as individuals move through various medical, educational, and social spaces and relationships, highlighting or minimizing different aspects of the experience of disability in each for various purposes (Nadesan, 2005). Following Butler, scholars have suggested that in the

construction of categories of disability, like gender, repetition in effect creates and solidifies the category it is believed to be referencing or describing, and in doing so renders certain kinds of bodies “legible” and recognizable (Samuels, 2002). The performances I observe clearly aim to make autism and autistic people visible and legible to Javanese and Indonesians. In doing this however, they are not only referring to autism, but also constituting it for their audience (“so this is autism!”). These performances of autism in Indonesia introduce a new category of difference, put it on display, and provide the audience with a particular interpretative framework for what they are seeing or experiencing.

Through a series of examples culled from participant-observation at various autism events held across Java, I will show how such pedagogical and performative performances of new autism and disability culture re-signify autism and disability, or give these categories new meaning, significance, and associations, teach new vocabulary and concepts felt to be critical for autism response, re-interpret values and beliefs about both normal and autistic children’s behavior, and question beliefs about appropriate parental and family behavior.

Re-signifying Autism, Disability, and Developmental Difference

As described in the previous chapter, dominant cultural narratives about autism and developmental difference in Indonesia can be insensitive or ignorant at best, and negative at worst. Here I will let a group of parents speak for themselves. This particular group of statements was taken from an online forum where I asked participants to describe the general public’s perception of their children. These are some of the responses I received:

Rosi: The social problem is that the community thinks that autistic = a child without hope

Mira: In general people here still really don’t understand what “autism” is so that

the word “autistic” is often used to in a mocking way or as a joke.

Lupi: Autistic kids are made into the fodder for insults, and it’s like they are not fit to be friends with, despite the fact that my child really longs to be friends.

Lili: Sometimes the saddest thing is that our children are seen as just bothering other people’s good time... it is so sad... [Why can’t people] understand our special children. Accept them and hang out with them so that they don’t feel excluded and don’t lose their self-esteem.

Ava: The general public really needs counseling about autism... because in their ignorance they look at autistic people as stupid, destructive, naughty, unable to be controlled, unable to talk... there are even some of them that think children are crazy because they laugh to themselves...talk to themselves...this becomes a heavy burden on parents to want to help their child socialize with others.⁹⁷

Compounded by a local emphasis on smooth and predictable social exchanges and proper etiquette, for some Javanese Indonesian parents their child’s autism might be so negative or embarrassing that they find themselves driven to desperation or even considering causing themselves or their children harm. At the same time, again because of Javanese attitudes towards the interdependent family unit, parents may not feel like they can discuss these negative emotions, nor the struggles of daily life, out of a sense of *mendem jero*, the drive to bury negative experiences, preserve decorum, and honor their families. To reprise briefly, in many Indonesian cultures including Javanese culture, negative emotions such as disappointment, anger, or grief, and suffering or shame experienced within the family system is not seen as an appropriate topic for public discussion. It is seen to disrupt social harmony (*rukun*), perpetuate negativity, and put the individual and the wider community in a vulnerable position.⁹⁸

⁹⁷ Online Facebook forum facilitated by Annie Tucker and Any Sonata Bagwanto. Opened 18 January 2012.

⁹⁸ One respondent summed up the Javanese approach as, “Shame should be completely covered up. Don’t put it on display because even to discuss it is already taboo, especially if the shame involves family problems” (Kurnianto, Interviewed by Annie Tucker. 20 April 2012, Yogyakarta).

Activists and educators at workshops and other events address these issues, both the feelings of shame and the reticence to discuss it or its causes, by encouraging parents to talk about their difficult experiences openly, while supporting them and acknowledging what they are going through. “Sharing” (using an Indonesization of the English word) is a key component of many of the talk show and workshop events I attended. Parents were frequently reminded that much like their children they, too, needed support and therapeutic attention and were thus encouraged to open up to others, to describe and process even the most negative aspects of their experiences so that they might move through it and emerge feeling more hopeful and empowered. Many workshop facilitators modeled and encouraged common strategies of clapping for parents and providing them with verbal encouragement and praise as well as hugs and physical reassurance after they talked about their personal experiences, be they painful or embarrassing or triumphant. It is not an uncommon sight for parents to stand up at the microphone during a workshop question-and-answer period only to break down crying halfway through their question, and be comforted by those sitting to their left and right, who perhaps only hours before were complete strangers. For many parents this process in itself may be highly unfamiliar, but for many, such open discussion brings great relief.⁹⁹ If some parents feel marginalized in their local communities, compounding their shame, at talk shows and workshops they may often feel surrounded by others just like them. As one mother stated it,

We need community... Because I have the experience, most of the parents who are having children with special needs, like [my son], they keep struggling with themselves. I mean, they don't have friends who they can really trust to talk to, so it's really a struggle for them (Nana, 2010).¹⁰⁰

⁹⁹ As has been found in the study of neuropsychiatric disorders, mental illness, and other distressing topics in Java and Bali, often the pressing need to talk about negative experiences or emotions may overwhelm cultural norms of etiquette or disclosure (Lemelson, 2009, 2010).

¹⁰⁰ Nana. Interview by Annie Tucker. Solo, 15 July 2010.

At the same time these events strive to create an atmosphere of trust which facilitates an acknowledgement and discussion of the often painful and challenging experiences parents are dealing with, they also make a self-conscious effort to combat the feeling that autism is shameful or depressing while praising and celebrating people with autism and their families. For example, at the event “Talk Show About Autism” held at the Muhammadiyah Public Hospital in Solo on July 17, 2010, Muhammad Farhan was chosen as the event’s master of ceremonies. Farhan is a celebrity radio announcer and television MC known both for his sense of humor, his involvement in social causes, and for being one of the few public figures in Indonesia vocal about having an autistic son. At the beginning of the talk show Farhan came out to greet the audience dressed casually in jeans, sneakers, and a lime green t-shirt that proclaimed in bold type, “PEACE. LOVE. AUTISM.” As part of his opening monologue he gestured to this shirt and said, “Does wearing this shirt serve a purpose? Not really. But I’m trying to say that autism can be fun too!”

This “fun” atmosphere created at workshops and events often seeks to normalize and destigmatize behaviors that might usually garner negative reactions elsewhere. Nancy Bagatell, in her article “From Cure to Community: Transforming Notions of Autism,” has stated that one “critical aspect of the autistic community is a coproduction of specific activities and ways of doing things ... not constrained by the conventions of the discourse of normalcy” (Bagatell, 2010, p. 38-39). As described in the previous chapter, because of the rejection or recrimination they have felt in reaction to their child’s appearance or presentation, many parents are embarrassed by aspects of their children’s behavior, and in a state of ongoing worry about what they will do in public. Many talk shows and workshops, which welcome autistic children not just as performers but also as participants and audience members, create a different kind of atmosphere through accepting and affirming responses to autistic behavior, which to those unfamiliar with autism

might seem unpredictable or non-normative. For example, during the question and answer period at the talk show event in Solo, while Farhan was answering a question from an audience member, one teenaged boy suddenly jumped up out of his chair, and proceeded to run around the room flapping his hands and making loud vocalizations. Without missing a beat Farhan joked, “Well that’s the perfect therapy for the sleepy folks out there in the audience!” This comment was met by warm laughter. During a panel at the “Prospect of Empowerment of Autistic Persons for their Future” workshop held at Gadjah Mada University on November 19 and 20th 2011, a young autistic man named Daniel was being interviewed and so was handed a microphone. Soon into the interview however, he noticed an old friend in the audience, and started quizzing her for updates about her, her family, and all of their mutual friends. He eventually walked away from the podium and approached her in the audience, asking perseverative questions about her address, her son, her mode of transportation to the conference, and etc., and inviting her to respond into the microphone. This detour in the proceedings was met with warmth, patience, and good humor.

Creating a safe space with different expectations and values for behavior, that is welcoming of people with autism and their communicative differences and sensory and expressive needs, would not be out of place in other global autism communities. For example, Autreat is an international neurodiversity conference held in New England, run primarily by and for people with autism, which was founded on the principle that autistic people have characteristically autistic styles of relating to others, which should be respected and appreciated rather than modified to make them "fit in" to typical society and as such it provides a social outlet for autistic people to explore and participate in autistic social experiences. This participation is facilitated by things like color-coded name tags that indicate whether people are

up for verbal conversation, “cool-down” rooms that provide for sensory decompressing, and the baseline assumption that certain forms of socialization—including stimming and perseverative questioning—are part of being autistic and hence are expected and accepted (Autism Network International, 2013).

If in this the talk show and workshop events I attended may be taking their cue from international autism movements, they make a similar concerted effort to let local participants know that autism is an international concern and connect them to an international community. This is accomplished in part by screening “inspirational” news stories and documentary clips about families with autistic members culled from America, Australia, Britain, and beyond. Workshop programming also highlights the skills and talents to be found within the members of this international community; for example, the talk show event in Solo featured a viral YouTube video of Stephen Wiltshire, the British-born autistic artist of West Indian heritage whose exceptional talent in hyper-realistic drawing helped popularize a positive view of autism in the United States and who is now world-famous for his intricately rendered urban panoramas (Sacks, 1993; Murray, 2011). Other similar events shared a viral news story of a young autistic American boy who scored multiple slam-dunks for his basketball team, and various clips of Temple Grandin, the famous author, speaker, autism advocate, and animal science expert.

After establishing the autism community as international and multitalented, many events then also claim a space for local autistic people within this community by showcasing their particular skills. For example at the “Prospect of Empowerment of Autistic Persons for their Future” workshop, during breaks in instruction and discussion sessions adolescents with autism were invited to the stage in order to perform their various talents—Faisal from Semarang eloquently sung Koranic verse, Jocelyn from North Sumatra demonstrated the precision art of

paper cutting, the aforementioned Daniel from Jakarta impressed guests with his ability to accurately name the day of the week for almost any date in history, and a local group of students from the hosting institution, *Sekolah Lanjutan Autis Fredofios* performed a traditional dance from Southern Sumatera, *Tari Lilin*. A final student read a speech that he had written about being a young adult with autism, and for doing so the moderator of the event hailed him “a pioneer.”

The strategy behind these performances can be considered analogous to a common strategy mobilized worldwide in both the neurodiversity movement and the disability rights movement in general: rejecting the idea of disability or developmental difference as “tragic” by promoting an abilities-based view of autistic individuals and autistic difference.¹⁰¹ Rather than using a deficit model, which focuses on what autistic people cannot do, ability-based efforts celebrate the unique talents that people with autism might have. Global advocates such as Grandin, one of the most well known speakers on autism and on the spectrum herself, support this recognition of talents as one key to the inclusion of people with autism in mainstream society (Grandin, 1996). Indeed part of the work of the global autism and neurodiversity movement is to raise consciousness within autistic and allied communities to build a sense of positive and visible autistic identity by claiming and celebrating autistic heroes and role models, including those who are declared on the spectrum or those who are speculated to be on the spectrum or have affinities with the spectrum (Schwartz, 2008; Murray, 2011).

The message of a positive, inclusive, and far-reaching community has the power to extend and grow beyond the confines of the immediate workshop locale or experience. One way

¹⁰¹ Particularly in the performance of the dance from Sumatra, there is also an interesting intersection between the fostering of an “abilities-based” model of disability and historic strategies of using performance to bolster a sense of Indonesian “unity in diversity,” where various regional, ethnic, and cultural groups from across the archipelago are represented at tourist, corporate, and cultural diplomacy performances through dance, music, costume, and culinary performance in an evocation of Indonesia’s inclusive national diversity (Hughes-Freeland, 1997).

it is easily spread is via merchandise booths at such events, which sell the “Peace. Love. Autism.” T-shirts described above as well as other T-shirts, autism-awareness puzzle-piece key chains, bumper stickers, and etc. Bagatell has considered such tangible and accessible objects “shared artifacts” (Bagatell, 2010), a common term in ethnographic fieldwork referring to things people make and use, that has also become a strategy used in global autism movements to help build a sense of autistic identity. These seemingly innocuous pieces of clothing, knickknacks, or souvenirs become a sign of group membership and solidarity that can spread across the island of Java, if not the archipelago. A number of people I came to meet and interview in later fieldwork in Jakarta and Yogyakarta were wearing these T-shirts (see Appendix I, Figure 4.1), and occasionally when I was traveling through these and other cities I would catch sight of passersby wearing similar garments and feel surprised by a sense of affinity or membership in a broader community, the boundaries of which were otherwise invisible. These artifacts became useful strategies of location and a way to refigure the Indonesian landscape—to help families with autism find and identify others like themselves or sympathetic to their cause or experience, or to re-envision a surrounding group not as hostile or as an audience for embarrassment, but as welcoming and understanding.

The palpable feelings of inclusion and optimism speak to the benefits such events confer for Javanese and Indonesian families. Attending a workshop or seminar may introduce parents to local, national, and global peers and comrades they didn’t even know they had, meeting a significant need, helping them reframe their own awareness and approach to their situation, and perhaps even effectively changing the felt experience of having a child on the spectrum from one of isolation to one of inclusion. As one mother explained her response to such gatherings; “There are so many stories about us, parents with special needs kids and I see that, and I learn so

much from that, that we are not alone. Yes, I am not alone” (Ningsih, 2011).¹⁰² By meeting others in a similar situation, being introduced to the idea that the autistic community is a vibrant and global one, and being initiated into a community where new autistic norms are accepted—even welcome--and participants are invited to celebrate their children’s differences and accomplishments, such events performatively resignify autism from a “family shame” into a “pioneering” shared adventure. Bagatell, borrowing the term from Skinner (2010), says that such events are part of the creation of new “figured worlds” or “historical and social phenomenon into which individuals enter or are recruited and which are reproduced and developed by and through the practices of their participants” (Bagatell, 2010, p. 38). Workshops and other events provide safe gathering spaces that invoke such figured worlds.

I suggested earlier that these figured worlds are expressing aspects of “disability culture.” This culture has been influenced by the global disability movement, which through activism, consciousness-raising, coalition building, and critical inquiry has enacted a significant shift in the way many people view physical, cognitive, emotional, and other differences. Key elements in this culture include: generating new vocabulary to garner respect and inclusion, re-writing narratives of disability to resist shame and tragedy, promoting an abilities-based vision of people with disabilities, and arguing for accommodation, inclusion, and valuation of the difference inherent in human diversity. The shared values and practices of such disability culture are at once experimental and emergent and globally recognizable; disability culture has been called “a cross-cultural phenomena that knows no national boundaries” (Peters, 2000, p. 584). Petra Kuppers, in her work *Disability Culture and Community Performance* (2011) suggests that certain disability-focused events or performances, and the spaces they create, become what she calls “laboratories of experimental disability culture” where the possibility of new forms of

¹⁰² Novi. Interviewed by Annie Tucker. Yogyakarta, 15 October 2011.

engagement and community take shape at the intersection of the past and an emergent future (Kuppers, 2011). While criticized by some as “sanitizing” autism or only being relevant to those whose children are not severely affected, by providing support and encouragement for families, allowing and even celebrating autistic ways of being and expression, creating shared artifacts, and promoting a positive view of autistic people and their abilities, these workshop events evoke figured worlds wherein Indonesians can begin to craft an environment more amenable to their children and more conducive to an adaptive approach towards autism in the family and community.

Is “Autism and Disability Culture” a New National Culture?

To a certain extent, I believe this new autism/disability culture can be considered national in scope. The workshops from which I culled my examples above were attended by people from all over Indonesia including the major metropolitan centers in Java including the West Java cities of Jakarta and Bandung, Central Javanese cities of Solo, Yogyakarta, Semarang, and East Javanese cities of Malang, and Surabaya. However, there were also often participants from smaller cities on Java (such as Bekasi, Kudus, and Panderang) and from other cities on other islands including from Denpasar, Bali; Pontianak, Kalimantan; Medan, Sumatera; and Makassar and Manado, Sulawesi. Some people had flown in and some people had taken bus rides of 18 hours or more to attend. (In recognition of this, many events provided ice-breaking and closing events where gifts are given away to participants who have come from a certain city, or who have travelled the farthest).

Yet some of these workshop and talk show participants from far-flung locations know each other from attending previous workshops together and from online forums such as the LRD

Facebook group. And at each workshop, these networks grow as friends introduce one another, parents meet professionals, and teachers who in their home villages might be the only ones interested in autism or special education have the opportunity to share resources with one another. After conducting months of fieldwork and attending a number of these functions it became clear to me how far-reaching this community is; I myself discovered unexpected connections within an autism world that was both geographically diffuse but also quite “small,” as I met people at workshops in Jakarta that knew some of my other research participants in Yogyakarta, or was introduced to one person traveling to Yogyakarta for a conference whose son happened to be the classmate of another child whose family was living in Semarang, or met people at conferences who had previously corresponded with some of these subjects online. For some, clearly the Indonesian autism community has become quite a close-knit one. The members of this community provide one another with emotional support, pray for one another, and sometimes chip in to help each other pay for therapies, medical treatments, or family emergencies. They share an inside knowledge of autism and share a vision of an Indonesia that is more accepting and inclusive of their children.

In the previous chapter I discussed Javanese local moral worlds within which autism emerged. But clearly the Indonesian autism world is wider than such a local world, encompassing the local worlds from families living in many different locales from many different ethnic groups with their own approaches to personhood, childrearing, and family life. Learning about autism pulls parents out of their local worlds to connect with others across the nation, and this learning process then reshapes these local worlds in terms of language used to describe children’s behavior, and significance ascribed to these behaviors, practices, and expectations. The “figured worlds” that are shaped around autism performances and events are

themselves shaping new scattered local cultures that are united by similar experiences, concerns, and goals. Parents are coming to these worlds with shared histories of marginalization, stigma, and misrecognition, and often while undergoing processes of significant life adjustments and reorientations. As one mother expressed it, she has experienced

a significant change in my way of life. We have changed everything in order to adjust ourselves to the condition of our special child, in trying to give all the support we can so that this child can develop as fully as possible (Siwi, 2012).¹⁰³

Parents with the means to do so venture out from their local worlds trying to learn more about disability culture and autism culture—and all the particular perspectives, values, specialized skills and vocabulary that these cultures bring—from a group of mentors and key figures who are framing autism for them and guiding them in how to think about and react to autistic difference. “Local” worlds are further disrupted and geographies are further re-organized as many families who can afford to, like Redno and Ningsih and others mentioned in Chapter Three, will move to urban centers looking for treatment. In entering these figured worlds, in undergoing these enculturating or educating processes, Indonesians with autistic family members are entering new national communities.

In proposing this national aspect to autism and disability culture, I follow Tom Boellstorff’s theory of globalized subject positions and an “archipelagic” national identity in Indonesia as developed through his work with Indonesians who identify as *gay* and *lesbi*, elaborated in *The Gay Archipelago* (2007). In this book Boellstorff acknowledges a long-standing historiography of ethnography in Indonesia where the local was privileged, in what he terms an “ethnolocal” approach. It has historically been argued that one couldn’t conduct a ethnography of “Indonesia” because there were so many regionally specific cultural differences. Certainly these differences cannot be discounted, although their contours arguably have been

¹⁰³ Siwi. Online Facebook forum facilitated by Annie Tucker and Any Sonata Bagwanto. Opened 18 January 2012.

smoothed both by oppressive top-down attempts at national integration headed by the New Order regime and by a bottom-up movement towards democratization, however perhaps they have been over-emphasized by anthropologists. Even if already in 1973 Clifford Geertz was saying that social change in Indonesia was characterized by “a movement away from a situation where the primary integrative ties between people are phrased in terms of geographical proximity to one in which they are phrased in terms of ideological like-mindedness” (Geertz, 1973, p. 148), anthropologists have historically privileged various sites in their ethnographies, which were often particular towns or villages such as “Modjokuto” in Central Java (Geertz, 1960), or Bajoeng Gede in Bali (Mead & Bateson, 1942). With regards to Boellstorff’s interest, the study of sexuality, in Indonesia this has meant focusing on categories of gender and sexuality that were particular to a certain region--the transgender *bissu* of Sulawesi, for example (Graham, 2001). But Boellstorff argues that if scholars used only the lens of ethnocentricity, *gay* and *lesbi* subjectivities, which are in a large part based on local interpretations of globalized identity categories of “gay” and “lesbian” and not on indigenous gender identities, would be lost. Furthermore, he argues, when it came to *gays* and *lesbis*, assumptions about similarity had to be questioned; no longer could ethnographers assume that physical or geographical proximity necessarily indicated similarity or identification. Instead, Boellstorff argues that in a post-Reformasi Indonesia where the pace and frequency of global exchange and connection has exponentially increased along with more frequent access provided by internet and mobile technologies, “a subjectivity shaped by “global” forces may be experienced as more foundational than one shaped by “local” forces” (2007, p. 44) and therefore,

For these Indonesians difference is no longer isomorphic with distance. *Gay* and *lesbi* subjectivities...are imagined archipelagically; someone thousands of miles away might be “closer” than someone next door who is not *gay* or *lesbi*” (*ibid.*, p. 34).

He finally argues that in the case of those who would study *gay* and *lesbi* Indonesians, there is no one “field site,” rather an archipelago of shared spaces that then “open into” *gay* and *lesbi* places, encompassing far-reaching but scattered geographical and social islands of affiliation across the nation. Boellstorff proposes this “archipelagic” framework as a new way to look at emerging local/global/national subjectivities, and accordingly proposes that a more nationally focused “Indonesian” ethnography is made possible, perhaps even demanded, by such an archipelagic framework.

I believe this could be a fruitful model to apply to autism. Much like *gay* and *lesbi* Indonesians, parents who adopt the construct of autism in making sense of their children reach outside their local culture to find the terms and identity categories that seem to best fit them. In Chapter Three we saw that there was a sense of there being no appropriate local term, no local identity category, that seemed like a good fit for autistic children. To reiterate, while there were many different terms that fit a number of different manifestations of autism symptoms and behavior (“crazy,” “left behind,” “possessed,” “naughty,” and etc.) many of those felt “wrong” or were contested by the parents of autistic people or autistic people themselves—instead, the label that fit the best came from globalized autism discourse. Once autism was explained, it felt more “right” to many families than any of the familiarly available local labels.

As for *gays* and *lesbis*, in the case of autism globalized media and identity politics provide new available subject positions that bring with them new hopes and expectations for acknowledgement, self-advocacy, networking, and support. These globalized subject positions are indeed then taken up and interpreted locally; and yet ethnocentricity, or its analogue in global

disability studies, a “local moral worlds” framework, is clearly not enough to understand the dynamics and usefulness of these new categories of personhood or experience.

Similarly, there may be no stable “place” at which one can study autism in Indonesia; rather, across the nation, spaces suddenly open up into field sites of autism culture, suddenly emerge or coalesce into a new figured world.¹⁰⁴ Much as Boellstorff charts in his book, how in Makassar or Yogyakarta a typical market area might turn into a *gay* space or a place for *gay* culture on certain nights of the week when *gays* gather there, so for the Indonesian autism community a public hospital or university lecture hall suddenly opens up into a site of disability or autism culture—or, with the help of shared artifacts such as an autism awareness t-shirt glimpsed on a street corner, a familiar neighborhood suddenly might similarly temporarily become a site of disability culture.

These emergent sites, these “laboratories” of autism and disability culture, are then stitched together into a cartographic construction of an autistic archipelago that is simultaneously local and national, a group of islands and cities drawn together by the process of autism education and outreach and populated by people with autism and other developmental differences. Consider the powerful image of an autistic nation evoked by autism awareness activist Diyah Puspita at the end of her memoir:

At this point, it is very difficult to imagine my life without autistic children ... what’s more, when I remember my experiences in a number of areas in the most far-flung corners of Indonesia ... with a group of extraordinarily dedicated therapists on the outskirts of Banjarmasin city, or the road trip I took that lasted for hours and hours, in order to reach the most remote area in Sumbawa so that I might share my experiences with parents of autistic children there. Then there was the cafe in Denpasar, where I stood in front of a number of parents who peppered me with questions that sometimes I felt there was no way for me to know the answers to. And I keep following the development and progress of the

¹⁰⁴ It has also been suggested that a similar archipelagic framework is applicable to those with neuropsychiatric disorder as well, a framework which is in evidence in the *Afflictions* series about Indonesians in Java and Bali with major mental illness (Robert Lemelson, personal communication).

children of all of my friends in Makassar, Bandung, Solo, Semarang, Surabaya... (2004, p. 215-216).

Autism is both the cause that has sent Diah out across the archipelago, and the force that draws these far-flung locales of Sumbawa, Solo, Makassar, and Denpasar all together, as autism culture and disability culture becomes a basis for a new “imagined community” (Anderson, 1983), a new force for national identification.

Bahasa Autis: Learning the Language of Autism

As I have described above, certain aspects of this new autism and disability culture can be quite welcome, be experienced as a positive development, and provide benefits for those families who choose to enter into it. Other aspects of autism and disability culture might feel quite foreign, requiring processes of education, translation, and interpretation; those ambassadors already familiar with autism and disability culture have a number of choices to make with regards to how this process can be done effectively.

The autism world is in some ways a rarified world, filled with specialized vocabulary and specialized knowledge, much of it stemming from an information bank and cultural base that is foreign to the average Javanese parent. For example, one mother said that when her child was diagnosed with autism she herself had to adjust, explaining that compared to what she had known about childrearing before, “this was totally different. The world of autistic children is closely knit (B.I. *erat*) with psychology and medicine. Whether I wanted to or not, I had to enter this world” (Uni, 2010).¹⁰⁵

¹⁰⁵ Uni. Interviewed by Annie Tucker. Malang. 22 September 2010.

Indeed, being introduced to the concept or label of autism is to be introduced to a whole constellation of symptoms, treatments, ideas, and practices. Parents are plunged into an immersion learning experience that, because of autism's complexity, may affect many different areas of family life. Navigating this world—from reading research papers and educational materials to meeting new therapists to consulting with specialists to sharing information with other parents—can be overwhelming enough for native English-speakers, but is even more challenging for those Indonesians for whom English is a second or unfamiliar language. Because most autism research materials, popular psychology books, and self-help guides are as of now still in English, those in the autism field must learn to speak a hybrid dialect peppered with English psychological, educational, and medical terminology. And it is not just parents that have to master this daunting array of foreign-language vocabulary, but also educators and therapists who would work with an autistic population. For example one teacher I interviewed, Dewi Pertiwi, who is currently a senior teacher at Sekolah Lanjut Autis Fredofius, graduated from college in 2003 with a degree in psychology but received almost no information about autism let alone training working with students with autism during her education. When Fred Vrugteveen, a special education consultant from Holland, co-founded the Fredofios school in Yogyakarta he provided the small group of eager teachers with training materials that he himself had translated into Indonesian, but the bulk of the materials remained in English. Dewi remembers finding this challenging, and told me that it took many intensive training sessions with Fred for her to even begin to master the vocabulary, concepts, and information (Pertiwi, 2012)¹⁰⁶. An expert in cross-cultural special education, Dr. Adi Adinugroho has said that translation of training and educational materials is perhaps the primary need in the autism field in Indonesia (Adinugroho, 2010).

¹⁰⁶ Pertiwi, Dewi. Interviewed by Annie Tucker. Yogyakarta 9 January 2012.

In an exercise to see a sample of foreign terms and ideas Javanese parents or educators have to come to grips with, a cursory scan of the memoir *Meniti Pelangi* (Saraswati, 2004) for English words that remain untranslated turns up:

Autism Spectrum Disorder, Asperger's, Attention Deficit Hyperactivity Disorder, Immuno-deficiency, Pervasive Development Disorder, Severe Language Delay, flapping, self-stim, non-verbal, gastrocolitis, stereotypic behavior, toxic overload, self-regulation, neuro-biological disorder, echolalia, rocking, Picture Exchange Communication, American Sign Language, Auditory Integration Training, Applied Behavior Analysis, antecedent, behavior, consequence, speech therapy, individual therapy, haloperidol, parent support group, designated autistic class, full inclusion, mixed ability, one-on-one, visual learner, recall, recognition, functional communication, group home, reward, shadow, Social Stories, Individual Education Plan, intervention services, Teachers Aide

This cursory sampling illustrates not just the presence of English-language terminology used in autism materials, but that these terms are informed by the complex and sometimes contradictory theories and practices from which they emerge and the medical, psychobehavioral, cultural, activist, and educational histories and contexts that have helped to produce and redefine autism over the course of the past century. This web of terms has threads tracing back to Skinner Behaviorism and the Lovaas institute in Los Angeles, the Americans with Disability and IDEA Acts, neuroscientific research and remedial education, and “figured worlds” such as parent activist movements, illustrating how the majority of models being mobilized in the field to understand and respond to people labeled as autistic in Indonesia have originated elsewhere. This somewhat tautologically explains the fact that it seems almost impossible to tell a story of autism without using these rarified terms and foreign referents and also signals that the translation of materials, rife with autism-specific vocabulary, will not always (if ever) be a straightforward process. Much vocabulary requires some contextual understanding and background knowledge of autism and its assorted histories, which are imbricated in culture and therefore call upon shared assumptions, practices, and sentiments. Interpretive work is required

to make the concepts and terminology, so significant to the understanding of and response to autism outside of Indonesia, relevant and applicable to local lives. These processes of interpretation affect the way concepts from the autism field are taken up and applied in individual families.

To illustrate, one common issue, and therefore one of the terms relevant to parents of people with autism, is the tantrum. In response to the question “What is your most significant concern about your autistic child?” the group moderator posted on a Facebook group to jumpstart our online conversation forums, over half of 35 respondents said that their child’s tantrums were their primary concern and main difficulty, saying things like “when my child tantrums he can hurt himself or others,” “when my child tantrums in public I don’t know what to do,” and “I don’t know what is causing my child’s tantrums”.¹⁰⁷ However, although their children may be acting in ways that fit into the rubric of “tantrum,” those new to the vocabulary of autism may have never even heard of tantrums before. Educators and activists I observed used a number of various strategies to explain tantrums, including on the one hand translating the as yet unfamiliar word and idea into a familiar local psycho-behavioral concept, and on the other hand introducing tantrum behavior as foreign and exclusive to autism, distancing it from the familiar repertoire of emotional experience and expression. Here I will describe the two techniques as I encountered and explore their ramifications.

In her memoir *Faisal Loves Mama for Life*, mother turned activist Sri Murni talks about her own process of learning to avoid anger and instead lovingly respond to her son’s “crying and tantrums (*ngamuk*)” (Murni, 2010, p. 10). With this simple and quick parenthetical word substitution, Sri Murni translates new vocabulary into a local vernacular term; while “tantrum”

¹⁰⁷ Various. Online Facebook forum facilitated by Annie Tucker and Any Sonata Bagwanto. Opened 18 January 2012.

may not be a familiar term to many Javanese mothers, *ngamuk* is one of the most common Central Javanese idioms of distress used to describe emotional expression that is aggressive or out of control, encompassing a range of deviant behaviors that veer off course of smooth and harmonious social exchange. Historically understood as *amok*, or a culture-bound syndrome classified by moments of dissociative violent “rampage,” *ngamuk* is now better interpreted as a flexible, dynamic, and poetic idiom of distress which can refer to a wide range of aggressive, angry, or confrontational behaviors that evoke feelings of vulnerability in others. It is both used as a folk term and is incorporated into clinical diagnoses in psychiatric hospitals and community mental health care. *Ngamuk* behavior is often seen as erupting in response to unfavorable conditions that give rise to the negative emotions feared and avoided in Javanese ethnopsychology: disappointment, shock, and frustration, or a lack of self-awareness that makes the person vulnerable to spirit possession. As such *ngamuk* is upsetting on multiple dimensions, both causing rifts in interpersonal relationships and pointing to rifts that have already occurred (Browne, 2001). Translating “tantrum” as “*ngamuk*” situates the autistic person’s behavior within a familiar repertory of Javanese emotional expression, rendering it communicative, meaningful, and interpretable. *Ngamuk* is certainly familiar, if not desirable, behavior.

An opposite strategy I encountered does not introduce the tantrum as a variety of familiar Javanese emotional expression, but uses the tantrum to indicate autistic emotional expression as qualitatively different from normal human emotion. At an educational presentation held as part of a “Regional Seminar and Workshop To Get a Handle on Autism” held at Sekolah Tinggi Agama Islam Indonesia (STAIN) on August 1, 2010 Kholifatutu Diniah, a well-respected visiting therapist, endeavored to introduce autism to her audience, some of whom were parents and others of whom were local elementary school teachers. She showed a video of a child from

her bustling private practice biting himself on the hand and forearm repeatedly, explaining, “This child is having a tantrum. Do you know that word, ‘tantrum’? It’s autism speak (B.I *bahasa autis*)¹⁰⁸.” She let the video run for quite a while, as the child continued to self-injure and his arms began to show bruises and welts. The participants in the seminar, many who knew very little about autism previous to the day’s activities, were visibly and audibly uncomfortable, with some protesting and others covering their faces. The speaker ended the video segment with the dramatic pronouncement, “*This* is autistic anger.”¹⁰⁹

Besides upsetting the audience, such an approach made autism and autistic emotional experience and expression seem foreign, frightening, and even horrific. By using a worst-case example of how a tantrum could possibly develop, into a situation of extreme self-injury, autism itself was presented as a hyperbolic worst-case scenario wherein “autistic anger” is somehow different from ordinary anger that a typical person might experience. While I personally found this to be an unsuccessful presentation and translation of tantrum, some other therapists I interviewed also favored similar tactics, what they considered to be a harsh realism. Damai Sitompul, an American-trained occupational therapist and public figure frequently interviewed on the topics of children with disabilities is working on a documentary geared for television about how it “really is” for autistic children and she too focused on tantrums, showing the worst-case scenarios of painful self-injury and aggression from the private clients she works with. Her logic is that a sense of public urgency needs to be created so that the general public realizes that autism is a pressing problem, that people are actually suffering and getting hurt; parents, teachers, service providers, and the government need to be proactive, and it is hard to justify a

¹⁰⁸ The structure of the phrase *bahasa autis* indicates that it its own form of language or dialect, such as *Bahasa Inggris* (English), *Bahasa Indonesia* (Indonesian), or *Bahasa gaul* (Jakarta slang).

¹⁰⁹ Diniah, Kholifatutu. Observed by Annie Tucker. Salatiga, 1 August 2010.

weak or apathetic response when looking at such footage (Sitompul, 2011).¹¹⁰ Such tactics have also been the subject of debate within the autism field in America, most controversially in the film *Autism Every Day* (2006), produced by the organization Autism Speaks. *Autism Every Day* showed footage of children apparently throwing tantrums, alongside interviews with their exhausted and despairing parents. Some have accused Autism Speaks of asking parents to avoid any kind of helpful therapies in the week leading up to filming so that they would be at their most exhausted, and others have criticized the organization for their negative portrayals of autistic people and making autism seem like the worst-case scenario tragedy, of which *Autism Every Day* was just one example (Broderick & Ne’eman, 2008). However, as the largest autism advocacy, service, and research organization in the country, Autism Speaks has been able to garner impressive funds for research and policy that has led to research advances and much-needed service support by using such tactics.

To sum up, autism educators and parents in Indonesia are faced with the task of learning “*bahasa autis*,” interpreting primarily foreign-language materials based on psycho-educational paradigms based on, and research conducted in, other cultures for local individuals and groups. This is a significant task, as the way terms and concepts are introduced to Javanese or Indonesian audiences and translated into vernacular psychological paradigms will effect the way autistic people more broadly are viewed and responded to by others.

Reinterpreting Behavior and Learning to “Recognize the Signs”: Sharing Personal Narratives

The above examples illustrate that the process of teaching and learning new vocabulary and concepts informed by disability culture and autism discourse helps parents make meaning

¹¹⁰ Sitompul, Damai. Interviewed by Annie Tucker. Yogyakarta 19-20 November 2011.

out of their children's behavior. Similar processes of re-signification are also encouraged through other genres of cultural production and other performances of autism. Written memoirs and other forms of autobiographical narrative play an important role in this re-signification process because in describing their own children, parent narrators introduce the signs and symptoms of autism to their readers in a personal rather than a clinical context. Without being pedantic, they provide an informal guide or framework for recognizing autistic difference. This might take the form of a "list" of symptoms other parents can study and then perhaps look out for in their own children or others' children. As parental testimony in the last chapter revealed, parents whose children might be considered as being on the spectrum may yet be mostly unfamiliar with the autism diagnosis; it is possible that their children may be exhibiting the classic symptoms of autism, but they are interpreted as either uniquely idiosyncratic and therefore not cause for concern. As Warno from Salatiga said, his son was late to speak and respond socially, adhered to strict routines, and exhibited other autistic traits but "I had no idea my son had autism, because I didn't know the signs" (Warno, 2011).¹¹¹ Or as a mother from Sumatra said that when her son first started exhibiting signs of difference, "We didn't know anything about autism at all" (Rumiris, 2010).¹¹² In some instances, as described in the previous chapter, children's symptoms are troubling, but the parents are unclear as to how to further interpret or respond to such symptoms.

In both spoken narratives and written memoirs parents clearly delineate the symptoms in their own children that are ultimately be associated with their diagnosis of autism; avoiding eye contact, being drawn to the wheels of cars, fans, or things that spin, walking on tiptoe, "flapping," crying or laughing without apparent cause, and etc. This provides a guide for their

¹¹¹ Warno. Interviewed by Annie Tucker. Yogyakarta, 20 October 2011. 2011.

¹¹² Rumiris. Interviewed by Annie Tucker. Bogor, 15 July 2010.

listeners and readers, bringing certain behaviors and signs into awareness and teaching others how to “see” or recognize autism. Storytellers trace their own journeys—describing their personal experience, their reactions, their mistakes, and their developing understanding of autism—and in doing so invite a similar trajectory from listeners and readers.

Such narratives are both circulated in written form and heard at live events. To illustrate, we can return to the aforementioned Talk show event in Solo, and the event’s MC, Farhan. As part of his opening monologue, Farhan told a personal narrative about the moment he realized his son was “different.” He explained that leading up to this moment, his wife had voiced some concerns, which he easily shrugged off. For example, his wife noticed that his child couldn’t, or wouldn’t, ever point. But Farhan said,

I was thinking, no problem! So he can’t point? I myself couldn’t point until I was five years old! My wife said, “We need to do something.” I said, “Nah, it’s nothing.” But six months later, one day my wife told me to join her. “Where are we going?” In Jakarta, they have a lot of playgroups and they open their doors to meet with the prospective students, like an open house. “Ok, let’s go!” We went to the group for parents with kids around two years old. “OK, let’s go.”

The other kids there, they were... normal. While I don’t really like to use the word normal, I have to say, the other kids were normal! My child was the only one who was different. My kid didn’t like to play with others. My child gathered his toys and lined them up in a semi-circle. And he didn’t play with his toys the way he was supposed to. He’d turn a toy car upside down and just spin the wheels, and if there were toys that spun, the point is if there was anything spinning [he’d play with it]... The others, at the age of two years old, they already knew how to play together and do what they were supposed to do.

And only then did I realize: my child is different. Something is wrong. (Farhan, 2010).¹¹³

Farhan’s story is implicitly diagnostic, but it is couched in personal experience and reflection. In addition to the more specifically didactic sessions at live events, which

¹¹³ Farhan, Muhammad. Public presentation as part of Talkshow All About Autism, held at the Muhamaddiyah Public Hospital. Solo, 17 July 2010.

provide training in interventions and education, this sharing of personal narrative continues the work of introducing autism, translating important concepts, and guiding parental response, but in a more conversational rather than directly instructional fashion.

Sometimes parental narratives do get more explicitly diagnostic or directive; for example, one author includes the Modified Checklist for Autism in Toddlers (M-CHAT) screening tool in her personal memoir (Saraswati, 2004), and the activist Diyah Puspita chooses to include a segment entitled “If I had Known” after each chapter of her story, which explicitly outlines the ways she could have been more proactive in responding to her son’s developmental differences if she herself had been familiar with autism. For example, after the first chapter where she describes her puzzled response to her son’s delays and how long she waited before pursuing diagnosis and treatment she says,

If I had known... I would have worked hard to learn about the signs of healthy child development, in order to understand what was the same or different about [my child]’s development compared to his peers. I would have paid attention to the behavior of other children his age in our immediate environment... I would have quickly sought a doctor’s confirmation to obtain the correct treatment the second I felt there was a ‘problem’ or a ‘gap’ (Puspita, 2004, p. 34).

Both Farhan and Puspita refer to an opportunity for early intervention that they themselves missed but that they can now afford others, hoping to inspire or instigate a more pro-active approach in their listeners and readers.

Personal genres of storytelling become an important tool in grass-roots awareness methods beyond the confines of workshops or events, as many parents say they would not feel bold enough to counsel another parent or suggest that someone else’s child was exhibiting the signs of autism or developmental disability, but they might feel more comfortable sharing their own experience. As one mother told me, she was once asked

by a family member to look at another relative's child who seemed to be exhibiting signs of developmental delay.

I said, 'Sure, bring him to the house!' It was exactly like autism! He wandered all around, he couldn't sit still. He had autism... But, you know, all we could do was share our own experience, right? We wouldn't dare say anything... If I had indeed been asked flat-out, I would say that the symptoms are like my son's but that I don't know about anything in other kids. I would tell them to go to a pediatrician (Ningsih, 2011).¹¹⁴

Other parents and therapists I spoke to echoed this sentiment. For example Florida, a behaviorist originally from the eastern island of Flores working with well-off families of children with autism in Malang, East Java, noted the local Javanese etiquette which caused a certain reticence for parents to speak up about others' children, which is such a sensitive topic that it might even make early screening a challenge. She felt the best method of spreading awareness about the early signs of autism would be through one-on-one "heart to heart" or sharing talks (*B.I. curhat*) where a parent could talk about their experiences with her own child, and leave it up to the other mother listening to connect it to her own life and child, or not (Florida, 2010).¹¹⁵

These parental narratives, whether performed onstage, written in a book, or shared over tea, teach others how to see or recognize autism, and hence respond to it, sooner. The lack of early response to autistic symptoms is often interpreted as a lack of autism awareness, a perceived void that many parents and activists are struggling to fill by asking the government for treatment and educational facilities and providing workshops to educate parents and train a capable workforce. Some in the global autism field see such educational processes as positive and positivist, asserting that we are currently in the middle of a global era of autism, wherein

¹¹⁴ Pratiwi, Ningsih. Interviewed by Annie Tucker. Yogyakarta, 13 October 2011.

¹¹⁵ Florida. Interviewed by Annie Tucker. Malang, 22 September 2010.

people know more about autism than ever before because we are learning how to recognize it more accurately than ever before. Similarly, it is argued that many societies are learning how to welcome or accommodate those with autistic difference, who have been present as part of naturally occurring human diversity but up until now invisible in their communities. Interpreting “autistic” behaviors as individual quirks, or not flagging them as particularly meaningful, may be fairly common in cultures where autism is not yet a commonplace label. For example in her work in South India Tamara Daley cites research where parents did not initially report concerns about their children and “it had never occurred to most parents that their children’s troublesome ways were anything other than an accepted part of family life, until a researcher came along” (Hackett & Hackett, 1999, p. 226 as quoted in Daley, 2002). Viewed in this light, the work of parental narratives—and even the work of global autism research—is helping other Indonesians learn to “see” autism by calling its symptomatic expression into attention. This is the viewpoint put forth by Roy Richard Grinker, who has become one of the most significant and influential global autism scholars, and others, such as Cohen and Volkmar who believe that “there is no other developmental or psychiatric disorder of children (or perhaps, of persons of any age) for which such well-grounded and internationally accepted diagnostic criteria exist” (1997, p. 947).

Other scholars, who take a more critical view of autism history, remain skeptical of autism as an entity, proposing instead that it has become a category grouping together a heterogeneous group of individuals whose socialization, learning, and communication practices may vary from the typical norm. From this perspective it is not so much a matter of “learning to see autism” as it is learning to apply a new term or conceptual category to various constellations of social and communicative behaviors that in a different moment might as convincingly be ordered or organized differently. From this perspective, it is not so much a question of

Indonesian parents learning to recognize the thing called autism, but a question of producing or constructing autism within Indonesian culture, bringing a concept into being that is then applied to individuals and mobilized in personal, familial, civic, political, and institutional practices.

It may be that when looking at autism in different cultural places, noticing symptoms and negotiating labels may be more of a complicated balancing act than either of these two perspectives account for, as parents seek to determine what will best support their child's and their family's inclusion. In many personal narratives, some children's earliest behaviors that could be interpreted as "signs" of autism were instead interpreted as individual quirks rather than signs of a developmental disturbance or cause for alarm. But rather than sign of ignorance of autism, I believe the lack of a specific label may be a meaningful, if not always wholly conscious, choice that allows a family to avoid embarrassment, social stigma, and financial burden. Seeming to overlook differences and saying, as Farhan did, that the child is "normal" while sheltering him or her from potentially hurtful or uncomfortable situations with outsiders and limiting expectations beyond being a member of the household who is healthy, safe, and self-sufficient enough to manage his or her daily needs, is a common strategy that could be identified as a model of inclusion.

Indeed, sometimes even if the label of "autism" becomes available, the strategy may not significantly change. One parent, Warno, said, "I had a principle. Because his older brothers were normal, I looked at my child as normal and I treated him as if he was normal." Warno did note certain things about his son's communication and behavior, but he says he did not necessarily think that meant that anything was "wrong" or "different" with his son. This was not an unusual response for parents with young children who would ultimately come to have the diagnosis of autism. For example, another respondent, Ayu, brought her son Mahfud to the

hospital near where they lived in Jakarta when he was three years old because he was having digestive problems. There he also received the diagnosis of autism. This diagnosis came as a big surprise to Ayu who said, “At first of course we were totally shocked, startled, because we never would have thought that at all, because we saw Mahfud just like any other normal kid” (Ayu, 2012),¹¹⁶ despite the fact that Ayu noticed Mahfud had what seemed like an “empty gaze” (B.I *pandangannya kosong*) had stopped singing and speaking altogether by the age of three.

In a Javanese cultural context that values group harmony, favors against scrutinizing differences in behavior, and avoids openly acknowledging painful or negative things, “burying” problems within the family to avoid shame, the most adaptive response for the family unit might be to say that everything is just fine. Hence, it may be that denial of difference becomes a strategy of inclusion. The question of “seeing” or “not-seeing” is therefore perhaps more complicated than has been laid out by previous anthropologists and it may not necessarily be the case that “learning how to see” autism, will translate into an increasing investment in the diagnosis, better accommodations, and ultimately integration. In the Javanese context it seems that there are adaptive benefits for the family in “not seeing” their child’s autism. Indeed, in Grinker’s own later work in Korea (Grinker & Cho, 2013) he has explored some of the socio-cultural factors influencing parents’ preference for or avoidance of the label of autism, including a cultural preference for homogeneity and the parent’s desire to preserve that for their children and family, and the costs and benefits of accepting that their child had a “permanent” rather than “curable” condition. He ultimately concluded that there is always a “dynamic social construction of the behavioral features that constitute a local diagnosis” (p. 66) and a rich complexity to the relationship between social scientific approaches to mental disorders and the individuals and families that experience distress and seek ways to understand it.

¹¹⁶ Ayu. Interviewed by Annie Tucker. Tangerang, 1 February 2012.

Interpreting A Quiet Baby: A Sign of Precocious Maturity or Autistic Pathology?

Whether autism is being brought into awareness or actively constructed as a category of difference or both, it nevertheless is clear that the introduction of autism or autistic difference as a newly available interpretive framework for behavior and development may lead Javanese and Indonesian families to call locally familiar interpretive frameworks, long-held beliefs, and practices into question, and might even result in efforts to change these beliefs and practices.

Aside from bringing previously unremarkable behaviors to attention, teaching parents how to “see” autism, memoirs and education and awareness events also teach parents to reconsider certain behaviors that have already been seen and attended to but afforded a particular local interpretation. For example in the first chapter of the aforementioned memoir *Faisal Loves Mama For Life* entitled, “*It Turns Out I was Wrong!*” Sri Murni explains how her interpretation of her son’s behavior was “incorrect.”

In the morning after breastfeeding, I lay my little one down in a crib in front of the television and I started to boil water to make *es lilin* [the drink that I sold in the market]. When I did that, Faisal really helped me out because he rarely cried. “Father, our child is so smart, you know! He’s never cranky, even when I leave him alone,” I said.

Through breastfeeding I wanted only the best for Faisal’s physical development. And up until the time he was two years old, he experienced the process of creeping, crawling, sitting, and walking without any significant problems. But when he was 2.8 years old, after I weaned him, he began to show signs of unusual development, different from his older sister. Because Faisal never cried except when he had peed or to ask for milk, I thought he was so smart, so sweet, and so well behaved... well it turns out, I was wrong! (Murni, 2010, p. 3-4).

At the time of the book’s writing, Faisal was already a young man; after many years of being deeply involved in the autism world, Sri Murni has learned that from a developmental psychologist’s perspective, unresponsiveness in infancy may be one of the earliest manifestations of autism’s delay or impairment of socialization and communication skills. In certain cases, it is

argued that autism can be diagnosed in infancy based on behaviors such as avoidance of eye contact, a failure to assume an “anticipatory posture” upon being picked up by a caregiver, and an apparent unresponsiveness to the environment (Kanner, 1943; Tronick & Beegly, 2011; Glickman, 2013). As the child develops, these social and communication differences or deficits are later expressed through a lack of, or delay in, verbal language and impairments in the use of multiple nonverbal behaviors to regulate social interaction, as well as apparent lack of social reciprocity.

Coming from a different paradigm of behavior interpretation, however, Javanese folk models of development may actually approve of “unresponsiveness” or low interactivity in a baby and hence a parent of such a baby might interpret such presentation, as did Sri Murni, as evidence that a child is “smart, sweet, and well-behaved.” In somewhat older children, in fact, Javanese paradigms of development view comparative unresponsiveness as a sign of maturity. This may be because it indicates *isin*, or the awareness of vulnerability in encounter. To reprise from the previous chapter, an unwillingness to assert oneself or state one’s needs and behaviors of self-effacement are prized qualities of comportment. In fact, Ward Keeler describes a time in the typical Javanese child’s development where he realizes the stakes and requirements of encounters with people outside his family, and in response becomes shy, avoidant, or as Keeler describes it “completely unresponsive,” which is met with parental understanding and approval (Keeler, 1983). During my fieldwork stay in Java I frequently witnessed comparable behavior amongst typically developing children where I (a stranger) would be introduced to young children only to have them freeze stock still, actively turn away from me, or sit solemnly and silently, all behaviors which were met with approval of their shyness by their parents, precisely as described by Keeler from his work in Java three decades ago.

In addition to shyness, as previously described, Javanese cultural values emphasize harmony, intuition, and the ability to suppress one's own desires for the good of the collective. In her story, Sri remembers interpreting her son's behavior with such a framework of values. While it may seem premature to read such volition onto the behavior of a young infant, many parents do anticipate the later expression of culturally valued ways of being and interpret their infant's behavior as indicating progress towards these, which is itself an enculturating process. Heidi Keller's book *Cultures of Infancy* (2007) and other works (Kartner, Holodynski & Wormann, 2013; Kartner, Keller & Chaudhary, 2010; Karter, Keller & Yovsi, 2010; LeVine & New, 2008; Schiefflin & Ochs, 1986) illustrate such maternal inferences about their babies' behavior and the world around them. Clearly, parents do both project cultural values onto the behaviors of their infants and interpret their behaviors as communicative and meaningful; and in interpreting Faisal's silence and lack of interactivity as a precocious understanding or even mastery of a later Javanese goal of suppressing or denying one's own needs for the good of the family, Sri Murni was doing just that.

Beyond Javanese ideas of comportment, local gender norms also influenced Sri Murni's interpretation of her quiet son. In Java there is a common folk developmental paradigm that boys will start to talk later than girls. In her book, Sri Murni goes on to describe that when she noticed that Faisal was late to speak in comparison to his older sister "my neighbors thought that was normal because boy children usually experienced a speech delay compared to girls" (Murni, 2010, p. 5). This is one of many folk developmental theories regarding delayed speech, which according to psychologist and Indonesian autism specialist Dr. Rudy Sutadi include believing

that children who walk earlier compared to other babies will talk later, or those whose teeth grow in early compared to their peers will experience a minor speech delay (Sutadi, 2012).¹¹⁷

It is possible that these folk models may in fact favor against the early detection of autism. Because of cultural factors, the Javanese family may not notice the early signs of autism; unresponsiveness or low interactivity may be viewed positively as indication that the baby is well behaved and not as a preverbal indication of autism. Furthermore, in the face of developing symptoms parents may be counseled patience, or to avoid harmful startle or negative feelings in the child, which could further impede development. Due to this cautious approach I have met families where a child has reached the age of 9 or 10—or even older—without having received any targeted intervention of any kind as the family lovingly and anxiously waits for signs of typical development to emerge. Yet those trained in autism intervention believe that early intervention is crucial for the best long-term prognosis (Matson & Konst, 2013; Matson & Smith, 2008; Glickman, 2012); this requires teaching parents that unresponsiveness in an infant is something to worry about, not to something to let slide and certainly not something to feel proud of. Indonesian mothers with children with autism, who had an unresponsive child and who have read and learned about autism, attempt to teach other mothers the “correct” interpretation of a calm, unresponsive, or late talking baby, to help them recognize this behavior as troublesome. With this new autism-informed interpretive paradigm, Sri Murni now considers the Javanese-influenced interpretive paradigm of her infant’s behavior as “wrong.”

Conclusion

To return to the premise upon which I have based this chapter, “autism” is in many ways a new model for interpreting developmental difference that involves social, cognitive, and

¹¹⁷ Sutadi, Rudy. Interviewed by Annie Tucker. Cipinang, 26 January 2012.

behavioral shifts for those who might take it up and put it to use in their lives. As other scholars have suggested, these shifts can be taught and learned through various acts of cultural labor, translation, and interpretation. The above has provided a survey of what some of this labor looks like, indicating how “talk shows,” workshops, personal narratives, and memoirs play an important role in introducing, performing, and literally and conceptually “translating” ideas about autism and disability into locally relevant concepts of vernacular psychology, development, and behavior. These didactic performances enculturate families into new disability and autism cultures, re-signifying developmental difference in a way that can be positive and meaningful for families, and introducing parents to the significant vocabulary, associations, and debates that come along with this culture.

Debates about the accuracy or relevance of certain aspects of autism culture being performed, performatively instantiated, and taken up might be raised: some promoted treatments might be accused by some of being self-interested scams or fervently believed but false notions, other aspects of autism being presented might feel more or less relevant to groups or individuals. These processes are not always easy or straightforward, especially as parents try to take up these ideas and apply them in their everyday lives. In this case, local moral words and their ideas of personhood, comportment, and development do sometimes clash with the values, mandates, and “best practices” of a globalized or nationalized autism culture. As in the example above, a Javanese fostering and hence anticipating of *isin*, which in some cases can manifest in silence or avoidance of interaction, and of *ngalah*, or putting other’s needs before one’s own for the benefit of family harmony, a Javanese mother believes she has misrecognized symptoms of autism for a precocious cultural maturity. From one perspective, the situation may appear simple: mothers, who are overwhelmingly unfamiliar with autism, need to be taught its early signs so that they

might respond proactively to their child's developmental difference to mitigate these differences and minimize their impact to the best of their ability. In other words, an understanding of autism will necessarily change mother's behaviors in certain contexts.

However, as situations analogous to this multiply— as alternative interpretations of children's behavior are promoted and adjustments of parental behavior is encouraged—some complicated questions arise; is the focus of intervention on the child with autism, or actually on the Javanese or Indonesian family itself? In being trained to look for or respond to autism, are Javanese or other Indonesian families being in a sense “trained out” of culturally specific values or practices that are then framed as “wrong”? And if these dynamics are being enacted across the nation, in a process of fostering social change at interconnected sites of disability and autism culture, what are the intersections or ramifications of this process when we consider other sweeping national changes that Indonesian families are undergoing?

Chapter Five

On Food, Love, and Bad Behavior: Family Interventions and Conventions of Care

Introduction

The example provided in the previous chapter of learning to re-interpret a quiet baby using the framework of autism intervention rather than the framework of Javanese philosophies of development, personhood, and childrearing is just one example of how parents of autistic children themselves must learn how to react to and interpret their children's behavior differently than they might otherwise, and shift their own behavior accordingly. In the trajectory encouraged by some autism educators and awareness advocates, once parents have been inducted into disability culture and come to realize that they don't need to be ashamed of their children; once they have been enculturated into autism culture and learned what it is their child "has," learned to recognize the signs of autism and begun to master the specialized vocabulary and esoteric knowledge that goes along with getting a handle on autism; then they must turn their focus to themselves and their own behavior. From the perspective of many specialists in autism education, children with autism need certain crucial things from their parents and families in order to be optimally educated and socialized, and from the point of many specialists working in Indonesia, they are not adequately getting these, particularly because of certain characteristics of Javanese and Indonesian parents and families.

Indeed, some interventionists believe their primary task and goal is to change the behavior of Indonesian families such that they might be more effective in raising their autistic children—some perceive their own attempts to do so as thus far unsuccessful. For example, in an interview Gayatri Pramodji, the previously introduced ex-hotelier turned activist and founder of The Autism Society of Indonesia told me,

What I really would like to find out, what I haven't been able to find out, is the key to behavior change. And I'm not referring to the children here, that part's actually easy! I'm talking about the key to behavior change for Indonesian parents!" (Pramoedji, 2010).¹¹⁸

She explained that up until this point, implementing behavior interventions in the family has been very difficult. She has studied with behavior therapists and special education experts in Australia, where her son was receiving therapy for his autism, and where she earned a Masters degree in health counseling and learned tools of behavior intervention. Her goal is to disseminate these tools and these interventions, but she feels that getting families to actually carry out the interventions is challenging. This was a common theme that I encountered in interviews with therapists and parents alike, causing charged and often emotionally fraught debates about the "right" way to parent an autistic child, where significantly the "right" way was often not the typically "Javanese" or "Indonesian" way. Through these debates, complex concerns about the Javanese or Indonesian parenting style emerged, mobilizing discourses of indulgence and inconsistency, permissiveness and weakness.

Autism, Feeding Practices, and the "Wrong Kind of Love"

During the course of my fieldwork I found that perhaps in no area are debates about parental behavior and childhood autism more heated than on the topic of food, both in terms of *how* and *what* children with autism are fed. In folklore and anthropology it has been documented and illustrated how in normative contexts food, foodways, and practices of food preparation and consumption are often highly symbolic, communicating cultural values, philosophy or ideology, identification, and sentiment (Jones, 2007). As such, foodways are invested with emotion (Choo, 2004; Dusselier, 2002), and may communicate feelings of wellbeing, consolation, and reward as

¹¹⁸ Pramoedji, Gayatri. Interviewed by Annie Tucker. Jakarta, 13 July 2010.

well as teach and indicate aspects of status and social relationship. Feeding and eating practices also socialize children by contributing to the symbolic expression of values (Bossard, 1943; Ochs, Pontecorvo, & Fasulo, 1996). Food becomes even more significantly charged in the context of autism for two reasons. The first is food's perceived relationship to a broader repertory of self-care and living skills; for children whose motor, sensory, and social deficits may mean that they are dependent on others to complete various daily tasks, being able to feed themselves is seen as a basic element of self-sufficiency and a stepping-stone on the path to a more complete independence. The second reason is the connection many Indonesian parents and specialists see between diet and the general health of autistic children, favoring stringently restricted diets that they believe counteract some of the allergic reactions and internal imbalances that exacerbate (or to some minds, even cause) the symptoms of autism. Looking through both a local cultural and a globalized autism intervention lens, then, food and eating practices are powerful socialization tools tied to other significant aspects of health and development. But in thinking through how this socialization should work, and in determining what aspects of health and development should be given priority, autism intervention is sometimes at odds with the feeding practices of Javanese families with autistic children.

The problem of food and family behavior first emerged for me as a point of focus when I was listening to an anecdote provided by the autism educator and consultant Fred Vrugteveen who splits his time between the Netherlands and Indonesia. During a question and answer period at the "Prospect of Empowerment for Autistic Persons" Conference held in Yogyakarta, Fred was trying to explain that autistic kids need structure, in terms of regular schedules, clearly stated and consistently enforced rules, and mapped out goals for the child's development. From his vantage point on an elevated stage facing an audience of Indonesians, he voiced his own

frustrations at translating this goal of “structure” into actual behavior in Indonesian families. He mentioned a case of a family with an eight-year-old autistic son, and re-enacted a scene from his therapeutic practice with the family for the audience.

I was sitting at the family’s kitchen table and I said to the boy’s mother, “Well we need to build the skills for your son’s long-term independence starting now, so let’s work on eating. The child needs to be able to feed himself and eat on his own.” The mother agreed.

Here Fred role-played the mother in question, mimicking, “I totally agree, independence is important and as part of that independence and he needs to be able to eat on his own.”

He continued his story,

Our meeting went on and about five minutes later, the child approached his mother. She promptly reached out and spoon-fed the child some rice!

Fred then said to the audience with over-dramatized incredulity, slapping his forehead, “She already forgot what we had just talked about!” (Vrugteveen, 2011).¹¹⁹ The audience laughed.

In Indonesia spoon-feeding or hand-feeding, known as *suapin*, is a common practice in many families. The youngest children just being weaned will be spoon-fed, and it is a common sight to see mothers with their little ones nestled in a sling on one hip and carrying a container of rice porridge, the spoon dipping into food at regular intervals. Babies are spoon fed in the home, in malls, at food stalls, and even on the back of a motorbike while the family is zipping along. The practice continues for toddlers and even children as old as six or seven. A common sight in any neighborhood or private yard is a Javanese child being chased down by his or her mother or older sister or nanny to be spoon or hand fed in the middle of whatever else he or she is doing. This spoon-feeding may be done surreptitiously, slipping the food into the child’s mouth as if the

¹¹⁹ Vrugteveen, Fred. Presentation at Prospect of Empowerment of Autistic Persons Conference, observed by Annie Tucker. Yogyakarta, 19-20 November 2011.

caretaker was hoping the child wouldn't notice, or just as often with a cajoling or coaxing demeanor.

Beyond being a product of sheer habit, this common practice is redolent with meaning, expressing and instantiating core aspects of Javanese personhood as described in Chapter Three. Perhaps most importantly, *suapin* expresses social values of interdependence. First of all, it is a practice of anticipating the needs of others and in doing so protecting them from negative feelings: by spoon-feeding a child before it asks for food, the mother or caretaker is indicating that she can sense or anticipate the child's hunger, and would not wait until the need got so pressing that the child would experience discomfort or have to speak up. Furthermore, spoon-feeding inculcates interdependent social values in the child, indicating that no one eats on their own, or even on their own schedule, but depends on others to eat and submits to others' will. Such spoon- and hand- feeding, even at a similarly advanced age, is present in other interdependent cultures, which anthropologists have interpreted as being practiced to a similar effect; in her work in Bhubaneswar India, Susan Seymour observed Old Town mothers and caretakers hand-feeding children as old as ten, which in her analysis physically enforced interdependence (Seymour, 1999, p. 76) and in her work in Bali Margaret Mead noted children being "fed in a helpless prone position as a mound of pre-chewed food is piled on its mouth" (Mead, 1970, p. 206), and came to similar conclusions. Both of these anthropologists saw an instructive and disciplinary aspect to this "indulgent" hand- or spoon- feeding, which trained the child in an obedient acceptance of whatever the parent gives or desires, no matter what the child is involved in or would prefer to be doing.

The deep symbiosis with the mother, grandmother, older sibling, or other care-taking figure ideally later translates into the sense of identification, gratitude, but also submission and

indebtedness described in the previous chapter as being so central to concepts of Javanese personhood.¹²⁰ Ultimately, however, spoon-feeding is an expression of love and care, emotions that can be captured by the Indonesian word *sayang*. This may be the case for even typically developing Javanese parents and children; when grown children go home for a visit, even if they are successful professionals, they may be briefly and symbolically spoon- or hand- fed by their parents. Husbands and wives may also spoon- or hand- feed one another as a romantic expression of “babying,” indulging, and lovingly tending to one another (Field Notes, 2010-2012).

The relationship between food, *sayang* or loving care, and “indulgence” in Indonesian families was further illuminated for me in an interview with Jerry, the older brother of a young autistic man, Bima. As introduced in Chapter Three, both grew up in Yogyakarta; Jerry is now a young man in his early twenties while Bima is still a teenager, but Bima is already taller and broader than his older brother, and somewhat overweight. Jerry explained that this is because,

my mom, if she’s feeding us, she gives him extra. I eat maybe twice a day, three times a day, my little brother eats five times a day! So his body is as big as it is. I always, every day, I ask my Mom to make Bima’s portions smaller, or even put him on a diet. But, because my mother cares about him so much (B. I. *saking sayang*), because she already loves my little brother too much...[she doesn’t change her behavior].

When I further asked Jerry why he thought it was hard for his mother to curb Bima’s food intake, and what he thought she was getting out of feeding him so much, Jerry answered,

It’s the feeling of indulging. Feeling that he is protected by my mom and dad, feeling like he is being noticed and taken care of (Jerry, 2011).¹²¹

¹²⁰ Perhaps this is why the give-and-take dynamic of *suapin* is used as a common metaphor for the ever-present bribery in Javanese and Indonesian culture: in essence, the meaning is, I indulge you and give you more than you need now, with the expectation that you will give me something I need in return in the future.

¹²¹ Jerry. Interviewed by Annie Tucker. Yogyakarta, 13 October 2011.

Given the significance of food in typical Javanese families, in the context of autism food may play an even more significant role than usual for families who may have difficulty communicating with their child verbally, or remain unsure about how much their child understands their environment. For these families, fulfilling their child's material need for food may feel like the most important form of communication. In my interviews with Jerry, he said the hardest thing about having a younger brother with autism is the challenge to communication; because they cannot really talk with one another, it is hard for him to feel like they have a connection. He fiercely loves his younger brother, assumes a large amount of responsibility in caring for him, and defends him against callous or insulting family members or strangers. But what Jerry longs for, and what he finds it so difficult to foster, is a feeling of a back and forth, a give and take, an exchange. When I asked Jerry what he did to try to get closer to his brother, or to build communication or intimacy he answered,

Well at the heart of it, I fulfill his needs. Bima likes to eat. So, I drive him around, wait for him, sit around with him at restaurants and food stalls. (*ibid.*, 2011)

The anticipation and fulfillment of needs, and a sense of loving indulgence, is a powerful sentiment in Indonesian families that is practiced, among other ways, through food. Feeding and being fed leads to warm feelings, a sense of role fulfillment and nurturance on the part of the person feeding, gratitude and submission on the part of the person being fed, and an experience of communication and connection on both sides.¹²² Therefore, families may continue to spoon-feed their autistic family members or feed them much more frequently than is nutritionally

¹²² Perhaps it is also relevant to note here that in behavior intervention it has been recognized that food is a "primary re-enforcer," or something that meets basic biological needs, hence is often the first reward used in training children in behavioral modification, e.g., if a student performs a desired task directly, he or she will be given a piece of candy. A sweet or tasty food is seen as being the most concrete way to reward a child, and hence indicate that their behavior is good or desirable.

required.¹²³ From this perspective they are fulfilling their family member's needs, communicating with them, and perhaps providing them ongoing training in interdependence.

In addition to these sentimental and didactic purposes, parents or other caregivers are constantly chasing down their children to make them graze and snack for reasons of physical health. To the Javanese conceptualization, a plump person is a healthy person. This is because plumpness indicates happiness and relaxation, and in a holistic conception where the body is connected to the state of mind, a happy and relaxed person is a healthy person. Tourists and anthropologists alike have remarked that Javanese people freely use the descriptor *gemuk*, which means fat or pleasingly plump (Ferzacca, 2001), and are often quite persistent in their invitations to eat. This can be chagrining or worrisome to those Euro-American foreigners who strive for a thin, muscular body as the ideal indicator of fitness and beauty, but in the Javanese physiology thinness is associated with worry and stress, and hence vulnerability and ill-health.¹²⁴ I was surprised to learn that from some locals' point of view ice cream is thought to be a "health" food, specifically because it is known to make you fat (Field Notes, 2012). While many Indonesians do engage in certain forms of fasting—for example as part of an intentional practice to achieve a goal, for purification, or during the holy month of Ramadan—those kinds of fasts are for adults engaged in ascetic practice, not for growing children. This paradigm of health further factors into practices of *suapin* and an encouragement of frequent or even somewhat forced eating, especially for children. As one mother explained,

[Our child] didn't like to snack. But since we didn't know our child was autistic, we *forced* him to snack. So, you know, chocolate, chicken, fried noodles. It was forced on him, even though he didn't want to eat. Even just milk was hard. But

¹²³ For similar instances of food, and in particular, over-feeding and over-eating as expression and communication of love, see Liburd 2003.

¹²⁴ For women *langsing*, or "shapely," is a compliment; *khurus*, meaning "thin/skinny" is taken as an insult by both women and men (Field Notes 2012).

we thought at that time—classic!—that little kids have to snack and have to drink milk (Ningsih, 2011).¹²⁵

Feeding, whether directly spoon-feeding or later merely providing frequent meals and snacks, is clearly redolent with sentiment and social meaning as well as vernacular ideas about healthy development. As such it is a significant interpersonal practice that is implicitly related to other forms of social relationship within the family.

Yet from many interventionists' perspectives, Javanese and Indonesian family practices of spoon-feeding or over-feeding their autistic family members is seen as preventing them from learning the building blocks of independence and self-care, "spoiling" them, and perhaps actively damaging their health. Here I want to introduce another component to the discourse on food in the context of autism in Indonesia, which heightens the stakes of its significance. In the emerging debates over food, foodways, structure, discipline, and parental responsibility in autistic children's long-term health and development, it is integral to understand the role of restricted diets. The DAN! approach has been influential in Indonesia, due to its being utilized by some of the most well-known and vocal practitioners in the field, including some of those whom I introduced in Chapter Two; Dr. Rena Adeline and Reni Yulia at The Biomedical Intervention Clinic, Dr. Melly Budiman who is in private practice and affiliated with the organization Autism Indonesia, Dr. Rudy Sutadi at Kid ABA, Any Sonata Bagwanto, and others. Therefore, a significant number of Indonesian parents and therapists I encountered support restricted diets as the most significant way to positively impact the health and development of autistic children. Like behavior therapists and interventionists, these restricted diet supporters also emphasize the need for structure in foodways. If Fred, the consultant quoted above, supports structure in feeding as a building block towards independence, wherein structure

¹²⁵ Novi. Interviewed by Annie Tucker. Yogyakarta 13 October 2011.

primarily refers to consistent rules about self-feeding, those in favor of restricted diet support structure in eating, where ‘structure’ primarily refers to what is being eaten, because they believe that food content will actually remediate or exacerbate symptoms of autism. Both are united, however, in faulting Javanese families for being lax or incorrect in their attitudes towards structuring meals and eating practices. As the mother quoted above, who used to enforce constant snacking for her son, including foods like instant noodles and sweets (“Classic!”), now says

It turns out we were wrong! At that time we saw, which actually we were aware of but we didn’t give it any special meaning, because we weren’t thinking that way, was that if he finished eating sweet foods or drinking milk, or eating ice cream, it was hard for him to sleep. He’d be up until 12:30, 1:30. But we never thought, oh that’s a symptom of autism, never (Ningsih, 2011).¹²⁶

Uni, a mother of a teenaged boy with autism, agreed with this sentiment. She told a story of an autistic classmate of her son’s being sent to school with donuts to eat every day as a snack, even though in her mind it was clear that such food had negative effects on his health and his behavior. She said that she herself understands those eating habits weren’t right but believed the parents persisted because they “love their child so much, with the wrong kind of love” (B.I, *saking sayang, dengan sayang yang ngak benar*) (Uni, 2012).¹²⁷ Yet soon after this statement in the same interview, she shared the difficulties she has had herself with adhering to a restricted diet with her own son. First and foremost, she can’t bear the feeling of denying her child anything, can’t stand to think she might be the cause for him feeling sad or disappointed. She felt like it was just a part of any child’s character (B.I. *namanya anak-anak*) to want to eat sweet things, and it was very hard to say no or deprive them of that experience. Other parents expressed how difficult it is to keep a child on a restricted diet because it differentiates the child

¹²⁶ Ningsih. Interviewed by Annie Tucker. Yogyakarta 13 October 2011.

¹²⁷ Uni. Interviewed by Annie Tucker. Yogyakarta, 16 January 2012.

from the rest of the family. Forcing autistic children to eat something different from the rest of the family feels like excluding them,¹²⁸ but it is difficult to change eating habits for the whole family, who may have developed a “Javanese” taste for sweetened foods or foods containing forbidden ingredients. Food is part of a local cultural and familial identity, from which the child on a special diet is in part cut off.

All this may lead parents to feel like they are actively harming their children with a restricted diet, when in the Javanese and broader Indonesian conceptions of proper development they should be preventing their child from experiencing negative feelings, such as frustration and disappointment, not just because they are in and of themselves unpleasant, but because they can lead to further ill health. A child who is clearly already experiencing some kind of developmental disturbance should not be subjected to further negative feelings; disappointment, in folk psychology, might lead to *ngamuk*, another major issue for many children with autism. In addition, adopting a restricted diet may cause children to lose weight, because they are not consuming as many carbohydrates. This leads families to worry because their child is “getting skinny” which as I described above in Javanese culture is associated with feelings of stress, worry, confusion, and unhappiness.

In short, restricted diets go against many of the culturally shaped parental instincts. Javanese parents have to keep their child safe, happy, and healthy, in fact go against food-based norms of expressing love and affection. However, just as Sri Murni came to believe that her baby’s quietness was not in fact a positive sign of maturity but an early sign of autism and hence qualified her earlier interpretations as “wrong,” parents and therapists who have received information about the potential link between autism and diet and are influenced by behavioral

¹²⁸ For similar instances of dietary needs making people feel excluded from families at mealtimes or special events see Broom and Whittaker 2004; James 2004.

and pedagogical special education techniques, have come to interpret food-based Javanese expressions of love and care as the “wrong kind of love.”¹²⁹

Indeed, in conversation about the topic of food Any Sonata Bagwanto, an autism activist and educator, the founder of the LRD newsletter, and a restricted diet enthusiast, told me forcefully, “These parents say, ‘Love is food and food is love.’ But love is an excuse, and the excuse is love.” She argued that many parents are merely habituated to certain feeding practices and unwilling to move out of their “comfort zone,” and their problems carrying out diet plans and adjusting food practices is just one manifestation of this unwillingness (Bagwanto, 2012).¹³⁰ Any’s approach is to help these mothers move out of this comfort zone by meeting them half way, translating GFCF diets into cultural imagery that she thinks they will understand. She offers private workshops on diet modification in her own home and gives similar talks at various workshops and events. Her task, in a comparatively short period of time, is to try to explain what foods are unhealthy to eat and why, and impress on the mothers the importance of pursuing and strictly adhering to the diet regimen. As in the previous chapter behavioral concepts of autism are translated into vernacular understandings of emotional expression and behavior in the case of tantrum/*ngamuk*, so Any tries to translate the theory and practice of a GFCF diet into a socio-religious framework she thinks local mothers will understand.

Autism Halal: Translating Intervention into A Familiar Socio-religious Framework of Acceptable Behavior

I observed a diet information session Any held in Bintaro with a group of parents and teachers from a small private school serving children on the spectrum in a nearby but less

¹²⁹ Similar problems are encountered in other populations and other contexts wherein people feel they must change their diet or the diet of their loved ones in the name of better health, but have difficulty doing so because of the rich cultural, personal, and communicative power of food (Jones, 2007; Chapman & Maclean, 1993).

¹³⁰ Bagwanto, Any Sonata. Interviewed by Annie Tucker. Bintaro, 24 January 2012.

affluent neighborhood of Tangerang. Any herself is Christian, but like many of the mothers Any works with, the attendees were all Muslim. Also like many of the mothers she counsels, after hearing a primarily scientific presentation about the physical effects of forbidden foods on the body, these women wondered how strictly they had to follow the diet: wasn't it OK to give their children just a little bit of the foods they loved, perhaps just one bite here and there, or perhaps just on weekends, or couldn't they just eliminate some foods containing gluten or casein or sugar while feeding their children others? To explain the consistency required, Any used a metaphor that was powerful and familiar to the women and asked them to explain to her the difference between *haram* and *halal*. According to Muslim belief, *haram* can be glossed as indicating those things that are forbidden or sinful, while *halal* refers to those things that are pure or acceptable. These words can be applied to behavior, such as smoking or premarital sex, which are *haram*, but also of course determines what is acceptable or unacceptable for devout Muslims to eat or drink; the two most commonly known forbidden, or *haram*, foods under this law are alcohol and pork. Any asked the women to reflect on their own eating practices: was it acceptable to eat "just a little bit" of pork, or food cooked in pig lard? Was it OK to eat pork just on weekends? The women replied that of course it was unacceptable.

They then were introduced to a menu of 'autism *halal*' foods prepared by Any's staff including a vegetable fruit smoothie and a bowl of noodles cooked with organic rice-flour preservative-free instant noodles and veggies free of MSG. Some of the women claimed enthusiastically that the food tasted good, while others somewhat guiltily reached for the provided sugar, adding a few extra spoons to the smoothie and dousing their noodles with hot chili sauce before they could find the offerings palatable. After the information session, the women browsed the selection of restricted diet-friendly foods that Any has for sale in a small

shop in the front of her home in order to provide easier access to Indonesian families seeking to follow this diet.¹³¹ All of the women, whether they had claimed to like the taste of the food or not, were dismayed to see the high price of this food—the organic gluten-free rice noodles they had just eaten cost 45.000 Rupiah a package, ten times more expensive than the regular, readily available instant noodles.

As with examples in the previous chapter, in her outreach sessions Any is interpreting or “translating” a concept of autism intervention into a local idiom that she believes women will understand. Any believes if individual parents only could understand the concept of structuring meals in a way familiar to them, they would then be able to stick to the diet regime she is proposing. By pathologizing parental behavior as it currently exists as “sinful” in addition to educating them about proteins, biochemical reactions and physiological effects, Any aims to create change by transferring knowledge and skills and by using socio-religious metaphors and idioms of practice in order to improve adherence to a DAN! diet.¹³² The challenge for Any in this situation is; how can she get Javanese families to give up those practices and beliefs that are not in accord with autism intervention practice, or how can she get them to learn and implement autism interventions despite those beliefs and practices.¹³³ From such a perspective, some Javanese and Indonesian practices in foodways and childrearing are a complication and

¹³¹ She also sells these foods, and products such as organic soap and cleaners and books on autism, to locations throughout the archipelago via mail order.

¹³² To reiterate an earlier point, this diet has not been shown to significantly alleviate the symptoms of ASD in clinical trials; while it may lead to general improvement in certain children, the mechanism of such an effect still remains unclear.

¹³³ Here I am following David Hufford’s framework regarding medical doctors and folk medicine in the clinic (1994, p. 125), wherein he asserts that the primary issue for many health care professionals is that of “How can we get patients to give up those health practices and beliefs that are not in accord with medicine or, failing that, how can we get them to follow medical advice regardless of those beliefs and practices?”

impediment to the treatment of autism and the fostering of a healthy development for the autistic individual.¹³⁴

The metaphor of *haram* and *halal* is powerful and convincing for Muslim audiences, in that it makes the concept of “forbidden” foods immediately clear. This is useful for Any, who has a short time to convince parents of her position and who understands that scientific explanations might not be compelling to, or understood by, parents. But this translation may ultimately not be effective: for those mothers who don’t end up following the diet, it may leave a sense of being accused of feeding their child sinful food, and by extension leave them feeling blamed for their child’s autism. Indeed, in talking to other mothers I heard that there was some animosity in parent communities towards Any, and they took the opinion that she was just an aggressive “pusher” of the specialty products she was trying to sell, trying to make a profit for herself.¹³⁵

While I don’t believe this to be the case, in framing parents as lazy (in personal conversations and interviews) and/ or sinful, Any is choosing to overlook the emotional, psychological, and spiritual etiologies that are guiding parents’ feeding behaviors with their children, dismissing their “love” as merely an “excuse.” Family testimony suggests that the response to children with autism is in fact shaped by familiar norms of Javanese parenting and habits of expressing love via food. In the case of GFCF and other restricted diets, practices of feeding and childrearing are further reinforced by economic limitations. The result is that many parents are put between a rock and a hard place with feeding, and by extension “loving,” their children the “right” way.

¹³⁴ And here I follow Jones’s analysis of Hufford’s position (Jones, 2007).

¹³⁵ None of the Islamic mothers I observed took issue with Any’s use of *haram* and *halal*, although it might be interesting to hear what religious leaders might have to say about the use of these terms for this purpose.

Fostering Functional Adults: Anxieties in and about Indonesian Family Practices

I found that these discussions about the “right” and “wrong” kinds of love in the Javanese family may start or center around feeding practices, but soon slip or widen in scope to encompass additional aspects of the Javanese family, ultimately concerned with a whole host of sentiments and practices—a repertoire of as Jerry phrased it above “indulging,” “protecting,” “noticing” and “caring”—that become cause for worry, and that some believe should be changed.

Much as Fred intimated in his narrative about a lack of “structure,” food practices are part of broader norms of family practices that some see as overindulgent and unhelpful for autistic children. For example, Treesy Prawdrosurojo, an American-educated therapist working at the Jakarta-based Institute for Psychological Assistance and Mediation sees spoon-feeding or over-feeding as just one expression of over-permissiveness and a “coddling” in Indonesian families that prevent kids with special needs—and even typically developing kids—from achieving a satisfactory level of independence. She said that special needs kids are “overprotected by their parents like an expensive crystal” because “Indonesian families don’t understand tough love” and that even in dealing with typically developing children, “before the child has even fallen down their parents have already prepared a mattress” to ease the blow. Treesy said she preferred the American approaches to both mainstream and special education she encountered when she was getting her psychology degree and sending her child to public school in Southern California, which emphasized individual accountability, independence, and a value placed on learning through mistakes, even failure (Prawdrosurojo, 2010).¹³⁶

¹³⁶ Prawdrosurojo, Treesy. Interviewed by Annie Tucker. Jakarta, 14 July 2010.

Diyah Puspita, the founder of Sekolah Mandiga in Jakarta, also considers spoon-feeding just one aspect of a “babying” approach that continues indefinitely, so that in addition to being fed some autistic family members are also being toileted well into their adolescence, with no expectations for them to ever take charge of themselves. In this case, the permissiveness and protectiveness that often accompanies early childhood in Java in the context of autism and developmental difference continues into adulthood. The sentiment and practice of self-guided development—a reticence to “force” a child to do something they have not yet exhibited a readiness to do, an expectance that the child himself will indicate when he is ready to move onto the next developmental stage by displaying increasing self-control and awareness—actually prevents autistic people from being encouraged to become self-sufficient when they might be quite capable of becoming so, or prevents parents from providing the behavior intervention that through strictly-enforced rules and goals will push the child to develop these self-care skills of independence (Puspita, 2010).¹³⁷

In one final representative example of the way many interventionists see Javanese and Indonesian family practices I will quote from my interview with Agus Haryanto, trained as a therapist and educator and now working as the director of a private school for autistic children based in Bintaro, South Jakarta. Agus also criticizes the common “Indonesian” approach to raising children and prefers what he sees as a Euro-American approach. One of his favorite television shows is *Nanny 911*, in which a British nanny visits the homes of American families with “problem” kids and teaches them how to enact proper discipline. Agus explained to me that he prefers the nanny’s strict approach as opposed to the Indonesian approach because

A number of Indonesian families who have handicapped children... because they are too accepted, because they are too protected, because they are given too much, that is the primary reason, that ruins independence, the child’s independence.

¹³⁷ Puspita, Diyah. Interviewed by Annie Tucker. Kebayoran Baru, 13 July 2010.

And they forget that these children have a pattern that is delayed (Haryanto, 2012).¹³⁸

To Teeryse and Diyah and Agus, Javanese and Indonesian parents baby and indulge their autistic children and in doing so fail to foster a functional independence. Teeryse and Agus in particular make this judgment in explicit comparison to Euro-Americans who they feel are doing it “right.”

In the context of autism intervention, when therapists and educators are referring to the challenges of getting parents to change their behavior—provide “structure” and “tough love” and increased expectations that might mean the child has to endure some failure before they can succeed, rather than being “too accepting” or “too protective” they are often either implicitly or explicitly referring to behavior interventions that fall under the rubric of Applied Behavioral Analysis (ABA), or have been influenced by the principles of ABA and the values ABA embodies. ABA is the most commonly endorsed and covered therapy in the United States and Canada (Dillenburger, Keenen, Dogherty, Burn & Gallagher, 2012; Perry & Condillac, 2003).¹³⁹ The principle behind ABA is that behavior can be shaped through the response to that behavior (operant conditioning), most commonly through reacting to desired behaviors with positive reinforcement such as praise or tangible rewards (e.g., saying “great job!” or giving a high five, giving child favorite food, stickers, or access to desired activity) and reacting to undesirable behaviors, such as aggression or tantrums, with “consequences” (such as saying “no,” giving a time out, or taking away privileges).

Situating behaviors within a dynamic and relational environment, ABA asks therapists and parents to think about the function the behavior is serving for the child and the “ABC’s” of

¹³⁸ Haryanto, Agus. Interviewed by Annie Tucker. Bintaro, 27 January 2012.

¹³⁹ The philosophy behind ABA has evolved, can be applied in a variety of settings from more strict “discrete trial” to naturalistic environments, and is quite complex. One can get a Master’s degree solely in its behavioral science. Space limitation precludes an extensive discussion of ABA here; rather, I try to illuminate some of its core practices and principles in order to explain how it might feel counterintuitive to a Javanese family. Future studies about the cultural efficacy of ABA in Javanese Indonesia surely would prove illuminating; such studies have been carried out in China (Liu & Li, 2007) and Wales (Jones, Horger, Hughe, Williams, Jones, Mosely, Hughes & Priss, 2011).

any behavior—the antecedent, the behavior, and the consequence. Understanding what precedes the behavior helps explain what function the behavior might be serving for the child, while attending to the consequences helps understand what message is being sent to the child about that behavior, with the ultimate goal of teaching the child pro-social and adaptive “replacement” behaviors. So, for example, if every time a child hits a therapist they are allowed to stop doing an un-favored task such as schoolwork, then it can be determined that the hitting is designed to “escape” and therefore the appropriate response would be to not respond to hitting by releasing the child from responsibilities, but instead to teach the child a more socially adaptive “replacement behavior” such as asking for a break.

ABA also is used to encourage desired behaviors such as using speech to communicate, and to provide targeted training for desired skills, from getting dressed or using the bathroom independently to self-soothing to participating in group activities, all designed to progress on a schedule from accomplishing small goals or individual aspects of a larger set of behaviors to the whole complex tasks. It shapes various behaviors through practicing the smaller components of these; this involves strategies such as “chaining”—for example if you were to teach a child to brush her teeth first you teach the task sequentially in its constituent parts, first only rewarding for going to get her toothbrush and toothpaste, then for getting her toothbrush and toothpaste and unscrewing the cap, then getting the brush, paste, unscrewing the cap and squeezing out toothpaste, and so on. Techniques can also be used to build endurance for particular activities—for example if you want a child to be able to sit still first you give a reward after 30 second increments, then minute increments, then a minute and a half and so on.

ABA is favored by many interventionists because it accomplishes two main things: it makes rules and expectations as explicit as possible for people with autism, who for various

physiological reasons may need as much consistency, clarity, and routine as possible. It also makes progress measurable and observable for parents and therapists; if the child at first could only sit for ten seconds and now can sit and attend to a task for five minutes, then that is considered more tangible than the general sense that the child “seems calmer” or can “focus better.”

However, there are aspects of ABA that seem counterintuitive to some Javanese and other Indonesian families. The first is that, in ABA positive reinforcement is conditional on performance in any given situation; the child is not to be told they are doing a good job or “rewarded” with things they want or enjoy until they have completed the desired task or engaged in the desired behavior. They also will have to be told “no” when engaging in behaviors that are unacceptable. Furthermore, in ABA goals are set to exceed the child’s current capabilities, meaning that they may at times feel frustrated. ABA often involves a level of conflict between parent/therapist and child, as the older person is framed as clearly “in charge” dictating behavior and the child is supposed to “obey” and, via the process, learn and ultimately internalize desired ways of acting and interacting.

While perhaps a familiar dynamic to those American parents implementing ABA who are surrounded by implicit beliefs about “power struggles” (Hoffman, 2013) between parents and children and the “generative tension” (Rothbaum, Pott, Azuma, Miyaki & Weiss, 2000) inherent in parent-child relationships that result in successful maturational processes, this goes against the Javanese mother’s primary task, which is to keep the child safe and help the child develop by avoiding frustration and disappointment, which are destabilizing and unhealthy and make the child vulnerable to spirit possession or illness. To reprise from Chapter Three, goals of Javanese socialization on the part of the parent are to cultivate a sense of symbiosis, unity with others, and

sensitivity to others, train for the habit of passive resistance and avoidance of conflict. From a Javanese point of view, engaging in a power struggle with one's child would be pointless, misguided, embarrassing, and even potentially dangerous for the child's health. As Douglas Hollan noted in his work in Indonesia, the continued tolerance for children reflects the belief that

it is pointless to attempt to discipline children before they come to 'know', 'understand', and voluntarily accept the rules of proper social etiquette. But it also reflects a concern that older children may also become sick if they are too often denied their wishes or too often forced to do things against their will (Hollan, 1990, p. 372).

These values dictate a particular response to children's' behavior that might be at odds with those dictated by the principles of ABA. This can be illuminated with the example of a child crying or screaming in reaction to the frightening stimulus of a clap of thunder. Responding to an ABA rationale, a parent might be counseled not to comfort the child because comfort is pleasurable to the child and therefore "reinforces" the "tantrum behavior" as a way of getting attention or comfort from a parent when there are other more desirable ways to do so, such as asking for a hug or saying, "I'm scared." This example, taken from an ABA website "Healing Thresholds, Connecting Community and Science to Heal Autism"¹⁴⁰ stands out to me in its direct contrast to Hildred Geertz's description of how parents see it as their responsibility to protect their young child from shock or startle by covering their child's ears with their own hands at the sound of thunder (Geertz, 1961). Javanese mothers are trying to intuit what their child needs and provide it, protect the child from shock or disappointment by giving it what it wants, and trying to mitigate conflict. These goals and practices are not abandoned once a family knows that their child is autistic; if anything, they may be further emphasized or embraced more wholeheartedly. If the child appears to be experiencing a developmental delay, then implicitly

¹⁴⁰ Available via <http://autism.healingthresholds.com/therapy/applied-behavior-analysis-aba>. Retrieved 28 February 2013.

those things that are thought to support their development may be more aggressively pursued.

As one mother Nana described it:

We as parents can't push them to do whatever we want. We just give him the chance, and whatever we have to help them grow into themselves. And we keep telling them that they are special, that's what they need. And giving them love, and safe, as long as they need. I think that is the most important (Nana, 2010).¹⁴¹

The normative Javanese approach to childrearing is somewhat self-guided and uses minimal discipline. Many parents want to avoid seeming harsh or frightening, and feel quite uncomfortable with scolding or punishment or even giving their children directives. Many mothers and teachers said to me, looking quite uncomfortable even at the idea that, “we cannot force children” to obey or do something they don't want to do. In *The Javanese Family*, Hildred Geertz noted low affect and minimal response when a child misbehaved in favor of patient repetition. Other, more contemporary, scholars of Javanese culture have noticed a hesitance or reticence to say no to anyone directly, including children.

the negator is rarely used. The active bearers of Javanese tradition say that *inggih* (yes) does not always mean agreement, in fact it can have the opposite meaning. In daily life, Javanese people frequently use the word *inggih* (yes) with a certain facial expression, which means *mboten* (no). Hence, someone who is being addressed is expected to have a full understanding of the situation and context in order that he or she does not misunderstand (Sutarto, 2007, p. 45).

In my own field observations, parents seem willing to wait until children develop enough understanding to know when they are doing something wrong without having to be scolded. I have seen Javanese parents patiently enduring being repeatedly slapped on the head and face by their children, and a weary mother riding the bus repeatedly asking her young daughter, who was standing on the only available seat, whether she would mind “sharing” her seat with her mother,

¹⁴¹ Nana. Interviewed by Annie Tucker. Solo. 15 July 2010.

only to be repeatedly denied.¹⁴² My observations are not substantively different from the kinds of interactions Ward Keeler described witnessing in the early 1970's, saying

True differences of opinion are difficult to express in Java, direct criticism almost impossible [...] The treatment of small children is similar. If a small baby picks up a knife his mother does not wrest it from him immediately but tries to distract him with something else. Once my neighbors left their two-year-old son to visit their grandparents in another hamlet for a couple of days. When his mother went to get him, he refused to come. His mother was in tears when she told me the incident the following morning, but when I asked why she didn't insist that the boy come back with her she said simply, 'He didn't want to' (Keeler, 1975, p. 98).

In a typical case, outside of the context of disability, there are a variety of areas where a stricter or more explicit approach to discipline is taken—external authority figures, such as schoolteachers, play a large role in enforcing proper behavior via scolding and punishment, and older children may be temporarily sent to stay with extended family members or relatives, who also may play a more explicitly disciplinary role than parents (Geertz, 1960). Other children mature by becoming an older sibling, developing a sense of shame in asserting their will onto others, and understanding that they are no longer in the position to be indulged but must now indulge the youngest member of the family (Keeler, 1975, 1987, 1983). It may be that in the case of autism, families are waiting for such a mature awareness to develop and behavior to

¹⁴² Throughout this chapter I am using the phrase “Javanese or Indonesian” to indicate that in many Indonesian cultures there is an overlap in values with regards to childrearing. For example, much of what I am saying here would resonate with Torajan communities (Hollan & Wellenkamp, 1994). However, some Indonesian cultures may deviate markedly from the norms I am outlining here. One such comparative view was offered to me by Damai Sitopmul, a behaviorist and physiotherapist who has been working with special needs children in the Jakarta area for over a decade and is a spokesperson for the cause of children with developmental differences frequently interviewed on television and invited to host events in the field. Damai herself, while raised in Java, is of Batak origin. Batak are from a number of ethnic groups originating in North Sumatra. In Java and elsewhere in Indonesia, Batak are known for being “fierce” and much more aggressive and straightforward than other Indonesian groups (Bruner, 1972; Field Notes, 2011-2012). Damai indicated that Batak families may have quite different reactions to their children because Batak approaches to child discipline are very different from the Javanese approach and for Batak “no-no-no comes easy.” She said it is possible in such families that the principles of ABA behavior therapy, for example, rather than being uncomfortable for families could be misinterpreted in a way that she herself found to be too harsh (Interviewed by Annie Tucker. Jakarta, 24 January 2012).

change, but this may be difficult for people with autism, as some aspects of this maturity reflect a growing understanding of subtle social cues, which are notoriously difficult for people with autism. Furthermore, those avenues of discipline may be inaccessible to children with autism because lack of access to education may mean they cannot go to school, and their unique ways of being and unique challenges may mean that they cannot spend as much time with extended family members.¹⁴³

A reticence to make rules explicit and tell children “no” may make ABA and other behavioral intervention particularly challenging for Indonesian families. Florida, a behavior therapist originating from the Eastern island of Flores working in Malang East Java, acknowledged that it is a challenge to implement ABA with Javanese Indonesian parents, or that if she does try to implement it, it has to be with “a softer style” (B.I. *dengan cara lebih lembut*) to fit better with Indonesian parents. She gave me the example from her practice of teaching a child to sit still, saying that from an ABA perspective if a student is expected to sit nicely for 5 minutes then they have to sit nicely for 5 minutes and that’s it, no matter what they would prefer to be doing. Prompts and/or negative consequences are seen as standard strategies to help them meet that goal. However, to the Javanese parents Florida works with, making a student sit still for five minutes if they would prefer to do something else feels almost unbearably uncomfortable, and some have even accused Florida of acting with too much “force,” “coercion,” or “imposition” (B.I. *pemaksaan*) and it distresses them. So she says she has to find a way to compromise with parents in doing ABA, but it’s a challenge for her (Florida 2010).¹⁴⁴

¹⁴³ In India, Roy Grinker found a similar pattern of maturation processes involving shaming techniques and increased caretaking by extended family members according to age, which were similarly disrupted by autistic difference (2008).

¹⁴⁴ Florida. Interviewed by Annie Tucker. Malang, 22 September 2010.

In this fundamental difference of approach, there is a fear that the Javanese or Indonesian approach leads to a passivity, helplessness, or lack of development on the part of the child with autism. What Diyah Puspita calls “learned helplessness” (Puspita, 2010) is not primarily an aspect of the condition of autism but how Javanese families respond to it, in that some typical childrearing practices may interact with autistic symptoms in a potentially unhelpful way. According to Puspita, Indonesian “enabling” behaviors that go against expectations of independence mean that developing autistic children are never expected to learn how to control themselves or do anything for themselves, and so they never do learn.¹⁴⁵

If at times certain therapists or professionals seem to take a scolding or exasperated tone towards their clients or advisees, it is important to note that these are core issues that clients and families themselves also struggle with. Families wonder what kinds of behavior express the “right” kind of care or affection, and what kinds of behavior is actually “babying” that will ultimately have the negative effect of “spoiling” the autistic child’s later chances at independence and healthy functioning. They worry about how to provide the structure and consistency that autistic children seem to need when it goes against familiar norms of childrearing; and these efforts only become more complicated in a situation of extended family living and shared childcare.

When conducting interviews at Kid ABA in Bekasi, a bedroom community of the Jakarta metropolitan area, I sat with Susana on a low couch while we watched her five-year old nephew, Andi, receive intensive ABA therapy in a small room via a video monitor. Andi and Susana came to Jakarta to pursue ABA, and planned to stay with relatives until the money they had brought to pay for this therapy ran out, perhaps a few months. Back in Banjarmasin, Kalimantan, they live in an extended family that includes parents, siblings, aunts, uncles, and

¹⁴⁵ Puspita, Diyah. Interviewed by Annie Tucker. Jakarta. 13 July 2010.

grandparents, and everybody shares care-taking responsibilities for Andi.¹⁴⁶ Susana told me that out of this large group there are those family members that better understand the purpose and implementation of Andi's diet and therapies and those that don't really understand at all, so that there is not a lot of structure or consistency in those treatments that are carried out at home, including ABA and the restricted diet. She believes this causes his development to come slower than it could be, because for these therapies to work you need consistency above all. Furthermore, she explained, some family members have "the tendency to serve (B.I. *melayani*) Andi" and because of "too much love (B.I. *sayang*) and too much pity (B.I. *rasa kasihan*) we spoon feed him, we dress him, and that does not make him independent." She feels for his advancement to be better, the whole family would have to be on the same page and equally dedicated to the course of action. She feels like the "whole family needs some kind of therapeutic intervention" to change their behavior because they care about Andi so much it is hard to break them of their desire to serve him and to fulfill all his needs (B.I. *sangat sayang, ingin dilayani terus*).

However, this tendency gravely worries Susana. She continued,

But how long can we act like this? If we spoon-feed him, when will we ever stop? What happens if he gets to be 12 years old and he can't do anything for himself? We are afraid, because we have seen other [children like him], that are just so coddled... (B.I. *serba dilayani*) (Susana, 2012).¹⁴⁷

She mentions a family acquaintance in the neighborhood, a 17-year-old autistic boy who cannot do anything to help himself, seems to have little impulse control and has developed "bad habits" like stripping naked in public. Andi's aunt concluded, "We are afraid it will be like that. We would like to put forth our effort so that he can be independent, so that he can help himself"

¹⁴⁶ The family is living in Kalimantan but has extended family in Jakarta and is culturally Javanese; the Suharto *transmigrasi* initiative to mitigate overpopulation in Java by sending Javanese to outer islands, as well as extraction and other business opportunities, have allowed Javanese families to resettle on other islands and in other provinces.

¹⁴⁷ Susana. Interviewed by Annie Tucker. Bekasih, 30 January 2012.

(Susana, 2012).¹⁴⁸ In Andi's aunt's story, as in many narratives of family practices, spoon-feeding is folded into a wider set of concerns: over-indulgence, "serving" the child out of love and pity rather than demanding the child complete tasks, and a lack of cohesive sense of purpose within the family regarding the need for other members to change their *own* behavior with regards to the person with autism in order to carry out treatment.

Families worry about the influence of these childrearing practices on long-term development. To return to Bima and Jerry, in Jerry's description of his family's dynamic, he sees a correlation between indulgent feeding practices and difficulties setting limits on behavior: part of the reason why it is hard to set limits is because the family "cares too much" by overfeeding Bima so that his body is large and difficult to control. According to Jerry this difficulty "controlling" Bima means that their family life is somewhat strained.

His body is getting bigger and bigger, so if I try to grab him he gets away again and again. I can't do it. He's too big, he's too grown up, so he can't be handled. [...] At home, if you want to know, at home he's like 180 degrees from [school] where he's compliant, obedient, prepared, like that. At home he's different, free, so... He acts naughty. He can truly be called a naughty person (Jerry, 2011).¹⁴⁹

Other parents expressed a similar dismay at the difference between their children's behavior at school and at home. Ningsih said that while her son was well behaved at school, at home he was not. She described him as "Spoiled, so spoiled! You don't even know. Wow!" (Ningsih, 2011).¹⁵⁰

In Javanese practice it becomes difficult to parse food from behavior from love from discipline, as they are woven together in the daily lives of families. Hopefully the above makes it clear that in Javanese models of family and development nutritional and other "indulgences"

¹⁴⁸ All above quotes from Susana. Interviewed by Annie Tucker. Bekasih, 30 January 2012.

¹⁴⁹ Jerry. Interviewed by Annie Tucker. Yogyakarta, 13 October 2011.

¹⁵⁰ Ningsih. Interviewed by Annie Tucker. Yogyakarta, 13 October 2011.

have multiple positive effects that harmonize with broader socialization goals that Javanese Indonesian families have for their developing children, norms of emotional expression and affection that they have for themselves, and beliefs about physical and emotional health. However, the fear is that these norms become less appropriate, even dangerous, in the context of autism, as developmental challenges threaten the normative pathway towards a mature capability to care for the self. This may lead to what feels like a culture clash between families and the therapists trying to help them as Javanese families are framed, or frame themselves, as overindulgent, inconsistent, too “understanding” and accommodating when they should be demanding, too obsequious when they should be strict. The context of autism leads to an internal or self-conscious questioning of cultural norms within the Javanese parent, family member, or caretaker.

From many behaviorists’ point of view, this lack of familiarity or fit with a structured behavioral approach means that Javanese families are accepting and forgiving of behavior that is actually unacceptable and may ultimately threaten the well-being of the family unit, the view of the family in the eyes of the community, and potentially endanger their autistic family members in the future. The educators, therapists, and activists I spoke with seemed to criticize the families they were working with, but ultimately had goals such as easing the burden on family members and promoting positive functioning family relationships while building independence for the autistic child so that they could have as rich a life as possible. But they also had grimly realistic ideas about the kinds of protection autistic people and their families need, and viewed a “stricter” approach as part of that protection. Gayatri Pamoedji situated early behavior training as a preventative measure against institutionalization and criminalization, saying, “Indonesian law

does not recognize autistic people,”¹⁵¹ meaning that they do not receive any special treatments or protections under the law. Diyah added that part of her job is to change the parents’ way of thinking about their children: they tend to think the children will be children forever, even though as they mature (and particularly because they may not look visibly “different”), society may hold them responsible for their actions as competent adults.¹⁵² Poignantly, Javanese Indonesian families are motivated by love and care and pity for their autistic family members; and they are dismayed the norms of expressing this love and care may not be enough to shepherd them into adulthood, to keep them safe or teach them the skills that they need. Meanwhile interventionists, often influenced by their own family experiences and training abroad, want the best for autistic children but they end up feeling frustrated by the very families they are trying to support.

Disability, Nation, and Logics of Developmental Difference

The case study of debates over feeding practices illustrates that the translation of autism goes both ways—that just as local concepts are used to translate “autism” into meaning for local families, so too the guiding framework of autism and disability enculturates families into new childrearing practices that may be quite different from the “local” Javanese or Indonesian

¹⁵¹ Pramoedji, Gayatri. Interviewed by Annie Tucker. Jakarta, 13 July 2010.

¹⁵² She provided me with this example of child discipline with an eye towards the future: according to Diyah, if a child takes a piece of paper off a desk without asking, this must be considered “stealing” and the child must be punished. But parents will look at her with a mixture of confusion and remonstrance: why should the child be punished when it’s just a meaningless piece of paper? Her reply is that, now it is nothing but someday your child will be a full-grown adult and that meaningless piece of paper could be a certificate of land ownership and your “child” can be incarcerated. Diyah echoes Gayatri’s fear that the law will not make special provisions for citizens with developmental differences. (Interviewed by Annie Tucker, Kebayoran Baru, 13 July 2010). Cases of vigilante justice have been reported in the context of mental illness, where inappropriate gestures or behaviors can be met with group violence. See Lemelson 2011, for the example of a man with schizoaffective disorder in the full throes of mania who is beaten severely for making inappropriate comments to a group of girls.

models. This bi-directional process accounts for some of the challenges both educators and families face in adjusting their behavior, and the anxieties—both about local norms and about potential outcomes for autistic Indonesians—the presumed need for such adjustment triggers. Javanese goals and practices of socialization favor protection, patience, “indulgence,” and embodied practices of interdependence for the growing child. Meanwhile autism educators and others with experience in the world of autism take their cues from interventions developed in the West to promote a new family culture that they see as more healthy for those with developmental disabilities, one that emphasizes biochemical regulation, rules and routine, proactive steps towards independence, and the need for “tough love.” Amidst debates and not without some intense emotions, this new family culture is being promoted by individual therapists, educators, and parents, at talk shows and workshops, in written memoirs, and is being adopted by many families.

I have spent some time in this chapter discussing debates over the restricted diet. This may seem to some readers like a comparative non-issue, in that many in the mainstream autism research community believe that restricted diets, even if followed perfectly, are not proven effective and hence, to a certain extent, are a waste of time and effort (Elder et al., 2006; Christison & Evany, 2006) despite the fact that anecdotal evidence for the diet remains compelling to many parents. I focus on it here because it has become a heated topic within the autism field in Indonesia due to the significance it has been afforded by influential figures in the country—diets and feeding practices were one of the most frequently discussed, and one of the most contentious, issues I encountered in my fieldwork with interventionists and families.

There are a few other interesting aspects to the debates over diet. First, a national or regional investment in certain forms of intervention is notable within a global history of autism;

certain theories or practices may already be considered “outdated” or disproven in some countries or regions while they continue to hold sway and influence behavior elsewhere, as has been noted with the psychoanalytic approaches to autism still prevalent in France and Argentina (Feinstein, 2010; Grinker, 2007).

A second notable aspect to the debate over diet and feeding practices is how it is so frequently couched in arguments about the expression of love. Previously popular early psychoanalytic etiologies of autism also suggested that autistic symptoms were caused or exacerbated by the “wrong kind of love” from mothers and families; in the theories put forth by Bettelheim and other Euro-American psychoanalysts treating autism in the late 1960’s and 1970’s, autism was caused by mothers who were cold and over-intellectual and made their children feel unwanted (as encapsulated in the use of Kanner’s now infamous term “refrigerator mothers”). Scholars have suggested that in a cultural and historical context, such an etiological theory reflected the anxieties over socioeconomic changes in the family at that time: women were increasingly entering the workforce and negotiating their own ambivalence about career and motherhood, feeling guilty about wanting to be apart from their children outside the home. Due to new family mobility, many women were separated from their relatives and isolated in suburban homes, increasingly turning to expert childcare and psychological advice rather than channels of folk knowledge. Meanwhile the changing social norms and protests of the sixties created a national moral panic about the role parents had to play in raising responsible, connected, law-abiding citizens (Grinker, 2007; Nadesan, 2005). Therefore it might be argued that ideas about etiology and intervention, and anxieties about family practices in relationship to autistic family members, say more about the “zeitgeist of the times” (Nadesan, 2005) than they do about autism.

I want to suggest that much as in the American context, where anxieties about mothers providing the “wrong kind of love” to their autistic children were related to anxieties over socioeconomic changes in the family and the role of parents in these changes, so it might be the case in Indonesia, and that debates over feeding practices—but more particularly the metonymic relationship of feeding practices to a complex of indulgence, overprotectiveness, and “babying” as the “wrong kind of love”—are revealing deeper anxieties about the Indonesian family and culture in the context of socioeconomic, cultural, and political change. I believe the moralistic tone taken in autism intervention and an emphasis on functional independence and “tough love” has significance beyond only families with autistic members, and in fact gesture to broader debates and processes of marked social and cultural change experienced by certain Indonesian families in the post-colonial and post-Reformasi era. While all of the interventionists I quote here are primarily concerned with autistic children, and while ostensibly they are talking about autism, they are voicing broader concerns about the Indonesian family and its ability to raise self-sufficient, resilient, and competitive children. In this case, some of the issues that arise in autism treatment within the family may act as a lens that magnifies anxieties about the Indonesian family more generally.

In the previous chapter I suggested that autism and disability culture might be considered a new national culture, where archipelagic spaces of affinity and new practices take root and grow. If this be so, is this new culture exercising a liberatory or disciplinary power in the Javanese or Indonesian family, or both? It would appear that these new figured worlds are at the same time sites of identification and affiliation but also sites of contestation—members might identify with globalized disability and autism culture, and yet might disagree or struggle with the practices promoted by this culture. Tensions arise between local practices, such as Javanese

styles of parenting and approaches towards food and affection and discipline, and these new national identities, which are invested in new or unfamiliar ways of doing things because they believe that is what is best for autistic children. Such tensions have the capacity to refashion the intimate dynamics of family life, creating a new self-awareness about the “right” or “healthy” way to express love, communicate, or respond to another’s behavior, weighing comfort and nurturance on the one hand and the long-term repercussion for functional independence and a healthy maturity on the other.

In this context I believe it is possible that ABA and behaviorism, diet recommendations, and other interventions become cultural ambassadors of sorts, instructing and influencing values, practices, and long term-goals, training Javanese families into some of its most basic concepts-- such as enforced compliance, conditional reward, and generative tension—that happen to align with Euro American values of childrearing and out of indigenous values and emotional economies. Teaching and learning about autism and disability is in effect teaching and learning a new “culture” of childrearing and that seems to highlight some of the anxieties and debates about Javanese parenting and Javanese culture. Nadesan has said that the changing interpretation and representation of autism in any culture “reveals current desires, anxieties, and opportunities for personhood in the early twenty-first century” (Nadesan, 2005, p. 2). In talking about the different approaches to autism intervention, my respondents were also addressing fundamental debates and worries about the changing Indonesian “character” as the country continues on its transition away from local collectivist values to those of neoliberal capitalism, which carries very different ideas about the capacities and expectations for individual personhood.

This transition proposes a dilemma in the realm of autism intervention. Western interventions seem to hold the promise of success for including and supporting autistic

Indonesians, in part because of the image of the West, and its infrastructure, material resources, and perceived ethos and global dominance. Many parents and therapists I spoke with idealized the West as being more “developed” than Indonesia in general, and believed that this development had direct ramifications for autistic children and others with disabilities. As one mother put it,

In Indonesia, in my opinion it’s obvious that there’s not a lot of hope for support and that kind of thing. Because Indonesia, it’s not a rich country. There are many bigger problems here, like joblessness, things like that. But America already can really do it. America has the ability to truly engage with autism until the roots (Intan, 2010).¹⁵³

Some explicitly believed that the material or global success of American and other Western countries—as opposed to Indonesia—is reflected in Western intervention strategies for autism. As Dr. Rudy Sutadi said enthusiastically, he knows that principles of behaviorism and ABA have been applied to teach all kinds of skills and have been put to use in management strategies and occupational psychology so that companies learn how to reward employees (e.g., different levels of skill are “positively reinforced” or rewarded with different pay scales and bonuses). He continued, “America already uses ABA for training athletes, that’s why they are the best in sports. Maybe if Indonesians started using ABA for sports, then *we* would become Olympic champions!”(Sutadi, 2011).¹⁵⁴

Ideas about the correct way to respond to autistic or disabled children frequently slipped into discourse more broadly about the impact of childrearing practices on the nation. In my interview with therapist Agus Haryanto, as he was talking about the overindulgence of “handicapped” children by their families, it became clear that his frame of reference was broader than only these families. He said,

¹⁵³ Intan. Interviewed by Annie Tucker. Bogor. 15 July 2010

¹⁵⁴ Sutadi, Rudy. Interviewed by Annie Tucker. Cipinang Prison, 26 January 2012.

Mature adults have to provide the right form of structured discipline. Or you can put it this way: if your right hand is giving your child love and affection, then your left hand better not forget to bring the discipline. If you only want to give love and affection, then you are not preparing a generation that is ready to be used, you are creating an idiotic generation (B.I, *generasi yang ngoblok*) (Agus, 2012).¹⁵⁵

In Agus's mind, there seems to be a telescoping out from the microcosm of the family with a disabled child; in discussing the right balance of "strictness" or affection, not just a small minority of autistic children, but an entire generation is at stake. This concern with love, affection, and discipline relates to the idea discussed above that Indonesian or Javanese interpretations of autistic difference are wrong, and that reactions to autism only highlight the fear that Javanese families more generally take the wrong approach in raising even their typically developing children—acting indulgent, weak, coddling, rather than strict. In Agus's statement, "strictness" "discipline," or "structure" is not only relevant to people with autism or developmental disabilities but is framed as a basic need for creating a generation of Indonesian citizens who are ready to succeed, who won't be "left behind."

In these discourses surrounding developmental difference, certain kinds of familiar Indonesian family practices are being framed as in essence wrong, leading to both typical and autistic citizens who are undeveloped, who are not reaching their potential. In these didactic and moralizing narratives, Javanese norms of affection, discipline, and comportment as enacted through particular childrearing practices are considered bad for development, whereas "Westernized" or globalized norms of childrearing, as informed alternately by Dutch or Australian family practices or Euro-American intervention pedagogy have a better developmental "prognosis."

In these examples, Western nations and approaches are framed as successful while

¹⁵⁵ Agus. Interviewed by Annie Tucker. Bintaro, 27 January 2012.

Indonesia is the foil, and the Indonesians providing these examples call upon common beliefs about Indonesia—as a post-colonial “developing country,” Indonesia has limited infrastructure and public services, it is still “catching up” and trying to deal with other large scale problems, but if it could catch on and learn how to do things the way America or other Western countries do things, it would be better off and thus could do better for autistic children. For some, there is an implied moralizing perspective in models of disability and inclusion, where approaches to autism are directly related to class issues, where “modern” means “Westernized” means “upper-middle class” and the modern upper middle class family is a manifestation of good or successful development with bargaining power to advocate for their developmentally different family members and access to the services they are understood to need. Meanwhile the “traditional” family, often equated with lower socioeconomic status, is seen as poor, ignorant about autism, and unable to offer their child anything beyond affectionate care. The sense that villagers are ignorant about autism is widespread in urban areas, as seen in this representative quote from an urban Bogor mother,

Nowadays, the era of 2000, now there have begun to be a lot of people who understand about autism, I’ve noticed. To our family members though, for the most part it has been us who have informed them what autism is. But maybe if I’m outside, like if I’m in isolated areas ... They think or say, like “a crazy person, a stupid person,” their thinking is like that. But family members and people in the city, they already understand about autism (Roro, 2010).¹⁵⁶

Wealthy and/or urban parents also suggest that those families that might be mistreating their autistic members—hiding, maltreating, or depriving their autistic children—are poor rural families (Field Notes, 2011).

¹⁵⁶ Roro. Interviewed by Annie Tucker. Bogor. 15 July 2010.

Despite this moralistic tone that suggests rural Indonesians remain ignorant about autism, there also seems to be nostalgia for an imagined traditional agrarian lifestyle and orientation. While in one stream of thought “traditional” families are bad for people with autism because they neither properly recognize their disabilities nor maximize their abilities, on the other hand they are imagined as a haven for people with autism or other developmental disabilities as a prototype lost form of community that enabled a set of values where full personhood, full citizenship, and full inclusion or participation was automatically afforded. In some of my interviews in Jakarta I encountered a belief that more rural or agrarian family structures, both their daily practices and the values they espouse, are actually *better* for people with autism. This is in part because they afford tasks that are achievable by people with developmental disabilities, and because of their lifestyle and orientation they allow developmentally delayed people to better blend in.¹⁵⁷ For example, Agus Haryanto suggested that such agrarian family and community structures allow people with autism to have a more productive, integrated, and respected role in society.

If you asked me, what’s the ideal family, like if we were imagining the ideal family, what’s that family like? I would say, a farming family. Why, because from when they are young they are already contributing. The boys help their fathers in the rice fields, waiting for the harvest, planting seeds, waiting to see what needs to be done, from the time they are little they already are learning those skills. And the girls help their mothers. Cooking, taking care of their younger siblings, and those become skills that become one with them, that are integrated into their sense of self.

[...] They just live by contributing, in a village like this the problem of independence or self-sufficiency doesn’t become that big of a problem, because

¹⁵⁷ Again here, one could potentially draw a comparison to the (disputed) findings of the WHO and DOSMD studies on schizophrenia (Hopper et al., 2007). There is also a resonance with the argument raised by Desjarlais in *Shelter Blues* (1997), his ethnography of people who are homeless and mentally ill, which questions whether the impetus to “be all you can be” to strive, achieve, and be busy and productive, a notion behind most intervention and “development” efforts is in fact the best approach for certain communities or whether other life rhythms and trajectories might be more suitable or desirable for some.

they are already integrated, and that makes children like that [with autism or developmental difference], makes their deficiencies just not that noticeable. (Haryanto, 2012).¹⁵⁸

There seems to be a sinking feeling that there is something in and of capitalism—or rather something in and of a Western model of intervention that is inherently intertwined with capitalist economies—that values people just for their output or the gain they provide, that turns them into a commodity in the “identity marketplace,” that even in addressing their needs asserts a hierarchy of human value wherein those who don’t meet a certain criteria of productivity or advancement is read as a lesser person. There seems to be a tension wherein Western-influenced educators and activists are both proud of the services they are able to provide autistic citizens and yet occasionally wistfully remember a different system of Indonesian collectivism where such members might be already, inherently valued and included. So, even as Agus worried about a “useless generation” that might result from a typically Javanese lack of family discipline, he also imagined ideal “traditional” Indonesian communities that were welcoming and accommodating to people with autism. On the one hand it seems like new movements of autism education, advocacy, and services, is providing something that Indonesia has never had before, and on the other hand it feels like these services are required because things are changing and something has been lost, namely a lifestyle and an indigenous ethos that provides satisfying occupational opportunities and community inclusion, respect and care, for all kinds of people.

In thinking through these ideas, I was reminded of another respondent, Jerry’s comment about his uncle’s offhanded treatment of his autistic brother, which I shared in Chapter Three—that in refusing to attend to his autistic nephew the uncle is acting “individualistic, not like a real

¹⁵⁸ Agus. Interviewed by Annie Tucker. Bintaro 27 January 2012.

Indonesian, who cares and works together” (Jerry, 2011).¹⁵⁹ In asserting that his uncle has lost touch with Indonesian values, Jerry evokes the idea of *gotong-royong* or community work where people act as a collective to meet each other’s needs without hope of direct personal reimbursement or recompense. This is a “local” agrarian value that was seen as so fundamental that it was translated into the founding of the nation of Indonesia as a *gotong-royong* state (Bowen, 1986).

The nostalgic and doubtful elements of discourse about autism intervention within different groups of Indonesian citizens are nostalgic and doubtful perspectives on Indonesia’s development more broadly, and part of Indonesia’s ongoing post-colonial and now post-Reformasi debates. These doubts call into question hegemonic narratives of both disability and national development, worrying the boundaries between disability, delay, and difference. Indonesians are self-conscious about the nation’s “developmental delay,” the fact that they are still seen as part of the “developing” world. Certain aspects of what is framed as “traditional” Indonesian or Javanese culture are seen as a delay, a starting point beyond which many middle class Indonesian would like to progress; meanwhile those “delayed” Indonesians, be they traditional rural people or those with neurodevelopmental disabilities, are those for whom this starting point remains a perpetual way of being. Yet in alternative narratives, parts of this traditional culture might be emphatically argued for positively, as a developmental *difference*, inherent aspects of local culture that ideally would be preserved as Indonesia finds its way in a globalized economy and society. These thorny co-construction of categories of development and value inform and are informed by intervention methods and approaches.

¹⁵⁹ Jerry. Interviewed by Annie Tucker. Wonocatur, 19 October 2011

Chapter Six

Therapeutic Gamelan: Fostering a Javanese Development and Embodying Javanese Inclusion

Introduction

The previous chapters have been designed to describe the current situation in Javanese Indonesia with respect to the emergence and treatment of autism diagnosis there, but out of this description have emerged a number of concerns. Chapter Three suggested that for many Indonesian families efficacious therapy for autism is both difficult to find and afford. It also illustrated a particularly local Javanese “cultural toolkit” that was often mobilized by families to respond to people with autism which included the emotion work of patience and acceptance and an emphasis on family practices of protection and intimacy. Chapters Four and Five further complicated this picture by demonstrating that often the response to autism promoted by many professionals and advocates in the field seems to include—or even depend on—attempting to acculturate families out of local values and practices, attempts which often have been understandably resisted or unsuccessful. These findings suggest a need for accessible and culturally coherent therapy for autistic people. I have attempted to trace a thematic tension in this discourse; on the one hand, the increasing attention to autism is experienced positively because it encourages the recognition of people with autism and a targeted response to their needs with specialized services. On the other hand, there is a concern that the autism interventions associated with an increasingly urbanized and “modernized” Indonesian society instantiates forms of community where value and inclusion is accorded conditionally and Indonesia itself is framed as “developmentally delayed” in relationship to other countries. This concern gives rise to a nostalgia for local forms of community and citizenship that are imagined as more comfortable for Indonesian families with autistic and disabled members and raises the

possibility that locally guided and grounded pathways and practices of development might serve as a powerful therapeutic alternative.

This chapter provides an investigation of one reaction to the current emergence and rooting of the autism diagnosis in Indonesia, which offers a cogent response, perhaps even a potential solution, to the problems raised in these previous chapters. This is the creation of an experimental therapeutic gamelan percussion ensemble for Javanese children on the autism spectrum. The Yogyakarta gamelan group of *Sekolah Autis Bina Anggita* is the first of its kind, an exciting and investigative effort taking root at the intersection of the comparatively new globalized diagnosis of autism and a rich and long-standing local musical heritage. An experiment in traditional arts application, advocacy, and inclusive community, therapeutic gamelan holds promise as an autism intervention that provides key sensory information and interpersonal interaction for participants in a context that is culturally relevant and socially efficacious.

Through a case study based on participant observation with this gamelan group, I will draw some provisional conclusions about music as therapy, traditional arts practice and performance as enabling the development of an embodied inclusive community, and therefore the capacity of therapeutic arts to enable new—or, renewed—models of inclusion. I will consider gamelan as an appropriate and potentially widely applicable therapy for autism in the Javanese context, continuing to use the ethnographic, socio-cultural, and critical methods that have guided me thus far while also providing a developmental perspective on arts interventions.

Bina Anggita School

Sekolah Autis Bina Anggita, or Autism School for Independent Thinkers, is a small school for children on the autism spectrum in Wonocatur, Bantul, South Yogyakarta on the outskirts of the bustling Ring Road that encircles the city. Its modest campus is located off a quiet street in a residential neighborhood next to homes, small local stores, food stalls, and a preschool. It is comprised of a small cluster of buildings encircling a peaceful, swept courtyard. The school has administrative offices, a computer room, and two large classrooms each of which has cupboards full of books, games, therapeutic and educational materials, a communal area as well as subdivided cubicles where students receive one-on-one instruction. Across the yard there are two swing sets, a music rehearsal room, and a prayer room.

Muhammad Yasin, the school's founder, is a soft-spoken man with a kind and calm demeanor. He is a trained educator who has been working with autistic children since 1994, when he was first hired as a private teacher for a single young autistic boy in Sleman. He found that he liked the work, and word spread about his successes educating his pupil. He opened his own school in 1999, which first started as a pre-school and grew to provide elementary and middle school level instruction. As it grew, the school changed locations a number of times. In 2008 a pupil's family helped him obtain the facility in Wonocatur, which was a vacant elementary school, and Bina Anggita in its current iteration was born. Yasin remembers that at first he was operating out of the building without any furniture or facilities. He would work with students with whatever he could scrape together, and if the school had visitors he would unfurl a simple bamboo mat for them to sit on. As schools geared towards the education of autistic students are few and far between in Indonesia, Yasin was soon at capacity, receiving requests not just from families in Yogyakarta but from across the archipelago. He was able to open a second

school, about an hour to the North in Magelang, but even with these extra facilities he soon reached the point where he reluctantly had to start turning students away. Today, Bina Anggita is now one of only five special education schools in Yogyakarta that is state-recognized and supported.¹⁶⁰ Bina Anggita's educational vision is to "form autistic individuals who are able to socialize, be independent, and develop their talents and interests" (Bina Anggita, 2010).

Yasin's vision of autism treatment is bidirectional, or dually focused. He understands that improving the lives of people with autism is not just about treating or teaching individuals but changing the way they are perceived and treated by their local cultures and communities, espousing what disability studies scholars would term a "social model" of autism. He traces this mission back to his experience privately teaching his first autistic student. Yasin remembers that at that time his students' parents did not let the boy outside the house because they felt ashamed of him. Due to this fact, the boy was not only unfamiliar with his local surroundings, but also clearly restless and yet also quite sedentary and significantly overweight. Yasin instituted daily walks with the boy, so that he could get physical exercise and gain access to a broader world; just as importantly these walks became an opportunity to introduce the community to the boy, and educate them about him. Now the mission of educating the broader public about autism and helping them grow accustomed to developmental difference (B.I. *socialisasi masyarakat*), is accomplished by Bina Anggita through weekly walks through town that continue to this day, but also through the school's participation in events such as walk-a-thons, carnivals, field days, and performances. Yasin and his fellow teachers and administrators also promote broader awareness about autism by opening the school's doors to a number of researchers, including professors, graduate students, and undergraduates from diverse departments (including communications,

¹⁶⁰ This means that they are a private school that charges students about 400,000 rupiah a month in tuition (approximated \$40 USD), but they receive some additional funding in the form of meal subsidies and scholarships from the Department of Education (Yasin, 2011).

psychology, and education) in a number of local universities across the city. So far over thirty research projects on various topics have been carried out in collaboration with the school, from parent engagement in therapy to the efficacy of various target interventions. I was similarly welcomed.

Between them, the two Bina Anggita partner schools currently serve approximately 25-40 students at any one time. The students ranged in age from 2 to 19, receiving an elementary through middle school education (for high-school level instruction students must graduate and go elsewhere). They attend class in morning, midday, and afternoon sessions; some attend for only one session and some attend for the whole day. For certain pupils, Bina Anggita is the only education they are receiving, while other students alternate their time there with time spent at inclusion schools or participating in other therapeutic activities. The curriculum revolves around one-on-one instruction for academic subjects and is enhanced by offerings of group sports and recreation, swimming, art, experiential learning through various field trips and excursions, and, on Thursday and Saturday mornings, karawitan, or gamelan practice.

Karawitan Bina Anggita

Coming from the Javanese word *gamel*, meaning hammer, the gamelan is a musical ensemble or orchestra composed of variously sized metallophones, gongs, xylophone-like instruments, and hand drums. Individual gamelans will vary in size, material, instrumental makeup, sound, and style, depending on the region they are from and their owner and purpose. For example, the slow sonorous subtlety of a traditional Central Javanese gamelan will look and sound very different from the lively and kinetic Balinese gamelan, and a humble village set will look and sound somewhat different from a royal palace orchestra. While the cultural role,

meaning, philosophy, and instruments of the gamelan will be addressed below in greater detail, at this point suffice it to say that gamelan has been a central part of Javanese civic, spiritual, and cultural life for centuries. It has also long been a major interest to foreign artists, ethnomusicologists, and researchers, and remains a significant tourist attraction and one of the prime referents for Indonesia. Accordingly, some eventual (albeit at times cursory) study of gamelan is expected for most Javanese people during their lifetime and many public schools will have gamelan as part of the official school curriculum determined by the Department of Education (Romadhon, 2011).¹⁶¹

And yet, a gamelan orchestra with special needs participants, let alone wholly comprised of special needs or autistic children or musicians, is almost unheard of; it was the brain child of Budi Raharja, a professor in the ethnomusicology department of the prestigious Yogyakarta Institute for the Arts (ISI Yogyakarta).¹⁶² Budi has been teaching music to elementary-aged children since 1987, and has conducted research on gamelan pedagogy and revitalization. Budi was intrigued by the music's physiological effects on players and audience members; according to formal research he encountered and his own observation, he found that Javanese gamelan has a calming effect. Apparently, this effect is not limited to those listeners who are culturally primed to enjoy gamelan or experience it as calming, as those unfamiliar with Javanese culture or music exhibit similar effects as evidenced by both qualitatively stated responses and by similar changes in brain activity (Raharja, 2012).¹⁶³ Budi believed this calming power could be harnessed for healing purposes, and hence partnered with Bina Anggita to investigate the promise and potential of music as therapy for children on the autism spectrum.

¹⁶¹ Gamelan is also taught in a number of ethnomusicology programs across the United States, including at UCLA.

¹⁶² Budi is also currently a doctoral candidate at the University of Indonesia, Yogyakarta.

¹⁶³ Raharja, Budi. Interviewed by Annie Tucker. Yogyakarta. 24 December 2011.

As mentioned above, gamelan rehearsal at Bina Anggita is held twice a week, on Thursday and Saturday mornings for about an hour and a half each session. The set of instruments the students use has been adapted to be especially appealing and accessible to children, with smaller-scaled instruments that are painted to look like animals, camouflaged tanks, trucks, and planes, or decorated with Barbies and flowers and pink hearts (see Appendix I, Figure 6.1). Bina Anggita's therapeutic gamelan has also been reduced from a complete gamelan, which can have up to 30 individual instruments including stringed instruments and flutes, to include those instruments that are most accessible, primarily those percussion instruments that only require one hand playing at a time. Accordingly, Bina Anggita's orchestra has a *kendhang*, a leather drum which sets and guides the rhythm of the piece, a larger and a smaller *gong*, a *bonang* and a variety of *sarons* (see Appendix I, Figures 6.2-6.4). Each child is assigned to one of these instruments according to their skill and interest. In addition to playing instruments, the children and teens take turns verbally introducing the particular piece to be played and singing the lead melody to the song.

After some trial and error, Budi decided that it was not just the kind, size, and appearance of instruments that could be adapted to suit these young musicians to maximize their experience. He also modified the gamelan in terms of the structure and content of the songs played as well as the way they are performed. The gamelan plays *nardosabdho* songs, which are songs played in the style of the famous gamelan musician by the same name who reworked many regional pieces and innovated a lively "pan-Javanese" style of gamelan that was influenced both by various local regional styles and by additional extra-gamelan musical influences (Sutton, 1991). Initially Budi wanted to teach *uyon-uyon*, which are those Javanese melodies that are based on traditional legends and lyric poetry, are especially slow, and in Budi's investigations had a previously

proven calming effect; but upon teaching these compositions it appeared that the music was just too slow for the children and couldn't capture their interest for an extended period of time. Budi found that sessions were much more successful when they played "bright, happy" songs at a quicker tempo. Budi also modified the music in that it is standard for gamelan music to be played as accompaniment to sung melodies, with different instruments following a slightly different musical line to complement, complexify, or "decorate" the piece. After some experimentation, Pak Budi modified the style of playing for the Bina Anggita gamelan such that the musicians did not accompany the melody but joined in playing it. Furthermore, the children playing the saron, xylophone-like instruments, do not use the closing or "damping" technique, where the left hand is used to quiet the key previously struck while the right hand has already moved on to strike the next note. While this technique lends a clearer sound it is also quite challenging to master.

Even with these modifications, not every student at Bina Anggita is yet able to participate in the gamelan, and participants are selected for the gamelan and assigned to a particular instrument by Budi and the teachers according to age, capability, and their own interest. This selection is somewhat important because while the group does practice gamelan for its own sake, both as a therapeutic activity and part of an arts curriculum, they also practice with the clear goal of performing. Their karawitan group has already performed at a range of events and occasions; since they began performing in 2009 they have played at local events at Taman Pintar, a children's park and learning center, Taman Budaya, which houses many significant cultural events in the city, Gadjah Mada University, and Universitas Negeri Yogyakarta, among others. They have also performed on TVRI, a national television channel, and are especially proud of a one and a half hour performance that was broadcast live on the local channel which lives on in

the school's collective memory as an exceptional performance during which the children played at their peak with incredible focus, composed behavior, and a clear sense of purpose.

My research activities with the gamelan included: observation of rehearsals, the lessons and activities carried out during the school day, children's, teachers', and parents' interactions with one another at school, at performances, and at their homes; participant observation, which entailed playing gamelan in rehearsals, interacting with the gamelan students and their peers during breaks, helping out with whatever was needed at performances; and attending teachers' meetings and *pengajian* (monthly prayer and reflection gatherings for instructors). I also conducted guided interviews with Yasin and Budi, focus groups with teachers, and guided interviews with teachers, students, and willing parents, caretakers, and siblings.

This research was carried out in two different periods of fieldwork in 2010 and 2011. The membership of the gamelan shifted during these two stays, as previous students graduated, moved away, or were mainstreamed into public schools, and new students arrived. The children I was able to observe and join playing gamelan included Gana (age 16), Cindy (15), Andre (17), Adinda (15), Iko (18), Arka (13), Okta (12), Dian (9), Pando (9), and Wawan (9). The children are all somewhat verbal, with most being able to state their desires and answer simple direct questions, but back and forth conversation remains challenging for most hence I could not privilege verbal exchanges as the only way of gaining information about the students or insight into their perspectives on gamelan. I also had to consider their body language, responses to various situations, and stories told about them by family members and teachers. My understanding of the gamelan as a therapeutic practice was greatly enriched by interviews with the students' parents and siblings; however, not all the parents were available to be interviewed. This was partially due to the realities of finding appropriate education and care for autistic

children in Indonesia; for example, Wawan's family was currently living in Kalimantan, in an area where there were limited options for students with autism, and they had decided to send Wawan to school in Yogyakarta, where he was boarding with Yasin. Alternately, two of the other parents permitted observation of the gamelan and school activities but declined to be interviewed or participate in any further way in the research. I thus was able to glean more information about some of the children—their in-depth personal histories, their hobbies and behavior at home, the effect of their participation on their families, etc.—than the others.

The Multiple Benefits of Therapeutic Gamelan Practice

Bina Anggita's offers karawitan activities as a therapeutic activity that affords cognitive, sensory, and behavioral benefits for students with autism and promotes their social acceptance and civic recognition. My research reveals that there are also numerous corollary benefits to the practice, including strengthening family bonds and school community spirit and providing opportunities for the instruction and practice of numerous social and pro-social skills. I will first catalogue and elaborate upon these many reported benefits before moving into a discussion of the salience of gamelan as a culturally coherent intervention.

Gamelan Provides Sensorimotor Stimulation

A typical gamelan practice session at Bina Anggita starts casually, with no formal beginning to class. Some of the older children come in on their own, sit right down, and start to practice while other children wander in and do not play until an older student or instructor prompts them. Teachers and students trickle in, in pairs, groups, or on their own. There is an incredibly cheerful environment, with teachers and children seeming festive and enthusiastic. Once the group sits down to play, the students know a wide variety of repertoire, and each take turns being the singer. You can feel their focus and investment emanating throughout the room. Those who cannot play on their own get help from teachers.

The teachers sit behind or beside those who are playing; some of them have a lot of body contact (which is a common Indonesian form of teaching), with full torsos touching and hand-over-hand grasping, while other just lightly touch students in a kind of guidance at their elbow or wrist. Others tap out the rhythm on students' bodies. Some students are sitting on their own and playing without any assistance at all. Those students joining the session who are not playing the instruments are banging on the floor, clapping their hands, or rocking or dancing along with the music.

It's a very social atmosphere. The teachers are playing instruments or attending to their children, but they are also constantly talking to one another, correcting and singing over each other, working together, teasing each other. It is friendly, warm, bustling, where everyone seems to be enjoying the somewhat cacophonous process of figuring out a new song... (Field Notes, October 2011)

Sensory issues in autism have been receiving more and more attention as a fundamental aspect of the diagnosis to the point that revisions to the diagnostic criteria in the soon-to-released DSM 5 will account for these. Recent research suggests that many of the recognizable symptoms of autism—including “stimming” such as rocking or hand-flapping, difficulty making eye contact, etc.—are expressions of sensory needs or sensory integration difficulties (Kapp 2013, Tomcheck & Dunn, 2007), which reinforces many first-person accounts from people on the spectrum who have been able to articulate those aspects of their own sensory experience that seem atypical or unique (Grandin, 1996; Mukhopadhyay, 2007). Common sensory symptoms of autism include a hypersensitivity to certain stimuli, such as light or sound, as well as hyposensitivity, often indicated by seeking out sensory stimulation through touch or other powerful stimuli such as strong smells or loud or repetitive sounds.

Gamelan may be providing the kind of sensory input or sensory information hyposensitive children with autism might seek. Gamelan practice at Bina Anggita is a profoundly sensory experience that provides input on multiple channels. The practice is loud, providing auditory stimulation. However there is a considerable amount of tactile stimulation as

well; in addition to the close physical contact among the bodies of teachers and students, the students are also grasping the hammers used to play the instrument. When you yourself or a fellow player strikes the instrument, the sonorous vibrations of the gamelan pots can be felt reverberating throughout one's entire body. A mother of one of the gamelan players seemed to suggest that this might be rewarding for her son as she said,

Maybe, I don't know whether they understand music or not but the vibration, gamelan has a vibration, so if you play, dung! Dung! They enjoy that. Because Pando, even if he's at home, if he listens to music—or, not even music, just sounds, he will be sure to turn it up until the speaker is bouncing, dung! Dung! Dung! For us, you know, it hurts our ears, but he enjoys it. Maybe that's what makes them able to enjoy it (Ningsih, 2011).¹⁶⁴

Another common sensory challenge in autism is a kinesthetic and proprioceptive hyposensitivity: some people with autism might be unable to feel or orient their body in space, or may experience gaps in sensation so that certain body parts remain outside of their awareness (Bogdashina, 2003), and this may lead to “stimming” or repetitive physical movements that help people with autism feel themselves. One young student in the group, Okta, frequently moved his body wildly through space, swinging his torso through large quick arcs, or lunging forward repetitively. This is not uncommon for people with autism and those on the spectrum who exhibit similar behaviors have been able to explain when engaging in these movements, they are seeking sensory information about their bodies; however, such movements can be disruptive or off-putting to others. While I witnessed Okta having difficulty remaining still for other lessons, during my observations of gamelan practice he was almost always able to sit still. Gamelan may prove highly regulating for those on the spectrum with sensory disturbances by

¹⁶⁴ Ningsih. Interviewed by Annie Tucker. Yogyakarta, 15 October 2011.

providing a holistic and integrating experience in which through percussion techniques, one can literally feel what one is playing, providing sensory input and integration.

This medium of sensorimotor experience and expression may be beneficial for the cognitive development of these gamelan players. Every infant is born with neurophysiologically determined capacities for various cognitive styles, but their emergence generally comes in a developmental sequence. The first modality of cognitive functioning is the enactive modality, which is primarily sensory-motor and works through gestures, postures, and the movement subsystems. The next acquired is the image modality, which works through the other senses including visual and auditory, wherein develops the ability to make connections and see relationships between objects through mentally held images. The final modality to develop is the lexical modality, which garners linear and sequential thinking and allows progression to new levels of conceptualization, abstraction, and reasoning (Horowitz, 1971). It has become clear that from birth, infants are engaged in a process of non-verbal meaning-making about themselves in relation to the world, developing a “biopsychosocial” state of consciousness, that is monitored and shaped by their primary caregiver. While a definitive cause for autism has yet to be found, and there may indeed be “multiple pathways” towards the disorder, it is suggested that those with autism may experience a disruption during this developmental process that hinders the synthetic and adaptive development of these various cognitive capacities and limits subsequent engagement with their particular cultural world (Tronick & Beeghly, 2011). For example, in a typically developing person, the different cognitive modes can be used simultaneously, and indeed often merge and mutually inform the increasing development and sophistication of all modalities. However, in some developmental differences or incidence of brain injury there may

a loss of translation, and conscious thought may only easily occur in one of those modes (Horowitz, 1971).

In order to best communicate with people with such needs interventionists must develop a model of the patient's world and understand the mode in which they most comfortably think, and conceptualize treatment techniques that match or correspond (Horowitz, 1971). By addressing sensory concerns of autistic people—such as sensory hyposensitivity, proprioceptive dis-regulation, and body boundary confusion—sensory interventions may prove regulating. And by providing sensory stimulation and building capacity for sensory attention and interpersonal communication and attunement on a non-verbal level, such interventions may also be particularly adaptive to those autistic people who are not yet able to produce, or not yet comfortable communicating, via speech. In the field of creative arts and music therapies it has been argued that in meeting people with autism where they are and speaking “in their language” a more flexible and adaptive self might ultimately be developed and the child might become increasingly fluent across different situations (Adler, 1970; Bakan et al. 2008).

Gamelan Is Amenable to Individual Strengths and “Autistic Culture”

It is possible that gamelan is beneficial for certain students because it matches their pre-existing aptitudes and allows them to develop these further: some parents of participants describe their child having an interest in or talent in music since they were young. For example, I frequently observed Dila singing and during the students' break time she would often go to the mirror and practice favorite songs, dance movements, and poses. Pando's parents told me that before he learned how to play gamelan they noted he had an affinity both for very loud music, which he often turns up to full volume on the speakers at home, and for Kenny G, which he

listens to in order to help him fall asleep. For Iko, gamelan music is just one aspect of a special talent for music and memorization which he has exhibited since he was a little child. His father remembers that at a very young age Iko had memorized the family's record collection and has collected his own eclectic mix of karaoke music videos, cassettes, and CD's. Both his father and his teachers have remarked on Iko's ability to sing or play songs on the keyboard after hearing them only once. For another one of the members, Cindy, gamelan was just one aspect of a young life dedicated to the performing arts: she for many years has also participated in a drum band, is a talented traditional dancer who has won trophies in dance competitions including earning first place on the provincial level as well as placing in national level competitions, and most recently as a singer and keyboardist has joined a group of autistic teens to form Band Autis, which since its inception a little over a year ago has toured to Jakarta, Bandung, Surabaya, Jember, and Pojonegoro and was chosen to represent children with autism and special needs at various functions including a Global Autism Day event put on by the Ministry of Education.¹⁶⁵

However, gamelan per se may be a particularly good fit for some people with autism due to aesthetic preferences and expressive conventions based on their neurological differences. One of these noted preferences is for repetition or perseveration (Strauss, 2010; Headlam, 2006). In the gamelan orchestra, each person's part often involves a repeated single note or series of notes played at predictable rhythm for the duration of the song, and this is especially true for the simpler instruments, such as the gong. While any piece of gamelan will be somewhat "perseverative" for each player, Budi's simplifications to the musical pieces contribute to this effect. So, for the duration of a song, a gong player might strike the gong on every third beat and a *saron* player might alternate between two notes on the instrument, played every second and

¹⁶⁵ In December of 2010 the band was given an entry in Indonesia's book of national records for being the first youth pop band composed entirely of autistic musicians.

fourth beat, and so on. While the ultimate effect is of a rich tapestry of tones and notes, the repetitive rhythms of gamelan percussion may meet the needs and preferences many autistic people have for “perseverative” or predictable rhythmic movement.

Gamelan Provides Accessible Social Experience

These preferences, although they may be based on neurological and physiological differences and needs, have interpreted by some to indicate a particular autistic “aesthetic” or “culture” (Strauss, 2010) which may influence preferred modes or styles of sociality. Two hallmark characteristics of autistic sociality that have been traced through ethnographic, psychological, literary and critical scholarships are that interaction may often be non-verbal and/or peripheral. A preference for non-verbal communication may be partially due to dyskinesthetic challenges in producing speech, or partially due to a preference for silence and space with others, an emphasis on other forms of communication and communion (Bagatell, 2010). But as folklorists, anthropologists, therapists and those familiar with those on the spectrum know, “non-verbal communication does not mean no communication” (Puspita, 2010); enactive communication is still a powerful way to express ideas (Dosamantes-Beaudry, 2003), and shared corporeal experience is also a powerful mode of collective meaning making and exchange (Sklar, 1994). Making and listening to gamelan music may function as a successful realm of communication between autistic people and between autistic and non-autistic people, as it provides a way of communicating or sharing experience on the physical, enacted level without having to talk. At the most basic level there is direct physical communication—taps, touches, guiding hands, which is considered part of a typical Indonesian teaching style (Geertz, 1960; Mead & MacGregor, 1951). But as I have mentioned, there is also communication that is felt on

an even more intimate corporeal level that I experienced as I joined in rehearsal with the group where bodies and instruments, or bodies and bodies are literally resonating with one another. In the practice area, people are sitting very close to each other and playing relatively loudly. As I hit the instruments, I could feel the resistance from the pot, and its lingering reverberations traveling up through my arm. But similarly, when nearby musicians struck their own instruments, I could also feel those vibrations in my hands and chest. It was a surprisingly intimate and body-felt experience of music.

This level of resonance can be achieved without conversation or direct address; interestingly, “resonance” is another word that has been used to describe a characteristically autistic sociality, where two people are engaged in “peripheral” or “parallel” socialization, in other words, not engaged in face-to-face dialogue discussing a topic but enjoying each other’s company side-by-side even if apparently engaged in separate activity. In her ethnographic work in the United States, Bagatell describes one particular social event during which two gentlemen engaged in rhythmic bodily movements (“stims”) that ultimately aligned with and played off of one another (Bagatell, 2010). Like other forms of music, gamelan may provide for a peripheral rather than dialogic group communication (Headman, 2010), which unifies players through a common framework of physical rhythm.

The communication in gamelan might be more accessible to autistic children due to what we might call neurocultural preferences, however it is also accessible owing to the nature of the instruments used to access this resonant communication. Musicians of any skill level and a wide variety of physical abilities can play each individual instrument in the adapted gamelan. This is unlike a classical orchestra or jazz band for example, which certainly requires and fosters social

cooperation to achieve a musical goal but also requires significant fine motor skills and sophisticated music technique.

Gamelan is Collaborative

For those students who may not have exhibited a previous interest in music, gamelan is accessible and provides a way to feel like they are working in tandem with others in a clear yet non-verbal way. However it also depends on collaboration. Pando's mother added that aside from the sensory stimulation, in playing gamelan she thinks her son most enjoys the aspect of working together

[Through] the coordination in the music the teachers are teaching them how to concentrate. Or the cooperation (B.I. *bekerjasama*), maybe he also enjoys that. "Play!" "Dung!" "Play" "Dung!" Yeah, that's what he is enjoying (Ningsih, 2011).

Her husband added, "One, two, and then he plays. He waits for the three to play" (Teguh, 2011).¹⁶⁶ Here his parents are referring to the fact that Pando plays the gong, which in certain songs he is responsible for striking every third beat in an even rhythm. The teacher assigned to assist Pando will help him stay on the beat by either indicating that it is time for him to strike by tapping him, counting out the rhythm with his or her hand and making a signal that mimics striking when it's time for him to play, or verbally saying "Play!" Pando then strikes the gong in response. Anis, an instructor who is active in the gamelan, also mentioned the pleasure and benefit of cooperation, using the same word as Novie, *bekerjasama*. In her interpretation gamelan by its very nature fosters this cooperation because in order to play anything, "They have to be unified, they can't do it alone" (Anis, 2011).¹⁶⁷

¹⁶⁶ Ningsih and Teguh. Interviewed by Annie Tucker. Yogyakarta, 15 October 2011.

¹⁶⁷ Anis. Interviewed by Annie Tucker. Yogyakarta, 3 October 2011.

It may be that, as Novie suggests, it's not solely the harmony of the music that the children are enjoying—the ability to play a piece successfully with one another, or the resulting sound—but this processual interaction with the teachers that itself is almost like a dance or a conversation (see Appendix I, Figures 6.6). Some of the students play instruments on their own, but some of them depend on this prompting or interaction to maintain their focus on the instrument or play their parts. If their attention wanders, a gentle redirection will be enough to get them back on track. For example, during one rehearsal I observed Okta's attention wander away from his instrument, but his instructor partner, Ami, was looking in the other direction, momentarily busy helping another student, so she wasn't available to guide Okta back to the proper tune. I saw him waiting increasingly anxiously, seemingly wanting to play but unwilling or unable to move forward on his own. Once Ami was able to focus her attention back on Okta, and re-engage in the back and forth of playing the bonang together, prompting him and reinforcing him, he immediately calmed and began to enjoy himself again.

This collaboration in playing each individual instrument, for those who are as yet unable to play on their own, is then mirrored within the larger group collaboration of the entire orchestra.

Gamelan Encourages Self-Expression

It was commonly said that playing gamelan allows children to express themselves through music. In practice, they are able to exercise a certain level of choice about how they play the instruments, and how they choose to introduce and sing the songs they are tasked to lead. However the teachers reported that it goes even deeper than that. One compelling example is found in the story of one of the young players, Arka.

Arka is a soft-spoken and mild-mannered teenager who loves gamelan, and usually plays the *saron*. When I interviewed Arka he told me that when he plays gamelan he feels “happy.” When I pressed him about what made him happy about playing he said, “Well yes, I’m happy because I’m playing gamelan.” He reported that he does not feel nervous before he has to perform and his favorite song to play is *Baris Serampak* because that’s the one he usually leads as singer. Arka has two sarons of his own at home that he uses for independent practice. According to the teachers, he had never asked for anything in his entire life, but after being taught gamelan he asked his parents for a saron, and was given two for Christmas. This seems to the teachers to be a clear sign of gamelan’s positive influence. They believe that gamelan allows Arkha to express himself; and in this they don’t just mean that he can express himself artistically or musically through the music he plays or sings, but they mean that the experience of playing gamelan was so powerfully rewarding for Arka that it motivated or helped him to express himself verbally, to literally “speak up” and spontaneously share something about himself and his desires.

Gamelan Strengthens Focus and Attention

In addition to these sensory, personal, and social benefits I have mentioned, the benefit most commonly cited by Yasin and the teachers when discussing the effect gamelan has on their students is that it either enables or invites improved focus and concentration. Parents and teachers alike note that gamelan seems to have a calming effect on the students’ mood and energy level. One mother said,

At Bina Anggita my daughter plays the *kendhang*, and her teacher was kind of amazed, meaning that whatever condition Cindy was in she could be in.... prime

condition. Even if she was angry, or really emotional, crying, sad, but when she played she could overcome all of it (Redno, 2010).¹⁶⁸

In this calm state, the children seem to be able to achieve a longer and deeper focus or concentration than usual. As Budi described,

On the topic of attention, they played on Yogya TV. And for about an hour they were able to concentrate, imagine that! That's really extraordinary. Before we went on air, all of the teachers were nervous. Would the children stay calm? I was nervous too. And it turned out that the reality could be like that. For us, we consider that truly extraordinary. Usually, the chubby one, you know him? Gana. He can never be still. There, he was still. He did great. If the frequency of practice was increased, ongoing practice, then things would get really interesting I think (Raharja, 2012).¹⁶⁹

Budi is still speculating about what it might be about gamelan that fosters this calm concentration. Ultimately it may be that, particularly for the children in the orchestra, this focus is the result of the constellation of factors described previously. Gamelan may help the students feel socially engaged and connected, feel physically aware and integrated, and feel like the focus of positive attention, understanding that they are expressing themselves and being valued for this expression. Gamelan provides a structure for heightened concentration. These calming effects may last well beyond the actual practice session. Gana's brother further suggested that it might be that the energy required to sustain this focus drains his brother of the excess energy that seems to propel him to pace from room to room, noting that on Thursdays and Saturdays after gamelan practice his brother is usually more physically relaxed at home.

¹⁶⁸ Redno. Interviewed by Annie Tucker. Muga-Mugu, 14 October 2011.

¹⁶⁹ Raharja, Budi. Interviewed by Annie Tucker. Yogyakarta. 24 December 2011.

Gamelan Exercises Cognitive and Motor Skills

Gamelan also provides the opportunity for students to exercise their cognitive skills. In learning how to read music (gamelan has its own notational system indicating rhythms and using numbers to indicate notes to be struck), students are introduced to numbers and symbolic systems. They practice counting and following instructions. Those who are verbal also have to memorize the songs they are singing and playing.

Gamelan also practices and strengthens physical fitness and motor skills, which may be crucial as some people with autism may have difficulty with physical and postural control (Travers et al., 2012). For example, Yasin told me that Gana used to be so overweight and physically weak that he was unable to sit cross-legged. This is an incredibly important physical but also social capability in Indonesia, where many activities, from daily meals to friendly visits to social events and meetings are conducted in this position. Sitting cross-legged is also required to play the gamelan comfortably, as the instruments are low to the ground. Gana first started playing in a modified position of sitting on his feet with his knees facing forward; he was willing to sit this way because he wanted to participate in music, and after many weeks of practice he worked up the core strength and flexibility to sit cross-legged.

The act of holding the mallets used in gamelan may also provide a form of indigenous occupational therapy, as children practice grasping and striking skills with build strength and coordination. Some people on the autism spectrum commonly find such fine motor tasks challenging (Dzuike et al., 2007; Dawson & Watling, 2000), which impacts their ability to perform academically (if they have difficulty grasping a pencil). This physical skill is also to a certain extent a social and daily living skill (Jasmin et. al., 2009). For example one of the students, Pando, had difficulty eating with the family because it was challenging for him to hold

a utensil. His mother remembers, that it was so frustrating that she abandoned trying to teach him how to use a fork, much to her parents' dismay, but since he has begun playing gamelan his grip has gotten stronger and it is easier for him to hold a fork and hence join in family meals, promoting greater acceptance within his extended family.

Gamelan Incorporates Social Skills, Provides Social Capital, and Strengthens School Community

While, as I argued above, gamelan provides an experience of non-verbal communication, gamelan practice also does give the children an opportunity to practice their verbal communication skills. Those children who are able take turns singing, in which case they get to pick the song they want to sing, and are responsible for properly greeting the audience, introducing the song, counting it off for their peers, and thanking the audience when the song is done. Such singing provides rehearsal for social communication: the singer is directed to face his playing peers, the people he is currently communicating with, and is coached in using clear pronunciation and a socially appropriate tone. Budi created this aspect of gamelan practice and performance specifically for this purpose and has ideas about how these benefits could be extended. He explains,

I thought to provide interaction, make some interaction. [So they say], "Hello friends..." actually that was to give them a chance to interact... And later, what I imagine is more than that. You could make a play. Interaction could be built from there. And in the middle of that, they could improvise. And you could tempt them to speak... That would make their socialization even more (Budi, 2011)

It is worth noting here as well that in the musicology and pedagogy of gamelan, a direct correlation is drawn between the structure of gamelan music and the structure of language, where for example the gongs are described as providing the "punctuation" for the music, with the small

gong acting as a comma or pause and the large gong acting like a period or longer pause (McPhee, 1949; Sutton et al., 2006). Other correlations have been drawn between gamelan and verbal language skills, both in terms of prosodic elements that convey meaning in speech such as modulation in pitch, tone, and speed, but also in the ethos of proper interpersonal interaction in which individual players are providing freedom to “say” or play what they want within an overarching structure that demands a collective agreeableness and frequent points of contact or accord (Keeler, 1975).

The communication and attention required to play the gamelan as a unified whole therefore provides support for future linguistic development as well as other interpersonal skills; for example, in every gamelan song the players in the orchestra are following the rhythm of the *kendhang* and must respond to it and modulate their own rhythm accordingly, so when the *kendhang* slows down or speeds up, every child must follow. This can be seen as a skill of social attunement or mirroring (Dosamantes-Beaudry, 2003). Through this the players must practice being flexible and responding to subtle changes in one another’s behavior. There is also the back and forth, the kind of call and response described above involved in prompting and collaborative playing, an added layer of communication in this adapted gamelan that other gamelan groups might not experience but that may be quite rewarding.

Through all of these social aspects the gamelan activities “strengthen the bonds of the Bina Anggitta family” and help shape foster a communal spirit. Anis, one of the senior teachers in the gamelan, explained to me that it makes the teachers feel closer to the students. She believes the teachers enjoy playing gamelan as much as the children do, and because they are all partaking in a pleasurable and happy experience together, this experience makes the community

feel closer and more intimate (B. I. *mengakrabkan dan merekat*).¹⁷⁰ The students spend much of the school day working one-on-one with an instructor, at home they may spend most of their time with one parent, a sibling, a caretaker; gamelan rehearsal is good practice for being in a larger group, the cheerful, lively atmosphere encompassed in the Indonesian word, *ramai*. Gamelan rehearsal is a chance to be together. Even for those children at the school who are not yet able to play music, the session provide an opportunity to interact with the instruments and with one another, leading to small and spontaneous moments of friendship and connection (see Appendix I, Figure 6.6).

In addition to being together, the rehearsal provides a kind of cultural capital or currency that might allow children to more fully participate in future social gatherings by teaching them popular songs. These traditional and contemporary melodies are those that will be played at weddings, and sung with great gusto by betel-chewing grandmothers and tattooed young punks alike at different kinds of social gatherings and events (almost all good times in Java seem to incorporate singing or karaoke). The framework of gamelan practice also introduces children into a cultural symbolic, interpreting their behaviors as culturally meaningful, or shaping them to become so; for example, I witnessed interactions such a teacher taking a “stimming” child, seating him on her lap, hugging him, and then re-positioning his arms and hands, thereby transforming his personally significant movement into the shared or socially meaningful movements of *joged*, or popular dancing. Teachers would also reach out to those children who were dancing along with the movement alone to create a shared or social moment through dancing together (see Appendix I, Figure 6.7).

¹⁷⁰ Anis. Interviewed by Annie Tucker. Yogyakarta, 3 October 2011.

Therefore, while gamelan may be particularly suited to the skills and preferences of children with autism, it also encourages and rehearses a host of other social and pro-social skills and behaviors that may help them access, enjoy, and be accepted into mainstream social interaction.

The Multiple Benefits of Gamelan Performance

The gamelan performance events seem to confer additional benefits for the students, who enjoy donning costumes, performing onstage, and being the focus of positive attention. They clearly take pride in themselves and enjoy demonstrating their skills. In gathering this data I focus on observed behaviors rather than language, noting the children's big smiles and their eagerness to sing when they know it is their turn (see Appendix I, Figure 6.10). Performance at festivals and other events provide a venue for social integration and interaction as they get to meet and watch others perform that may broaden the children's own interests and provide avenues to additional meaningful activities for them. For example, Woro remembers how at one performance her daughter Dian watched another young girl perform *Tari Merak*, or the peacock dance, a standard in the repertoire of young Javanese dancers. Dian was enamored of this performance, practicing the movements she had seen at home. Woro responded to this interest by purchasing Dian a recording of the music and elements of the costume so that she might learn the dance and practice with other little girls in the neighborhood (Woro, 2011).¹⁷¹

It is not solely the students who benefit from gamelan performance, however. The teachers, who join in playing onstage just as they do at practice, report feeling like the performances are positive for them as well. The teachers work very hard for their students,

¹⁷¹Woro. Interviewed by Annie Tucker. Bantul. 13 October 2011.

dedicating not just class sessions but many additional hours outside of work time thinking about how to best serve them, attending workshops and monthly prayer sessions where they meditate on the spiritual meaning of autism. Some of the teachers take in students as temporary boarders as Yasin does. Clearly the teachers are deeply invested in their students' success, not just for the children's own benefit but also to feel like they are accomplishing something themselves, doing something meaningful with their work. A successful gamelan performance reflects well on the students and the school, and by extension people with autism and the people who work with them more broadly. As one teacher explained to me proudly, "Autistic people are looked down upon (B.I. *dipandang sebelah mata*) and people think that autistic kids can't do anything, but these performances are proof that they can." The teachers feel like they are honoring these children by giving them the skills to perform and honoring themselves by showing the positive results of education for autistic or disabled children.

These performances are another way for the community of teachers to draw closer to one another and to the parents of the children they work with. They spend time together while getting the children into costume and waiting at the venue, often sharing a meal during downtime. At the end of every performance, the school clusters together laughing along with any parents who have attended to take pictures. These pictures are then often posted on Facebook, and commented on enthusiastically both by parents and teachers, and by their friends outside of the autism or special needs child community; for example, one picture of a mother-child pair I posted received over forty positive and admiring comments by the end of the day (see Appendix I, Figure 6.8). These virtual "likes" and "shares" widen the circle of people who know about autistic children as capable performers even further and create an opportunity for positive interaction around the topic of autism.

As such, in addition to the benefits that the children might directly experience, the benefits of their participation in gamelan may extend to their parents as well. Gamelan practice, but perhaps particularly performance, may prove therapeutic in the way it helps parents and siblings re-envision their family members not just as disabled or as limited but as capable, shifting their focus from the child's deficits to his or her abilities. Such an abilities-based perspective enabled by the child's participation in the arts provides a fertile ground for parental hope and a way of keeping the parents energetically engaged in the child's development if they are so inclined by supporting their child in the development or pursuit of an interest, turning it into an arena of shared or collective energy.

In the many autism workshops I attended and in interviews, parents were commonly counseled to look for their child's talent both for the child's own sake and as a way for them to protect and nurture their own motivation in raising the child, to avoid "giving up." Indeed I found that parents found a sense of deep consolation and encouragement from watching their child perform. When I asked Ningsih how she felt watching her son perform gamelan she said,

It's like, when the doctor says that you cannot get pregnant, and then suddenly you're pregnant! It's like that. The feeling is extraordinary, it's 'Oh I can't believe it, my child, that child of mine!' (Ningsih, 2011).¹⁷²

One might interpret Ningsih's sentiments to mean nothing less dramatic than seeing her son play gamelan gave her hope where there was no hope, a promise of new life. All of the parents I talked to had painful stories about feeling that their child was misrecognized and wrongly labeled, similar to what I have outlined in Chapter Three, and often have felt like they are raising their autistic children in an environment where they may have some allies but where for the most

¹⁷² Ningsih. Interviewed by Annie Tucker. Yogyakarta, 15 October 2011.

part their child's disability is stigmatized as a family shame, and their child is labeled as crazy, stupid, or possessed, denied opportunities for education, and assumed to be a personal disappointment or embarrassment. The parents themselves are often judged by strangers, members of their local communities, and even family members as not taking the effort to teach their child properly. For some, the embarrassment, anger, frustration, or shame that these kinds of experiences evoke lead them to further isolate themselves and their child. In this context participation in the arts, and in gamelan specifically, is something that can make parents proud. For some it serves as a hope and a kind of proof that their child will be recognized as worthy of positive attention and acceptance. Participation in gamelan performance allows the parents to believe that their child's capabilities might become ever more visible to, and acknowledged by, the broader community.

This dynamic was encapsulated by the news coverage of one of the events Bina Anggita participated in during my fieldwork stay. The karawitan group performed at a three-day event, "Highlights of the Potential and Talent of Special Education Students and those receiving Special Education Services," sponsored by the National Department of Education that was held from October 14-16, 2011 at Benteng Freideburg in the Culture Park complex in Yogyakarta. The coverage of the event in one of the most popular Yogyakarta newspapers, *Kedaulatan Rakyat*, was presented under the headline, "Children with Special Needs Have Potential and Accomplishments: Parents Don't Need to Feel Ashamed" (Ria, 2011). According to this article, the two main barriers to education and success for special needs children were discrimination and parents' shame (B. I. *rasa malu*). While lack of special education facilities is a significant part of the problem, the article argued, many parents don't even send their special needs children to the schools that do exist because they are too embarrassed to try to integrate them into the

community, preferring to keep them shut away at home. The article addressed this issue and described some of the activities at the event, which included performances of traditional music and dance and exhibits of traditional crafts such as batik and woodcarving; the “proof” the article offered to readers that students have capacities and need not be cause for embarrassment was a photograph of a young girl from Lombok engaged in weaving on a traditional loom.

For one parent, it was not as simple as the article’s emotional economy of a performed skill erasing shame—poignantly one parent, Asto, who is clearly proud of his son, and who faithfully transports students, teachers, parents, and instruments to all the performance events in his truck, told me that he still can’t watch his son perform because he’s so afraid something embarrassing will go wrong, and prefers to wait in the van. However, those parents who do watch have the pleasure of witnessing others praise or admire their child’s talents, and in doing so they get the powerful feeling that their child is perhaps for the first time being acknowledged for who they really are. As such, the performance aspect of the gamelan is a particularly powerful element of its therapeutic practice. A mother explained,

In my opinion, it’s essential. To build their belief in themselves. To develop what they have inside. The potential that they have needs to be acknowledged by those around them. To teach the community. To give motivation to parents so that they understand that even if their kids have quotation marks, it turns out they are quite capable.

We have to clearly see what child A, 1, 2, 3, 4, they have their own talents. This, this is what we need. And after that we can show others, that here you go. To motivate other parents, or even not other parents, but other people who are willing to gain wider insight (Redno, 2011).¹⁷³

Gamelan performance, for some parents, feels like a way to improve their child’s future.

A common worry of many parents of children with autism and other special needs is how to

¹⁷³ Redno. Interviewed by Annie Tucker. Muga-Mugu, 14 October 2011.

ensure that their child will be healthy, cared for, and safe, after they themselves pass on. As Ningsih puts it, her parents are constantly asking her about her son Pando, “What have you done to guarantee his future?” She tells them that his future is in the hands of God, but the question does worry her. For some parents, a developed talent and established record of achievement in the arts might serve as one such guarantee. Redno explained,

I know the day is going to come, when we are no longer young. But if we have prepared [our daughter] with what she has been given, then later she won't be mocked, perhaps even she'll have something to be proud of. That's my goal. I'm already thinking about the future. At least I will have maximized what she has, and at the very least lessened the burden that accompanies her. So I can be at peace. When I think of when I'm no longer around, I'm peaceful. What's important is that I have already done all I possibly can to maximize this child. That's my goal.

Sometimes when we are sharing with others like ourselves, who also have “quotation mark” children, with all of their deficiencies, sometimes we cry together [...] but that's why I believe that her work should also be displayed [...] for her to be recognized and acknowledged (Redno, 2011).¹⁷⁴

In summary, from the vantage point of Indonesian families and teachers, and from my own observation, it can be surmised that therapeutic gamelan is an overwhelmingly positive experience, with numerous benefits found in both practice and performance catalogued above. But if participation in gamelan can have all of these positive effects, why is that exactly? I propose that in addition to its sensorimotor, communicative, and other components, gamelan becomes as significant as it does in the context of autism in Java because the ability to play gamelan is a prized ability that has a rich cultural history and multiple positive referents. To understand how and why this might be further amplifying gamelan's effect on students, parents, and onlookers, we must delve into gamelan itself a little more deeply.

¹⁷⁴ Redno. Interviewed by Annie Tucker. Muga-Mugu, 14 October 2011.

Role and Philosophy of Gamelan and Performing Arts in Javanese Culture

According to Javanese mythology, the original gamelan was a set of three gongs created almost two thousand years ago as a way for the gods to communicate with one another. Carvings in the world-famous Borobudur temple, built in the 8th century, show depictions of what is believed to be an ancient form of the gamelan and the gamelan has continued to play an important role in ritual and communal life. Many gamelan ensembles have been handed down and cherished over multiple generations; some are even believed to be imbued with spiritual energy or special powers, with the capacity to inspire strong emotions in listeners or even catalyze natural events such as rainfall. All gamelans are given offerings treated with respect (e.g., not stepping directly over the instruments) and the more powerful sets are only played on auspicious or religious occasions. The best and most extensive gamelans are kept at the Sultan's palace in Yogyakarta, where the instruments are handled with reverence and lavished with adoring names such as "The Foremost and Venerable Honey Thunder" and "The Foremost and Venerable Harmonious Dragon" (Prijosusilo, 2011). Gamelan music has been, and to a certain extent remains, intimately connected to Indonesian culture, often played at life cycle rituals and important village events. The kinds of events gamelan will be played at include wayang shows and other performances; family celebrations such as birth, circumcision (*kitanan*), weddings, the completion of a house being built, family reunion (*arisan keluarga besar*), or the celebration of someone of age and status (*tumbuk yuswa*) as well as state and religious ceremonies such as the Yearly Blessing and Thanksgiving at the Palace (*Sekaten*), *Sesakan*, *Srikraton*, *Denda Sewu*, etc. (Kodrat, 1982). Perhaps because of gamelan's ubiquitous accompaniment of significant events marking stages in personal development as well as occurrences in public life, it is thought to both

illustrate and contain elements of the human life cycle “or the life journey of humankind” (Susteya, 2007).

According to Budi,

In the olden days officials would imitate the king, and the king would say “If my child can’t play gamelan, I will not recognize him as my own son.” It used to be like that. The officials were like that too. “The offices beneath me have to have a gamelan. Because gamelan is good for all these different things.” [...] Gamelan *is Java*” (Budi, 2011).¹⁷⁵

In Jakarta and some other urban areas, gamelan might be falling out of practice. But Yogyakarta is a city in Central Java where the art of gamelan is still particularly active, or as Indonesians might say, it still sticks (B.I *masih kental*). Gamelan is valued and performed on its own, as well as part of other arts practices and performances such as wayang shadow puppetry, dance, theater, cross-cultural and cross-genre collaborations. Gamelan performance also still marks significant civic, folk, political, and spiritual events. These performances and events are ample and amply promoted as part of the city’s vibrant and lucrative tourism industry, which draws national and international visitors year round.

The gamelan is part of the broader world of Javanese performing arts, which have historically played an integral role in Indonesian society, supported by rich local traditions and a complex indigenous philosophy of arts practice as a path towards self-improvement and collective well-being. In Javanese philosophy the performing arts have long been associated with not just beauty or entertainment but also wisdom and awareness, seen as an embodied interpenetration of “ethics and aesthetics” and a pathway to fuller civic consciousness and spiritual agency, the practice of which confers self-improvement and connection to others. There

¹⁷⁵ Raharja, Budi. Interviewed by Annie Tucker. Yogyakarta. 24 December 2011.

is a well-researched and resilient holistic conceptualization linking arts practice to mystical and devotional practices, which are believed to strengthen individual spiritual power and morality, and cultivate an intuitive skill for attuning to others, which fosters interpersonal connection and inter-subjective harmony (Hughes Freeland, 2008, 2001, 1997; Foley, 1984). Hence, Javanese performing arts are recognized as being significant bearers of cultural values and beliefs, refined over centuries to uniquely express a Javanese way of being-in-the-world. It can be said that “Karawitan music has a profound meaning that was not just randomly stumbled upon, but in every aspect, every instrument, every note of every song truly has a philosophical meaning” (Nastiti, 2011, p. 16-17).

In this cultural environment the power of the performing arts to enhance and transform communities is taken seriously. Indeed, artists and the arts have historically been afforded healing and safeguarding properties. *Ruatan* performances are held to provide protection during important times of transition such as childbirth or circumcision, and are believed to be able to cure the sick or restore balance in times of distress (Foley, 1985). Historically, certain master artists have also been seen as healers, with *dalang* especially sometimes fulfilling a priestly role, working for the betterment of his people and helping to illuminate the meaning of life (Foley, 1985; Keeler, 1987). As such, the traditional arts are seen as not just aesthetically pleasing, but actually capable of affecting change in individuals and communities (Foley, 1985, 1984).

In addition to according benefits that the performing arts more broadly offer, the Javanese gamelan in particular serves as a model for inclusive and interdependent communities.

Supported by a rich philosophy of collective harmony, the very structure of gamelan provides a social model for inclusion: no one can play gamelan alone, as each instrument is dependent on the accompaniment of others to create its complex fabric of sound. Furthermore, as mentioned

above, the simplicity of the percussive instruments is accessible to people of all levels of skill while dedicated practice will encourage a constantly evolving maturity in attuning to other players. According to its philosophy, the prerequisite to playing gamelan is not musical technique but a sincere desire for harmony and a willingness to listen to one's inner self, one's fellow players, and the power of the instruments themselves; because of this deep attention and intention that gamelan may cultivate, some have classified the practice as musical worship. Many find that these values, learned through music, ultimately reverberate into daily life. As the ethnomusicologist Henry Spiller describes,

Gamelan music of all sorts is about playing together with other people in a unified group in which mutual cooperation is rewarded with harmonious music. Expert gamelan musicians use their knowledge and skill not so much to stand out and shine in a group, but to blend seamlessly into the complex musical texture and make everybody shine—an approach to exerting power in all social actions which Indonesians tend to value highly. I did not realize it at the time, but even from the very beginning of my involvement with gamelan music, the musical processes required to play it were retraining my body and mind to think and act in accordance with these values (Spiller, 2004).

In fact it may be that gamelan remains on so many Javanese public school curriculums because the practice of gamelan is understood to provide a profoundly integrating psycho-developmental-educational-social-spiritual experience based on a rich and considered philosophy and is believed to foster positive personal and interpersonal development that harmonize with Javanese values.

According to Khisbiyah, an Indonesian arts scholar and pedagogue, gamelan's

ethic and aesthetic aspects will give birth to refined sensation and feeling (B.I. *kehalusan rasa*), wisdom and discernment (B.I. *kearifan*), magnanimity (B.I. *keluhuran budi*), creativity, intelligence, togetherness (B.I. *kebersamaan*), the spirit of mutual assistance for the benefit of all (B.I. *kegotong-royongan*), character (B.I. *budi pekerti*) and the best possible attitude and behavior (B.I. *sikap laku utama*) (Khisbiyah, 2004, p, 149).

Because of this, it is seen by many as being particularly valuable for contemporary Indonesians who understand themselves as being tasked with living in a pluralistic and diverse society. The above quote is taken from a treatise on applied arts practice, an apology of sorts for why gamelan should remain part of a Javanese public school curriculum. The performing arts more broadly and gamelan in particular are seen as embodying and developing some of the main values of Javanese personal comportment and interpersonal behavior.

Using Traditional Performing Arts to Support the Development of Javanese Personhood

Multiple genres of Javanese performing arts been seen as having curative powers in the context of physical illness and emotional distress and also as providing moral guidance and developmental support. Gamelan is not the only traditional art that has been accorded such belief and veneration, nor is it the only art form that is believed to be beneficial for children with autism. Another professor at the Yogyakarta Institute for the arts, Sumandiyo Hadi, also created a (now discontinued) experimental dance therapy program for youth with autism and other developmental disabilities based on the philosophy of Central Javanese court dance (B.I. *Joged Mataram*). *Joged Mataram* is a philosophy of “acting-dancing” which involves embodying the traits of different characters, aligning the inner self with physical self (B.I. *lahir dan batin*), and attuning with others. The practice of *Joged Mataram* is believed to confer spiritual and moral development, but these benefits have usually been restricted to classically trained dancers. Hadi’s work sought to provide such a development through a series of simplified movement exercises for children with autism and special needs, but he ran out of funding.

In addition to dance and gamelan, wayang shadow puppetry has been accorded the ability to encourage positive development and a reduction in symptoms associated with autism. For

example the national newspaper Kompas published an article entitled, “Kuncir Recovers from Autism After Discovering Wayang,” about a young boy whose autism was “cured” by practicing shadow puppetry. According to the news story the boy was first attracted to one wayang character he frequently saw on a televised shadow puppet program—Gatutkaca, a bold superman-type figure who has “nerves of wire and bones of steel.” Through this interest Kuncir began to study shadow puppetry, and has since performed and competed in various dalang or puppeteer events, memorizing the parts of up to 213 characters. His parents claimed that after two years of puppetry study his IQ had risen from 78 to 117, and while he still had difficulty socializing his behavior was no longer hyperactive and his emotions had stabilized such that they considered him “cured” (Kompas, 2008).

In talking to an Indonesian friend about this article, we considered a number of ideas as to why wayang could be such a successful practice for this boy. Much as I have theorized about the gamelan performance, we thought that being a dalang might be a particularly good fit for someone with mild autism, in that it provided a way to channel autism-specific gifts (in this case, perhaps, for memorization) into a culturally meaningful practice, and through the medium of puppetry and theatre provided a way to rehearse and learn about personality and socializing without having to endure potentially overwhelming person-to-person contact. My friend put forth the theory that in addition to this, Kuncir must have received a kind of psycho-moral tutelage from the art form itself, the *wayang*, that supported his development. *Wayang* and the other Javanese arts are believed to have the power to evince certain kinds of changes in anyone, so why not for someone with autism?

Interestingly, these expected developments align very closely with the kinds of changes that are observed in the young Bina Anggita players by their teachers. This becomes clear if we

compare Khisbayah's description of the effects gamelan might have, cited above, with Yasin's observations of how gamelan practice has affected his students with autism. In general, Yasin says,

Playing *karawitan* affords the opportunity to practice solidarity (B.I. *kekompakan*) and harmony/conformity (B.I. *keselarasan*), practice rhythm, practice tolerance for one another, practice emotion[al control], practice patience. The spirit of mutual assistance for the benefit of all (B.I. *gotong-royong*) will be formed, and it will develop an attitude of understanding (B.I. *kearifan*) that every role, no matter how small, in *karawitan* we need to work together (B.I. *kerjasama*) (Yasin, 2011).¹⁷⁶

In other words, gamelan offers an opportunity to practice Javanese values of community, and hence trains for a Javanese personhood. We can further explore how gamelan is perceived to have affected development of one particular student, Arka, the boy who requested his own *saron*, in the eyes of his teachers. Anis, a senior teacher at the school who plays a key role in organizing gamelan activities, said;

Take Arka, for example, before he joined *karawitan* his level of capability was significantly lacking, he never wanted to talk, he didn't want to even socialize with other people, his emotions were out of control. Praise God, after he joined *karawitan* there have been a number of observable changes, like he wants to talk to other people even if he is slow to read their signals, he wants to socialize, he has started to accept the presence of other people, his emotions have become controlled, he's starting to tease and joke around with his friends. That's why I put him right in the front of the group to play (Anis, 2011).¹⁷⁷

Yasin added,

Arka's personality and appearance has become more mature, more regulated, and his emotions are peaceful. He is familiar with the other children, he cares, and he can lead the children that are younger than him. He always makes himself available to help the teachers... many positive behaviors have appeared since he has been participating in *karawitan* therapy (Yasin, 2011).¹⁷⁸

Budi agreed with these observations.

¹⁷⁶ Yasin. Interviewed by Annie Tucker. 1 October 2011. Yogyakarta.

¹⁷⁷ Anis. Interviewed by Annie Tucker. Yogyakarta, 3 October 2011.

¹⁷⁸ Yasin. Interviewed by Annie Tucker. 1 October 2011. Yogyakarta.

Arka has experienced a truly extraordinary change. Before if he was mad... His mother even noticed the changes, she told me, before if he was angry, he would [makes angry faces] right at his parents. Now, if he's mad he just goes into his room, listens to gamelan music, and drinks tea, like a mature person. He can control himself now (Budi, 2011).¹⁷⁹

During my observations of the gamelan I did notice that Arka seemed particularly mature, focused, and both aware of and able to help or redirect others in the group. Not knowing him before he began to practice gamelan I have no basis for comparison, but what is important here is that his teachers ascribe this way of being to the positive effects of playing gamelan.

What Arka's teachers are describing is the boy's development of a more Javanese personhood and Javanese citizenship. It is these specifically Javanese qualities that they believe have been cultivated and drawn out by gamelan practice. Acknowledging others' presence and needs, caring about these and adjusting one's own emotional expression accordingly, being willing and able to be both a helper and a leader according to the status of the relationship; these are all the hallmarks of Javanese citizenship as described in Chapter Three, and all apparently successfully cultivated by gamelan practice. This might be why the traditional arts have such prestige for typical and autistic children who are able to perform them, and why parents might be so touched and encouraged by their children's participation.

There are certain aspects of gamelan practice, and how it is perceived as catalyzing the development of a "Javanese personhood," that illuminate Javanese models of maturation and development and by extension further explain why some of the "tough" and "structuring" interventions discussed in Chapter Five are a poor cultural fit for many. As I mentioned, the Javanese see the process of development as internally guided, spontaneously arising as the child him or herself feels ready for the next step according to his or her own schedule. According to

¹⁷⁹ Raharja, Budi. Interviewed by Annie Tucker. Yogyakarta. 24 December 2011.

Budi, it is this Javanese process of development that is supported by gamelan practice. In portraying gamelan practice, he describes a practice that builds and encourages individual character through a feeling of comfort and happiness and acceptance, a sense of improvisation, individual initiative, and spontaneity that flowers from within, and within the safe buffer of a supportive collective. Here I quote him at length discussing his impression of another student's observed and potential future progress.

Well for Gana, his model is like this. If I play like this [sings an example of a song in straight time], he plays like this [sings the same tune with a syncopated improvisation]. He stretches it out. It's truly like that. Later, that might become a signature of his character, and every song will be sure to be played that way. It will be his specialty, his trademark. Because that is his personal expression.

And if that starts coming out, it will affect other things. For example, we can tell him about feelings, if other people are happy this way, [then he'll think] I also have to be happy, but in my own way. Maybe it can be done in such a manner.

In gamelan, creativity is wide open. With the understanding that with creativity, within the scope of the rules, there is independence. If you are still within the framework it is very much allowed for, that's totally normal and independent. Every *karawitan* group, let's say they are playing the same song, the feeling can be different. And similarly, if the same group is playing that song during a different practice, you can feel the difference there too. It's because of that! Maybe in an orchestra, you have to follow the conductor. But here, the interaction between members is very flexible. So it's that, it's actually that *freedom*, that I want to use to bolster and awaken the children's feelings so that they can create.

Gana's performance is just like an autistic child making art. And recently, the children have begun to come up with their own activities. Before, for example, if they played something it was just the same as ordinary people. But now, he has his own style, he has his own melody. That's great isn't it?! This is actually what I want to develop. And with Gana, I can see he is starting to have that kind of development.

If you use art, they don't feel like they are being "treated." It just happens spontaneously because they are involved. In art, there are a lot of things like that. "I just have to get this out," like that. Let it out. For example, in improvisation, even normal people will be like, "Oh, this really draws me out, makes me want to try!" That's what I want to develop.

Well actually what I really want to explore.... For autistic kids, maybe because of the fact that their parents are embarrassed, there are a number of things that don't get expressed. I want to use gamelan in that aspect, actually. With that, my assumption is later if they have been practicing frequently, the model will already be different, and it will make them different. Maybe their faces will be bright. Now, they are constrained. That's what I imagine. And with that there is a little bit of rehabilitation.

My assumption is that, if people play music they have to be happy first. If they are already happy, they are used to feeling the music, there is something that they can feel, [communication and self-expression] will emerge on its own. It doesn't have to be like this [mimics a strict teacher scolding]. With that understanding, I made a gamelan that could be appropriate to their world, so that they could be happy. The important thing is that he can enjoy it, he can play. And if it turns out that people can acknowledge, yes that's truly *karawitan*, well, that's important, too (Budi, 2011).¹⁸⁰

In Budi's concept of gamelan practice and the development of children with autism, it is "flexibility" and "freedom" that awakens creativity and hence, personal development.

Development emerges with an improvisational sense of being "drawn out" as a kind of inner impulse or a spontaneous trajectory. This kind of creativity and growth can only happen when the individual player feels happy and approved of, not when they feel like they are a source of shame, not when they are being scolded or when they feel like they are being "treated."

In previous chapters I mentioned the possibility of a poor cultural fit of other behavioral interventions for Javanese families. One problem with these is that they feel punitive, and Javanese models envision children growing because they are happy and safe. While it happens within a broader collective structure, development is seen as coming from within the self, not as the result of externally imposed rules. One strength

¹⁸⁰ Raharja, Budi. Interviewed by Annie Tucker. Yogyakarta. 24 December 2011.

of gamelan music as a therapeutic intervention may be the fact that most children find playing music enjoyable and are eager to participate, hence the activity is a natural motivator and reinforcement and has the power to shape behavior in ways that strict behavioral focused interventions might not be able to do while at the same time fitting in with Javanese cultural logics of development and interpersonal interaction. As Ward Keeler said in his study of gamelan and compartment, there are “lines beyond which a Javanese feels no longer permitted to influence others. I think this discretion is congruent with what could be termed the musical discretion which governs the Javanese gamelan” (Keeler, 1975, p. 86), by which he means the freedom to play how one wants according to one’s desire and ability within the broader structure of the collective.

Ultimately, the Javanese are working with a quite different model of personhood and development than in the USA and Europe, and these different models are reflected and instantiated in models of autism intervention, and in this case models of music practice and performance. The different intervention methods promoted envision the person, or envision the healthy developing body differently: ABA envisions the healthy autistic child as a trained instrument responding to ever-increasing demands with the hopes of personal reward or praise who learns to obey rules and master schedules. The restricted diet envisions the autistic body as that which must become ever more rigid, measured, quantified and closed off to options in order to stay healthy. These models are not so different from normative ideas about functional personhood and physical health in the contemporary United States. Meanwhile the therapeutic gamelan imagines the healthy autistic body as a porous, sensate member of a collective who must both align in

harmony with others and is yet free to express itself, who must be flexible and agreeable. This, too, is not far away from the Javanese ideal.

“I too can make something for Indonesia”: Disability, Citizenship, and the Arts

As I mentioned in my introduction, therapeutic gamelan practice has a bi-directional goal, both to support the children in the development of important skills and to influence their communities so that these skills might be recognized. In other words, for gamelan practice to be as effective as I believe it is as a holistic intervention, its practice must have the power to cultivate a Javanese citizenship in its players, but its performance must also provide an opportunity for this citizenship to be recognized by others. Participation in the traditional performing arts, such as gamelan, will change the social construction of autism in Javanese Indonesia if or because it can change the perception of the capabilities (and personhood) of people with autism.

Looking at some of the contexts within with karawitan Bina Anggita performs provides one key to understanding the reframing of autistic citizenship through the performing arts and music. On September 30 2011, the group performed on a stage at the event Yogya Edu Expo, which provided information on the programs and opportunities available to primary, secondary, and high school students from across the city as well as showcasing their talents. At this event, Bina Anggita joined many other school groups, comprised of typical students from across the city, in performing karawitan. This illustrates how participation in the traditional arts is a way of showing development, capability, and civic pride for all students; indeed, some form of traditional arts education and performance is compulsory (B.I. *wajib*) for young Indonesians as part of their cultural and civic education to help them develop into proper Javanese adults. What is important in this musical education is not necessarily musical skill per se but the cultural skill

practiced through an activity that exemplifies certain values (Mack, 2007), much as American children might participate in team sports as a way not necessarily to turn into exceptional athletes but to learn the values of honest competition.

In the case of autism, participation in the performing arts goes beyond merely demonstrating citizenship or reaffirming citizenship by joining in exemplifying these values, to actively creating it where it has been forgotten. Through performing traditional arts, and mobilizing this symbol of diversity and inclusive unity, the students are afforded a way to demonstrate their equal citizenship here. At their next performance event, as part of the aforementioned “Highlights of the Potential and Talent of Special Education Students and those receiving Special Education Services” event in October, the students of Bina Anggita performed in front of a tall banner with the words of a poem by a young man and what appeared to be a photograph of him passionately reciting it (see Appendix I, Figure 6.10). Entitled “I Too Am the Hope of the Nation,” this poem was a forceful statement that provided a powerful socio-political context for Bina Anggita’s activities as well as gesturing towards the broader goals that envelope and motivate similar efforts, so I quote it in its entirety here:

I Too Am the Hope of the Nation
By Allen Zefo Umbah

Who says that I don’t have a bright future?....
Who says that I can’t make anything of myself?
It’s said that there’s nothing about me to be proud of
It’s said I’m just the butt of a joke for those who are smart
Because I’m just someone labeled a defective speaker
 They say...
 But shhh... wait....

It’s true that I am different from all of you
I was created by God with a number of imperfections
While you can stand up tall and speak
And are able to hear

But we are one inside the womb of Mother Earth.

You are Indonesia... I am also Indonesia
You are Indonesia's young generation ...
I am also Indonesia's young generation...
You can make work (B.I. *berkarya*) for Indonesia...
I can also make work (B.I. *berkarya*) for Indonesia...

We're the same, aren't we?
Only our bodies that are different
We both equally make up the country of Indonesia
We both equally have the same right to education
We both equally are the successors of Indonesia
Because I am also the hope of the Indonesian nation.¹⁸¹

I have described the feelings of embarrassment many families have experienced due to the discrimination and misunderstanding of their children. This poem acknowledges these feelings of shame, but it goes beyond suggesting that families do not have to be embarrassed of their disabled members or even suggesting that disabled people themselves do not have to be embarrassed, to forcefully argue for an inherent, natural born equality, and claim equal rights to social equality and inclusion, education, work opportunities, and national recognition. This focus on equal citizenship is a significant reorientation from a past or lingering present situation, where shame went hand-in-hand with neglect and discrimination.

I was drawn to the word *berkarya* in this poem, which is translated as to “make work” or “create something” in the artistic and expressive sense. Allan Zefo Umbah claims his membership in Indonesia's next generation by asserting that he can “*berkarya*,” or make creative work, the proof of which is the very poem in which he asserts this. The implication is that a significant aspect to citizenship and inclusion is the ability to “*berkarya* for Indonesia,” that making artistic work and being publicly recognized as a full citizen are conceptually linked. *Berkarya* was also a word that emerged in family members' understanding of what it was their

¹⁸¹ This poem was written in Manado, on 7 September 2011.

child was accomplishing through participating in gamelan, or what their performance was communicating. As one mother said,

So, don't look down on them. Don't look down on their creations (B.I. *karya-karya*). It turns out that kids like this, can do something. Perhaps within their own limitation... But their work (*karya*), even with its limitations, is noble and precious. And that's where I find joy. My daughter is limited, but she is capable. She's happy, she's enjoying herself.

So what I'm saying is, I'm not looking for pity, but just that our presence be acknowledged, so that she can develop herself, even if she is a quotation mark kid. It turns out, she can do it. So she can create, and create, and create (B.I. *berkarya, berkarya, dan berkarya*) (Redno, 2011).¹⁸²

Another family member continued,

People watching will definitely feel proud, plus it can show that autistic people can *berkarya*, that's the basic idea. Sometimes, right, for average people, their question is what is autism and what can autistic people do. *Karawitan* can give a sort of preview to the audience, that autistic people can *berkarya* like that. That's how it is (Gary, 2011).¹⁸³

Based on my previous examples, in Indonesian discourse there is a directly felt historic link between arts participation and civic life, active arts participation and active citizenship; gamelan, alongside the other performing arts of shadow puppetry and dance, all have a long-standing history and philosophy of promoting values of simultaneous self and communal development for the good of all. These local Javanese values linking performance and citizenship are to a certain extent forwarded and extended by nationalist projects, from Sukarno's support of the arts as both local and national "cultural capital" (Sutton, 1998) to Suharto's more aggressive *Pembinaan Kesenian* policies. Both leaders sought to shape and project a vision of a harmonious, united, and diverse Indonesia for tourist, dignitaries, and fellow citizens, where in a mnemonic relationship a particular repertory piece or performance genre might stand in for a

¹⁸² Redno. Interviewed by Annie Tucker. Muga-Mugu, 14 October 2011.

¹⁸³ Gary. Interviewed by Annie Tucker. Wonocatur, 19 October 2011.

region, an ethnic group, a set of local laws, customs, practices, and aesthetic styles on the “national stage.” The effects of this nationalist policy on local art forms has been robustly critiqued on accounts of “sanitizing” local performances and leaching them of their original meaning and turning them into mere “spectacle” or commodities (Lindsay, 1995; Yampolsky, 1995) otherwise intervening into local performances to make them more “suitable” for national audiences or fashioning them anew (Harnish, 2007). However, performances of regional art forms at a variety of events are intended to, and often *do*, self-consciously bolster a construction of an Indonesia that is harmonious, inclusive, and diverse. Gamelan performance thus triggers and manifests both these national values of “unity in diversity” and the strategies of representing it, while simultaneously serving as an embodied mnemonic for inclusive, tolerant, and harmonious communities that Javanese Indonesians pride themselves on. As Redno describes it, the felt response in the audience is amazement and an “opening of the heart.”

If the creativity they have and work that they can make can be displayed, that gives insight to others, who before did not want to understand and underestimated them, so that even their hearts are opened. This problem is a problem of the heart. That’s what I think. We are not asking for pity.... We are thankful simply to be acknowledged (Redno, 2011).¹⁸⁴

This opening of the heart, this acknowledgement, might then ultimately lead to equality and inclusion. As I thought back on all the different places where the gamelan has performed, I realized it included some of the main cultural and educational centers in Yogyakarta including Taman Budaya, the presenter for international arts festivals and local fine art exhibits, and Gadjah Mada University, one of the most well-known universities in Indonesia. I realized that through these venues, the gamelan participants have been invited to literally share a stage with some of the most significant thinkers and artists of their city and beyond.

¹⁸⁴ Redno. Interviewed by Annie Tucker. Muga-Mugu, 14 October 2011.

Restoring Javanese Models of Embodied Inclusion through Gamelan Performance

In addition to being an indigenous musical practice highly applicable as therapy, gamelan practice and performance acts as an embodied mnemonic for Indonesian values of inclusive citizenship. Visible inclusion of people with autism in the performing arts triggers an acknowledgment of their full citizenship and reminds onlookers about local and national values of inclusive diversity, tolerance, interdependence and cooperation that encourages this dynamic in the context of autism and facilitates the development of social, political, and infrastructural inclusion support in other arenas such as education. As a mother of a participant sees it, the message of the Bina Anggita gamelan is, “Come on, let’s support one another, give to one another, accept one another. Diversity is an inherent part of humanity” (Redno, 2011).¹⁸⁵ As such it provides a forum for voice and self-expression but also for reminders that nobody makes it alone, everyone is interdependent. This both allows for and minimizes differences.

The application of traditional Indonesian arts as a therapeutic practice for people with disabilities inserts disability into a debate that has been going on in private conversations and public forums for a while now, which questions: Do the traditional arts still have an active, relevant role in contemporary Indonesian society or are they valuable only as “museum pieces”? Another way of asking: Are the values that these arts embody still alive? Or are they also “museum pieces”? Contemporary Indonesian discourse is fraught about the role of traditional arts, and how and why these art forms should be best preserved to benefit contemporary Javanese.

¹⁸⁵ Redno. Interviewed by Annie Tucker. Muga-Mugu, 14 October 2011.

Many people believe the decline and desiccation of the traditional arts have led to a decline in contemporary Indonesian citizenship and a loss of Indonesia's moral compass. For example, at one recent convention a *dalang*, or puppeteer reminded audience members that traditional Javanese performing arts marry aesthetics, the science of beauty with ethics, the science of good behavior, and that both of these are integral in *wayang*, which not only entertains but can provide guidance and "bring enlightenment to the human race" as each spectator is asked not just to enjoy the art but to meditate on its meaning and application in everyday life. Hence, losing touch with the art form means losing touch with cultural values and aesthetics, which means losing touch with Javanese soul. He warned, "cultural materialism is growing stronger. Its constraints are intangible but haunt the faith in and of the puppeteer" (Suparman, 2011).

A cultural critic writing for the *Jakarta Globe* similarly mourned the decline of gamelan in a recent passionate op-ed entitled "Indonesia Needs the Harmony of the Gamelan" (Prijosusilo, 2011). The author points to the cultural changes wrought by industrialization and globalization of Javanese agriculture in the early 1970's, which pressured villagers who then no longer had the time or mindset for gamelan as a moral and spiritual practice. He says that gamelan practice has not disappeared but its "central function" was lost and "the teaching and learning of gamelan began to follow the logic of an industrial culture instead of the logic inherent in the gamelan instruments themselves." According to Prijosusilo this inherent logic is one of the broadest possible inclusion and accord, saying "with a set of gamelan instruments, any group, including people of any age, gender or ability, can be guided in worshipfulness and harmony" and "all one needs to take part and contribute meaningfully in a gamelan composition is the ability to maintain harmony and worship with heart in the practice of hitting the instruments in a sincere manner." Pointing to a "culture of materialism" and referencing frequent interreligious

violence, he argues that the lack of worshipful gamelan practice is a “cultural loss” and he encourages a return to gamelan and the philosophy it embodies, “because right now we desperately need more sensitivity and harmony in our communal lives.”

In this discourse about traditional arts, there are echoes of the same worries that I have noticed emerged in discussions about people with autism: something has been lost in Indonesia’s transition to capitalist consumerism. As I have phrased it in previous chapters the questions is, is Indonesia developmentally delayed, or do its local cultures have something to offer that is developmentally different, that actively cultivates different values than globalization or Westernization? Interestingly, I found that the application of gamelan in the context of autism provides an almost circular or tautological positive reinforcement for both gamelan and people with autism that unites and resolves both of these concerns. I have suggested that the fact that these autistic people can play the gamelan in some way seems to prove their rights to full citizenship. If autistic citizens are full citizens, then they have a right and responsibility to access and preserve their cultural heritage. Similarly, playing and performing the gamelan not only proves to the general public that autistic people are capable, but gamelan’s function in making autistic people recognizable as capable citizens also proves its continued relevance and value as a tool for pro-social development, self-expression and self-realization in the context of a harmonious, tolerant, and inclusive society.

This logic was illuminated for me in various conversations including one with Tofik, a university student who hopes to become a music teacher. Tofik was initially doing an internship with the school rehearsing contemporary music, teaching the children to sing while accompanying them on the keyboard. However he observed the gamelan practice and was astonished: “I couldn’t believe they could do it!” he said. The fact that they could not only built

his interest for working with special needs children but also triggered his interest in teaching gamelan in addition to contemporary music. He now practices with the children every week. In group discussions, the Bina Anggita teachers echoed the sentiment that gamelan is a valuable cultural practice that has been abandoned in recent times; foreign researchers and tourists care about gamelan, but Indonesians don't anymore. It's almost as if Javanese people want to care about gamelan, but they do not see the use of doing so. In a surprising alchemy, instead of a marginalized gamelan practice pairing with a group of marginalized citizens with autism further marginalizing both, the opposite is true. Gamelan's apparent efficacy in treating autism suddenly makes people realize that it can still effect positive change, is still "useful," and therefore still might have an important and relevant role to play in contemporary Indonesian culture. The participation of autistic citizens reflects well on gamelan, and reflects positively on the children, who seem to be displaying a kind of cultural maturity and authenticity in responding to it and respecting their cultural heritage. The therapeutic application somehow recentralizes gamelan, includes autistic people as audience members and others notice or "remember" what being Javanese is all about, as they witness their cultural heritage providing an inclusive alternative to behaviorist approaches or a "culture of materialism."

And yet, the mobilization of gamelan could even have economic ramifications. Indeed, Bina Anggita's gamelan performance has brought some financial benefits for their school as well, as they often get a small "reimbursement" or "thank you donation" for their participation at events, particularly those sponsored by the Department of Education. Near the end of my fieldwork with Bina Anggita, Yasin stepped down as principal of the school and an employee from the Department of Education took his place. The Department's attention was drawn to the school because of its active gamelan, and solidifying the ties to the Department through this

change in administration has allowed the school to access more government funds to support the gamelan and the school's other activities. After I went home to the United States, I heard that the students and teachers had been made beautiful new costumes to perform in, and that school facilities had been expanded and renovated. Bina Anggita's gamelan group may have seemed like an ideal recipient for this recognition and funding particularly because of its performing capabilities. Gamelan performance turns the ensemble into a visible, mobile promotion—for inclusion, for education, for autism awareness—that can tour and perform at various events, as well as reach a broader audience through television shows. Gamelan performance is able to give autism and autism education a public face and thus could serve an important strategic purpose for a national government trying to develop sustainable disability infrastructure for the country: it both proves that they are helping even the most vulnerable of its citizens and actively preserving their cultural heritage.¹⁸⁶

Conclusion and Potential Applications

Gamelan practice and performance is experienced as both pleasurable and therapeutic for those autistic children and their teachers who participate in the experimental group of karawitan Bina Anggita and is valued by their families for numerous reasons. Regular practice is perceived and reported as being efficacious as a music therapy for those on the spectrum and having positive effects for individual students, promoting physical, cognitive, social, and emotional wellbeing, although these perceptions and reports remain to be further studied in order to determine how such effects might compare to a control group, or whether or not such effects can

¹⁸⁶ As with the body of scholarship that is critical of Indonesia's political manipulation of the performing arts to further a nationalist agenda that covers over a history of violence and hence serves as a very relevant caveat against a naïve embrace of the power of the arts to support an uncomplicated diversity, so might some find reason to criticize the use of performance in this context, arguing that creating "poster children" or groups for fundraising can be harmful to the overall mission of disability equality (cf Smart 2009); however in this case I personally think that these potential dangers are outweighed by the benefits that have been stated.

be generalized and/or sustained. Beyond such benefits, gamelan practice and performance also draws the school community closer together, as music becomes a tool for communication outside of language and a way of transmitting culture and providing enjoyable meaningful interpersonal connection that other modes of social interaction may not yet be able to provide for those on the spectrum. It serves as a channel for parental pride, motivation, and engagement with their children and serves as a powerful social intervention, where children perform publicly to build awareness about autism and break down stereotypes about what autistic and special needs children are capable of.

Gamelan provides a “locally coherent” intervention that addresses autistic people’s inclusion and recognition within the larger community through triggering indigenous models of personal development and accessible and inclusive societies, a model where the collective supports the development of the personal, and group practice fosters each particular individual’s ability to develop the self and attune to others. It is interpreted as catalyzing the development of a particularly Javanese personhood, and is perceived to cultivate this specifically Javanese development through particularly Javanese means, which emphasizes spontaneous and internally motivated development, which evolves out of a source of pleasure and exploration, where students feel comfortable and slowly coaxed to emerge. This may make it a more culturally salient intervention than some other options, such as behavior intervention, which is based on compliance and may make children feel like they are being “forced,” judged, or “treated.” The perceived efficacy of this local traditional art has the additional corollary benefit of making local Javanese feel more proud of their local culture and more certain of their local values, rather than other forms of intervention which exacerbate tensions and anxieties about Javanese culture, family, and community practices, which are often compared unfavorably to those in more

“Western” or “developed” nations. As such, it promotes the wellbeing—that is, the ability to engage with and participate in culturally meaningful practices (Weisner, 1998)—of both autistic children and the school and family communities.

Therefore, while it may not completely supplant or eliminate the need for other approaches, I believe the therapeutic gamelan can serve as a useful model for those looking to explore options for culturally coherent and locally logical autism intervention in Indonesia and elsewhere. First of all, Bina Anggita’s therapeutic gamelan could be easily replicated and applied more widely, at the very least throughout Java and Bali, where gamelan is still widely played and still a part of many school curricula. At the same time the power of such local models that are discovered does not necessarily need to be seen as being only locally applicable. Just as Western-innovated interventions, such as behavior therapy or speech therapy, are exported and taught in other nations and cultures to become part of a therapeutic toolbox, so could the strengths of local interventions be imported or shared.

As I thought experiment, I was asked what it might look like if the attempt to diagnose and treat ASD had started among the Javanese, given their particular models of personhood and community: what modalities would be used and how would people in the United States react to those Javanese treatments if they were exported to the United States?¹⁸⁷ Gamelan provides an answer to this question, and intriguingly, new therapeutic applications of gamelan music only provide support for the powerful legacy of this particular musical tradition. Cutting-edge research in the emerging field of medical ethnomusicology suggests that both the accessibility of the instruments and the model of social interaction that gamelan music facilitates may even have cross-cultural benefits outside the culture that shaped it. In part, gamelan and gamelan-like

¹⁸⁷ Personal communication with Thomas Weisner, 2013.

instruments may be useful for those with Autism Spectrum Disorders or other disabilities because they are “high yield,” in other words they produce rewarding sounds with minimal technique or effort, thereby encouraging individual expression and socio-musical interaction, and have received positive attention in the music therapy literature (Mendonca, 2010; McIntosh, 2005; MacDonald et al., 1999; Sanger & Kippen, 1987) in part because of its accessibility and “culture of inclusion” (Loth, 2006; Bakan, 2012). As Budi and the other gamelan teachers have suggested, gamelan applied even outside of the Indonesian context has been able to improve focus and concentration. For example preliminary results of “The Gamelan Project,” a research project run out of the University of California, San Diego shows that studying gamelan strengthens “ensemble synchrony” and that the ability to synchronize in an ensemble setting—regardless of other musical abilities—seems to correlate strongly with ability to “pay attention” or maintain focus not only in music class but in other areas as well, a skill that is challenged in students with autism and ADHD but that can improve with gamelan practice. This as yet unpublished research suggests that gamelan practice demands a unique level of integration in temporal processing and may thus play an important role in the refinement of temporal perception and facilitate coordination and communication (The Gamelan Project, 2011). Meanwhile therapeutic gamelan held in a group for at-risk youth in New Hampshire by ethnomusicologist and gamelan expert Jody Diamond has also been reported as having qualitatively positive effects on groups of young people with developmental, behavioral, and mood disorders (J. Diamond, personal communication, 2 August 2011).

Western biomedical approaches have often excluded a focus on bodily-felt experience and the sensory-motor aspects of treatment (Dosamantes-Beaudry, 2001), but this may be precisely the kinds of interventions that need to be further explored in autism treatment. While

there are a number of sensory-motor interventions available in the United States, behavioral interventions continue to be those most commonly endorsed. However, these may be a poor cultural fit for many Javanese and Indonesian families and communities, and their implementation may be strategically near impossible. Meanwhile, attention to the sensory and sensory-motor aspect of healing is something that folk medicine, traditional medicine, and creative arts interventions have long been known to provide. Researchers should not ignore these key levels of intervention that might be more readily available to various populations and perhaps quite beneficial. Tellingly, in an effort to help their children, American families are increasingly turning to other cultural healing modalities and finding some success with them (Isaacson, 2009). It might be that strategies from other cultures may prove effective and might be incorporated into holistic or integrated intervention for other people with autism. The Creative Arts Therapies are arts-based modalities of healing that incorporate aspects of ritual, creation, intersubjective relationship and often community-building. As such they may be particularly necessary for contemporary urban dwellers coping with national traumas and political change outside of supportive coping ritual structures or frameworks (Dosamantes-Beaudry, 2003). Using elements of play, bodily felt experience, and personal expression, Creative Arts Therapies focus on what the person can do rather than their areas of deficiency, and may be especially efficacious for nonverbal patients (Adler, 1970; Henley, 2001).

While acknowledging the possibility of wide cross-cultural enjoyment and mobilization of the practice and ethos of gamelan music, I also want to emphasize the model or underlying structure of the intervention, abilities-based sensory motor activity that is able to mobilize locally coherent practices and values to instantiate inclusive citizenship. Even if gamelan per se is not the medium of education or expression, the same theoretical approach used to identify gamelan

as therapy could also be used in developing local intervention in other cultures and contexts, but researchers and practitioners will need to look to local cultures to find what these might be. In Javanese Indonesia, gamelan might work because it proves both personally and socially therapeutic. It is community supported and hence participation in the practice is able to promote inclusion, acceptance, and a positive view of people with autism. It is also accessible in terms of being readily available and not exclusionary based on the skills it requires, and it mobilizes an abilities-based model that reinforces local values. It works through sensory-motor modalities, which may be particularly important in addressing the particular developmental needs and capacities of autistic people and incorporates folk beliefs, folk arts, and elements of folk healing, therefore potentially providing a culturally coherent method of treatment. These qualities may very well be found in other musical traditions in other cultures, but might also be found in local crafts or sports or other arts practices. Whatever the locally coherent intervention is, I propose cross-cultural autism interventionists could use these parameters to identify accessible, culturally logical interventions that are both symbolically and empirically efficacious in promoting personal development and social inclusion.

Chapter Seven

Conclusion: Implications of Research

While the neurodevelopmental difference we now call autism is quite likely a universal part of human diversity that has always existed across all cultures, “autism” is more than just a label; rather it is a historical and cultural construct which is both shaped by and dynamically shapes beliefs, ideas, values and practices. As far as I can determine, this study is one of the first English-language studies of autism in Indonesia in any discipline, if not the first; as such it remains preliminary and suggestive rather than comprehensive. Using an interdisciplinary ethnographic approach I have tried to address a range of ways that “culture” and “autism” intersect in Javanese Indonesia, from local labels and beliefs about developmental difference, to normative childrearing practices, to a recent swelling in genres of cultural production about and referencing autism, including films and written memoirs. I believe this sociocultural framework has provided a base from which further work can be done within the country and allows for multiple points of entry that future researchers from various fields might build upon with their own methods and research foci. Furthermore, certain significant issues emerging from my research may prove cogent to a variety of populations and may prove fertile ground for further investigation, both in Indonesia and many other geographical and cultural locations across the globe where it is safe to assume the concept of autism will eventually take root if it has not already begun to do so.

Findings and Implications

Autism is a rapidly globalizing diagnosis. I have begun to trace autism's emergence and rooting in Indonesian therapeutic, vernacular, and media realms, identifying key influential texts and theories about autism from abroad and key Indonesian figures who have educated others about these and implemented treatment methods. Autism is a powerful organizing framework for interpreting and responding to those with certain kinds of behavioral and communicative differences, and to a certain extent seems to have filled in a gap in indigenous conceptualizations of these. Many Javanese families, who felt that local labels of "madness," "idiocy," or "spirit possession" were stigmatizing and did little to actually capture the reality of their children's condition, welcomed the idea that their child might have a disability that causes certain specific challenges, even as they struggled to meet their children's needs and to fully understand what their children were going through and what was required of them as parents of autistic children. Even as parents called upon cultural frameworks of coping and responding—being patient and submissive to God's will, calling upon the entire family unit and particularly sibling support—many of them were still able to accommodate the idea of autism.

Clearly, autism as a set of ideas and practices conveys potential benefits for those putting it to use in various cultural contexts, as well as potential challenges. The potential benefits mirror those that have been outlined in Disability Studies for labeling and identifying disability in general (Wendell, 1996; Smart, 1994) including: (a) providing orientation and legitimation for those advocating for entitlement to assistance, accommodations and services, (b) recognizing and confirming certain aspects of the disabled individual's (and their caregivers) reality as qualitatively and significantly different from the norm, (c) illuminating stereotypes regarding the disability being defined and providing an opportunity to clarify and correct these, and (d)

providing a potential foundation for both personal identity and community building and a way to get support (as individuals with disabilities and their families realize they are not alone and work together to achieve affirmative and adaptive self-concepts). Thus labels and definitions determine outcomes that profoundly affect the lives of people who adopt them, or to whom they are applied. Such benefits of labeling autism as such were evident in my research, where for some autism provided a new framework for thinking about those with developmental delay and developmental differences, perhaps most clearly for those families involved in the national networks of support and invested in models of experimental disability culture that took root at workshops and events and in the slow but real advances in amendments to national health and educational policy.

However, the potential challenges of mobilizing or applying the diagnosis of autism in a cross-cultural context often stem from the fact that the ideas and practices associated with autism may be a poor cultural fit for the environment within which they are being applied. This situation is certainly not unique to autism; similar cultural challenges have been explored in the contemporary treatment of other neurological and neuropsychiatric disorders in Indonesia (Good, 2009; Lemelson, 2010). In the primarily Javanese Indonesian communities within which I did my research, the complex of autism that had to be taught and learned was in certain cases experienced as foreign, if promising, and required acts of cultural translation. Furthermore, intervention settings where Javanese families and therapists felt the need to learn how to interact with autistic people in a way that was “less Javanese” or “less Indonesian” and more “Western” actively triggered pre-existing anxieties and aspirations regarding local and national Indonesian identity, echoed often painful a vernacular post-colonial self-consciousness of Indonesians as “developmentally delayed,” and a re-animated a history of national projects intervening into

Indonesian families to forcefully “develop” them. Ultimately, it may be the case that trying to negotiate these anxieties and associations while also trying to best serve and support Indonesians with autism may prove an unhelpful or exhausting project. Interventions that are dependent on unfamiliar histories and/or discordant values, that require vast amounts of cultural translation to even begin to implement, and that make local families feel like they are already doing everything wrong, may not be practical or sustainable for many Indonesian communities. The more general point here is that any intervention or any kind will not be taken up if it cannot fit well enough into the everyday beliefs, daily routines, and world of a family or group.

To approach this same point proactively rather than just critically, I suggest that what Indonesian families need are autism interventions that are efficacious but also make local sense and build empowerment and pride in local and national identities. The therapeutic gamelan project provides a fascinating example of this dynamic in action: it frames inclusion as authentically Javanese, provides embodied models of inclusive sociality, and mobilizes both indigenous and national models of harmonious diversity so that Javanese may feel confident and secure in interacting with autistic citizens, rather than alarmed or painfully self-conscious. Furthermore it uses sensory-motor and non-verbal modes of interaction and attunement, which are increasingly understood to be crucial modalities for building self-awareness and capacities for interpersonal relationships.

At the same time, autism interventionists trained in the West do have some crucial information that, while culturally unfamiliar, might play a key role in improving the lives of people with autism; perhaps most significantly, the importance of early intervention. High dialogic interactivity and/or making active or challenging demands in many ways goes against the norms and ideals of Javanese personhood, while low interactivity during infancy may be

interpreted by Javanese mothers as a sign of maturity, and not a cause for concern until the developing child's speech is significantly delayed. Furthermore, Javanese norms of childrearing and beliefs about development do not favor much interference, enforcement of rules, or strict developmental schedules; but instead favor flexibility, and spontaneous expression over tension, conflict, or challenge. There is every reason to believe that these values and practices guide most Javanese into a normative, adaptive, and healthy maturity. However, the possibility exists that children with autism have needs that might be better served by some modifications to these norms of childrearing, and in this case practices that go against norms of childrearing might have significant impact despite being unfamiliar or perhaps somewhat uncomfortable for Javanese mothers.

It is important to reiterate that there appears to be significant value in beginning a range of autism interventions as early as possible, including outcomes of increased skills for children in terms of language, daily living, and adaptive social behavior and decreased stress in both children and parents (Corsello, 2005; McConachie & Diggle, 2006; Remington et al., 2007). Perhaps the greatest therapeutic benefits are afforded if such interventions begin pre-verbally, even under the age of two (Boyd et al., 2010; Dawson, 2008; Volkmar, Chawarksa & Klin, 2005), despite the fact that such intervention might run counter to the cultural developmental view of Javanese childrearing practices. Javanese mothers do deserve to learn about possible therapies or interactive strategies that might benefit their children and be offered tools and supports to implement these as early as possible; just one of many possible such early interventions might be structured joint attention and symbolic play interventions such as the kind described by Kasari, Freeman, and Paparella (2006), wherein mothers might be taught how to elicit more interactive behaviors through play with their young children. In this or a similar case,

the initial cultural unfamiliarity has to be balanced against the proven or potential efficacy. Furthermore, strategies need to be developed that would ensure that the take-up of effective interventions—and therefore the benefits of them—would not be confined to an elite group of Indonesians, who perhaps through diasporic communities and networks of educated professionals are already more fluent with models of childrearing, therapy, health, and education that some of these might be based on.

My research revealed that, depending on location but particularly in Jakarta and to a lesser extent in other urban areas on Java, there are a wide variety of services available for children and families with autism, including special education; behavioral interventions; sensory, speech, and occupational therapies; biomedical treatment; and traditional and alternative medicine. One limitation of my study is that, while providing an overview of such services, I am unable to make any assertions regarding the efficacy of these beyond parent and teacher reports. I hope that this preliminary survey might provide further researchers with a starting off point and I encourage others to take the opportunity to study in further detail how all of these local school experiments work, how they fit into Javanese life, and whether or not they are efficacious or have any lasting impact.

Further Research Directions

After these initial findings, much remains to be done in terms of gathering information about autism in Indonesia. Since this area is so new, the possibilities are vast, but my research points to a number of directions.

Statistical and Epidemiological Data

While certain practitioners and professionals have estimated how many people in Indonesia might have autism, comprehensive data regarding incidence and prevalence rates and total number of people diagnosed with autism in the country remains to be gathered; this is information that is highly desired by families and activists, and has been repeatedly requested by those working on the ground and in the field in Indonesia because it would be quite useful to advocate for equal rights, greater governmental and private sector attention, and additional educational and therapeutic services.

Of course, my dissertation has shown that official diagnosis is only variably pursued by families due to a number of factors ranging from both lay and clinical lack of familiarity with autism, to inaccessibility of services, to particular strategies of inclusion that are adaptive for families and individuals in particular socio-economic contexts. Thus, it would be reasonable to assume that even were such studies to be carried out, those with the diagnosis of autism would still only represent a fraction of the total population of Indonesians with spectrum neurological differences.¹⁸⁸ Furthermore, my dissertation has tried to address some of the benefits as well as challenges of using the label and construct of “autism.”

Longitudinal Studies, Indigenous Practices, and Outcomes

As I noted in Chapter Two, autism is still considered a “new phenomenon.” The diagnosis began to be used in the medical field in Indonesia in about the last 10-15 years, and

¹⁸⁸ Other researchers doing work in the global south concur that in many countries, national prevalence studies are likely impossible at present (Grinker et al. 2011) and hence a host of other research questions might be more important for this generation of autism research. However if one were to estimate for Indonesia, India, or other countries by starting with known rates from Western nations, plus or minus a generous margin of error for national and cultural variations, for any country the number would still be very big (Tom Weisner, personal communication).

entered vernacular awareness even more recently. So, as is the case in the United States and many other countries where histories of autism scholarship have been targeted towards parents and educators of young children, there is not yet adequate information about adults with autism or the trajectories of their lives. Longitudinal studies might prove useful in understanding the course and outcomes of people with autism in Indonesia, which—as is the case for people with a variety of neurological differences—may be as heterogeneous as the individuals themselves (Good, 2009; Manderson & Smith-Morris, 2009). From my research, given concerns about lack of facilities still quite high levels of social stigma against those with autism and other developmental disabilities, it might prove the case that those who are more severely affected may lead highly restricted lives. However, it might be predicted that some of those less severely affected might experience a fairly high level of acceptance and integration into their local communities. It would be interesting to determine whether there are any similarities between outcomes of people with autism and/or other developmental disabilities and those of people with major mental illness, such as schizophrenia, as described by the WHO ISSoS and DOSMD studies which found that, contrary to expectation, those with major mental illness in the so-called “developing world” had much better long-term prognosis than those in the “developed” world (Hopper et al., 2007).

As I have addressed in this dissertation, a common assumption might be that more reliable diagnosis and comprehensive targeted treatments (developed in Euro-American cultural worlds) will translate into better outcomes for those with neurodevelopmental conditions such as autism. However, the WHO findings and ethnographic research in this report and elsewhere (Grinker, 2007) insert an element of doubt into this assumption. A sociocultural rather than biomedical approach that takes into account the benefits of high levels of social support,

accommodating jobs and tasks, stable and predictable environments, and low levels of expressed emotion, which can still be found in many Indonesian regions and communities, may ultimately result in satisfactory long-term prognoses without such treatments. Less-stigmatizing labels, and access to basic skills and social opportunities, which are also associated with better outcomes, however, may not be available for those with autism who are more severely affected and do not receive more pro-active and comprehensive interventions as compared with peers suffering from mental illness. My research reveals that there is still a high level of stigma among Javanese communities towards developmental disability, although this is being actively challenged by certain families and educators, and there are very few efficacious treatments locally available to address the complex needs of someone with autism. This may mean that such individuals with autism may be essentially left to languish. Ultimately it may be that the level of severity and which functional impairments individuals with autism have will be even more significant than whether they qualify for the diagnosis of autism or not. It is possible that severe symptoms for any illness or disability will predict outcomes, more so than the diagnosis itself. Still, for those researchers interested in sociocultural effects on the trajectory of autism in Indonesia, perhaps in particular studies comparing those Javanese Indonesians diagnosed with autism and receiving ongoing behavioral, occupational, speech, and/or other therapeutic treatment and those not formally diagnosed and/or treated would prove illuminating here.

Another area for future research that might contribute to this discussion of outcomes is a comparative focus on childrearing practices in relation to symptoms of autism, and the evolving neurobiological capacities and challenges of autism faced by the growing child. Clearly, childrearing practices were a topic of significant interest for the families and interventionists that I encountered and interviewed during my research, from disciplinary to feeding practices, from

helping the child feel safe and included to keeping him or her physically healthy. What was underscored in these discussions was primarily worry and anxiety that Javanese Indonesian practices were harmful at worst, or not helpful at best, for children with autism, the reasons for which I have tried to analyze and explain. However, it is possible that numerous Javanese child-rearing practices may actually provide a buffer for autistic children, acting as a kind of “indigenous early intervention” to prevent amplification of autistic symptoms (cf Weisner, Matheson & Bernheimer, 1996).

For example, as supportive of meeting the goals of protection and harmonious interdependence, the developing baby is subject to a sensory bath of constant stimulation through processes of neonatal massage designed to make the baby’s body “flexible and supple,” constant carrying of the baby by the mother or other caretaker close to her body in her shawl, often fairly constantly for the first one to two years, and then on demand for a while afterwards, and co-sleeping with mother, father, or siblings. Hildred Geertz thought that this physical symbiosis made the Javanese baby “deeply passive” (Geertz, 1961), a quality that would enable him or her to grow into a conflict-avoidant adult, and a quality that is prized, perhaps quite problematically in the case of autism.

While the “passivity” and its connotations that results in typically-developing children is debatable, these practices of “body manipulation” and close constant physical contact fit into the practices of childrearing known as “proximal childrearing” which Heidi Keller in her book *Cultures of Infancy* (2007), has illustrated in typically developing children leads to a longitudinal result of more precocious self-regulation as contrasted with practices of “distal parenting” (more focused on object stimulation, and dialogic face-to-face contact). This may be so for autistic children as well, who often have self-coherence and self-regulation issues, as well as many

sensory needs. It has been shown that many autistic people benefit from sensory stimulation and proprioceptive input (such as deep pressure, massage, etc.) So it is possible that Javanese culture mitigates against issues that are significant for some autistic children in other cultures who don't receive this early stimulation, such as poor impulse control (cf Kartner et al., 2010; Kartner et al., 2008; Keller 2007). How might a Javanese proximal caregiving style influence the neurological challenges that autism poses?

Along similar lines of speculation, the Javanese teaching pattern involves tactile, repetitive, teaching of skills. Geertz marveled at the Javanese parents' patience and persistence in repeatedly pulling the child's right hand to give or take something (important to Javanese etiquette). Neurological differences in autism implicate the mirror neuron system, a brain circuit that enables us to better understand and anticipate the actions of others and that activates in similar ways when we perform actions or watch others perform the same actions (Dapretto et al., 2006; Elsevier, 2011). Due to differences in this mirror neuron system, autistic people may have inherent difficulty in learning via mimicry, and yet be open to tactile learning (an intervention known as "hand-over-hand" in American autism treatment). Tactile learning is the same kind of learning that is employed in therapeutic gamelan sessions, which parents believe to be both pleasurable and instructive for their children. It may be another "indigenous intervention," or strategy already at work in the culture, that might be emphasized and encouraged.

Regional, Ethnic, Cultural Differences Within Indonesia

Although in this dissertation I have made the claim for a new national culture of autism, I have dealt primarily with Javanese Indonesia and interviewed families either originally from the island of Java, from Javanese ethnic groups, and/or currently living there. However, Indonesia is

a staggeringly diverse country filled with hundreds of distinct local cultures with their own languages, beliefs, and practices that implicate different models of cosmology and personhood and are situated in different social contexts which may impact the interpretation and treatment of autism; so, the experience of autism and its significance and particularities might look quite different in other Indonesian cultures.

For example, in this dissertation I have outlined some of the ways Javanese systems of knowledge and beliefs might influence the interpretation and treatment of autism, but the Batak from Sumatra have their own distinguishing features that might influence the interpretation and treatment of an autistic child in unique ways. Damai Sitompul, herself a therapist and of Batak descent explained to me for example, that in Batak culture marriage joins two extended families, and the first-born son plays a very important role in solidifying this new unit. She said that in these families, if the first-born son was autistic it could radically upset the balance of the Batak extended family and that in such families she had seen blame and recrimination about which side of the family was “responsible” ultimately erode extended family units of support and isolate the parental couple, which in certain cases dissolved the union (Sitompul, 2012).¹⁸⁹ In thinking about ways to talk about autism across the archipelago, it is important to remember that Indonesia’s diverse regional and local worlds across the nation, each with their own ecological, occupational, and socio-cultural specificities, might cultivate quite different responses to, and trajectories of, autistic people and their families. The same might be said for other cross-cutting factors such as class, status, and so forth; as Grinker et al. have underscored in their work on culture and ASD that in the globalized present “culture” can no longer be considered synonymous with place, race, class, ethnicity, or even nationality and that “the rich person in India and the rich person in England may be more culturally similar in terms of values associated

¹⁸⁹ Sitompul, Damai. Interviewed by Annie Tucker. Yogyakarta 19-20 November 2011.

with health and disease than the rich and the poor person in either one of these countries” (Grinker et. al, 2011, p. 122).

Socio-economic Differences and Autism Response in Indonesia

While beyond the scope of this dissertation, my research identified two different models of inclusion active in Javanese Indonesian families. The first actively rejects labels of difference and accepts limited expectations for the autistic person, while the second embraces labels of difference and both seeks out and advocates for the specialized education and services that would help the child develop to their full capacity despite limitations. These models, which I believe both promote successful inclusion in their own specific contexts, are influenced not just by a cultural and philosophical orientation regarding life paths and trajectories, but also by changing socio-economic realities and related approaches to personhood and anxieties about this change. It would be beneficial to further explore how approaches to autism and explanations and anxieties about people with developmental difference reveal explanations and anxieties about the broader developmental differences that exist within the nation. Perspectives on autism and the family are imbricated in aspirations about “Indonesia” in general—ideas about the country as a competitive global nation, the changing values, sentiments, and models of personhood and citizenship suitable for such competition, and the role of the family in promoting these. In the future I would like to explore how strategies that promote the “development” of autistic individuals and national development become mutually informative and how “developmental difference” becomes a key analytical tool to explain relationships that exist between Indonesians’ ideas towards autistic people and towards uneven national socio-cultural and economic change.

Cultural Production

Social narratives of autism are constructed across genres of cultural production and expression. As much as this dissertation calls for further ethnographic and experimental activities to build an understanding of autism in Indonesia, so does it call for ongoing media and literary analysis of the ever-growing body of news stories, documentaries, memoirs, folk art, cartoons, and more on the topic of autism. In this dissertation I have briefly mentioned an archive of such material that I have begun to collect, and while I have asserted that this archive, and these channels of meaning are important, I have not devoted as much time as I would have liked to in analyzing and discussing these. However, I believe that a close reading and comprehensive analysis of this material might help to explain how and why autism finds a cultural niche. Again, because there is an approximate historical point of origin for the concept of autism in Indonesia (the mid-nineties)—a historical trajectory which could be further fleshed out through oral histories and other historical research methodology—archival and media analysis of representations of autism would be able to track its development and shifting associations, symbolic power as a trope or theme, and changing specificities within the culture.

One intriguing finding I have discovered in my own media analysis of feature films and popular novels, is that characters with autism and developmental difference appear with some frequency as a narrative and metaphoric device. I hypothesize that reactions to people with autism and other developmental differences and opinions about which models of response to autism are most appropriate intersect with moralizing and modernizing narratives of national development amidst a context of sweeping socio-economic change. Within this context, the interpretation and treatment of autism is colored by the changing needs and sentiments towards

nationalization and globalization. These needs and sentiments, and their associations with disability via fictional and cultural narratives, are topics that I plan to explore in the future.

Autistic Presence, Voice and Personhood in Indonesia

While I was able to meet, interact with, and observe a number of autistic Indonesians, my primary sources for interviews, and hence the voices most frequently heard throughout this dissertation, were those of parents, educators, and therapists, not those of Indonesians with autism themselves. This was primarily due to the fact that many of the autistic people I met were children and many of them were either non-verbal or not comfortable or facile with either a spoken or written question-and-answer interview format. I find it problematic to write a dissertation about autism in Indonesia where I am not providing an adequate venue for autistic Indonesians to share their perspectives on the topic; in this sense I fear my dissertation at best leaves a lot to be desired and at worst is adopting a problematic stance resisted by many in the critical autism and disability field. While I have tried to share the stories and perspectives of people with autism as best I can, in places by using research techniques that don't exclusively privilege verbal communication, I feel like the time devoted to the arc of my argument here left little time for more leisurely and evocative descriptions of individuals and scenarios that might have fully fleshed out a portrait of autistic Indonesians as individuals. I do hope to explore this kind of ethnographic writing in other venues.

Indications for Policy and Programming: Autism “Outside the Archive”

In concluding her memoir about her life with her son and her work as an activist, Diyah Puspita concludes,

If God allows it, I long to see Ikshan and his friends and peers grow into mature adults. Independent and happy. I also want to see some place where autistic individuals can gather together, “work” together, enjoy their free time together, without having to be looked at with blank stares by the people around them. I long to make Indonesian society realize that autistic individuals are part of them, part of the next generation, so it is only right that they receive as many possibilities as possible to mingle with others and maximize the potential that they have. Not reviled, insulted, hidden away, or turned into second-class citizens (Puspita 2004, p. 219).

In concluding an interview with me, the older brother and primary caretaker of a young man diagnosed with autism said to me earnestly,

My hope from your research, is that this doesn't just become discourse, Miss, that it doesn't just become part of the archive. Indonesia and other invested parties have to be practical. In my country, there's not enough attention paid to this issue. My hope is that with research like this that at minimum, the autism situation is given some attention. It would truly be a blessing if some kind of solution, or therapy, or something like that could be applied by my government, of course with cooperation, because Indonesia will not be able to solve this problem without outside help. [...] Maybe there is a therapy or a drug that can help, that's my hope, a solution. That's what I am waiting for (Jerry, 2011).¹⁹⁰

I was constantly reminded throughout this research that a lot is at stake for families with autism, and what they hope for more than anything is practical assistance and tangible support so that their loved ones might be granted the rights and equality they deserve and that they might lead enjoyable, included, and fulfilling lives. Family members and activists told me they needed information, medication, research on best practices in terms of treatment strategies, additional channels of intra- and inter-national knowledge sharing, and expert guidance and consultants. The additional research I have recommended above would help provide the knowledge to develop and provide these in a useful manner. However, there are practical steps and tangible resources that need to be provided.

¹⁹⁰ Jerry. Interviewed by Annie Tucker. Wonocatur, 19 October 2011.

General Services

This dissertation has been concerned with the “cultural”—that is, beliefs, practices, conceptual models, and shifting shared realities—but many significant aspects of Indonesian families’ experience of autism were shaped by economic, institutional, structural, and infrastructural conditions; in a word, resources. Families were concerned about the influence of other public health threats such as viruses, typhus and other illness causing high fevers, and environmental pollution on their autistic child’s symptoms and overall health. Meanwhile, specialists were for the most part clustered in Jakarta and many local doctors were unfamiliar with autism. Many schools did not admit children with disabilities or developmental challenges, and the impact of such limited resources was exacerbated when families had to relocate for work, which often interrupted progress that had occurred and separated families from kin and village networks of support. Many families were engaged in a kind of balancing act, considering the needs of their spectrum child but also the needs of the greater family unit. These considerations are important not just for families but for policy makers and sociocultural researchers; on the one hand, overall family stability and sustainability is a therapeutic and valid outcome for children with autism or other disabilities (Weisner 2002), and the accommodations made and actions taken on behalf of a child with autism have to be weighed against the costs to others in the family to ask if they really helped the child. This question about balance becomes even more important when more radical accommodations—such as moving far away from friends or family or support networks and/or draining much-needed family funds in order to provide therapy—seem to actually stress the child’s condition more than ameliorate it. Yet at the same time, some families who did make significant sacrifices felt that the education and therapy they were able to provide for their child were incredibly beneficial. It is not surprising then that parents and

siblings dreamed of comprehensive and accessible support, including services in place for adults after their parents passed away.

Unfortunately, none of these issues is unique to Indonesia and concerns about environmental pollution, inadequate access to both basic and specialized and health care, and uneven access to education will be part of the autism experience in many low-income countries of the global South. While it might seem facile, or even naïve, to say that people with autism will benefit from things like basic health care, and equal access to education, as much as any other citizen would benefit and therefore, these need to be better provided, this is the truth. In everyday lives, these simple things may be the most meaningful, more important than the implementation of cutting-edge therapies. Therefore, asking for basic services and resources is asking for something that all kinds of disabled people are asking for; that their forms of difference be expected and planned for, that they be accepted as members of their community and afforded full rights. Some Indonesians, both autistic and typically developing, already have access to these kinds of services and resources. They clearly need to be more uniformly dispersed, so that families affected by autism need not be disrupted and challenged by unsustainable commutes or forced separations in the quest for treatment, education, or safe and healthy living environments.

Building Autism Awareness

Another need that the people I worked with voiced frequently was the need to take any fruits of scholarly research and use it to build autism awareness in Indonesia; both a functional clinical awareness of the signs, symptoms, and options for treatment, and in particular improve

awareness about the importance of early intervention and a social awareness of what autism is and the ways to interact with autistic people to promote their integration and decrease stigma. One way to do this would be to move outside the realm of clinical practitioners or educators, to work with community leaders and groups. As the special education expert Adi Adinugroho put it:

there has to be a cultural approach, it cannot just be in or from academics and professionals but we have to try to teach people about autism using religious (*agama*), traditional (*adat*), and village (*desa*) leaders” (Adinugroho, 2010).

I believe autism awareness advocates could also tap into networks of information sharing that already exist. One such example that comes to mind is the *Pembinaan Kesejahteraan Keluarga* (PKK), or *Fostering Family Welfare* organization, which a well-established organization that unites and organizes women from the national to village level across the archipelago and carries out all kinds of work including public service, counseling, and event organizing. Structured as it is to develop and function through networks of female friendship and support, PKK neighborhood meetings and/or national campaigns seem to me to be one way to spread information about autism.

Various popular genres could perhaps also play a key role. As I mentioned earlier in this dissertation, Roy Grinker found in his work in South Korea that one fiction film in particular, *Marathon*, had a huge impact on the way Koreans were viewing people with autism and other disabilities. Parents and advocates are increasingly exploring this option. In Chapter Two I reviewed a number of films about autism; as I finish writing this dissertation I have learned that there will be a new movie coming out in July of 2013 entitled *I Am Star*, which appears to be in some ways groundbreaking, in that it is a fiction film featuring actors with autism in a storyline focused around the process of inclusion and directly addressing some of the stigma and

resistance encountered in mainstream Indonesian society and the personal struggles of individual families, framing autism response as a question of both equal rights, human empathy, and a negotiation with difference (see Appendix I, Figure 7.1).

Efforts like this, across various domains, are sure to have a swift impact even in a short amount of time; the history of autism awareness in the United States provides a clear example.

Culturally Coherent Interventions

The United Nations, in its Convention on the Rights of Persons with Disabilities, says that people with disabilities have right to community-based treatments that preserve their cultural identity. Depending on how we interpret “cultural identity” I think my dissertation has argued that some interventions do seem to threaten this within Javanese families. Therapeutic gamelan is just one idea that locals have come up with to meet both the unique needs of people with autism, and the universally recognized needs to develop and preserve such a cultural identity. It has been pointed out that in addition to culturally appropriate interventions, there is also a need for culturally appropriate instruments. As special education expert Adinugroho said,

Half of the population of autistic children are difficult to detect because there are not yet instruments that are adequate and in accordance with Indonesia, and there is not yet any collaborative system of intervention that is clearly overseen in legislation or policy... foreign models will never be a good fit for us if we do not make our own model... so I challenge to you come up with models that will be the best fit for Indonesia.” (Adinugroho, 2010).

It is my hope that clinicians and academics working in a variety of fields will soon rise to this challenge, and people working in psychological anthropology and comparative development, public health and global development and special education might test diagnostic instruments, study how to best modify or adapt various interventions, determine how to best expand services,

and train special education consultants, educators, and others who can both translate information about autism and remain sympathetic to the cultural worlds of the families they are serving.

While ethnographic research such as I have provided is helpful for understanding the cultural worlds within which autism occurs and is interpreted, in addition to naturalistic observations, there is also clearly a deep need for psycho-behavioral and/or educational research into which interventions are most efficacious and how interventions might be best explained, adapted for, or implemented in Javanese and other Indonesian communities; real world evaluation, practice to research models and continuous improvement models of research would all be relevant here. It may ultimately be the case that such context-informed kinds of research may support some kinds of indigenous therapies for some Indonesians with ASD and not others, or might support some biomedical interventions for some but not others, may find different therapies to be complementary, and so forth. However in carrying out this work, my dissertation advocates beginning by looking what kinds of interventions are already available within the community, even when they may not be immediately apparent as such.

Appendices

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Appendix A: Families Interviewed

<u>Interviewee</u>	<u>Child</u>	<u>Sex</u>	<u>Age</u>	<u>Order*</u>	<u>Location</u>
Any	Ade	M	19	1/3	Bintaro, WJ**
Diyah	Iksan	M	19	α	South Jakarta, WJ
“Heni”	“Haryo”	M	17	2/2	Tangerang, WJ
Dewi & Dera (S) ^o	Aby	M	16	2/2	Bintaro, WJ
“Kasih”	“Taufik”	M	13	2/3	Tangerang, WJ
“Hani”	“Djoni”	M	12	1/3	Tangerang, WJ
“Eliana”	“Fajar”	M	12	3/3	Pamulang, WJ
“Roro”	“Felix”	M	11	α	Bogor, WJ
“Ayu”	“Mahfud”	M	11	3/3	Ciputat, WJ
“Norma”	“Willie”	M	11	α	Jakarta, WJ
“Arum”	“Waro”	M	9	α	Depok, WJ
“Nani”	“Amien”	M	8	α	Bogor, WJ
“Susana” (A)	“Andi”	M	5	4/4	Bekasi, WJ
“Intan”	“Mercedes”	F	4	α	Bogor, WJ
“Warno”	“Bayu”	M	18	3/3	Yogyakarta, CJ
Sri Murni	Faisal	M	17	2/2	Semarang, CJ
Redno (& F)	Cindy	F	16	3/3	Yogyakarta, CJ
“Lia”	“Astu”	M	16	α	Yogyakarta, CJ
“Jerry” (B)	“Bima”	M	15	2/2	Bantul, CJ
“Lala”	“Melissa”	F	15	α	Solo, CJ
“Sari”	“Rizky”	M	14	3/3	Yogyakarta, CJ
“Atit”	“Suci”	F	10	2/2	Magelang, CJ
“Ningsih” (& F)	“Pando”	M	9	1/2	Yogyakarta, CJ
“Woro”	“Dian”	F	9	3/3	Yogyakarta, CJ
“Lili”	“Teo”	M	5	α	Yogyakarta, CJ
“Nana”	“Peter”	M	6	2/2	Solo, CJ
“Sinta”	“Khadir”	M	8	2/3	Magelang, CJ

“Alfred” (F)	“Adam”	M	13	2/2	Malang, EJ
“Mary”	“Jojo”	M	3	α	Malang, EJ
“Joko” (F)	“Karno”	M	7	α	Surabaya, EJ

Key

* Order refers to birth order. α refers to an only child. For others, birth order is indicated by numbers before and after slash. First number refers to child order: 1 refers to a first-born, 2 to the second child, and etc. Second number refers to total number of children in the family.

** Letters indicate region of Java. WJ= West Java, CJ=Central Java, EJ=East Java. While coming from diverse SES backgrounds, all families were currently living in or on the outskirts of urban centers.

° S=sister, B=brother, F=father, A=aunt. Unless so indicated, respondent is the child’s mother.

Appendix B: Question and Observation Guides for Parents and Siblings of Children with Autism

History and Course

Tell me your child's story.

Tolong ceritakan bagaimana perkembangan pertumbuhan anak Ibu/Bapak sejak kelahirannya.

When did you start to notice that something was going on with your child? Why do you think it started then? What caused their difference/ behaviors/ symptoms?

Kapan Ibu/Bapak/Saudara menyadari ada perubahan atau kelainan pada anak Bpk/ Ibu? Setahu B/I, apa yang menjadi penyebab kelainan atau perubahan tersebut?

What are your child's main symptoms or behaviors? Have these always been the same or have they changed over the years?

Apa gejala-gejala utama untuk anak B/I/S? Apakah Anak B/I/Saudara punya kelakuan yang berbeda/ di luar kebiasaan? Apakah gejala atau kelakuan ini tetap sama sejak dulu, atau apakah ada perubahan?

Did you have any words for your child's behaviors/ symptoms before you called them autism?

Istilah apa yang Ibu gunakan sebelum anak B/I diberi diagnosa "autisme"?

Has your child ever seemed to get much better or much worse? Can you tell me a bit about that time? Why do you think the improvement/ worsening of your child's condition happened then?

Apakah keadaan B/I/S pernah membaik atau memburuk? Tolong ceritakan sedikit tentang saat-saat itu; apa yang terjadi saat-saat itu? Bagaimana perasaan B/I pada saat-saat itu? Mengapa perubahan itu terjadi pada waktu itu? Apa yang menyebabkan perubahan-perubahan itu?

How severe is your child's condition? How can you tell it is/ is not severe?

Seberapa parah kondisi anak B/I/S pada awal mulainya? Kalau sekarang? Bagaimana B/I/S tahu kondisi anak seperti itu?

What do you think will happen in your child's future? Do you think s/he will get better or worse? How long do you think the autism will last? What do you think s/he will be like in 10, 20, 30 years?

Bagaimana menurut Ibu, masa depan anak Ibu 10 tahun mendatang? Autisme/ gejala-gejala ini akan berlangsung berapa lama? Apa harapan Ibu untuk anaknya 10 mendatang? Bagaimana menurut pandangan Ibu masa depan anaknya?

What are your chief fears or concerns about your child for the present? What do you hope for your child, in the next year? Are there any goals you hope to meet?

Apa kekhawatiran Anda terhadap anak Anda sekarang ini?

Harapan perkembangan seperti apa untuk tahun ini? Apakah ada tujuan atau untuk anak B/I/S?

Child's Personality

How would you describe your child's personality?

Tolong jelaskan sifat anak B/I/S? Dia anak bagaimana?

What does your child like to do? What are the activities that make him/her the happiest?

Apa kesenangan anak B/I? Apa kegiatan/aktivitas yang paling dia sukai?

How does your child prefer to spend his or her time?

Biasanya, kalau ada waktu ruang, apa yang anak B/I ingin melakukan?

Does your child have any fears or strong dislikes? Is there anything s/he refuses to do or that frightens him/her?

Apa yang tidak paling disukai anak B/I? Apakah ada kegiatan yang dia menolak, atau yang menyakuti dia?

Caretaking and Role in the Family

Who takes care of the child?

Biasanya, siapa saja mengasuh anak B/I/S?

Please describe a typical day for your child from morning until night.

Tolong jelaskan jadwal untuk anak B/I/S; menerangkan atau menggambarkan satu hari biasa untuk anak B/I/S, dari pagi sampai malam.

Please walk me through your own day.

Tolong jelaskan satu hari biasa untuk B/I/S, dari pagi sampai malam.

What are the most important activities that occur in a typical day? Why are they important for your family?

Apa saja menjadi kegiatan sehari-hari yang paling pokok untuk keluarga B/I/S? Kenapa kegiatan ini penting?

Is your child able to participate in most daily family activities? Are there any family activities that your child cannot join because of his or her autism or symptoms? Are there any activities that your family cannot engage in because of your child's autism?

Apakah anak B/I/S bisa ikut kegiatan sehari-hari? Apakah ada kegiatan keluarga dia tidak bisa mengikuti karena gejala-gejala, perlakuan, atau penampilan autisme dia? Apakah ada kegiatan yang keluarga B/I/S tidak bisa ikut karena anak B/I/S penyandang autisme?

Please tell me about your family's favorite activities. What are some activities that everyone can enjoy together? Have you developed any new activities to include your child?
Tolong ceritakan tentang kegiatan keluarga yang paling disukai oleh anggota keluarga. Apakah ada kegiatan yang diikuti semua? Apakah B/I/S/K mewujud kegiatan baru supaya anak bisa dimasuki?

Has your child's autism ever cause any difficulty for your family?
Apakah autisme anak B/I/S pernah menyulitkan keluarga B/I/S?

Has your child's autism ever helped the family in any way?
Apakah autisme pernah menolong keluarga B/I/S?

What concerns you about your family routine nowadays? How do you keep your routines going? Which activities are you trying to encourage or change? Why?
Masa kini, apa menjadi isu penting dalam hidup sehari-hari keluarga? Bagaimana menjalankan jadwal kegiatan? Apakah ada kegiatan keluarga yang B/I/S sedang merubah? Kenapa?

Who will help take care of your child in the future?
Kalau melihat ke masa depan, siapa akan membantu B/I/S mengasuh anggota yang penyandang autisme?

Treatment

What kinds of treatment(s) or interventions have you tried for your child in the past? Who recommended this treatment? How long did you apply the treatment? What effects have these treatments had on your child's condition?
B/I/S sudah mencoba perawatan, pengobatan, atau intervensi apa saja untuk membantu anak B/I/S? Siapa yang nya? Perapa lama menjalankannya? Apa dampak mereka terhadap keadaan anak B/I/S?

Have you been to a *dukun*, a priest, an imam, or other religious figure? What, in their opinion, has caused your child's condition? What do they recommend in response?
Pernah mencari nasehat dari dukun, pendeta/romo, kyai/ustadz, atauh tokoh agama/ banyu bening yang lain? Menurut pendapat mereka, apa yang menyebabkan keadaan anak B/I/S? Apa yang mereka menyarankan?

What treatment(s) are you using now? Is it working? What are the helpful effects of this treatment? What do you expect from this treatment? Are there any side effects or drawbacks?

Pengobatan/ intervensi apa saja yang sekarang dijalankan? Apakah sudah mengalami perbaikan? Apa yang diharapkan dari pengobatan/ intervensi ini?

Apa dampak yang baik? Apakah ada akibat samping yang kurang baik atau “kontra” dalam cara pengobatan/ intervensi ini? Apakah pernah mengalami kemunduran?

In America, there are some alternative ways of treating autism families try that many doctors don't know about or use, like yoga, or spending time with animals, or removing heavy metals from the body. Have you heard of any alternative treatments like that? Have you tried any of these?

Di Amerika ada beberapa cara “alternatif” yang dipakai untuk merawat autisme yang para doktor belum kenal atau memakai, seperti yoga, terapi yang memakai hewan, atau mengeluarkan logam berat dari tubuh anak penyandang autis. Apakah B/I/S pernah dengar tentang perawatan “alternatif” seperti ini? Apakah pernah dicoba?

Ideally, what do you think would be the most effective course of treatment for your child? Kalau dalam keadaan teladan, apa yang B/I/S membayangkan adalah penanganan anak B/I/S yang paling efektif?

Autism in the Community

How has the school/ village/ neighborhood/ extended family/ friends reacted to your child's condition? Did their reactions changed at all once you got the diagnosis of autism?

Bagaimana reaksi atau penerimaan dari sekolah/ RT/RW/ lingkungan/ keluarga besar/ teman-teman B/I/S terhadap anak B/I/S? Apakah persepsi atau reaksi mereka berubah setelah anak B/I/S diberi diagnosa autisme?

How do you explain your child's condition to other people?

Bagaimana B/I/S menjelaskan perlakuan atau pertumbuhan anak kepada orang lain?

Do people treat you or your children differently from others because of your child's disability?

Apakah anak, keluarga, atau B/I/S sendiri diperbuat jelek atau dihadapi berbeda karena kebutuhan khusus anak B/I/S?

What kinds of support have you sought in dealing with your child's autism? Have you joined any parent groups? If yes, how did you learn about this group? If not yet, are there any support groups that you know about?

Dukungan atau dorongan apa saja dicari atau diikuti oleh B/I/S dalam proses menanangi autisme anak B/I/S? Pernah ikuti perhimpunan atau perkumpulan orang tua? Kalau ya, di mana dapat informasi tentang perhimpunan ini? Kalau belum, setahu B/I/S, apakah ada perhimpunan seperti ini di daerah/kota B/I/S?

What other resources have you accessed in learning about autism? What kinds of support or information do you wish you had?

Sudah mencari atau dapat materi atau informasi yang lain dalam proses belajar tentang autisme? B/I/S ingin punya dukungan atau informasi apa saja?

Defining and Living With Autism

What is autism?

Apa sih autisme itu?

What causes autism?

Autisme disebabkan oleh apa?

Do you think “autism” is a good diagnosis for your child? Why/ why not? Are there any other words you use to describe your child’s condition that might be equally fitting or more appropriate? What are these, and can you explain what they mean? Why do you feel this is more appropriate?

Apakah autisme adalah diagnosa tepat untuk anak B/I/S? Kenapa ya atau tidak? Apakah ada istilah yang lain yang pernah B/I/S pakai yang setepat atau lebih sesuai? Kalau ya, apa istilah ini dan tolong menjelaskan artinya.

Has your child’s condition ever been called or diagnosed as something else that wasn’t as fitting? What? Who gave this diagnosis?

Menurut B/I/S, apakah “autisme” adalah diagnosa yang tepat untuk anak Anda? Kenapa (tidak)? Apakah keadaan anak B/I disebut lain dari “autisme” yang juga/lebih tepat? Kenapa? Apakah kondisi anak B/I/S pernah disebut atau didiagnosa lain dari “autisme” yang kurang tepat? Kenapa?

How did you learn about autism?

Dari mana B/I/S belajar atau tahu tentang autisme?

How do you explain to others what autism is?

Bagaimana menjelaskan kepada orang lain kalau ditanya, “apa sih, autisme itu?”

What do you think others don’t understand about autism?

Menurut pendapat B/I/S, apakah masyarakat umum sudah tahu tentang autisme? Apa yang masyarakat umum masih kurang mengerti tentang autisme?

What’s difficult about having a child with autism?

Apakah ada kesulitan dalam hidup dengan anak penyandang autis? Apa yang sulit?

What is good about having a child with autism?

Apakah ada keuntungan dalam hidup dengan anak penyandang autis? Keuntungan apa?

Do you have any advice for parents/siblings of kids who have just been diagnosed with autism?

Kalau ada orang tua/saudara yang anaknya baru diberi diagnosa autisme, bagaiman B/I/S menyarankan mereka?

Why do you think autism is emerging as a diagnosis in Indonesia now?

Kenapa autisme muncul di Indonesia masa kini?

Appendix C: Online Chat Group Discussion Questions

What is your most pressing concern in being at your special child's side?

Keluhan apa yang paling dirasakan para ibu / bapak ketika mendampingi anak2 spesial kita?

Out of all the interventions that you have tried for your spectrum child, which have been the most effective? Please mention the intervention, and explain the changes you witnessed in your child.

Dari semua intervensi yang pernah dicoba untuk anak spectrum Anda (bisa metode terapi, suplemen atau apa saja), yang mana adalah yang paling efektif? Tolong sebutkan intervensi, dan menjelaskan perubahan yang dialami anak.

What have been the least effective interventions, and why?

Dari semua intervensi yang pernah dicoba untuk anak spectrum Anda, yang mana adalah yang paling tidak efektif dan kenapa?

What do you wish the general public understood better about autism?

Apakah pengertian masyarakat umum terhadap autisme masih kurang? Apa yang Anda ingin masyarakat umum mengerti tentang autisme?

What are the best parts about having a child with autism?

Apa menjadi pengalaman terbaik dalam membesarkan anak autis?

What are your hopes and fears for the future of your spectrum child?

Apa menjadi harapan dan keceguhan Anda untuk masa depan anak spectrum Anda?

Where do you get most of your informon about autism?

Dari mana Anda dapat informasi tentang autism?

What's the most important piece of advice you would give parents who have just learned that their child has autism?

Kalau ada orang tua/saudara yang anaknya baru diberi diagnosa autisme, bagaiman B/I/S menyarankan mereka?

What kind of support do you wish you had from your local government or your local community?

Dukungan atau layanan apa saja Anda inginkan dari pemerintah atau masyarakat local?

Appendix D: List of Treatment Centers and Schools Visited

<u>Site Name</u>	<u>Type of Site/Service Provided</u>	<u>Location</u>
Sekolah Putera/Puteri Mandiri	Private School for Students With Disabilities Eclectic Methods	Tangerang
Sekolah Mandiga	Private School for Autistic Students Eclectic Methods, ABA, Life Skills	Kebayoran Baru
Citra Anandiya	Private School for Students with Disabilities Eclectic Methods	Tangerang
Yayasan Anak Mandiri	Private School for Students with Disabilities Eclectic Methods, Sensory Integration	Serang
Wila Kertia	Private School for Students with Autism Speech, Sensory Integration, Eclectic	Bintaro
ABA Kids	Classical/Lovaas ABA Therapy Center	Bekasi
SLB Bina Anggita	Private School for Autistic Students TEACHH, Music Therapy	Bantul
Sekolah Lanjut Fredofius	Private School for Autistic Teens/YA Eclectic Methods, Life and Job Skills	Yogyakarta
Sanngar Anak Alam	Private Inclusion School	Yogyakarta
SD Muham. Bangutapan	Private (Religious) Inclusion School	Yogyakarta
Balance Yoga	Yoga For the Special Child	Yogyakarta

(con.t)

<u>Site Name</u>	<u>Type of Site/Service Provided</u>	<u>Location</u>
Melka Excelsior Dolphin Assisted Therapy	Dolphin Therapy	Lovina, Bali
A Plus Integrated Therapy	Private School and Therapy Center Eclectic Methods	Malang
Biomedical Intervention Clinic	Private and Travelling Clinic Behavior, Diet, Medication Counseling	Bogor
Talenta Kids	School and Therapy Center ABA, SI, Massage, Play Therapy	Salatiga
MataHatiku	Therapy Center OT, Speech, Ed Therapy	Bintaro
Spectrum Education and Treatment Center	K-12 Private School for Students with Disabilities Psychological and Psychiatric Treatment	Jakarta
Dr. E. Siti Herini	Private Practice; Specialty in Pediatrics and Neurology Prescription Medication Management	Yogyakarta
Autism School Al-Ishan	School for Children with Autism ABA, SI	Serang

Appendix E: Treatment Site Question and Observation Guides

Question Guide for Clinicians and Healers

What kind of medicine or therapy do you practice? How long have you been practicing?

Bapak/I mempraktek cara mengobati atau cara menyembuhkan apa saja? Sudah berapa lama B/I mempraktek ini?

Please tell me a little bit about your training or background, including education and work experience.

Tolong ceritakan tentang latar belakang Anda dalam bidang ini, termasuk pendidikan dan pengalaman kerja?

Please share with me some fundamental principles of your healing or therapeutic modality?

Tolong bagikan prinsip dasar dari praktek B/I.

In your opinion, what is the problem in this case? What's your diagnosis?

Menurut B/I, apa menjadi masalah dalam kasus ini? B/I memilih diagnosa apa?

What has caused this condition?

Kondisi ini disebabkan oleh apa?

Are there any other diagnoses you considered for the child?

Apakah ada diagnosa yang lain yang Anda mempertimbangkan untuk anak ini?

Have you seen other patients with a similar problem in the past? About how many? How have you treated those patients?

Apakah B/I pernah merawat pasien yang lain dengan masalah/ kondisi/ diagnosa yang sama? Kira-kira berapa? Bagaimana B/I mengobati mereka?

Have the treatments been effective? What kinds of improvements have you seen after those treatments? How long did it take to improve? Was the improvement permanent?

Apakah pengobatan ini efektif? B/I sudah melihat perbaikan apa saja setelah pengobatan ini? Berapa lama diperlukan untuk pengobatannya jalan/masuk? Apakah perbaikan permanen?

Have any of treatments been ineffective? Why do you think they didn't work?

Apakah B/I pernah mencoba pengobatan yang kurang efektif? Kira-kira kenapa mereka kurang efektif?

What treatment do you recommend for this child and his/her family now?

Pengobatan apa yang direkomendasikan untuk anak dan keluarganya sekarang?

Is there anything that might make the child's condition or family situation worse?
Apakah ada sesuatu yang kemungkinan memburuk keadaan anak atau keluarganya sekarang?

When and where did you learn about autism?
Kapan dan di mana B/I belajar tentang autisme?

What is autism exactly?
Apa sih, autisme itu?

How do you explain autism to the families you counsel?
Bagaimana autisme dijelaskan kepada keluarga yang disarankan B/I?

Why do you think autism is the right diagnosis for this particular child?
Menurut B/I, kenapa autisme adalah diagnosa yang paling tepat untuk anak ini?

Do you think there are any other factors that might be influencing the child's condition or behavior?

Menurut B/I apakah ada faktor-faktor selain autisme yang berpengaruh dalam kondisi, ketrampilan, atau kelakuan anak?

Treatment Observation Guide

Setting and other framing devices for healing event

Characteristics of interaction: number of participants, length of treatment, quality of relationship, attitudes and "roles" of participants

Idiom of communication (mode of communication, e.g., somatic movement, auditory, etc., explanatory models)

Therapeutic actions, mechanisms, and expectations

Ending and evaluation of treatment

Appendix F: Selected Workshops and Events Attended

“Talk Show about Autism”

Sponsored by Masyarakat Peduli Autisme

Muhammadiyah Hospital, Solo, 17 July 2010

Topics Covered: Basic Information About Autism, Intervention Strategies

“Regional Seminar and Workshop on Handling Autism”

Sponsored by Talenta Kids

Sekolah Tinggi Agama Islam Negeri, Salatiga, 1 August, 2010

Topics Covered: Basic Information about Autism, Intervention Strategies

“Recognizing and Educating Children with Special Needs (Autism and ADD)”

Sponsored by the Psychology and Public Health Departments, Satya Wacana University

UKSW Campus, Salatiga 2 August 2010

Topics Covered: Detection, Integrated Services, Developing Models of Services

“Annual Showcase of Potential & Talent of the Recipients of National Special Education and Services 2010”

Jogja Expo Center, Yogyakarta, 25-28 October 2010

National Convention of Special Education Schools, with Information, Presentations, Performances

“Annual Showcase of Potential & Talent of the Recipients of National Special Education and Services 2011”

Sponsored by the Department of Special Education and Special Services

Benteng Vredeburg Yogyakarta 11-15 October 2011

National Convention of Special Education Schools, With Information, Presentations, Performances

“Prospect of Empowerment of Autistic Persons For Their Future”

Sponsored by SLA Fredofius

Gajah Mada University, Yogyakarta, 19-20 November 2011

Topics Covered: Behavior Intervention, Sexuality in Autistic Teens, Job Skills

“Sharing Our Experiences about Diet and Rotation”

Private Home of Any Sonata Bagwanto, 25 January, 2012

Topics Covered: Restricted Diet and Supplements

“World Autism Day Celebration”

Sponsored by ABA Kids

Various Locations, Bintaro, 2 April 2012

Family Activities, Performances, Information Sessions

Appendix G: Question Guide for Autism Awareness Advocates/Activists

Please tell me the story of how you personally became involved in autism awareness and treatment.
Tolong ceritakan tentang latar belakang keterlibatan B/I dalam dunia kesadaran autisme.

Please tell me the history of your organization. When did it start? What were the steps required to establish it? What are some of the most important tasks or duties of the organization? How large is it and who are the most important members?

Tolong ceritakan sejarah [yayasan/organisasi B/I]. Kapan didirikan? Langkah-langkah apa saja yang dijalankan untuk mendirikannya? Apa tugas paling penting yang dikerjakan oleh yayasn/organisasi? Berapa besar yayasan/organisasi (maksudnya, berapa karyawan) dan siapa saja menjadi anggota yang sangat penting atau dihargai? Kenapa?

What are the main goals of your organization? What are you trying to accomplish?
What are some of the fundamental principles of your organization? What are your working methods?
Apa menjadi visi dan misi yayasan/organisasi B/I? Apa tujuan yayasan/organisasi B/I? Bagaimana filsafat dan working methods?

Who is your prime target audience? How many families or members of this target audience do you think you've reached? How many more do you hope to reach?

Siapa saja menjadi target audience Yayasan Ibu? Sudah berapa keluarga atau anggota yang sudah Yayasan berjumpa?

What activities do you engage in to promote autism awareness? Have they been effective, and if so why are these activities particularly effective for the Indonesian public?

[Yayasan/ organisasi] mengerjakan kegiatan apa saja unuk mempromosikan kesadaran autisme? Sampai sekarang, apakah kegiatan ini cukup efektif? Kalau ya, menurut pendapat B/I, kenapa kegiatan ini efektif untuk masyarakat Indonesia? Apa harapan Mpati untuk kegiatan pada masa depan dalam mempromosikan kesadaran autisme?

What do you think most Indonesians don't know or don't understand about autism?

Menurut B/I, kira-kira apa saja yang orang Indonesia belum tahu atau belum mengerti tentang autisme sampai sekarang?

When you explain to people what autism is, how do you describe it?

Kalau orang bertanya kepada B/I apa saja "autisme" itu, bagaimana dijelaskan?

What do families who are living with autism most need from your organization? From their communities? From health care providers? From the government?

Menurut B/I, para keluarga yang tinggal dengan autisme perlu apa saja dari [yayasan/organisasi] B/I? Apa yang diperlu dari lingkungan mereka sendiri? Dari dokter, perawat, dan pekerja dalam bidang kesehatan atau pertumbuhan? Dari pemerintah?

Why do you think autism is emerging as an important concern for Indonesian families today?

Menurut pendapat B/I, kenapa dewasa ini autisme muncul sebagai perhatian bersama penting untuk keluarga-keluarga Indonesia?

What are the most important points you hope to get across, to families and to the general public, through your work?

Apa menjadi informasi paling penting yang ingin [Yayasan B/I] sampaikan kepada masyarakat Indonesia?

How might foreign researchers, such as myself, be most helpful to the cause of autism awareness and treatment in Indonesia? Do you have any suggestions for me, or anything information that you feel will be important in carrying out research?

Bagaimana peneliti asing, seperti saya sendiri, bisa berguna terhadap gerakan kesadaran dan perawatan autisme di Indonesia? Apakah B/I punya nasehat atau saran-saran? Apakah B/I punya keterangan yang bisa berpengaruh untuk penelitian tentang autisme di Indonesia?

Are there any recent developments in autism research in Indonesia? Do you think there are any best practices in therapy outside of Western methods that might work best for Indonesian families or sama saja? Do you think there are techniques that would work best for Indonesians from different provinces? Do you think the needs are similar or different across Indonesia?

Apakah ada perkembangan baru dalam bidang autisme di Indonesia? Menurut Bapak/Ii, apakah ada "best practices" dalam terapi (dari teknik-tenik atau selain dari teknik-teknik Barat) yang paling sesuai untuk keluarga Indonesia? Apakah teknik-teknik ini masih cocok untuk keluarga Indonesia dari propinsi-propinsi yang lain? Maksud saya, apakah keperluan dalam dunia autisme sama di seluruh Indonesia?

In Indonesia, who should be responsible for special education, therapeutic intervention, etc.? With so many families in Indonesia unable to access even basic education, how can the country best accommodate those with learning or behavioral differences?

Di Indonesia, siapa bertanggung jawab untuk pendidikan khusus, intervensi, dll? Dengan keadaan di mana masih banyak keluarga di Indonesia masih belum bisa akses pendidikan dasar, bagaimana pemerintah bisa mengakomodasikan yang berkebutuhan khusus?

Appendix H: Question Guide for General Public

Have you ever heard of “autism”? What exactly is autism?
Pernah dengar tentang autisme? Apa sih autisme itu?

Where or from whom did you hear about it?
Di mana atau dari mana Anda tahu tentang autisme itu?

Do you know anyone with autism? Do you know anyone with special needs?
Apakah Anda punya kenalan dengan autisme atau kenalan dengan anggota keluarga yang penyandang autisme? Apakah Anda punya kenalan yang berkebutuhan khusus?

What causes autism? What are the main symptoms of autism? What are people with autism like?
Apa menyebabkan autisme? Apa gejala-gejala atau ciri-ciri utama autisme? Orang yang penyandang autisme adalah orang kira-kira bagaimana?

How do you treat autism?
Bagaimana merawat atau menanganakan anak penyandang autisme?

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Figure 2.1: Promoting Inclusion Education.

This is a pamphlet created by the NGO ASB designed to promote awareness of inclusion education, which was posted at various educational and cultural institutions throughout Yogyakarta Fall 2011. The first image reads “Everyone can go to school if the school is an inclusion school!” In the second image, a little boy in a wheelchair cries, “I want to go to school and play with my friends.” In the third image, a teacher asks the boy why he is sad and he tells her he wants to go to school. The teacher says they can talk to his mother about it. In the third image, the boy’s mother expresses doubt that the boy will be allowed in public school and the teacher encourages her by saying that “many schools now accept children with special needs.”



Figure 2.2 Students at Inclusion School SD Muhammadiyah Bangutapan Classmates with and without autism pose for a group photo with their “guest English teacher.”



Figure 2.3 PECS in Indonesian. PECS, or Picture Exchange Communication System allows non-verbal people with autism to use images/printed words to state their wants and needs. These cards can be arranged on a Velcro board to make sentences. At Sekolah Mandiga, teachers have worked to create sets of picture cards used in PECS using Indonesian instead of English. Here is “mau” or Indonesian for “want.”



Waiting for Rainbows: The Journey of a Mother Who Never Gave Up in Leading Her Son Out from the Shackles of Autism and ADHD by Sarasvati



Pearls of Suffering Become Strands of Wisdom: The Blessing of Being a Mother of an Autistic Child by Diah Puspita



Faisal Loves Mama for Life: The Struggle of a Mother With Many Limitations to Raise Her Autistic Son by Sri Murni



Growing Up in the Middle of a Storm: The Steadfast Heart and Powerful Love of a Mother who Succeeded in Raising an Accomplished Autistic Child by Herniwatty Moechiam

Figure 2.4 Memoirs by Mothers of Autistic Children A sampling of memoirs authored by mothers of children with autism.



Figure 2.5 Autism in Popular Cinema Autistic characters are increasingly incorporated into narratives of popular cinema; here seen as having “savant-like” singing skills in *Simfoni Luar Biasa* (“Extraordinary Symphony”); as a violated innocent in *Perempuan Punya Cerita* (“Women Have Their Stories”); and as a neglected rich child who is befriended by a cherished poor child in *Rumah Tanpa Jendela* (“House without Windows”).



Figure 2.6 Autism in Folk Speech/Slang A comic drawn in a style evocative of traditional Javanese *wayang* shadow puppet characters intended to dissuade the vernacular use of autism as a slang word or derogatory term. The character in the red shirt says, “What are you doing just laughing to yourself about nothing? That’s so autistic!” The character reading the newspaper responds, “Hush! Don’t use the word ‘autistic’ so thoughtlessly like that. It’s not appropriate to talk that way!”



Figure 4.1 Creating “Figured Worlds” of Autism Awareness Simple strategies such as creating “shared artifacts” of autism T-shirts turn everyday space into new experimental spaces of “disability culture.” Here, in Jakarta, a young man with autism poses, his shirt proclaiming, “Peace-Love-Autism.”



Figure 4.2 Question and Answer Sesion at Autism Workshop Once again, halfway across Java in the city of Solo, the “Peace-Love-Autism” shirt makes an appearance. Here, a mother takes the microphone during a Q & A session to ask a question about her child’s autism. Farhan, a celebrity MC with an autistic child and an autism awareness advocate, moderates the session and shares his own experience.



6.1 Smaller scale instruments are more appealing and accessible to young players.



6.2 Dian playing the *gong*.



6.3 Okta playing the *bonang*.



6.4 Wawan playing the *saron*.

Figure 6.1-6.4 Bina Anggita's Adapted Gamelan uses smaller-scale instruments with kid-friendly decorations.



Figure 6.5 Collaborative, Tactile, and Interactive Playing Gamelan rehearsal involves ongoing collaboration between teachers and students, including tactile teaching styles similar to the autism intervention strategy of “hand over hand.” Students’ parents suggest that their children learn well in this environment.



Figure 6.6 Gamelan Rehearsal: Moments of Connection Even those students who do not participate in gamelan rehearsal as musicians enjoy the festive atmosphere of being together in the music room, and socialize nonverbally.



Figure 6.7 Creating Meaning through Shared Movement As Arka sings and the other children play gamelan, a teacher creates an opportunity for interaction and helps shape a classmate's movement into socially meaningful dancing.



Figure 6.8 Students Take Pleasure and Pride in Gamelan Performance
Using non-verbal expression to determine children's evaluations of performance; the smile says a lot!



Figure 6.9 Spreading Positive Views of Autism This picture of Pando in his costume with his mother got over 40 "likes" on her Facebook page soon after it was posted, as well as a host of encouraging and supportive comments.



Figure 6.10 Taking the Stage to Advocate for Equal Rights: “I too, am the hope of the nation” Arka pauses before playing underneath the banner displaying the poem by activist student claiming equal rights for those with disabilities.



Figure 7.1 Film Stills from *I Am Star* Groundbreaking and forthcoming new film uses actors with autism to tell a story about inclusion and equal rights. In still one, typical students reject their autistic peers and wonder whether inclusion will turn their school into a “special” school. In stills two and three, the voice-over of a young advocate reminds her friends that autistic people’s “parents raised them with patience and love” and thus “they deserve equal rights and attention.”

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