Parents Speak: An Ethnographic Study of Autism Parents

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This ethnography documents the everyday experiences of the parents of children diagnosed with autism with whom I conducted fieldwork from April 2010 through September 2011. It describes the daily activities of self-proclaimed “autism parents” living in Queens, New York, who tirelessly campaign for their children’s medical, educational, and social needs. The parents described are all members of a local support group, and together, they engage in practices of self-education, advocacy, and activism. By recounting parents’ stories, this ethnography demonstrates the difficulties of the early moments of becoming an autism parent: the official diagnosis, receiving Early Intervention services, and navigating relationships with friends, family and loved ones. Through descriptive fieldnotes from the 18-month study, it also interrogates the uniqueness of parents’ circumstances as they are shaped by their children’s bodies and their own bodies, and urges the reader to think about the peculiarities of bodies and the particularities of the situations in which they find themselves. Furthermore this ethnography traces the navigational obstacles parents face as they work to secure educational and medical services for their children. Finally, the project examines the educative practices that parents engage in as they learn from each other, tell their stories to others, and work to express their experiences with autism to the world. The content presented in each chapter works to answer the question, “how does one become and be an autism parent?” by demonstrating that the paths of autism parenthood are multiple, varied, and textured – each a unique autism experience.
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This ethnography is dedicated to the families of APSG.
To your welcoming arms, your instructive moments, and your ceaseless inspiration,
I am forever grateful.
Parents and Caregivers, are you an Autism Warrior?

If not, are you willing to be taught? The Autism Parent Support Group (APSG) is a highly committed, highly passionate, and dedicated group of parents and caregivers, who are working in the community as one for the progress of their child/ren against Autism. APSG parents do not just sit back. They take action! We are more than a support group. We are family!!

The text above is boldly displayed on the homepage of the Autism Parent Support Group website. The images conjured in this text, the pictures and words that beckon the reader into the site, are reflective of the concepts that pulled me into research on the daily lives of parents of children diagnosed with autism, living in Queens, NY. I wanted to know what it meant to be an “autism warrior,” or “autism parent,” as many are called. Throughout my research I found that to answer this question, I needed to learn about parents’ daily activities, the decisions they make when caring for their children, the relationships they create, maintain, and relinquish, and the
ways that they learn about what it means to each of them, to be a parent to a child with autism. In doing so, I chose to explore not only the parents’ individual experiences, but also the collaborative efforts of support groups for parents of children with autism and how the groups serve as a forum for parents to "take action" and to be part of an “autism family”.

To better understand these issues, I conducted fieldwork with individuals connected through APSG, a New York City support group for parents of children diagnosed with autism. By observing group and individual practices, listening to stories, and participating in activities, I was able to learn about parents’ experiences and to interrogate the ways that those experiences have influenced their lives, and from this research, I present three main arguments:

First, parental experiences of autism are multiple and varied, and the moments and spaces parents encounter, the practices they engage in, and the decisions they make for their children, constitute the production and reproduction of their lives as “autism parents”. Throughout this text I trace the negotiations and renegotiations that parents engage in as they manage personal relationships, cater to their children’s bodies, and navigate various bureaucratic institutions to seek services and supports.

Second, parents engage in collaborative, educative work as members of families, schools, parent support groups, neighborhoods, etc., as they learn about their children’s needs, and teach others about them as well. This work consists of reading books and blogs, Googling new treatments, attending meetings, sharing the information they learn with other parents, with strangers, with loved ones, and making crucial decisions about their children’s lives, based on this information.

Third, parents do this work by employing the “autism” label, one that is applied - by themselves and others - to their children, their activities, and their identifications as parents.
They call themselves “autism parents” and “autism warriors”. They recognize that this label has had a tremendous impact on the reorganization of their lives, and so they own it, use it, and manipulate it, in order to care for their children. But while they recognize it as a term to index, an identity to reference, or a label with which to situate themselves, they explain that it can never fully describe the complexities of their lives. And through their stories, I have come to recognize that it is not the autism label that defines their lives, but rather that the daily activities they each dedicate to caring for their children define their lives, and in so doing, define autism for each of them.

It is my goal throughout this ethnography to tell the stories of the parents with whom I spent 18 months, as well as to show how parents not only work within the constraints of their daily lives, but engage with those constraints to produce their lives in meaningful ways. In so doing, I strive to demonstrate the power of the educative practices in which the parents in my study engaged, and to suggest that if we want to know more about autism, we must recognize the multiplicity of parental experiences, listen to parents’ stories, privilege those stories as expert knowledge, and take care to learn about the daily activities that define their lives.

**Aims of this Ethnography**

Educational anthropology has been interested in how people learn about the world around them and how to live in it. Anthropologists in this field have explored how people understand their surroundings cognitively (knowing the slope of a hill where one grows crops, knowing how to read a map and street signs), and culturally (knowing what social cues and behaviors are appropriate, knowing the dos and don’ts of a community). They have researched the deliberate ways that people obtain this knowledge through parents, schools, media, churches, etc., and how they pass it on to others. This research has shown how people become socialized into their
families, local communities, workplaces, and societies. As an extension, my study provides an unique example of how this socialization occurs – what practices people engage in, how they talk about their experiences, how they adopt a new lifestyle – when they are suddenly faced with a situation they may have never dreamed of facing: raising a child diagnosed with autism. By interrogating this socialization process, my study describes in real life moments how the practices of autism parents are negotiated and renegotiated through a collaborative, educative process. This process simultaneously teaches them what it means to be an autism parent, while allowing them to co-construct the meanings of autism parenthood.

Additionally, this ethnography extends the work of disability studies by documenting the quotidian practices and experiences of parents in my study to ask the question “Does ‘autism’ matter?” It explores the elements of care, stigma, guilt, worry, and work that pervade the everyday experiences of parents of children diagnosed with disabilities. Many of the practices and situations documented here could be experienced by parents of children with mental illness, learning disabilities, or physical disabilities, just as readily as by autism parents. However, the parents in my study identify as “autism parents,” and regardless of the differences between one child in the group with autism, and another very different child in the group with autism, the parents consider them all autistic – they consider their lifestyle an “autism lifestyle”.

Throughout the ethnography, I grapple with what this “autism” label means to parents and how they use it in their lives to address and learn from experiences that they consider unique to autism. I document moments when the label seems to be forgotten, and other times when it is the only way a parent can describe an experience, and I question, who or what makes autism important, when or why does it become part of a parent’s experience?
Furthermore, this study contributes to a dilemma with which anthropologists have historically struggled: how can we describe the uniqueness of human beings’ varied experiences, while still demonstrating and analyzing the powerful commonalities that allow them to come together in groups? How do we describe the power of these groups without generalizing characteristics to all members of the group? How do we explore their intra-group heterogeneity without neglecting the bonds that keep them together? I interrogate these questions throughout the study as I present the multiple, varied experiences of parents in my study, while at the same time, describe the support group that they have formed, their collectively constructed identifications as autism parents, and the ways they consider themselves different from other parents.

I address these issues, and the others raised above, throughout the ethnography, and in order to do so clearly, I have organized this ethnography to first introduce the journey that led me to this work, then trace the path of my ethnographic journey with the parents in my study, and then to finally begin to chart a path for future journeys in educational anthropology, disability studies, and applied work with parents of children diagnosed with autism.

First, I situate myself both within the academic fields of study, and "the field" where I collected data, describing how I entered this research literally, figuratively, and physically. Through this step I introduce the reader to previous research I have conducted that paved the way for this dissertation study.

Second, I situate the study within a theoretical discussion that involves two parts: 1) the notion of space, the constraints that define spaces, and what happens around and within spaces, specifically as these activities are educative in nature, and 2) anthropology's understanding of
children's bodies labeled as disabled, the parents who care for these children, the social spaces in which they find themselves, and the social activities in which they participate.

Third, I introduce an overall methodological approach to my work that emphasizes a shifting focus from discussions of autism at an abstract level to discussions of individuals' experiences at a localized, situational, observable level. I describe the dangers of relegating our understanding of autism to this abstract level and show how this ethnography responds to these dangers.

Finally, I introduce three thematic threads that run throughout the ethnography - re-ordering, multiplicity, and temporality - which are used to understand the complexity of the activities in which parents engage, in certain situations and at certain times. In this section I also introduce the reader to the content of each of the following chapters and how it connects to the overall thesis of the dissertation.

**Engaging in a Study of Autism Parents**

The journey began approximately six years ago when I worked as a Special Education Teacher in a public school system in Virginia. I taught children with a variety of diagnostic labels, including those with autism. As an educator trained to understand the characteristics associated with an autism diagnosis - the repetitive behaviors, the trouble with social communication and awareness, the difficulty with language - I considered myself to be very knowledgeable about autism and about what the children in my classroom with this diagnosis experienced and needed from me as their teacher. I knew what special educational tools and tricks a teacher could employ to motivate and engage students - reinforcements, visual schedules, clear, tangible examples, etc. - and what goals I needed to set for them - making eye contact,
initiating play with peers, self-regulation of emotions, etc. As a teacher, this was the autism that I knew.

Autism to me was a problem that caused some of my students to struggle with learning things that some of my others students could do easily. I interacted with autism through students who had similar educational and social needs, goals, and strengths for which I was required to program. I provided these services and supports to the children and saw their caregivers as a means to better understand the children. As a teacher, the children with autism were my unit of focus, my unit of analysis. I saw the people in their lives - parents, siblings, other relatives – as a means to better understand the child and to help me better focus on "the child with autism". I saw these individuals as other people in the child's life who, too, must be focusing only on the child. I used to become frustrated when parents did not implement social skills, academic habits, or progress plans at home in the same manner that I did in school. I could not understand why family members saw different behaviors, or different moments of progress and regression than I did at school. I did not know why it seemed like parents and other caregivers had a different understanding of autism than I did. This interest led me to learn more about autism, and eventually to pursue a doctoral program, for which I conducted my first pilot study during the summer of 2009.

*Previous Research Informing the Ethnography.* The major findings from my first study taught me about the ambiguous nature of autism as a label, put on students in educational settings. During this study I focused on the educational programming of students diagnosed with autism at the elementary school level. I was interested in learning about how teachers understood the autism diagnosis (how the diagnosis has changed over the years, how the rates of diagnostic incidence have increased, how they learned about what autism is, and how they saw
their role in the lives of students diagnosed with autism), and how this affected the educational programming that they provided to their students. The first truly instructive finding came from a discussion with several Preschool teachers at an elementary school in Virginia, while they discussed which children I should observe during my fieldwork.

A child diagnosed with autism, whom I had initially been encouraged to observe, moved to a new school one week prior to my arrival. Trying to be helpful, the teachers began to consider other kids who did not have official autism diagnoses, but whom the teachers believed had "autistic-y tendencies" or behaviors, and whom they thought I might benefit from observing. Before my very eyes (and ears), teachers informally labeled children as being “autistic enough” for an autism researcher to observe, despite having no official medical diagnosis. This showed me how powerful an unofficial diagnosis, created through such a discussion, could be, and made me wonder how these informal diagnoses would impact how teachers view, assess, talk about, and program for various children in their classrooms. This informal labeling taught me that autism is not simply an official diagnosis, not simply a cluster of behavioral symptoms or characteristics attributed to an individual. Autism as a phenomenon to study meant looking not only at a diagnosis, a label, but also at the changes in others' treatments and responses to that label and that individual, even when applied informally. In this way, the practice of labeling, formally and informally, instructed teachers about how to understand and address autism in their classrooms. These practices determined teachers' notions of autism, and in turn how they would identify and address autism and kids they thought to be “autistic-y” in the future.

A second finding from that study demonstrates how classroom practices can inform the presentation of autism, as well as what characteristics and behaviors a person diagnosed with autism may exhibit. I found that the decisions to operate an "autism classroom" in a particular
way (versus a general education classroom), including scheduling, seat arrangement, division of labor between educators in the room, etc., and the practices involved could bring about the characteristics of autism, such as a child’s frustration, self stimulatory behaviors, and acting out, that are used to define it. At an elementary school, I observed autism classrooms with autism teachers in special autism summer school programs created to address the needs of students with autism. Despite their good intentions to help students, I observed these people and supports create the kind of confusion and inconsistency that can lead a child to exhibit hand flapping, inattention, and frustration.

For example, during independent work time, the teacher rotation (a highly structured model in autism classrooms where students rotate around the room to work with different teachers on different activities) got mixed up and a student was sent to an activity he had attended, rather than the free time he had earned. This injustice made him very upset, but because he could not speak, he could not communicate the error to his teachers. Instead, to get the teachers’ attention, he began to flap his arms, shake his head, and refused to complete the assigned activity. In this research I found that the organization and implementation of some classroom practices could actually highlight these autistic characteristics in students, and was able to see that autism is not simply an internal neurodevelopment difference, or a set of behaviors exhibited by a child with a diagnosis, but rather is comprised of a complex interworking of people, places, rules, paperwork, behaviors, practices, and structures; the behaviors children present are impacted greatly by the environment around them.

Reflecting on the findings from this study, it seemed almost as if autism was being socially constructed in front of me - teachers were calling kids "autistic-y" and classrooms were being arranged in a way that only seemed to heighten autistic behaviors, and all with the very
best intentions. This theory of autism as a social construct is not novel, however. Timimi et al., for example, suggest that autism is a social consequence of society’s changing definition of emotional competence (2010). Nadesan, a mother of a child diagnosed with autism, offers a different kind of theory, suggesting that autism does have a biological component, but the way that autism is described, treated, managed, interpreted, etc., has socially evolved from the work of institutions and organizations, work that now defines what it means to be autistic (2005). Hacking (1999), also writes about the social construction of autism by presenting autism as something he calls an interactive kind, a label or category that is able to interact with the ideas, discussions, and actions around it and can be transformed by these interactions. For example, when the category “autism” interacts with a new piece of health insurance legislation that details the symptoms necessary to receive coverage, those symptoms may be recorded by doctors more often in order to help families receive coverage, and in turn, those symptoms may soon seem more characteristic of the label than others.

Remembering my own time as a classroom teacher, however, I was not content with dismissing autism as simply a social construction. Through my research I was noticing that practices surrounding and beliefs concerning autism were made and remade through everyday interactions in the classroom, but I was not prepared to say that this was simply “made-up”. My experience as a teacher had been real. The experiences of the teachers and administrators I studied had been real. And thinking back to the parents I had struggled to understand, the experiences of families, I thought, had to be real as well. As a teacher I had seen too many parents sad, angry, frustrated, and confused to wave off autism as without a realness, without a reality. It was at this time that I started to recognize the research paradigm that I was forming in
regard to autism: There was not just one autism reality - there were many. Infinitely many, even, and for my doctoral dissertation, I wanted to study some of them.

I soon realized that for my dissertation, the focus would never be on coralling a finite definition of autism, discovering the ultimate cause, or ridding the world of autism. I instead began with the premise that autism had meant something very different to me as an educator than it may have to the parents of my students with this diagnostic label, and that the only way I would be able to understand what those meanings were, was by asking them about autism and experiencing their autism with them through participant observation. With this approach, I became interested in learning about how parents of children diagnosed with autism learn about autism. This led to a dissertation pilot study conducted with several parent support groups in NYC from April through July, 2010, which I discuss in Chapter 2. Having now presented the previous research that has informed this dissertation, the next section of the introduction will discuss the theoretical paradigms that I have worked with, learned from, and researched within, as my project grew from these earlier studies of autism in schools and several parent support groups, to this final ethnography of parental experiences.

**Theoretical Situation**

To think about the experiences of parents of children diagnosed with autism, I think first about how bodies interact with the world – how parents’ bodies interact with children’s bodies, how children’s bodies interact with their environment, how parents’ bodies interact with the bodies of family members, neighbors, teachers, strangers, and others who will never experience the child in the way that they do. These interactions happen in various spaces (at school, at the supermarket, in the home, etc.) and at various times in individuals’ lives (when children are infants, when parents are new mothers and fathers, when children are teenagers, when parents
It is the interactions of these bodies, in these spaces, at these times, that bring challenges to the surface, that make activities and events important to parents, that make autism matter. Merleau-Ponty writes of the importance of such spaces and spatial perspectives, and demonstrates how the body is intimately connected to those spaces, in fact as the primary tool for interacting with the world. Merleau-Ponty (1962, 1973) tells us that spaces in the world (swimming pools or art studios, for example) are available to us to experience if we use our bodies (gliding through the water, holding a paint brush, etc.). It is not the case, however, that each parent and each child, can whimsically and unboundedly interact in these spaces doing whatever they want, whenever they want. In fact, if this were the case, perhaps “autistic behaviors” would not be seen as so problematic and in need of remedy. But alas, there are constraints on behavior and actions – rules about what people can do with their bodies, at what times, and with whom. Goffman (1961), for example, uses interactions with the world which occur in various spaces to suggest that institutional constraints (rules, regulations, appointed guards, etc.) create and maintain these spaces, and also manage, survey, and control the movement and interaction of bodies within them. Hence, children are required to keep their hands and feet to themselves while in school, and if they break this rule, there are consequences for the child, as well as for the parent. While these characteristics may become written on the body in identifiable, detectable ways, and while parents’ and children’s behaviors must continually interact with the constraints around them (school rules, diagnostic procedures, therapies, regimens, stigmas, etc.), these limitations are not so constraining as to eliminate the possibilities for change, growth, or play. In fact, these spaces in which parents and children interact with each other and others around them, these spaces supported and constrained by boundaries, also allow great flexibility. The boundaries are constantly being renegotiated as
parents grow older, children grow older, new goals are made, old goals are attained, and impacting family, community, and world events occur. The experience of autism in the lives of parents and their children is flexible and no one label can be adequately applied to those experiences that will ever truly capture their depth, course, or possibility.

De Certeau’s work (1984), explores this flexibility of interactions within social spaces. He suggests that while the constraints Goffman points to are certainly present, people can maneuver around and through them, and ultimately can play with spaces and their boundaries. While Merleau-Ponty takes into account the presence of spaces, and Goffman emphasizes the constraints of spaces, de Certeau demonstrates how people can really perform these spaces. For de Certeau, the focus should not just be the skill of speaking, but the art of communicating, and likewise, the act of walking down the streets of New York (a famous example he provides) is not just about moving one's body in a particular direction, but engaging in the nuances of movement and playing with the other bodies and objects that surround you. Parents engage in these nuances as well - changing their child’s diet and then carefully observing the child’s behavior, mood, and fatigue, attending a workshop about sexuality as their child begins to enter puberty, asking other parents for advice about setting up a trust fund for their child that will ensure their financial security after the parents are deceased. None of these activities in and of themselves constitutes “autism”, and yet they are all activities that consume the energies and efforts of parents, becoming the way that they define themselves as autism parents, if only for the moment that a particular activity is relevant in their lives.

As parents engage in such activities, they are not simply moving within the confines of what their family, community, or society allows, but they are also working to create new boundaries, propose new definitions, destroy old limitations, and otherwise re-invent the spaces
in which they interact with their children and with others. Autism parents are not passive in their activities, but rather engage with schools, healthcare systems, social stigmas, historical understandings, medical tests, insurance coverage plans, statistical analyses of autism, and various other intersecting factors. Bruno Latour’s Actor-Network Theory (ANT) can be used to describe this phenomenon of production of culture. ANT charts the ways that social actors and actants\(^1\) are always in the process of creating these spaces and constraints, which can connect, overlap, and themselves lead to the creation of new activities, spaces, and constraints. For Latour, not only are these constraints and spaces dynamic, but they are also inseparable from "culture" and cannot be distinguished from the activities that occur within them (2004). Parents are not products of autism culture, but rather active producers, as are their activities, their efforts, and the documents, groups, brochures, blog posts, parent-teacher conferences and multiple other artifacts they help to create. Without the efforts, however defined (birthing a child, taking a child to the doctor for a diagnosis, fighting against a school system about a special education label), of autism parents, there would be no activities of autism, no ways to describe or capture an understanding of autism. As Latour explains that culture cannot be separated from the activities that constitute it, without parents of children with autism, there is no autism.

As the theoretical argument of this ethnography I claim, through the above description, that parents of children with autism interact in multiple, varied ways within spaces bounded by pliable constraints – spaces and boundaries which they can and do create through their everyday activities. It is these activities that parents use to define their lives as autism parents. Furthermore, I assert that parents employ a crucial instrument to engage in these activities, to

\(^{1}\) In Latour's work actants can include human and non-human actors such as organizations, objects, and ideas.
reflect on them, and to make meaning of these activities in their lives, a meaning that they call “being an autism parent”. This instrument is education.

In reaction to the early 20th century work of educational philosopher John Dewey, which largely concerned education in school settings only, in the 1970s Lawrence Cremin wrote about informal learning and learning that takes place outside of schools (at churches, in homes, through the media, among friends, etc.) With this broader perspective of education, Cremin defined education as "the deliberate, systematic, and sustained effort to transmit or evoke knowledge, attitudes, values, skills, and sensibilities" (1974:567). Since then, anthropologists such as Brice Heath (1983), Lareau (1989), Miller (1982), and Moffat (1989), have used ethnographic methods to document the kinds of everyday, outside-of-school, learning and teaching practices that Cremin considers education. They have done this work in communities, families, and peer groups to show how people educate themselves and others about what they need to know in order to be successful in their environments. Some researchers such as Gundaker (2007) and Kalmar (2000) have even been able to document how individuals utilize these informal methods and spaces of education when educative practices as otherwise restricted, inaccessible, or prohibited. Focusing on these kinds of informal educative practices highlights the cooperative work that people do to navigate their life circumstances and can even demonstrate that people do not require formal education and educators in order to learn (Ranciere 1991, Mitra 2007).

Perhaps the most influential extension of Cremin’s work has been that of Herve Varenne and his long time collaborator, Ray McDermott. Together, they have looked at the various and ever-changing ways that people organize their activities, and thus their lives, through a constant renegotiation of their present situation and the challenges that lay ahead. They consider this work, education, and have examined in formal and informal, ideal and less than ideal settings.
Varenne’s work specifically, has looked at the ways the people, often in families and in communal spaces, work collectively to devise and attempt to achieve their goals, and in so doing, constantly learn from one another, the environment around them, their activities, and the mistakes they make along the way.

The parents in my study engage in such efforts to learn about their children and the world that they must inhabit with their children. They also engage in these efforts to show each other new ways of overcoming challenges, navigating bureaucratic systems, and understanding the experiences they are each encountering with each of their children. Furthermore, they engage in these efforts to express their experiences, their hopes, their needs, and their expectations to others in their lives – from the neighborhood postal worker to the school board superintendent. Using Cremin’s definition, the processes of education in which parents engage are not restricted to the spaces of the school building, which is often thought to be the location of education, but instead occur in spaces throughout their daily lives. As parents employ education as a tool for interacting with their world, for making and remaking the boundaries and spaces in which they engage with others, they are learning about what it means to be an autism parent, by being an autism parent.

Lave and Wenger describe this process well – the process of learning through doing. They describe how people change positions within the spaces they inhabit (butcher shops, tailor shops, ships, birthing rooms, Alcoholics Anonymous meetings) as they participate in activities that enable them to learn how to master new skills and how to interact within these particular spaces as inhabitants of the spaces – as members of the groups. In these spaces, learning is presented as a social activity, and one that follows social interaction, rather than precedes it. Parents do not consider themselves autism parents only after having thoroughly researched a new
diet. They consider themselves autism parents while they research it. Likewise, they do not come to identify with other autism parents only after receiving an official diagnosis, but while they read blog posts and compare developmental stories with other parents at the park. And each time they engage in a new activity (fighting with a spouse about treatment, explaining a tantrum to the supermarket clerk, quitting a job to stay at home with the child), that experience further contributes to their identifications with their autism parenthood, in a process of production and reproduction of identities – identities that are used at different times to relate with different people, different places, and different activities. Throughout the ethnography, when I site moments of parents’ constructing their identification as an “autism parent,” I am using the identity theory of Lave, one that considers how people engage in educative practices through which they learn in which practices autism parents engage.

Similarly, yet with need for differentiation, I use Dorothy Holland’s work to address the cultural co-construction of identifications as an autism parent through their relationships with others (strangers, relatives, spouses, the media, etc.) As Dorothy Holland explains, within social spaces (patriarchal Hindu villages in Nepal, mental health institutions, American colleges, Alcoholics Anonymous groups) the interactions that occur not only teach people new hands-on skills like those in Lave and Wenger's groups, but also teach people how to identify within their society and how to author their "selves". By interacting with others in these social spaces, and by managing the institutional constraints (caste requirements, mental health regulations, gendered activities, guidelines for drinking behavior, etc.) placed upon them, people produce their various identities.

The theoretical approach outlined above serves as the deep structure for this ethnography. Additionally, this ethnography is situated in a contemporary conversation held by social
scientists focusing on disability and the body, especially as it concerns parents and children. Concentrating on these topics, I extend the work of the theorists I will describe below, to consider how social actors - parents, children, professionals, family members, etc. - and social actants - large institutions, legislation, documentation, therapies, diets, etc., interact within social spaces to produce and reproduce parents' identifications as autism parents.

The works of Rayna Rapp and Gail Landsman have been invaluable to my understanding of the experiences that parents encounter as their children are labeled “disabled”, “special”, or otherwise different, and the subsequent actions that they take to manage these experiences. My ethnography draws from each of the authors, expanding or narrowing the focus of their work in a way that gives new light to their findings and to the social situations that they studied, yet at the same time, harkens back to the critical points made in each of their texts. My work also draws on anthropological and sociological studies of autism by Elinor Ochs and Olga Solomon (2004, 2010), as well as Gil Eyal (2010, 2011) and Roy Grinker (2007), which have been immensely instructive in understanding of the context of the study of autism in social sciences, and for narrowing my own focus on the parents of diagnosed children.

Rapp's work (2000) on amniocentesis is especially powerful as it enters this discussion of childhood disability and parenthood in the first critical moments as well as during fetal development. As parents, notified that something may be abnormal about the fetus they are carrying, work through the shock of this realization and the pain of having to make a decision about whether to abort, Rapp documents the process of their decision-making and reflections on it. This process involves not only the parents and the unborn child, but also the technologies, health institutions, "results", and professionals that surround these new possibilities of reproductive health and choices about peoples' lives. My study extends this work as it follows
parents out of the health institutions and into their lives to see what those lives look like when abortion is not chosen, or when a disability label is granted later in the family's life.

Landsman's work (2003, 2005) considers parents' experiences further along in this journey than Rapp, once children have been born and subsequently diagnosed as disabled. Her work looks at the ways that parents of children with various disabilities come to terms with the rewriting of the motherhood story they thought they would live, now suddenly different than anything they had expected to endure. With parents, she travels through the experience of coming to identify as a mother of a child with a disability and engaging with a narrative that calls for both mother and child to be strong, work hard, and overcome all obstacles ahead. Greatly informed by Landsman's work, my study narrows her discussion by focusing only on parents of children diagnosed with autism. This is done to show both the similar experiences that parents dealing with the same disability label (and all that comes along with it) encounter, as well as to highlight the multiplicity of experiences within that same label.

The work of Ochs and Solomon (2004, 2010) has been particularly informative and inspiring for my study, as they explore autism as a complex system of language and social connection with others. A large body of their work looks at sociality and autism, a topic they have been focused on for over a decade. Their approach is one of anthropological and linguistic inquiry, with much of their data collected through the Ethnography of Autism project, which looks at social repertoires of children diagnosed with autism and the people (and sometimes animals) around them, to see how children are able to socially coordinate in a range of situational conditions. They have also done excellent work in bringing together anthropologists researching experiences of adults diagnosed with autism (Bagatell 2010), how diagnosed children craft narratives of the self (Sirota 2010), how diagnosed children and their parents co-participate in
social interactions (Sterponi and Fasulo 2010), and how parents deal with autism and mealtime
(Wilkinson, 2009), by collaborating on a special issue dedicated to anthropology and autism in
the journal, *Ethos*.

Eyal's sociological focus is on the historical change of the autism label over time - how it
has been defined, understood, managed, who or what has been cited as a cause. He claims, “The
causes for the recent exponential rise in autism spectrum diagnoses should be sought neither in
purely biological factors, nor in purely social factors, but in a complex process of looping
between the two” (2010). He proposes that the increased rate of autism diagnoses arose from the
period of deinstitutionalization in the United States, when large populations of "abnormal
children" were found labeled with neither mental retardation, nor mental illness, the two most
utilized labels previously, and instead a space emerged for a new label, "autism". During this
time, parents, who may have otherwise sent their children to institutions and become completely
uninvolved with their day to day activities, became the primary caregivers, educators, therapists,
and advocates for their children. Tracing these changes in parental responsibility and response to
children diagnosed with autism, Eyal also looks at autism parents' collective strength historically,
citing the formation of many advocacy groups, therapy and treatments centers started by autism
parents, and a strong voice in politics and legislation surrounding the disorder. Extending Eyal's
historical account of the changes of autism parents over time, I chose to focus on the quotidian
experiences of some of the individuals who may be representative of the large populations of
autism parents that he documents.

Grinker's work too, has been influential to the perspective that this ethnography takes on
autism. As an anthropologist and father of a daughter diagnosed with autism, Grinker (2007)
shares the personal story of his family’s struggles with a school system in the United States when
they attempt to access the best services that they can for their daughter. Comparatively, he writes about autism in South Korea, South Africa, Peru, and India, speaking with parents of other children with autism around the world about their experiences and struggles with inclusion, acceptance, and understanding from other family members. He also explains the shift from psychoanalysis to psychiatry in the US and how it has impacted the change of diagnostic criteria (DSM), which in turn impacts the rates of individuals given a label of autism. By using Grinker's work to think about the change of autism over time - as a term, as a label, as a diagnosis, and perhaps now as a way of being in the world - I made a deliberate effort to turn my energies away from studying the autism label, and instead to study the experiences of individuals who claim to be affected by the autism label in some way. In the next section, I describe this methodological strategy - moving from a discussion of autism, a social fact that is always changing, to a discussion of the experiences of the parents in my study - as "abstraction to experience".

From Abstraction to Experience… and Back

De Certeau, in his famous chapter, Walking in the City (1984), describes the physical acts people engage in - walking, turning, stopping, and otherwise navigating the space - as they walk through New York City. He contrasts these "practices of everyday life" with an operational concept that is abstracted to define the city, "creating a universal and anonymous subject which is the city itself". de Certeau explains that with this abstracted subject:

it gradually becomes possible to attribute to it, as to its political model,... all the functions and predicates that were previously scattered and assigned to many different real subjects - groups, associations, or individuals. 'The city,' like a proper name, thus provides a way of conceiving and constructing space on the basis of a finite number of stable, isolatable, and interconnected properties.
This abstraction too, has happened to "autism". All of the functions and predicates that would otherwise describe the individual experiences of the parents and children in my study, have been conceived of and constructed as "autism" on the basis of a finite number of stable, isolatable, and interconnected properties (i.e., diagnostic criteria, administrative labels, medicines, therapies, terminology, clinical responses, etc.). Throughout this ethnography, I choose to focus on those functions and predicates, those "practices of everyday life", rather than on "autism" as a reified subject. This has presented a methodological choice, which I have grappled with throughout data collection, analysis, and even this ethnographic presentation. I will introduce you to the quandary here, and will attempt to resolve it in the ethnography’s conclusion.

My aim since I began thinking about the conception of this project has been to focus on parents' individual experiences rather than to look abstractly at autism as a thing itself. In fact, my emphasis had become so strongly anchored on individual experience that I considered not including the history of autism, the making of autism as a thing, in the body of this text, but rather, relegating it to the appendix. My rationale for at first wanting to banish this information to the appendix was that I find it too often the case that the pretext for any discussion about the experiences of autism is hinged upon what this “thing” is – characteristics must be listed, statistics spouted, etc., that by the time the reader gets around to the experience he or she is being presented with, he or she is already saturated in jargon and has a certain idea in his or her mind about how the experiences recounted will play out. Below I discuss how this tension arose throughout my research, including the writing of this ethnography, and the strategies I’ve employed to both honor and address this tension.

*From Abstraction to Experience.* If I have to describe the characteristics that Leo Kanner documented in the first report of 11 children diagnosed with “autism” in 1943… If I then must
compare these characteristics to the ones that Hans Asperger documented in his study during the same time period… If I must discuss the labeling, management, and treatment of individuals with autism in mental health facilities during the period of institutionalization, and then later as they entered community services and schools… If I am required to report on the diagnostic scales and measurements clinicians use to find a child eligible for a medical autism label… and if I am required to present you with reports on “the autistic brain” or “the autism gene”… all in order to prepare you for the stories of the parents in my study, then I will have created for you, a very particular picture of “autism” – not “autisms”, not various experiences with “autism”, and likely not any possibility of thinking outside of the notion that autism is a thing. And in fact, only one thing – a thing that is observable, documentable, perhaps treatable, or maybe even curable. This picture would not do justice to the complexity of the lives I present in this study.

If I were to present this work in the field of autism, as many do, with an opening like, "The CDC currently reports that one in every 110 children born in the United States has an Autism Spectrum Disorder,” you may begin your journey through this text with the idea the “autism” is some definite thing, and perhaps even that those one in 110 children are the same. The danger in this is that too much emphasis on these statements, too much focus on the autism label and how it is defined or measured, detracts from parents' individual experiences, and such has become the case in the last several decades. Since the term's appearance in scientific literature in 1943, increasingly focused efforts of psychologists, geneticists, behavioral specialists, neuroscientists, and various other medical and educational professionals have tried to define, categorize, and isolate an understanding of what autism is. The majority of this research and these applied efforts have focused on individuals diagnosed with this disorder. At present, autism is most widely understood as a neurodevelopmental disorder, and furthermore, one that is
diagnosed using purely behavioral criteria. Researchers are exploring genetic causes (Blundell et al. 2010, Geschwind 2009, Insel 2009, Masconi et al. 2010), cognitive differences (Frith 2008, Baron Cohen 2000), environmental causes (Kirby 2009, Offit 2009), and social clustering (Liu et al. 2010, Marzumdar et al. 2009), in desperate attempts to figure out what autism is and how to deal with it. With all of these efforts focused on what autism is, who has it and in what form, what causes it, and what can treat it, there has been little scholarly attention paid to the way that it can be experienced in the everyday lives of those affected, especially parents.

For example, in recent decades, autism has become known as a "spectrum disorder", one that affects individuals to varying degrees, ranging from severely to minimally affected. This is problematic as it puts individuals on a scale, ranking their experiences based on what those without an autism diagnosis have decided is profound or negligible. For example, those diagnosed with Asperger's syndrome are often talked about as being "higher functioning" and on one side of the continuum, while those diagnosed with more classical notions of autism are considered "lower functioning". This leads to an assumption that the experiences of those "lower functioning" are worse, more difficult, or that they somehow endure greater suffering than people at the other end of the spectrum who can speak and perhaps perform better on IQ tests. This also assumes that those who care for "higher functioning" children are better off, or have it easier. How is it possible to help individuals with their daily struggles if they are immediately categorized as better off or worse off than others and treated accordingly? In this way, when the unique needs and experiences of individuals and their loved ones are abstracted to a level of simply existing as points on a continuum that determine and categorize their experiences, the human quality of those experiences is neglected. Through this ethnography I intend to bring those experiences to light.
...And Back. There is danger too though, in leaving out the history. Parents in my study identify as “autism parents”, not “parents of children with mental retardation”, not “parents of children with schizophrenia”, and often even when their children are multiply labeled (for example with both autism and mental retardation medical diagnoses) they still identify as autism parents. This identification is shaped by Kanner and Asperger’s studies, by the awareness of the autism label presented in the media, by doctors’ checklists (influenced by historically created criteria), and insurance companies (mandated by the historical revision of private and public health laws).

So I struggle here, with wanting to represent the present lives of parents in my study, as I observed them, and with needing to demonstrate the historical factors that may have influenced these present lives (and will undoubtedly instruct their future activities). Additionally, as my theoretical stance about parents’ lives is one that suggests that parents are always in the process of producing and reproducing their lives, history, a critical tool for that (re)production cannot be neglected (Holland and Lave 2009). Alas, for the sake of the production of this document however, I must make a choice, and so I choose to refrain from presenting a litany of chronological historical accounts in my introduction, but rather to provide historical background that is relevant to each of the parent stories I discuss throughout the text. In this way, I hope to honor parents’ stories and activities as they were presented to me, as well as to couch them in a historically contextualized understanding that makes sense for that parent, in that moment.

Three Thematic Threads

In this section, I describe the three thematic threads that run throughout the rest of this ethnography. They are found in the stories I relay, the analysis I provide, and the composition of the study's participants.
Thread One: Re-ordering Activity. One day Julia, the mother of a nine-year-old diagnosed with autism, told me something that has intrigued me for months. She said, "Autism disorders the family". I found myself immediately struck by the power and perception of this insight, but did not know at the moment how important it would be to understanding autism parents' experiences. After several months of research and thought, I began to see a different way of understanding autism, and as I began writing this ethnography, I conceived of a response to Julia that I believed could fully reflect all of the complexities and particularities - good, bad, celebratory, traumatic, exciting, and agonizing - that I observed throughout my fieldwork. After 18 months of trying to understand the lives of the autism parents in my study, I wanted to tell Julia that, "Autism may disorder the family, but it also orders it, and re-orders it."

Throughout this study, evidence of this ordering and re-ordering will be presented. By ordering, I mean that the various obstacles parents face are instructive about what activities they can and can't, may and must engage in. For example, if a child has particular food sensitivities, this may uniquely order what a parent can and cannot serve for dinner. If children have a difficult time adjusting to new activities in their daily routine, this will order how much time parents must allow in their schedule for a bedtime routine. When parents are told that a particular therapy or toy will be good for their child, this may order the family budget, and if parents feel embarrassed when their child has a temper tantrum in front of family friends or a co-worker, this may order who they interact with in their professional or personal relationships. In these various ways, the struggles that parents face with their children, which they abstractly refer to as "autism" order parents' lives and families' activities.

When things change, and they always do, reordering occurs. For example, when children go through puberty, move to a new school, when a sibling is born, etc., parents look to their own
personal experiences with the struggles they call "autism" to think about how they must reorder their lives to deal with these new issues. At some point, these activities may seem disordered, chaotic, and frustrating for parents. At other times, these activities may give them a sense of control and calmness. Both these concepts of reordering and ordering are discussed throughout the ethnography, giving texture to the participants' stories and activities, providing a constant reminder of the efforts that people engage in as they live their lives, as well as a reminder that life for these parents is always in the process of being re-ordered.

Thread Two: The Multiplicity of Experience. The focus of this study, unlike many others, is not on the child diagnosed with autism, but rather on parents. I am most interested in parent perspectives and caregiver experiences. Additionally, the study focuses on the variability of those experiences. For some time now there has been a saying among educators: “If you’ve met one child with autism, you’ve met one child with autism”. This understanding of differing ability and need has led to differentiated instruction in the classroom, Individualized Education Plans (IEPs), and various other tailored services for children diagnosed with autism. Recent genetic and brain studies of chromosomal abnormalities and brain connectivity have even led researchers to suggest a shift in understanding from an “autism spectrum” model, placing autism experiences on a continuum, to an “autisms” model, suggesting perhaps multiple types of autism, expressed differently in each individual (Geschwind 2009).

If such insight into the variability of genotypic and phenotypic presentation has been garnered concerning individuals diagnosed with autism, why has such little attention been paid to the possibility of variability in family experience? Bureaucratically, medically, and often educationally, autism parents are all lumped together as the same kind of person, and along with this lumping comes the assumption that their experiences and needs are the same. By presenting
some possible examples of what an “autism lifestyle”, as parents in my study called it, can look like at a particular time, in a particular place, with particular resources this study pays careful attention to these real, important, life defining differences and urges educators, policymakers, and medical professionals to recognize that autism parents' needs are individual, change over time, and are affected by many situationally dependent factors.

*Thread Three: The Temporality of Experience.* The study strives to describe the dynamic nature of how participants are variously identified, situationally and temporally. Ethnographies sometimes portray a snapshot of participants' lives without suggestion and analysis of ongoing change. Presenting human activity in this way can create a sense of stasis - allowing the reader to believe that participants' lives will remain as they are presented in the text, forever. Equally problematic is creating a sense of social reproduction, allowing the reader to imagine that the next group of participants occupying a given space will go through the same experiences, in the same way, as those documented in the study.

This study attempts to challenge these modes of ethnography by presenting experiences in motion. This study was conducted with a particular group of individuals, at a particular time, and in a particular place. These are methodological constraints that are unavoidable. However, the analysis and presentation of data collected seeks not to claim that all autism parents do "this" or "that", but rather that some possibilities of autism lifestyles have been carefully documented and are here to be shared. By providing rich, descriptive details of some of the experiences of some parents of children labeled with autism, this ethnography aims to highlight the variable and negotiable properties of parents' experiences with autism. In doing so, it seeks only to generalize the processes through which this variation and negotiation takes place, rather than generalizing
characteristics, behaviors, or experiences observed during fieldwork to the entire population of individuals who identify as autism parents.

Throughout the text I aim to demonstrate that parents identify with autism in multiple ways – as feeling frustrated by their child’s behaviors, challenged by their school systems, inspired by their child’s growth, etc. Some parents experienced some of the events that I discuss throughout the ethnography; others did not. At some point, all were faced with the realization that something called autism was becoming important to their lives. How this realization comes about, how it is reacted to, and how parents move on from there is far from definite. All autism parents engage in some experiences that signal entrance into an autism lifestyle, the production of an autism parent. After these moments, parents begin to see these changes as part of the autism lifestyle. Their lives may be later punctuated by other moments of dramatic change as new problems arise, and these too become incorporated into this lifestyle over time. As they engage in new activities, they reflect on their experiences, become conscious of what makes their new lifestyle different, and may come to acknowledge this difference as something worthy of discussion. Many parents come to embrace this lifestyle, these changes, and communicate with others about them, expressing to others their new way of being in the world, but this way is never static. It is constantly in motion as they face new challenges, learn about new resources, services, etc., and have experiences with other parents, educators, bureaucrats, strangers in the supermarket, and various other persons that they encounter throughout their daily activities.

**Structure of this Ethnography**

I structured the text to reflect my focus on parents' multiple ways of being in the world, and employ parents' own words about their experiences, their perceptions of their lifestyle, and their reflections on changes in their lives throughout the text. These passages have been taken...
from interviews, discussions during meetings, and Internet posts. Data are also presented in the form of field observations, documented as fieldnotes. The data can be found in block quotes throughout the text.

Chapter One presents the participants of the study as individuals with whom I interacted throughout my 18 months of fieldwork, April 2010 through September 2011, and as members of a support group, Autism Parent Support Group (APSG), during the period of my study. Members welcomed me into their group and into their lives, enabling me to learn about what it means to them to be an autism parent. In this chapter I introduce the reader to the key actors and to the ways in which I saw them interacting. Additionally, the chapter demonstrates variation among various parent support groups in New York City, as I discuss the comparative pilot study I engaged in prior to studying APSG in depth, as well as variation between parents within APSG.

Chapter Two presents the methodological framework for the study, detailing my activities, tools, and reflections on data collection. This section begins by describing what kind of study I chose to undertake and why. I then proceed with a discussion of methodologies I used in this particular study and suggest other methodologies that may be helpful for further research. Additionally, I reflect upon the particular methodological choices I made throughout the study and how they may have affected my positionality and the data I collected.

Chapter Three focuses on parents’ multiple identifications, and the process of adopting these identifications, by introducing three critical moments of dramatic change that are possible for autism parents. Nearly all of the parents in my study experienced these moments, but each in very different ways. These three moments, the diagnosis, Early Intervention, and telling others about autism, signaled to parents that their lives had forever changed and that they must, in some way, confront the changes. This chapter addresses several powerful experiences that parents
reported after they became aware that their lives had changed. Parents engaged with these experiences in different ways - some as prolonged periods of involvement, others as isolated events. Some were more affected by these experiences than others, and they also had different levels of acceptance regarding how and why they encountered these experiences.

Chapter Four focuses on bodies by highlighting five possible topics of concern that may be present in the lives of autism parents: activities of daily living (ADL), gastrointestinal issues, safety, sexuality/puberty, and long-term caregiving. This chapter demonstrates that parents may identify in various ways with autism based on their own prior experiences, the unique needs of each child’s body, their family dynamics, and the access they have to resources and support. For some parents, toilet training was never an issue, for others, it was a battle they struggled with for years. Whatever problems arose or successes were celebrated throughout the period of my fieldwork, none of these obstacles or triumphs were static - they often became easier, more complex, forgotten about, or commemorated, but they never stayed the same. This chapter serves to describe these changes in motion.

Chapter Five focuses on the institutions of healthcare and schools by exploring the ways that they limit parents, as well as the creative strategies parents employ to navigate those limitations. In order to secure services, maintain supports, acquire information, or access resources, parents often interacted with large institutional structures that both informed parents' various identifications with autism and structured their daily activities. This chapter focuses on two major institutions that many of the parents in my study interacted with - school systems and medical bureaucracies. The experiences that parents have with these various institutions inform the ways they understand and negotiate their relationships with autism in their lives. In some ways these institutions order and reorder parents lives, instructing them about what to do to
secure services, where to go to file paperwork, who to talk to to receive support. In this way, the institutions are limiting and restricting. The parents however, are able to navigate these limitations and at times, even to reorder the institutions.

Finally, Chapter Six focuses on communication and education by looking at how parents share with each other, and how they advocate for themselves and their children. This chapter looks at the various ways that parents present their daily experiences to others; these presentations often came in the forms of "sharing" and "fighting". In addition to the family members who are described in Chapter One, the "others" that I witnessed parents presenting themselves to, include fellow members of APSG, strangers who stare at them when their children "misbehave", and various media outlets. The individuals that are included in this category of "other" had varied levels of familiarity with autism and often very different responses to parents' activities. How parents choose to recount their experiences to these individuals or groups further ordered their lives and their daily activities and made possible many future opportunities for advocacy, awareness, the formation of new relationships, and activism, as well as served to define how parents experience autism in their lives, and even to impact the way that the autism label is experienced by others.
Chapter 1: Participants and Setting

When Leslie Met Sarah

Leslie became a member of APSG in 2009. About six months prior to the beginning of her membership, she met Sarah in a pediatrician’s office in Queens, NY. Sarah’s daughter Ava, who was diagnosed with autism a few years prior, was “having a meltdown”. When autism parents talk about “meltdowns”, they are referring to loud, violent, inconsolable crying fits that can often start with little warning. Unlike a temper tantrum that most people have witnessed thrown by a small child who wants a toy she can’t have or when she doesn’t want to leave a party, when children diagnosed with autism have meltdowns, they are often a result of a new environmental stimuli, such as a high pitched noise that no one else can hear, the touch of a texture that their sensory system feels invaded by, or the result of an internal manifestation that they cannot communicate about, such as a headache or a stomach ache.

On this particular day, neither Sarah nor Leslie remembers what prompted the meltdown, but I'm told it was a bad one. Ava was dropping to the floor, screaming and pulling Sarah's arms in various directions. As Ava scrambled to hide under the table, her mother wrestled to pull her back into her chair, into composure. Leslie stared at Sarah as this struggle ensued, not because she thought Sarah was a bad mother or Ava was a bizarre child, but because she had only moments before read the inscription on the canvas bag hung from Sarah's small, tensed shoulder: "I love someone with Autism." Leslie wanted desperately to talk to Sarah, to connect with her and to tell her that she, too, knew what it felt like to experience an autism meltdown in the middle of a busy doctor's office. But instead, she just stared - transfixed by the relatedness of the situation which she never would have dreamed of before the diagnosis, yet now clung to desperately.
Finally, Sarah looked up and met Leslie's gaze. She now describes her awareness of the glare that she shot toward Leslie, a "Go ahead and say something about my child. Just see what happens to you!" kind of glare. Leslie moved toward her as Ava calmed down, wishing nothing more than to be this woman's best friend, to share all of her experiences with her, and she commented on Sarah's bag. Leslie said, "I have a son with autism too, he was diagnosed only a few weeks ago". A feeling of calmness came over Sarah. Leslie was not there to judge her, to criticize her, to "help" her by telling her how to quiet her daughter. Leslie was looking because Leslie understood. She related to the experience Sarah was enduring. She related to the shrieks, the tantrums, and the stares from strangers.

Sarah then reached into her bag and pulled out a business card for APSG, handing it to Leslie. She explained that she had founded a support group for parents like them and told Leslie about the purpose of the group. Then she welcomed her to join. Leslie went home that day and cried, thankful that she had found someone to relate to, and terrified that this made her experiences ever more real. Trying to process all that the diagnosis meant to her and her family, Leslie did not join the group right away. Instead, it was another several months before she saw Sarah a second time, again in the pediatrician’s office. Sarah and Leslie exchanged greetings again, and Sarah, aware that Leslie had not joined the group, and aware of all the possible reasons for not joining, again gave Leslie her business card. And this time, Leslie was ready to join.

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In this chapter I focus on individuals like Leslie. I introduce several of the autism parents with whom I became acquainted during the course of the study and discuss how they differ from other autism parents locally, as well as how they differ within the support group through which
they are all connected. I pay close attention to parents as individuals and parents as members of a group, APSG. The individual parents in my study may have had fundamentally different experiences if they were not members of APSG. Likewise, APSG would likely operate in a different way if a particular individual, Sarah, had not founded it, or if the individual members of the group were replaced with different parents. Throughout this dissertation, this situatedness and interactional dynamic remains a constant focus. The parents all have different ways of understanding their lives with autism. These understandings inform and are informed by their relationship with the support group. How they joined, why they joined, how they participate, and where they participate greatly informs their relationship with autism.

That being said, I also describe the various settings of the study, which are largely bound geographically to Queens, a borough of New York City. These are the settings where parents met for workshops, playdates, and other social gatherings. If these meetings were organized in Botswana, Kentucky, or even a different New York City borough, the experiences had at these gatherings may have been fundamentally different. I begin by discussing how I came to study parents of children diagnosed with autism living in New York City, and demonstrate the great difference between various parent support groups within a 10-mile radius. I then explain on which group I chose to focus my dissertation research, and why. Then, I explain the particular settings in which this group met to share ideas and resources, provide each other with support, and discuss their lives with autism. The opportunities, constraints, limits, and possibilities of some autism parents meeting in various locations in a particular New York City borough, during a particular period of time (April 2010- September 2011, when I conducted this study) are unique to these people and these settings, and in order to adequately present their stories, these particularities must be identified, recognized, and discussed. I set out to do that in this chapter.
Participant Selection - Autism Parents in New York City Who Attend a Support Group

After deciding to focus on parents of children diagnosed with autism spectrum disorders, I next had to decide where to study these individuals. Based on my first ethnographic study about autism in schools in Virginia, I was invited to work on a research team with my academic advisor, Herve Varenne, to investigate moments of everyday education in inner city populations. The other members of the research team were also conducting their research in the New York City area, so I found it fitting for my pilot study (which later led to this dissertation) to also focus on individuals living in the New York area.

I initially wanted to meet parents living in New York City who had received an autism diagnosis for a child within the last six months. After weeks of attempting to find participants through various networks, I began to recognize that my efforts were futile. I then attended a conference at Teachers College, where I learned from one of the parent presenters about the hectic activity, frustration, and anxiety that often accompany the first few months after diagnosis. I realized that I might have been having such great difficulty finding parents who had been recently diagnosed, because those parents were not ready to be found.

From there, I decided to investigate parent support groups in the New York area. I began by looking online first, having read a report about an increase in parent online communities in the past few years, developed and maintained by many stay-at-home mothers. In a keyword query for support or resource groups for parents of children with autism (often including other disabilities) I created in 2012, the Google search returned over 10 groups within a 20-mile radius in the New York City area. This list did not include the many groups that were created for adults diagnosed with autism living in the area, or for many other groups for parents of children with disabilities whose online descriptions did not specifically include autism. Many of these groups also have online activity (message boards, chat functions, online personae) so I
decided this would be a great way to meet parents who have children with autism and who are willing to talk to others about their experiences. My goal of the pilot study was to investigate how parents get access to information about autism spectrum disorders before, during, and after an official diagnosis is rendered. I was particularly interested in how this learning takes place in social spaces such as parent support groups, online communities, and through family and community activities. Through online searches, I found five groups with online personae who also met in person for a number of different activities. As the majority of the members in these groups identified as autism parents, I decided this would be a great way to learn about parents' access to resources and supports concerning autism.

While I attended five groups in total throughout the pilot study, only three became groups that I frequented. The other two did not meet often or had a lapse in organization that caused the groups' energy to fizzle during the time that I was conducting the study. The three groups that I did focus on, however, are comprised of members who have been able to create a schedule and group delegation strategy that has allowed them to maintain their group or even grow it, over the last 18 months.

The first group is a local chapter of a national organization and meets once per month for a support session, once per month for a presentation with a biomedical professional or other medical expert, and a couple of times per month for family activities. This group's orientation toward autism focuses on treating or curing autism through medical interventions; many parents in this group cite vaccines as the cause of their child's autism. Many of Group One's parents would arrive in well put-together business attire, and would snack on bottled water and gluten free, organic snacks before the meeting. All of the meetings that I attended with this group were held in the gymnasium of a private school for children with autism, located in midtown
Manhattan. This group overall has a biomedical view of autism and relies on the expertise of
doctors of alternative medicine rather than more mainstream approaches to intervention.

The second group was organized several years ago by a pediatric neurologist who wanted
to bring parents that he met through his practice together to learn about autism and how to
support their children. These parents meet once a month at a hospital in the Bronx and have little
contact with one another outside of the meetings, although they live in the same neighborhoods.
The neurologist and his staff coordinate the meetings, select the speakers, and provide the
meeting space inside the hospital. Group Two's parents live in low-income neighborhoods and
many require a Spanish-speaking interpreter for the meetings. The neurologist often spoke of
having to feed the parents during meetings and cited them as a "low income group" with little
access to autism education.

The mother of a little girl with autism, frustrated by the lack of social support in her
neighborhood in Queens, NY founded Group Three. This group now has over 25 families listed
as members. Group Three met in person often (in addition to corresponding online) – usually in
each others' homes - on weekday mornings to discuss various topics of interest regarding autism
(behavior management, Medicaid, toileting, etc.). Group Three also coordinates weekend
workshops during which time members invite educators and specialists to speak about particular
topics that members would like to know more about. They also coordinate weekend and holiday
gatherings to which members bring their families together to have fun and try new activities.
The parents in Group Three identify with a great variety of cultural backgrounds, have diverse
schooling experiences, and represent a large income range, the average of which suggests middle
class New Yorkers.
All of the parents in the study had access to different kinds of information about autism because of the people and materials they interacted with. They recognized, employed, manipulated, and disregarded information as they felt it applied to their children and their personal lives. For example, parents who followed a more biomedical model may have been more interested in learning about diets and cleansing therapies, while parents who did not share that approach may have no use in a recommendation for a therapist specializing in those treatments. Seeing that there was such diversity in the supports, services, and resources that parents found helpful across New York City, yet knowing that all of these parents strongly identified as autism parents, and made it clear that being an autism parent was a distinct lifestyle, I became further interested in exactly what this lifestyle entails. Parents talked about "adopting an autism lifestyle", "becoming autism warriors", "finding a new normal." I wanted to know what these sayings meant and how they became almost daily mantras for some autism parents. This interest brought me to the focus of my dissertation project.

**Participant Selection - Autism Parents Who are Members of Autism Parent Support Group (APSG)**

Based on my findings from the pilot study, I chose to further investigate the parents who are members of Group Three, Autism Parent Support Group (APSG). I chose this group for a methodological and theoretical reason that has since become ever more clear to me. The members of APSG are parents who are vocal about their experiences and want to share them with others for purposes of education, advocacy, and awareness. The first group invited me to attend all of the family activities and the evening professional presentations but would not allow me to attend the monthly support groups because I do not have a child with autism. The leaders of this group told me that the topics discussed during the support meetings were too private and sensitive to be discussed with those outside of the experience. Group Two was created, directed,
and maintained by a professional. While parents were encouraged to share their stories, to ask questions, and to get to know each other, the themes of the meetings were always decided by professionals, led by professionals, and shaped by professional influence. Contrasting Group Two to APSG, APSG was started and maintained by parents of children with autism. They have a very fundamentally different foundation upon which they made decisions about what topics to discuss, which speakers to invite, and what activities to organize. For APSG, autism parents are the ultimate decision makers for the group and have as part of their mission, a willingness and determination to teach others, like myself, about their experiences with autism.

Situated Learning

Because my research questions focus on how parents learn and live their autism lifestyles, and since I was researching the activities of parents within a group setting, Lave and Wenger's theory of situated learning had a particular resonance with my work, both theoretically and methodologically (1991). Theoretically, Lave and Wenger talk about knowledge being co-constructed through a social process. They reject other theories that view learning simply as the transmission of abstract or decontextualized knowledge, and instead put great emphasis on the specific context in which the process of learning is embedded. Using this theory, I consider throughout this ethnography, not what knowledge lies within the heads of parents, but how parents engage in social practices that themselves are educative moments.

For example, one parent may tell another about a great experience with a particular doctor. A third parent may agree with this piece of advice, which brings a fourth member into the discussion and encourages her to ask about where the doctor is located and how she was helpful. This may then lead to a further discussion about which insurance companies cover her services and when is the best time to schedule an appointment with her. A parent may pull out a
cell phone and look up the doctor's email address, then forwarding the information to other members of the group. As parents work together to learn about these important matters, and subsequently teach about these matters to others, they engage in multiple learning processes.

Methodologically, I look to APSG as both a group that functions as a site where parents can meet to talk to one another, and also as a place where they co-construct their understandings of autism, and what it means to engage in the activities in their lives. As new parents bring new topics of discussion into the group, the group itself changes as well. The individual parents rely on their relationship with the other members in the group to share, exchange, and manipulate knowledge, but the group itself also relies on the individuals' activities within it. In this way, I was not able to focus my unit of analysis on "parents" solely, because they are inevitably shaped and molded by their relationship to the group. Conversely, one may suggest that the whole is greater than the sum of its parts, and thus the unit of analysis should be the group, but this may be difficult to attest to in the case of social activity, when the parts are constantly in flux, and there is always the possibility of more or less parts at any one moment. Therefore, I rely on a shifting approach that sometimes zooms in on particular parents, and at other times zooms out to look at the group as a unit, always aware that the two cannot be untangled.

**History and Activities of APSG**

APSG consisted of approximately 20 families throughout my 18 months with them. I use the term approximately because some families moved in and out of the group during my time with them. Overall, there were about 9 families that comprised the core of the group. Four of the nine main parents - Sarah, Julia, Kate, and Leslie, made up the leadership team. The Party Planning Committee, which was established in 2010, was composed of four mothers - Margaret, Bala, Meghan, and Jessica. Finally, the ninth core member, Richard, was a member of the
Fundraising Committee. Patricia was the second member of this committee, but because of her busy work schedule and other personal obligations, she was less involved than Richard. The parents from these families were present at most of the activities I attended, frequently posted on the online forum, and even held designated positions in the group. These were the families that I got to know best.

Sarah established APSG in 2006. Sarah, a Filipino woman in her mid 30s, lived in a house in Queens with her two elderly parents and her nine year old daughter who is diagnosed with autism. Her two teenaged sons both live with their fathers, but visit her often. During my study she began to pursue an online master’s degree and ran A.P.S.G, as well as worked for local branches of another organization created for families of children with disabilities. In 2006, her daughter had recently been diagnosed with autism and she did not know any other parents who had children with disabilities. She searched online for local support groups, but all of them were too far from her home. After learning more about autism, Sarah was convinced that there must be other parents living within the same NYC borough raising children with autism. She imagined that they were facing the same feelings of isolation from which she was suffering. She decided to use an online platform to make a digital group where parents could connect with one another, share resources and information, and organize get-togethers or playdates face-to-face.

The group started off very small. Sarah met another mother (who had moved away by the time I began fieldwork) and they began talking at a coffee house and other local places on weekday mornings. Soon after the first few in-person meetings, Sarah met Julia. Julia is a Greek woman in her 40s who resides in Queens with her husband and two sons, the eldest of which is diagnosed with autism. Before his diagnosis, she worked as a hairdresser in Manhattan and now serves as the Vice President of APSG, and also works for the same disability
organization as Sarah. Her husband does construction and renovation on local NYC building projects. Sarah's daughter and Julia's son were in the same preschool class together. The mothers knew of each other and had occasionally said hello when they picked their children up from school, but had never had more than a brief interaction. One day, Julia saw Sarah's daughter wearing an identification bracelet. Wanting to buy one for her son, because she was always concerned about him wandering off and not being able to communicate if he got lost, she asked the teacher to connect her with Sarah, so that she could learn more about where to purchase the bracelet.

The parents spoke on the phone and after realizing that they both had children diagnosed with autism, Sarah invited Julia to join the online group. Julia was so happy to meet another mother of a child with autism and eagerly joined. Julia had been (and continues to be) part of a parent support group at her son's school, but since it only met once per month, she felt that it was not enough for her. She wanted to see other parents more often, talk to them on the phone, arrange playdates, and have more immediate access to those going through similar experiences. Sarah and Julia began to work together to organize family activities for the parents and children who had joined their group. They became strong leaders in the group, taking on the roles of President and Vice President, and even created a terms of agreement document and set rules for participation.

The next leader to join was Kate. Kate resides with her husband and one young son diagnosed with autism. Both she and her husband work in Marketing and Sales respectively, in fact they first met at work, and live in an apartment in Queens. Her husband grew up in a nearby neighborhood and has family who live close to them. Kate first met Sarah, Julia, and some other mothers at a Starbucks cafe in 2008. She often recounts the fear and anxiety that she felt prior to
and during the meeting. She told the parents present her diagnosis story and began to cry. After sharing her story, she sat quietly amongst the others, listening to conversations about their children's unmanageable behaviors, difficulty with self-expression, self-stimulatory activity, and she pulled away from the discussion, so overwhelmed by what she was hearing.

Kate explains that after that initial meeting she went home and did not return to APSG until nearly one year later, during which time she "dealt with" her son's diagnosis and struggled through the process of accessing and acquiring services and supports for him. When Kate finally returned to APSG, Sarah and Julia said she seemed like a different person. She was ready to participate, seemed strong and confident, and wanted to get involved in the interworkings of the group. She then took on an organizational role as the Treasurer. A few months later, Leslie, the member whose entrance into the group was described in this chapter’s introduction, joined and soon became the group’s secretary. Leslie is a Puerto Rican woman in her 30s, who lives with her husband and four children in an apartment in Queens. Leslie is a stay at home mom and her husband works in the bail enforcement industry. After she became a member, she was eager to join the leadership team and quickly took on responsibilities related to meeting announcement and online activism.

Since its establishment in 2006, APSG has gone through many changes. Parents have come and gone, sometimes realizing that they could not dedicate enough time to the group, other times having to move away for professional or personal reasons. Since Leslie (described in the opening) became the secretary a few years ago, the leadership team had stayed constant, but even so, sometimes there were disagreements among the four mothers that required a reworking of delegated duties, or discussions about how to divide up the work of running the organization.
There was also a major change to the group after receiving official non-profit, 501(c)(3) status in the fall of 2010. Filing for this status was a long and arduous process and Sarah recounts having to submit and resubmit paperwork many times, interact with various bureaucracies, and make tons of phone calls. When the request was finally approved, however, the group was able to accept donations and provide donors with a tax break in return.

Additionally, the status allows APSG to organize big fundraisers and apply for federal grants for non-profit organizations. While this organizational change certainly brought about benefits for the group, it also created new responsibilities, largely concerned with the documentation of financial transactions, in case of an audit. The involvement of some parents (and not others) in the process of filing for this status came to further highlight the difference in degree of participation in the group. Those who I refer to as "core" throughout my description of the group had a hand, either physically or emotionally, in getting the status request approved. Those who played more peripheral roles in the group did not participate in this process.

The heterogeneity of the group is not only evident in the participation stratification I describe above. The backgrounds and experiences of all of the members are also very diverse. The members of APSG nearly all live in the same NYC borough (one lived in another nearby borough through the study, and another moved to that same borough near the end of my fieldwork), and all have children diagnosed with autism, but otherwise represent a very diverse group of people. This New York City borough itself is very diverse, a point that was demonstrated to me when I rode through several neighborhoods in a car with Julia one day. She explained to me that the neighborhood we were driving through is home to the family of a world famous entrepreneur. Only minutes later, crossing a highway overpass, she told me that we were now driving through "the hood". There is a great range of wealth and of ethnic identity in this
area and this is also represented in my participant population. Some parents are married, while others are divorced. Some make $10,000 per year, while others make $100,000. Some identify as Black while others identify as Puerto Rican, Pacific Islander, or White, or various other ethnic or racial categories. Some parents graduated with a liberal arts degree, while others pursued trade school. Some parents live alone with their child, while others live with extended family members.

**Mothers**

The majority of the APSG parent participants whom I got to know best were mothers. This finding is similar to other studies that have shown higher levels of involvement from mothers of children with autism than fathers (Benson, Karlof, and Siperstein 2008, Konstantareas and Homatidis 1992). Traditionally filling caretaker roles, mothers are most often the parents who are involved in the educational activities of their children as well as in the special healthcare activities of children with special needs (Valle 2009). Mothers were more often present at the activities than were fathers and had closer relationships with one another. Many of the mothers had become close friends since joining the group and often called each other on the phone, posted on each other’s Facebook walls, and set up times to have coffee or breakfast together. The fathers organized two “fathers nights” during my fieldwork, would sometimes text each other about upcoming family events, and sometimes commented on each other’s Facebook walls, but were not nearly as close as the mothers. If we were attending a "family activity" mothers would often come with their children regardless of whether their husbands or significant others attended. They would also sometimes talk about the lack of the father's involvement. Mothers often discussed their way of understanding autism as very different from fathers’. A few of the mothers worked part time (Margaret from her home doing
some web design projects, Sarah and Julia working for a grant funded organization that supported the work of APSG), but most were stay-at-home mothers, and dedicated all of their time to caring for their children and managing household responsibilities. For some mothers, they felt their involvement in childcare was different from their husbands’ or partners’ because they spent more time with the children while fathers were at work. For other mothers, they believed that the fathers had not accepted autism the same way they had. Finally, for many mothers, a unique connection to their children and to autism, which they contrasted to that of the fathers, was the pregnancy with the child with autism. All but one mother in the study is a biological mother of a child with autism, so mothers often described a connection that was developed during pregnancy, and an accompanying guilt about their possible physical involvement in their child's diagnosis. Mothers said that fathers could never understand this guilt, and never feel the same way about autism that they did.

**Fathers**

For some big parties (Halloween, Christmas, etc.), more fathers would attend, compared to the more frequent weekday meetings. Fathers often came for fun activities and for some weekend meetings, so during these times I was able to get to know them as well. Of the four fathers who regularly attended events, I had several longer interactions with one particular father, Richard. He was going through a divorce with his wife and saw his son on weekends, so he was always excited to bring his son to the group’s weekend activities. He was the most involved man in the group and made comments about his ex-wife's lack of involvement in the same way that some of the mothers did about their husbands. In this group, Richard seemed to be an exception to the rule, but there may be many other autism fathers like him locally or nationally, who were simply not represented in this group. In addition to the lower frequency of activity participation,
another possible reason for getting to know fewer fathers than mothers may be that I am a young, single female. The only father I got to know very well and was able to speak to for prolonged periods, Richard, attended meetings without his wife. The other men in the group were all husbands of the mothers I was getting to know better, and I was wary of the amount of attention I paid to the husbands when the wives were not present, because I did not want to inadvertently overstep any marital boundaries. My interaction with the husbands may have been very different had I been a man or even an older woman. Nonetheless, the roles of fathers and husbands were clearly present in the lives of the families I studied, whether these roles be filled through participation in APSG activities, or as referenced by the mothers in attendance (i.e., my husband works during the day but always tucks my son in at night, or Braden and Daddy love riding their bikes to the library together on Sunday mornings).

**Settings**

New York City is divided into five boroughs. All are accessible by public transportation and all have residential, business, and retail/restaurant areas. The bulk of my fieldwork was conducted in one of these boroughs, Queens, which is considered the most ethnically diverse urban area in the world. According to the US Census Bureau, this borough has a population of over 2.2 million, 46% of whom are foreign-born, representing over 100 different nations and speaking over 138 different languages (2012). Queens is the largest borough in the NYC area, the second largest in population, and is situated as the easternmost borough. The research territory itself was vast and the fieldwork sites often far from one another. The settings where I met with the parents varied each time we met. In some ways, this made data collection tricky because I had to constantly navigate new terrain, often going to parts of the city I was unfamiliar with, waiting for tardy buses or trains, and commuting alone at night. In other ways, it allowed
me to become familiar with a variety of neighborhoods in the borough and to visit participants' houses, see where they have coffee or go shopping, and attend activities in parks, playgrounds, public libraries, and schools across the borough. I always commuted to the meetings and gatherings by subway or bus, but was then often offered a ride to the subway from the meetings by one of the parents. During these times, I got to know parents better, individually.

One of the places I visited most was Julia's home. She often offered her house for the mid-day meetings during which parents – almost always the mothers only - gathered for about two hours to discuss a topic of discussion such as toileting, behavior, sleep issues, etc. The parents would all bring a breakfast snack to share. Then we would have coffee and snacks and talk about the topic of the day. The group also met at other parents’ houses for this same type of meeting, but Julia's place was centrally located, so it was used most often. We also held all of the yardsales at Julia's house. She has a two-bedroom apartment on the first floor of a two-story building located near a busy road. She also has access to a 300 square foot driveway, so all of the members would drive their donated items and display tables to Julia's house and set up for the sale there. Because she also has a fenced and gated backyard about the same size, with patio furniture, it was the perfect place for people to sit and chat while they were taking turns helping with the sale.

Another location we frequented as a group was a local library. Several of the borough libraries have meeting spaces they rent out to groups, clubs, and organizations. For example, a women's knitting group often meet in the room later in the afternoons, after our group was finished. We would usually meet for two to three hours at a time. Most parents in the group own cars, but a few do not, so some would carpool to and from the library. While in the small, freezing library space (we soon learned to always bring an extra sweater), we often set up the
elementary-classroom-looking room in different configurations. Sometimes we put the chairs in a circle, when the purpose of the meeting was mostly sharing, other times we sat at tables of 4 or 6, and still other times, there were longer tables that we put into rows where a presentation was being held. The room also houses various boxes of knitting materials, children's books, arts and craft supplies, and other groups' materials. We did not ever touch any of these items, but did sometimes use the old wooden chalkboard on wheels during presentations. During one presentation, a presenter brought a laptop and projector, the parents enjoyed this so much that APSG is now currently trying to raise funds to buy these two pieces of equipment for future use at the library meetings.

Aside from these physical locations that I commuted to and from, I also conducted fieldwork through virtual sites. The methodology of this work will be discussed in more detail in the next chapter, but it does present an interesting discussion about setting. By conducting technology-based ethnography I followed the activities of my participants as they navigated through various spaces and locations near their homes. I found that adopting a flexible methodological approach, which, like the people it studies, bounces around from place to place and from time to time allowed me to "plug in" to multiple events, with multiple people, gaining multiple perspectives about their varied experiences. In this way, my fieldwork sites also included Facebook, the APSG online forum, Twitter, and by extension, all of the technologies that parents used to connect with these social networking tools. Given the fast-paced energy of urban living, this methodological approach gave me an opportunity to both track and mirror the often hectic experience of everyday life in a city that surrounds autism parents in NYC.

Conclusion
The mothers and fathers I met, had lunch with, went to the park with, screamed on rollercoaster rides with, laughed with, cried with, and walked proudly with are some of the most courageous and inspiring people I have ever known. As you can see in Chart 1, parents came from different family backgrounds – some were raised in New York, while others moved her for work, family, or love. They identify with a variety of different racial and ethnic backgrounds. They each had different educational and career paths, and each may have different retirement plans. Despite all this diversity what has brought them together – and keeps them together - is the need for a tool, one that is crucial to production of each parents’ life; and these tools are different for each parent, and are even different for the same parent, depending on the time in his or her life, or in his or her child’s life. For some it was a tool to calm a tantrum. For others it was a tool to get through a bad day, or to make their voice be heard. For still others it was a tool that allowed them to celebrate successes that few others would understand.

Parents were not part of this group only because they have a children diagnosed with autism, and this was evident as some parents attended a session or two, but never returned. Nor did geography account fully for participation, as some parents commuted from outside of the borough where meetings were held. The parents who became members of this group chose to live their lives – the good days and the bad days – as part of a group of autism parents. They stand strong in their identification with the group and call themselves a family.

The reader will notice that even if the stories throughout this ethnography are about one parent, he or she will often reference other parents or the group as a source of support, strength, or understanding. These parents’ lives and the experiences that fill them do not exist in isolation, but rather are in constant dialog and negotiation with the group and its members. Furthermore, those not in the group, and therefore often not “in the know” are also referenced by parents and
serve as additional, often very powerful, social actors who help parents to organize the activities of their daily lives.

When I present parents’ stories throughout the rest of the text, I attempt to do so with careful respect to the relationships and bonds, as well as boundaries, that the group creates and maintains, but recognize that the group can be separated from the parents as individuals no more than the parents can be separated from discussions of the group. At this point in their lives, with their activities so entwined, the participants (parents, APSG, children diagnosed with autism, siblings, family, friends), the settings (parents’ homes, the local library, the subway and cars that transport parents and children) and activities (playing at the water park, crying over an autism movie, educating a passerby, bandaging a wounded knee) are all so much a part of parents’ experiences, that I cannot present them as isolated units, but instead must interweave them as the building blocks with which parents produce and reproduce their lives.
Chart 1: Participant Chart

* Age range of children over the 18 months of my study
** Second child in the process of being evaluated for an autism diagnosis during my study
Note: Race/Ethnicity defined by participants in open-ended questionnaire

<table>
<thead>
<tr>
<th>Name</th>
<th>Parenthood Status</th>
<th>Race/Ethnicity</th>
<th>Age</th>
<th>Relationship Status</th>
<th># of Children</th>
<th>Children with Autism</th>
<th>Child Gender</th>
<th>Child Age*</th>
<th>Highest Schooling</th>
<th>Household Income</th>
<th>Profession</th>
<th>Housing Status</th>
<th>Time in NY</th>
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<tr>
<td>Sarah</td>
<td>Mother</td>
<td>Pacific Islander</td>
<td>35</td>
<td>Never Married</td>
<td>3</td>
<td>1</td>
<td>Female</td>
<td>8 to 9</td>
<td>Bachelor's Degree</td>
<td>15-25,000</td>
<td>Nonprofit/Human Services</td>
<td>Rent</td>
<td>7 years</td>
</tr>
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<td>Julia</td>
<td>Mother</td>
<td>White</td>
<td>46</td>
<td>Married</td>
<td>2</td>
<td>1</td>
<td>Male</td>
<td>8 to 9</td>
<td>Vocational/Trade School</td>
<td>50-75,000</td>
<td>Outreach Specialist</td>
<td>Rent</td>
<td>17 years</td>
</tr>
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<td>White</td>
<td>NG</td>
<td>Married</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Vocational/Trade School</td>
<td>50-75,000</td>
<td>Painter</td>
<td>Rent</td>
<td>17 years</td>
</tr>
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<td>Married</td>
<td>4</td>
<td>1</td>
<td>Male</td>
<td>4 to 5</td>
<td>2 years college High School Diploma</td>
<td>25-35,000</td>
<td>Secretary</td>
<td>Rent</td>
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<td>Married</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>25-35,000</td>
<td>Bounty Hunter</td>
<td>Rent</td>
<td>8 years</td>
<td></td>
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<td>Male</td>
<td>7 to 8</td>
<td>Bachelor's Degree NG</td>
<td>25-35,000</td>
<td>Print Production</td>
<td>Own</td>
<td>NG</td>
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<td>NG</td>
<td>Married</td>
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<td>Married</td>
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<td>Male</td>
<td>6 to 7</td>
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<td>1</td>
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<tr>
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<td>1</td>
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<td>5 to 6</td>
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<td>2</td>
<td>1**</td>
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<td>1</td>
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<td>5 to 6</td>
<td>2 years college</td>
<td>75-100,00</td>
<td>Homemaker</td>
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<tr>
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<td>NG</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2 years college</td>
<td>75-100,00</td>
<td>Production Manager</td>
<td>Own</td>
<td>9 years</td>
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Chart 1: Participant Chart (Continued)

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<th></th>
<th>Name</th>
<th>Relationship</th>
<th>Race</th>
<th>Age</th>
<th>Marital Status</th>
<th>Gender</th>
<th>Income Category</th>
<th>Education Level</th>
<th>Day Habilitation Specialist</th>
<th>Friends/Relatives</th>
<th>Other Information</th>
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<td>White</td>
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<td>Male</td>
<td>5 to 6</td>
<td>2 years college</td>
<td>Court Reporter</td>
<td>Rent</td>
<td>10 years</td>
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</tbody>
</table>

NG = Not Given. Parents were provided with an online survey and were asked to answer demographics questions, but were given the option to decline to answer any question.
Chapter 2: Methodology

This study of the experiences of parents of children diagnosed with autism takes an ethnographic form for several reasons. First, the descriptive quality of ethnography and its ability to present the words and ideas of study participants is critical for creating a full, rich picture of parents' experiences. The methodology allows an in-depth look into parents' daily activities and experiences and places a high value on parents' reflections on those experiences. Second, many other anthropologists have successfully employed this methodology to study various aspects of autism, such as autistic sociality (Ochs and Solomon 2010), parent-child interactions (Sirota 2010, Sterponi and Fasulo 2010), animal-child interactions (Solomon 2010), at-home routines (Wilkinson 2009), the experiences of adults diagnosed with autism (Bagatell), and autobiographical parent experiences (Eddings Prince 2010). Leonard also used ethnography to document the experience of four families of children diagnosed with autism in the 1980s, looking at communication strategies within the family, the creation and revision of parent agendas, and how the family projects particular images to the public. Finally, by focusing on a small group of individuals and the activities they engage in, ethnography aligns itself well with the proposed focus for educational and healthcare initiatives when working with individuals diagnosed with autism. That is, ethnography does not boast a focus on generalization of findings, but rather details individual experiences. In special education there are Individualized Education Plans, in social science research there are ethnographies, and these two are well married.

This chapter is divided into two main sections: data collection strategies and data analysis strategies. I begin first with an introduction to the timeline used throughout the study, which includes collection and analysis of the pilot study, followed by a discussion of trustworthiness. I
then describe observation, interview, and Internet data collection strategies, citing limitations of each strategy. These strategies include when, where, and how data was collected through each of these methods. Then I move to a discussion of how the data was handled and analyzed. These strategies include a discussion of data organization and thematic indexing. Finally, I further elaborate of the discussion of my reflexivity from the introduction and consider ways that my perspective and background may impact the data I collected and analyzed.

**Timeline**

Entrance into the field began "officially" with my initiation as a member of APSG's online community. I wrote to the organizer of the site on April 14, 2010 and explained: "My name is Juliette. I am a PhD student at Teachers College, Columbia University. I am interested in studying young children with autism and their families. I would like to meet families who may be interested in this unique opportunity." Later that day I was added as an official member and received a message through the online system, welcoming me to the group. Two weeks later I attended my first APSG meeting, on May 1, 2010. The members of the group were very welcoming and asked me to come to their future meetings.

From May 1, 2010 through August 7, 2010 I met with members of APSG on a bi-weekly basis, communicated with them via email and Facebook frequently, and was involved in discussions through their online forum. This data collection period was part of my pilot study and also included visiting the other two groups I discussed in the participants section. From August 8, 2010 through the end of May, 2011 my fieldwork with APSG was less involved, as my pilot study had officially ended. I had not fully removed myself from the field however, and still communicated with parents through Facebook and the online forum, spoke with some of them on the phone, and attended meetings and events three times per month, on average.
On June 4, 2011 I began intensive fieldwork again, this time focusing my dissertation project on APSG solely. Through the end of September, 2011 I met with the group and was involved in meetings, family activities, and fundraisers. These activities were held mostly on weekday mornings and weekend afternoons. Throughout this time I was also engaged in Facebook communication and discussions in the new online forum created by the group in the beginning of August. In the middle of August the group also set up a Twitter account, which provided an additional medium by which I could keep track of the members. In mid July I began an interview schedule with 11 parents who agreed to speak with me. I met with them in their homes or at local restaurants when they were available to speak without their children. Most of these interviews were conducted on weekday mornings and lasted an average of two hours. Five interviews were conducted in the second half of July, four in August, and two in September.

During this month I was also spending time organizing and cleaning up my fieldnotes, familiarizing myself with the qualitative data analysis software, NVivo, and began transcribing participant interviews as I recorded them. Beginning September 28, 2011 I left the field and officially began data analysis. I dedicated all of my time to transcribing the 11 interviews, inputting fieldnotes and interview transcriptions into NVivo, and indexing common themes. Thanks to a rigorous record keeping system developed early on in my pilot study, all of my fieldnotes were indexed after they were each typed. This allowed me to have many of the themes already identified prior to official engagement with data analysis, speeding up the analysis timeline. Following a two-week period of data analysis, outlining began, soon followed by a drafting process.

Trustworthiness
This study employs the four issues of trustworthiness as described by Lincoln and Guba (Lincoln and Guba 1985): credibility, transferability, dependability, and confirmability. To demonstrate credibility, I utilize both an early familiarity with the site (as developed through the 2010 pilot project) and with the context (as a special education teacher trained in the instruction of individuals with autism). Furthermore, I have chosen to employ a reflexive commentary throughout the development and presentation of the study that demonstrates a credible conceptual interpretation of my findings. This reflexive commentary is evident in my initial description of my background, qualifications, and experience as a special education teacher, as well as an autism researcher (found in the introduction), and also in my discussion of the variety of experiences individuals may have with the same concept, in this case, autism. The transferability of this study is established by first acknowledging that parental experiences with autism are varied, not simply across geographic or socioeconomic clusters, but even within the same group. Second, transferability is suggested as this study proposes that the variance of experience and the response to and communication about such experience is an integral part of the human condition - one that can be found not only in groups of autism parents, but in other self-identified groups as well. However, one limitation of the external validity of this study may be that the social support of the population I am studying is very strong, therefore their experience may not extend to parents of autistic children who do not have the same social network, or who have a different perspective on their child’s autism (e.g. that it is a disease).

The dependability of this study is demonstrated by a use of overlapping methods - participant observation, interviews, and Internet posts - as well as by the ability to access the communicated experiences of autism parents through a variety of new social media. Facebook, blogs, YouTube videos, live streaming, and other modes of everyday technological
communication are now readily available and present the communicated experiences of many autism parents who would have been confined to their own thoughts in their past, with few forums for discussion. This particular study began first with participant observation, recording how parents live their daily lives - trips to the grocery store, outings in the park - and then listened to how parents discuss these experiences with one another and with friends and family. Then the study moved into an interview process that asked parents to think about how they communicate their experiences with others. Throughout months of data collection, the process of noticing and remarking on experiences, communicating about them, and then thinking about this communication built on itself and gave substance to the theoretical framework that now privileges those experiences and the communication of those experiences through this ethnography. Finally, confirmability is demonstrated by a number of elements, the first being the admission of my beliefs and assumptions and an acknowledgment that these will undoubtedly impact the data I collect, analyze, and present. There is also present, a recognition of this study's shortcomings, which is provided in the discussion of the data collection and analysis strategies sections. Furthermore, an in-depth methodological description allows the reader to scrutinize my strategies and findings; this will be presented now.

**Data Collection Strategies**

*Participant observation strategy:* Participant observation with this participant population may look like anything from pouring juice for a child at a picnic to hanging decorations for a holiday party in an apartment building basement. I also sold old clothes and toys for a yard sale, organized to raise funds for the support group’s efforts in the community, attended an annual dinner where I was honored as a member of the group, and received advice about a “must-see” autism lecture. Participation in all of these activities won me a special place in the lives of the
parents I studied and allowed me to develop a casual rapport with them. To understand the daily experiences of parents caring for children with autism, my strategy required first that I observe and participate in these experiences in everyday settings. Watching parents interact with their children, with each other, and with other family members gave me a clear picture of what activities they engage in, what kinds of conversations they have, and what they consider important for getting through a day with their children. Further, participant observation gave me the opportunity to experience nasty looks from strangers who didn't understand why a child was tantrumming on the floor, or to better understand how a parent felt as she painstakingly prompted a child to overcome his frustration and master the fine motor manipulation needed to button a jacket. Participant observation provided a strategy for me to be able to live through all of these quotidian complexities alongside my research participants.

In order to collect rich ethnographic data about parents’ everyday experiences, I traveled to homes, parks, schools, etc. and watched parents and children interact. I also attended many parent-only group meetings that were usually held at a local library, and listened to parents talk to one another about their experiences. Listening to the parents speak with each other during the support meetings, or watching them interact during a workshop provided me with an opportunity to see what they are learning from one another and what topics they find valid and relevant. I was also able to see how parents interacted with professionals - educators, administrators of various bureaucracies involved in autism services, autism specialists, financial planners, etc. - and how parents presented their experiences to these professionals.

In order to collect these data, I recorded fieldnotes by documenting information about each particular setting, participants involved, and activities performed on any given day. I documented orienting descriptions of each event that occurred, using a specific, detailed,
chronological description of people, places, and events, at various moments in the field. For example, sometimes I would take notes in my notebook at a meeting because parents were also taking notes about resources or services that they were learning about that day. Other times, I was at the playground or in a bowling alley with families and it would seem out of place to write fieldnotes during these activities, so I waited until I got on the subway to go home, or sometimes I went to the restroom and made a quick jotting.

For further documentation, I also used a video camera to record activities when appropriate, and took pictures at events or downloaded them from the group’s website after the event was over. These data may be used for future presentations about my fieldwork, but were also shared with the group on their website. The parents often took pictures of activities we engaged in, whether this was at an adults-only dinner, or at the beach with many children. Like the parents, I always had my camera with me, and parents would often encourage me to upload my pictures on the group's website, just as they did. I used a video camera to tape some of the workshops that the group held. Often, there were some parents who could not attend a workshop because of lack of child care, so after I videotaped the session, I would offer to give it to the group's leader so that she could post it on the website and make it available to all of the group members.

Additionally, I collected and filed handouts and other materials from information sessions and events. Especially during parent-only workshops that focused on discussions about legal or medical paperwork or filling processes, there was an abundance of literature given out to attendees. All of the parents kept the packets and brochures for their personal use, and I kept mine as data for my dissertation files. Other materials of importance that I collected included brochures made by APSG to represent their group's mission, ticket stubs and entrance receipts
for a variety of activities and events I attended with parents, and a syllabus from a university course for special education teachers-in-training that I attended because two of the parents in my study served as special guests in some course discussions.

There are some immediate limitations to participant observation that should be addressed. First, in building such a rapport with a group of people - spending time with them in their daily activities, visiting their homes, talking to them on the phone - the number of participants that a researcher can get to know so intimately is limited. Another facet of such prolonged engagement with a group in individuals, is the worry that the researcher hasn't engaged enough, or for long enough. When I left a park, home, or library meeting room, I often wondered what happened when I was not around - did parents' presentation of selves change during a bedtime routine I did not observe, or perhaps was there an important conversation that occurred before I arrived that I would not be told about. In trying to capture everyday interactions and events through participant observation, a researcher may always wonder what she may have missed, or what opportunity may be lost forever. While participant observation does indeed provide a study with rich, detailed information about the way people live their lives, it may never fully encompass all aspects of those lives, all shades or degrees, and for this reason is an excellent, but imperfect approach.

**Interview strategy:** It was only after several months of participant observation that I found it appropriate to begin interviews with my research participants. I felt that parents were doing something very brave and very inspirational by inviting me into their lives and participating willingly in my study. Because of these feelings, I decided to wait until nearly the end of my research to conduct interviews. After months of getting to know my participants, I felt that I had an adequate grasp of how to connect with them while asking them questions, and
that I had successfully developed an intimate rapport with them. During some interviews, participants even alluded to how well I understood their experiences. For example, during an interview with Sarah, the mother of nine-year-old Ava, she spoke about the difficulty her whole family is experiencing as they teach Ava to be independent in her daily activities.

Yeah, it's not consistent yet. So, until she can establish some kind of little bit more independence than you know, I could leave her like in a respite, even if it's three days a week or something after school. You know, can't do that now. So, you know, and, and the boys (her sons), they see it. They see it. You know, and they know how hard it is, and that's just how life is for us right now. But you know that, I don't have to tell you. You know that!

July 10, 2011

Another reason for deciding to conduct interviews after months of participant observation was that I thought my prior experience with the parents would more fully inform the interview questions. I recognized that time is limited during interviews, especially with busy mothers who want to participate in the interview when their children are absent, so I wanted to maximize my time by honing the focus of my questions prior to the interview. If I had begun conducting interviews at an earlier phase in my research, I may have asked parents only to tell me about their everyday experiences and what they feel about them. Months after meeting them and realizing the importance of the ways parents communicate about their experiences, I was able to create interview questions that interrogated this crucial research sub-question as well. I emailed nine parents and two professionals, each individually to request interviews with them, and explained that I would be willing to accommodate their schedules. Most participants chose to meet with me on weekdays mornings, although some chose to meet on weekday evenings after work instead. The interviews were held at various locations - some in parents' dining rooms, others at playgrounds, coffee shops, or diners near their homes.
Originally, my strategy was to conduct life histories with four parents. I wanted to learn about the parents' lives prior to beginning to care for their children with autism to see if parents came from similar backgrounds or had varied previous experiences. I chose to conduct life histories with the four women who hold the positions of President, Vice President, Treasurer, and Secretary, as they constitute the immediate core of the group, and they were four of the women with whom I became most familiar. Of those four parents, all are women. Two of them gave me detailed characterizations of events in their life prior to having a child with autism, even focusing on stories about their parents and grandparents. The other two gave me some background information about their adult lives prior to having a child with autism, but most of the conversation soon turned to discussions about current, everyday experiences with raising a child with autism, despite my efforts to redirect. For these interviews, I asked parents to share pictures with me of people, events, and places that have been important to their lives and used these as memory starters for our conversation. These interviews were unstructured and proceeded as informal conversations about their life stories, with me occasionally asking addition questions for clarification or to find out more about earlier in their lives.

I scheduled interviews with five other parents - four women and one man - with whom I discussed the research questions in Appendix A. All of these parents were "regulars" in the group, and each of them also held a position to help coordinate fundraising or event planning. I asked these parents to speak about their everyday experiences with autism, including their diagnosis stories, as well as to give insight into how they communicate their experiences to other people in their lives. I was specifically interested in hearing stories about communicating with family members, friends, educators, medical professionals, and strangers. I then asked parents to talk to me about negative moments they experienced due to autism's presence in their lives, as
well as positive experiences they had acquired through their journey as autism parents. Finally, I asked these parents to talk to me about their hopes for the future - for themselves, their children, and for the public's understanding of autism.

Additionally, I sought the perspective of two professionals who are also members of the group, and whom are very close to the parents in my study. One is a behavior specialist whom the group calls on often for workshops and trainings. He is also conducting a behavior study for his doctoral research, in which several of the families are participating. The second professional is both a student of autism studies and also a family member of one of the parents in my study. I was interested in their experiences working with parents of children with autism, and how they think about autism parents through a professional lens. I also took this opportunity to interview them so that I could compare their experiences with my personal perspective as a special education teacher, and so that I could better understand the potential practical implications of my study on the connection between schools and families of children with autism.

The data I collected by using this interview strategy may be considered limited, as the number of participants interviewed was 11. More in-depth research could be conducted if I interviewed only two or three participants as case studies, or a more comprehensive survey of data could be gathered if I interviewed 1,000 parents across New York City. For the purposes of this research however, the sample size 11 is not only sufficient, but also appropriate. With my research question I wanted to investigate the everyday experiences of children with autism, and how parents communicated those experiences. Interviewing the core eight participants in the group provided me with an appropriate overlap of my participant observation data and my interview data. I was able to better understand the parents' interactions and experiences as I had seen them through observation, and then to ask them about their reflections on those experiences.
In terms of group dynamics, it was also important that all of the core group members be invited to participate in the study, as they are all closely connected to each other as friends, and there could be an adverse effect on interpersonal relationships within the group if some were invited and others not. This may be contrasted to the more peripheral members of the group who were not privileged to the core members' frequent contact, and did not know of my interview activity with parents in the group, but only of my participant observation activity. Additionally, I found it important to invite some professional members of the group to participate in the interview schedule. Some of these reasons have been mentioned above, but to elaborate further, since I am a former special education professional, and I often heard parents in my study speak about their frustrations with education and medical professionals, I considered it helpful to speak with some professionals whom parents cited as "getting it" - understanding the autism lifestyle. I wanted to find out what exactly they "got", how they understood the interworkings of an autism lifestyle, and how they had positioned themselves to become privy to that understanding.

Internet data strategy: During fieldwork, I found that following online postings provided a fresh, innovative way to capture how parents share information and communicate their experiences in a digital age. The Internet has been a fascinating platform for individuals with autism to discuss their experiences and to promote autism advocacy and awareness. Many online communities have been created by individuals diagnosed with autism or by parents of children with autism. There are also an increasing number of groups for autism siblings. Coupled with participant observation, I used online data to see how often individuals commented on a topic, what the sentiments toward the topic were, and who else was commenting on the topic. I looked specifically at two kinds of online communication - 1) online posts on the APSG website and 2) individual Facebook posts from group members. The first kind of online data
was organized through the website, accessible only to APSG members. The member forum was divided into many categories, ranging from topics about school transportation to nutrition and vitamins. Parents used this forum to share links, post information about daily happenings, ask for advice, or lend moral support during times of need. When I first began my relationship with APSG, the group used a site that was hosted by a national organization for Internet groups. After petitioning for and receiving 501(c)(3) status as a non-profit organization at the end of 2010, APSG had to move their forum to a new site. I followed both sites throughout my fieldwork, and also took notes on the parents' experiences with transitioning to the new site.

While I did become nervous about potentially losing data when the original site was being abandoned for a new one (and subsequently copied the content from the original site through a cut and paste method because no Internet scraper program was available to automatically download the content from this particular site), the content from the original site still remains intact. Otherwise, I did not "collect", as in take away, data from the online sites and put it into folders or some other kind of research organization system. I instead chose to use the data, in its original Internet form, as a way to continue my contact with parents and their experiences even after I had left the field for the day, as well as to maintain an ethnographic present. Parents had already chosen how to organize their topics, comment on one another's posts, and interact with each other through this online community. As a participant observer, I simply participated in the forum and allowed my experience with this participation to further inform my face-to-face interactions with participants. While there is certainly always the danger that posts will be deleted or a glitch will occur, throughout my engagement in this fieldwork, my involvement with the sites and that of the parents' remained intact, available, and live.
I also became "friends" with all of my participants on Facebook and was privy to their status messages, in addition to being part of APSG's Facebook group. Access to Facebook data provided an easy way to continue participation with parents even when I was not in the same location as them, and also allowed me to see what they were posting about autism throughout the day. As APSG does not have an office or common space, much of my interaction with participants usually occurred in parents' homes or in public spaces. I found that following parents on Facebook, in addition to face-to-face interaction was an excellent methodology to use when trying to keep up with the busy lives of parents in disparate places; if I was having a lunch with one parent, I could still read about a daily crisis of another parent who was miles away.

While accessing online data is a wonderful new methodology for social science researchers, it is not without limitations. While data is stored, time stamped, and even categorized by websites and social networking sites, data can still be purposefully or accidentally deleted; it is not a perfect record. Additionally, it is difficult to surmise appropriate context when reading one-sentence posts, and there is a possibility that the language communicated through a written blog entry or online response will not accurately convey the intended tone or meaning of the author. Furthermore, some of the data generated, such as Facebook posts, has some of the same limitations as survey data. Online posts are like an extreme example of self-report and for this reason I do not think I could sufficiently capture the richness of parents’ experiences by using this methodology solely. However, paired with face-to-face participant observation, I found that this methodology provided an important compliment to data collection.

Furthermore, ethics and online data that has yet to be fully routinized by social science research. Ethical dilemmas may arise while doing this work, dilemmas that do not yet have strict research protocol. For example, because I was accepted into the group as a member and had full
 access to the APSG online forum as well as the group's Facebook account and the individual members’ Facebook pages, I felt comfortable looking at these data as a way to better inform my understanding of parents’ daily experiences. The parents in this group made it clear to me that I was not only a researcher, but also a valued member of the group and encouraged me to post articles about autism that I found online, or to engage in online discussions on the forum. Had I been seen as a more peripheral participant, just collecting data for my own purposes, I would have felt far less comfortable using online posts as data. Ethically, the use of Internet data was something that I needed to carefully and personally navigate as a researcher. This meant having to consider all implications of presenting direct quotes from online data. To make sure that this information would remain confidential, I attempted to search some of the quotes I decided to use in this ethnography to see if they would show up in a basic Internet search as connected with any individual. After finding that such connection could not be made, I decided to proceed with my use of direct quotes from online posts.

**Data Analysis Strategies**

*Data management and organization:* After making jottings during participant observation, I turned those jottings into fieldnotes using Microsoft Word documents that were divided into two columns - the large left hand column for fieldnotes, and the narrower right hand column for indexing. On the right side of the document the fieldnotes included three "layers" of notes. First was a further elaboration on people, places, and events, I observed and jotted about. These notes were documentation of direct observations or quotes, and make up the majority of the fieldnotes. The second layer was presented in italics and described my thoughts, feelings, assumptions, etc. about what I was observing in the field. Sometimes these italicized notes were inserted immediately after the documentation of an observation, while other times I inserted
them at the bottom of a fieldnote. The third layer was used to present a more metacognitive practice, usually indicated by a * or brackets and allowed me to think about my thinking from the second layer notes. Specifically, this third layer was used when I was reminded of a scholarly work that connected to a fieldwork musing, or a theoretical connection to something I had observed in the field.

I organized the fieldnotes in a folder on my password-protected laptop and filed them by date. I also had a folder system for handouts, brochures, and other non-digital data collected, which was kept in a collection of manila folders labeled by date. Each interview was recorded using a mini digital recorder. The audio files were then stored, by date, in a separate folder on my laptop. Later, when I transcribed the audio files from the interviews, I created a transcription document for each interview using Microsoft Word, and subsequently filed these in a separate folder on my laptop. Additionally, all electronic data folders were all backed up on an external hard drive that I kept in a locked drawer at my home.

*Thematic indexing and NVivo:* Preliminary data analysis began after each field observation. As part of my fieldnote write-up routine, I would read through my fieldnotes and pick out important themes or names to index. Quickly, this allowed me to categorize behaviors, activities, people, and places, that I was observing and do basic "word find" queries to see how often certain themes such as "tantrum", "toileting", "argument with family member", etc. came up in my fieldnotes. I also began the process of interview transcription. I purchased big headphones that eliminated external noise and downloaded the Express Scribe from the Internet. I began transcribing the interviews in the order in which I conducted them, and found that I was able to transcribe roughly 10 minutes every hour. The process was slow going at first, but was immeasurably helpful later when I inserted direct quotes into the ethnography as examples of a
particular point being made. The interviews were transcribed verbatim, often after repeatedly playing of the audio file to ensure that I was accurately noting the speakers' words. Because this study looks more broadly at the everyday life experiences of autism parents and their overall communication of these experiences, rather than focusing on the minute communication of those experiences through specific speech acts, discourse analysis was not conducted on these interviews.

After participating in two NVivo9 trainings at Teachers College, I chose to use this qualitative data analysis software to assist with the further organization and analysis of my fieldnotes and interview transcriptions. I first moved the documents from word into NVivo and then utilized the preliminary thematic indexing that I had done with my fieldnotes to create "nodes" in NVivo. These nodes help to sort out important themes that may recur throughout the project. From there, I was able to use the software to see how many times certain nodes were occurring, as well as how nodes were occurring in relationship to other nodes. Names of the nodes ranged from "Abuse" to "Emotions" to "Grieving" to "Transportation" and were categorized in NVivo alphabetically so as to make the coding process more efficient. As my list of nodes began to increase, I decided to make subnodes, so the node "theories about Autism" for example, had four subnodes: "Environment", "Genetics", "Refrigerator mothers", and "Vaccines", each an important topic that was documented in my fieldnotes.

NVivo not only helped me to see how often certain topics were being discussed, but also allowed me to aggregate the discussions and contexts in which they were being discussed. This proved especially helpful during the writing process when, for example, I wanted to look up all of the conversations - in both my fieldnotes and interviews - when the official diagnosis was discussed. I was able to run a query on the topic "Diagnosis" and then view a layout of all of the
quotes or discussions identified as relevant to the topic of diagnosis. NVivo also has the capability to create quantitative data based on the accumulation of qualitative data such as fieldnotes and interview transcriptions. For the purposes of this research project however, I did not want to boil the unique experiences of my participants down to numbers. Instead, I employed NVivo as an organizational and theme-sifting tool that would allow me to collate the similar experiences of parents, yet still reveal the variation of those experiences.

**Reflexivity and My Potential Impact on the Project**

I entered the field as a PhD student of anthropology, a former special education teacher, a disability rights activist, and a young woman without any children of her own. All of these qualities (and others I do not list) can and will impact any research I ever undertake. When I first met the parents of APSG I told them that I was a PhD student studying the experiences of parents of children with autism. They constantly teased me for having a notebook with me and said that while I seemed to be on the outside at first, scribbling notes, I had soon become a part of the group and a participant in their activities. Also, because I am a grad student parents often assumed that I had little money, and they would sometimes decide to pay for things for me, like when we went out to dinner or lunch. Usually if I was with mothers only, I was able to convince them that I'd like to pay myself and that while I was very grateful for their offer, I wanted to decline. When I was out with mothers and fathers, however, I always had to concede after a few minutes of back and forth about how I was being silly and it was not right that I pay.

This desire to take care of me may have also been affected by my age. Younger than all of the parents, I existed in this limbo space between babysitter age and parent age, or at least I felt this way. While I came to develop deep relationships with the parents, I saw them as parents and as I am not a parent, I saw myself as still somehow occupying the space of a child. This
ambiguous role allowed me however, to shed the toughened layers of an education professional and profess to parents that I was ready, willing, and able to learn from them and to accept them for the experts they are.

After a few times meeting the parents, they asked me about other jobs I had in the past and I explained my work experience as a teacher. They would sometimes ask me about my experiences teaching in Virginia for a comparison to their experiences with schools in New York. It seemed however, that this part of my identity was soon forgotten, as the parents vented freely to me about how their children's educators were not being understanding or didn't "get it", and seemed not to consider my feelings about those venting sessions as an educator myself. I appreciated this openness and believe that it served my relationships with them greatly. While I was technically considered a professional member (in contrast to a parent or caregiver) as indicated by status in the online community, I was never called upon for educational advice or expert opinion. This ambiguous status allowed me to participate in the workshops, meetings, and activities in an interactional capacity as a learner and listener.

Another aspect of my identity that shone through to parents was my willingness to learn about their experiences and their children not because I want to change, cure, or treat them, but because I personally believe that physical and cognitive differences are something to be accepted, shared, and celebrated by all human beings. I identify very strongly with a social model of disability, which asks society to consider the consequences of power structures, labeling, and injustices on persons with physical and cognitive differences. This differs from a medical model which regards "both disease and sickness as medical conditions that are produced by specific entities and assumes that the role of medical intervention is to control the symptoms of a disease and, where possible, remove their causes" (2001:257) and places the onerous on the
individual labeled with a disability. I consider myself a disability rights activist and have a strong desire to work toward equal opportunity for all individuals regardless of sight, processing, hearing, mobility, etc.

Last of all, a very important aspect of my identifications that may have impacted my interaction with the participants in my study as well as with the experience of parenthood is my gender identification as a woman. Parents, especially mothers, would sometimes talk to me about what will happen when I am a mother, and would ask me if I am waiting to have children until after I graduate. With some of the core mothers especially, they asked me about my romantic relationships and dished about their past experiences with boyfriends or husbands. They also felt comfortable talking to me about menstrual cycles, swollen breasts, PMS, how "men are unbelievable!", and how hard it is to be a woman sometimes. This female bond that was formed had a certain deep, yet indescribable quality. At times it was as if the mothers thought that while I do not currently have children, I could easily become connected to them through autism one day - as an autism parent - and that autism itself does not discriminate, does not pick and choose who will be affected. Through this unspoken agreement, we both knew that if I were to become an autism parent later in my life, they would welcome me, share with me, comfort me, and that I couldn't imagine living through these moments with anyone else.
Chapter 3: Re-charting Territories, Redefining Roles: Identifications and Relationships

Sarah’s Diagnosis Story

Sarah's daughter, Ava, was identified as having a speech delay after her first birthday. She received special services with a speech therapist, and Sarah hoped she would "catch up" to meet the milestones that are deemed so important to the development of a "healthy", "normal" child. Sarah had two older sons, neither of whom had been identified with any developmental delays, so this was new territory for Sarah. Sarah watched Ava closely, sensing that something more was wrong with Ava's development. On the playground one day, she realized that instead of playing with her classmates, Ava lay on the ground eating woodchips, alone. Behaviors like this caused Sarah to feel very concerned, and she decided to take Ava to a neurologist to have her further evaluated. Sarah described her experience at the neurologist's office the day that Ava received an official diagnosis:

Sarah: I really have to tell you that when the neurologist told me her diagnosis, I really thought he was joking. I really didn't think he was serious.

Juliette: Had you heard of the word (autism) before?

Sarah: I did, but, I assumed that it had something to do with mental retardation. I didn't know that it was a disorder all on its own, cuz when he said au... she has autism, I was like, "No she doesn't". He was like, "Do you know what that is?", and I was like, "Yeah, like, mental retardation", and he was like, "No", and then I remember, I was, asked him, I was like, "You didn't run any tests on her." I'm like, "You just asked me a whole bunch of questions and then you just tell me, you know...". I was like, "Well, just give her a shot". You know, you know what I mean, like "Give her a shot, give her a pill, what can you do?" He was like, "No, that's a life long disorder". He was like, "There's no cure for that". And once he told me that, I was devastated.

July 15, 2011

Sarah's diagnosis story did not end there, however. In fact, it had just begun. While trying to make sense of the diagnosis, she researched anything and everything that she could about autism, tried to keep herself from succumbing to the depression that she later did endure,
and decided how to move forward with Ava's therapies and education. She also talked to her family about this new path that she and Ava had happened upon, and about what it might mean for their future as a family. Her mother suggested that Ava be institutionalized and suggested that what had happened to Ava and Sarah - autism - had been a result of Ava's past life decisions. All of these events - the months of uncertainty and concern, the conversation with the neurologists, the research, the discussions with loved ones - make up Sarah's arrival story. They also contribute to her identifications with autism. Six years later, it may seem that these crucial moments are over, but they are never gone. They have shaped the way that Sarah understands autism, medical professionals, her daughter, herself as a parent, and her relationships with others. While major changes have happened in Sarah and Ava's lives since these events played out, and Sarah's understanding of her experiences may certainly have changed in turn (her identifications with autism may be different now than six years ago), these moments were dramatic, and signaled to Sarah that there were new territories to be charted, and new roles to be defined.

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To understand how parents embark on their initial experiences with autism, the issues of identifications and relationships must be considered - how parents come to identify as autism parents and with an autism lifestyle. During my fieldwork I was introduced to several crucial moments that signaled dramatic change in many autism parents' lives, like Sarah's, described above. I describe three here: 1) the diagnosis moment, 2) early intervention services, and 3) telling family and friends about autism\(^2\). These moments came to define the ways that parents identified with autism and what autism meant in their lives. In this chapter I explore the

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\(^2\) I’d like to note here that these moments do not necessarily occur in this order. In fact, often parents experience #3 well before #1 or #2, or perhaps have several #1 experiences before arriving at a final autism diagnosis. The order that these moments are presented is purely a stylist choice on the part of the author and does not indicate in any way a purported trajectory of experience.
production of parents' multiple identifications with autism and the moments that signaled such
dramatic self-change. The term "identifications" is used here to denote the multiplicity of
possibilities. Not all parents will identify as autism parents in the same way, or at the same time.
As this chapter shows, there are many routes to these identifications and they can change over
time. Drawing on the work of Dorothy Holland et al. I explore parents’ identifications with
autism as "variable”, “multivocal”, and “interactive” (1998). The moments that are discussed in
the chapter occur at a specific point in parents' lives, and influence other moments later in their
lives, but do not predetermine them.

Specifically, I find the work of Holland et al. (1998) helpful for thinking through parents'
everyday experiences with autism as a means of coming to identify as an autism parent and
adopting an autism lifestyle. Social practice theory, employed by Dorothy Holland and Jean
Lave, among others, emphasizes “the historical production of persons in practice, and pays
particular attention to differences among participants, and to the ongoing struggles that develop
across activities around those differences” (Holland and Lave 2009:1). This ongoing production
of identity can be used to think about groups as well as individuals, and to pay particular
attention to the ways that interaction experiences frame the production of identity. According to
this theory, identity is not a fixed concept, but rather is constantly renegotiated in various
situations, at various times, and with various other social actors. Furthermore, the theory insists
that this production is happening over time, and is continually in the process of renovation,
rearrangement, and re-imaging.

The historical quality of identity over one's lifetime (Holland and Lave, 2009), also points
to the change of identifications and perceived lifestyle as a process shaped by both gradual
change over time, and critical moments of dramatic change. While people interact with each
other, they have experiences that allow, limit, motivate, or caution them about how to identify in a given situation. This identification is not simply internal, but is further defined by the way it is presented to others. This ethnography aims to show the moments when parents interact with others and also considers the importance of parents' reflection on and communication of their everyday experiences as an integral part of the production of their autism lifestyle and identification as an autism parent. What motivates these parents to enter and maintain the autism lifestyle is not just their daily engagement with autism, but also their reflection on that engagement and their discussion of that engagement. The work of Lave and Wenger (1991), is particularly salient here, because through the process of obtaining a diagnosis, engaging in new practices like inviting a therapist into the home, and telling friends and family about the diagnosis, parents are participating in a "community of practice" one which enables them to learn how to be autism parents, by participating in the community as autism parents. If parents choose to enter a specific support group, as the parents in my study did, they additionally learn how to be members of a support group, by participating as members. As parents enter these social spaces where they engage in practices labeled with the term “autism”, they come to identify with these practices and with these spaces, and ultimately as people affected by autism, and as parents who must care for their diagnosed children.

While all parents may undergo these processes, the way that one parent identifies with autism upon first hearing the diagnosis may be very different than how that parent identifies with autism ten years later while attending a workshop on sexuality and puberty. Parents are constantly interacting with the people, materials, and ideas around them concerning autism, and these interactions help to shape their multiple, and changing identifications with it. Kleinman (2009) describes this new life that parents are entering into, this new life of caregiving as "not
easy". He explains, "it consumes time, energy, and financial resources. It sucks out strength and
determination. It turns simple ideas of efficacy and hope into big question marks. It can amplify
anguish and desperation. It can divide the self. It can bring out family conflicts. It can separate
out those who care from those who can’t or won’t handle it. It is very difficult" (2009). This
chapter presents some of the initial, formative interactions that introduce parents to this reality.

The first critical moment concerns the official diagnosis of an autism spectrum disorder. The second is the introduction of Early Intervention services, and the third involves notifying friends and family of the diagnosis and the changes to the family schedule, activities, and priorities that accompany the diagnosis. For some parents in my study, these moments all occurred within rapid succession of each other, for others they lasted several weeks, months, or are still ongoing issues in their lives. Despite the duration, parents identified these moments as signaling abrupt change in their lives and indicative of something new, something different, that they would endure for the rest of their lives. In this section I describe detailed accounts of each of these critical moments, using the words of parents I interviewed and observed, as well as fieldnotes about various activities and events.

These stories help us understand how parents became autism parents, how they came to identify as caretakers of children diagnosed with autism. For some parents, it is a label attributed to them, one that is stamped on them as they are shuffled through various medical, educational, and other bureaucracies in search or services and supports for their children. This shuffling and stamping often begins in these initial critical moments. For other parents, and often in addition to the labeling, identifications as an autism parent become an internalized sense of self and a lens with which they see the world.
Kelly explains that when raising a child with a disability "an understood and relatively taken-for-granted sense of what it is to parent becomes the subject of conscious making, unmaking, and remaking" (2005:187). According to Kelly this "conscious reembodiment of the social category of parent takes place through myriad daily activities, including the intimate and private management of a child's physical and emotional needs, public presentation of self as parent of an impaired child, and public representation of parent and child across a variety of public domain" (2005:187). In Kelly's study parents create metanarratives of progress and rehabilitation which reflect the hard work of their children and their families, by focusing on therapeutic approaches, searching for a label, and adapting the environment to support the child's impairment. Over time these metanarratives come to define and describe their new identifications as parents of children with impairments. For many parents in my study, the diagnosis narrative is crucial to the process of identifying as an autism parent. These diagnosis moments contextualize, shape, and decisively signal a major change that they begin to undergo.

The Diagnosis Moment

Many different kinds of professionals diagnose autism spectrum disorders using a variety of different instruments. Some of the parents that I studied were referred to developmental pediatricians by their primary pediatricians. The specialist examined the child, observing behaviors detailed in the Diagnostic and Statistical Manual-IV, and asked the parents a series of questions. Other parents received a diagnosis after taking their children to a university hospital or medical campus. At these sites, assessment instruments like the Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnosis Interview - Revised (ADI-R) are employed. The ADOS is administered to the child and documents the child's behaviors while the

3 For a more extensive description of autism diagnostic tools and procedures see Rossi's 2011 dissertation.
ADR-I is used to interview parents about behaviors they observe in the home. Still other parents were referred to a neurologist where a similar diagnostic procedure was done. Whatever process parents went through to obtain a diagnosis (whether they sought it out or it came as a surprise to them), I found that when I asked parents to explain to tell me about their children, the diagnosis story often emerged immediately.

For Sarah, described earlier in the chapter, even though Ava had been diagnosed with a speech delay a few months prior, the moment that the neurologist told her that Ava had autism was shocking, devastating. This was a profound moment when Sarah knew that her life was changing, and as the doctor began to explain, this was going to be a life long change. Landsman (2000, 2003, 2005) writes about this realization of lifelong change as well. In her work with mothers of children diagnosed with various disabilities, Landsman looked at the ways that mothers reimagined motherhood after the diagnosis. For many parents, their idea of motherhood prior to the birth of their child or prior to the diagnosis, was something very different from what they had expected, what they had prepared for. For these mothers, she saw a gradual change in mothers' expectations following the diagnosis, and a slow acknowledgment that their identification as mothers would be forever changed from their earlier ideas about it. In coming to grips with this loss of potential "normal motherhood" and with the gain of this new "motherhood for a child with a disability", mothers came to identify as mothers of children with disabilities.

Kaleena, an African American woman in her 30s, also has a child diagnosed with autism, but her experience with the official diagnosis of her son, Jacob, was very different from Sarah's. For Kaleena, the official moment of diagnosis in the doctor's office verified and validated a change that she had seen in Jacob's behavior, and in her experiences as his mother. Unlike Sarah
who found the moment of diagnosis devastating, Kaleena was relieved to have a name for the changing experiences she was enduring and was happy to be able to move forward, armed with the power of naming her experiences:

Well, definitely, I mean, he, like most (autistic) children he progressed slowly and he's a twin so, he spoke later. He did others things later than, or different than his twin sister and I had a, I didn't know. I wasn't sure and I didn't really know. People were like "Oh, he's a boy. Boys are slower than girls." But I just knew. I felt like something wasn't right, um, and so when he got diagnosed it was kinda like relief, cause I'm like, okay, now I know it's something. I could put a name to something. Now we can figure out what to do, but it's like, what do we do? What is autism? I don't even know what that is. So it was like you're happy, but you're confused at the same time.

August 10, 2011

After receiving the official diagnosis, Kaleena came to identify as a mother of a child with autism, and this identification helped her plan for the future and move forward. She no longer identified as a mother whose child was behaving in inexplicable ways, and this gave her a sense of control. Sarah, however, was identifying with autism as a terrible, devastating thing that had happened to her and her daughter. This new way of seeing her daughter and seeing herself was confusing, scary, and did not provide her with the sense of control that it gave Kaleena.

The evaluation process and official diagnosis were specific signals of life change for some parents like Sarah and Kaleena, signals that indicated a new way of understanding themselves in the world, and their relationships to their children. These diagnostic procedures and the paperwork that follow also become crucial to autism parents for later securing special education and special healthcare services for their children, and for further codifying their identifications with autism. However, it is not always the hours spent in the specialist's office or the doctor's official word that signal a major change in other parents' lives. For many parents, the moments leading up to the evaluation process are just as, if not more revealing of what changes are to come. Meghan, an early 30s Guyanese woman who works in the fashion
industry, also had early indications that her son Jack's behaviors were cause for concern. So like Kaleena, she was not shocked by the diagnosis, but her experience was also different from Kaleena's because Meghan did not have any other children to which she could compare Jack. Jack was her only child at the time (she now has a little girl as well), so she was unsure about what behaviors were considered “normal” or “abnormal” at various developmental stages. In an interview, she shared her diagnosis experience, focusing on the moments leading up to the official diagnosis:

Meghan: ...he was, he always had delays, from a, from a very young age. And my, I noticed, I noticed it, but I didn't, I, living in that household like, I was very blindly shaded, blinded to everything that was going on. You know, I had concerns, but I didn't know what it, what it was. I didn't know what to look for. I didn't know what to compare it to, you know.

Juliette: Right.

Meghan: It was my first child. My first child, the only kid that was actually very - I was, you know, I never had any other little kids growing up...

Juliette: Yeah...

Meghan: You know, so I didn't know what to compare.

Juliette: No like, frame of reference?

Meghan: No reference, yeah. Like how a, what should a, you know, two year old do, or a 9 month old, you know, whatever. I mean, I knew the standards, like the different um, you know, uh

Juliette: Like the milestones?

Meghan: Yeah, the milestones you read on the Internet, like he should be doing this. So once he was 9 months, and I remember this because he was, he had a lot of sensory issues, and around that age

Juliette: Like noise, or lights?

Meghan: Well it was noise. He had this very high-pitched scream, which he still has, up until this point. Umm, he had, like he would put everything in his mouth. And he would like chew on all of the shades, like the blinds, like we had those shutter blinds, like he
would like chew them up. It was just a lot of sensory issues. So, you know, and then he
would, he wouldn't respond to his name, and you know, in, in our culture, it was like, if
you don't do certain things, oh, you're just bad.

August 5, 2011

When Meghan speaks of how living in "that house" blinded her, she is describing living with her
in-laws who are very religious. This is also the reference that she makes to her Guyanese culture
and how not doing certain things (or behaving in certain socially appropriate ways) makes one a
bad person. Meghan did not have anyone around her with whom to talk about Jack's behaviors
or how she felt about them. She knew that her experience as a mother and her son's behaviors
were somehow different than what she expected, but was not able to communicate this with
anyone else in her home or compare her son to any other children. She began to see herself, to
identify, as a mother with a bad child, a loud child, a child who wouldn't listen. This kind of
identification is one that involved rejection by her family, and when she wanted to communicate
about her experiences to her in-laws, she was reminded that Jack could be considered a bad child
because of his behaviors. Meghan remembers when her mother finally visited from Florida and
gave her insight about Jack's behaviors. Her mother's comments about Jack validated her
concerns about him and prompted the evaluation:

Juliette: Did you end up getting the diagnosis from that pediatrician? Or did you have to
go see someone else?

Meghan: Someone else. Yeah, he actually recommended, this went on for two years,
until he turned two. Right before two, um, he, I, we said "He's not speaking, you know,
this is everything, you know..." And then he said, "Um, call Early Intervention. You
know, they help with speech." So we only thought he had speech delays. Which is you
know, a lot of the, it's normal, you know.

Juliette: Yeah.

Meghan: Boys, you know, they're slower than girls, developing. And my mom actually,
I remember one day, she lives in Florida. She came to visit, um, and, he was about, I
think a year old, and he was doing something, and my mom said, "You should get this
boy checked out." I'm like, "What do you mean?" You know, by a psychologist, 'cause
my mom, she used to babysit and she babysat a child with the same type of, you know, symptoms, and she said he seemed very similar to the child that she was babysitting, and I said, "Okay" so she kinda planted that in my head. So that's when I started looking for things...

August 5, 2011

Meghan's mother helped her to change her previous identification as a mother with a bad child, to a mother with a child who needs help. This slight change in identification gave Meghan the impetus to reach out for a diagnosis and to begin to talk to her in-laws about how to move forward with Jack.

Kate, like Meghan, did not have a frame of reference from which to compare her six-year-old son, Braden, as he is he only child. As she described to me, there was a clear dramatic moment of change that alerted her to take her son for an autism evaluation, which was given impetus by an opportunity to observe Braden interacting with his preschool classmates at school. Until then, while she thought some of his behaviors were unusual, she was not sure how he differed from his same aged peers:

Braden's preschool teachers talked to her in the hallway one day and suggested that Kate come in to observe Braden while he was at school. She watched him from a window that looked into the classroom. She watched as the kids worked on a craft project where they glued cotton balls to construction paper. Braden sat at the table eating the cotton balls. He then went to the other side of the room and lined up (toy) cars like he did at home. Kate noticed that throughout the day he did not interact with any of the other kids.

July 2, 2011

It was during this moment of silent, reflective observation that Kate had the shock of her life. She watched her son's movements, his awkwardness in social interaction, his unwillingness to reach out to his peers, and for her, this was THE moment. This moment, this recognition, diagnosed her life as forever changed. A few weeks later she was given an official autism diagnosis, a rubber stamp on a piece of paper, but that day in the preschool office, looking in
through the two-way glass, that was her official moment of change. That was the signal of a new identification with her son and with something that would come to pervade their lives, autism.

Richard's experience with the diagnosis of his only son, Marcus, was very different from Kate and Meghan in some ways. Richard, a Caucasian male in his 30s, is a special education teacher and has worked with children diagnosed with various disabilities for over twenty years. He has also worked with children without disabilities throughout his career. Richard had an extensive frame of reference with which to compare Marcus' behaviors and development, and already had a particular identification with autism as a special educator. Like Meghan however, Richard was reluctant to speak out about his experiences with his son for fear that it would cause upset in relationships with his family, specifically with his wife:

I'm like obsessed with doing the laundry. I'm always doing it. Every two days I'm doing laundry cuz I'm in school, come home take off my, change, cause you know, gets old, this and that. You don't wanna bring that in the house, you know. I got Marcus in the same obsession. Hey, we're doing laundry together, you know. We go down to the laundry room. And that girl Janelle, yeah they go down there too, so the boy Joey who used to live there, dad used to live in that building, all would go downstairs together, and they're all playing. Marcus is typical - grabbing toy, fighting, you know. And, he's like, "I said no! No! No! No!" You know, really getting over the top with it, just like, I'm like, and that's when I'm like, you know, he's got something. He's got some issue. You know, it's always been. It's more than just a tantrum. I noticed, and I remember he just reaches out and he hits both of them in the face, like simultaneously. He's flapping. He gettin' mad, this and that. I really gotta think about this. You know what I mean? I'm like watching for like days at a time and one of the OTs (Occupational Therapists) from my school came to come play with him and to see like his, you know, bouncing off the wall. And she's like, "but you could benefit from OT." I'm like, "Yeah. He's clumsy cause I'm clumsy, but I think I'm on the spectrum too", you know. He definitely has the sensory issues, like hyper acuity of sound. It's always a big thing for him. "I can hear you!" You know what I mean? Or, like, and, more and more I get into it and I really wanted to get him diagnosed right then. And to be honest I wanted to get the diagnosis for my um, my piece (sic) of mind, um, I wanted, I wanted the diagnosis to be like, oh no you're crazy. He's fine. Whatever kinda thing. And I didn't even get that because when I told his mother that's when the beginning of all our real problems, really began.

August 4, 2010
Richard's identification as a special educator, and then his new identification with his son as a child who could potentially be diagnosed with autism, had a major impact on his relationship with his wife, and on her identification with the diagnosis process. She thought that Richard was reading too much into Marcus' behavior because he was primed to see disabilities in children due to his line of work. She became angry with him for suggesting that anything could be "wrong" with their son, and blamed it on his close identification with special education. After many arguments, Richard called on the expertise of a fellow educator for assistance. This signal for help positioned him as a parent, not as a special educator, and was significant for his identifications with autism, and with his son, and for the steps that they then took as a family to get Marcus evaluated. From his discussions with the co-worker, he became more confident about his concern and while he did not receive the diagnosis for Marcus until many months later, he was able to learn more about autism in the meantime.

For some other parents, they were able to make an unofficial diagnosis by using their own resources. Because information is available easily and immediately through the use of new technologies, some parents did not even have to leave their homes or talk to specialists to experience their first dramatic moment of change. Bala describes the moment when she was sure that her two-year-old daughter, Anna, had autism:

I didn't think that much of it, but then that week after my mom saw on the news about "Autism, early signs" and then she said to me, um, you know she saw that they were showing things. I said to my husband cuz she was banging her head one night when we were both putting her to bed. And, like, maybe she has, Mom saw something on the news about autism. We didn't even know what autism was, at that point. We had no idea what it even was. So he went online that night and looked it up and he didn't say anything to me the next morning. He just said, "Call Early Intervention", and I was like, "What did it say online?" And he was like "Oh, it said a few things that she did" and whatever. He didn't wanna tell me the truth because he didn't wanna stress me out. So, I went and did my own research and then when I started seeing all the things and all the descriptions, I knew. I already knew. I was like 95% sure at this point. I didn't need
nobody to tell me. I already knew. Cuz all the things that they were listing was what she was doing. They were like little things you never thought about.

July 26, 2011

Parents of children with autism arrive at the moment of diagnosis by taking various paths. Some have supportive loved ones who help them through this often confusing process, others go it alone. Some are certain of the diagnosis because of their own research or observations from friends and family, others have a shocking moment in a clinician's room. Whatever path parents take to arrive at this major junction in their journey, Diagnosis, they all end up there eventually. This is their first introduction to what an autism lifestyle may come to mean to them, how their lives have been forever changed, and how they may become multiply identified by themselves and by others as autism parents.

**Early Intervention**

The introduction of Early Intervention (EI) services is another moment autism parents cite as signaling a major life change. This life change may impact their identifications with autism, as the diagnosis moments do, but they also impact the way that parents think about their own space and time and their roles are caretakers. EI is a program that began in the 1990s to address the special needs of children administratively labeled "at risk". Services are provided to students to address specific deficits identified during the evaluation process. After receiving a special needs diagnosis, parents are given a long list of service providers that they can call to begin EI services. The providers are often local organizations that implement services and supports for individuals with disabilities throughout their lives. Most of these organizations have an EI department that focuses specifically on the provision of services to children of three years or younger. These services include Speech Therapy, Occupational Therapy (OT), Physical
Therapy (PT), Special Education, Applied Behavior Analysis (ABA), Nursing, Counseling, and some others for more specific physical disabilities.

Many children eventually diagnosed with autism spectrum disorders are not first officially diagnosed with autism. They may be first diagnosed with speech impairments or developmental disabilities because the children are often too young to officially diagnose autism. Whatever the initial diagnosis, services are introduced to the child in the home or daycare setting at intensive levels. For example, a child diagnosed with a speech impairment may receive five hours of speech services per week. This means that a speech therapist will come into the home five days per week for an hour each time. For a child who has a speech impairment and low muscle tone, she may receive five hours per week of speech, but also an additional three hours per week of PT (Physical Therapy). This means that two separate therapists will come into the home at separate times to work one-on-one with the child. If a child is diagnosed with a developmental disability, the child may receive, for example, five hours of Speech, three hours of PT, five hours of OT (Occupational Therapy), and five hours of special education per week.

This example schedule places four different therapists in the home for 18 hours per week in a one-on-one setting with the child. Other children receive an initial diagnosis of an autism spectrum disorder and the family's introduction to EI services is through a schedule to meet the needs of children with autism. When a child is diagnosed with an autism spectrum disorder, he is often given a schedule like the one above, but is also provided with at least 20 hours per week of intensive ABA instruction in the home; many parents even request and are granted, 40 hours per week.

These therapy hours become part of the child's life, but also of parents' lives. Many parents have to reorganize their schedules. Some even have to quit their jobs in order to make
themselves available during service provision. Parents are also encouraged to see to it that these services are provided as prescribed because they have only a small window of opportunity (while the children are still young) to get them to "catch up" to their peers and to hit their developmental milestones on time. As they enter this whirlwind of EI services, parents must dedicate hours and hours of their time to therapy and to the paperwork, scheduling, and progress reporting that accompany it. When parents enter this stage of intensity, they have entered uncharted territory, and must make due with these rapid changes in the best way that they can. For many parents this means canceling other plans, decreasing regular communication with friends and family, and spending less time taking care of their other children.

This hectic schedule of five therapists providing 38 to 58 hours of intensive one-on-one instruction to the child in his or her home may result from a slow progression of accumulating services as a diagnosis changes from a speech impairment to autism, or it may be the family's first introduction to EI services. It may also be a referral forced on families by a pediatrician, or a referral that parents pursue. Whatever the route a family takes to arrive at the provision of EI autism services, upon arrival, they are met with what many parents call the "revolving door" of therapists:

Leslie: So Joey was in school already before he was two.

Juliette: Before he was two? Wow. Plus you were still having the um, specialists come to the house?

Leslie: Yeah, he would come home, and as soon as he would come home - he would go (to school) from 10(am) to 12:30(pm) - he would be here by 1(pm), and by 1:30(pm) services started.

Juliette: Wow.

Leslie: And ask my kids. They didn't even have to go down and open the door. It was, as one therapist was leaving the next was coming in. And this stood like this from 1(pm), til about 6 (pm).
Juliette: Oh, wow.

Leslie: We had PT. We had Speech. We had OT, and we had uh, ABA teacher, cause Joey was receiving 20 hours of ABA a week - along with going to school.

*September 6, 2011*

This revolving door, especially one that doesn't even need to be opened by someone living in the home, presents an interesting issue concerning the blurring of boundaries between private and public. When EI service providers enter the home, it is with the intention to help children "catch up" to their peers, to hit developmental milestones, and to be ready to perform in school. For the parents in my study particularly, the schools that their children will attend are public schools, ones that will later test, assess, and evaluate them based on their ability and performance. EI therapists enter the home (the private sphere) to teach children how to become citizens (work of the public sphere) and to increase social and academic skills so that they will be meet the social and academic requirements of Kindergarten. When EI services begin, parents oblige this boundary blurring because they are told that it will help their children learn better, feel better, act better, and while many parents have a wonderful experience with EI and attribute much growth and success in their children to these services, they often feel their private lives are invaded in the process.

Additionally, when most EI therapists enter the home, they do not work with the family as a unit, but rather focus on the child, individually. This means that they work with the child in a secluded space in the home. Many parents spoke of their children as babies when they first entered EI services. Only recently identifying as these children's parents, autism parents then felt that they were being excluded from the therapy activities, and disconnected from their children. They feel that their role as caregivers is taken away from them during the therapy sessions, that their schedules are completely rearranged, and that their living spaces are taken over. For some
parents like Leslie or Julia, who live in an apartment, the kitchen or main living area is used for therapy sessions or planning sessions:

Juliette: Were they doing it just in this room (kitchen)?

Leslie: Yeah. Speech was uh, half an hour sessions, and then of course if they didn't make it one day, then they would do like a double up, and then I had parent training. So parent training was every week, and then every month we would have all the clinicians come, and we would have, we would discuss Joey's progress, what were the next goals we wanted to work on. ----

*September 6, 2011*

For other families with more space in their homes, like Bala, the playroom or living room is transformed into a therapy workspace. The door is closed and parents and siblings do not enter the space until the session is over. Bala describes how hard it was for Anna to be away from her during the EI sessions:

I had to move forward so I called Early Intervention and I had all these people coming in, we had to take her to the neurologist, and everybody to get everything started, and about 20 months she started EI. So her services started very early and it was like very hard for her in the beginning. Like, she was screaming and crying. She was very attached to me at that point. To be separated and in another room with somebody else. She would go to sleep. She would talk and other things to avoid therapy, so it was a struggle...

*July 26, 2011*

For still other parents who work full time and send their children to babysitters or daycare centers, EI services are provided in these spaces instead of the home. Kaleena described some of the confusion that can occur, however, when parents are not the primary contact or supervisor for EI visits. She told a story about how her son Jacob missed out on services because of such miscommunication:

Juliette: Did you go through Early Intervention with him, or was this, was the diagnosis after Early Intervention?

Kaleena: Actually, he went through Early Intervention for speech. But, through kinda weird circumstances it ends, cause I believe Early Intervention ends at three.

Juliette: At three, yeah.
Kaleena: And what happened was his speech teacher was coming to the house and I would have to leave work early or my grandmother would have to come home, and he, him and his sister were going to a babysitter, and the babysitter said, "Well, why don't you just have them come, why don't you just have the speech teacher come here? It's much easier so you don't have to take off work."

Juliette: Yeah.

Kaleena: And when I, when that happened, I finally wasn't on top of it, so she (Speech teachers) ended up having a surgery or something like that and she stopped coming and I didn't know that she stopped coming, cause she didn't tell me and my babysitter assumed that she told me, cause my babysitter didn't say, "Oh, she stopped coming." She just thought I knew. And I got kinda, well, she's going there, you know, he's talking more, and I really wasn't on top of it. I didn't know, so his um, the, what do you call it, um, the service coordinator called me and she was like, "Oh, how, I can't believe you let this happen." She's blaming me. Like, "I can't believe you let this happen. You know, he missed out on all these services. This is your fault." I said, "Actually, this is your fault. That was your job to oversee this and you didn't."

August 10, 2011

In this situation, Kaleena’s role as caregiver was asserted and assumed to have particular responsibility attached to it. The service coordinator assumed that Kaleena's job was to make sure that the EI provider was going to the babysitter's home, and Kaleena assumed that it was the service coordinator’s responsibility. Having never experienced the process of scheduling and implementing EI services, Kaleena was in uncharted territory, and her roles in it were unclear. She wanted to provide her son with the best care and opportunities possible, but because the boundaries between private and public had been blurred, she did not know how much responsibility she had to this particular task, and was should be left to the responsibility of the professionals.

Meghan also works full time, and when her now five-year-old son, Jack, went though EI she and her husband were living with her mother and father in-law. They looked after Jack while she went to her office everyday, so it EI services took place under the grandparent’s care. She explains how overwhelming the rush of therapists was:
They all come to the house. But they, I, I told them, I'm like "This is what he needs." At first they were like, It's, oh my god, it's so much. It's very overwhelming. You know, don't overwhelm him. He'll grow out of it." I'm like, "No. This is what needs to be done. I've researched. This is what they say is gonna help. You know, therapies are the only thing."

They just had to let them in, yeah. And she (mother-in-law) would lock the, the way the house was, um, you know, there's a living room, a dining room, the door that goes to the kitchen, so, she would lock that door, have them sit. Because the therapists, they need to work with him alone. They can't... He gets distracted very easily so they need to be, you know, so. Yeah, so they, they would come and she would just like, just leave them until they leave.

In this situation, Meghan had to manage not only her own personal relationship with her in-laws, trying to define the role of caregiver when she was at work, but she also had to help orchestrate the scheduling of EI services in her in-laws' home. When her in-laws felt overwhelmed and invaded by the process of EI, she had to remind them that this was the decision that she made for her child, and that she, as his mother, had the ultimate say about what good for him. She too, was navigating new, uncharted territory with her work life, her relationship with her in-laws, and her relationship with her child, and through the course of these activities, she balanced and employed multiple identifications to manage the EI experience.

**Telling Others and Testing Relationships**

A third critical moment in becoming an autism parent concerns explaining the diagnosis to other people in parents' lives and explaining the lifestyle changes that are occurring. The expression of these feelings happens over time and parents' relationship with important people in their lives are tested and strained. Some parents come to rely heavily on their family and friends for understanding and support after they tell them about the diagnosis and continue with an autism lifestyle. Other parents make the tough decision to end relationships because people do not understand the everyday challenges that they now face or do not agree with their responses to
various situations. In Rapp and Ginsburg’s study of parents of children with special needs, the researchers found that many parents engage in a process of constructing a normalizing narrative, and that this is an ongoing process which often involves re-imagining kin networks. By speaking with families of children with Down syndrome, for example, they found that "The established script of Down syndrome is being rewritten across a range of sites in a way that opens up a supportive universe for disabled people and their kin. The Special Olympics; infant simulation programs; consciousness-raising and other sorts of events organized by the disability rights community; and Internet chat groups are all examples of sites that can help reconfigure community and dubious family members" (2001:547). Many parents in my study experienced this as well, as their relationships with loved ones were tested and tried, and they looked to supportive relationships outside of traditional kin groups to help them along their journey with autism.

As Kate explains, telling others about the diagnosis is a difficult process. As she described to me, explaining Braden's autism to everyone was hard. She sat down three groups of people in her life, separately, and told them all about the diagnosis: 1) her family, 2) her husband's family, and 3) her friends. She said that since then she only has one friend who has been able to understand. The others either don't understand or have taken her lifestyle changes personally (like when she shows up late to a party or has to leave early because Braden can't stay). Now her friends are the women in APSG.

Kate's experience of telling important people in her life about autism was a critical moment that had a significant impact all of her relationships. Her friends changed, her husband's family (including her husband) disagreed with her and said Braden just needed some time to work on his speech, although her own kin tried to support her as best as they could. Throughout
these difficult moments, many of which are still ongoing as the people in Braden's life continue to deliberate about what is best for him, Kate's roles as a mother, wife, daughter-in-law, friend, sibling, and adult child were affected. She never stopped playing any of these roles, but how she identified with each role and the meaning she attached to each was altered profoundly by her son’s diagnosis.

For Jessica, redefining her role as a mother, in relation to her role as a daughter, was something that she struggled with as she explained her understanding of autism to her father. He had a very different way of seeing Elias' behaviors and believed that their cause was spiritual rather than developmental:

So, my father is very attached to Elias, and Elias to him, and that they play a lot even though they don't use the language. And I remember he told me once. I have a big argument with him. "You know, what is wrong with Elias? Because I think Elias has a demon inside of him. That's why he's like that." I'm like, "How could you possible say something so ignorant!? Out of, has no name to say something like that. How can you say you see your grandchild? Don't you see that he's an angel? He's so innocent. He has no, no bad things. You can see. You can tell him. You can tell when you see him and you're telling me that he has a demon? How can you say that?" And still, still he believes that most of the, all, all the kids out there that has problems like him, like Elias, diagnosis like Elias, has a demon. And he's telling me one of the members of the church has a child like that and she's been taking her child there and the child has been, has more language. And I tell him, "Yeah! Because the child is progressing. But that doesn't mean that's gonna go away and this, and this." That is just something that I can't, I can't process in my mind. I don't understand it, but I said to my father, "If you want to keep seeing Elias, you have to stop with that, because I don't want to hear about it. I don't want to hear anything about it. I can't tell you you can't see my son, because he's your grandchild, but I know you love him. But you need to stop with this. It's nonsense and it's hurts me. It hurts me. You have no idea." And he stopped. He stopped and he never said that again, never.

July 27, 2011

For parents, getting their friends and relatives "on board" with the “autism lifestyle” is not just about explaining the diagnosis to them and having them understand what it means as a term or as a label, but also making sure that they follow new family rules that are implemented to address specific needs, and understanding why parents feel how they feel and do what they do.
Some parents had to teach friends and relatives about ways to address their children's behaviors. Other parents had to tell their loved ones what foods or toys to give to their children. Similar to Jessica's situation with her father, Bala had to redefine her role as mother, as daughter, and as meal provider after she introduced a new diet for Anna that severely restricted the kinds of foods she could eat. This situation affected not only her role as mother to Anna, but also as mother to her two other children:

They (her family) didn't understand a lot, but they followed it, and understood that that's what she can have and whatever, so they understood what we were doing and it was for her benefit. Like, my mom would help me with her a lot, so like my mom would have to be careful of everything that she gave her, and you know, I felt bad sometimes, she couldn't have this, and other kids, so you know, she'd make sure the other kids were somewhere else when Anna was having this, so she wouldn't see the other kids eating something else, and, cuz she would be like looking, even though she wouldn't even want it. She would look though, what everybody's having. She would look, like, check and stuff. But they were pretty supportive of it. It was like hard, my dad didn't understand. He would like bring out all these, grandpa bringing out all this candy, and M&Ms, and I'm like, "No, you can't give her that". So, it was kinda hard explaining that, cuz they're like, "It's candy!"

July 26, 2011

Meghan went through a similar process with her in-laws when she introduced a special diet for Jack and when she had specific responses to his behavior that she wanted to be consistent for all of the people who provided care to him. After she found that her in-laws were not following the rules that she had laid out for the caregiving of her son, there was tension in the home:

Juliette: Um, did you find that, the other people in your family, they were on board with, when you said, you know, "We're not gonna give him these kinds of foods anymore, like, no more cookies for him." Did people listen to you?

Meghan: No.

Juliette: ...or did you have to educate them about

Meghan: I mean, no matter how much I try to educate them, they still don't understand, but I had, it came to a point where I had to do what I had to do.

Juliette: Right
Meghan: By, being very, I mean, I don't wanna say, I don't know, I'm trying to find a word to explain how I, I had to be very, cold, about it. Like, my in-laws, we have this thing, where now whatever I say about my kids has to go, because it's never gonna work.

Juliette: Right.

Meghan: So, that's how it is right now. Because I kinda had to make it like that, or else, I can't say like, "Okay, do that", and then they do something else and then it's never gonna be consistent and the only way to make him better is to be consistent. That's the only way for me to teach them, 'cause they wouldn't listen to me. So, I had to, you know, I had to make it like that, you know.

Juliette: Yeah.

Meghan: Like, this, it's either this way or no way, or, it's either this way or I quit my job and I stay home with my kids.

Juliette: Yeah.

Meghan: You know?

Juliette: So was it that way too with responses to behavior or what he's allowed to do and what he's not allowed to do? Did you have to be very strict, almost with them about?

Meghan: Yeah. I had to be that with everyone, with my, with Charlie, I mean, that's why he always says I'm such a rigid, cold person. That's how he sees me now, but I had to.

Juliette: I can't ever imagine that...

Meghan: I had no choice, you know. That's not who I am, but I had to be that way or else nothing would ever work.

Juliette: Yeah

Meghan: But it's hard for me, because I'm at work all day. I'm not there to see what's going on, so if you don't instill these, these ideas, you know...

Juliette: Yeah.

Meghan: There has to be some type of fear. I don't wanna use that word, but there has to be some type of, oh, if, if, if something happens, they're gunna get, they're not gunna get in trouble, but I'm gunna be upset.

Juliette: Yeah.
Meghan: I had to do that, or else it'll never work, you know. And it's sad, but, it's true, and I had to do it like that.

Juliette: Yeah.

Meghan: So right now, my relationship with my in-laws, we're not, you know...

Juliette: Not good?

Meghan: We don't have a good relationship, but it has to work for my kids.

When Meghan speaks of "doing what I had to do" and becoming a "cold, rigid person", she is talking about the specific steps she deliberately took to change her role in her family. She was living in her in-laws house and prior to the diagnosis had been wary of telling them how to care for her son. After the diagnosis though, she decided to do whatever it took, including being "cold" and "rigid" in order to ensure that her in-laws followed her rules regarding Jack.

As an example of how she redefined her role as caregiver in her relationship with her in-laws, Meghan describes an incident with her mother-in-law regarding potty-training. She was trying to potty-train Jack and needed all of her relatives to be consistent with the potty-training schedule and procedure that she had implemented for him. When she returned to work, and he went to Grandma's house, her work began to unravel and she had to be firm about her expectations:

Meghan: And I made sure. I made sure he was fully potty-trained before I went back to work, you know? So then he had to go to Grandma's house, and that was, that was another thing. You know, so he had all these accidents, and I'm like, oh my god

Juliette: Yeah

Meghan: Everything you know we worked on, is, you need to be consistent.

Juliette: Did you have to start all over again?

Meghan: I didn't have to start it all over, but I had to keep reminding them over and over and over again. "You need to be consistent and don't let him do this and don't give him
the Doodle (a favorite toy)." 'Cause I used the Doodle as the reinforcer (to get him to use the toilet) and he wouldn't get, he could not get the Doodle until he does it, in the potty.

August 5, 2011

Sarah describes the impact that adopting an “autism lifestyle” had on her relationship with a childhood friend, and friend who understood what autism is, but did not understand or support the parenting techniques that Sarah employed and the daily changes that Sarah had to make to her life:

...the reason why I don't speak to her anymore is because uh, I know you heard us, I know you heard me speak when we say that autism tests all your relationships. I was friends with her for 26 years before we stopped being friends, because uh, when Ava got diagnosed, maybe 3,4,5,6, maybe 3 or 4 years after, I started to notice that she was another one too, that kind that would say that I was making a big deal out of, out of it, that I just needed to leave her (Ava) be, and she would kind of even criticize how I was parenting her. "Just leave her be. Why are you so overprotective. You're always on top of her. Just let her be!", and I'm like, you know, "I can't!", I'm like, you know, I used to try to explain to her, do you see when I call her she doesn't turn around? I'm like, so if I'm letting her just walk, you know, what if she walks out front and gets hit by a car? You know what I mean?

July 15, 2011

Some parents felt that they had the support of their friends and relatives in acknowledging the diagnosis but that despite that support, their loved ones could not fully understand what autism meant for the parents' lives. Kaleena describes her mother's relationship with Jacob's autism:

Juliette: Did you find that you needed to talk to like any family members about what was going on or how did you present it, you know, to them?

Kaleena: I did...

Juliette: Were they familiar...

Kaleena: No. No. I mean I did speak to them. I spoke with my mother um, with everybody - my mother, my grandmother, and my sister. But they weren't really helpful cause they didn't really know, you know, they were just like, "We can try to support you." But they didn't really

Juliette: Yeah
Kaleena: And some of the things they didn't understand. Um, like my grandmother, she didn't understand why he needed speech therapy. "Why does he need that?" Uh, you know, "He's just a little delayed. Nothing's wrong with him. He's just a boy. He'll be fine." You know, but he's not talking.

August 10, 2011

Richard echoes Kaleena's sentiments about his own mother who loves and supports him and his son but who doesn't fully understand the everyday experiences of autism and how they impact Richard:

You know, like I just did Marcus' First Communion at the church, and I'm, I'm not very religious. My mother is very Christian, kinda person, and I stay there sometimes at her house, in between friends, because obviously stuff is going on, but I'm like, and when we went to the church, she's like, "He's fidgeting! He's tapping this. He's always pulling on the hymnal!" This and that, and I'm like, I'm like, "He's not freakin out. He's not yelling out at the priest. He's not, you turning around looking at the people." and I'm like you know, what I'm accepting as like man, really adjusting well, she's like "Why's he, why's he fidgeting? Why's he this, why's he that?" And I'm like, you can't judge him for that standard, like, you know, if you ask my mother, sure, "Oh, oh yeah, my grandson's autistic. He got Asperger's. He goes to a special school", this and that. Um, you know, "He flaps his hands" you know, but she couldn't tell you why he, you know, how to react necessarily, you know.

August 4, 2011

Richard's mother also worries about the impact that Marcus' autistic behaviors have on Richard's life and when Richard and Joan's custody battle began, she gave him a suggestion that created tension in Richard's relationship with his mother:

And the other side of it to is that, you know, like I said, my mother who doesn't get it said to me, "You know what? This could be the best thing for you. Just write her a check every month and go live life! You don't need to be tied down to her and you know, that kid's autistic and she's gunna raise him a certain way and he doesn't listen to her and she's gonna create a monster outta him and you don't need to be involved in that." And I'm like, "Yeah, but that's my kid."

August 4, 2011

For these parents, it was not just important that their friends and family acknowledge and accept that their children have autism diagnoses, but also that they understand the everyday changes that were going on in their lives and respect parents' responses to behaviors, diets, scheduling, and
priority shifts that happened as a result of the diagnosis. Figuring out how to care for their children, whose advice to take, when to stand firm about their own beliefs about autism, and when to negotiate control, was all uncharted territory for these parents. For some parents, they had already seen their social lives change or had tensions with family members about parenting styles with their other children. For other parents, this experience with autism was their first experience with parenthood. To manage these disagreements and differences of opinions, parents had to consider the various roles they played in their own personal relationships, and also how much they would allow other people to play a role in their relationship with their children, and with autism. All of these various deliberations and decisions have in turn, shaped their identifications as autism parents.

**Marriages and Partnerships Tried and Tested**

Another type of relationship heavily impacted by the daily changes that occur when a child is diagnosed with autism is marriage or romantic partnership. Of the 18 households I came to know over my 18 months of fieldwork, 11 are currently married, one is single and has never been married, four are divorced, and two are separated. All of the divorces occurred after the diagnosis, often because parents had different experiences with the autism diagnosis and the daily changes that occurred thereafter. Some parents say daily struggles make them stronger as a couple. For others, the fights over response to the diagnosis and parenting styles signal the demise of the relationship. For still others, the struggles and tensions surrounding the daily changes caused by autism are compartmentalized and become a separate part of the relationship.

Within romantic partnerships, an autism diagnosis marks the beginning of uncharted territory. The couple may be able to navigate together, or they may find that it order to keep themselves happy, they have to split up. Appearance of autism in a partnership may require
parents to redefine roles in that partnership, based on who is willing to commit their time, energy, and emotions to taking care of some of the more difficult daily tasks that may come along. Jessica explains that right after the diagnosis she and her husband struggled. They were able to work through the tension regarding their contrasting responses to the diagnosis and now work as a unified team:

Andres, in the beginning, he was in denial. Still in the Early Intervention he was in denial. He didn't want to believe it. When they say maybe he needs to go to the special school, he's gonna be like, no, no, no, and I said, "Well okay, you are, are you with me or just leaving. Because I'm not gonna stop. Something is going on, we need to figure it out what it is." And since then, if I don't call the school to complain, anything happen, he will call. If the bus is late, he will call. He will do the complaint. He will write a letter. If I don't do it, he will do it. Because he is with me. He is 100% my support, all the time. If something happened the school, an incident, sometimes they don't call me. They call him, even at the office, because they know. They know, and the teachers, especially the school coordinator, she knows Andres. She was like, "Okay Andres, I don't know how to tell you this, but something happened today." Because they already know. Not to say they're afraid of us, but they know us. So every IEP meeting we have, we go to together.

Juliette: You both go, yeah.

Jessica: We go together. It's not just me. This is not about me, and even though they're like, Andres is like, "You know better. You know everything you do." I want him to come with me and he's always like, "What we have to do? What we have to do?" and we call for this and we do it together. And the same we're doing with Sergio. For the IEP meeting we're going to together. For the orientation in the new school, we went together. I'm like, I mean, that's the way it's supposed to be, right?

July 27, 2011

This may be contrasted with Richard's relationship with his wife Joan, with whom he is currently going through a separation and divorce process. As Richard explained, it was their different responses to the diagnosis, and later their parenting styles that signaled the end of their relationship. After Richard spoke to his OT friend about Marcus' behaviors, he wanted to start an evaluation process to see if his hunches about autism were right. His wife however, did not want to start the evaluation process and this became a major battle for them:
Richard: ...When I told his mother that's when the beginning of all our real problems, really began. We weren't doing great before that, well like, "How dare you say your child's not perfect!" this and that, "You're a monster!" blah, blah, blah, blah. And that became like, and so we decided on not getting him diagnosed and I deal with him how I deal with him and she deal with him how she deal with him, for about 2 years until he had Pre-K. And I mean, we tried preschool out but he needed 1-1 when he was there. They told her he might need something and she's like, "We're not going back to that school." this and that, so

Juliette: Did you have...

Richard: Getting him evaluated would have been like the death knell for her, you know, accepting, and at the same time I was perfectly happy if to avoid the fight and I was also perfectly happy not to hear it myself even though I knew it, you know what I mean? And, you know, one of those things when if you had the magic Delorian to go back and you know like, "No. No, really. We gotta go do this (get the diagnosis)."

August 4, 2011

In other relationships, the parents do not become unified like Jessica and Andres, nor do they end their marriage like Richard and Joan. Instead, they use other tactics such as avoiding the conversation or delegating the "autism related duties". Often this means that one parent will attend meetings, trainings, take care of school and medical paperwork, and fill the role as parent advocate. Such tactics were employed to deal with the underlying struggle that Kate and her husband, and Leslie and her husband, endure in their marriage. During a financial planning session for special needs children that I attended with some of the parents, Leslie raised her hand and asked the presenter a question. We had been learning about a special saving plan called a Special Needs Trust. Parents establish such a trust in order to ensure that their children with special needs will have access to family money and still be eligible for government financial support when they turn 18 years old. Leslie asked:

Leslie: "What happens if one person wants to and one does not?" Leslie is asking this question for herself and for Kate, who sits next to her. She looks at the presenter and back at Kate as she waits for an answer.
Financial Planner: "You can set it up on your own, but if you pass first, you will not have any control and the money will be left to child... or just take a bat to his head (implies the husband's head). Several women laugh.

January 22, 2011

Later that day in the car Julia commented on Leslie's struggle with her husband, and told me about some problems that Kate was also facing:

    Julia said that Leslie is having a lot of trouble with her husband not being understanding and mentioned that Kate is really struggling too. She said that Kate and her husband had a huge fight after the January 8th workshop because Kate came home to find Braden climbing on a cabinet while his dad was watching T.V. She said that she's sick of going to all of these parent trainings when he's not being involved. Her husband responded by saying that she shouldn't have to go to trainings to know how to be a parent. January 22, 2011

I later met with Kate and talked to her about her perspective on the issue Julia has raised with me a few days earlier. Through her story, she was able to show me that within a romantic partnership, it is not just how Kate identifies with autism and as an autism parent, but whether or not and in what ways, her spouse identifies. Because they are in this together, their multiple identifications impact each other:

    Kate told me that she is so grateful for fathers like Andres and Galen because they get it. She said that her husband is still in denial and that his family thinks that Braden just has a speech delay and that he'll catch up. She said that she and her husband got into a big fight about it. There was a fathers workshop with Matt (the ABA presenter) held in the community space in Kate's husband's parent's apartment building (Kate reserved the space, as she has for several other events). She assumed that her husband would go, but he refused. He said that he doesn't need some experts telling him how to be a parent. She told me that she doesn't even invite him to the events and workshops anymore because he won't come. She said that one day he will get it, but she can't make him. July 2, 2011

Leslie and her husband also had different ways of understanding their son Joey's diagnosis. Leslie describes the day that a psychologist came to her home to do a pre-evaluation of Joey. Joey had been receiving Early Intervention services for months already because of low muscle tone and Torticollis, a muscle stiffness and pain often experienced by premature babies,
so she had been alerted to and concerned about some of Joey's behaviors for a while. The day that the psychologist came for this important evaluation, her husband was not present, as he has not been for many workshops, trainings, support meetings, and office visits since.

And then, when the psychologist came in. It was October - October '08. And when he came, I remember he was coming to tell me whether he was or he wasn't (autistic), and um, I had the kids here and everything. It was like 4 o'clock in the afternoon, and he just said, he just looked at him, and Joey was just doing his thing - just watching TV, just doing his thing. And he said to me, um, "If I tell you what I feel, you know, you tell me if I'm wrong." So I said, "Okay", so he said, um, he didn't pull anything out specifically - books or anything like that, just was like, "Do you see this? Do you see this?" Like "This?" All these things, like the classifications, like, you know, Joey with the hand flapping, and um, certain characteristics and stuff, um. "Do you agree?" So I said to him, "Yeah. Like, you know Yeah." And then before that - maybe like an hour or two, three, a couple hours before that - I did that autism checklist on the computer, and I had a feeling. And I remember Nathan wasn't here. He had to, he was going to a doctor's appointment, and he said to me, "You want me stay home with you?" And I was trying to be this tough one, like, "No. Go. I'm fine." You know, "I don't need you. Go." and um, cause my whole thing was like, if you wanted to be here you woulda been here, you know?

September 6, 2011

The strain and tension that Leslie and Kate felt in their marriages was known by all of the other parents in the group and sometimes became a topic of conversation. One evening in November I attended an annual honorary dinner with many members of APSG. During a particularly moving moment when Kate read an "Ode to Leslie" about how wonderful a mother she is, Nathan began to cry. Kate also thanked the fathers, Nathan, Galen, and Andres, for being a part of the special evening and for being there to help her son Braden. She said that her husband is not ready to be here and that she appreciates the other fathers caring for her son.

For Kate and Leslie, dealing with the diagnosis and its everyday implications in their marriage is something that they continue to endure. It is a territory they continue to chart together with their spouses, and they lean on each other as mothers when their husbands are not ready to be there. As Leslie describes, her husband Nathan still doesn't have the same
understanding of their son's behaviors and diagnosis as she does, even three years after the official moment. Leslie thinks of autism as a way of life in which she will always have to provide her son with care. Her husband and his relatives instead refer to the diagnosis of and identification with autism as something to outgrow or get over. Mediating these different experiences is something that many parents of children with autism continually have to work at within their romantic relationships.

And um, I remember calling Joslyn, which is his (Nathan's) sister, which is like the matriarch of the family now, um, she's his godmother, and I remember calling her and telling her. And I remember, you know, I was crying, but what bothered me so much was, they didn't know - they didn't understand what it was, but just the fact how everyone was like, "Oh, he's gunna outgrow it." It was something to outgrow. It was something within time he would get over. And my husband for a long time too, he was the same way. Like, up until now he'll still say," He's gunna be fine. He's gunna be fine." It's something that I've learned to deal with, you know? Not everyone interprets it or deals with it the same, which is fine. Now I can say that, which is fine, back then I was like, "What's wrong with you! You don't understand me! It's not something that you're just gunna put a bandaid and the boo boo's gunna heal." No, it's not like that. This is a life long... And sometimes, I'm not gunna lie, sometimes I get really, really, really angry and I blurt out things like, "You don't understand! He needs help."

September 6, 2011

For many autism parents, the sentiment of frustration that Leslie shares is very real. Upon diagnosis, caregivers must respond in some way. This requires them to formulate an understanding of exactly what autism means to them, to their child, and to their other loved ones. Some decide that autism will become part of their lifestyle and choose to celebrate the good moments and work through the bad by seeking resources and supports that ameliorate the daily struggles. Others respond by ignoring the behaviors that their children exhibit and the medical issues that manifest, hoping that the child will "out grow" autism. Still others decide that autism is something that must be fixed, removed, or cured and work to get rid of autism so that they can have their "normal" child back.
Because researchers and experts in the field of autism studies are still uncertain about what causes the differences in behavior, brain structure, and capabilities of individuals diagnosed with autism spectrum disorders, parents are forced to choose their own way of knowing about autism in order to get through the day. They must chart this territory themselves. When two individuals in a caregiving partnership have fundamentally different responses to autism and its affect on family life, the tension is palpable throughout daily interactions and it is difficult to move forward without entering into the same arguments over and over again.

**Conclusion**

Parents like Sarah and Julia who have nine-year-old children diagnosed with autism told me repeatedly about how they live the autism lifestyle. They explained that it is a different way of organizing, scheduling, and seeing one's life that comes into begin when your child is diagnosed with autism. The three critical moments that I have described above - diagnosis, Early Intervention, and telling friends and family - signal a clear moment when their lives have changed. The way that parents engage with the everyday experiences that occur after these critical moments is equally important and will be the focus of the next few chapters. Here however, I find it crucial to focus on these critical moments because of their intense emotionality and the fundamental changes in one's belief about one's life that they create. When parents begin to suspect that their child may have autism, or when they receive an official diagnosis from a doctor, their emotional engagement with their children and with autism as a concept to consider, discuss, and analyze becomes nearly all consuming. They are often unsure of where to go, what to do, who to listen to, what advice to dismiss. The experiences they have as they figure all of these things out through interactions with people, ideas, and objects around them, shapes the
ways that they identify as parents, children, siblings, romantic partners, and a variety of other relationships in their lives.

Parents must process simultaneously what they believe autism to be (a different kind of way to experience the world, an illness that must be cured, a bunch of behaviors that should just be ignored, etc.), how it impacts their child (something innately part of the child which cannot be removed or changed without changing the child, something that can be isolated and extinguished, something that should be treated and given therapy so that they child can blend in, etc.), and what this means to their everyday lives (hide the diagnosis from family and friends, invest in therapies, pills, and other treatments to get rid of autism, seek resources and supports to assist in their child's development as a human being, educate strangers and the media about autism and how they experience autism in their families, etc.).

The decisions that they make about autism as a part of their world and what they will do to move forward in their lives certainly may change over time through experiences with literature, scientific findings, doctors, educators, friends, family, and their children. For example, Sarah's initial response to the diagnosis as "devastating" has changed as she has seen Ava's progress and her growth as a person, and she now understands autism as a way of life. As she describes autism in some of her Facebook posts, one can see that this lifestyle is filled with ups and downs, but that the sentiment of a devastating existence is now absent and that her identifications with autism have transformed over time:

September 28: It truly is a blessing to witness Ava's progress each day. So happy that slowly but surely she can walk independently without darting off. I have high hopes for my little girl.

September 17: Ava's therapeutic horse back riding lesson. She is doing great! So proud. ;)
— at Riding School
September 12: Autism adventures: delayed reaction to change in routine of the school bus. Resistance to boarding the school bus, whining, dropping to the floor. *sigh* My poor little princess. I need coffee. -_- 

August 16: Realizes that an Autism lifestyle is one that is NEVER dull! ;)

August 16: First day that summer session is out for Ava and our visit to the eye doctor to determine if she needs glasses or not. I am dreading her meltdown and hope that Hercules give me some of his strength to restrain her if she does. :/ Just another day in our Autism adventures. 

August 17: The next time you see a child having a "tantrum" don't think "brat" instead think it possibly could be autism. 

While parents' responses to everyday challenges and how their lives are affected by autism may evolve throughout their lives and as their children grow and change, it is during these critical early moments above, that parents establish an overall understanding of what autism means to them. The literature that they read in books and on the Internet helps to establish their scholarly understanding of the autism diagnosis - as a difference to be celebrated or a problem to be fixed, or somewhere in between. Their early interactions with diagnosticians, clinicians, and doctors inform how they will think about autism and about their children - as a psychological difference, a differently working brain, as a special gift for yet to be discovered talents. How this moment unfolds helps them to think about how to move forward and what to do next. For parents who go to specific kinds of clinics, like Defeat Autism Now (DAN) for a diagnosis, the next stop may be chelation treatments and a hyperbaric oxygen chamber. Other parents who are referred to a local specialist for the diagnosis find that their next step may be finding a support group and filling out insurance paperwork. For some parents like Sarah this moment is the statement of the fact that autism is going to be a part of Ava's life and her life forever. For Kaleena, it is both a relief and a route to a new confusion - what to do next. For Joan, her ex-husband, Richard, feared that it may have been a "death knell", something too
devastating to overcome, and yet three years later she is still moving forward, albeit on a very
different path than he has chosen.

The introduction of Early Intervention services forces parents to rearrange their schedules
and often to quit their jobs or restructure their time. It also forces families to open their homes to
therapists, clinicians, educators, and other specialists and to play with the boundaries between
home and school, private and public. The services often start so soon after diagnosis that parents
are not able to take time to focus on how to process the news of the diagnosis. They are
immediately caught up in a whirlwind of therapists and intensive interventions and are reminded
over and over again of the critical window of opportunity for helping their children. There is a
sort of frenetic urgency involved in Early Intervention that signals to the parents that the goal is
to work hard, fast, and diligently to get their children to catch up to their peers and bridge the
learning gap.

Margaret often told me that her son Elliot went "from the bottle to autism - it's all he's
ever known". What she meant by this is that as soon as he left infancy he was inundated with
autism therapies, special education programming, and the documentation of his deficits and
progress. The summer that he turned eight years old she was so happy for him to finally be
committed to only a few hours of related services (Speech and OT) per week, and to otherwise
"just be a kid!" Parents endure this sense of immediacy, rush, and haste too, however in a very
different manner than their children. This - autism - is not all that parents have ever known. In
fact, this is what parents have never known, and they are suddenly forced to know it, to live it.

The unraveling or strengthening of relationships with loved ones gives them the support
and assistance to increase those bonds, or the impetus to change their relationships and seek new
ones that are better able to support and understand their new lifestyle. The result of these
relationships being tested and tried may also lead to a blurring of the boundaries between private and public as those parents who sever their familial ties with relatives who "just don't understand" strive to redefine their sense of family and community. Parents find that many friendships they have maintained for years fail the test of the autism lifestyle. Their friends may not understand why they have to leave parties early or suddenly have to get off the phone, why they can't go out to dinner in some restaurants, or why they often have to cancel outings and get-togethers at the last minute. Sometimes this causes a major fight that signals the end of the friendship. Other times the frequency of their visits becomes less and less until they realize that they can't remember they last time they saw their best friend from college.

Their relatives may also not understand the diagnosis or the changes in daily routine and activities that ensue. There may be fights with relatives over what food to feed the child, how to respond to the child's behaviors, or whether to keep the diagnosis a secret. Especially when parents live with or in close proximity to relatives, there may be arguments over who has the authority to make the ultimate decisions about giving care to the child. This tension broods within marriages and other romantic partnerships as well. When parents have fundamentally different ways of understanding what autism is and what impact they will allow it to have in their lives, fights over educational programming, medical issues, expectations for the child, and division of labor may grow more and more intense and parents struggle through the process of finding their footing in an autism lifestyle.

However parents chart these new territories, they all pass these major junctions - Diagnosis, Early Intervention, and Telling Others. These are places where some people stop and take a break, reevaluating their expectations of their child, their relationships with loved ones, their expectations for their careers or personal timelines, and their priorities. These are also
places where some autism parents veer off from others, deciding to focus on curing autism, or instead on celebrating their child's different abilities. Some people take a longer rest at these junctions than others, afraid of what lies ahead. Others refuse to break and continue to speed ahead, arming themselves with knowledge, support, and determination. It is through the individual charting of these new territories, and the defining and redefining of roles along the way that parents come to identify with autism, their children, professionals, and their other loved ones in various ways. The obstacles that they encounter, the problems that arise, and the opportunities that become available because of various factors related to autism - the official diagnosis, a new therapy that insurance does not cover, a decision to take a part-time job to accommodate an EI services schedule, etc. order how parents live their lives, and what activities they involve themselves in. These activities present spaces where parents' understandings of themselves and others become variable, multivocal, and interactive, existing as ongoing sites of the production of autism parent identifications and renegotiation of relationships with others.

Chapter 4: Peculiarities and Particularities: The Issue of Bodies

Getting Franklin Ready for School

Nine-year-old Franklin has had only a few quality hours of sleep and is now sitting on the couch before breakfast. He has a straw in his left hand and is flicking it with the index and thumb of his right. Every few minutes he stops flicking and shakes the straw with his left hand. He then pulls it up closely to his right eye and tilts his head ever so slowly to the left. The corner of his right eye makes a perfect diagonal with his left shoulder and it seems as though all of the possible intensity, energy, and muster in his body shoots out through that corner, sharpening its focus on the straw as its movement glimmers in the wee morning hour's light. He sits on the
couch like this for about 30 minutes while Julia showers and dresses; Dad has already left work for an early construction job. Occasionally he rocks back and forth and emits a long, deep, drumming sound that lasts for a few moments. Franklin's five-year-old brother, Victor, sits on the couch watching T.V. while filling in a picture of the big red dog in his Clifford coloring book. He pays no attention to the flicks, the tilts, or the sounds.

Around 6:45am Julia puts a box of cereal and a gallon of milk on the kitchen table for Victor. He pours himself a bowl of cereal and eats while Julia begins to make spaghetti for Franklin. Franklin will only eat pasta, potato chips, and french fries. Julia has tried for years to introduce Franklin to other food options. All attempts are met with inconsolable crying and gnashing at his own skin. Needing to avoid such incident in order to get the children ready for the bus on time, she boils water for the pasta. Franklin eats his pasta, cooked for exactly 10 minutes and served with only butter, while Victor washes his face, brushes his teeth, and picks out a pair or shorts and a t-shirt to wear for school.

At 7:15am Julia takes Franklin into the bathroom to help him brush his teeth and wash his face. She helps him to steady the toothbrush in his mouth and then assists him, hand-over-hand, with his toothbrush - back and forth, back and forth. She sings a little song to him as they move the toothbrush together: "One, two, three, spit! One, two, three, four, spit! One, two, three, four, five, spit!" and repeats until they are done. Hand-over-hand again, she helps Franklin pump soap out of the dispenser so that he can wash his face. She reminds him several times to look at his hands while he pumps: "Not too much. Not too hard. Look at what you're doing. Look at the soap." Franklin stares into the mirror at his reflection. She helps him to lather his face with the soap and then instructs him to rinse his face with warm water.
Victor calls to her from the living room. He is looking for his backpack and needs her help to find it. She tells Franklin to rinse the rest of the soap off of his chin and neck. Upon entering the living room she finds Victor's backpack behind the couch, and then reminds him to make sure that all of his supplies and homework are in his backpack. She goes back into the bathroom to check on Franklin. His head is tilted. His hand is raised in front of his face, and out of the corner of his eye, he is staring at the water droplets running down his hand onto his forearm. The soap on his chin and neck remain. He has been standing there for more than five minutes. She prompts him to look at her and tells him that they have to hurry so they are not late for the bus.

Now Julia must help Franklin get dressed. They have been working on this for months now. Julia chooses a shirt for him and flattens it on the bed. Then she prompts Franklin to pick up the shirt and move his arms through the sleeves, one at a time. She reminds him to stand straight and pull the shirt over his head. As he tries to pull the shirt down, his head gets stuck. He begins to make noises out of frustration and she can see his body become tense. She wants desperately to pull the shirt over his head in that effortless movement that she makes for herself everyday. She wants to put an end to his frustration and to hurry through this activity so that they can move on to his shorts and shoes, but she doesn't. Instead, she stands in front of him, prompting him to use his own hands to find the head hole and pull the shirt over his head. After what seems like an excruciatingly long time, his head pops through and she claps excitedly. She tells him how proud she is of him and how she always knew he could do it by himself. They then move on to his shorts.

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Experiences of autism are inscribed on bodies in varied ways. Unlike other disability labels such as Down syndrome, or Fragile X syndrome, there are often few physiological features associated with autism. In general the bodies of individuals with autism look "normal" and are not immediately stigmatized. Only when those bodies move and are used as vehicles of communication or as interactants with the world, do the characteristics termed “autism” become present. The physical manifestations of autism are often identified as hand flapping, toe walking, staring or flicking at objects, lining up or stacking objects, and a retreat from other bodies. It is not only what bodies of individuals diagnosed with autism do (or do not do) that signals the disorder, but also what the bodies around them do (or do not do). In this way, experiences of autism are also written on the bodies of their parents, siblings, teachers, and other individuals who occupy the same space. In this chapter I begin by presenting two terms - peculiarities and particularities - that I use to describe the multiplicity and uniqueness of the everyday experiences I observed parents enduring throughout my fieldwork. Next, I introduce the work of Merleau-Ponty and apply it to the data that I collected as I observed parents interacting with their children's bodies or heard parents' stories about such interactions. Then, I shift my focus to present data that demonstrate how these concepts (peculiarities, particularities, and experiencing the world through one's body) are played out in the experiences of parents and their children by focusing on four topics: Activities of Daily Living, Gastroentestinal Issues, Safety, and Sexuality and Puberty. Finally, I close this chapter by reflecting on the activities of the parents in my study as long-term care-giving and discuss how their engagement with the topics mentioned above is constantly changed to adapt to the changing bodies of their children, and their own.

Peculiarities and Particularities
This chapter discusses the peculiarities of bodies and the particularities (places, events, situations) in which these bodies find themselves. I use these terms in reaction to the current medical model of disability language, which identifies and labels not only the differences in peoples' bodies and behaviors (one leg instead of two, an extra Y chromosome, a cleft palate, hand flapping, difficulty concentrating, etc.), but also the individuals themselves ("disabled person," "autistic," "mentally retarded," etc.). I use the term "peculiarities" because all bodies are in some ways peculiar, in some ways a bit different from the other bodies around them. By using this term we can talk about differences in bodies without attaching a value or judgment to those differences, but instead discuss how they impact peoples' daily lives. I use the term "particularities" to emphasize the importance of time and place, both current and historical, for how the peculiarities of peoples' bodies are responded to, cared for, and understood. This concept includes an understanding of the changes that occur in and around someone's body over the course of a lifetime (bodies may need to be addressed and cared for differently at ages 2 and 42), as well as the social changes that occur which may affect the reactions and responses that others have to bodily peculiarities (bodies that would have been cared for only by doctors in institutions in the 1960s are now cared for at home by parents and community workers).

Scientific discussions of autism focus on the autistic body and whether there is an autism gene, or whether autism is a bodily deficit that occurs during early development. Therapeutic discussions of autism talk focus on how to change the body of the autistic person to make him or her better able to adapt to sensory stimuli or other individuals. Throughout these discussions there is an underlying, or perhaps overwhelming, assumption that autism is a present, static something that occurs in one's body. Bodies labeled with autism are approached professionally as being the same kind of body, in need of the same therapies and treatments, hence the ever-
present search for "a blanket cure". I argue that this is not the case, and that parents and children experience the peculiarities of each other’s bodies and the particularities of the situations in which they find themselves (toilet training, puberty, dealing with privacy, etc.) multiply. Professionals - those who label, those who treat, those who provide therapy, those who determine lifelong outcomes – must take the multiplicity of these experiences into account, otherwise we risk limiting the potential of individuals' bodies and neglecting their individual needs.

Based on months of observations of Julia's interactions with her son Franklin, and conversations with her about their daily activities, the composite sketch above shows many of the peculiarities of Franklin's body and the specific activities through which he and his mother must orchestrate the movement of his body. In this chapter, I argue that what autism is or where it is located (which have largely been the focuses of those studying autism) are not of vital importance, but rather the focus should be shifted, the discussion should be changed, to consider the peculiarities of individual bodies, like Franklin's, the particular spaces and situations in which they are found, like getting ready for school, and the various tools, resources, or support they require.

While attempting to change this conversation, I must first contextualize it by explaining the models of disability that are currently available in the United States. One is a medical model, which “regards both disease and sickness as medical conditions that are produced by specific entities (such as a virus) and assumes that the role of medical intervention is to control the symptoms of a disease and, where possible, remove the causes" (Turner 2001:257). Within this model, physical impairments, psychological disorders, cognitive differences, etc. are all considered deficits of or challenges to the individual, and can be tested, medicalized, treated,
assessed, and sometimes cured. Conversely, the social model of disability focuses on how notions of disability are socially produced and calls for social accountability to adequately accommodate the needs of individuals' impairments. According to Kelly, some scholars have expanded the social model to include the disabling of families of an impaired child who struggle for social inclusion against social and physical barriers and medically defined disability labels (2005); I take after these scholars in the way that I conceptualize disability as well.

In this chapter, I demonstrate how the requirements of children’s autism labels, order parents’ lives, dictating how parents address children's eating, toileting, and dressing behaviors, how daily activities are planned and scheduled, and how parents interact with their children's bodies. Finally, I look at the future of these activities and the sense of anxiety that they create for parents as they picture life for their children after they themselves have died. How children's bodies will be cared for after one dies is a constantly underlying fear - a nagging, torturous question for many parents. This question too is riddled by the peculiarities of each body and the particularities of the situations in which it may find itself. There are no definite answers, no "right" ways to handle these situations. As parents make choices about how to engage with these dilemmas, or as they find themselves in the middle of a difficult situation, their actions determine future paths (seeking help from a professional, going to a support group, changing a family's schedule or diet, etc.) which inevitably order and reorder parents' lives by instructing them about how they will need to plan their time, whose company they will keep, what materials they will read or listen to, etc.

**Experiencing the World Through the Autistic Body**

Merleau-Ponty describes how we understand the world, the human body, and the consciousness one has of one's body in the world, as interconnected and as together creating the
phenomenal quality of experience. For Merleau-Ponty, the elements of the natural world do not remain static, and neither do our bodies or our bodies' connections to those elements. In thinking about autism parents, their bodies, their connections with their children's bodies, and their connections with other elements of the world that they encounter, I think of how experiences are informed by the peculiarities of our bodies and also by the situations that we happen upon. By peculiarities I mean the ways our bodies are put together, how they function, what they look like, and the ways that they move. These include stature, facial features, weight, mobility, sensory engagement with the world (sight, sound, touch, taste, smell), and many other possibilities. Each body is unique and each has a varied experience in the world because of these peculiarities.

Additionally, these peculiarities are not static - people grow older, their bodies change - nor are the particularities of situations static. Merleau-Ponty speaks of perspective and the unique perspective that each person may take when looking at a chair, for example. These perspectives are not affected solely by the peculiarities of each body looking at it, but also by the situatedness of the person (looking from afar vs. looking up close), the chair (next to a desk inside an office, vs. suspended upside from a vine in the jungle), and the situatedness of the moment (in 1990s Beijing vs. Pre-Industrial Revolution France). Throughout this chapter I use Merleau-Ponty's work to understand the body as a peculiar vehicle through which people interact with the world, a vehicle that must and does make adjustments to the particularities of various situations. I use the term peculiar to describe each body in order to describe the singularity and strangeness of experience within each body – in other words, no experience will ever be the same for two different bodies, and because of this, any experience one body has will always be in some way strange, unfamiliar, and foreign to another body.

Using Topics of Concern to Interrogate Experiences of the Body
I use this vehicle to interrogate the interactions between parents and their diagnosed children, by focusing on topics that concern children's bodies - how they move their bodies, what they do with their bodies, and what others do with their bodies. Likewise, they concern how parents' bodies interact with children's bodies. The relationships between parents' bodies and children's bodies, and the changes to these relationships, order parents’ daily experiences and order their interactions with their children. In this section, I will pay close attention to the peculiarities of different children's bodies, and what those bodies require from their parents.

These peculiarities are particularities as well. Changing from moment to moment, they depend on children and parents' individual developmental paths, situational contexts, surrounding people and events, and parents' unique interactions. For example, the situation in which a 30-year-old mother changes the diaper of her four-year-old daughter will likely be very different than that same mother at 50 years old, changing her 24-year-old's diaper, or perhaps helping her apply a sanitary napkin. Throughout this chapter I focus on the particularities of these bodily peculiarities and give some examples of what these interactions may look like in the context of autism parenthood.

In the next four sections I focus on topics of concern that were discussed by some specific parents who participated in this study, all of which in some way "disable the family" as Julia suggested in the introduction. These topics are sources of daily struggle for many parents as they care for their children's bodies. In presenting them, I aim to emphasize the importance of bodies and the variability of those bodies. Many of the conversations between parents that I listened to were about these topics. For some parents, these topics and the issues associated with them became all consuming, albeit, temporary. For other parents they were simply passing
issues to discuss, get a bit of advice about, and move on from rather quickly. Each of these four topics meant something different for each parent and ordered parents' lives in different ways.

*Activities of Daily Living (ADL).* A major focus of many autism parents' attention is on "ADL". This term is used in healthcare and therapy to refer to daily self-care activities within an individual's place of residence, in outdoor environments, or both. Health professionals routinely refer to the ability or inability to perform ADLs as a measurement of the functional status of a person, particularly in regards to people with disabilities and the elderly. ADLs are defined as the things we "normally" do, such as feeding ourselves, bathing, dressing, grooming, work, homemaking, and leisure. Different ADLs are required for different people at different times in their lives. For example, a four-year-old is not often required to engage in a sale transaction and count the correct amount of change for a purchase, but this may be required of a 16-year-old. For many of the children whose parents I studied, the ADLs usually required for their age range created struggle and frustration.

For example, common daily practices such as brushing teeth or putting on sandals were often incredibly challenging for the children of many of the parents I observed. They can and do learn how to fasten a Velcro closure or wash their faces thoroughly, but it takes much more repeated practice than many other children require, and progress in this work is often very slow paced. Because of this pace, I observed several of the parents preparing to end an activity (leaving the park to go home) and pack up very early, in anticipation of some of the struggle they would have to manage. They also would often leave extra time to get ready to leave their houses than they would have otherwise, knowing that they would have to help their children get dressed, brush teeth, etc.
One afternoon I went to a large public playground with several parents and their children. The children played in the sprinklers, on the playground equipment, and ate snacks on the park benches. The parents supervised these activities and engaged in play or ate snacks too, at various times. At the end of the playdate, after all of the children had played in the sprinklers together, Sarah had to put her daughter, Ava, into a dry sundress, and Julia had to change her son, Franklin, into his dry shorts before getting into the car. The public bathroom at the park was locked for some reason, so the children had to be dressed in the park. In my fieldnotes I describe the scene:

Rachel (Sarah's mother-in-law) and Sarah worked together to put a towel dress on Ava so that they could take off her bathing suit beneath it and then put on clean underwear and a dress. It took both of them to hold and maneuver her body to get her dressed. She did not fight them during this time, but did not move her body in any cooperative motions. Julia was undressing Franklin at the same time. Both of these children are nine years old and their parents still have to undress and dress them. Julia wrapped a big towel around Franklin and asked him to hold the two ends of it together to create a dressing area around him so that no one at the park could see him naked. It was very difficult for Franklin to hold the ends of the towel. He kept dropping one end of the other and when she had him move his feet to get them in or out of his shorts, he had to hold on to her for balance and would drop the other side of the towel that he was supposed to hold. It took over five minutes for each set of adults to change the children's clothes.

Fieldnote written June 30, 2011

The fine motor skills, focused attention, and executive planning required to dress oneself is great. Most of us do not think of a daily living skill such as putting on pants, would require so much effort. We may think about learning to tie our shoes when we were children and remember the patience and repetition it took. We may even think about young children we know now who are learning to dress themselves, acknowledge the learning process required, and giggle when they accidentally put their shorts or dress on backwards. What Sarah and Julia endured here is different. Their children are nine years old and struggle to put on their own clothing. Franklin has to be prompted repeatedly to get through the process of putting his right leg into a pant leg,
and then his left leg into another. Even when he can focus enough to do this with minimal prompting, the pace is excruciatingly slow. He concentrates, looks at Julia constantly for approving nods, and slowly plods through the activity. Franklin is 5'5" and weighs at least 120 lbs. When he has to lean on his mother to position himself so that he can put on his underwear, the experience for both of them is something difficult, and time consuming, yet has to be done.

This scene, and many like it, unfolds in the middle of a public park. Few people take notice when a baby or toddler requires a mother's help to get dressed, but when a boy nearly as tall as his mother has this need, the stares from onlookers are common. Yet Julia and Sarah press on. They have seen the stares before, heard the whispers behind their backs, but must focus on their children and this ADL so that they can eventually leave the park. The parents, however, do not rush. Instead, they use this time, in the middle of the park, with their half-naked children, as an educative moment. Julia prompts her son along, positioning his hand on the towel, reminding him to hold on to her for support. Sarah shows Ava where the tag in her dress is and tells her that it goes in the back, as she puts the dress on. When Sarah's mother-in-law slides Ava's foot into one sandal, Sarah tells her to make Ava do it, and reminds her that this is practice - always practice.

Meanwhile, Julia's other son, five year old Victor, who has not been diagnosed with autism, runs toward Julia and asks her if he can get an ice cream from the truck that has stopped near the sidewalk. Julia motions him away and shifts her attention back to Franklin, buttoning the last of the buttons on his shorts. She then prompts him to pull up on the zipper and shifts her attention back to Victor's request. She tells him that they can get an ice cream soon if he is patient while she finishes with Franklin. She tells Victor that Franklin is trying to get dressed by himself, and that Victor has to wait until they are finished.
Difficulty with ADL has become a central characteristic of autism and many therapeutic programs now address these issues in schools and in private settings. Professionals may see Franklin's difficulty with this ADL as a symptom of "autism". Julia may see it this way, too. At this moment though, does it really matter whether this problem is labeled "autism" or some other word? At this moment, Julia's attention is not focused on a piece of paper labeled with the category "autism". It is not focused on a genetic difference in chromosomes between Franklin and Victor. It is not focused on grey matter in the brain or the possibility of a link between autism and childhood vaccines. At this moment, Julia is trying to help her son put on dry pants so that she can take her boys to get ice cream and can then get into the car to drive home. At this moment, what matters are the peculiarities of her son's body, as well as the techniques that she will use to interact with him, whereas "autism" does not matter. What does matter is the particular situation that Julia has found herself in - helping her son pull up his pants - enveloped by the other quotidian occurrences she is involved in - tending to Victor's request, a schedule for returning home, etc. Getting through this challenging moment, navigating this problem, overcoming this obstacle is what is important to Julia at the moment, and it is this particularity that should be given attention.

As Merleau-Ponty tells us, we experience the world through our bodies and we interact with others through these experiences. The peculiarities of Franklin's body are important to Julia's experience. The size of his body, the way he struggles to grasp with his hands, the way that he processes each step in an activity like putting on shorts, all affect Julia's experience. Likewise, Julia's bodily peculiarities impact the experience. Julia is a tall, strong statured woman, who unlike many of the other mothers in the group, still stands taller than her own child. These peculiarities allow her to stand sturdily even when her son leans on her for help. Franklin
is only nine years old and as his body continues to grow, he may soon stand taller and stronger than his mother. At this time, the particularities of their situation will shift, and their experience changing clothes at the park will be different. The peculiarities and particularities of this kind of event will (re)order their lives differently and they will have to change accordingly.

Autism is diagnosed by looking at the behaviors an individual exhibits. These behaviors are always presented through the body, whether they be an absence of eye contact during an interaction, a one-sided conversation about a particular topic, repetitive hand flapping, or the repetition of a word or phrase over and over. These behaviors, and many others, are used as markers to identify a body as autistic. The ways a body so labeled moves and interacts, however, is always subject to the peculiarities and particularities discussed above. A three year old diagnosed with autism may flap his hands excitedly and hop up and down on his toes. This same boy however, by age 11, may have been taught that people will think he is strange if he does these things, so instead he taps his pencil and squeezes his toes together inside of his shoes. Is this body still autistic? Is it less autistic than it was eight years ago? What determines to what extent it is autistic? These are important questions as we consider the process of diagnosis, currently only made by documenting observable behaviors.

Gastrointestinal Issues. Another example demonstrates the importance of the peculiarities and particularities of bodies concerning autism. Some children who are diagnosed also have gastrointestinal problems. They may have very easily upset stomachs, and some doctors have suggested that parents eliminate certain things from their diets, like gluten or casein to calm their digestion. Some parents and doctors find that for these peculiarities, changing the diet can also have an effect on children's ability to focus and can decrease irritability. For any of
us who have ever had an upset stomach, we can certainly relate to how difficult it is to concentrate and how cranky this may make someone - just imagine having this discomfort daily.

Conversely, many children who have been diagnosed with autism seem to have no issues with different kinds of food. They can eat wheat products, drink milk, and enjoy any kind of food one could imagine, without any stomach discomfort. Does this mean that gastrointestinal issues are a part of autism, or does it mean that they aren't, or are these two separate kinds of autism? Trying to answer these questions can send our thoughts spiraling out of control, and deter us from focusing on what each individual body needs.

An example of just such a deterrent can be seen in the controversial past (and to a great extent, present) of gastrointestinal issues and autism. In 1998 Dr. Andrew Wakefield and his colleagues in the United Kingdom, published a paper in the Lancet detailing a connection that he and twelve other authors found between a bowel disorder and autism (1998:637-71). Of the twelve children in the study, the researchers claimed that eight presented behavioral symptoms after receiving the Measles, Mumps, and Rubella (MMR) vaccine. These behavioral symptoms included gastrointestinal issues, and as each of the children in the study were cited as having been diagnosed with autism, the researchers coined this newfound phenomenon "autistic enterocolitis". The publication of these findings and the suggestion that the MMR vaccine had caused this autistic enterocolitis quickly became a hot topic in the autism community.

Many parents, desperately seeking answers to questions about what autism is, what causes it, and what to do with it, noticed that their children had been diagnosed soon after receiving their childhood vaccinations. They looked to Wakefield's study as an answer to their questions - vaccines had caused autistic enterocolitis, so vaccines must have caused autism. The implications for these findings impacted the medical community as well, as many parents chose
not to vaccinate future children or to spread out their vaccine schedule over several visits to the doctor. This also resulted in a change in 1993 from a triple vaccine (M, M, and R together) to separate vaccines for each. While the controversy in the medical community largely surrounded the issue of whether vaccines cause autism, the topic of gastrointestinal also became entangled in this debate. Many parents who chose to side with Wakefield also came to focus their energies on special diets, discussions about a "clean gut", and vitamins that would help to support gastrointestinal processes. These two topics became interconnected and divided the autism community. Bala ran into this division when she was seeking care for her daughter, Anna:

We went to see this gastric doctor once and he was just totally close-minded to everything. Yeah, I had wanted to do gastric tests on her just to make sure everything was okay because she wasn't eating. She would barely eat and school wouldn't do feeding therapy with her until they knew that she didn't have any gastric issues. So I had to have this test done and the doctor refused to do it because he didn't believe that anything was linked to gastric problems with autism. That was not the case. There are so many kids with these issues, but he was totally close-minded to it. I was so upset when I left there.

July 26, 2011

As Bala explained to me later, the doctor did not want to consider her daughter's gastric issues because she had autism and the gastric/autism relationship had been so connected to the vaccine controversy, in which he took a firm stance for the proposed vaccine schedule. In this situation, Anna's autism was considered first, not her bodily peculiarity. The doctor did not want to get involved with treating an autism patient for gastrointestinal issues because of the controversy, even though it was the stomach issues that he should have been addressing, not her autism diagnosis.

Stomach issues are peculiarities. They may really cause discomfort in children, and this may really cause issues in school and at home, but it is these peculiarities that need addressing, not autism. Instead, parents and professionals alike enter into arguments about whether certain
diets or vitamins are good for people with autism, and have conversations are espousing that a child cannot eat a certain food because she has autism. This talk about autism detracts us from a focus on the particular peculiarity of that body and what that body may benefit from at the moment in order to calm the stomach. When considering the implications of this knowledge, a diet may be helpful for one child with specific stomach peculiarities, but may cause trouble for another. Likewise, abstaining from a certain food may help a child when he or she is two years old, but that diet may be no longer needed when the child grows older.

Of the parents in my study, two mothers adhered to strict diets for their children diagnosed with autism for at least some of the time that I knew them. By the time that my fieldwork was complete, both had discontinued the diets, citing that their children no longer needed them, and that they were not conducive to their lifestyles. Bala described her experience with a gluten-free, casein-free diet for her daughter Anna, and the reasons for why she decided to stop:

I was reading a Jenny McCarthy book at this time, and then, um, I mentioned it to my husband and he kinda said that, cuz I was like thinking that I had to convince him to do this and put all this money into this, but when I kinda mentioned it to him, he was like, "It kinda makes sense", so he was on board. So once he was on board I went straight at it. I did everything with that (diet), and I didn't tell the therapist, but then the third day of taking out milk from her diet, they were coming to me like, "What did you do? She's responding to us" and she's like saying things that I had been telling her for the past nine months, and she wasn't responding. "She's repeat...she's finishing my sentences. She's having conversation with me". I was like, "Okay", so then I told them, okay, "Well I took out the dairy, out of her diet". But I hadn't taken out the wheat yet. Then I continued to do what I did, with the wheat, and I didn't really see that much changes with wheat, with her. With dairy I saw more changes, but not the wheat. So we did that diet for about a year, and then I didn't really see much progress after that. I didn't see her moving forward like anything getting really better. She was very cranky, and a lot of tantrums. It just wasn't benefitting. So we did a trial where we said, okay, let's give her some of the stuff, and take her off and see what happens. Her behavior stayed the same, so we were like,

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4 Jenny McCarthy is an American actress, game show host, and model. She is also a parent activist who claims that vaccines caused her son’s autism. Through her activism, she has spoken loudly against the vaccine schedule and has also claimed that chelation treatment helped to cure her son’s autism.
okay, there's no point in doing this anymore. ... they (Anna's siblings) would be eating Oreos and I would have to send them in like, the other room to go hide and eat it because she would cry if she saw him eating it and she didn't have it. Cuz she didn't understand. She thinks she's gonna be punished, I mean like, cookies, Oreos, she can't have, so that was like really hard to do.

July 26, 2011

Reflecting back on the experience when she stopped seeing benefits for her daughter, she explained her understanding of the peculiarities of her daughter's body in relation to other children diagnosed with autism:

I don't think I'm going to be trying the diet again. Unless there's something specific thing they say that she's allergic to this and it's gonna cause a problem with her, I don't think I can do it anymore because, you know, I don't see any significance in it with her. Because the kids who did benefit from these diets, from what I've found, were the ones who have digestion issues, like gastric problems, they do benefit. But, she never had those issues, so she's not one of them that, this fits into.

July 26, 2011

Bala's experience above captures the potential complexity of this topic of gastrointestinal issues and autism. Bala read a book written by a celebrity mother of a child diagnosed with autism who is a strong advocate of the vaccine-autism connection. In her book, she speaks of a diet that can be used to help child with autism. Bala tried the diet and found that eliminating dairy seemed to help her daughter focus and she saw an increase in her daughter's conversations with therapists. When she decided to eliminate gluten though, she saw no changes. Through these actions, Bala works in a way as her own child’s doctor, experimenting with what foods and food schedules work best for her. She observes her child keenly, asks Anna’s teachers about her progress, makes notes to herself about what foods seem to stimulate, aggravate, or calm her daughter. Through these informal experiments, she collects data about her daughter and about the diet, and uses it to make important decisions about her daughter’s medical care. This cultivated expertise also can give her insight to notice when her knowledge and a doctor’s knowledge conflict, as well as the courage to verbalize this insight.
She later realized that the elimination of dairy was no longer helping her daughter either, and because keeping her daughter's snacks separate from her other children's snacks was so hard on Anna, she decided to stop the diet. She realized that some of the diet (eliminating dairy) was helpful for her daughter's body at a particular point, but later, was no longer helpful. Then she noticed that eliminating wheat was not ever helpful for Anna, and in fact, she saw increased tantrums. She also realized that some children who are diagnosed with autism who have different bodily peculiarities might benefit from certain diets, but that it was not right for her daughter's needs at this particular stage in their family's life.

*Child and Parent Safety.* While safety is a crucial concern for all parents, autism parents speak of a specific concern that affects their anxiety about taking their children to public places. In this section I talk about some possible effects on the body as they pertain to danger/safety and anxiety. While very young children are often not aware of their surroundings, this is generally an understanding that is learned through natural consequences over time. For example, if a young child burns her finger on a hot stove, she will learn to stay away from the stove in the future. For many children diagnosed with autism in my study, these natural consequences do not seem to have the same effect. This may be due to difficulty generalizing the experience of a burn from one particular stove to a potential burn from another hot surface, or perhaps because of sensory responses that keep the child from feeling the burn with the same intensity that another person may feel the same amount of heat. Either way, knowing that awareness of personal safety is a difficult concept for many children diagnosed with autism, many autism parents live in constant fear about the relative ease with which their children may find themselves in dangerous situations. While some children may not feel any bodily sensations when in close proximity to danger, their parents feel these sensations strongly, in the form of
anxieties that are almost palpable. Sarah gave an account of a terrible incident that occurred when Ava was five years old and how Sarah is now always anxious about it happening again:

"I don't know if you noticed or if I told you before, but when Ava was 5 years old she got burned. She received a 2nd degree burn to her right leg. She was visiting with her father on the weekend. At that time her father was living with his mother in Long Island. And um, he uh, at that time Ava was uh, uh, chewing on those chew tubes, they look like a "P". So he said he was getting ready to bring her home, so he went to the microwave and he put a thing of hot water in there with the chew tube to sterilize it. I don't know what he was doin', so you know the microwave, (makes microwave sound) it goes like that, so I assumed what happened is she didn't like that noise, or maybe it drew her, she started stimming off of it. Guess what happened? She opened the microwave, boiling hot water fell on her. Thank god it didn't go on her face or her chest. It was just on her leg. That was one of the worst days of my life, cuz I tell you when I went to, when I went to the emergency room, I wanted to beat the shit out of him, when I saw that. She had these 2nd degree burns to almost 70-80% of her leg - the front and the back. This poor kid, this poor baby. And when I saw it, cuz they had like this cold packs, and I, I don't, that material they use for the burns, when they took it off, Juliette, I wanted to vomit. I was like, "Oh my god, my baby"..."

I was very traumatized with that. I mean, she was traumatized, but I was traumatized even more with that. Even still, you think the kid would learn, right? No! Even in the house she, I've taught her. I've continually taught her with the social stories and the pictures - that's hot, that's danger, don't go there. You would think she would never, ever gone near a microwave again, yeah, everytime that microwave goes off she's right there in the kitchen, goin to look at it, you know, and I'm like, I'm like, lordy, I don't take enough drugs for this.

July 15, 2011

Because Sarah wasn't present when her daughter was injured, she said that she feels an extra sense of responsibility to always be around her. This sense of responsibility is not just something that she feels toward her daughter, but also something that she feels toward herself, for she wants to avoid the trauma that she too, endured as a result of the burn incident. She talks of how only parents of children diagnosed with autism really understand the added dangers that their children can experience, and she is weary about trusting anyone else to look after her daughter. Some parents in the study, like Sarah, said that they felt like they always needed to be in control of situations regarding their children diagnosed with autism, and many of them said
that they really tried to work on reminding themselves to sometimes let go of this control. For example, some parents of children with autism are constantly on high alert about their children running or wandering away, but they are torn between their anxiety about potential dangers, and their hope for their children to one day become independent. Meghan, a mother of a three-year-old daughter not diagnosed with autism, and a five-year-old son diagnosed with autism explains:

Yeah, but, like, I know that, I kinda know that they won't go in the streets. I know Christina (three years old) wouldn't, but I'm like always curi... I'm like always cautious with Jack (five years old) because what if he runs and there's a car like trying to park you know, like to the edge. And he's obsessed with those signs, like those street signs, the stop signs, his letters, you know. He always wants to touch it and he always goes and he touches it and that's like at the end of the block, at the street, so I get nervous. Yeah, so I'm always running behind them. But you know, like at the same time, I know people say "You need to let them go. You need to let him be free." You know, let him, you know, you can't always try to control him, and try to, you know, which is hard for me...

August 5, 2011

As the children get bigger too, there is an increased physical danger for parents as well. One day Jessica explained to the group that the reason why she doesn't wear sandals anymore is because her toenails have all been ripped off due to her son Elias' meltdowns, during which he often unknowingly steps on her toes. Other parents sustained various injuries through such meltdowns, including bruises from punching and kicking, scrapes from fingernails, and other injuries caused by falling over during the struggle. For all of the parents in the study, the children are still currently smaller and physically weaker than the parents; this will not always be the case.

Julia too, has talked about how Franklin now wears the same size shoe as his father. She explained that as he gets bigger and stronger, she has less and less control over him, both physically, and in terms of what she calls her "hold on him" (i.e., listening to her when she tries to calm him down or tell him "no"). Franklin is usually very easy-going and mild mannered, but Julia reports that sometimes he becomes very upset, the cause of which is often never identified.
On a few occasions, I saw such a meltdown occur. Once at the park Franklin became very upset while sitting on a bench, shortly after arriving with his mother and younger brother. No one was able to figure out what was bothering him and he was unable to tell anyone because he does not speak. Suddenly, he just started to rock his body forward and we could see him tensing up. He then began to scratch at his arms and pull at his hair while making agonizing grunting noises and breathing heavily. Occasionally, he would emit a loud whisper of a sound.

Anyone attempting to interfere during such an occasion can easily be scratched by Franklin, because he appears unable to control his frustration and body at these moments. Julia, of course, always wanting to help her son, figure out what's bothering him, and make him feel better, often interferes and restrains him by holding his body in place or putting his arms by his side so that he does not hurt himself with his own hands. That day at the park, she was able to calm him down after a few minutes and then gave him some time to himself before she prompted him to do anything else. When she talks about the future, though, she fears that as his body grows larger and hers grows older, their physical dynamic will change, and she will no longer be able to keep him safe from himself or keep herself safe from him.

While these meltdown situations can be physically dangerous for parents, even when there is no physical threat involved, the emotional impact can still take quite a toll. According to some autism parents, the best way to avoid the fear and anxiety associated with taking their children into places where environmental dangers cannot be controlled is to keep them in a place that has already been "autism proofed". Bala, a mother of a seven year old boy and two five year old twin girls, one of whom was diagnosed with autism, describes why she avoids taking her kids to the park or other public play areas:

Like, there are places that I won't go if I don't feel safe. Like there's like, the park when we go, unless I have somebody there with me, I can't go because I cannot watch three
kids in three different areas. It's like you have to give and take whatever's gunna be safe for them. Cuz safety's my most important thing. That's why I honestly would rather have the kids over here. They have the whole back yard, they have everything here, and the gate is locked so I know they're safe. Nobody can come in, go out, and everybody's okay. That's why I prefer doing playdates and stuff here. Cuz it's just easier than going to a public place and everybody else to because when you're out in public with your kids and even at Funtopia, you gotta watch them every two seconds, but at least here they know there's no where for them to go. We're all here with each other. So whatever meltdowns, whatever, who cares, we're all here. Nobody's like, "Oh, why's he doing that?" or whatever, like, "What can I do to help you? What do you need?"

July 26, 2011

In Bala's quote above she also mentions safety from not only physical dangers, but from social dangers as well. She references the social dangers of public "meltdowns", dangers that can affect parents and children alike. Parents may fear not only potential injury, but also stares and questions from others about why their children are behaving in a particular way, and why they are moving their bodies or emitting sounds in the unusual ways that they may. Jessica described the concern that she feels about both the physical and emotional safety of her son, Elias, because of his lack of personal awareness:

He doesn't understand about...He understands like the light, green means go, red means stop, but sometimes he's like everywhere. He's not paying attention. I'm trying to let him go and see like he's about to cross the street and I just have to grab him. And I tell him. I always prompt him. "Check the street. Do you see cars coming?" "No." "Can we cross the street?" "No." "Yes, Esteban, we can cross the street." I always have to ask that question a million of times, but I have to do it because I don't see any other way to teach him how to cross the street and be aware that you have to be careful. Oh, we don't, sometimes, I let him, like walk in the sidewalk on (Main) Avenue, and he's bumping to people. He's not aware. He doesn't care so, and people they will look at him. He's so tall. He looks fine. Perfectly fine. There's nothing wrong with him. People look at him like, "What's wrong with him" and look at me like, "Pay attention to your child". I already have that feeling. I already have the looks. I already, you are, at this point, I am like so defended. I'm ready to, you know, who's gunna say anything, or, not to start a fight, but to defend myself because I have to. I know I have to control myself because I don't want my son to see, none of the boys to see that I'm fighting.

July 27, 2011
After her child had a meltdown at the aquarium, Sarah described similar feelings from her situation, and via the online forum, thanked the APSG members who were there to help her with her daughter, Ava:

The exhibit is closed so Ava is basically staring at nothing but water and rocks. She keeps asking me where are the walruses and I had to make something up and say they were sleeping. At this time they announce that the seal show is about to begin. I prompt Ava to go, but she becomes fixated at the spot where the walruses are. She won't budge! She's got the major vice grip on the fence. I feel my anxiety growing and my blood pressure rising. I try everything to get her away from there. I prompt her to go to see another exhibit, but at this point, nothing is working. I tell her again about the seal show. She's not "hearing" me. She starts to escape and make excuses saying she has to go to the bathroom. I know she doesn't have to, but I allow her to go into the direction of the bathroom, but when I actually take her, she doesn't want to go. It begins to be a tug of war match. At this point she is dropping to the floor, pulling, and dropping, kicking, and whining. Then, to the rescue here comes a few of my APSG family. Leslie, Julia, and my mom step in. Ava is NOT having it. Julia tries for dear life to distract Ava, but Ava is just so strong. I tell everyone else to go ahead to see the show because at this point, I feel bad that they are waiting for us and they may miss the show. Julia stays behind with me for a while to help me, but Ava is NOT budging. I tell Julia to go ahead as well. Then, Matt steps in to help me, picks Ava up, but again Ava is NOT having it. Finally, I just leave her on the floor. She sits there for a moment, whining, then gets up and goes into the next exhibit.

July 15, 2011

Onlookers stare, perhaps wondering why a girl well over four feet tall is having such a fit, perhaps wondering what kind of mother Ava is to let her act this way, or to treat her this way. Many parents who have experienced these meltdown situations with their kids say that they've become able to tune out the stares and the comments from passersby. Other parents are still heavily affected by these situations and fear that they may happen any time that they leave the safety and security of their homes. Still other parents worry about their own reactions to the comments of others - whether they might yell at someone for being rude or say something mean in the heat of the moment.

The ways that bodies perceive, enter, or react to dangerous situations may vary based on the peculiarities of those bodies and the particularities of the moments they encounter. For Ava,
going close to a microwave that has burned her badly before does not upset, worry, or concern her. For her mother, this situation causes a feeling of trauma and anxiety. Likewise, meltdowns are perceived and experienced differently based on different bodies. For some bodies like Franklin's there may be such sensory stimulation around him that his only reaction to what he is feeling is utter panic and distress. An environmental factor (a cicada buzzing noise from the tree, another child splashing in the sprinkler 40 feet away) may be too much for his body to handle. His urge to stop this feeling by creating another (scratching his arms, pulling his hair) may feel like the best option for him, while his mother and others watching may think of the latter sensations as presenting an immediate danger to Franklin's body, motivating the adults to interfere and stop him.

When communicated, such peculiarities and particularities may be better understood, but unfortunately this is often not an option for children who cannot speak to their parents or who cannot convey their feelings in a way that their caregivers understand. Conversely, the anxiety a parent feels when thinking about a child's future may not be communicated to the child for fear that he or she will not understand, or because one believes it is not appropriate to talk about such things with children. As children grow, they may be able to communicate their understandings of danger to their parents, and their parents may be able to engage in conversations with them about their own experiences and anxieties. When thinking about how to care for bodies and how to keep bodies safe - physically and emotionally, we must think about both the peculiarities of those bodies and the particularities of the situations they happen upon.

These relationships of bodies to one another are never fixed and their articulations with one another can change depending on what individual bodies need at any particular time. Margaret, for example, told me that she decided this past summer that she wanted to teach Elliot
how to gauge his own physical state. While we were at an indoor playground one day, he bumped his head on the climbing tubes and looked at her immediately. She spoke with him for a few minutes alone and then told me that when he was younger he would often bruise or scratch himself accidentally during play and not notice the injury. He would never communicate to her that something had happened to his body, and this caused her to constantly worry about him when he played. Because she would react to his injuries through her anxiety about them, over time he began to as well, later reporting every time he had the slightest bump.

When she decided the timing was right, she began to introduce to him a way of thinking about what happened to his body and whether he needed to communicate it to someone. She told me about how she would bump her head very lightly and then model for him how to think through whether it was worth telling a grown up about the incident. Then she would bump her head slightly harder and tell him that she thought she might need to tell a grown up that she hurt herself. She explained to him that this would help her know whether he was really hurt and needed help. Whenever she saw him fall or bump himself during play, she would ask him to think about what part of his body he hurt, and where he hurt it, and then think about whether he needed to stop playing, or whether he would be okay to continue. Through a constant negotiation and renegotiation of what mother and son needed at any particular moment, they were able to find a way to communicate their bodily experiences with each other and ensure that their focus on the peculiarities and particularities of safety for their bodies benefited them both.

Sexuality and Puberty. Issues of sexuality and puberty are another place where some parents talk about the peculiarities of bodies and particularities of the situations in which they find themselves. Take for example, Sarah's present situation with her nine-year-old daughter. Just under a year ago, only a few weeks before her ninth birthday, Sarah was able to potty-train
Ava. Before then, Sarah was diapering Ava every day and dealing with an inconsistent potty-training schedule. She tried picture cues, and bribes, and consequences, and nothing had worked. At a loss for what to do, and realizing that if she kept on this path she'd one day end up diapering her 30-year-old daughter, she sought the advice of an Applied Behavior Analysis specialist whom she had become acquainted with through the group. The specialist asked her if she was ready to make a real commitment to the effort, and cautioned her about how difficult the process could be. He challenged her to throw away all of Ava's diapers so that she would not be tempted to use them when the process became too unbearable or too inconvenient. She took the challenge and began what she calls the "three weeks of hell".

Sarah has told the story many times, and each time she emphasizes how she thought she'd never make it through. She had to walk her daughter upstairs to the bathroom every 15 minutes for three weeks straight, sometimes kicking and screaming. Once in the bathroom she would prompt her through all of the steps - pulling down her pants, then her underwear, then showing her where any urine and feces go. She would applaud and congratulate her whenever she did use the toilet, and then take her downstairs and give her a favorite toy (a reinforcer) to reward, or reinforce, her good behavior. If Ava soiled her underwear, they would still have to go through this process, but she would not receive a reinforcer after they left the bathroom. Sarah said she barely slept, had to take very quick showers, and had to interrupt meal preparation many times in order to stick to the fifteen minute schedule that the ABA specialist had proposed. In order for the process to be consistent, Sarah and Ava had to dedicate their lives to these activities for three solid weeks. At the end of it though, Ava was able to recognize when she needed to go to the bathroom, walk upstairs by herself, use the toilet, and ask Sarah for help with wiping. Sarah then threw Ava a huge party with balloons, cake, and all of their close family members.
Fast forward about eight months, and Ava had not worn any diapers since before the three weeks of hell. She had had some accidents since, but usually on her way to the bathroom, having been too engaged in an activity to take a bathroom break. Ava had learned that the white plastic diapers with the adhesive closures on either side that she had been wearing since she was a baby were no longer right for her. She had been told time and time again that she was a big girl and that big girls don't wear diapers. Once all of these ideas had finally clicked for Ava and it was clear to her that these diapers would no longer go on her body, after Sarah struggled so hard to get diapers out of their lives for good, Sarah began to think about Ava's future menstruation. Ava, now nine years old was rapidly approaching puberty, an awkward, confusing, and sometimes scary time. For an individual who has difficulty communicating to those who care for her, who needs repeated instruction regarding ADL skills like toileting, dressing, and feeding, and who has just recently come to recognize a white plastic diaper with adhesive closures as something that she does not need for her body, the onset of menses can be incredibly difficult to understand, especially when it is addressed with a sanitary napkin.

At one APSG meeting, Sarah talked to the other parents about her concern regarding Ava's future menstruation and how she planned to approach it. She said that she always felt like she needed to be several steps ahead of Ava, planning for what she would need, preparing her for life experiences that she would have, and knowing how to deal with them before situations arise. She had noticed Ava arousing herself in their home and became aware that Ava was beginning to explore her own body. She also was aware that Ava would one day grow breasts, and she would have to be instructed about how to put on and secure a bra by herself. Like she had with the toileting process, Sarah decided that she would make pictures of these various activities that Ava would have to learn about over time. She looked for coloring books about puberty on the
Internet and also constructed some images of her own. By the end of my research study, Sarah was beginning to introduce Ava to the materials that would become important to the care of her body as she grew older - sanitary napkins and bras - and reported to the group that Ava even liked to try on her mother's bra to pretend that she is a grown up.

During a group meeting Sarah talked about these matters that would become quite important to her, to Ava, and to their relationship as mother/daughter and caregiver/child. While some of the puberty issues that Sarah struggled with in her relationship with Ava resonated with Julia and her son Franklin, others were issues that Julia would never have to worry about. Julia laughed about how glad she was that she would never have to deal with Ava's peculiarities in her relationship with her son Franklin. She was so happy that she wouldn't have to try to explain the concept of a sanitary napkin or why monthly bleeding occurs. However, Julia and Franklin had their own peculiarities to deal with. Franklin, well over five-feet tall, and more than 120 lbs. was a big boy for eight years old. When he began to explore his body in public or attempted to explore his mother's, Julia became uncomfortable. She knew that he was noticing some changes in his body and becoming aware of the differences between her body and his own and she wanted him to become comfortable with himself. When, where, and how this would occur was something that she thought about a lot. For example, one day Julia took Franklin to the doctor. She reported on her conversation with the doctor, to the group:

She said that Franklin is getting older and is curious about sexuality. She still undresses in front of him sometimes and she said sometimes during the day he reaches for her breasts. Julia explained that children diagnosed with autism really rely on their parents for everything. Their mothers especially are the ones that make them feel better when they need it and she’s afraid that Franklin is reaching out to her sexually because she gives him everything (in terms of providing for him as a loving, nurturing, caring mother). Julia said that she told the doctor she tries not to make too big a deal out of it when he grabs at her, and that the doctor said she has to make a big deal out of it. The doctor said that he will have to be taught explicitly that touching women like that is inappropriate and that he won’t learn unless she makes a big deal about it.
In response to this, Sarah employed a strategy that many parents used throughout my fieldwork. She cited a recent article where the local community petitioned for the closure of an adult group home because some of the adult men were exposing themselves in public outside of their house. She said that this was inappropriate, but the men did not mean any harm, and it was their parents' duty to teach them not to behave in that way. Julia added that because the men are now adults, they most likely grew up in an era when autism was not as widely understood and parents of individuals diagnosed with autism did not have the resources to learn about or teach about sexuality and sexually appropriate behavior in public places.

Prior to this time in his life, Julia had always bathed her son, but in light of her conversation with the doctor, and then with the other group members, she started to think about whether his father should begin to care for his body in these specific situations. She talked with the other parents about how sometimes she is the only adult around when her husband is at work, and that she could not let her son go throughout his day without bathing or changing his underwear. In this way, she thought that ideally, she had reached a place in her relationship with her son where boundaries between their bodies needed to be re-negotiated, yet logistically, she had to think about what worked for their family's schedule and from what kind of arrangement Franklin would most likely benefit.

During this conversation between the mothers, Leslie began to cry. Julia asked her what was wrong, and she told the women that her son was only three years old and it is far too early for her to think about puberty. She said that he's still a baby and she can't even begin to imagine teaching him about his body, about masturbation, about sexual intercourse. Julia and Sarah told her that she must begin to think about it. They both had eight-year-old children at the time of the
conversation and were considered *oldtimers* in the group. Leslie, however, had one of the youngest children in the group and was considered a relative *newcomer*.

Lave and Wenger (1991) use these terms, *newcomer* and *oldtimer*, to discuss positionality within a group, and to explain how those who have been in the group longer instruct newer members about what to do and how to do it. Julia and Sarah often talked about these differentiated positionalities as a powerful force in the group, one that allows newcomers to learn from oldtimers and avoid the mistakes oldtimers may have made when they didn't have anyone to guide them through the obstacles they encountered. Deciding how, when, and where to teach a child about puberty is considered of great importance to this group. Oldtimers like Sarah have learned from the story about the young men whose parents never taught them about privacy and who are now engaging in public masturbation; they have learned from the inactivity of those autism parents. They have chosen to actively teach their children about these topics, and want to encourage newcomer parents like Leslie to do the same, even though her son is still very young. The two oldtimers told Leslie that she must at least begin to empower herself with knowledge about the topic, so that when she feels ready, she can begin to teach her son.

Margaret, another oldtimer, and mother of a seven year old at the time of the discussion, agreed with Sarah and Julia about taking things one step at a time, and talked to the group about gradually introducing new concepts that concern the topic of puberty and sexuality. She told us it may be helpful to start talking first about body boundaries and privacy, and reminded us all that teaching about these issues is always an ongoing process. This notion of an ongoing process is important because it points to the changing nature of learning about the changing activities of one's life. At a time in Sarah's life, teaching Ava to use the bathroom was the direct focus of all of her energy. Months later, toileting was no longer an everyday concern, but preparing for
Ava's menstruation was becoming more important. When Ava does begin to menstruate, teaching about sanitary napkins or tampons may become the focus of Sarah's energy, but that too shall one day pass, and yet some other issue, some new obstacle will come into focus for Sarah, because caring for Ava in the multiple ways that her body requires will be a life-long process.

*Long-term Caregiving.* As exemplified in the story about Sarah and Ava, dealing with autism becomes a life-long experience for parents. The demands, tensions, and failures that Kleinman (2009) describes in the previous chapter become part of parents' everyday lives. The parents who participated in my study came to see themselves as their children’s primary caregivers, and often saw themselves as the only people capable of providing for their children's physical, cognitive, and emotional needs and overcoming these obstacles. As parents feared (or at times assumed) the incapability of others around them, they often described a very intense anxiety about the future for their children and what could go wrong when they were no longer there to care for their children.

These fears about the future include protecting children from strangers, from accidents, from those who judge their appearance and behavior, from those who might take advantage of them, and in sum, from the world. During a trip to Dutch Wonderland Amusement Park Julia expressed to me the recent recognition of her heightened fear and anxiety as we rode the skyline across the park. In my fieldnotes I commented:

> When we got to nearly the highest point of the ride (right over the middle of the park), Julia started to get very anxious. She told me that she's noticed that she has become more and more anxious in the last few years. Galen (her husband) told her that it's just because she's getting older, but she thinks it is because she always has to be so careful with Franklin and she's always worried about him. She said that the SkyRide never would have bothered her before but she is always so anxious about what might happen to Franklin and now she's anxious about everything. She said that she is also more anxious about something happening to her because that would mean that she wouldn't be able to take care of Franklin.

*July 16, 2011*
The following week I went to the beach with Sarah. In the car ride there, Sarah mentioned that she had spoken to Julia about the anxiety conversation I had with Julia on the SkyRide. This issue of anxiety was also a personally important topic for Sarah:

Sarah also said that she has noticed that as she has gotten older she has a lot more fears than before and that they are spreading into her everyday life. She said that Julia told her about the conversation she and I had on the SkyRide at Dutch Wonderland, when Julia explained that her worries about Franklin have spilled over into other parts of her life. Sarah said that she feels the same way and that she's anxious about everything all of the time.

July 21, 2011

Sara and Julia both talk about their anxieties and fears and how they are beginning to impact other parts of their lives. Whether it be skinned knees or long-term care that parents worry about, the production of these anxieties and stressors are experiences of autism, written onto parents' bodies – creating fatigue and other physiological effects of stress on the body. During a support group meeting, Julia even told some other parents that she has become afraid of driving in the car with her husband, because she always worries that if they have an accident, there is a higher chance of them both being killed, and she says that no one would know how to care for Franklin.

Parents, unsure of whether their children will ever be able to care for themselves independently, often discuss anxiety about dying and leaving their children with no one to care for them, or in the care of people who may not be able to understand their children's unique needs. For autism parents this is a concern that many live with daily, as they struggle to contemplate who would be able to help navigate their children through this world if they were gone. They consider their own mortality, the aging of their own bodies, and how this will affect the bodies of their children, the special healthcare they desperately need, and the scarring - both physically and emotionally - that their deaths may cause their children. In an interview, Kaleena,
the parent of fraternal twins, one of whom has autism, talks about her fears and anxiety regarding long term care for her son, Jacob, who is eight years old:

I think about how his relationship gonna be with his sister. Are they gonna be close? Is she always gonna look out for him? You know, are they gonna be together somewhere and she's gonna be like, that's my brother and I'm always gonna look out for him or is she gonna be like, I don't wanna be bothered with him. You know, I don't know. But I'm not gonna live forever, so it's like, so, who's gonna take care, if he needed somebody to take care of him, who's gonna take care of him?

August 10, 2011

Kaleena's concern about who will take care of Jacob and how his adult relationship with his twin sister will endure concerns her even as her children enter second grade. Even as young children, Kaleena sees her daughter's body as one that will be able to care for itself, and her son's as one that may not. She realizes the difficult caregiving circumstances this may cause for her daughter, as she will work to provide for the needs of her brother's body, and worries that this work will be burdensome. Mary, a mother of a twelve-year-old son with Asperger's syndrome, echoes Kaleena's concern:

So it's like, you know, I always say to God, you know, "Keep me here because my son needs me." I mean, my ex is a good person, but he has zero common sense, which is scary. He has none. And though my parents love him, and my sister and brother-in-law would be there for him, even though they have four boys of their own, and my daughter, she's gonna be his guardian if I'm not here, you know, I know he needs me.

August 10, 2011

The experiences of this anxiety and concern began to write itself on the bodies of the parents in my study throughout my time with them – literally making them feel and look different. Some parents mentioned constant fatigue, not enough time to exercise, overeating, bags under their eyes, lethargy, feelings of nervousness, and concerns about their own mental health. The physical manifestations of parents' emotional responses to the demands and challenges of caring for their children - keeping their bodies safe and healthy - played an enormous role in the formation of their identifications with autism and as caregivers for children with autism. For
many parents in my study, being an autism parent meant waking up early to prepare your child for school even though you are exhausted, overcoming the accelerated heart rate that accompanies shopping with a child in the grocery store, or even compromising your own healthcare in order to provide financially for a child's doctor visit; these experiences of autism were all written on parents' bodies, as well as on their children's.

**Conclusion**

What at first glance may appear to be a homogenous group of life experiences - all of the parents in this study care for a child diagnosed with autism - turns out to be varied, multiple and textured. It is the way that these bodies interact with each other and the world around them at any given time that creates their individual experiences and exposes the variations of their experiences. Parents have to make important decisions about what their children will eat, how they will wash and dress themselves, where they will go and who they will interact with, and all of these decisions impact and are impacted by their individual experiences.

Parents who have children diagnosed with autism cannot be lumped into one group together, given one series of treatments, or one prescription for services. Sarah and Julia are not having the same experiences with Ava and Franklin as the children become adults. Some experiences may be similar, and when those similarities occur, they can lean on each other for support, talking through their problems and various strategies that may be available to manage these problems. They can certainly learn from each other and from other parents that have had similar experiences, but they should not all be equated, their lives should not be generalized.

The peculiarities of their own bodies and of their children's bodies, and the particularities that they happen upon at various moments in their lives make them unique and special. Autism parents, like all individuals, are able to recognize the peculiarities and particularities that their
lives are comprised of, and use this recognition to figure out their circumstances and plan for next steps - to help a child learn to dress himself, to talk to family members about a new diet, to plan when and where to hold a playdate, or even to discuss masturbation and menstruation with a child. These peculiarities and particularities order and reorder parents' lives, and to understand their lives, these ordering mechanisms must too be understood.

Chapter 5: Navigations and Limitations: The Issue of Institutions

The activities of daily life required when a child is diagnosed with autism introduce parents into relationships with various institutions. These activities order parents' lives and determine their priorities, with whom they associate and interact, and ultimately how they experience autism. Several of the parents in my study called themselves "autism warriors," and saw themselves in a position of battling various institutions, fighting for the rights of their
children. Why do parents enter into battle? What about autism requires them to engage in "combat"? How does autism order parents' activities with institutions in such a way that they come to identify as warriors? In this chapter I explore these institutional interfaces by considering the Latour's concept of social actors and *actants* (2005), by considering institutions, such as schools and healthcare systems, as capable of social action themselves, as well as the individuals and technologies within the institutions. Using social actors as a way to understand the power of institutions and the processes they create and require, I explore how "war-like" activity orders parents lives. First, I begin by discussing Latour's term, actants, and the ways that I apply it to the institutions with which parents engage. Next I draw on Erving Goffman's work to discuss how these institutions manage and order children's and parents' bodies and activities. Then I introduce two management techniques, *discursive authority* and *bureaucratic processes*, practiced by institutions, which often serve to subjugate parents and deter them from securing supports and services for their children. In order to present these techniques in detail, I provide a case study for each, both of which proved to be topics of great debate and discussion within APSG throughout my fieldwork.

**Institutional Actants**

Parents in my study most often began to interact with institutions when their child received an official diagnosis from a medical professional. Immediately after this moment, parents began to seek help, usually in the form of Early Intervention (EI) services, which were discussed in the third chapter, as well as from doctors, teachers, and other specialists. These interactions with medical and educational professionals signal the beginning of their journey as autism parents and continue to influence their experiences with autism for years to come. In this chapter, I describe some interactions that parents from APSG had with these institutions. In
doing so, I describe struggles with social actors, people whose actions and inactions impacted the
daily activities of parents’ lives. In addition, I also look at non-human actors, or *actants*, and the
impact of their action and inaction on parents’ lives.

When I use the term *actant*, I am drawing on Bruno Latour's Actor-Network Theory. I consider
the institutions that parents must navigate, as well as the documents, rules, regulations,
barriers, and activities of these institutions to be actants, non-human social actors who are
capable of affecting the lives of the parents in my study. To understand social activity, Latour
considers not only how people (actors) act, but also how things and entities (actants) act. As he
explains, “*any thing* that does modify a state of affairs by making a difference is an actor - or, if
it has no figuration yet, an actant” (2001:71). This way of thinking about action is very helpful
for investigating parents’ interactions with institutions created to service them and their children,
because the activities that parents engage in are not solely with people, but are also with non-
human entities such as organizations, departments, applications, procedures, etc. What’s more,
these non-human entities are not only passively interacting with parents, but are also able to
modify parents’ lives.

For example, a document, prepared by a doctor, stating that a child has been diagnosed
with autism, has the capacity to provide that child with educational and medical services
otherwise unavailable, stigmatize the child as “disabled” and the parent as “the parent of a
disabled child”, grant the family access to insurance deductions, and move the child to a different
classroom, or even a different school. While the doctor who created the document is certainly
impacting the family through this act of documentation, the document itself comes to serve as a
crucial key to access important resources, or a label that may incite pity, ostracism, relief,
disgust, sorrow, or hopelessness, and may survive long after that doctor has retired, or after the
family has moved to a different state or even country. Likewise, the institution (an actant itself) that manages and legitimizes the activity of that document, for example requiring a certain signature, or for the document to be filed at a certain office, within a certain number of days after completion, also impacts the parent and dictates the activities of that parent (the parent must obtain those signatures, turn the paperwork in on time, make sure that it’s completed as the instructions designate, etc.), should he or she want to have the document fully legitimized and able to serve its function.

Some parents, particularly those wealthy, highly educated parents discussed in my comparative pilot study, may interact with only a handful of actors and actants at a local Early Intervention office, then a few educational professionals and a little paperwork when their child enters school, several medical professionals and procedures over time, and a few other bureaucratic agencies and regulations that oversee medical equipment, support services, or legal issues. These parents have the resources and knowledge with which to navigate the vast terrain of educational and medical bureaucracies. Most of the parents I spoke with, however, were not so lucky. Many of them knew little about “abnormal” child development, did not have money for high-priced private advocates, and were friends with doctors or lawyers who could make this journey easier. Instead, many of the parents in my study described how they fought to secure services and supports for their children and the rest of their family, spent hours meeting and speaking with various professionals daily, engaged in constant battle with different institutions, and often felt frustrated and overwhelmed. This chapter focuses on two of the institutions about which parents spoke most often. In doing so, I highlight how parents' interactions with these institutions (which are actants themselves) and the actors (people) and actants (paperwork,
policies, ideals, laws, etc.) that comprise these institutions, impact parents lives and their experiences as autism parents.

The first is the institution of schooling. "The school" itself can be considered an actant, using Latour's theory, but so can each of the departments, systems, documents, and committees that are formed and employed through it. A school system encompasses the assessment, schooling, transporting, feeding, care, and safety of students during schools hours, but also spills over into family life, intersecting with and ordering parents everyday activities. In this way, parents are in constant interaction with the social actors and actants that comprise a "school". In interviews, some parents told inspiring tales of talented, dedicated teachers who helped their children learn and grow. Other parents told horror stories of struggling through litigation over unwavering rules to secure basic therapeutic services in their children's schools. All of these experiences were important to parents not just as moments that their children spent in classrooms and lunchrooms, but also as reflective of their child's potential to learn, grow, thrive, and live in the future.

The second is New York State Medicaid, specifically its Medicaid Waiver Program. This program, itself an actant, was put into place to provide families of children with cognitive disabilities with special access to healthcare services that would otherwise be restricted to families meeting low income qualifications. These services are often cherished and celebrated by parents, but the work parents must engage in to secure the services is often laborious and stressful. The program itself has a relatively recent history, but there is a longer, deeper history situated in the corridors of old asylum wards and this history is intricately connected to the ways that parents experience the interface with state medical services and discussions about their rights as parents.
Ordering Bodies Through Institutional Action

In this chapter I examine these two institutions in order to interrogate the ways that parents' activities are ordered by these institutions, and the social actors and actants within them, in order to present some ways that parents navigate these obstacles. The information presented about these institutions is from the view of the parents whom I observed and interviewed. It is not meant to be a comprehensive assessment or survey of the interworkings of the institutions. In some cases, information presented here about the way an institution operates may be at odds with what an employee from that institution would consider "correct". "Facts" are not important here, but rather how parents interpret the interactions they have with these institutions and what these interactions cause them to think about their experiences with autism.

The discussions in this chapter draw on ideas about the management and control of bodies. Goffman, a seminal scholar in such work, wrote about what he called “total institutions.” These institutions, usually places where people lived (boarding schools, asylums, prisons, etc.) bureaucratically control the existence of their inhabitants. While the parents in my study did not have children in mental health facilities or boarding schools, and thus were not under the control of a total institution in Goffman’s respect, the suggestions from his work are relevant here, as much of the education and medical care frameworks for individuals with disabilities was born out of these total institutions, and that bureaucratic control still lingers today. Having control over the behaviors of children, and thus their parents, is something that is surely a great task for a school system that services over 1 million students each year, over 100,000 of whom receive special education services. Similarly, New York's Department of Health, which services nearly 1.5 million individuals eligible for Medicaid in New York City, has a tremendous amount of

5  http://schools.nyc.gov/AboutUs/data/stats/default.htm
6  http://www.health.ny.gov/health_care/managed_care/reports/enrollment/monthly/
work to do in order to provide medical care and services for those in need. An understanding of the measures and ideas used to control, move, and maintain masses of individuals, especially those who have been deemed incapable of speaking or acting for themselves, is crucial to understanding the ways that individuals diagnosed with autism, and those who care for them, are labeled, categorized, zoned, processed, and situated amongst those individuals around them without this diagnosis. Goffman found that in these total institutions, inhabitants’ identities were confined and restricted, documented and filed. They were often humiliated and required to engage in practices to demonstrate deference to those in positions of authority. Barriers, both physical and spatial, were placed between those with control and those without. The parents in my study, while not in the mandatory confinement of total institutions, experienced all of these practices as they attempted to navigate educational and medical bureaucracies.

This chapter explores two ways that the institutions of schooling and healthcare surveyed, regulated, and controlled the parents in my study through discursive authority and bureaucratic processes. By discursive authority I mean who has the right to talk, to be present, to make decisions, contribute knowledge, assess decisions, question others and their decisions, to ask for help, to provide help, and many other activities that are required when setting up a school environment for a child. This understanding of discursive authority also assumes that the authority and the opportunities to exercise it are legitimized. Drawing on Bourdieu's work on power relations in social life, specifically his notion of symbolic violence, I also consider the creation and maintenance of bureaucratic work (filing, paperwork, bureaucratic offices, registering, applying, waitlisting, returned paperwork, authorization, authorized access, etc.) a mechanism of symbolic violence that can be, and is, employed when deemed appropriate by those who hold discursive authority (Bourdieu and Passeron 1977). Parents spoke of these
bureaucratic processes often throughout my fieldwork, and described how limiting and frustrating these processes made their efforts to provide for their children. I see these processes as an available mechanism for the deliberate effort to force individuals, in this case parents of children labeled with autism, into positions of subjugation.

**Discursive Authority**

To understand the discursive power relations between parents of children receiving special education and schools, it is important to understand the history of such relationships. As Jan Valle describes, from the 1960s to the present, despite parents' increased legal rights to participate in educational decision-making for their children with special needs, they often encounter challenges to exercising these rights (2009). In her study of 15 mothers whose children, labeled with learning disabilities, attended public schools from the 1960s through the first decade of the 21st century, Valle found that special education discourse - about labels, needs, strengths, accommodations, placements, programming - demonstrated the uneven power relations between parents and schools. Drawing on Foucault's understanding of discourse as not just what is said, but what *can* be said and by whom, Valle shows how educators exercise control over education planning, programming and assessment by using the language of "experts" and devaluing mothers’ knowledge and expertise. Valle shows that the language of special education has always been based on a scientific model - assessing students' intelligence, considering performance ratings, utilizing definitions and ideologies created by psychiatry. This knowledge and the data, figures, and "proof" that come with it has become institutionally legitimized and is often at odds with the experiential knowledge parents present.

Parents of children labeled with disabilities in the United States have historically been put in devalued positions, subordinate to professionals, first by medical practitioners and
psychiatrists during the period of Institutionalization in the 20th century (Whitaker 2002), and later by educators and therapists who deemed parents (especially mothers) unfit, and often even the cause of the disability (Bettleheim 1967, Pollack 1997). Some parents, including many whose children were diagnosed with autism, have fought their way out of these subordinate roles by becoming actively involved in research efforts, working hard to develop treatments and therapies, and advocating loudly for the legal rights of their children and themselves (Eyal et al. 2010, Silverman and Brosco 2009). Especially in the case of autism, for which no gene, chromosomal abnormality, or other scientific cause has been identified, parents have had a space of freedom in which to question "expert" knowledge, engage in inquiry, and to express doubt (Kaufman 2010). Unfortunately, these parents usually represented only a small percentage of the parent population who were very well educated and of financial means.

For many other parents however, involvement in their children's special education has continued to be a source of struggle, their efforts often belittled by educators, their knowledge often devalued. In the U.S. these subordinate positions for parents and children alike have been tied to race, class, and gender. For children diagnosed with various disabilities, race and class have always been an issue. Especially in the earlier years of special education (1960s and 1970s), children from low-income families, many of who were identified as “Non-white”, who were struggling in school were quickly labeled as learning disabled or mentally retarded, and were put into special education classes. Even today, children identified as Latino, Black, or Native American or from low-income families are disproportionately diagnosed as requiring special education (Harry 2008).

Varenne and McDermott (1998) see the work of school systems in the United States as a deliberate effort to deem such students as "disabled" (special needs, minority, poor, urban,
English language learners etc.), while designating other students as "able". The programs, schools, and areas that house the schools that produce these "disabled" students are then seen as failing, while others are designated as succeeding. Using the lens of Varenne and McDermott’s work, one can see school systems as mechanisms of disability construction, which maintain themselves by creating social positions (general education students, special education students, gifted students, at-risk students, struggling students, etc.) that must be filled by children, and then further supported by educators, programs, assessments and assessors, etc.

While the social positions may be socially constructed, the implications for the lives of individuals so labeled are very real. Disability labels often accompany children throughout their entire school careers and can affect access to certain programs, colleges, and social or employment opportunities in the future. The stigmas attached to these labels affect not only children, but their parents as well. The same social constraints that have deemed the children "disabled" (race, class, income, etc.), are often then used to explain why their parents' knowledge should not or cannot be valued - "the mother isn't well educated", "they are too poor to afford that service for their child", or "they won't be able to practice this skill with her at home".

Another important factor in the issue of discursive relations between parents and schools is gender, as the parent most actively involved in a child's special education is usually the mother (Valle 2009). Historically, the medical professionals and educational administrators making important decisions for children labeled with disabilities have been men. The mothers, already in a subordinate power position as women, have historically been expected to follow the orders of the male professional. While many more women now hold these positions of authority in medical and educational contexts, the issue of gender can still arise for mothers who find themselves in front of female professionals for whom they have certain expectations.
Placing and maintaining parents in these subordinate positions is accomplished through discursive practices including everything from the process of diagnosis to the transition out of high school. School officials, administrators, educators, and personnel are heavily involved in all of these decision-making processes which affect and are affected by a child's body and emotions, as well as the activities, opportunities, and limitations that child may encounter. Such involvement was not always the case. The level of this involvement has increased as the reach of schools has expanded since the inception of compulsory public schooling, and continues to widen to reach children earlier in childhood and to stay with them later into adulthood. While the involvement of school professionals and policies in a child's life, and thus in parents' lives, can be critical for accessing services and supports for the child, the force of that involvement can subjugate parents to subordinate positions.

Mehan (2000) details such subjugation in his work on the politics of representation in important school meetings. By politics of representation, he means whose words are accepted as expert, knowledgeable, and legitimate, and what this legitimation means for how disability is codified through discourse. Like the story you will soon read about with Julia and her struggle to secure services for Franklin, the parents in Mehan's study are positioned as non-expert and powerless, set against expert school officials whose power will make the ultimate decisions for the child. Mehan found that in a meeting to determine a student's eligibility for special education, three languages were present in the room: a psychological language, a sociological language, and a historical language. By considering how reports about the student were presented, grounded assertions, and represented the child, Mehan found that the psychological language (used by the psychologist and other school professionals) was the language that prevailed throughout the meeting. While the mother in Mehan's study presents first hand
observations and accounts of the student, it is only the scientific language of the psychologist that is institutionally sanctioned as the correct version of experience.

*Discursive Authority at Work: Securing Educational Services.* When a child receives a medical diagnosis of an autism spectrum disorder (including any of the five pervasive developmental disorders described in the introduction), that child is eligible for special education services through his or her school. Those services may include related services such as speech therapy (Speech), occupational therapy (OT), physical therapy (PT), Special Education Instruction (Special Ed.), counseling, etc., but may also include accommodations such as extra time on tests, preferential seating in a classroom, special transportation to and from school, etc. The services are awarded to the student based on need, following the administration of various assessments to look at academic, social, and physical strengths and needs. Information about these services, including the frequency, duration, and location of them, is documented in the child's Individualized Education Plan (IEP) and the school is then legally obligated to provide those services to the child. Ideally, these services are made available to the child in his or her neighborhood school - the school he or she would regularly attend if no specific educational disability had been identified. However, this was rarely the case with the parents I studied. One mother was able to enroll her son in his neighborhood school in a special education program, but the rest of the parents were given, or had to search out, other placements.

The Individuals with Disabilities Education Act (IDEA) mandates all of these rules and regulations via federal law. IDEA's predecessor statute, the Education for All Handicapped Children Act (EHA), developed in 1975, requires that all children with disabilities in the United States be given access to public education. This law also protects parents' rights to be notified of

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7 For some children who require at home care or care provided by another institution (mental health facility, hospital, etc.), related services may be provided in those locations.
all meetings and decisions regarding their child's education, to be involved in the planning of their child's special education program, and to appeal any decisions made about their child's education. Prior to this act, hundreds of thousands of children could not access public education and their families were left to care for them or institutionalize them. After several revisions, EHA, now IDEA, ensures that states receiving federal funding under this law provide a free and appropriate education (FAPE) to children with disabilities, preschool through age 21. IDEA legally requires school systems to provide reasonable accommodation and related services for special education students and provides parents with legal channels through which they can obtain this specialized programming, or make changes to it as students grow and develop. While these legal channels have been developed, navigating them is not easy, and parents often struggle to maneuver through them in search of supports and services for their children.

This section will focus on Julia's story and the legal channels she navigated in search of additional in-school Speech and Applied Behavior Analysis therapies for her son Franklin. The story serves to describe the experiences that some parents had with the Department of Education (DOE) as they tried to secure services and programming for their children. These experiences include elements of control and regulation that Goffman would most likely argue are indicative of the power structure employed to regulate the massive amount of bodies that must be handled by the DOE. They also include the parent perspective of the DOE's role in providing services to individuals and addressing family concerns on an individual basis, something that may prove difficult to do in such a large bureaucracy. Finally, these experiences also demonstrate how parents navigated these institutional constraints by seeking information and sharing information with each other.
In 2007, at age 5, Franklin entered the DOE for Kindergarten. He already had an Individualized Education Plan (IEP) prior to entering the DOE because he had been receiving special education since Early Intervention, at age 2. When his mother enrolled him in a program for students with autism spectrum disorders in the DOE's District 75 (a school district created exclusively for special education students with "high needs"), she asked the professional members of the IEP team (teachers, administrators, school psychologist) if he could continue to receive the same number of related service hours, specifically Speech and ABA, that he had received prior to entering the DOE. They responded by saying, "He will be entering a new school, a new environment, a full day with all sorts of things happening, a full curriculum, perhaps we should not overload and overwhelm him," and suggested a decreased number of hours for related services of 3 times per week for 30 minutes, each session, for Speech and for ABA respectively. Concerned about overwhelming Franklin during his Kindergarten experience, she followed the teachers' lead and agreed to no additional related services, so none were documented on his IEP.

That first year came and went and Julia saw very little progress. Because Franklin was enrolled in a 12-month program, she decided to meet informally with Franklin's teachers during summer school. During that meeting, she voiced her concerns and they agreed with her assessment of his progress. She decided that she wanted to increase the number of service hours per week and began lobbying with the school administration. She wrote emails and letters to the school, faxed them and called them, hoping to be able to make adjustments to his IEP that would provide him with more related services for the next school year.

She was told that she would have to go through an impartial hearing to secure those services. An impartial hearing is usually the second step in resolving disputes between families
and the DOE concerning special education programming. This is a more formal process and its resolution, determined by a court officer, is final. The first step is usually mediation, which is a much more informal process where family members and school personnel try to work through their issues and come to a compromise that is best for the student; this process is facilitated by a trained mediator. Julia, not aware of the possibility of setting up mediation first, filed a request for an impartial hearing. Fifteen days prior to an impartial hearing, a resolution meeting must be scheduled by the school district. The meeting serves to allow parents to state their concerns and produce any evidence that would be used in the impartial hearing.

The DOE did set up a resolution meeting for Franklin's case, but Julia was not notified of this, and it was only after Franklin's teacher accidentally mentioned it to her during a phone conversation one Friday morning, that Julia realized a meeting had been scheduled without her knowledge, for later that afternoon. She made it to the meeting, but because she had not been given any notice, the results from the neurology appointment she had taken Franklin to the Thursday prior had not arrived in the mail. She wanted to share these important documents with the school professionals, but was unable to because the resolution meeting had already been scheduled. During the meeting she sat at a table with Franklin's teacher, his related service providers (therapists), the school coordinator, and a psychologist for the DOE to discuss Franklin's progress and her request for an IEP addendum. The DOE had not hired an impartial facilitator, (as is required during a mediation).

The professionals in attendance said that Franklin had made about 10% progress on his academic goals for the school year, as documented on his IEP. After listening to Julia's concerns and hearing from the teachers, the psychologist from the DOE determined that while Franklin had made very little progress, he had still made some progress, and therefore the DOE was not
prepared to offer additional services without the impartial hearing. Julia was shocked. As she relayed this story to the members of APSG, she described how one therapist had to hold her back because she thought she was going to the kill the psychologist from the DOE. He just looked at her and then continued to scribble in his notebook.

Limited by the constraints of the DOE's budget and the mistake regarding notification of the resolution meeting, Julia was expected to accept the services that the DOE had given her son as he entered Kindergarten. Instead, she decided to contact NY Lawyers for Public Interest to see if they would be able to take her case and help her through the impartial hearing. The organization requested copies of all of Franklin's medical and school records, report cards, IEPs, and anything else pertaining to his health or education. As she navigated this process and difficult decisions for her son, she also used this experience with the DOE as a way to instruct other parents in the group about the potential dangers they may encounter when trying to secure additional services. She said to the parent support group, "I just want to let the members know that once the child goes into the DOE it's a whole other ball game. I felt sorta tricked from the year before because when I did ask for services I sorta felt they talked me out of them and now one year later they are like 'Ha! Screw you now'." After meeting with the lawyers, she gave another bit of advice to her fellow group members:

"So the bottom line is this: HOLD ON to everything you have, test results, report cards, IEP's every single paper that can help you down the road. I know with all of the things that our children need the paperwork is ridiculous, you need a whole trailer to store them in and these kids should have their own secretaries who by the way really is US.... But it's very very important to keep everything."

Copied from an online thread posted August 9, 2008

In October of 2008 Julia and her husband went to the school district office for their borough to have the impartial hearing. NY Lawyers for Public Interest had decided not to take
her case, so she entered the situation alone. Julia described the event to the members of the group:

I had certain expectations on what was about to go down, I can say this, it was way beyond worst then (sic) what I thought. They conducted a hearing as if we were going to put on trial the biggest mass murderer ever. They were going to deliberate on all this evidence. There was swearing in's and court reporters, tape recorders, headphones, shuffling of papers, signing papers for 15 plus min., two reps from DOE yes, that's right TWO of them, they all came for the hanging. And an officer to conduct the whole circus, he was very judgelike with great authority.

_Copied from an online thread posted October 6, 2008_

To prepare for the hearing, Julia had written a letter about her concerns that she wanted to voice to the court officer. Attached was a picture of Franklin. She wanted to make sure that the judge thought of her son as a person, not just another number. She wanted all of his needs to be considered on an individual basis and feared that the IEP related services the DOE was proposing were just part of a "one-size-fits-all" approach to education. Julia explained that her feelings throughout the hearing were that the DOE was fighting against her, against her wishes for her son's education, and ultimately against her son. She explained that the DOE called witnesses for their side, all of whom were Franklin's teachers and therapists and each of these professionals ultimately sided with the DOE.

During a short recess yet another incident occurred that left Julia disappointed and frustrated by the lack of compassion and relatedness she received from one of the female professionals. She explained the scene:

The DOE rep's were women. The one who was the 'leader' sat exactly across from me. At one point we were off the record so they could change tapes and her cell phone rang. She answers it and says "Hi, oh? You're home, ok good, now sit and do all your homework." At that moment my insides were turning - here this person, this mother who obviously had a perfectly healthy, typical child sat across from me telling me "the DOE wants to help all the children, but we can't pay for ALL them " So here she is determining my child's future while hers is sitting at home with no therapists, no home attendants, both her and her husband working, doing their homework.

_Copied from an online thread posted October 8, 2008_
When it was her time to talk, Julia read the letter she had written and became very emotional, crying and asking the court officer to understand what her child needed to be successful. After nearly three hours of opening remarks and testimony from the DOE, Julia was then asked if she had any witnesses of her own to present. She presented documents from Franklin's pediatrician and neurologist, both of whom had written recommendations for additional services. The court reporter told her that those documents were required to be submitted five days prior to the hearing so that the opposing side could evaluate them - this had not been done. She was then told that if she wished to continue the conversation that day, she would have to remove the documents from the evidence submitted for the case. She refused, telling the court that she had not been told that materials needed to be submitted prior, and asked that the hearing be adjourned. The court agreed, and allowed her to submit the documents for a rescheduled hearing date two months later.

In the meantime, Franklin would continue receiving the basic related services his school was currently providing. Julia felt frustrated, angry, and betrayed. She still had to send her son to school the next day, knowing that the educators and other school personnel who participated in the hearing had sided against her. This tore apart what had previously been a good relationship with some of Franklin's teachers and therapists, and left Julia waiting in limbo. A few weeks later she received a phone call from her son's school. The principal offered to give her son Speech services four times per week for half an hour (an increase of one session per week), if she would agree to drop the case. She refused the offer, saying that it was ridiculous to give only an additional 30 minutes of Speech per week to a six-year-old who was not talking at all; she demanded more time and planned to get it at the hearing.
She appeared at the rescheduled hearing in December and again, she explained what she wanted and needed for her son. The court accepted all of the documents that she presented and she was told that the hearing decision would be mailed to her a few days later. When that letter arrived, Julia was devastated. The court officer had ordered the school district to re-evaluate her son. Despite the evidence she presented from her son's neurologist and pediatrician, the officer believed that his academic and social potential needed to be reassessed. Having her son assessed by a diagnostician of the DOE's choosing terrified her, for she feared that it would be biased toward the DOE. She explained her fears to APSG: "Now let's see, hmmm... oh sure the DOE chooses someone they contract with and Oh Yes, those people would be willing to lose the contract with the DOE, will give my child a FAIR assessment? I DOUBT it."

To her it seemed that the institution she was fighting against, was the same one she would have to rely on to ultimately secure the services she wanted for Franklin. The story continues this way, with back and forth between Julia and her husband, Franklin's school, the DOE, and the courts, for several months until Franklin was finally awarded some additional services. Despite all of this struggle and frustration though, the court’s decision to add more services only lasts for the remainder of the school year in which the decision is made, so Julia and her husband would unfortunately have to engage in this fight all over again if they wanted those additional services for the following school year as well. For the DOE however, whatever basic services they initially offered would be offered to the family again in future years without any deliberation - parents always have to fight to get more.

Throughout Julia's ordeal with the DOE, there are multiple examples of institutional power. The first occurred when the educators recommended that Franklin not receive any additional services that would overwhelm him. Thinking that the educators probably had more
experience with this transition to kindergarten than she did, Julia complied but then later felt like they "kinda tricked" her. Uneven power dynamics were at play again when Julia and her husband attended the impartial hearing and they were overwhelmed by court reporters, headphones, two representatives from the DOE, and a court officer who Julia thought was very "judge-like". This was a new, intimidating environment for Julia, yet one in which the DOE representatives felt comfortable.

During the hearing Julia also had a difficult experience with a particular female representative from the DOE. The position that the female professional maintained during the case was not that of a mother or a wife, but of an official. Likewise, Julia's position was only that of Franklin's mother, not of the Vice President of APSG. This positioning kept the professional from having to respond to Julia's case as a fellow mother, and Julia from representing herself as an expert in the case, which made Julia feel an internal tension between the gendered relationship she thought she should have with the woman, as one woman to another, and the one that she was in fact having with the woman, as a mother against a professional. Furthermore, Julia had to sit through the witness testimony of Franklin's teachers for the DOE's side, an exercise of power that made Julia question who she could trust. This mistrust was further exacerbated when the court official decided that the DOE would have the power to contract an evaluator to assess her son.

In Julia's story, power is exercised not only through the examples of discursive authority discussed above, but also through the moments in which Julia and her husband are required to jump through bureaucratic hoops. This happened when Julia's emails, letters, and phone calls to the school initially go unanswered, when the NY Lawyers for Public Interest request extensive documentation, yet decide not to take Julia's case, and when Julia is scolded for not submitting
her medical documents to the court prior to the impartial hearing, and required to resubmit them for a rescheduled hearing date. In addition to forcing parents into positions of subordination by exercising discursive power, such a feat can also accomplished by these bureaucratic practices.

**The Bureaucratization of Autism**

Bureaucratization is a mechanism that utilizes the processes of creating, manipulating, and legitimizing various documents that describe individuals, their various activities and behaviors, their statuses within a particular system, and ideas for how to engage with them, for purposes of subjugation. It also includes the documents themselves, as products of that work. When attempting to secure services for children diagnosed with autism, parents enter a landscape littered with obstacles that require completing and filing masses of onerous paperwork, calling various bureaucratic offices to secure appointment times and document trainings, having the "proper" signatures and the "designated" codes on each individual application, etc. These tasks are laborious and often redundant and can be nullified with the simple mistake of "losing" or "misfiling" a document. Bureaucratic processes can be employed to subjugate parents in two ways. The first is by requiring parents to complete and file paperwork that describes their situation or that of children in a way that they do not agree with. The second is by giving parents an administrative "run around" as they attempt to secure services and supports for their children and their families.

Despite the challenges that bureaucrats and their work present to parents, they can be overcome. Parents can dedicate their every waking minute to filing the appropriate paperwork or making the necessary documentation of their child's behaviors or healthcare needs. They can also become aligned, often out of sheer luck, with a bureaucrat who understands what needs to be filed where, when, and with what content and which signatures. This is all to say that
paperwork was not devised by a person or a personnel position in order to make parents' lives more difficult or to deter them from getting supports and services for their children. Documentation is not some grand conspiracy, and the process of creating documents in and of itself is not an act of control. Bureaucratic processes, however, can be and are used as a mechanism for deterrence when parents seek to obtain supports that are costly, such as the additional ABA and speech therapy services Julia requested for Franklin. They are also often used when parents' requests or needs take up too much of a professional's time, or are seen as "out of the norm". In these cases, the employment of bureaucratic practices becomes a deliberate tactic, on the part of the professionals who hold discursive authority to delay or deter parents from meeting their children's needs.

The idea of the agency of non-human actors, actants, from Latour's Actor-Network Theory (ANT) is helpful for understanding how powerful this bureaucratic utilization of documentation can be. Latour uses a material-semiotic method to understand how people, materials, ideas, and institutions come together to form a network that hangs together, and which is always in the process of being re-made (2005). ANT assumes that in Julia's case for example, the DOE representatives, the parents, the court as an institution, and the medical documents from Franklin's neurologist are all key players in the situation. The documents that determine Franklin to be disabled, assess his ability, prove Julia is his mother, designate him as a first grader, rather than an eighth grader, these actants, are all able to modify other actors in the situation through a series of actions - by proving, designating, determining, etc. For example, during my study I spoke with parents who, despite a serious internal conflict about their actions, filed paperwork that designated their children as having both "Mental Retardation" and "Autism" in order to receive additional services that would have otherwise been withheld.
To understand the potential effects of such an act, I look to Ian Hacking's work on autism as an *interactive kind*. Hacking says that the category, autism, is produced through a looping effect, that is "new knowledge about (people with autism) becomes known to people classified, (and) changes the way these individuals behave, and loops back to force changes in the classification and knowledge about them" (1999:105). I believe that this new knowledge about autism can be produced in many ways, including documentation and paperwork parents are required to complete, rulings on educational hearings like Julia's above, and bureaucratic hoops parents must jump through in order to secure services for their children. When a parent has a child evaluated by several doctors until he finds one that diagnoses the child with Mental Retardation and Autism (rather than just Autism), as in the example above, and this decision is documented, filed, and later used for statistical analysis of funding allocations, service provision, etc., this can have a major impact on the overall understanding of autism. Additionally, if that document is used to create an educational plan, to enroll a child in a special summer camp, etc., the actions that the document itself will incite, may be very different than a document that solely states "Autism" as the official diagnosis.

**Bureaucratic Practices at Work: Securing Healthcare Services.** It is not only the institution of school, such as in Julia's case above, which can employ the mechanism of bureaucratic processes to this effect. Medical systems do this daily as well. One such system, Medicaid, which includes the Medicaid Waiver Program, is especially important for parents whose child require special healthcare supplies, therapies, equipment, etc. that may otherwise be far too costly for families to finance. People finance basic healthcare services such as doctor's appointments, hospital expenses, medicine, and some adaptive equipment in four ways: 1) out-of-pocket (this is unusual, unless someone has a lot of money), 2) personal/individual health
insurance, 3) health insurance from an employer, or 4) government funding. To receive government funding for these basic healthcare services, parents living in New York can receive assistance through a variety of different government avenues. To begin the process of applying for this financial assistance, parents must first find out what they and their children are eligible for; they do this by reading a massive amount of paperwork.

First there is Supplemental Security Income (SSI). Individuals with documented disabilities in New York are eligible for SSI, a federal income supplement, if they meet certain low-income criteria. If the individual is under 18, the family's income and resources are also factored into eligibility. In the case of families of children with disabilities, this money can be used to supplement the income that the family misses out on because a parent has to stay home to care for the child. To receive SSI parents must collect and present at least 13 different pieces of information about their child's healthcare needs and their family's financial situation and then wait several weeks to months for approval. Several of the parents in my study received SSI for their children because their families met these criteria.

Next there is Medicaid. Medicaid is government money that is used to finance healthcare costs of individuals who cannot afford to pay for their own healthcare; it is available only to individuals (and their families) who meet certain income qualifications. Families that meet the income criteria for SSI are also eligible for Medicaid, which will provide for basic healthcare services for their children; during conversation parents call this "straight Medicaid". If parents are found eligible for SSI for their children, all of the application can be theoretically transferred to the Medicaid application. If parents do not apply for SSI, they must apply for Medicaid with a proof of address, birth certificate, and social security card. This process too, can take several weeks to months. Additionally, if a child has Medicaid, the parents must go through a re-
certification process each year which requires proof of address, a renewal form packet sent to Medicaid which includes, a MAP-2161 form, a support letter, and a resource verification attestation. If the application is not renewed on time, the Medicaid status becomes inactive and within 30 days the case is closed. If this happens, parents will have to resubmit all the initial documentation again to re-open the case. Because of their income eligibility for SSI, many of the parents in my study who received SSI also received Medicaid and went through these processes.

Finally there is the Medicaid Waiver Program. Because the medical necessities of caring for a child diagnosed with autism often go beyond basic healthcare services described above, parents apply for the waiver. For these additional services, even families whose personal or employer-paid health insurance cover the basics, often find themselves in need of more support. The waiver covers additional supports and services for individuals with developmental delays such as: 1) case management and service coordination, 2) residential habilitation (“res hab”) which provides care and therapy in the home, 3) day habilitation (“day hab”) which provides supervised experiences in the community, 4) respite services which relieve caretakers by temporarily caring for the individual, 5) environmental modifications (to the home, community spaces, etc.), and 6) adaptive technologies to help the individual function independently and safely (these may range from very low-tech to high-tech, depending on the individual's needs). The program also gives parents access to horseback or swim therapy, diapers for children over five years of age, a home attendant, and other resources that families may require.

To make this program available for all families of children with developmental disabilities the 2006-2007 Governor's Bill mandated that the waiver program eligibility consider only the income of the child, not the parents. In the case of the parents in my study, their young
children have no income, so they are all eligible, and they all spent time working through the process to obtain the waiver. While the idea behind waiving parent income for eligibility is excellent and was critical for parents to obtain these services, the paperwork that parents must sign and submit is troubling. The form reads:

This form is to be completed and signed by the applicant or recipient in all instances where the applicant/recipient is living with a legally responsible relative (LRR) who is refusing to make available income and/or resources for the cost of necessary medical care and services.

MEDICAID APPLICANT/RECIPIENT COMPLETE SECTION BELOW:

I declare that my □ spouse □ parent has refused to make his/her income and/or resources available for the cost of necessary medical care and services.

______________________________
SIGNATURE OF MEDICAID APPLICANT/RECIPIENT

______________________________
DATE

Parents are required to sign this form stating that they refuse to make their income available for the "cost of necessary medical care and services" for their children. For all of the parents in my study, this statement could not be further from the truth. Parents saved, budgeted, and worked extra jobs, to provide for their children and their healthcare needs, yet in order to secure these additional services, they were required to state a refusal to provide. During an APSG meeting about how to complete and file the various documents required for the waiver program, several parents commented about the language used on this form, stating that it was untrue and that they did not refuse to pay for medical services, but that they were unable to. The Medicaid service coordinator, who led the workshop, agreed with the parents' sentiment, yet reminded us all that in order to get the services, the form must be signed.

Despite the path that leads them here, when parents arrive at the waiver application process, in addition to the form above, they must also present paperwork for "determination of disability". This includes an 1151 form, which provides basic information about the child and
his or her disability label and can be filled out by anyone (doctor, parent, teacher, etc.), and a 20 page 486T form, completed, signed, and stamped by the child's doctor. These forms are to be submitted to the local Medicaid office, along with the original detailed reports of both psychological and psychosocial tests used to assess the child within the last two years, and any other documented medical information about the child.

Parents with whom I spoke waited several weeks to several months to receive an eligibility determination for their child. When some parents' applications were denied, it was often because their child scored too high on the psychological or psychosocial test. Children who score above 70 are not eligible for the waiver program, and when this happens, parents must have their children retested to score below 70 or submit an appeal to prove that the child has "high maladaptive skills", or difficulty with activities of daily living (ADL). When parents took the retesting route they would often make concerted efforts to affect their child's score by sitting outside of the testing room so that the child would not look to them for prompting or support, or even purposefully changing the child's morning routine to make him/her less focused for the test.

If parents are finally approved for the Medicaid waiver program, they must next apply for a Medicaid service coordinator (MSC). This process begins by receiving a list of MSC vendors. The Office for Persons with Developmental Disabilities (OPWDD) often supplied the parents in APSG with this list. MSC vendors are local organizations that will help the child and family access services available to them through the waiver program. Parents choose MSC vendors who are close to their homes, referred by other parents or professionals, and have room on their caseloads. Once the parent decides on an MSC vendor, then the parent and an employee from the vendor complete a request for Medicaid service coordination and submit it to OPWDD. The request can be denied for a number of reasons (Medicaid paperwork previously submitted has
not been approved yet, the child's disability is not appropriately documented, OPWDD requests additional information from the MSC vendor or the parent and such information is not presented, etc.). If the request for an MSC is finally approved, then an MSC contacts the parents and they begin to program for the child's needs by setting up service appointments with the appropriate agencies. For some parents in my study, this MSC process took as little as one month, for other parents (even very diligent ones) the process took over six months.

Once an MSC is secured, the parent and MSC create an Individual Services Plan (ISP), which designates what services (and in which locations, durations, etc.) the child requires. This plan will inevitably change as the child grows older and no longer needs some services but requires others. The MSC must meet with the child (and parent if the child is a minor) once per month, and make a home-visit once every three months. The home visits were more frequent in years past (usually monthly), but as MSC caseloads have grown recently, they no longer have the time to meet with families as often. If the individual with a documented disability is an adult, the MSC may work closely with him or her to explain the various processes involved in service acquisition. In the case of the parents in my study who have young children, the MSC’s job is to help parents secure services by talking to service providers, and to help parents understand the requirements, paperwork, application processes, etc. of all service providers. Navigating service acquisition is no easy feat. There are waiting lists and application processes, denials and appeals. While some parents praised their MSCs and said they were lucky to have their help through this journey, I also heard stories of frustrated parents wondering why their phone calls went unanswered, why their children's needs were being ignored. Jessica and her husband Tony shared their letter of complaint, written to the head of their MSC vendor, with the rest of the parent group. When the couple received a response, they acknowledged the response as a
necessity on the part of the vendor because they had filed a written complaint, but noted that "on this kind of situations and dealing with this "professionals" we have to wait until they walk through the door to believe it (that the vendor will address their concerns)." The letter reads:

When we heard that our son Elias has Autism was devastating, we didn't know anything about it and we start learning and preparing ourselves to help my son with this condition; then comes the services he needs to cope with it. That was the second nightmare because is something that has to be almost demanded, hours of phone calls, meetings, etc. Is ironic that to treat and help children with this condition has to be so bureaucratic and chaotic. When Elias was approved for Medicaid we thought was over but nobody explain us the process about the "WAIVER"; then I contacted your office and we start the process; is been a long one, almost 2 years and the only services that he has is Respite services. As a parent is discouraging to have and agency where once the child is “in” suddenly all the programs and services start to be on a "Waiting List"; if I knew or was told that to get and MSC will take months, that to get a "parent Training" will take months and RESHAB will be on a waiting List for "5 YEARS"; not mentioned the phone calls and e-mails that don’t get answer; will without a doubt look somewhere else because my son is 7 years old and the sooner he gets services, therapies the better chance he has to overcome some of his behaviors, etc.

Copied from online thread posted on September 30, 2010

Once parents are "in the system", the fight has only begun. They still must deal with the waitlist issues that Jessica and Tony mention above and other complications can arise as children become older and begin to have more involvement in the planning and implementation of their own services. Many individuals are trying to access these additional healthcare services. The MSC vendors are not equipped with enough staff to handle all of the cases and their resources are stretched thin. When vendors are presented with these challenges, they can employ bureaucratic practices as a way to delay one family as they attempt to meet the needs of another. Some parents in APSG whom I spoke with said that they had become frustrated with the lack of MSC support as they attempted to navigate the landscape of service providers, and they began to do the work themselves. Sarah often reminded the other parents that it is important to stay in touch with the MSC so that he or she can sign off on some important paperwork, but cautioned them never to rely on an MSC for service acquisition:
No matter what agency you use, you will have to stay on top of them and primarily manage (the) caseload. Do not fully rely on the MSC. You are the parent and therefore the primary caregiver. You will need to organize a file for (the child) if you have not already because the amount of paperwork you will accumulate for (the child) will be tremendous. You will be (the child's) secretary if you are not already.

_Copied from online thread posted July 8, 2010_

Parents do indeed become secretaries for their children. They are encouraged by the Parent's Handbook for Special Education to save all documents, create a paperwork folder for the child, and be actively involved in the educational and medical events of their children. They are encouraged by IDEA to know their rights, know special education law, and to speak up for themselves and their children. This, they're told, is the work of a good parent, of a good advocate, (that is, if they have been introduced to the 162 page law). For some parents, engaging in these activities comes naturally, especially if such activities are required for their own careers or have been learned in various educational settings. For other parents, these activities may be new, intimidating, and overwhelming.

**Conclusion**

Learning about what a child needs and how to get it can be a difficult process for any parent. When a child is diagnosed with autism, the perceived needs may be greater and the access to resources, supports, and additional information may be more difficult to obtain. Parents quickly learn that accessing even some of the most basic services requires an immense amount of paperwork, errand-running, phone calling, disagreeing, and petitioning. As parents engage in these activities, they learn more about them and become familiar with them - faster at filling out the paperwork, better connected to helpful people in important office positions, more familiar with the laws, regulations, and loopholes that they will encounter. Over time, institutions such as school and health care systems may become easier to deal with, easier to navigate. Still, initial entrance into these spaces can present great challenges for parents, and
even once some supports are put in place for a child, that child will inevitably grow older and have new needs that must be addressed by another application, evaluation, or bureaucratic office.

In this chapter I have focused on just two of the many spaces where parents may encounter issues of discursive power and bureaucratic processes, but there are countless others that parents may be forced to face as they struggle to provide for their children's needs. Even through these two examples though, we can see how complicated these processes can be, how emotionally charged the interactions between parents and professionals can become, and how crucial it is for such barriers to be removed in order to cater to the best interests of the child. As is evident in the two examples above, parents often feel at war with the institutions that they are told have been created to help them and their children. When some parents talk about being "autism warriors," this is what they describe. They are not fighting against a diagnosis label. They are not fighting against their child's body. They are fighting against the social (in this case institutional) barriers that keep them from ensuring that their children are as happy, healthy, safe, and cared for as they can be.

Parents are also fighting for and with the power required to care for their child. In cases where a parent enters a decision-making space (we can perhaps consider this a battleground) feeling intimidated, overwhelmed, unprepared, and is met by a professional who navigates the space with ease, power is produced and throughout the experience reproduced, further subjugating the parent. This is accomplished through various acts of discursive authority - holding one type of knowledge as legitimate, holding pre-meetings without the parent before the parent meeting, documenting some ideas and not others, censoring or guiding language used in discussion, and by employing bureaucratic practices. Parents find themselves required to engage with institutions and the professionals employed by them, in order to meet their children's needs.
The activities they must engage in - attending meetings, calling professionals, filing paperwork, order their lives and become the make up of their everyday lives. These activities are their experiences with autism and so being, ultimately shape the way that they understand autism and what it means to their lives. In the next chapter, I will describe how parents prepare for these battles, what weapons they use to enter the battleground, and who they align themselves with in order make sure that they meet the needs of their children.

Chapter 6: Sharing and Fighting: The Issue of Communication and Education

How does a parent describe his or her experiences with autism to others? How does sharing those experiences affect and order their lives, the lives of their children, and the lives of others around them? Parents in APSG called themselves “autism parents” and "autism warriors", and to understand what it means to become and identify as a warrior, one must look closely not only at the activities parents engage in, as I have in the previous chapters, but also at how they talk about those activities with other people, how they present themselves to others. This presentation of self is an issue of communication, and I would also argue, it is also fundamentally an issue of education.

Drawing from Cremin's widely encompassing definition of education presented in the introduction, I see parents' communicative activities - how they talk about their personal experiences - as evidence of educating each other and others around them. Whenever parents describe their experiences to a family member, an educator, a fellow APSG member, or even a stranger, they are engaging in an act of education. Throughout my fieldwork I observed these
educative activities in various interactions between parents, with professionals, and with relatives as they were often used to evoke understanding, ask for help, or solicit advice; these activities therefore are collaborative as well. As they had new experiences, parents were constantly involved in the process of educating others about those experiences in order to seek support, locate resources, ask for help, fight for their children's rights, teach others who had never had such an experience, or relate to those who had.

In this chapter I focus on three contexts in which I observed parents sharing their experiences and "fighting" for their children: group meetings, encounters with strangers, and interactions with media. During group meetings they asked each other for help and advice, shared tips and strategies, swapped important phone numbers and website addresses, reminded each other to stay strong through difficult times, and praised each other for their accomplishments and dedication. When faced with a public experience, such as a "meltdown" in the park, parents also employed several techniques to communicate their experiences with autism to curious strangers (many of whom often stared or gave looks of shock or awe). Additionally, several parents, especially when they presented themselves as a group, extended this notion of communicating with strangers, and became actively involved in news and other media correspondence, describing their experiences and expressing their feelings in magazines and other periodicals, class presentations, and even on television. In all instances, parents were presenting themselves, their children, and their experiences with autism parenthood to some end. Individually and as a group, parents often (co)constructed narratives of their experiences of diagnosis, living "the autism lifestyle", and adopting a "new normal" to meet specific ends in specific contexts; these narratives were critical to both parents' presentation of self and to larger changes in public understanding of autism.
Throughout this chapter, I argue that through educative practices of co-constructing narratives, parents in APSG begin to author and identify themselves as autism parents, and even as "autism warriors". The process of becoming an autism warrior consists of membership in support groups through which parents educate themselves and “others”, strangers and the public, about what it means to "fight against autism". Together, these individuals challenge stigma and valorize their struggles and the struggles of their children by becoming advocates, “warriors” for their children. First, I discuss the use of narrative in autism studies and autism awareness, as a way of educating the public about experiences with autism. Using the findings from my fieldwork, I trace the construction of these narratives through APSG's members, beginning with the founder and her personal narrative of becoming an autism warrior. Next, I discuss group narrative, focusing on the ways that I observed parents sharing narratives within APSG in order to educate each other and to seek advice or guidance about issues of concern in their lives. Then I introduce and discuss some of the strategies that parents used to communicate about autism, about their children, and about their family's wants and needs, to strangers whom they encountered in their daily lives. Finally, I describe some of the activism activities that parents engaged in throughout the course of my fieldwork, as they employed various media to publicize their individual and group experiences with autism.

**Narratives: An educational methodology**

*Reasons to employ narratives.* Listening to and documenting personal and group (familial, tribal, etc.) narratives has long been a hallmark of ethnographic fieldwork in anthropology (Reck 1983). The work of story-telling and story collection in anthropology has been so powerful and effective because it allows people to describe their experiences and their relationships with the world around them in a way that uncovers the complexities of their daily
lives. This practice of story telling is one that is uniquely human. Reck recollects an exemplary story by the anthropologist Gregory Bateson “about a computer which, having been programmed to respond exactly as would a human, was asked by the programmer how it could be determined that its responses were actually those characteristic of a human. There was a pause and whirring of spindles before the computer finally responded with a tape which began, "That reminds me of a story...." (Reck 1983:8). Anthropologists collect and tell stories, as do the people and groups that they study.

For the human subjects of ethnography, creating and presenting personal narratives is a method of presenting the self (Reissman 1990). Drawing on Goffman's seminal work, The Presentation of Self in Everyday Life (1959), I treat the communication of one's experiences as a critical component of presenting oneself to others. This kind of self presentation has been honored by researchers in the traditions of psychological anthropology (Bruner 2004, Kleinman 1989) symbolic anthropology (Turner and Bruner 2001) and medical anthropology (Good 1994, Sontag 1991, Young 1976), and treated as expert knowledge centered on peoples’ experiences with their bodies, minds, and emotions that otherwise would be difficult to communicate to an “other.”

Throughout my study, I observed parents employing the method of creating and sharing personal narratives to present themselves to “others,” including me. How parents presented themselves and their children to family members, educators, strangers, and others, impacted how those others viewed them, and further ordered the activities of parents' lives. Landsman found that the creation and presentation of these parent narratives could have a profound impact on the future activities of parents and the people around them. When analyzing the conversation between the mother of a child who had suffered a stroke and her pediatrician, Landsman found
that "mothers’ narratives, by utilizing the concept of "developmental delay", can assert personhood (of the child), or rather, the potential for its future attainment; in doing so, they justify ongoing nurturance of a disabled child in spite of negative attitudes about disability" (2003:1947).

Eddings Prince (2010), in addition to using personal narratives to affect parents' and families' futures, shows that sharing these narratives can also be a reflective process. Eddings Prince, an anthropologist, mother, and woman diagnosed with autism, reflects on her history with autism, the transformations that have occurred in her life, and how those transformations affect her son, whom she claims "would himself be diagnosed as autistic in a different context". For Eddings Prince, the power of her personal narrative is that it allows her to reflect on and share "the reward of the struggle and the gifts that are part of a different way of being" (Eddings Prince 2010: 56).

While parents may employ these narratives to meet personal goals or engage others in their private reflection, the work of these narratives may also extend beyond the individual and familial levels, entering the public realm, and enacting social change. Rapp and Ginsburg argue "that such public storytelling (of experiences with impairment and disability) - whether in family narratives, memoirs, television talk shows and sitcoms, movies, or, most recently, through Web sites and Internet discussion groups - is crucial to expanding what (they) call the social fund of knowledge about disability" (2001:537). As this social fund grows, Rapp and Ginsburg hope that kinship may be rewritten, citizenship reimagined, and the domain of public intimacy linked to disability, expanded. In expanding this domain, the authors look to disability narratives as a site for the "transformative cultural work that can help resituate disability in contemporary American social life (2001:539).
In Kelly’s work, a mother named Nora speaks of coming to terms with the illness of her daughter Grace, expressing the themes of motherhood and loss, and describing the "embodied, moral, physical, and emotional work of parenting (which) is intimately connected to her experience of her daughter's illness" (2005: 189). Nora also speaks about the social contexts of her daughter's disability and the independence that she and her daughter work towards. Kelly explains the power of this narrative:

On one hand, the physical, mental, and emotional engagement with Grace's body, her frailties and vulnerabilities, is the engrossing and embodied activity of parenting. On the other hand, the meanings inscribed on Grace's body and impairment by her mother are social, reflecting the values, beliefs, and desires that she brings to parenting and that she projects, through Grace's presence, into the broader social world (2005:190).

**Modes used to present narratives.** In recent decades, autobiographical narrative has been used frequently by individuals affected by autism to communicate their experiences. As Hacking explains, "Autism narrative is a new genre; not expert reports by clinicians or reflections by theorists, but stories about people with autism, told by the people themselves, or their families, or by novelists, or by writers of stories for children" (2009:1467). Many now famous adults diagnosed with autism or Asperger's syndrome such as Temple Grandin (1986), Tito Mukhopadhyay (2000), Tim Page (2009), Daniel Tammet (2006), and Donna Williams (1992), have written various memoirs and autobiographical accounts of their early lives growing up with autism. Parents of children diagnosed with autism have also shared their stories through books (Anderson and Forman 2010, Crown 2009, Harland 2007, McCarthy 2007) and films such as "Autism the Musical" (Regan 2007), "Loving Lampposts" (Drenzer 2009), and "The Horse Boy" (Scott 2010).

In addition to book publication, the Internet has also made available the space for blogs, websites, videos, and other online interfaces through which individuals diagnosed with autism
and their family members can share their stories with each other and the world. Non-fiction accounts of experiences with autism have also been presented in books such as The Curious Incident of the Dog in the Night-time (Haddon 2003), Daniel Isn't Talking (Lembach 2007), Rules (Lord, 2008), and With the Light: Raising an Autistic Child (Tobe 2007), among others, and films such as "Adam" (Mayer 2009), "Mozart and the Whale" (Naess 2005), "I am Sam" (Nelson 1998), "Mary and Max" (Elliot 2009), and "The Other Sister" (Marshall 1999). These narratives accounts of the diverse experiences of autism are helpful for pushing readers and audiences to rethink their understanding of the lives of individuals affected by autism and to see the varied ways that people manage, cope, triumph, struggle, and otherwise live with autism.

By creating and sharing narratives, the parents in my study reflect on their life experiences, consider the difficult challenges they have faced, and stand proud as they describe their determination and achievements. They also present and define the individuals they have been, have become, and hope to be, and make it known to others around them that they are autism parents, and that each of their stories is unique and precious. Sarah, the President of APSG, and self-proclaimed autism warrior, often told her story of transformation and struggle, as she became an autism parent and the leader of APSG. Below is a short excerpt:

Courage, I have learned, means taking a risk for an unknown cause. Courage is all that I have come to know as a single parent with my youngest child living with Autism Spectrum Disorder (ASD). I received the diagnosis of autism for my daughter, Ava, in June 2005 - right before her third birthday. After the initial shock and devastation of such a diagnosis, I knew eventually that I would have to accept it, so I could help her. However, I was always such a timid and introverted person; I did not know how to go about being a voice for myself, let alone my own daughter.

…I was terrified. I thought, “I don’t know anyone else who has a child with autism. Where do I go for help? Where do I go for support or education? What do I do first?” I felt so alone. I felt like no one understood what I was going through…

Although the beginning of my journey resulted in many dead ends, I knew that I could not get discouraged or give up. I knew I had to be my daughter’s biggest advocate, because no one else would be…
I pressed on learning as much as I could about autism. I collaborated with my daughter’s preschool and the members of her care team, all who had constant interaction with her every day. I observed their strategies and techniques and brought the same into my home. I asked questions all the time, and I asked the therapists for recommendations on how I could help my daughter… Each minute of gained knowledge turned to an hour. An hour turned into a day. A day turned into a week. Now, here I am almost two years after Ava’s diagnosis and I now have a little bit more confidence in holding her hand along this journey, just because I was willing to take the risk of studying a disorder I had never heard of.

In November 2006, a little over a year after Ava’s diagnosis, I decided to turn my unfortunate event into something positive. Although not a master of the mysterious disorder, I formed The [Autism Parent Support Group] designed to serve parents of children with autism in the Queens, NY, and surrounding areas. The support group is an online forum where parents of children with autism meet online and in person in order to network with one another for moral support and resources. We also get together to share family-oriented events, such as picnics and play dates. The group is still fairly new, with 21 members so far. My goal with the group is for all of us to help one another by sharing our experiences. Our motto is: “Empowering ourselves. One parent at a time.” It is important for the autism community to come together to help one another, because the journey of autism can be a very long and lonely one.

Taken from an APSG website

Co-constructing Narratives

We can see in Sarah's narrative that she places a heavy emphasis on her experiences with the group. As she explains, "the journey of autism can be a very long and lonely one", and she and the other parents often told me how their membership in the group had changed their lives and their outlook on autism. Sharing their experiences with each other, and being able to talk to others who related to their struggles and their daily activities, was something that many parents attributed their survival to; for parents, learning from and teaching each other allowed them to get through the day, navigate difficult, uncharted terrain, and overcome challenging obstacles. Parents talked about how fellow members "just get it" when others in their lives "don't get it." Together they worked to not only create and present their individual narratives, but to also co-construct a group narrative that they then referenced as part of their identification as autism warriors. According to Holland et al. these moments of narrative construction are part of a
process of authoring the self. As they explain, "It is not only being addressed, receiving others' words, but the act of responding, which is already necessarily addressed, that informs our world through others. Identity, as the expressible relationship to others, is dialogical at both moments of expression, listening, and speaking" (1998:172). At times narratives of parents in my study were initially presented as individual, but throughout conversation they became co-constructed, reflecting the experiences of not just one parent, but also of the group collectively.

Karen Sirota (2010) observed this co-construction process in families of children with autism as well. Sirota recorded the everyday narratives of 17 children in the US who had been diagnosed with high functioning autism and Asperger’s syndrome and found children employed narratives as a "technology of the self" by interacting with their parents. Sirota found that narrative coparticipation can be difficult for children with autism, and suggests that family members engage the children in the construction on their own narratives, by giving them opportunities to reframe what it means to be autistic, helping them to create narratives where they participate in activities that any other child without a disability would engage in, and even highlighting moments of sociality that are uncharacteristic of autism spectrum disorders. Through these practices, children learned to identify as autistic and began to recognize that their way of experiencing the world was affected by autism, but that this could be a positive affectation.

Similarly, in Emily Martin's (2007) work, members of a support group for people diagnosed with bipolar disorder used the process of "authoring the self" to connect with each other as members of their group. She explains that, "a fabric of relatedness is created for people over time. Other people remember them (experiences); other people understand their experiences in light of life stories they have told in the past; other people have experienced
something similar"(2007:143). In Martin's work, a common tactic of the group members was asserting that other people share the individual's experience, and then by adding their own experience to the original narrative, they were able to weave together experiences and co-construct a notion of what it means to struggle with bipolar disorder.

In Mariana Valverde's (1998) study of members of Alcoholics Anonymous (AA) groups, narrative co-construction not only helps to produce and maintain member's identifications, but also serves to author the group self. By incorporating themes of powerlessness, self-control, acting through the twelve steps, and living "one day at a time" into their personal narratives, members of AA reiterate the group's identity and further solidify their place in it as active participants in the group. As Valverde (1998) explains, for AA members, the narratives that they live and tell are not just an authoring of the self, but also a means of self-governance. What AA is, who AA members are, and what AA members do is represented through a co-constructed narrative of what drinking does to members' lives and what they must do to refrain from it; the narrative serves to govern drinking "for the sake of the soul" (1998:120).

Co-constructing and Sharing in APSG. Much of the time I spent with parents in my study was within group settings like the ones Martin and Valverde describe. The parents came together to share in common life circumstances that they had all found themselves in, through some path or another. Like the participants in Sirota's study, the parents of APSG saw themselves as a family too. The parents often talked of having to "stick together as family", placed a high value on building relationships between parents and between children from different families, both those who were diagnosed with autism and not. At times, parents even discussed financial plans to create a group home for their children when they became adults, so that their children would be able to live together, with individuals they had known for years.
APSG is a group that was bonded by more than temporary circumstance, and whose members had made the conscious decision to help one another collectively, to understand, endure, and thrive through the experiences they faced individually; as proclaimed on their website homepage ("We are more than a support group. We are a family!!")

To maintain close ties, parents met frequently, often with their children on weekends, but also without their children. Parents (almost always mothers) met on weekday mornings while their children were at school or on weekend afternoons in order to discuss various topics that impacted their lives. During these meetings parents talked about toileting, managing violent behaviors, how to improve their children's reading comprehension, how to cope with feelings of parent guilt, and how to care for their children's various light, sound, and touch sensitivities. These meetings were spent sharing stories, giving and receiving advice, laughing, and sometimes crying. As a researcher, each of these meetings was an educational experience, a lesson learned about these parents' lives. For parents, these meetings were critical spaces for gaining knowledge about difficult, pressing matters that affected their daily lives. They were also places to share knowledge, to teach others and to reflect on obstacles that had been overcome, and to learn tricks and strategies that had led to successful outcomes in their lives.

During these groups, parents constructed, revised, presented and reflected upon personal narratives by describing their personal situations, asking for help, and giving help; through this process, they wove together their stories to create a group narrative of sharing and educating. APSG, created in 2006, started with just one narrative - Sarah's - but soon incorporated the stories of many parents, each from different walks of life, each with very different children, home dynamics, and expectations. By communicating their experiences and co-participating in a process of educating one another and themselves through story telling, advice giving/receiving,
and support lending, the narrative of APSG, a dedicated, family-oriented group of autism warriors, was produced and reproduced each time they met. Below, I present a vignette of just such a co-constructive process, an ordinary, quotidian occurrence during my fieldwork, but one that, wrote and rewrote the history of the autism warriors and their group.

One morning I met five mothers from APSG at Margaret's house. On that particular summer day we were talking about children's sleep issues. Jessica and Leslie were the two women who were having the most trouble with their sons sleeping. Jessica said that everything has to be dark or else her son Elias won’t sleep. She explained that he only sleeps well when he is very physically tired but that involves her being very physically active with him every day and she doesn’t always have time for that. She had been trying to figure out what makes him tired some nights and wide awake other nights, but said that there didn’t seem to be a stable sleep pattern. Margaret told everyone in the group that children need at least 8-10 hours of sleep per night and that their ability to have a good night sleep would set up the rest of their day for them.

Leslie responded by saying that if she allowed her son, Joey, to stay up, he would never go to sleep. She said that at 7:00 pm she sends everyone else in her house to bed and then she stays up with him on the couch and holds him like a baby (she demonstrated for us with a pillow) until he falls asleep. She said that she is giving him the vitamins that Bala, another mother in the group used to give to her girls, but they don’t seem to be working. Margaret then suggested an incentive system (like tokens) to stay in bed and gave Leslie advice about how she got her son, Elliot, to sleep through the night. She said that she had to start slowly by just getting him to stay in his bed for a little while. Once he was able to sleep through the night, they had a party for him in the living room when he woke up. Margaret did mention that she had the help of a coach to get her through it and that in the beginning she had to sit on her hands and not be tempted to go
soothe him when he was crying or yelling about not wanting to go to bed. She said that it was really hard and she used to cry a lot and that’s where she got all of her grey hairs, but she said it was worth it.

Leslie started to get upset and asked many of questions about how to deal with it when he started crying. She kept saying that she couldn’t do it. Margaret and Bala kept telling Leslie that she has to just put him in his bed and then get reinforcements to get him to stay there. Bala suggested that Leslie put up a baby gate so that she can still see in the room but he can’t get out. Leslie then started crying and said that this was too hard. Bala and Margaret said that she should close his bedroom door after she puts him to bed, but Julia disagreed, saying that she doesn’t have to close the door for her son. She then described how she really had to battle with her son Franklin, to get him to go to bed, and that Leslie has to do it, no matter what. Leslie asked Margaret when she puts Elliot to bed. Margaret told her that it was about 8:30 every night. Leslie said that she wanted to call Margaret that night at 7:00pm so that Margaret could walk her through what to do with Joey; Margaret said she would be happy to help. When I spoke with Leslie several days later, she told me that with Margaret's help, Joey had slept through the night.

By talking to Bala, Margaret, and Julia, Leslie and Jessica were able to describe their experiences with their children's sleep issues to other parents who could then give them advice, commiserate, and even lend a hand. As Leslie described her experiences to her fellow group members, she was able not only to create a narrative of her personal experience with Joey, but also to co-construct a narrative of the group members' collective work to help each other and to care for all of their children together.

For parents in APSG the focus on discussion was how to get through each day - how to alleviate problem behaviors, how to keep their children safe and happy, how to plan for their
children's futures, how to access daily services and supports. Parents' individual narratives, such as those presented by Leslie and Jessica above were weaved together to create a group narrative which focused on making life better for children and families by becoming educated about the medical, legal, and school related information concerning autism, becoming an advocate for one's child, and working as an "autism warrior". By giving each other advice, adding input to each other's individual narratives, and reflecting on their fellow member's experiences, APSG members co-construct an APSG group narratives that showcases the collective work of its members to "warrior" through an autism lifestyle, not to eliminate it.

This particular narrative is not generalizable to all groups of autism parents. In fact, I noticed a strong contrast between the narrative from APSG's, which I was introduced to during my research, one that I see as focusing on daily survival and progress, and Group 2, whose narrative I explain in detail in Chapter 2. Group 2's focus was on eradicating autism, eliminating it from a child's body, "defeating autism now". Instead, APSG members think of autism as a life-long condition, one that creates struggles and challenges for the child and the family, but that will be part of the family's life forever. Rather than discussing what pills to take or treatments to try in order to get rid of autism, APSG members spend time presenting and co-constructing personal narratives about how to live with these difficulties and struggles, and in turn construct a group narrative of collective survival which draws strengths from its membership in the group.

**Communicating with Strangers**

Parents in APSG often talked with each other about how to deal with stares from onlookers at the park, people who ask them questions about their child's behavior in the grocery store, and people who whisper about their family on the subway. These people are *strangers*, individuals with which parents have no acquaintance, but whom, especially in a large city like
New York, parents encounter throughout their daily activities. Strangers live in parents' neighborhoods, shop at parents' local stores, frequent parents' favorite restaurants, and walk down the same streets as parents, as they commute to and from work, school, errands, and recreational activities. Strangers are not just "others", such as extended family, bosses, familiar neighbors, etc., with whom parents may have separate discussions about their children and their experiences with autism. Strangers are those that parents do not know at all, and may never know. Strangers are those who interact with parents and their children in fleeting moments, but whose comments and whispers, stares and reactions, linger for parents long after the moment has passed. For many parents in my study, dealing with the social stigma of autism and how strangers responded to it was a daily struggle, one for which they devised several creative strategies.

Goffman's theory of social stigma is helpful for understanding how these interactions affect parents, shaping their identification as autism warriors, and ordering their lives. Goffman (1963) describes stigma as "the phenomenon whereby an individual with an attribute is deeply discredited by his/her society and is rejected as a result of the attribute. Stigma is a process by which the reaction of others spoils normal identity". Goffman identified three main stigmas: physical attributes (including scars, deformed features, missing limbs, etc.), social attributes (including mental illness, drug addiction, criminality, sexual indecency, etc.), and "tribal" attributes (including race, ethnicity, religion, nationality, etc.).

For Goffman, stigma can be attributed to an individual in several ways. In the case of individuals diagnosed with autism, the stigma may be either physical or social, depending on the situation and the individual. Many individuals diagnosed with autism do not have any immediately detectable physical differences that mark them as different from individuals not
diagnosed with autism. It is often not until a "strange" behavior, such as hand flapping, awkward social interaction, repetitive movements, etc. is exhibited that any stigma may be detected. The label of autism itself is also stigmatizing and can impact the way others react to an individual. Others may learn about an individual's label through some official account (a teacher receives a child's IEP paperwork, which documents a medical autism diagnosis) or through a less formal account (a young woman explains to her co-workers that she has Asperger's syndrome), but either way, the label impresses upon the individual a social stigma.

One of the parents in my study, Bala, described her thoughts about trying to prevent that social stigma from affecting her daughter's experiences in her new ballet class. During an interview, she explained to me that she had been concerned about other ballet students or their parents knowing about her daughter's disability. She didn't want the other children to treat her differently and was afraid to sign her up at all until she decided that she could put her daughter in ballet without presenting her to the other students as disabled:

When I joined her up for ballet, I wasn't planning on sending her to ballet. I was planning on sending her sister only, but then when I got there I started speaking to the teacher, I was like, you know, "How do you guys deal with special needs kids? My daughter has autism, whatever, but I'm worried to sign her up because I think she'd be disruptive to the class" and the teacher said to me, "Well, there are kids here who have no disab-, nothing, and they are disruptive to the class", and then she said to me, "I would give it a try and see what happens". And then "It's nobody's business to know anything about her other than she's here for her class". I was like, "Okay", so I signed her up as well, but I kinda like that idea, like if it's not necessary, like I'm out somewhere and it's really bad and I need to get to somewhere I will say it, at that point, or if like she hits some person's kid or something I might like have to say to the parents, "I'm sorry. She has a disability or whatever" in that situation, but other than that, I don't say anything. I just let her be, if people have a problem with it, that's their problem. I don't care.

July 26, 2011

In Bala's situation however, we can see that the stigma of being labeled autistic impacts not only her daughter, but her as well. However, Bala chose to provide her daughter with an environment where her disability does not matter, but only her interest in ballet, her identity as a
young girl, and her desire to attend the same activities as her sister. Here, Bala made a conscious decision to let her daughter be who she is and to experience the same activities as her peers, regardless of her disability label. She decided that if other people "have a problem with it, that's their problem. I don't care," and this took hope and courage – the hope that her daughter will not get into trouble and the hope that others will understand when she does, and the courage to confront a situation that may occur if he daughter has difficulty in class. In this case, Bala’s decision to not care suggests that in other cases, other peoples' reactions to her daughter are something that she may in fact care quite a lot about, and this is indeed something that upset many of the parents in my study. Many parents of individuals diagnosed with autism, like Bala, encounter something Goffman calls courtesy stigma, which is stigma acquired as a result of being related to a person with a stigma. Much has been written about courtesy stigma for family members of individuals with mental retardation (Birenbaum 1970, 1992), Alzheimers (MacRae 1999), gay and lesbian children (LaSala 2010), with a variety of disability labels (Green 2003), and autism (Gray 2002, Dehnavi et al. 2011, Mahoney 2003, Mak and Kwok 2010). Of the scholarly work that has focused on courtesy stigma and parents of children with autism, much of it has looked at how parents are impacted and what this has done to parents (increased levels of stress, implications for parents' mental health, etc.)

In this stigma-center section of a chapter on parent communication and education, I chose to take this concept in another direction by focusing on what parents do to communicate to strangers who react to their own and their children's stigmas. In doing so, I present three communicative ends that parents in my study strove to meet. The first is to teach strangers about autism, either by educating them about autism as a disorder, or by telling them specifically how the child or family is affected by things like sensory issues, tantrums, routine, etc. The second
approach is to focus on providing support to a fellow parent who is going through a difficult time with a stranger. This may entail inserting oneself in the conversation, providing words of encouragement to the parents, or various other strategies. The third approach is an absence of communication, which itself is communicative. In these instances, parents practice planned ignoring, a strategy that they are often taught to use with their own children, through which they purposefully ignore the behaviors of others around them, and focus solely on their interaction with their child.

*Teaching Strangers about Autism.* During various conversations with Richard, the father of eight-year-old Marcus, he told me about a creative strategy he uses to communicate about Marcus to passersby when Marcus is having a tantrum. After dealing with stares and whispers from strangers for several years, Richard decided to print business card sized notes that describe his son's tantrums, in order to educate onlookers about what is occurring. He wanted to avoid strangers' misunderstandings of him as a bad parent, or of his son as a bad child, and to convey to others that he and his son were working collaboratively through a difficult time. He told me that when Marcus's behavior gets out of control, he can just hand a staring stranger one of these cards and then he doesn't have to spend him time or energy explaining the situation to onlookers, but instead can focus on Marcus. The card, which has a picture of brightly colored crayons on the left side, and Comic Sans text on the right side reads:
Thank you for your interest!

Yes my son is tantruming and/or having a moment right now.

My son is also autistic.

He is not spoiled, nor abused.

So, while you may feel the need to comment, rest assured that he is not being mistreated, nor am I a bad parent.

It's simply (sic) what it is.

Thanks again for your interest and have a pleasant day.

After handing me a card, Richard explained:

I had those made up because it's easier to hand that to somebody sometimes. They're like, "Oh my god! He's so spoiled! Why is he screaming? Why is he fussing?" This and that or you know, "Your kid just hit my kid. He's freaking out." And I'm like, "Okay, I'll be with you in a minute." But you know...you have to be so patient in life with not only your own child, but then, you tend to lose your patience with people who don't get your own child cause you feel like they should know better. What the fuck's wrong with you? You know he's autistic. That's why it's better for me to have the cards so I don't go off on the parents.

August 4, 2011

While Richard said that he had had a lot of success with the cards, he told me that at times Marcus' tantrums were so uncontrollable that he could not muster the strength or garner the opportunity to pull a card from his pocket. He told me of one such incident that occurred on the sidewalk, on a busy street in his neighborhood:

We were in the back of that ice skating thing and he saw Burger King. He wanted to go to Burger King on 82nd Street. You know, a very crowded street here. He's like, "I'm going to Burger King!" I'm like, "No. We're not. We're going home first." And then he hit me. I'm like, "Now we're definitely not going to Burger King." And this evolved into me standing on the corner with him grabbing my leg, you know, touching me lightly going "I wanna go to Burger King." cause he knows not to do it to a certain degree. But I look at him and he's like "I'm going to Burger King!" and I said I'm just gonna stare into space at the corner of that building until he calms down. I'm not gonna give him the
attention...Some old Spanish lady comes up to me. She doesn't say anything to me. She says to him "Shame on you! A big boy like you throwing a tantrum!" this and that, you know, and I couldn't reach in my pocket to give her a card cause he's on that leg, and I'm just like, in the back of my head, she's like, "Sir! Are you hearing me?" and I'm just like looking into space.

August 4, 2011

Support for Fellow Parents. In other instances, I saw that while parents may attempt to educate misunderstanding strangers about autism or about their children, at some point, parents often gave up and considered the attempt useless. In these cases, their fellow group members often tried to provide them with emotional support to get through the situation. One particular incident that had all of the parents talking occurred at an indoor playground the group frequented. After the incident, Jessica posted about the situation on the group's message board to inform some of the parents who were not in attendance that day:

I would like to share with all of you a little incident that happened to me last Thursday in Indoor Play. My boys were having a great time, as usual, and Elias was playing with one of those motorcycles and next to him was a little boy who was playing with the other motorcycle… Suddenly the mother of this little boy was yelling at my son telling him that he can’t touch her son, he can’t talk to him like that and cursing him… OMG! I was too steps from him and I heard everything and Elias wasn’t touching him or telling bad things to her son. Ok, first of all, my son is verbal but his language sometimes is not clear or doesn’t make sense; as a result, he uses his hands to try to fix or explain whatever he can’t SAY… Well, big mistake from my Elias because this woman was cursing him… I approached her, I explained to her about my son’s condition and her simple, rude answer was: “I don’t see anything wrong with your son, he doesn’t look like an ALIEN, he seems fine. You should teach him better. He doesn’t know how to behave, he shouldn’t be here”…

Oh God help me!!!! I just lost it… I lost my patience, my composure, and my prudence… Please don’t take me wrong, but I couldn’t take it anymore. I explained to her AGAIN what my son’s condition but this time I was yelling at her… She just didn’t care. She kept telling me that my son shouldn’t be there.

After I took my kids to bowling at one corner, I just broke down I couldn’t take it anymore… (Oh God, I’m crying again)… But I wasn’t alone, (APSG) mommies came to the rescue. Thanks to my Loyal Julia, the first one to approached (sic) her. Thanks to my sweetest Kate who tried her best with her kind words. Thanks to the smartest and practical Margaret, who tried to explain to this woman about our community and our dedicated labor for our kids; but unfortunately it was a waste of time because this woman didn’t care at ALL… Thanks to Juanita for her big Hugs (I really needed them), thanks to Marguerite because you girl were ready for action LOL. Thanks to Richard, for tying
(my other son)’s shoes LOL.

We are in a world where there’s no space for compassion and tolerance. We are in a world where intolerance, selfishness, prejudices and ignorance dominant our hopes, our faith, and our dreams… But in the middle of the moment of despair, I found myself lucky because I’m not walking this journey alone. I’m grateful to be part of this EXTEND (sic) FAMILY the (APSG) FAMILY, because you were there when I needed it the most and that is priceless.

April 25, 2011

In this particular situation, the strategies that the parents employ focus both on the stranger that the parents feel compelled to communicate with, and on the needs of fellow group members, in this case, Jessica. While Jessica, and later Margaret, tried to explain to the woman that Elias has autism and that he has trouble communicating verbally, they eventually gave up their efforts to educate her, and instead turned the focus of their energies inward to provide support through what had already become a traumatic experience for Jessica. When I spoke with Jessica about the incident later she explained:

Sometimes I have to deal with parents, who are more ignorant than their own children. They are even more ignorant. And they came up with you, with some stupid things, stupid answers, like, do you, I told a mother once, that, "Do you think I want my child to go and harm your child and act like that? Do you think I want that?" And that, it's, it's, a waste of time, or energy to explain things to people, but still I have to keep exposing myself. There's no way I'm going to keep Elias indoors. For Andres [Jessica's husband], I tell him that, you know, I will tell him what happened, he was like, "Don't take him again, over there." I said, "No. He has to learn and people has to see him. People has to see him." Some people, yes, I know they're, they make fun of him. People laugh at him. But you know what? I have to. I learn. I hate it. To just cover my ears and keep going. Just focus on him, and let's keep going. That's the only way. That's the only way, so.

July 27, 2011

**Planned Ignoring.** This sentiment of moving forward, of "cover my ears and keep going" that Jessica described in her interview with me is also a component of a third approach I observed parents take toward stares from strangers and comments from passersby. **Planned ignoring** is a technique often taught to educators, and this was not my first introduction to it. I realized through my study though, that planned ignoring is a technique that parents employ often
as well. The technique is generally used to address unwanted behaviors in children. For example, if a child is crying because he or she does not want to complete a math worksheet, or does not want to go to bed yet, an adult may utilize planned ignoring by recognizing that the child's behavior is exhibited for attention seeking purposes, and then by purposefully ignoring that behavior until the child complies with directions (complete worksheet, go to bed, etc.).

When dealing with strangers' stares and comments in public, I often saw parents employ this technique with other adults or children. Parents discussed this strategy as something that must be learned and practiced, and that is not easy for them to do. Meghan explained, "I just ignore it. That's one thing I've learned over the years, is to ignore it. That's one of the best things I could ever learn, for myself is to ignore, because, like I said, it's just, you know, it's too much. And even if people are looking, or whatever, I just you know, carry on and do whatever we do."

Kaleena explained that using this kind of planned ignoring is the best way to get her son and herself out of a difficult public situation quickly. For Kaleena, there is an assumption that trying to educate a stranger about a tantrum or a difficult situation with her son, the way that Richard does with his cards, is useless. Instead, she tunes out the stares and comments, and focuses on Jacob, and what he needs at the moment:

I'm just tryna get out of the situation and tryna get him outta the situation, as best I can, so I really don't pay attention to other people, uh, sometimes I will hear their comments, but I'm like, they don't know, like they don't understand, and I could take the time to say he's this way because of this, this, this, this but are they still gonna get it? Probably not. So I don't even bother...They're not gonna get it. Some people might, some people might be sympathetic. Some people might say, "Wow. That's really hard." and then some people, "Oh, he's just a brat." Or you know, "He need a spanking." or you need to give whatever it is, and they don't get it, so I don't even, it's not even worth it, cause you can try to explain it to them, and they're gonna think what they're gonna think regardless, until it happens to them, if they're those type of people, until it happens to them, they're not gonna get it.

August 10, 2011
In previous decades, many individuals with physical, cognitive, or behavioral differences were invisible to the public in the United States (Whitaker 2001). Kept in institutions, sometimes even locked in rooms or closets, those differences were not presented to the public, and when they were there was often a great effort on the part of family members to minimize their differences. Since the disability rights movement in the 1960s and 70s, an increasing awareness of physical and cognitive differences has been promoted, along with an effort to celebrate those differences publicly. These large-scale awareness campaigns, which will be discussed in the following section, began first with an effort to de-stigmatize individual difference through daily exposure in local spaces, during mundane activities. As Jessica stated earlier in the section, "but still I have to keep exposing myself...He (Elias) has to learn and people has to see him. People has to see him." For Jessica, these acts of exposure are for Elias, and the effort she makes to take him to the playground, even though others may stare, laugh, or think terrible things about her son or her as a mother, are all worth it if his rights to grow, live, and thrive are protected: "Some people just say nasty things, and that's it. But Esteban has to keep going to the playground. He has to learn to play. He has to the right to go play, jump, kick the ball, play with other kids, and understand that some people will be nice with you, some people won't. And that's it."

**Engaging Activism Through Media**

At present, a basic public awareness of autism exists in the United States, but prior to the late 1980s very few people had even heard the word. The increased awareness is largely attributable to media campaigns that have promoted autism awareness, raised funds for research, therapies, and treatments, and highlighted the accomplishments of individuals diagnosed with autism and their families, teachers, etc. Researchers, psychologists, educators, and individuals
diagnosed with autism alike have pioneered such campaigns. In recent years, parents of diagnosed individuals have also used various media to tell their stories and request from the public increased tolerance, including acceptance, education, and greater awareness of the difficulties they and their children may face. Employing media and a way to share experiences, parents of children with autism have been able to build an activist network that centers around the needs of individuals diagnosed with autism, as determined by those who care for them. Three of the largest autism organizations functioning in the United States: Autism Speaks, The National Autism Association, and Organization for Autism Research, were all established by parents or grandparents of diagnosed children. These organizations, like APSG, were all created by caregivers in order to learn more about autism and how to most effectively care for their children's needs.

In this section, I discuss some of the ways that I observed parents involved in media efforts to increase autism awareness. The parents in my study were all familiar with the three major organizations described above, and at times were involved in the organizations' awareness campaigns. Additionally, they sought to employ their own media campaigns to speak specifically about their own experiences with autism, as parents living in Queens, New York, working together to support each other and their children. Through these media efforts, both nationally and locally, parents were able to communicate their experiences to others on a large scale, and were able to educate people locally and globally about how they understand autism individually as parents and collectively as a support group.

One of the most effective ways that parents in my study used media to share their stories with others was through online technologies. When Sarah started the group in 2006, she used an online social networking portal to facilitate the group activities. While many activities on the
site were secure and membership was required in order to participate, the main page that Sarah created explained who she is, and why she started the group. In a Google search for "autism parent support groups, NYC" that I conducted in 2010 as I began my fieldwork, the request returned several "hits", one of which was for APSG. Anyone else searching within these parameters would also be introduced to Sarah, her daughter Ava, and Sarah's hope for the establishment of the group. In 2011, after the group attained 501(c)(3) non-profit status, they closed their membership with the networking portal, and started their own website. The new website also requires membership (including a contract and dues) to participate fully in activities, but also has a feature for a mailing list, to which anyone can subscribe. A few months after launching the site, APSG also created a twitter account, which is managed by Leslie, APSG's secretary. She tweets daily about her own experiences with autism, about upcoming meetings or workshops sponsored by APSG, about news regarding special education law, current events in NYC public schools, and medical or research topics of interest regarding autism. Through Twitter, the APSG group also follows other groups and families who discuss autism, as well as educators who tweet about techniques and strategies to help children.

APSG also used video to promote their group and describe what it means to be a support group and a family for children diagnosed with autism. In one such video, made viral via YouTube, Sarah shows the faces of the children in the group. Beginning with an introduction about how APSG is a group-organized by "mothers living with autism", the video describes how it operates as a "road map" for families of diagnosed children. The focus of the second half of the video is then a showcase of each child with their picture and age, proclaiming that these faces are of "everyday children like yours and mine". In a second YouTube video prepared by APSG, the mothers of APSG stand strong, tall, and proud together, arms locked in unity, while an
inspirational song plays in the background. This video is similar to the global campaign motif called, "Autism Mothers", which features groups of autism mothers from various countries around the world, demonstrating that parents lean on each other for support and work collectively to care for the needs of their children. The parents of APSG also stood together to describe the purpose of their group and the ways their lives are affected by autism for a news reporter and cameraman who were shooting video footage of the 2010 Autism Speaks walk in New York City. Sarah, the president and founder, stood in the middle of the group, holding her daughter Ava, who several times reached out to grab the microphone from the reporter. Sarah spoke about her concern that there were no support groups in her neighborhood and her determination to create a space for parents to support each other through their life journeys with autism.

In addition to using digital media to share their individual and collective stories, APSG was also featured in several magazines. Two of the magazines were created for local families in New York, the third is a magazine specifically about autism, organized by families in the United Kingdom. The local magazines regularly featured pieces about how to raise healthy, happy kids, how to involve children in fun craft activities at home, and how to prepare nutritious meals. Both magazines also featured special editions that focused on children with special needs. In these editions, Sarah's voice comes through to describe the process of learning about what autism is as well as how to connect with other parents who have similar experiences. She also speaks of the group's journey as they welcome professionals into their workshops to ask them specific questions about specific challenges they may face with their children, and of individual parents' journeys as they "transform", becoming "the best advocates for their children".
Parents in APSG also spoke face-to-face with students, educators, professionals, and the general public through various kinds of presentations. One such presentation was held in New York City at a massive conference for the social networking portal organization through which Sarah had originally started the group. From 10,000 group organizers, Sarah and Julia, and three other portal users leaders were invited to speak about their particular groups, why they chose to start the groups, and how they use the technology to connect with group members. The portal allows for people from a large variety of interest topics to form groups: adult athletic groups, poetry groups, knitting groups, rock climbing groups, elderly dating groups, etc. Many of the people in attendance of this presentation were not immersed in the world of autism as educators or family members, so when Sarah and Julia told their stories, the audience was introduced to autism through their experiences, through their eyes. The presentation was also streamed live over the web, and recorded for later viewing access online. Many of the people watching the presentations from their home computers were also not very familiar with autism, and were hearing about it through the words of parents who live with autism everyday. Furthermore, the creators of the portal organization were also invited to speak on a popular American syndicated talk show, and when asked which of their online groups they considered most influential and inspiring, they named APSG.

Conclusion
A common theme ran through nearly all discussions about autism at APSG meetings and activities: Parents must be ready and willing to share their stories, and they must be ready and willing to learn about autism and what their children need. The personal narratives described were often those of transformation - parents were shy, worried, upset, uncertain at first, but by sharing and learning they became strong advocates for their children. The group narratives
centered around these elements of sharing and educating as well, and additionally around the theme of exposure. Through the creation of these group narratives, APSG was described as a family, proudly supporting children diagnosed with autism, a group that would stand tall next to those mistreated because of their differences, that would fight for the rights of its loved ones, and that would support its members through good and bad times. By focusing on strength (emotional and at times physical), education, and a clear, loud voice, APSG parents strove to communicate their experiences with autism to others, to educate themselves and others about their experiences, and to help one another through these activities.

The power and necessity of communicating one's wants, needs, and experiences becomes engrained in parents as they attend workshops, read books and articles, watch videos, and engage in conversations with educators and other parents, which encourage parents to "be your child's voice", "speak up for your child's rights", and to "protect your own rights" by maintaining involvement in every step of a child's educational programming and medical care. Parents also learn to model communication strategies for their children, teach their children how to "use their words" and express themselves. Because so many of the children who are diagnosed with autism have difficulty communicating, parents often spend a tremendous amount of time teaching children to speak, to sign, to read social cues and respond appropriately, and to use various communication technologies for self-expression. In doing so, self-expression - communicating one’s experiences to another person - becomes part of their daily life, and inevitably something that they focus on not just for their children, but for themselves, a skill they constantly practice and reflect upon. Parents' target skills for their children, who struggle to communicate, and for themselves by choosing the appropriate time, place, platform, and strategy to get messages across to others. Parents bring this expertise into every narrative they create and present,
individually and collectively, as they fight to successfully convey their circumstances and educate others about what they need and want.

To become autism warriors, the group leaders constantly reminded all group members of how they must order their lives: They must attend meetings. They must take their children to public places no matter how anxious or nervous they feel. They must contribute to the online forum to help other parents in need. They must bring their children to family activities. They must contribute to the financial and logistical needs of the group. They must share the knowledge that they have with others in the group. They must share the knowledge that they have with family members, educators, and strangers. They must stand up for the rights of all individuals affected by autism. These mandates serve not only as requirements of membership but requirements of life activity. They order the way parents live their lives, plan their schedules, prioritize their activities, and interact with others. Sarah often said that in order to be effective in the group and as autism parents, all members must contribute to the group by educating themselves and others, and by being vocal advocates for their children. As parents practice activities of education and communication, they come to live the life of educative, communicative autism warriors, and that life further reinforces the ordering of their activities - parents participate in certain educative and communicative activities because they are autism warriors, and they are autism warriors because they participate in those activities.
Conclusion

“Autism Parenthood” as Varied Experience

When I began this project, I wanted to better understand the lives of parents of children diagnosed with autism. I wanted to know what parents experienced on a daily basis and how caring for a child diagnosed with autism impacted their daily activities, outlooks on life, dreams, fears, and hopes. I wanted to know more about the daily activities of autism than I was able to see in my elementary school classroom, and I wanted the focus to be on the caregivers. I had a feeling that the activities, emotions, and events I would observe would be different than the “autism experiences” I encountered as a classroom teacher, but still began this project with the
assumption that there is an “educator’s autism experience” that is different from a “parent’s autism experience.” With this binary, an “us” vs. “them” mentality, I entered my fieldwork. Yet I emerged with an understanding of the great variation of experience within “them,” which I believe is critical for any anthropologist to experience first-hand.

In the work of studying people’s lives and experiences, one is able to recognize patterns in daily activities and see ways that people are alike in their behaviors, expression of emotions, or reactions to situations. Despite all of these visible patterns however, people never cease to amaze, disorient, and surprise those who study them. Just when I thought I was able to pronounce clearly and matter-of-factly that all autism parents do “this,” I would meet a new parent who did the opposite. At the moment when I was sure that all autism parents could be described with “these characteristics,” I met someone who shattered the descriptive mold I had created. This, I found challenging and encouraging.

I suggest that parents were able to escape from these patterns and molds because I paid special attention to the changes occurring in their lives, recognizing and privileging the notion that this change was ever-present. They are, were, and will continue to be in the process of producing their own lives – in a process of changing, and each of these processes will look different for each parent. During my 18 months of fieldwork, children mastered new skills, new members joined the group, and some parents got divorced while other parents started new romantic relationships. These changes occurred before my eyes and altered the ways that parents responded to their responsibilities to their children and to their own personal experiences with autism. Since I began writing this ethnography, still more changes have occurred in the parents’ lives, and with each change, they were required to figure out what to do next in order to best support their children and other loved ones.
As I think about the future for the parents and children in my study, I consider the changes that will impact them going forward. For example, while Julia and Leslie both have sons diagnosed with autism, Julia’s son, because of his particular difficulty with language will need supports and services in his adult life that Leslie’s son may never require, and both parents will have to manage this reality in a different way. Leslie, instead of fighting for speech services for her son when he transitions into high school, may find herself needing to know about art therapy programs if her son shows an interest in sculpture or dance. These two women, both living in Queens, both self-proclaimed “autism moms” and “autism warriors” will continue to experience two different autisms. At some moments in their lives, these experiences may closely align and they may find each other attending the same classes and Googling the same keyword, while at other times they may feel separate, incomparable, and bonded only by a diagnostic label. They are both “autism parents,” and yet their experiences with autism may be radically different.

“Autism Parenthood” as Collectively Experienced

Through this study I have found that each parent’s autism experience is uniquely constituted by the relationships the parent has with those around him/her, the peculiarities of the parent’s and child’s bodies, the spatial and temporal particularities of a given moment, and the institutions, social actors, rules, documents, etc. that parents must navigate and manage. While this emphasis on uniqueness is important, the commonalities of autism parenthood cannot be ignored. These commonalities are evident when parents within APSG explain that those without children with autism will never truly understand their lives. These commonalities are clear when most parents in the room have taken their children to several neurological evaluations. These commonalities are obvious when all of the parents sitting at the table with me have been to
several IEP meetings and know that they need to keep records of all communication about their child, should the school district decide to withhold special services.

I began the write up of this work so engrossed in parents’ stories that I dared to say that, “autism as a term doesn’t matter.” I wanted to say that the term meant nothing and that each parent’s experience meant everything. As I mention in the introduction to this text, I even wanted to leave out historical information about autism (changes in diagnostic criteria, seminal publications on the disorder, gene studies, brain studies, etc.) for fear that it would cloud the reader’s experience with parents’ stories. I thought of autism as merely an index that parents use to refer to a certain kind of diet, or a certain support group, or to a document that states a diagnosis.

It was not until I began to think through the tension that exists in presenting the varied experiences of parents, and presenting their common bond as “autism parents” that I became fully aware of the conundrum. I have wanted to suggest throughout my research that “autism” shouldn’t be used as a term to describe the incredibly varied experiences (sensory, physical, emotional, cognitive, etc.) of the parents in my study. In fact, as the data are presented, it often seems like the term “autism” when I’m describing a parent experience could be replaced with “mental retardation,” “cerebral palsy,” “schizophrenia,” “learning disability,” or any other disability for which we may have a category. In this way, I think that my job is to describe the individual experience – some children and parents will struggle with noise and lights, others with schoolwork, others with self-help skills, nearly all with stigma and anxiety.

So what makes the experiences described in this ethnography unique to autism? In some ways they are; in some ways they aren’t. I may suggest that there is a uniquely autistic quality present when others around are not visibly (immediately) aware of a physical difference
in the child, but this could also be said of children with learning disabilities or mental illness. It is also true that there may be additional stressful situations for parents due to a child’s anxiety about his/her internal or external environment, but this can also be said of children with anxiety disorders or obsessive-compulsive disorder. There may be a social component that makes the experiences described in this text unique to autism, but this too can be said of children with depression, anxiety, or cognitive disabilities. Finally, the challenges presented with self-help skills (dressing, grooming, feeding, etc.) may also be uniquely characteristic of autism, but may also be characteristic of families of children with various physical disabilities.

But in so far as parents make the choice over time (by meeting, reading, blogging, talking, marching) to call themselves “autism parents,” these experiences become uniquely about autism. Together, they learn what it means to be an autism parent, and identify their activities as those of an autism parent. Oldtimers teach newcomers, who them become oldtimers themselves, passing on the knowledge. They begin to couch their experiences in the language of autism and to describe their lives as “autism lifestyle.” The same dressing routine that a mother may have to conduct with her child with Down Syndrome becomes one that the parent of an autistic child sites as part of her autism lifestyle, part of being an autism parent. She talks to other autism parents in the group about it and reads books for autism parenting about self-help skills. Through practice in the support group she learns to tell stories about this kind of autism dressing routine, and then other autism parents with the same autism experiences validate her frustrations and celebrations. Through this educative, collaborative work, the experiences of parents in my study become unique to autism.

In thinking through this work, I soon realized that I could not present parents’ experiences without considering the impact of the term autism on those experiences, because the
term *autism* does mean something to parents – often something very important. It is a word that may shock them during the initial diagnosis, rendering some unable to utter it for weeks or even months. It is a word that may make them cringe when they read about rising incident reports, yet may make them swell with pride when an inspirational young teen makes it to the front page of the newspaper. Autism is a term that parents may display loudly and proudly on fundraiser banners, and yet may keep quiet when meeting new neighbors. While Julia and Leslie have experienced different autisms in their own life, they know what it feels like to be receive a look of pity when they tell someone about the diagnosis, and they know what it feels like to have someone ask if “autistic” means “retarded”. They also both know what it feels like to look at another mother wearing an “I love someone with Autism” bag, and want to create a lifelong friendship, instantly.

**Reconciling the “Replication of Uniformity” and the “Organization of Diversity”**

In 1961 Anthony Wallace, responded to the School of Culture and Personality’s cultural generalizations by arguing that rather than displaying a “replication of uniformity,” societies are held together by an “organization of diversity.” In this argument, Wallace was speaking to individual personalities within societies, but this argument can be abstracted to speak of heterogeneity within cultures as well. This is essentially the issue that I have been grappling with throughout my study of autism parents. Educators, medical professionals, policymakers, the media, and anyone who has never cared for a child diagnosed with autism – have a tendency to think (and act upon this thinking) that all autism parents are alike, and that they all have the same experiences. This can be highly problematic thinking as it greatly influences access to healthcare, educational programming, insurance and benefits, legal practices, and the everyday treatment of one human being toward another. Those who demonstrate this thinking are reacting
to autism parents with a “replication of uniformity” approach, and this approach is no more useful than thinking that all people in The People’s Republic of China have all of the same experiences.

But if “organization of diversity” is the more appropriate approach to take when interacting with parents of children diagnosed with autism, what constitutes the “organization” of their diverse experiences? For Wallace, the organization of diverse personalities requires a systematic way for people to predict each other’s behavior, despite their personality differences. For the parents in my study, the organizational structure seems to be one devoted to story-telling and sharing information; they organize their diverse autism experiences (as members of APSG, as autism parents, etc.) through education. Parents educate themselves about what they need to know to manage their own autism experiences, and educate others about what their experiences are and what they mean to them.

It is in this organizational structure that the term autism reveals its importance. The term is used as a tool with which parents engage in story telling, and with which they educate others and themselves. Parents specifically choose “autism trainings” to attend, and read “autism blogs”. They connect with other parents who call themselves “autism warriors” and watch news reports about “autistic individuals”. They call themselves “Autism Parent Support Group” and display “My child has autism” bumper stickers. When describing “autism” to someone unfamiliar with the term, they site definitions and characteristics, clearly articulating the word and using it often. Conversely, when they meet together in a local library in Queens, over donuts and coffee, they rarely use the term, and instead allow its absence to speak to their intimate understanding of a collective autism experience. Parents’ experiences with autism are multiple, varied, and ever-changing, yet they are able to organize them in a way that can be meaningful to
each parent’s experience. In order to do so, they employ the term autism as a tool, invoking it loudly when needed, and yet silencing it when its essence may exist unspoken. They employ this tool to help them organize their experiences (and by extension, themselves) through story-telling, advice-giving and information-seeking.

As I reflect on the time that I spent with the parents in my study, and on my goals upon entering the research, I remember my desire to get to know parents’ experiences – to really get to feel their anger, shed their tears, clap for their joys, and weep for their sorrows – in order to become a better educator. Throughout my work, I’ve learned more about their experiences as parents, and overall as human beings, than I ever planned to learn, and I feel privileged by that. With this privilege comes a felt responsibility, one that I have taken as an opportunity to pass on the knowledge I’ve gathered from parents by sharing it with practitioners. Understanding the demands of practitioners, yet wanting to respect and honor the work parents have allowed me to engage in, I have attempted to condense this information into the directives below:

**Practitioners need to accept and value multiple autisms:** Parental experiences with autism are in fact different from practitioner experiences with autism. They may exist in overlapping spaces, but they are constituted in ways that practitioners may never have the opportunity to encounter. Within those parental experiences, each parent has her own autism unique experience, one that is being produced and reproduced as she grows and her child grows.

**Practitioners need to do more listening.** The most effective way to learn about parents’ experiences is to hear a father’s story, or read a mother’s narrative. Until then, practitioners cannot decide what any one parent or family needs for a child.

**Practitioners need to recognize the power of group education.** Parents have organized a huge diversity of experience through story telling, advice giving, and information seeking. In
ASPG this was done in a judgment-free environment where parents became the experts about their children’s unique needs and shared this information with others. Parents were able to feel connected as a group, but also to meet their own individual needs. Practitioners should continue to help create the spaces where this group education can exist.

Practitioners need to be aware of their use of the term “autism”. As described throughout the text, this term can have an exquisitely emotional connection for many parents, one that practitioners may never feel. When using this term, please think about the power that it holds, and the memories that it conjures. When parents invoke it to speak for their children, loudly and proudly, stand beside them, but during the moments when parents tell their story, consider just letting “autism” sit beside you, silently.
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Appendix A

Interview Guidelines and Prompts

1. Can you tell me about your experience with your child's diagnosis?
   - when did it happen?
   - how did you feel?
   - what did you do?
   - who was around you for support?
   - did you know what autism was?
   - how did you move forward?

2. How did you/ do you learn about autism services, supports, etc.
   - where do you go?
   - who do you talk to?
   - what do you read/watch?
   - do you share this knowledge with others?
   - how often do you learn something new about autism?

3. Can you tell me about what an average day is like in your family?
   - what is your morning routine?
   - what are shopping/errands like?
   - who is around your house
   - how do you feel throughout your day?

4. Do you communicate about your daily experiences with autism? How?
   - talk to friends, family?
   - talk to a support group?
   - share your experiences online? (blog, Facebook, etc.)
   - share in a private journal

5. Can you think of a moment lately when you felt very frustrated, or like an obstacle was in your way?
   - what happened?
   - how did you react?
   - what did you do to cope with or manage the frustration?
   - what was the result?
   - who did you share it with?
   - is this something that happens often?

6. Can you think of a moment lately when you felt hope or joy?
   - what happened?
   - how did you react?
   - who did you share it with?
   - is this something that happens often?

7. When you think about the future, what do you hope to see/experience?
   - for yourself
   - for your child with autism
   - for your family
   - for others who do not know someone affected by autism