

INTRODUCTION



Love as an Analytic Tool

Women's work is of a particular kind—whether menial or requiring the sophisticated skills involved in child care, it always involves personal service. Perhaps to make the nature of this caring, intimate, emotionally demanding labor clear, we should use the ideologically loaded term “love.” For without love, without close interpersonal relationships, human beings, and it would seem especially small human beings, cannot survive.¹

Of course, love is never innocent, often disturbing, given to betrayal, occasionally aggressive, and regularly not reciprocated in the ways the lovers desire. Also love is relentlessly particular, specific, contingent, historically various, and resistant to anyone having the last word.²

If You Think My Hands Are Full . . . You Should See My Heart!³

This is a book about love. It is a history of autism, one that pays particular attention to the importance of affect in biomedical research during the second half of the twentieth century and the first few years of the twenty-first. I explore the role of love as a social experience and technical discipline. I do this for several reasons. Passions are a key part of the production of knowledge and the identities of contemporary scientists and medical practitioners. Theories of affect, and love in particular, shape the discourses of developmental psychology, psychiatry, and, more recently, biology. Affect and its synonyms, including despair, anger, caring, and love, work as “good enough” analytic tools for interpreting contemporary biomedicine. Like

the parents described as “good enough” by the child psychologist and autism researcher Bruno Bettelheim in one of his warmer portrayals, our analytical categories need only be up to the task of illuminating key themes and conflicts in the material. Love works pretty well. It also helps me think through the role of the social scientist and historian negotiating the thorny issues of trust, complicity, and participant observation.

Autism refers to a symptom, a disorder, and a syndrome.⁴ The concept derived from the idea of negative social affect: “autistic isolation” in patients with psychiatric disorders. According to the current *Diagnostic and Statistical Manual of Mental Disorders* used by most psychiatrists and physicians in the United States, autism is a developmental disorder involving “qualitative impairments” in language, communication, and social relationships, alongside “restricted, repetitive and stereotyped patterns of behavior,” with onset before the age of three. Any additional claim is contentious, but the standardized diagnosis obscures the complexity of the behavioral and physiological syndrome in any given individual. Autism is also commonly seen as a lifelong disorder. To focus on children is to ignore entire lifetimes of membership in families and communities. Nevertheless, this book is about childhood because those are the years when families have to wrestle with the ambiguities of the diagnosis, invest in therapies and treatments, and prepare to live with the impact of their choices on their child’s future.

Understanding Autism traces the evolution of the diagnostic category of autism as people have understood it in different places and times, paying particular attention to how people have thought about autism in different ways depending on the type of work they performed. These practices included diagnostic interviews with parents, psychoanalytic milieu therapy, genetics research, and biomedical interventions. The first three chapters deal mostly with the past, the final three with the present. Because the focus is on practice, even the sections of the book that draw on archival sources read in parts like ethnography, as I describe social practices as symbolic systems and seek to illuminate how participants understood the meanings of their actions. However, unlike ethnography, my analysis depends on public statements. I focus on how people describe informal practices of nurturance and care—private activities—in journal articles, memoirs, conferences, and courtrooms.⁵ I attend to the language they use to communicate insights about the affective content of practices to those outside their professional or social communities. When people work to explain those parts of biomedical care that are difficult to render in technical language, they talk about love.

Looking at autism in terms of the affective content of practices associated with it does three things. First, it illustrates the degree to which ways of representing autism depend on particular institutional and epistemological arrangements. Second, it shifts the focus from psychiatrists, epidemiologists, and geneticists to parents, counselors, diagnosticians, and lawyers, as they try to make sense of and apply systematic, authoritative knowledge in their daily lives and work. Third, and most important, in describing changes in autism over time and how expert knowledge works in practice, it highlights the centrality of love as a way of knowing about bodies, persons, and relationships in biomedicine.

I use “love” because it is the term used by the people and found in the texts that I have studied. Love is one of those terms in a conversation where expert discourses inform everyday language and where the quotidian in turn shapes biomedical knowledge. It might be more accurate at points to refer, ecumenically, to “affective commitments” or “emotional connections.” I prefer the everyday term, even if it is occasionally necessary to point out the technical alternatives employed by particular actors. Freud called psychoanalysis a “cure through love,” but contemporary social psychologists favor “empathy.”⁶ Needless to say, empathy also has a specific and localized technical meaning. Therapeutic practitioners might insist that their work involves “caring” and “help” while resisting “love” on the grounds that it does not involve a rational or intellectual component, a criticism that I will return to.

I focus less on love as an abstract concept than on the statements of participants in several domains of autism research when they talk about love as a form of labor. Love has been seen sometimes as a liability, a barrier to reliable knowledge, and sometimes as the source of specific, focused, and committed knowledge. It entered autism research as something that psychologists studied. Autism seemed to demonstrate what happened when people developed without giving or receiving affection. Love became for a while a behavior that might be encouraged or cultivated externally, before clinicians abandoned it for terms more in keeping with behavioral and cognitive models. Beyond the laboratories, however, love continues to function in normative claims about the practice of research. Parents and their allies say that emotional knowledge enables them to observe and attend to their children in the right way, guides them in medical decisions, and helps them make the right choices for the person whom they love. Those who are concerned about the actions and choices of parents say that it is love that blinds parents and incites acts of desperation. They also worry that the idea of love is used to rationalize and naturalize labor by

making the hard work that parents do seem instinctive instead of intentional and sensible. There is truth in both sets of claims. These examples all show how the emotional work of science is made visible when parents and professionals interact.

People do not just talk about love in the world of research on developmental disorders like autism—they actively practice it, often because they are also parents. Clara Claiborne Park, whose daughter was diagnosed with autism in the 1960s, said that she had followed “the imperative that an eminent mathematician has given as a two-word definition of the scientific method: ‘Try everything.’”⁷ The approach was as appropriate for the parents of affected children as it was for scientific and medical professionals. The work of professionals and of parents is not, in the end, as different as we have been led to believe. For example, the leading journal of autism research, then called the *Journal of Autism and Childhood Schizophrenia*, ran a remarkable column between 1974 and 1985, “Parents Speak,” edited by the first two presidents of the National Society for Autistic Children. Park reviewed books for the journal, arguing for the importance of reading parent memoirs not only as historical documents but as clinical evidence, “raw data in the fullest sense.”⁸

To be clear, love may not protect against harm. People who love routinely commit acts of violence. Consider three apparent murders of children with autism by their parents in 2006. The editor of a daily Internet autism clipping service and father of a child with autism agonized, “I have been struggling with trying to find a response that does justice to these situations, and I don’t think I’ve been doing such a good job of it because the subject hurts so, the heart can get too much in the way.”⁹ These were not isolated instances. In one, grieving relatives of the parent called a murder-suicide “an act of love.”¹⁰ Different groups interpret such acts in line with their own beliefs. Some blame the lack of support services. Others curse promised cures that fail to deliver, “[leaving] the parents of a half-million autistic children feeling like failures.”¹¹ Some parents will admit that they have also considered violence in spite of, or perhaps alongside, their love for their children.¹² Such acts and the agony that precedes and follows them resist simple explanations.

In focusing on parental love, I am not suggesting that only parents can provide the particular kind of attentive care that I am interested in. Many parents do not love their children. They are completely absent from their children’s lives. Some actively and intentionally harm their children. There are also many caregivers in residential facilities or employed by families who are more intimately involved in children’s lives than are their parents.

When I discuss the love that is part of effective care and treatments, I am less concerned with biological relatedness than with attitudes of investment in and devotion to another's well-being. Counselors, nurses, and teachers are often the ones providing this care.

Clara Park listed the advantages that parents have in treating their own children, leaving one quality of parental care, "a parent's love for his child," until the very end of her list. Park's hesitant attention to the necessity of attachment and caring, even in instances where doctors and parents are expected to impartially evaluate different treatment options, points to a tension that affects medical research and treatment in general. Love is not a panacea, and "we must be aware of the ways to go wrong in loving, ways that help not the person we love but ourselves." Nevertheless, "there are millions of parents—as well as teachers, and social workers, and doctors, and ministers, and psychiatrists, and ordinary men and women—who practice this love daily, knowing that love is a technique as well as an emotion."¹³

Understanding Autism pursues Park's insight about love as a technique in biomedical knowledge and practice. It is about why love is the last item on Park's list, and why it is the most important.

Thinking about Caring: Theories of Love in Biomedicine

Research programs in autism, as in many areas of the life sciences, have been defined largely by the passions and commitments that have informed them. These commitments inform not only the broad theoretical framing of investigations but also the day-to-day practices of research. My interest in love is a consequence of taking seriously the commitment to analyze science as a social system. It is indebted to work in science studies on reason, rationality, and objectivity. If science is a culture, it should be possible to analyze the rituals and modes of behavior that enable scientists to comprehend and trust each other, and to produce facts that the community recognizes as valid. Sociologists have analyzed the behavioral norms that have allowed scientists to see their work as insulated from the pressures of politics, social aspirations, and commercial enterprise.¹⁴ Even when those norms are not followed to the letter, they have provided models for how scientists believe they ought to behave.

In addition to observing rules of conduct, scientists have also used representational techniques to establish their distinctive identities. They have adopted styles of observation that emphasize impartiality and objectivity,

extending to the way that they write up experimental results and illustrate their findings.¹⁵ As scientific work became more collaborative, the problem of knowing whether or not to trust an individual's observations or experimental results became a crucial one. Scientists solved this problem in many ways, but one important way was by making clear distinctions between appropriate and inappropriate attitudes and behavior.¹⁶ Because there is such a close connection between the identities of scientists and their ideas about what constitutes reliable knowledge, one way to learn about epistemology is to study scientists' own statements about acceptable behavior and attitudes. I am interested in particular about claims regarding the emotional content of scientific and biomedical practices.

Love has mattered to feminist science studies scholars for some time. It has been a focus of their work on the role of passion and commitment in maintaining careers and research programs, on the importance of both caring and pleasure in scientific work, and on the way that expectations about gender have influenced scientific investigations.¹⁷ Love also reminds us of the gendered structures of labor in American society, including the institutions of domestic life and the division of domestic labor, as well as ideologies of motherhood and parental work. Caring labor most frequently falls to women, and because women are socialized to accept that obligation, they develop moral systems that are more attentive to matters of care and dependence.¹⁸ Beliefs about gender and its connections to affective behavior inspire speculations into the biology of sex and cognition, as well as psychological theories about cognitive normality and typical functioning in social interactions.¹⁹ These are especially salient in view of the brute demographic fact that boys are diagnosed with autism four times more frequently than girls. Ideas about gender color ideas about "autism moms" and dads who "fix things."

Gender runs deeper than the division of labor, to what we could call gendered economies of care—types of labor can retain their gendered associations no matter who is performing the work. Parent memoirs of autism begin and end with love, while practitioners speak of parents' diligence and devotion. In this view, commitment explains their ascent to near-professional levels of expertise. This praise is not disingenuous, but it still is worth questioning because it goes to the heart of how American society categorizes caring labor and daily commitments. The top professions for women have changed little in the past fifty years, with low-status "pink collar" jobs in elementary and secondary education, nursing, and administrative work still ranking highest.²⁰ In addition, women continue to provide much of the child care in the United States, although many fathers of

children with autism work as hard as mothers on advocacy and treatment. However, caring labor continues to be devalued because of its associations with women, and the expertise associated with it is often considered suspect. To begin to understand the hidden forms of labor in science and medicine, we need to consider the erasure of the research, long hours of therapeutic work, and advocacy that the care of a child with autism entails. It is significant that the serious effort required to know a person well or care about them effectively is often described as a spontaneous expression of affection rather than conscious work.

The fact that caregiving is hard but also intellectually and emotionally demanding work is key to understanding the arguments that this book makes about the ethics of autism treatment. It is also important to understanding how the philosophy of disability can deepen our understanding of the affective components of biomedical practices.

Moral Personhood, Families, and Dependence

Through much of this book, I present the primary act of intervening on the bodies and behaviors of children with autism as relatively unproblematic. Specific practices draw criticism in retrospect as poorly justified, but from the 1950s through the 1980s, few questioned the idea of treating autistic children or of recovery as a goal, whether attainable or not. This has not been the case from the 1990s onward. A growing number of adults with autism have joined a self-advocacy movement modeled on gay rights and Deaf advocacy, arguing for the validity of autistic experience and autistic culture. For this reason, I want to address what treating autism can mean in terms of respecting and acknowledging the personhood and rights of people with disabilities. I return to this question in more practical terms in an interlude midway through the book.

The ethics of treating autism turns on a question of personhood: whether or not one sees it as a disabling condition, something that it would be better not to have or to be. As Evelyn Fox Keller has argued, the definition of autism as a pathology rather than a normal difference rests on the conviction that the ability to relate to other people is not only developmentally necessary but morally necessary as well. It is a component of personhood. Someone cannot be a “whole person” without it.²¹ Many disabilities scholars argue in the same vein. Michael Bérubé, in a memoir about his son who has Down syndrome, suggests that it is Jamie’s ability to relate to others, his sensitivity to the needs of people, and his sense

of humor that reveal his intelligence and his value as a person. Eva Kit-tay, writing about her daughter who has multiple physical and cognitive impairments, argues that it is her membership in a network of relationships of caring, kinship, and love that grants her “personhood,” the quality that makes it ethically necessary for society to protect people like her and provide for their care. One way that society can respect the personhood of people like her daughter is by providing for her caregivers, those who attend to her physical needs, but also those who care for her as a person.²²

Autism, though, poses a problem. There is no definitive model for how cognition functions—or fails to function—in autism. The dominant psychological and neurological models continue to emphasize the absence of empathy. If Leo Kanner first framed autism in terms of a lack of affective contact, contemporary scientists describe the disorder in terms of lacking the “theory of mind” that allows people to imagine others’ mental states. Neuroscientists point to malfunctioning mirror neuron systems, the part of the brain that helps us understand the behaviors of others by providing us with a mental model of their actions. In essence, we understand the behaviors of others in part by imagining ourselves doing the same things.

Although the terms may be more sophisticated, the argument remains the same: people with autism fail at empathy. Adults with autism disagree, but they do so within the terms already set. They say they experience empathy but arrive at it and express it in ways that are difficult for neuro-typicals to recognize.²³ This dissent is significant, and the scientific claims about autism and empathy have obvious limitations. It remains true, however, that autism can mean, in practical terms, that an individual is less tightly bound into the network of relationships that sustain most of us.

This is not the place to enter into a complex discussion of the human rights of people with disabilities and why people with autism deserve support and respect as full, rights-bearing humans and citizens.²⁴ It is clear that many parents have little trouble committing themselves to the well-being of their child and seeing their child as a complete person, even if their child does not reciprocate their caring in familiar ways. The question that is relevant to this book is whether researching cures for autism or choosing an intervention with the expectation that it can treat or cure autism—and by doing so, help people with autism participate more fully in the give and take of human relationships—can be an ethical choice. I demonstrate that people who provide services for or do research on or spend their time caring for children and adults with autism make ethical decisions about treatment. This is not a claim about the efficacy of particular treatments or the rightness of specific choices. What I mean is that they

weigh their decisions in terms that are familiar to students of ethical philosophy. Some of those decisions are life-changing in the sense that they entail therapies that can alter or eliminate the symptoms of autism. I will argue that these actions, whenever observers do describe them as effective and beneficial, begin and end with close, attentive relationships.²⁵

These types of ethical thinking are important beyond the specific question of autism treatments. Alasdair MacIntyre has argued that disability and dependence characterize our lives; and, to the same extent that our ability to reason depends on our intelligence, our humanity is characterized by inevitable periods of profound dependence on the care of others.²⁶ Nevertheless, many philosophers have begun their descriptions of social relations by assuming that humans are autonomous, independent agents. We need to think harder about our obligations to those with disabilities, including those who are entirely dependent or unable to speak for themselves. The reality of dependence without the prospect of eventual autonomy has an additional implication. Inevitably some members of society will be charged with making good decisions about the care of dependent people.

This book argues that parents think about these decisions in ethical terms, and that their love for their children is something that they cite as central to their ability to choose wisely. The two, love and ethics, may be related. To care well, Kittay argues, caregivers must not only go through the motions of care, but they must also care about the person who depends on them, because without it “the open responsiveness to another that is so essential to understanding what another requires is not possible.” In order to do a good job with the rational, arduous, daily labor of caring, an “affective bond” is necessary.²⁷

Think of the decision to choose residential care for a child for the long-term benefit of both child and family. In the short term, the decision is utterly wrenching for both. Or the decision that a parent makes to begin a regimen of behavioral therapy, against a child’s immediate wishes, because the child may flourish as a result of the temporarily unpleasant drills and repetitions. Children with cognitive disabilities are especially vulnerable to wrong decisions about their care and depend on the caring of others. The problem is that people rarely talk about these decisions in public. Such parents have few guidelines. In the United States, where pregnancy and motherhood represent “a private dimension of public life,” in Rayna Rapp’s phrase, parents must act as “moral pioneers” in their decisions about the justifiable limits of parental obligations.²⁸ Put bluntly, parents are utterly on their own.

What ensures a coincidence of interests between the child and his or her caregiver? Our ability to reflect on our actions, values, and beliefs is necessarily tempered and guided by our ability to love. The philosopher Harry Frankfurt calls love an act of “volitional necessity.” It is something we experience if not involuntarily than at least unavoidably. It is also a choice, a relation that is entered into willingly, not instinctively or unconsciously. Humans may have a unique and near-compulsive capacity to reflect on their actions, values, and beliefs, but constant reflection would be paralyzing without an equal capacity to love. Reflexive thought and reason matter crucially to functioning in the world, but if we are to survive and “get it right,” that is, live a meaningful life, we need to care deeply about particular things in order to make choices about our goals and actions.²⁹ Reason has no practical application without love, and reason has no fit with lived experience without the winnowing power and narrowed focus that love confers.

Because of the close connection between reason and love, “the ultimate source of practical normative authority lies not in reason but in the will,” meaning our choices about what or whom we will care about most deeply.³⁰ The psychologist Erich Fromm made the same point fifty years ago when he described the art of loving as a practice that involves technical demands of “discipline, concentration, and patience.” For Fromm, love required “rational faith,” that is, a future-oriented focus on the object of love, not only as it is, but as it might become given the opportunity to flourish. This nurturing attitude could describe the focus and passion required for fostering scientific research as well as child development.³¹ An orientation toward the future is central to the care of children with disabilities. It is why parents may accept the calculated risk of choosing a treatment plan that places more demands on their child but offers the prospect that he or she will have access to more experiences as they grow older.

Frankfurt’s description of a necessary alliance between reason and love may not apply to everyone, but it fits many parents of children with disabilities. Consider those engaged in the type of everyday moral philosophy that Rayna Rapp suggests is fostered by their unique position. Although Rapp discusses prenatal testing in particular, parents typically continue to wrestle with difficult questions of dignity, respect, and rights long after making the decision to carry a pregnancy to term. Parents decide what is most important in their child’s life. Where a child does not ask for a greater range of experiences but seems content with a sharply circumscribed set of activities, what ethical imperative allows parents to demand more of the child? Eva Kittay and others suggest that imagining independence as the

exclusive goal can be both damaging and unattainable for many. However, parents are obliged to increase their children's "capacities to experience joy," which can best be done by broadening their range of possible experiences—for instance, by pushing a child who does not process visual information well to learn to watch and enjoy movies, because learning how will eventually broaden that capacity.³² It is hard to disagree.

I draw on these philosophical concepts in order to more accurately represent the people that I care about, the families and children who are the central concern of this book. Many children with autism have language delays. Others are nonverbal. Even those considered "high-functioning" or mildly affected may have difficulty serving as advocates for their own cause. They have more effective representatives among the hundreds of thousands of parents, practitioners, and researchers devoted to autism.³³ Of necessity, much of my story centers on actors, technologies, and knowledge systems that affect these children. The children themselves play a limited role in the debates that swirl around them.

Adults with autism are a different story. These often highly effective self-advocates matter to arguments about the appropriate and ethical treatment of children with autism, and I agree that they are better equipped than others are, myself included, to represent their experience. Self-advocates have enjoyed greater visibility and a bigger voice within parent organizations in recent years. Organizations such as Autism Network International, the Global and Regional Asperger Syndrome Partnership, and the Autistic Self-Advocacy Network, founded both by and for autistic people, are an important presence within the world of autism advocacy. Children, adults in institutions, parents who feel that the state and the medical industry disregard their complaints, and researchers excluded from mainstream biomedical research are all silenced in one form or another.³⁴ The burden for all of us who do have an audience is to act as adequate witnesses for those who are not speaking and to avoid the temptation to assume that their silence is equivalent to agreement or assent.

As should be clear, I am centrally concerned with how parents understand their children in biomedical and affective terms, and what they do with that understanding. I am interested in how the different identities of parents and professionals work in the scientific field, especially when it comes to making claims about effective treatments. Much of the time, the social mechanisms through which scientists maintain their cultural authority—desire for credit from their peers, willingness to share and dispassionately critique each other's results, and a collective belief in the project of increasing knowledge about the natural world—help produce reliable

information. However, struggles for authority in autism research have not enabled practitioners to progress steadily toward increasing independence from external interests.³⁵ The central role of parents in the history of autism research helps illustrate how investments and commitments from outside have shaped the sphere of scientific research.

Autism in History

Like other disorders, autism has become a site for evocations of the stresses, tensions, and catastrophes of modernity. Professionals have described autism as a symptom of postindustrial and suburban modernity, and a range of techniques and specializations have developed to define and serve the population. The literature on autism brims over with metaphorical as well as technical uses of the idea of autistic isolation, and autism has become, in popular culture, a generic synonym for emotional isolation and conceptual solipsism.³⁶

Autism has proven almost infinitely mutable. For a mother struggling to implement a behavioral therapy program in the 1960s without the support of her skeptical, sometimes hostile husband, and plagued by fears that she caused her son's illness through unconscious rejection, the disorder is a behavioral anomaly that can be cured through hard work. If the head of an autism genetics project were to read that mother's memoir, however, he or she might pay more attention to the husband's aloof personality and difficulty articulating his emotional states. This reader might also pick up on the mother's chain smoking and lupus as indicators of compulsive behavior and tendencies toward autoimmunity, possible familial risk factors.³⁷ For others, autism has been a metaphor. Bruno Bettelheim's famous account of "Joey: A 'Mechanical Boy'" detailed how a patient's fantasy of himself as a machine was so effective that "not only did he himself believe that he was a machine, but more remarkably, he created this impression in others." Joey's case was a parable of "emotional development in a mechanized society," ripe for psychoanalytic dissection.³⁸ It looks different to a contemporary reader. Joey's obsessions and adherence to ritual, his idiosyncratic use of language, and his alarm at human contact characterize almost perfectly a person with Asperger syndrome, another disorder on the autism spectrum.

Some contemporary autism researchers speak of "secular trends" in autism, noting that the emphasis on early intervention has changed the natural history of the disorder itself.³⁹ Like children with Down syndrome, many of whom have blossomed under the combined influence of im-

proved medical management and heightened expectations of their intellectual capacities, children with autism today don't "look" like the children that these researchers remember from the early years of their work. Anecdotally, they are less like Leo Kanner's original descriptions of isolated children consumed by repetitive behaviors. They struggle more with communication impairments, social reciprocity, and according to some doctors, systemic illnesses.

The shifts in the symptoms that constitute autism tell us much about how different professional and social communities understood psychology, neurodevelopment, and disability during the second half of the twentieth century. They tell us even more about the practical aspects of medical treatment and the ways that physical acts and interpersonal relationships have contributed to knowledge of bodies, development, and relationships. Parents' and caregivers' accounts can provide valuable insights into informal aspects of care in the history of intellectual and developmental disabilities. That history has often been written from the perspective of professionals and institutions, with a focus on the way that diagnostic labels have been used to control populations, rather than on how disabilities have been experienced by individuals and families.⁴⁰

The history of the autism diagnosis is also an inseparable part of a larger story about biomedicine. Autism may have begun as a category in child psychology, but it is an increasingly *biomedical* diagnosis. Biomedicine itself is more than a static system of knowledge. It is also a powerful way of perceiving and altering the world. When I use the term I mean the particular complex of social and technical practices that emerged after World War II at the intersection of molecular biology, genetics, immunology, and clinical applications derived from this laboratory-based knowledge.⁴¹ This research in universities and corporations fostered the development of new medical technologies, including pharmaceutical research in particular. It also provided the context for doctors' increasing focus on diagnostic standardization as the first step toward characterizing a disease in terms of its underlying biological causes. Standard diagnoses became, in turn, a key way that managed-care organizations determined insurance coverage and reimbursement schedules. These trends in research, health coverage, and product development encouraged clinical and laboratory researchers to develop a mania for "specificity," the idea of a perfect correspondence between pathological mechanisms, diagnostic categories, and disease-specific treatments.⁴²

Research on autism spectrum disorders took shape within a late-twentieth-century scientific culture shaped by the cold war, dreams of pre-

cise control over life processes, and the dominance of biological models in psychiatry.⁴³ All of these intellectual trends shaped the scientific culture of which autism research is a part, lending models from computing, cybernetics, defense systems, and behavioral research to investigators' theoretical frameworks. The successes of the American pharmaceutical industry have encouraged popular acceptance of an idea of neurochemical imbalances as the main cause of mental illnesses. Brain imaging techniques and the wide circulation of computer-enhanced images of diseased and typical brains have reinforced public belief in mental illness as something firmly lodged in brain structure and function, rather than as having its source in early childhood experiences or interpersonal relations.⁴⁴ One challenge of understanding patient advocacy groups involves placing them within a broader history of American biomedical knowledge. Likewise, it is important to understand parent advocates in terms of the illness-based groups that preceded them in areas like HIV/AIDS treatment activism.⁴⁵

The American culture of scientific parenting plays a role in autism's history as well. Parenting in the twentieth-century United States was influenced by a fascination with psychoanalysis and by ideologies of childhood and child development that emphasized both autonomy and fragility.⁴⁶ Mothers did not always submit willingly to the intrusion of medical experts into the domestic sphere, but the pronouncements of medical authorities nonetheless shaped American childrearing practices.⁴⁷ Likewise, mothers themselves helped create a culture of competitive parenting that incorporated expert ideas about child development and parental obligations.⁴⁸ The experience of autism in the twentieth and early twenty-first centuries is difficult if not impossible to disentangle from ideas about the nature of a "good childhood" and beliefs about normal patterns of socialization, development, and relationships.⁴⁹ That said, families of different social and economic classes have not always been subject to the same expert recommendations. There is no single history of American childhood.

Biosociality and Contested Illnesses

Autism is one of a number of contemporary contested illnesses, including Gulf War syndrome, multiple chemical sensitivity (MCS), chronic Lyme disease, and breast cancer. We find similarities in explanations for all of them, from changing human environments and toxic burdens to individual vulnerabilities. Patients have similar difficulties finding professionals who will accept the reality of their symptoms when they don't correspond

to generally recognized disease entities.⁵⁰ All reflect contemporary trends toward patient networking via new communication technologies, even if in the case of autism such networks predated the Internet. They are also all “embodied health movements” in the sense that disagreements focus on the reality and nature of physical suffering. Treatment strategies often involve tinkering and experimentation, and knowledge about the cause and cure of the disorders is built up in close relationships between doctors and patients, making that knowledge particularly difficult to test or standardize.⁵¹

Battles over the identity of biomedical groups are one type of classification struggle.⁵² These disputes emerge not only from differences in access to material or symbolic capital but also from different ways of using empirical evidence and affective knowledge. The profusion of interest groups surrounding autism research includes autistic self-advocates who see the search for a cure as devaluing their own unique abilities. Psychologists use autism as a platform for constructing theories of cognition and gender. There are parent advocates who are committed to a theory of vaccine-triggered autism, and other parents equally convinced that autism is a genetic disease. Representatives of all these groups push for their positions as much through politics as through mustering empirical evidence. They counter the evidence of their opponents by raising questions about conflicts of interest, compromised objectivity, and suspect funding sources. When what is at stake is the question of who has the authority to act in the name of vulnerable populations, research methods can become as contentious as the findings themselves.

It would be naïve to suggest that access to resources and political power play no role in parents’ pursuit of innovative treatments or their founding of advocacy groups. Researchers have long observed that autism is more frequently diagnosed among children of wealthier and more educated parents, although they have disagreed about whether this points to better access to health care or a genuinely higher incidence. Family experiences of autism in different cultural and socioeconomic contexts deserve more study, especially as those experiences are shaped by variable diagnostic standards and different diagnostic expectations among parents.⁵³ Nevertheless, if middle-class parents may be more likely than those in lower income brackets to trawl Medline, the National Library of Medicine’s bibliographic database, in search of promising leads and confront their doctors for access to experimental treatments, skepticism about the prognoses and therapies offered by medical experts crosses class boundaries.⁵⁴ Parents’ capacity to choose different treatment possibilities within a biomedical

framework may be limited by their access to scientific information and professional guidance. However, the choice to acquire these capacities is less an indicator of social class than it is a form of participation in the biomedical community of parents of children with autism. It is difficult if not impossible to reduce disputes among parents over how to treat children with autism to simple differences in their access to economic resources.

Contested illnesses are especially useful for exploring the ways people mobilize around illness categories. Any illness category can destabilize when debates emerge about when and how to intervene and with what tools, or on the possibility and desirability of preventative measures. Medical diagnoses share a second characteristic, however, to which I have tried to remain attentive. Scholars have long recognized processes of “closure” regarding scientific facts about medical conditions.⁵⁵ Stability in biomedical facts is achieved at a cost, so that what seems to be a triumph of understanding in the present may in the future turn out to have led to the abandonment of otherwise fruitful approaches. Even the supposedly irrefutable evidence of a medical cure can look quite dubious in retrospect. Throughout this book I am concerned with theoretical and therapeutic stability as well as change in biomedicine, and the extent to which both theory and practice are necessary for a community to believe that a particular intervention is effective.

Scholars in the anthropology of science and medicine have observed the tendency of people to form social groups based on illness. Their work sometimes implies that it is the disorder itself that leads groups to form or that the biological similarities among members of an illness category are what bring them together. My work on autism leads me to question the spontaneity implied by terms like “biosociality.”⁵⁶ Disorders like autism do not act as agents that construct the social or biological identities associated with them. Designers of research programs and clinical trials, on the one hand, and organizers of advocacy groups, on the other, must all work hard to construct illness-based identities. Communities form around the diagnostic as much as the biological reality of the medical condition that comes to define them.⁵⁷

Genetic research in autism has developed alongside increasing knowledge about other disabilities with genetic components and the formation of patient groups around those diagnoses. Autism’s ambiguous status as a genetic disorder and the immense heterogeneity contained under the diagnostic label make it different from these disorders and related forms of “genetic citizenship.”⁵⁸ Ways of relating based on the idea of genetic kinship have certainly influenced autism advocacy. However, the purpose-

fully experimental approach adopted by many parents suggests that they resist the “pastoral” care that medical and genetic authorities offer those with well-defined genetic conditions.⁵⁹ Parents’ sense that their obligations to their children extend beyond nurturance to systematic monitoring and medical interventions is nevertheless in keeping with accounts of ethical responsibilities engendered by new genetic technologies and individualized medicine.

By virtue of its status as both a developmental and, mistakenly, a childhood disorder, autism can teach us about the political economy of disability in the contemporary United States. Medical and popular understandings of development both reflect and promote invisibilities in care and lapses in services. The definition of autism as a disorder of childhood has had tragic consequences for families of adults with disabilities who have fallen outside the purview of state-sponsored educational or therapeutic programs. Diagnostic requirements under disabilities legislation have influenced autism advocacy and the framing of autism as a developmental disorder.⁶⁰ We can go beyond an understanding of biosociality as the motivating force for forming patient organizations and move toward understanding the political and economic context that makes it necessary to organize around illnesses and biomedical facts in the first place. Biosociality might best be thought of as one kind of politics that interest groups use, rather than as a fundamentally new form of social organization.

Parent advocates in autism research have argued for an authority grounded in their particular perspective and degree of investment. One source of their beliefs is the economics of contemporary U.S. health care. Behavioral therapies and other interventions not covered by insurance or supplied by school districts must be administered in the home by parent experts or by assistants that they have trained. The unpaid, home-based labor of parents that is required by our health care system also contributes to parents’ legitimacy as experts about their children. These same parents argue that producing better biomedical knowledge in a world full of visible and invisible risks requires us to learn more about the commitments and passions involved in producing knowledge about bodies. The goal is not some kind of more dispassionate knowledge but a better understanding of passion’s importance to producing reliable knowledge about individuals as well as populations.

Affective investments can bolster claims of commitment and entitlement and at the same time weaken claims of objectivity and knowledge. Parent activist groups find the scientific work that they support marginalized because of their nonobjective, nonneutral position. Their work nonetheless suggests

that partiality and objectivity are techniques that are not always in conflict. Rather, the networked interactions of parents constitute one dispersed laboratory in which a type of situated knowledge is produced.⁶¹

Methods, Questions, Interactions

Understanding Autism engages with both texts and communities. I pay attention both to the factual explanations that participants offer for their actions and the embedded meanings that they attach to practices. I treat these practices, whether contemporary or decades old, as taking place within a particular culture of parenting and biomedical knowledge, so even when I work with texts, I treat them as artifacts that provide insight into a particular culture.

Although I spent time with a wide range of professionals, I focused on the role of parent advocates in autism research. These extraordinary individuals act as proxies and representatives for their children. They work to mobilize networks for information sharing and lobbying, and they serve as citizen-scientists arguing for changes in the criteria required for credible scientific research. They do so even while devoting the vast share of their energy and resources to the daily work of caring for their own children. Parents who work as activists do not represent all parents of all children diagnosed with a spectrum of disorders that affect as many as one in every 110 children in America, but many more act as advocates, if only for their own children.⁶² Taken together, activists' statements represent a broad range of ways of thinking about autism. Although not all parents have extra resources or time to spend on advocacy, those who do can tell us about the ways that parenting in contemporary America involves an investment of love together with other more scarce resources.

I carried out research for this book in many different places.⁶³ Over the course of five years, I spent time with designers of diagnostic and assessment tools, screeners who employ these tools, primary care practitioners with diverse orientations and beliefs about autism etiology and treatment, and members of an interdisciplinary team designing and implementing a Centers for Disease Control–funded epidemiological project to establish valid prevalence and incidence rates. I attended conferences on medical interventions for autism. I participated in intensive workshops on these interventions, and I visited practitioners who use these techniques at their homes and offices.

I interviewed linguistic psychologists, geneticists, and neuroscientists at their laboratories and clinics in the United States and United Kingdom and attended talks and conferences in the fields of autism research and neuroscience. I spent time at integrated treatment and research centers. I observed National Institutes of Health meetings on funding and priorities for autism research and on coordinating research programs. I also attended Institute of Medicine hearings on the connection between vaccines and autism, conferences devoted to biomedical treatments for autism, and neuroscience meetings where autism was only one topic on the agenda. I subscribed to listservs for parents and for practitioners who treat autism spectrum disorders. I visited schools for children with autism, biotechnology corporations specializing in treatments for autism spectrum disorders, laboratories with specialized tests for food sensitivities and other conditions associated with autism, and the offices of a gene bank. I spent time at a retreat for adults and children with autism diagnoses, and joined in a fundraising walk for a major autism organization. I wrote articles, corresponded, commiserated, and joked with any number of astonishing, resilient, and utterly brilliant parents, practitioners, scientists, and people with autism.

Autism has a history as both a diagnostic and clinical entity. Some of that history is told here for the first time. I worked in special collections in Chicago and New Haven. I spent a week in the then-uncatalogued Bruno Bettelheim papers and spoke with Jacquelyn Sanders, Bettelheim's successor as director of the Orthogenic School. I studied Amy Lettick's correspondence and followed up by interviewing her and Bernard Rimland. I read memoirs and publications devoted to autism and developmental disorders dating from the first years of autism research through the present.

"Studying up," or "studying at home," by concentrating on highly educated participants in knowledge production who are frequently aware of the limitations in their own work, entails a unique set of hurdles.⁶⁴ Scientists are obviously not a "vulnerable population." They spent some time and energy trying to shape my account. Parents are like scientists in this regard. I enjoyed it. I also realized early on that it would not be possible to maintain the position of detached observer. My temperament played a part, but so did my growing understanding of the process of research. Resistance seemed out of keeping with the work, especially when I saw my collaborators and subjects producing good knowledge in the midst of and through their own affective commitments.

Love Stories

I was trying not to watch and I couldn't help watching, the way it always is with pain. I thought that I could learn about diagnostic screening for autism spectrum disorders by sitting in on sessions in a university clinic. Although diagnostic screeners lack the authority to provide an official diagnosis, the doctor across the hallway was in a position to do so, and clearly had. I remember a mother weeping and I think that the father took their daughter, who had just been diagnosed as "on the spectrum," for a walk down the hallway outside the doctor's office. Their pain was palpable. Even though they had been living with their daughter's disabilities, a diagnosis can change everything.

I was standing in the exhibit hall of a meeting for a group promoting biomedical approaches to treatment for autism spectrum disorders. Even though I had been lurking on a listserv connected with this group, and even though I had been starting to hear about these interventions, I was nervous and found myself unprepared for the experience. Parents wore photographs of their children tucked under the plastic covers of their conference badges. I listened in on one lecture on the health benefits of omega-3 fatty acids marketed by the speaker, another that directed listeners to recipes for gluten-free/casein free chicken nuggets, and another on the myriad hazards of vaccination. It didn't matter that I had immersed myself in the scientific literature on autism. Like many of the "first time" or "newly diagnosed" parents there, I didn't know what to believe. Someone asked me if I had an affected kid, maybe because I was standing in front of a table of supplements, fingering the packets of samples, looking lost, or maybe just because I was there.

We drove a couple of hours through the Florida marshes to visit the offices of a medical practice that specialized in treating kids with autism spectrum disorders, including the son of one of the two owners. The shelves were lined with nutritional supplements bearing a biblical allusion for a brand name. One of the doctors invited us to watch while he demonstrated a quantitative EEG technique on a boy with severe autism. The boy's parents and a visiting politician stood nearby. The child watched videos of animated vegetables narrating bible stories while my colleague and I discussed disease definitions with the doctor and environmental health with the wor-

ried father, who had a degree in toxicology and wondered about the substances that might have affected his son's development.

More than a year later, I watched the same politician give a speech at an Institute of Medicine meeting on vaccines and autism. The published guest list included lawyers, congressional aides, pharmaceutical sales representatives, medical doctors, researchers, administrators from the Centers for Disease Control, antivaccination advocates, and a number of people who listed their institutional affiliation simply as "parent" or "mom" or "mother of a five-year-old autistic child." During the brief public comment period at the end, one mom stood up at the back of the auditorium and spoke to the committee members while her friends held up a poster of the heavy metals excreted from her son's tissues during chelation, a process for binding and removing metals from the body. A father stood up. He was long-limbed and looked like a person who was used to laughing easily. During his allotted time of two minutes he said, "You have friends; you have fallen in love. I want my son to have friends, to fall in love." He had waited through the entire meeting to say this.

These descriptions are from notes I made while researching this book. I offer them here as a way of explaining how love functions in this book not only as an object of analysis for my subjects and a description of practices that are invisible in biomedical research, but also as a description of my position as an observer. I try to be honest about my affection for and caring about my subjects, my emotional responses to the stories that they shared with me, and my own identity as an imperfect and invested observer of the human interactions that make up autism research.

The chapters that follow are loosely chronological accounts. They are love stories, although some of them contain elements of tragedy. They are about the late, beloved psychologist and parent advocate Bernard Rimland, who diagnosed his son's autism using an old college textbook; anthropologists visiting the homes of "disturbed" children to observe the interactions between parents; mothers forming lasting friendships on the strength of exchanged letters and shared grief; and the hundreds of newly diagnosed "little professors" with Asperger syndrome in Silicon Valley. Some books about autism use the conventions of genre fiction. Having autism is like a detective story, where the task is to understand an impenetrable maze of social norms, or like science fiction, where people inhabit other worlds.⁶⁵ Some researchers describe autism as a disorder of narrative. Therapeutic techniques like Carol Gray's "social stories" teach people with autism to

craft accounts of human relationships.⁶⁶ I use stories to call attention to the fact that most explanations draw on the conventions of narrative in order to shore up the connections between disparate observations.⁶⁷

Although I have organized the next eight chapters around key political, practical, and epistemological battles, it is important to remember that lines were not always so sharply drawn. Parents of children diagnosed with autism, from at least the 1960s through the present, explored treatments ranging from holding therapy and psychoanalysis through operant conditioning, megavitamin therapies, and heavy metal detoxification. Membership in social and research networks overlapped. Eric Schopler, who founded the TEACCH program in North Carolina, joined other prominent researchers to work alongside parents in founding the National Society for Autistic Children (now the Autism Society). In the 1960s, the psychologist Bernard Rimland collated the scattered evidence for the non-psychogenic and possibly genetic origins of autism, but he was as active in studying behavioral treatments for autism as he was in promoting megavitamin therapy. Uta Frith, Lorna Wing, Edward Ritvo, and Michael Rutter pioneered autism research in England. Rosalind Oppenheim, a mother in Illinois, read all of them as she developed educational programs.

Just as it is wrong to see affiliations or research commitments as exclusive or fixed, it is wrong to imagine that understandings of autism have evolved in a linear fashion, from psychogenic to neurological to genetic models. It is wrong not only because Bruno Bettelheim was able to review both Ivar Lovaas and Bernard Rimland in *The Empty Fortress*. Parents struggling with autism diagnoses in the 1970s and 1980s read Bettelheim and heard their pediatricians speak in psychogenic terms, but they implemented behavioral programs anyway. While it may be appealing to represent autism research as a succession of theories, it is more accurate to consider it as a series of temporary configurations made unstable and more theoretically diverse by the variety of disciplines involved, the centrality of parental participation in research, and changes in the population that the term “autism” represented. As I show, the continuities that have existed have been at the practical level, in terms of courses of action, modes of relating to children with autism, and in the language that has been used to describe autism and autism treatment. This language has continually incorporated ideas about love and its role in human development. The shared language of love is the key to understanding continuities among practices—all require caring labor.

Each chapter in this book illustrates an intersection between structured, formal knowledge and daily life, and in doing so highlights the way

that emotional commitments allow biomedical knowledge to become part of caring labor, of telling stories and of putting lives together. Each deals with the practical problems that people encounter when they try to transfer expert knowledge and techniques—whether psychotherapeutic milieu therapy, behavioral therapies, genetics, biomedical interventions, or immunizations—into the messy and indeterminate realm of everyday life. In almost all of these instances, the participants have discovered that their affective commitments—their love—played a crucial part in the efficacy of their techniques or comprised an important element in their beliefs. Love made their techniques make sense, but it was also what made them difficult to explain, transfer, or justify.

This book is divided into two parts. Part One covers the history of theories and treatment practices. Part Two brings us to the present. In chapter 1, I track the evolution of the concept of autism from its first characterization as a rare emotional disturbance in 1943 to its present status as a potential epidemic. The point is that autism, as a diagnostic and clinical entity, has never *not* been a subject of debate with respect to its parameters, its utility as a distinct diagnostic category, and its relationship to an underlying population characterized by a distinct biological identity.

In chapter 2, I describe what happened when the child psychologist Bruno Bettelheim, director of the Orthogenic School at the University of Chicago, designed a research program for training counselors based on the idea that autism represented a form of halted ego development. I analyze the particular social system in which counselors at the School experienced their treatment efforts as worthwhile and effective.

Chapter 3 considers parents emerging from the experience of wide-ranging psychogenic theorizing about autism during the 1950s and 1960s, of which Bruno Bettelheim's work was but one, well-known example. Parental efforts to help their children by training themselves in treatment practices became part of the formal methods of behavioral therapies as described by experts in the field. In both the case of the Orthogenic School's milieu therapy and parental work in behavioral therapies, the affective involvement of "semiprofessionals" was key to what was experienced as the success of the interventions.

In a brief interlude, I describe how advocacy for disability rights has influenced parents' understandings of their children's needs and how parents have justified their desire for treatments in ethical and experiential terms.

I begin the second part of the book in chapter 4, where I tell the story of two parent groups and their efforts to promote genetic research on au-

tism. Parents have argued with self-advocates about the status of kinship as entailed by genetic relationships and the meaning of genetic research.

Chapter 5 turns to the longstanding practice of biomedical interventions. These treatments rely on intensive observation and commitment. My analysis emphasizes how parents describe their ways of knowing about their child's distinct physical symptoms and metabolic needs as a particular form of knowledge.

In chapter 6 I address the contested issue of the relationship between childhood vaccines and autism. As parents make claims about the environmental causes of autism, I consider their explanations about the onset of their children's symptoms and the ideological importance of intervening in processes of injury rather than disease. In my conclusion, I briefly discuss some consequences of this work for other research on advocacy groups before returning to the general question of love's relationship to responsibility and to biomedical knowledge.

Autism research is a volatile field, not only because of the high political stakes involved or the ubiquity of love and related passions, but because of the often unexpected ways that knowledge and focused interests can come together to make accepted facts about the world change quite abruptly.

I am attending a meeting of a NIH committee devoted to coordinating autism research across the different member institutes. The members of the committee are drawn from a number of government agencies, member institutes, and parent organizations. A presenter from a major autism organization unveils a new advertising campaign designed to achieve the same level of prominence as a series of public service announcements from the 1980s that we all still remember. The new ad is meant to change minds, and its message is: the odds of getting autism are far higher than most parents realize. It could easily be your child, and all parents should be aware of the warning signs. A later presentation is devoted to diagnosing autism at ever-younger ages—researchers think that they can perceive the risk of autism in a six-month-old. A parent advocate is standing next to me at the break, and I mention to him that, if the number of children with autism has already dramatically increased, a campaign to increase diagnoses will be sure to strain overburdened educational and support systems. He shakes his head: "They have no idea what they are bringing on."

Before I can begin to answer how a parent organization—or anyone else—changes the life of child and a family by encouraging parents to ask

about typical development or doctors to recognize and diagnose a case of autism, I have to explain how autism became a condition that could be diagnosed. Psychiatrists and parent advocates worked over many decades to establish the autism diagnosis. Despite their continuing efforts to craft an objective and stable category, the characteristics of autism have shifted over time, and diagnosticians have had to combine intimate knowledge with standard protocols to arrive at reliable diagnoses. It is this history that I turn to in the next chapter.