Chasing Science: Children's Brains, Scientific Inquiries, and Family Labors

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Abstract

Over the last three decades, an escalating portion of U.S. school children has been classified for special education; those with diagnoses entitled to services now number 15 percent of all public school pupils. At the same time, American scientists have focused increasingly on juvenile brains, studying what one psychiatric epidemiologist labeled "social incapacities." This article reports on the laboratory labors of two scientific groups: neuroscientists who scan children's brains in search of resting state differences according to diagnosis and psychiatric epidemiologists who look to epigenetics to distinguish differential diagnostic populations. The article focuses on the medicalization of childhood differences and the harmonies and discordances between what researchers and parents understand to be at the root of children's learning and social capacities.

Keywords

ethnography of science, children's brains, neuroscience, epigenetics

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> From time to time, new forms emerge that have something significant about them, something that catalyzes previously present actors, things, institutions into a new mode of existence, a new assemblage, an assemblage that makes things work in a different manner.
> Paul Rabinow (2000)

Forgetting the Past

In 1998, I watched Paul Krazinsky, a young Eastern European MD-PhD, explain optimistically the electrophoresis results of his DNA ligation on a gene responsible for a particularly intractable and lethal form of Epidermolysis Bullosa (EB), a rare genetic skin disease. He had greater problems getting his gene-gun to yield results in mice models where mammalian analogues often fail in the gap between theory and practice. But Krazinsky remained enthusiastic about developing a conveyor system for gene therapy. Older, more experienced researchers were far more cautious, and by 2000, the National Institutes of Health (NIH) and Food and Drug Administration (FDA) were holding conferences rethinking gene therapy after many technical failures and the high-profile death of Jesse Gelsinger in a gene therapy experiment in Philadelphia. Gene therapy turned out to be a highly problematic concept and practice, although recent reports of its limited success in treating a small number of hereditary conditions may presage a partial come back.[1]

This interdisciplinary research focusing on experimental, applied gene therapy would later be dubbed "translational medicine,"[2] a key phrase at the present moment in NIH funding priorities. Current attempts "to improve human health (require that) scientific discoveries must be translated into practical applications," as the NIH now puts it.[3] This focus on pharmaceutical and other corporate alliances to bring the work of life science research to quick fruition fueled the search for gene therapy, as it now fuels "the molecularization of the environment"—in Hannah Landecker's felicitous terminology[4]—with increased velocity, as I hope to show in this ethnographically driven essay.

The late 1990s were a time of great social, economic, and scientific volatility: gene therapy was in the air and the headlines; the government was engaged in a race with brilliant private sector scientific upstarts to map the human genome; family activism was raising research money quite successfully. The American public was riveted. Public expectations of "revolutionary" new biomedical technologies to ameliorate and even cure diseases based on genetic interventions were running high; the potent link of

imagination and material support provided a translational bridge widely represented on the nightly television news, and in books, diagrams, photos, and other popular media as "the race to map the genome" unfolded (Collins 2010; Venter 2008; cf. Borup et al. 2006; Brown and Kraft 2006).

The search for experimental gene therapies took place in laboratories far removed from the distraught and often mourning families of children born with severe versions of EB. Among the scientists where I was working, many expressed and acted out quite serious connections to the intimate, intergenerational suffering that produced not only their tissue culture but voluntary health group meetings at which they frequently served as plenary and workshop speakers and—sadly and too often—witnesses to children's funerals. Family activism often raised money for scientific research, provided the tissue banks, and—notably—occasionally placed parents in the list of authors of scientific papers and government funding and outreach networks. Laboratory and life span were thus braided together for both scientists and families whose members lived with genetic disorders (Rapp and Ginsburg 2001; Heath, Rapp, and Taussig 2004; Franklin 2006).

During this research, I was privileged to participate in a lot of corridor talk: informally, many genetic researchers spoke of their deep ambivalence toward family activism when it breached a line they continually had to redraw in conducting their experiments. As one very talented head of a lab put it, "I'd grant the families anything, anything to relieve their suffering, make their children well. But no amount of reading and volunteering is going to give them the background to decide on the direction my research should be going." Her heartfelt yet intellectually hesitant acknowledgement of alliances based on entanglements of tissue, dollars, kinship, and emotion are widely shared among the scientists with whom I have worked, beginning over two decades ago.

Yet since that time, the role of family activism has only grown stronger at diverse sites such as the NIH, the Genetic Alliance, in U.S. and U.K. autism networks and in many other venues throughout the developed world:[5] As Gil Eyal, a sociologist at Columbia University now completing a book on the rise of public awareness of autism put it, "100% of this research is funded directly or indirectly by parent activism. Without their creativity and insistence, autism would still be an under-funded backwater disorder".[6] Scientists express a range of reactions to this heightened climate of activism: they welcome the resources and sometimes the opportunities for the ethical "modest interventions" (Heath 1998) it brings. At the same time, some scientists also expressed skepticism about the populism, rejection of expertise, and contested meanings of "peer review" that come with the

"can-do" ideology inspired by an activist business model making claims on the reorganization of science and determined to whip it up to investment speed. Nonetheless, all of the labs in which I have been privileged to observe are supported in part by family-driven funding. Alliance building among affected families, biotechnology start-ups, and pharmaceutical companies are structurally built into laboratory life.

The heady infusion of capital from family foundations, start-up biotechnology and big pharma businesses, and the NIH has rapidly transformed the work of the life sciences. As a neoliberal model has gained velocity in the last two decades, genome mapping and sequencing that had once taken many months to complete by hand quickly went to semiautomated and then to fully automated. Scientists' sequences were posted every twenty-four hours on a publicly accessible database. And the stock of PerkinElmer, maker of the sequencers that stood at the intersection of public-corporate technological genome mapping, went zooming up. Many U.S.-based scientists may be wary of the velocity with which their hard and patient research must be reported out to fit this enforced manic business model, even as they participate in its competitive reward system with differing degrees of enthusiasm (cf. Rabinow 1996; Krimsky 2003). And scientists certainly lauded the return of rational science policy as a promissory note in President Obama's inauguration speech and subsequent science-oriented stimulus packages.

Active and activist science therefore constitutes a great space of inquiry for an anthropologist interested in how expert tools, assemblages, methods, and ideas collide, clash, and sometimes harmonize in the global system of scientific training, practice, and influence. This system is, of course, wide open to its environment, including its very political environment. A recognition of this environmental openness also constitutes epigenetics, the study of the ecological forces that translate instructions at the cellular level to turn genes off and on.[7] The explicit relation between these two forms of openness—in the daily lives of laboratory scientists and in the epigenetic processes of the human genome they study in theory and in practice—provides the analogic basis of this essay.

I mention the recent and largely failed history of gene therapy and its promissory message *en passant* only to make an obvious point: scientific complexes are forward-thinking unstable objects of investigation. Their public afterlife may be substantial, yet their working benefits depend on the interdisciplinary biomedical arrangements whose development they both triumphantly announce and then prepay to develop through successful grantsmanship. Such assemblages have been usefully analyzed as "biomedical

platforms" by Peter Keating and Alberto Cambrosio, a term to which I return below (Keating and Cambrosio 2000). Otherwise translated: fashions in scientific research come and go, leaving in their wake connections that they both create and from which they are also invented. Despite the triumphalist assurances that must structurally be written into the promissory notes of grants getting, the majority of such promises never pan out but must be described as the hope of the future, if they are to raise funds in the present tense. Those forward-looking enunciations are built into the process of fund raising in support of laboratory endeavors. So, too, I would argue, is their selective forgetting: What remains after the grant is over includes a communicative network of researchers, enhanced by what they have learned together, sometimes by collaboration, often through competition in their wider communities. And, of course, the marvelous tools that their team's creativity and potent funding orchestrate into existence are a legacy that supports future investigations. But the promissory notes of immediate translation into "revolutionary" therapies announced with much public fanfare are often quietly folded into the next experimental platform. Indeed, some sociologists of technological innovation have argued that there is an "historical amnesia" built into the expectations on which such performative promises depend (Borup et al. 2006).

In the case at hand, the opening toward "molecularized environmental influences"[8] on children's emotional and cognitive differences has captured the scientific imagination, eclipsing prior largely unsuccessful experiments in an older model of more deterministic gene therapy. That recent and much-anticipated interdisciplinary endeavor has been marginalized in the "postgenomic" investigations now taking place under more open-ended rubrics that include epigenetics, with its environmental openness. Working scientists forget the past even as they use the tools its promissory notes have in large measure funded, folding them into newly imagined interdisciplinary futures in the work of the present. It is the job of the ethnographer, however, to remember.

Observing the Present

At the present moment, XX and I have embarked on fieldwork that focuses on "cultural innovation in learning disabilities." Science, of course, plays a part. Our focus grew from a simple question the two of us had batted around informally for years: As parents of youngsters with learning disabilities, we wondered where all these increasingly visible special education kids were when we were growing up? Our first efforts at investigation led to an

equally simple answer: they had not yet been invented. I hasten to add that this does not mean that they did not exist, for many lived under highly stigmatized labels of lazy, slow, mildly mentally retarded, minimum brain damaged, and so on. But what Ian Hacking calls the "looping effects" of labeling-into-existence a group of people who then perform the behaviors associated with the "dynamic nominalism" of their new classification, escalating their own and more widespread consciousness of a newly solidified category, had not yet produced a visibly marked group of high-cost special education students (Hacking 1999).

Now in the United States, special education student populations have doubled around the country each decade since the 1970s (Donovan and Cross 2002). Currently, diagnosed children constitute 15 percent of our school age population, and a higher percentage of our school budgets. There are fourteen Federal categories under which diagnosed pupils are entitled to remedial services and accommodations. Although the annual mandated individual pupil review focuses on shortcomings in each special education student, our research highlights the larger social map within which the growing world of remedial and individualized education has taken shape: Its terrain was deeply marked by the movement for deinstitutionalization in the 1970s, which sent generations of institutionalized children back to their families and communities. It was shaped by epic struggles for civil rights involving the conflation of race and IQ testing, and the rapid resegregation of classrooms after Brown v. the Board of Education of Topeka, Kansas, with the disproportionate assignment of African American children to special education segregated classrooms. These injustices were all legally contested. A growing constituency of activist disabled citizens also drew inspiration and creativity from those civil rights struggles by the 1980s and 1990s, embracing many of its strategies and inventing others of its own (Shapiro 1993). In mapping the learning disability (LD) world, we find ample room for parent activism, and increasingly, young adult LD activism initiated by those who grew up with the benefits and burdens of federal labeling.[9]

Ethnographic methodology thus brings us on to multiple research terrains, ranging from public middle schools where I observe college students with LD/attention deficit/hyperactivity disorder(ADHD) labels mentor youngsters who now struggle with the same descriptions; film festivals where creative and controversial representations of life with disabilities are shown; homes in Harlem and Astoria where families were willing to tell their stories of nurturing a child with an Individual Education Plan (IEP)—the Board of Education generated contract that entitles a student

to legally enforceable specific accommodations and remediation services after diagnosis—and interviews with friends and neighbors whose children's diagnoses were only revealed when I mentioned my work. Like all fieldwork projects, this one is unruly and expansive, seeping into many layers of educational, legal, familial, religious, community, and personal life. Ethnographers follow the leads put forth by the many and diverse people from whose expertise they learn how a social dilemma unfolds in "real time." In this methodological pursuit, laboratory-based scientific findings are one piece of a much larger puzzle.

Relevant for this special issue of *Science, Technology & Human Values* is my present fieldwork in the laboratory meetings of two different scientific groups. The first is neuroscientific, and focuses on picturing and interpreting children's brain differences. The second is psychiatric, aiming its work at the epigenetic effects of social stress and paternal age on children's mental disorders. In both, I want to understand how scientists think about childhood brain differences and neuroplasticity. Both laboratory teams are highly interdisciplinary, benefiting from the robust scientific productivity that had accompanied the reduction of "mind" to "brain" and the prolific work accomplished during and after NIH's "decade of the brain" in the 1990s.

The study of neuroplasticity and complex childhood mental disorders (most abstractly grouped together by one research psychiatrist as "social incapacities") is currently undergoing rapid transformations, in part under the pressurized resources provided by the NIH's "Roadmap" process, which has put translational research ("From Bench to Bedside," as both government and pharmaceutical publicists love to say) into the center of its funding agenda. A search for genome-based pharmaceuticals, often described as "personalized" medicine (although "tailored" medicine might be a more appropriate term) is central to this funded endeavor, whether or not individual scientists and their working groups are active in its pursuit.

At least three diverse foci are important to scientists who study childhood cognitive and affective impairments, and these are in widespread interdisciplinary use: First, a lively area of research occurs on the site of the older study of behavioral genetics—the study of "pathological phenotypes" as they run in lineages—has been reclassified. Scientists now study "endophenotypes" in research on autism, schizophrenia, ADHD, and dyslexia. Such studies of families at elevated risk for syndromes and disorders have been given a molecular assist in the field of neurogenetics: Here, scientists search for haplotypes (stretches of DNA that travel together across the generations in lineages where these problematic phenotypes exist). Since the

contribution of each haplotype to the disorder of interest is small and not usually expressed, something environmental in the broadest sense of the term must, the scientists reason, be activating the stretch of DNA selectively in some members, but not in others.

That something is "epigenetic," that is, it lives in the relation between genotype and phenotype, it is active in the environment within which the whole organism—in this case, a fetus, child, or adolescent exposed to everything from the neurochemical baths released in her developing brain by paternal or maternal gamete exposures or the childhood benefits of enriched reading; the food she eats and the air she breathes; the environments into which she is transported by her parents' peregrinations through refugee camps or silk stocking zip codes. As the head of one of the labs that has welcomed me put it, "Epigenetic inheritance is the transmission of information to descendants that is not encoded in the nucleotide sequence ... unlike DNA sequence, these mechanisms can change during development."[10]

The concept of epigenetic inheritance has a venerable history, traceable to C. H. Waddington who used the term in the 1940s to describe how genes might interact with their surroundings, before the mechanisms of DNA replication had been explained (Waddington 1942; Jablonka and Lamb 2002; Van Spreybroeck 2002). Epigenetics has more recently been used to describe the processes of environmentally susceptible cellular methylation and chromatin remodeling. Tamed and operationalized through scientific methods of reduction, epigenetics can now be investigated in vitro, in vivo, and in silica.

Thus, epigenetics as a concept, a horizon of research, and an assemblage of ideas and practices brings the environment back into the postgenomic era, where an appreciation of complexity and nondeterminism has replaced an older enthusiasm for the deterministic one-way rules of "DNA makes RNA makes proteins." Beyond the genetic code reproduced in cell nuclei by processes increasingly well characterized with the tools of molecular biology, there now stands another layer of complexity. Epigenetics is like the revenge of Lamark: it focuses on gene–environment interactions that may become heritable, accounting for the environmental activation and repression of human differences in genes, proteins, cells, and organs.[11]

Second, scientists have long been involved in modeling human differences through animal analogies. Since Nuremburg, many experiments with humans have, of course, been outlawed, and there is now an ethics structure in place in many countries whose express mission is the protection of human subjects (to say nothing of the protection of university grants).[12] Yet animal models—also increasingly government regulated—have accompanied

scientific investigation for many decades: animals are "good to think with"[13] and we now have autistic mice, learning-disabled nematodes, and memory-seeking sea slugs. As the Nobelist neuroscientist Eric Kandel so eloquently put it, "Some of . . . (our neural circuits) . . . were present in the cells of our most ancient ancestors and can be found today in our most distant and primitive evolutionary relatives . . . these creatures use the same molecules to organize their maneuvering through their environment that we use to govern our daily lives . . . " (Kandel 2007, xii-xiii). With the routinization of knock-out/knock-in genetic technologies, researchers can make mice (and other animals) whose genetic differences and consequences can be standardized and tracked over rapid-cycle generations. These, in turn, give rise to new streamlined understanding of normative life-form development and posited widespread mammalian capacities for learning and where it may go wrong, biologically speaking. The standardizing of experimental organisms is an ongoing strategy in bench science that has provided new resources for manipulation in the study of learning (Kandel 2007; Rheinberger 2008). As one senior scientist put it, "mice are the genetic workhorses of medical research, you can knock out or knock in. You can't do that with rats."[14] Behind this utilitarian manipulation of our rodent analogs (doppelgangers?) lies a rich field of evolutionary analogical thought.

Third, the relatively new technology of functional magnetic resonance imaging (fMRI) has powerfully increased the ability of neuroscientists and cognitive scientists to make computational models of the human brain, as children and adults with distinct diagnoses (or their controls) perform varied tasks. The lab in which I am currently working is distinguishing itself through its research on the youthful brain in resting states: without tasks, the scientists reason, the resting brain of a child diagnosed with ADHD, Tourette's syndrome, autism, or LD will exhibit low-level spontaneous activity, revealing how its neural networks are connected, prior to learned or task-driven behavior. Thus, baseline understandings of neurodiversity may be achieved. This makes the recruitment of children—as research subjects or their controls—central to the work of the lab, a topic to which I return below.[15]

Mapping out effective neural networks is complex business: As one young researcher commented, "They want scans that show straightforward autism, but it's not so easy." As the public encounters and interprets brain images in common and diffuse sites, there is often a disjuncture between popular, clinical, and research understandings of the status of imaging (Beaulieu 2002; Cromby 2007; Dumit 2003; Joyce 2008; Pickergill 2009). Indeed, the disease of connecting specific image to affective state

or action presents a long-standing philosophical conundrum, as Barbara Maria Stafford shows in Echo Objects (Stafford 2007). Commenting on the evocative nature of knowledge produced in the neuro- and cognitive sciences for humanities scholars, she observes that, "We can think of this array of images as cultural symbols with which to reach our biological selves. But they also capture how the independent and wandering brain-mind discovers palpable connections at the interface between body and world" (p. 5). Stafford employs reigning theories and findings in contemporary neuroscience to illustrate their resonance with humanist thematics in paintings from Early Modern to contemporary times. Such theories can be used as a sieve through which we make meaning of prior representational didactics. Yet they also suggest to an anthropologist that the fractal of mind/brain compels us again and again to see iterations of an underlying Platonic truth for which we are continually searching. In other words, the literate public is always already prepared for the arresting and compelling images that neuroscience helps to popularize.

Despite their computational, visual, and popular powers, correlations between mapping brain activity and diagnosis are associational, not causal: "Brain imaging is where infectious disease research was in the 1850s, before the understanding of bacteria reorganized the field," one pediatric researcher told us: "They knew they had something important, but they didn't yet know what it was." Two young researchers in the pediatric neuroscience lab both speculated on how difficult it would be to disentangle dyslexia (reading-disability-as-diagnosis) from ordinary pediatric brain variants. One pointed out that 20 percent of children are now normed in U.S. schools as having difficulties learning to read: he posited that they were the same kids who "never liked school," and now had a diagnosis based on a skill that was "man made," not part of the children's regular biological repertoire. If a variant is this widespread, he asked, what does it mean to diagnose and remediate it? The other young scientist doubted that much could be done to clarify the explicitly biological basis of dyslexia in New York or any global city: children, she pointed out, often come from households where multiple languages are spoken and read, so their strategies for learning to read, failing to read, or overcoming barriers to reading will be highly variable, as will be their brains.

In both cases, the young scientists were pointing out that reading was "in the world:" intractably connected to the times and places in which its absence as a social skill has quite recently taken on the shadow of disability. Exciting as new work in neuroscience imaging may prove to be, we should remember the nineteenth century history of phrenology and craniometry,

which were the sciences of their day: scientific measurements of the brain have long been associated with putative differences in behavior, and as researchers are quick to say, the use of fMRI is in its infancy, a new research tool used for measuring differences in brain activity for everything from tics and shyness to reading, gambling, and addiction to substances both licit and illicit. The quest for a neat association between a simple brain image and a complex behavior is beholden to a long genealogy and it has many covert and overt lines of influence in the world it seeks to simplify and represent.

Although I have presented these three strains of brain research—behavioral and neurogenetics; animal modeling; and brain imaging—as distinct, in real time, they are often intertwined in scientific literature, and in the laboratories that have hosted my research. Scientific connections are both an artifact of "big science," and an impetus to it, as recent resources turned toward translational medicine illustrate. Contemporary scientific research requires and regularly requisitions at least three types of connections. First, and most obviously: big scientific projects need substantial fiscal support. To fund an ongoing laboratory takes well-coordinated team work among secretaries, animal-technicians, project managers, and computer tech support as well as the work of bench scientists who are simultaneously always fund raisers: money must flow if labs and their skilled personnel are to be set working. A lab operates on a budgetary cycle that demands great discipline to grant deadlines, always specifying the search for an exciting and elusive new finding. Yet in reality, research is slow, arduous, requires patience and curiosity about failures, and it is full of culs-de-sacs. But money must continually be searched and found to feed the engines of laboratory life. The funding sources for laboratories and their skilled laborers shift priorities over time and the study of childhood chronic mental and affective disorders—including those which involve disordered learning—benefited from the NIH's "Decade of the Brain." Under its funding mechanisms, many highly motivated researchers found themselves moving into interdisciplinary formations in which the study of the human brain became a magnet for their work.

This capital-driven intervention into scientific curiosity is ongoing, as we note the very recent influence in the United States of a highly publicized NIH Roadmap and its highlighting of translational research and translational medicine, intended to move the utility of interdisciplinary research "from bench to bedside." This slogan—beloved by the pharmaceutical companies, where it originated, and championed by the Genetic Alliance, a consortium of activist voluntary health groups that works closely with the

NIH—now characterizes a direction in governmental funding. Money carves deep interdisciplinary tracks.

Second, monetary magnets are a necessary but not a sufficient cause of scientific innovation: mega-topics like the study of brain science (or the human genome or biosecurity) incite the curiosity, reciprocity, and innovation of scientific researchers, and their expertise is key to scientific accomplishment. Under new interdisciplinary umbrellas, the migration of researchers and their shared topics, tools, grants, and regulatory ethos, becomes a practical possibility: these flexible networks of scientific personnel and their support systems set up biomedical platforms on which new questions, research projects, and interventions bridging biology and clinical medicine can be imagined and staged (Cambrosio et al. 2009; Keating and Cambrosio 2003).

These entanglements are highly productive. Much learning and teaching permeates laboratory life, as, for example, when research clinicians acquire skills in manipulating epidemiological data or molecular geneticists become sensitized to evolutionary biology's attention to age-of-onset and sex differences as key to understanding complex diseases. In one of the interdisciplinary scientific research groups whose weekly meetings I attend, for example, a toxicologist recently learned to run fMRI brain scans, and in the other, a Japanese neuroscientist learned to administer psychophysical testing to New York children. Such intellectual migrations of personnel and skills now occur at high velocity throughout the life sciences. I underline the speed with which scientific alliances are forged. I have been struck, for example, by the increasingly dense presence of "translational research" and "epigenetics" in the conversations heard around seminar tables in lab meetings, far more so than it was when I started sitting in on such meetings in the fall of 2007. And in spring/summer of 2010, the neuroscientists whose work I am tracking began to speak of the "connectome," a concept that comprehensively synthesizes neural networks that can be theorized and pictured using fMRI technology. They have also set up an international data-sharing consortium. Currently they are exploring a collaboration with neurogeneticists who want to align their emergent atlas of gene expression in the human brain with the Diffusion Tensor Imaging (DTI) that "our" lab uses to capture scans of the brain's white matter where neurons connect (or do not connect). Children's brains are increasingly part of an emergent scientific horizon in which environmentally susceptible genetic predispositions are under investigation, and possibly, intervention.

Third, such scientific migrations are linked not only by funding streams and intellectual curiosity but by the nature of contemporary research tools

as well. Large data sets now characterize much productive laboratory-based work: you cannot understand the epidemiology of ADHD or autism spectrum disorders, for example, without statistical manipulation of huge databases acquired from a range of institutional sources—state-based, national, international, and local—and these require considerable biostatistical creativity and innovation if rare and multiple contributions to relatively common diseases are to be located, hypothesized, and tested. Thus, platforms enabling the exchange and sharing of large data sets (both clinical and experimental) and the hardware/ software to translate and coordinate them are continually in formation and reformation.[16] Meetings of one of the interdisciplinary research teams I am observing, for example, often focus on meta-analysis, evaluating strengths and limitations in reconciling and combining different methods of data collection. The same can be said of neurogenetics with its common distinctions between wet and dry labs, that is, the tacking back and forth between DNA sampling from "real-time" patient populations and their families (who may be located in South Africa or Korea or the Czech Republic, as well as throughout the United States, wherever enterprising scientists can find, sample, and share them), who must agree to submit to blood draws (hence: the "wet lab"); and the large data sets—both proprietary and public—that require sophisticated computer hardware and software to mine the "dry lab."

Into this medley should also be inserted a discussion of the child as research tool. The fraught history of children as research subjects in medical experimentation is complex (cf. Sharp 2006), yet I nonetheless suggest that we here consider children in a slightly different capacity: as necessary subject–objects to extend fMRI research. In neuroscience labs, children's brains provide developmental baseline data for an emergent field, as they are presumed to display not only the range of the pathological but also of the normal with more plasticity than adults. Yet many people outside biomedical research are troubled by the receding horizon of protection on which they now stand. How young is too young to be placed into the machine? Without their presence, the laboratory in whose meetings I sit cannot move forward its NIH-funded research, and much time is given over to solving recruitment problems. A child diagnosed or undiagnosed is research material, but children are understood to be hard to recruit: this research tool comes attached to its own will and consciousness and to parental time constraints and health concerns, as well. Scientists continually discuss problems not only of recruitment and child compliance or resistance; they also worry about child and family motivation in the decision to become research subjects. It may well be parental anxiety that pushes

a minor into the magnet. For example, I watched a father of a youth diagnosed with ADHD and anxiety disorder request immediate access to what he called "the preliminary studies" of his offspring's brain, despite the careful and comprehensive informed consent process and documents by which he had several times been educated about the essential research, nonclinical nature of the study to which both he and his son were consenting.

Research scientists themselves embody this mixed form: PhDs and MDs overlap at every level from interns to doctoral, postdoctoral, and medical students. Staff exchanges continually acknowledge the conundrum of the vulnerable but absolutely necessary child subject from both a clinical as well as a research population point of view. Lab chat is full of empathic observations about the specificity of personhood among the children whose brains are under experimental measurement: "Do you remember the kid with ADHD who jumped out of the magnet to do push-ups every time we gave him a break?" asked one researcher. "He told me he was bored of watching the Simpsons, and I get it. There's only so much Simpsons you can take," said a second. Another commented, "I've only done two dyslexic kids, but they're so different, it's intriguing, what different sorts of little human beings they are!" And a fourth researcher commented, "It's so hopeful, looking at a kid's brain: there's so much we may be able to do to help them, we know the mothers will help them, too. It's not like adults, who aren't going to take care of themselves. Children can be helped."[17] Another said empathically of a mother, "Such a tiny boy, he was so small for his age, his head was so small that it didn't really fit, it kept slipping out. I knew the mother wanted a diagnosis, I didn't know what to say to her, but I wanted to say something. Such a tiny boy." More informally, I have been told several times that a noted researcher at another institution whose website proclaims the importance of LD and ADHD brain studies in his lab has been unable to recruit the needed children, perhaps because of parental hesitation. He has thus put this work "on the back burner." This focus on recruiting children as necessary extensions of magnets should also be factored into any description of how assemblages of ideas, practices, and tools structure a new horizon on which an increasing number of laboring scientists now operate. In other words, the labor of children as research subjects helps to construct this biomedical platform.

Investing in Futures

Such complex and interdisciplinary teamwork may sound arcane, but its popularization is of substantial interest to a widespread public: the brains

of children in all their neurodiversity are increasingly pictured in the media and flow through our daily lives. For example, a recent article in the *New York Times* entitled, "Your Child's Disorder May be Yours, Too" quoted parents and pediatricians talking with considerable psychological insight about putting the genealogical pieces into place when a child receives a diagnosis of Aspberger's, ADHD, or LD: "As more youngsters than ever receive diagnoses of disorders—the number has tripled since the early 1990s to more than six million (in the USA)—many parents have come to recognize that their own behavior is symptomatic of those disorders . . . In effect, the diagnosis may spread from the child to other family members . . . " (Carey 2007, 10). Like *Shadow Syndromes*, an enduringly popular 1997 book that revealed how a diagnostic category becomes intimately familial, such popular texts also prepare the ground for acceptance of new human categories, their diversity, and pathologization (Ratey 1997). Does the popular horizon now also include tailored medicines for the whole family?

In examining the permeable membrane between scientific and familial practices, my message is quite simple. As with the diffusion of all things Freudian: you do not have to be trained in Freud's direct texts to have had your worldview transformed by them. Likewise, many sectors of the U.S. population now think about childhood behavioral variation in terms of brain differences, in large measure due to the popularization of scientific information. For example, the mother of a bright high school senior with a spotty academic record whom I interviewed told me that she only began to take her daughter's anxious ADHD jokes seriously when the teenager begged to be moved to a private girls' school after spending her entire educational career in local public schools. There, she was quickly diagnosed with LD/ADHD at the age of sixteen. The mother embraced the diagnosis: "When I think of the years of struggling over homework, riding herd on Louisa, I'm heartsick. Anger is just built into how I've handled her lack of discipline, and it didn't have to be this way. Now I know her brain works differently." This is a family tale in transition, scientizing intimate experiences recast through biomedical diagnosis. Might this young adult someday find herself in the scanner or giving blood for a research study?

Both the scientists and the pharmaceuticals are currently commonly visible in U.S. cultural life; two decades ago, both were relatively rare. This assertion leads to a less simple point: large sectors of the literate public, especially parents, are now being targeted and prepared as consumers of authoritative knowledge in which the scientific study and medicalization of children's brains plays an important role (cf. Rose 2006). Expectations for the role of new pharmaceuticals run high in a popularized version of

what Hannah Landecker has described as the "molecularization of the environment" (2010a, 2010b; Borup et al. 2006).

In both the labs in which I work, scientists are quite aware of this problem: as practitioners in a biomedical world, they intend their research to be helpful to children and families struggling with cognitive and affective difference either directly or indirectly. They worry about the abuse of psychotropic drugs and are acutely aware of their resale value. They are, however, far less prone to speculate on the role their presence plays in preparing the public to medicalize difference. This makes little sense (to them or to many of us) when human suffering is unambiguously present, for example, as in a family coping with adolescent schizophrenia or addiction. But the problem of diagnostic creep is everywhere: The really hard problems of the "slippery slope" only surface in practical activity for most scientists. For example, Paul Shattock, a British autism researcher, reports that in the course of his research career, he has noted that some children once diagnosed with mild mental retardation were transferred into the LD category and are now being reclassified as autistic, as they age and that category expands.[18] In the neuroscience lab, researchers report that the psychiatrists who are their collaborators often see ADHD in many of the research subjects that they themselves see as controls: in other words, the diagnosis is negotiable and steadily moving into medical consciousness. And in his attempt to recruit ADHD adult subjects to his research study, one neuroscientist/psychiatrist told his lab team that not many of the people he met when he spoke at their group would make appropriate subjects: in his judgment, "they had too much going on," and he considered many of them to be bipolar or to have Asperger's syndrome as well as ADHD. ADHD, like many psychiatric conditions, is a diagnosis of exclusion, so whether a particular patient falls within its criteria is often under intense negotiation in an interdisciplinary study. "We don't assess them, we just get them into the magnet," a researcher told me. At the risk of banality: a close study of the magnet reveals how intimately related to a larger and expansive cultural world of assessment and categorization its subject–objects already are.

In speaking about developments in science, Paul Rabinow opined, "From time to time, new forms emerge that have something significant about them, something that catalyzes previously present actors, things, institutions into a new mode of existence, a new assemblage, an assemblage that makes things work in a different manner" (Rabinow 2000, 44). The American government and its pharmaceutical allies are banking on translational medicine to be such an assemblage. Yet imagined pathways in science—as in other lifeways—rarely run straight from intention to action.

I have argued that when viewed through research into neurodiversity in children, the scientific assemblage now on the horizon depends on new uses of the older concept of epigenetics and a willingness to let the post-genomic world of environmental complexity into the research picture. Current usage of epigenetics homes in on the non-coded transmission of inheritance between children and their parents. In studying complex mental and cognitive disorders like LD, ADHD, and what was here referred to as diseases of "social incapacity," epigenetics as a concept also indexes how postgenomic environmental relations have reentered the extreme and elegant reductionism that accompanied prior genetic models in the life sciences. As with all moments of innovation, scientific instrumentality now finds itself in an open clearing. It has the capacity to foreclose that more environmentally capacious vision, to operationalize it out of existence.

Of course, we cannot yet predict where a focus on epigenetics in a postgenomic world will lead our life scientists, although many of us social scientists are poised in laboratories, biobanks, biotechnology companies, and clinics around the globe, reporting on these changes.[19] Clearly, social analysts are beginning to evaluate the significance of a laboratory shift toward operationalizing complex, molecularized worldviews. To repeat: Scientific assemblages are forward-thinking unstable objects of investigation. Fashions in scientific research come and go, despite the triumphalist assurances that must structurally be written into the promissory notes of grantsmanship. Forgetting prior promissory platforms and their utopian interventions is a professional skill and a hazard of which analysts need to remain acutely aware. In a few years, this discussion may feel like prior paeans penned to genetic therapy. Neuroplasticity and neurodiversity are now widely viewed—in science, and in public culture, as well—as eminently environmentally influenced. Closure of complexity in favor of reduced and elegant scientific evidence is of course the most likely outcome. Yet as we all become more environmentally conscious and concerned in the broadest terms, this is the horizon on which another assemblage of human diversity-in-sameness may yet be erected.

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Notes

1. I thank Dr. Gina Jae for teaching me that gene therapy has provided useful tools and models for the transfer of cord blood/stem cells as adjuvant therapy in the management and cure of the hemoglobinopathies. Recent reports of experimental short-term cure of rare heritable diseases like adrenoleukodystrophy in childhood also suggest that the platform gene therapy provides may have ongoing and potent utility (Naldini 2009).
2. "The concept of translational research has received very strong focus in the biomedical community over the last few years, as a new way of thinking about and conducting life sciences research to accelerate healthcare outcomes. Global Pharmaceutical companies and the NIH have been pouring billions of dollars into life sciences basic research . . . To fully realize this vision, Translational Research requires researchers and clinicians to have ready access to two critical types of information—(1) clinical information, including data contained in hospital systems and medical records, pathology reports and diagnostic labs, clinical trials systems and study participant questionnaires; and (2) biomolecular information, including genomics, proteomics, medical imaging and other high-throughput molecular and cellular research data." (http://en.wikipedia.org/wiki/Translational_research, accessed February 11, 2009).
3. http://nihroadmap.nih.gov/clinicalresearch/overview-translational.asp, accessed August 3, 2010.
4. I have borrowed the term, "molecularized environment" from Hannah Landecker (2010a, 2010b). I am grateful to an anonymous reviewer of *STHV* for calling my attention to forthcoming German language publications by this author.
5. Patient advocacy/support groups as intertwined with scientific funding and research are the subject of essays by Steve Epstein (2008), Chloe Silverman (2008a, 2008b), and Karen Sue Taussig (2005). A very important and thoughtful analysis of the goals and limits of activists in reorganizing French scientific

and public responses to muscular dystrophy is found in Rabiharisoa and Callon (1998); Rabiharisoa and Callon (2002).

6. Personal conversation, May 9, 2008.
7. As many analysts have argued, "epigenetics" is a concept that may encompass a broad-based worldview of environmentalism that undercuts genetic determinism; it is often, however, reduced and operationlized in the study of methylation and histone remodeling, processes that can become method and subject of laboratory investigation (Lock and Nguyen 2010; Jablonka and Lamb 2004).
8. See footnote 6.
9. Project Eye to Eye is the first national organization of young adults who grew up under the labels of LD/ADHD. My fieldwork with their members is properly the subject of another essay. Their work is described at http://www.projecteyetoeye.org/, accessed December 20, 2009. Likewise, the Icarus Project was founded through the outreach of young adults with mood disorders to others bearing similar labels (http://theicarusproject.net/, accessed August 1, 2010). And The Autistic Self-Advocacy Network recruits young adults and youth with this diagnosis to represent themselves and the concept of neurodiversity in public events and institutions (http://www.autisticadvocacy.org/, accessed August 1, 2010).
10. I am deeply grateful to Dr. Dolores Malespina, Head of InSPIRES/ Bellevue Medical Center, who sent me many of her slides in support of my inquiry to understand the work of the laboratory.
11. Lest my remark about Lamarck be thought too original, I discovered a slide showing Darwin's acceptance of Lamarckian thinking among the treasure trove of slides loaned to me. This conceptual horizon has not gone unnoticed in the social study of science. As one prominent sociologist cynically commented to me, "the social scientists are lined up to get in to the epigenetics labs, they're all frothing at the mouth for this version of environmentalism" (private conversation, October 31, 2009).
12. On anthropological approaches to bioethics see Hoyer (2007), Lederman (2006), Rapp (2006), Rabinow (2002).
13. The phrase, of course, is drawn from Levi-Strauss's (1962) *Le Totemisme Aujourd'hui* and here marks a cultural perspective on the taken-for-granted standardization, reproduction and sacrifice of animals as research tools in scientific activities.
14. Technically, the process can be effected on rat gametes, but it is much harder and less successful.
15. This raises a philosophically intractable problem, when viewed anthropologically: Can the resting state brains of children be viewed as pre-cultural when

they have for many years been exposed to a rich array of electronic and other stimuli prior to their entrance as laboratory subjects?

16. On cultural analyses of large-scale genomic data biobanking see Tutton and Corrigan (2004), Taussig (2005), Fortun (2008), Hoyer (2004), Hedgecoe (2001, 2004).
17. This empathic comment builds on unexamined assumptions about childhood innocence and the role of generation and gender in its protection, at least in middle-class contemporary cultures.
18. Interview with the author, April 2, 2010.
19. Recent works by Landecker (2010a, 2010b), Lock et al. (2006), Lock and Nguyen (2010), Hoyer (2010), and Rajan (2006) illustrate these ethnographic and theoretical commitments.

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