Making the Invisible Visible: an Anthropological Perspective on Learning Disabilities

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Introduction

Beginning in the 1970's, a series of remarkable institutional, legal, scientific, and cultural changes began to intersect in the United States. One of their outcomes was the increasing visibility of a category of "ambiguous" children whose tendency to "Learn Outside the Lines" (Mooney and Cole 2000)made them an increasingly visible problem in America's schools. Many advocates and specialists –from educational psychologists to business CEOs; from civil rights activists to remedial reading counselors; from neuroscientists to media moguls—would eventually become involved with the question of "Why Johnny Can't Read" (Franz 1966 (reprinted 1985, 2000)), weighing in on the reasons behind school failure, and policies that might make it more possible for children who did poorly in school to succeed. From the 1960s on, these kids, once categorized as "minimally brain damaged", were increasingly labeled as "learning disabled", a term that brought with it a series of philosophical, ethical, and policy controversies. Yet their shadowy and contested status would eventually become a visible presence in America's schools, communities, places of worship, and families.

Several professional groups involved in making LDs visible have produced accounts of the evolution of their work. Yet it is the hallmark of anthropology to provide a wider, more capacious view of how cultural categories develop and change along with the worlds that surround them, from the family on out. Here, we review the history and intersections which made possible the emergence and widespread acceptance of the cultural category "LD" in American public life. We are particularly interested in the hidden histories of accidental activists who contributed to this important sea change. While the legal and institutional history which frames this analysis is essential to this story, it is hardly sufficient. The new resources whose birth struggles are well-described in this literature must still be accessed by children and their families, often against the barriers of considerable discrimination and social stigma. Likewise, an exciting literature in Disability Studies has begun to reveal both the depths of those barriers, and the creative work that people with disabilities and their supporters have accomplished (e.g., (Longmore 2001). It is the argument of this essay that ethnographic perspectives have a specific role to play in this analysis: because the birth or development of children with disabilities is usually unanticipated, accommodations to its meaning first take place inside of families. Thus the world of kinship –for better and for worse—is the site where the meanings and practices involved in daily life with children who have disabilities first emerges. Ethnographic fieldwork has the capacity to highlight this social transformation, revealing the importance of families and their kinship systems as key actors in the appearance of disability consciousness in general, and accommodation to learning disabilities in specific. Long before a child with a disability is the subject of legal or educational action, she or he is a member of a family network. Anthropology puts kinship back into the center of the analysis of disabilities. Here, we provide ethnographic hints and a proposal toward the deeper fieldwork which makes anthropological contributions an important part of understanding this emergent public issue.

A Special Education: A Brief History:

> It is useful to understand that each child's IEP (Individual Educational Plan) is different. The document is prepared for that child only. It describes the individualized education program designed to meet that child's needs….States and school systems have a great deal of flexibility about the information they require in an IEP…(But) Federal law requires that school districts maintain documentation to demonstrate their compliance with federal requirements. (http://www.ed.gov/parents/needs/speced/iepguide/index.html, accessed 11 May 2007)

> Oh, no! Not another trip to the Board of Dread! Why do I need another learning experience? (TRO, age 11)

In 1963, education professor Samuel Kirk, addressed a Chicago conference of parents and professionals entitled “Exploration into the Problems of the Perceptually Handicapped Child”. He suggested that children of “normal intelligence” who regularly failed at school might better be labeled “learning disabled”, rather than “slow”, “lazy” or “mildly mentally retarded”. His coining of the term “learning disabilities” was quickly hailed by activist parents as a strategic intervention that took the burden off the child and "courtesy stigma" off the family, shifting it to the educational system, special education teachers and their methods.

Of course, questions of the "educability" of those who failed to learn within the parameters of what was considered normal in 20th Century US mass public education have a long history: for example, many educators noted the dramatically changing environment in which non-English speaking children of immigrants and working-class "ruffians" challenged their skills in the period before WW I. By the 1930s, they would also increasingly be guided by emergent scientific and medical research suggesting that brain injury might account for school failure (Carrier 1986) The belief that education should and could be the "royal road" to assimilation and upward mobility is deeply rooted in the U.S., where the provision of special education is closely tied to debates around the "sub-normal" on the one hand, and the performance of immigrant and ethnically and culturally stigmatized children, on the other. There has long been a tension between the ideal of the Melting Pot and the existence of those who just won't melt—a group whose boundaries shift over time to include but extend beyond markings of race, class, and ethnicity, encompassing those with "all kinds of minds" (Levine 1992). And there is a long literature on the importance of the social contexts that shape decisions as to whose children are sent to special education (eg, (Carrier, 1986) (Harry 2002) (Harry 2005).

Yet this lesson is continually at risk of being lost. While the scientific study of the human brain and its pathologies also has a long history, recent advances in neuroscience have added powerful evidence to debates on schooling. To summarize a complex phenomenon: the recognition of the diversity of human brains and the transformation of many relevant fields of knowledge over the last several decades constitutes a key paradigm shift that is widely distributed across many areas of investigation. These range from neurobiology to educational psychology to the "neuro-diversity movement". Thus the democratization of educational uplift both depends upon and is often trumped by more biological descriptions of the mind-in-the-brain. These debates, we argue, enter into the public understanding of "learning disabilities".

Recent scholarship on the relation between racial disparities and enrollment in special education highlights another aspect of this public issue ((Donovan 2002) (Harry 2005). Until the impact of *Brown v. the Board of Education of Topeka, Kansas* (1954), most African American children were educated in segregated schools. Cast to the educational margins, they only began to be counted in mainstream educational statistics as they were massively integrated into the public schools, often via bitterly-contested court-ordered programs. A disproportionate number immediately found themselves labeled for special education. It is only in the post-Civil Rights era that the racial dimensions of this problem surfaced in public debate. African American educators and their allies offered cautionary critiques of categories that reinstated racial divides via special education as soon as black children walked into predominantly white schools: many black children whose academic performance or classroom behavior was deemed problematic continued to be labeled and remediated in segregated classrooms as "MMR" (mild mental retardation) or "ED" (emotionally disturbed), especially if they lived in the inner city or were poor.

By contrast, middle-class children – overwhelmingly white and often suburban-dwelling – who learned atypically and/or displayed anti-social/erratic behavior were more likely to benefit from the emergence of the category of LD (Learning Disabled) as it became institutionalized throughout public education. The history of middle-class family activism and widespread, rapid acceptance of the LD description strongly suggest that some found these labels desirable for special accommodations, believing these might enable their children to succeed. ((Sleeter 1987); RR:Barry et al; Ogbu). And this interpretation constitutes more than an "urban myth". Whenever I have spoken about this topic in US colleges and universities, white students have disapprovingly told tales of classmates in their affluent high schools whose parents deployed private testers to "win" the learning disabled label for their offspring. This, in turn, entitled them to time-and-a-half for SAT and AP testing, hallmarks of the college entrance hurdles through which they and their peers were expected to jump. Yet the widespread, spontaneous response of these college students also needs unpacking: for every one of them who disparages the putative manipulation of the LD category by relatively privileged families, I have also encountered students enrolled in my classroom who benefit from the bureaucratic labeling which entitle them to supports that might include assistive technology, increased testing time, and note-taking assistance. In principle (but often not in fact), Learning Centers now provide such services at all American universities that receive federal funding. And it is notable that the majority of children enrolled in special education in New York City's public schools are most often male, and drawn from families and communities to which racial-ethnic or class-based labels are attached (RR: ref cf. Tomlinson 2004). Yet those who benefit from collegiate Learning Centers such as ours at NYU are equally young women and men, and far more likely to be white. This complicated demographic pattern needs parsing, as the racialized, class and gender politics of Learning Disability are highly contested. And these politics, too, have an important history.

The debate that began among African American educators regarding equity in classification and services expanded throughout the field of special education in the 1980s and 90s. Children of color seemed to be over-represented in special education, specifically in the categories of MR and ED (Donovan and Cross 2002) and under-represented in LDs, a category reserved for children who tested at "normal or superior intelligence". These discussions are made more complex by the irregularities at the state level in the referral, testing, diagnosis and placement of children, and the gathering of data on placement efficacy. Most recently, a state-by-state analysis by the National Research Council suggests a more nuanced picture is needed in order to understand how race and ethnicity appear as variables in special education as well as gifted and talented programs (Donovan and Cross 2002). Other research underscores the enduring role of subtle cultural bias and unexamined racial assumptions in educational practice, as the book entitled "Why Are So Many Minority Students in Special Education?" emphatically queries (Harry & Klingner, 2005).

Nonetheless, since the 1970s, the growth in attention to special education has been remarkable. LD has been the fastest growing of the 13 Federal diagnostic categories for children who are deemed to need more specialized educational support, and it overtook all other categories of special ed diagnosis except speech impairment by the late 1970s. Now, LD is the fastest growing category within special ed across the United States, arguably accounting for the growth of virtually all support services, and doubling its enrollment numbers in each decade (Donovan and Cross 2002). Yet on the ground, the twinned goals of avoiding stigma and gaining proper educational services in a timely manner continue to present substantial hurdles for families of all classes and colors.

Remediation is uneven at best, as are the consequences of being labeled. Parents are caught between accepting a bureaucratic label and process which may be helpful or harmful; and resisting it as a stigmatizing epithet. And substantial resistance to referrals, testing, diagnosis, placement and service provision may be mounted by different actors: school districts; principals; teachers; and parents have all been activists for and against the expansion of special education programs and the entrance of specific categories of children into them. Additionally, the historical experiences of particular actors should not be underestimated: an African American mother who cleaned houses for a living, for example, told me that she wanted to have her son tested and diagnosed because she knew he needed remedial services. But her husband, a car mechanic, was adamantly opposed: labeled “mildly mentally retarded” during his own elementary school years during the early 1970s, he regarded special education as a stigmatized prison term. On the other hand, a white, middle-class parent activist intent on getting special ed services enhanced in her son’s public middle school also said of the black and brown families whose children predominated in the facility, “They don’t come to meetings, they don’t want this, they think their kids will be warehoused. They’re rushing to get their kids de-certified while I know the answer lies in more services, not less”. The unwieldy categories that make a child eligible for special ed accommodation include substantial diversity, and may be applied to children with mild autism or severe dyslexia. Parents may themselves hold prejudicial or suspicious views of particular disabilities borne by other children in “special education”. This places families and educators in a complex position as they accept, negotiate, or reject specific labels for their children. Thus, special education in general, and the perceived “cultural epidemic in learning disabilities” in particular are expansive, volatile, and controversial topics.

The Social Life of the IEP or: The Bureaucratization of Difference

The juridical and legal roots of special education and the emergence of the LD category within them intersect the "American Dilemma" of racial injustice. Familiar to many Americans since the institutionalization of Martin Luther King Day and Black History Month, the retelling of our country's struggle to extend civil rights to African Americans placed the schools at the nexus of many battles, as anyone old enough to remember 1957 television footage of Governor Faubus barring school entry to Little Rock's first graders under National Guard scrutiny; or young enough to have been shown the 1998 Disney made-for-television version of Ruby Bridges' role in integrating Nashville's grade schools will recall. The integration of public education was in part a children's crusade, at least in the public eye.

What many of us do not know, or remember as clearly, is the tireless coalition of legal expertise and community activism which positioned these educational challenges, and shepherded key legal cases all the way to the US Supreme Court. There, *Brown v. The Board of Education of Topeka, Kansas* (1954) set the stage for the integration of America's public schools, often under bitterly contested court-order. *Brown* declared that separate schools could not be equal: equal education of all children was a necessity, not a luxury, if citizens were to exercise their rights; and that all children were therefore entitled to a free public education under the equal protection clause of the Constitution. Its impact was also felt in a series of court cases which placed the intersection of mental retardation, racial labeling, and special education programs in the public schools under scrutiny. These cases brought widespread and pioneering attention to abuses in the school system: collectively they found that racialized and special ed classifications resulted in educational exclusion and discrimination. These historic struggles concerning racism in public education still resonate for many parents who continue to evince suspicion and resistance to the labeling of their children.

During this period of social ferment, American schools were objects of community activism mounted in Congress, as well. The Civil Rights movement is often and correctly associated with demands for racial justice in the United States. But it also extended to the world of disability and schooling: "Special Education legislation began as an aspect of the civil rights movement of the 60s" (NJ website accessed 9 Aug 06; http://www.disabilityfunders.org/primer.html, accessed 11 May 07)), eventuating in The

Elementary and Secondary Education Act of 1965 (ESEA) and a series of amendments which funded state-operated programs to assist underprivileged and disabled children. In 1969, a coalition of parents and professional educators convinced Congress to pass the “Children with Specific Learning Disabilities Act” which marked the advent of LD as a federally-mandated category, and is part of a contested and racialized history concerning the use of IQ tests and other measures of intelligence and achievement to separate “slow learners” of normal intelligence from those deemed mentally retarded in the schools. (All were likely to meet at the Committee on the Education of the Handicapped, later renamed the Committee on Special Education. All would become bureaucratically marked and differentially empowered by the provision of IEPs, whose history follows below).

By 1974, The Education for All Handicapped Children Act Amendments incorporated the category of LD as an individual and measurable discrepancy between ability and achievement; IQ tests were most often compared with school reports, and a significant gap between the two taken as presumptive evidence of an LD. The category was enfolded into legislation later renamed IDEA (Individuals with Disabilities Education Act), as large federal budgets continued to be authorized for this purpose in the 1970s and 80s (Carrier 1986:119).

This legislation set up Federal regulations by which state and municipal special education assignments would be made. Abstracting from its history, three of its many purposes and provisions are particularly notable from our perspective: (1) All children aged 5-17 are entitled to a free, appropriate public education; (2) All children must be assigned to the least restrictive environment; (3) Each child’s specific handicap must be described functionally, not etiologically, and specific annual services and goals articulated. An IEP document must be generated anew each year for every child who has been assessed and referred for special educational services. The IEP thus describes a renewed commitment to each child’s development, as filtered through an extremely bureaucratic, legalistic sieve.

The Individual Educational Plan, or IEP, bears the marks of its contested birth. It is particularly sensitive to the abuses of discrimination, exclusion, and re-segregation of children who bear special ed labels; yet it also bureaucratizes a set of goals and services “as if” each labeled child could unproblematically be slotted into available programs. It thus straddles the border between a generalized and highly bureaucratic cost-conscious document (without which no services will be provided: like a green card attesting to legal immigrant status, its possession is desirable in some contexts, yet potentially discriminatory in others); and the individualized prescription for specialized “Educational Care” ((Levine 1994) that remediation is presumed to entail.

Yet as knowledgeable founders and administrators at independent special education schools have often pointed out, the IEP process requires that children with diagnoses be offered an educational placement in “the least restrictive environment”: they are to be included among their peers. This may work well, for example, for pupils using wheelchairs whose learning styles are the same as other classmates, and for whom access to a shared classroom is an essential ingredient. But it does not take into account the potential psychological damage of placing children with “different minds” in those same normative settings. There is an irresolvable diversity of experience between marking difference and mandating inclusion whose range and consequences will be well-articulated by ethnography. McDermott & Varenne (McDermott and Varenne 1995) (McDermott and Varenne 1996), for example, have used observations and notes taken at IEP meetings and parent-teacher conferences to point out the “social production” of slow learners, with attendant discrimination against them. Anecdotally, many parents have described this discrimination against those labeled as “IEP kids”. At the same time, many “IEP kids” would flounder without the special curriculum and accommodations that make the difference between their learning to read, or falling off the educational ladder. It is this complexity that we seek to capture in our forthcoming interviews.

Of course, like all bodies of legal documentation, the IEP is an evolving text which must be viewed in its enabling (or disabling) context. Later IDEA amendments defined new student populations, innovations in services, and the rights of their parents. As each new constituency became more bureaucratically visible, potential activists in the shape of parents, teachers, lawyers, school psychologists and OT/PT therapists became defined and mobilized, as well.

Most recently, IDEA’s 2004 reauthorization included a change in the assessment of learning disabilities. In an attempt to cut through the lengthy bureaucratic and under-funded pathways to individual referral and testing, a new language of “response to intervention" (RTI) based on scientifically approved educational methods is being used to assess LDs. (http://www.wrightslaw.com/idea/art/ld.rti.discrep.htm. Accessed 9 Aug 06). This places the burden on the classroom teacher to remediate rapidly. While this change –away from measuring the discrepancy between ability and achievement via lengthy and costly educational testing, toward rapid assessment of classroom-based RTI – may be democratic in impulse, it also makes general ed teachers individually responsible for early and aggressive intervention with their students, rather than referring them for multidisciplinary testing. Its practical effect may be overwhelming: without referrals, teachers are burdened with yet-another task in an overcrowded classroom for which they may well be ill-prepared and over-stretched. Some special education teachers also consider RTI to be "union busting": their more costly, specialized services are being replaced by increasing the tasks assigned to less expensive and unprepared general educational classroom teachers.

IDEA's mandates have also encountered the controversies generated by another highly visible cornerstone of Federal legislation. No Child Left Behind's 2002 unfunded mandates are beyond the reaches of a short essay, but suffice it to say that its test-driven effects waft through the conversations with educators in our pilot interviews. Additionally, important legislation not directly concerned with special education may nonetheless impact on the domain of public schools: Section 504 (of the Rehabilitation Act) and the ADA (Americans with Disabilities Act, 1990) intersect educational accommodation law. Many parents prefer the "softer" labels these legislative mandates provide to the starker classifications, stigmas, and rights associated with the IEP process. These complex legal pathways are often confusing to families caught between advocating for their children, and protecting them from the adverse effects of labeling. We anticipate that fieldwork will unearth the patterns by which families make labeling and legal decisions on behalf of their children.

Case law, too, has continued to evolve. Most notably, the case of Shannon Carter, decided by the US Supreme Court in 1993, ruled that if the school district was unable to provide a "free appropriate public education" for a child with an IEP, parents were entitled to reimbursement of tuition expenses if they could find an appropriate education in a non-approved, independent school. This stunning victory for parents of children with disabilities increased the potential for independent placement and reimbursement litigation. Indeed, all of the independent schools in which we have so far conducted interviews have administrators whose job it is to provide the documentation for annual IEP reviews and for “Carter cases”; without this support, even middle-class families would have trouble meeting the annual fees of independent school special education which may range upward of $30,000 in New York City. Thus, an escalation in public bureaucracy has been met with a similar escalation in the private sector. At one extreme, this might be viewed as a new market niche in the private commoditization of education (cf. (Katz 2006). At the other, such law suits represent a quintessentially American form of recognition of public responsibility for children bearing “all kinds of minds”.

Moreover, the existence of codified case law also opens up the possibilities of democratic action. Unsurprisingly, those who have the resources and time to navigate the complex legal system to receive such funding tend to be middle-class in origin. Yet the reach into other classes is now expanding. Since 1999, for example, Legal Services for Children (now: the Partnership for Children’s Services), an NGO founded by retired corporate lawyer Warren Sinsheimer, has provided legal counsel to over 7,000 New York families living in poverty whose children qualify for IEP service mandates. The work of the Partnership enables client families to move their children from special education placements in public schools that do not offer the curricula supports they need to independent (private) ones. Funded by the appropriately-named Robin Hood Foundation (among others), PCS advances the considerable tuition costs of an independent school education, winning back its investment through *pro bono* work with each family they accept. “Put a mother on the stand and it never fails to move a judge”, Sinsheimer told us (interview, summer 2005). The considerable commitment, hard work, and prejudicial treatment suffered by families living in poverty is evident when their children consigned to special education become subjects of public law suits. This legal activism resonates with the activism of parents interviewed, for example, in NPR’s radio series on “Disabling Diplomas”. Thus: educational law and the activism of parents and professionals here intersect in actions to hold the public educational sector accountable. Yet even here, the story of “the cultural epidemic in learning disabilities” cannot be written solely in educational changes, legal struggles, or the creativity of activists. The science of the brain intervenes, as well.

The Child in the Mindful Brain

When Alfred Strauss began working with brain-injured children at the Wayne County Training School in Northfield, Michigan in the late 1930s, he brought with him an interest in the evolution of "primitive" and "civilized" cognitive functions, and in developmental psychology; both were part of his German academic background. Separating the "hereditary mental defectives" from "normal" children who had suffered "brain injury", he posited that those with the later condition might reveal a universal hierarchical ladder of cognitive development. Strauss experimented on this "exogenous brain injured population" in the hopes of learning how their cognitive patterns worked. His colleagues and students would later advance the scientific study of brain injury, applying their findings to children who, in the Straussian model, would benefit from exposure to small classrooms, low stimulus, modified materials, and physical exercise. Later researchers would investigate the "hard signs" and "soft signs" of brain injury or damage, gradually disengaging physical and neurological evidence of documented traumas presumed to explain patients' learning behavior from the evaluation of "slow" learning itself. By the 1960s, a child might be labeled "minimally brain damaged" based on his or her learning behavior, minus a quest for the evidence of specific brain injury.

The scientific search for signs of idiopathic "minimal brain damage", on the one hand, and more general and functional school failure, on the other, entered into a larger debate –both philosophical and policy-oriented-- about the rights and responsibilities owed by society to its *diagnosably* disabled members. Was "brain injury" an individual misfortune, remediable to a unique degree for each learner? Or might there be general patterns to the breakdowns that researchers and educators observed in children who failed at school? Above all, was school failure *in and of itself* an adequate mark of "minimal brain damage", even without concrete pathological findings in the brain? Once the diagnosis of school failure was separated from its origins in the medical and pathological assessment of presumptive brain damage, the way was paved for educational psychology to assume an expansive position in the work of assigning students to appropriate categories and referring them for special education services; it would begin to do so by the 1970s (Carrier, 1986).

While US disability policy has “flip flopped” several times over the course of the 20th Century, when viewed as a whole, it exhibits a tension between entitlement programs aimed to economically support “handicapped” citizens –especially, those without the ability to work— and remediation which takes as its goal the production of individual and varied skills among the disabled. Education –especially, special education—lives on this fault line between the social reproduction of what is assumed to be a group of impaired, low-level workers, and the remediation of individuals whose reintegration to their “normal” classroom (and class!) is articulated as the goal. Historically, special classes for trainable but failing students presumed their incorporation into basic unskilled employment; while the demand for their inclusion into mainstream classrooms with special support services was widely hailed as a victory against labeling and abandoning the “throw-away” child, especially the child of immigrant, racial, or ethnic minority background. As we shall see, the entry of middle-class (overwhelmingly white) families into this debate on behalf of their children assigned to special education had quixotic consequences: it both reinforced an “endogenous” notion of brain difference to explain unacceptably low school achievement; and proclaimed “freedom from failure” for children whose class position offered a protective shield, up to a point.

State-of-the-Art Science of Brain Research

This older tradition of searching for brain pathologies to explain differences in cognitive style has recently been given several technological assists. First, molecular protocols have been brought to bear on older studies of behavioral pathologies: twin studies and familial populations at risk have been re-analyzed and re-tested to focus on DNA haplotypes which confer susceptibility for relatively common diseases such as autism, schizophrenia, heart disease, and the cancers. Put more simply: there is a large-scale, collaborative and vibrant search now ongoing in labs across the country and the world for genetic markers and postulated causative genes that contribute small but increased risks to known pathologies. Unlike the classic, rare Mendelian autosomal disorders, in which the presence of specific genes makes one either a carrier or an affected person, in complex behavioral traits and “pathological phenotypes”, scientists are talking about the contributions which multiple stretches of DNA—in interaction with other genes and with the environment in which they are differentially triggered—confer to increased susceptibility. These statistical patterns are complex. Certain combinations of markers may be highly predictive, while others may only increase individual risk slightly, or even confer individual protection. This new amalgam of older behavioral (essentially: genealogical) and current molecular genetics is fascinating and controversial (Parens 2006). It also provides the stuff of popular interest, and many scientists have written and spoken about it ((LeDoux 2003; LeDoux 2004; Gazzaniga 2005).

Second, “natural human experiments” such as identical twins separated at birth are a rare phenomenon; and—since at least Nuremburg-- scientists are rigorously regulated in establishing experimental conditions with humans. Thus, as anthropologists, we note the long tradition of “Mauss/Mouse” work: animals are good to think with. In laboratories across the developed world, animal colonies ranging from nematodes to rats to baboons have all been used to posit experimental pathways of learning, memory, and mood. We expect to have more to say about this work after we have finished our recently-launched project of interviewing scientists, and conducting fieldwork in their labs.

Third, the development of a relatively recent laboratory “toy” has changed the face of the neurosciences as they approach human difference. fMRI lights up the brain differences of many human variants, positing which brain sectors are engaged in diverse tasks: children and adults with schizophrenia, autism, attention deficit disorder and mood disorders have all had their brains imaged. There is an exciting and problematic literature reporting a large range of such imaging studies. In it, the effects of hypo- or hyper-doses of neurotransmitters (including chemotherapeutic enhancers) are hypothesized to cause individual or clustered pathologies (as the sites to which these neurochemicals bind are in many cases identical or closely located). A discussion of this diverse scientific literature is beyond the scope of this essay.

But as an offshoot of such methods and theories, some powerful scientific voices have spoken publicly as well as in their academic contexts about the variant wiring in brain circuitry as well as neurochemical differences which may produce learning disorders. These public intellectuals have addressed scientific findings on learning, memory, and emotions, making them "user friendly". They have also stressed the relative plasticity of the human brain, specifying its openness to remediation (e.g., (Shaywitz 2003; LeDoux 2004) (Levine 2002; Levine 2005).) Our present fieldwork queries scientists in neurogenetics and neuro-imaging about the status of such findings and their interpretation; and how this work shapes the social and cultural landscape of educational classification and pedagogy. In a world where evidence-based medicine is increasingly promoted as the "gold standard" of replicable interventions, it is our hypothesis that scientific findings, especially when derived through the uses of cutting-edge technology, lend new credibility to older debates and theories concerning pathology and difference among human minds: broadly speaking, are the brain patterns of children who fail at school "learning differences" or "learning disabilities"? What science-based interventions might make a difference? What role is science playing in this public discussion, and how might scientific findings influence its future trajectory?

The Family in the Maze

Of course, the thoroughly social changes in the structural, institutional, intellectual and activist map of the LD world that we are describing is experienced in isolation each time a family discovers that their child is not doing well in school, and accepts the testing, diagnosis, services and labeling that are attached to special education. Over many years, as participant observes of the system, we have developed a robust anecdotal sense of the confusion, acceptance, and instability which accompany this process. But the formal fieldwork to query what a systematic sample of "real" families think about the world into which they are being recruited remains to be done. What I describe, therefore, is a promissory note.

In our new fieldwork, we intend to recruit approximately one hundred families in New York City of diverse racial-ethnic, class, religious and national origins whose children have been identified for special education services. Our goal is to focus on families whose pupils are assigned to the LD category across a wide variety of schools. Based on prior ethnographic experience, however, we assume we will have to be more opportunistic than such an organized field plan implies, grabbing the chance to talk with virtually anyone who presents themselves as a special ed parent, across the spectrum of public, parochial, and other independent schools.

Recruitment from all three sectors is important to us: We know, for example, that New York's public school system serves the largest numbers of special ed children in the country, and also pays out the largest settlements in law suits for its inability to offer accessible, appropriate placements. At the same time, the Schools Attuned Program of the All Kinds of Minds Institute is a public/private partnership that aims to train public school teachers, parents, and the writers of IEPs to make a difference in how children with learning difficulties are remediated. Parochial schools also offer intriguing hints toward acceptance (or lack of it!) of learning diversity: for example, Jewish day schools in the metropolitan area, while not particularly receptive to students with special needs, have had to address reading issues in Torah-teaching. Catholic parochial schools, under financial siege, are the largest provider of non-public special educational services to the working and lower-middle classes in the City, and they begin from a long heritage of both strong discipline and strong acceptance of "all God's children" in their diversity. The independent sector is by far the smallest but is also the most innovative in its offer of special ed services: here, family activism lies behind the founding of Churchill, Winston, Mary McDowell, Stephen Gaynor, the Community School and many other metropolitan area schools in which we have begun to interview administrators and hope soon to interview school families.

Yet beyond the world of the classroom and its curriculum lie the family, community, religious institutions, and popular media in which children are saturated. Here, we expect our interviews and observations to reveal a complex world of stigma, support, resignation, and resistance to special ed labeling. Above all, we will track the work of kinship in making alliances and advocacy relations in the "intimate public" domain. How do parents (mainly: mothers) navigate the irrationalities and sudden changes of school bureaucracies? Ease their children into an unforgiving world of hierarchical jobs and social acceptance? What role might siblingship play in accommodating differences within families, as well as among them? To what extent is the stigma of a special education combated by the work of kinship and community as it is now expressed in the public domain? It is the strength of ethnographic method to reveal the strategic, affective, and symbolic relations of families whose key role in making cultural sense of the emergent category of LDs is frequently ignored (Rapp and Ginsburg 2001).

The Paint is Always Wet

The new activism we are investigating that surrounds special education is widespread in the public domain. In addition to the schools, scientific laboratories, courts/ congresses and families described above, we are tuned to the role of media in making special ed and LDs more “user friendly”. We find that media presence everywhere undergirds the “taken-for-granted” aspects of diversity in learning: Our local Barnes & Nobles store, for example, has a newly-minted “special needs” section in its children’s department. It is probably not an accidental addition: B&N’s CEO, Steve Riggio, has been a public advocate for the inclusion of children and young adults like his daughter Melissa, who has Down syndrome(Holeywell 2007). Metaphorically and sometimes actually, “The paint is always wet” on new offices, schools, media projects, and individual initiatives, where the cultural conundrums involved in special education are rapidly becoming more publicly visible.

On the shelves of the “special needs” children’s section at Barnes & Nobles, books like “The Gift of Dyslexia” ((Davis 1997), “The Learning Disability Myth” (Pauc 2006) and “Learning Disabilities A to Z” (Smith 1997) are on display next to neuroscientist Sally Shaywitz’s “Overcoming Dyslexia” (2001) and pediatrician Mel Levine’s “Ready or Not, Here Life Comes” (2005) described above. All of these authors have recently appeared on talk radio shows; some have been featured on television programs, and are on the national lecture circuit, as well. The literate (and auditory) adult publics are avid consumers of this literature. The public presence of this issue is rapidly responding to and helping to create “special needs” as a “niche market” of consumer culture geared toward family life.

At the same time, LD-consciousness has brought forth a wide array of self-help creativity, re-describing what strategies for “reading recovery” feel like to those who have endured them. A generation of young adults successfully remediated are beginning to represent their own lives: “Learning Outside the Lines” is a guide to college success written by Jon Mooney & David Cole who were moved to write a self-help book (and later, design “The Eye-to-Eye Institute” for LD peer tutoring between high schools and colleges) when they discovered one another struggling in classes at Brown University; “Inside Dyslexia” is a documentary produced by and about successful dyslexics who turned the cameras back on the schools they had attended, following three children and their families through their struggles, triumphs, and acceptance. During New York’s recent and quite hip Tribecca Film Festival, admission lines stretched around the block for tickets to “Autism: the Musical”, which showed to sold-out audiences. Older celebrities whose schooling including substantial stigma and grief over these issues have been vociferous in joining them, if the 2002 cover story of Fortune Magazine on dyslexic CEOs, or the Charles Schwab Foundation’s philanthropy on learning disabilities or the standing-room-only crowds attending the painter Chuck Close’s discussions of growing up with dyslexia are any indication.

And. parents, too, have a story to tell, judging by the success accorded fashion designer Dana Buchman’s “A Special Education” (Buchman 2006), a memoir of coming to terms with her daughter’s learning issues; or Children’s Workshop television script writer Emily Kingsley’s successful, early inclusion of disabled children –including her own son Jason—into Sesame Street programs and her recent speaking tour in conjunction with the republication of “Count Us In” (Kingsley and Levitz 1994).

In analyzing the successful activism of Jason Kingsley and Mitchell Levitt –two young men with Down Syndrome-- Michael Berube and Janet Lyon opined that “family values” had been key to their publicity (Berube and Lyon 1998). Children of middle class, professional and loving families, they thrived under the creative circumstances that each and both developed for them. We expect our analysis of racial-ethnic, class, gender and religious assumptions and resources to reveal similar pitfalls and possibilities. Unlike more overtly stratified relations of difference however, children with disabilities are largely unanticipated, and distributed across all kinship formations. New thinking about flexible and specialized brains takes root in a highly stratified world: schooling both reproduces and interrogates prior cultural categories. Two generations ago, some children similar to the ones now participating in this process might well have been institutionalized, while many others would have been barred from mainstream education because of racial prejudice. Their integration into their families, communities, and schools is central to the confluence of factors we here describe. These, in turn, now produce "All Kinds of Minds" that demand and create a new social landscape on which the perceived "cultural epidemic in learning disabilities" is becoming visible. In understanding this emergent public phenomenon, anthropology has a role to play.

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