A CHILD SURROUNDS THIS BRAIN: THE FUTURE OF NEUROLOGICAL DIFFERENCE ACCORDING TO SCIENTISTS, PARENTS AND DIAGNOSED YOUNG ADULTS

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ABSTRACT

This chapter interrogates notions of the child and her brain as configured in the laboratory of pediatric neuroscientists, and by parents (overwhelmingly: mothers) of children classified for special education services on the basis of their varied learning capacities and incapacities. Data are drawn from my current New York-based study in a laboratory conducting fMRI research on resting-state differences amongst controls and children variously diagnosed with attention deficit hyper-activity disorder (ADHD), learning disabilities, autism and Tourette syndrome. Parents of children with those same diagnoses struggle with the strengths as well as the school-based weaknesses of their children, and in interviews they picture their children's brains quite differently than do the scientists. Young adult activists who grew up with the diagnoses of ADHD and learning disabilities appropriate lab-based descriptions of neurological difference to their own purposes, claiming a positive identity for

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themselves. At stake in the space between these diverse perspectives on childhood difference is the future of human developmental variability as it comes under biomedical research and regulation.

The greatest dogma of neuroscience for the last 100 years (has been) the belief that particular parts of the brain were very highly specialized for a particular function ... that's not quite what goes on. There is more of a neuronal democracy. Neurons all over the brain are voting, albeit in different ways, to perform a particular behavior, to generate a particular behavior.... That's what the brain does. The brain is about the future. It plans the future of our motion and during that window, half a second or so, we discovered in the last 10 years that we could record these electrical signals...

(Miguel Nicolelis, neuroscientist, DRshow.org radio interview March 15, 2011, accessed on March 18, 2011)

ENTERING NEUROSCIENCE

At the entrance to the Neuro-Imaging Institute (NII, a pseudonym), a university guard stands at the door, checking IDs and the 'guest list' of volunteers who will participate in the day's experiments. This entry space is shared with several other departments and institutes, and as a public space, it is considered Zone One of the Institute, interfacing with the external world. The Institute is housed in a nondescript academic building, but its expensive equipment is secured with considerable technology behind locked doors in Zones Two, Three and Four, as the researcher or research subject discovers in making her way deeper into the facility. The functional magnetic resonance imaging (fMRI) machine that produces brain scans sits at the centre of a web of protective technology in the innermost area, Zone Four: there, it runs 24 hours each day. All equipment is wired for rapid shutdown to ensure the safety of participants in case of an emergency or the quench/sudden loss of the powerful magnetic field of the giant Siemens 3T scanner at its core. Researchers and the manager of the NII have assured me that no such emergencies have ever occurred, although the occasional research subject has grown uncomfortable or even panicky while undergoing brain scans. Then, the equipment is paused to renegotiate or remove the person expressing any form of distress. But it has never had to be turned off.

Behind its locked door, the Institute is divided into three additional zones. Everyone enters through Zone Two, a small waiting room painted institutional beige on whose couches and chairs research assistants (RAs) conduct intake interviews, check paperwork and read an age-appropriate

picture book, Getting Brain Pictures with an fMRI Scan, to the children who will serve as their research subjects. After double-checking the all-important consent forms and insuring that parents or other caretakers understand the timing of the experiments, child subjects enter zone Three in the company of the RAs behind a closed door, leaving their adults behind. A newcomer to the zone will be struck by its computerised buzz: seven screens are continually active, the room is full of blinking computer consoles and a printer, multiple phones and swivel chairs contribute to its high action appearance. So, too, does the full wall's length window separating Zones Three and Four that enables researchers to observe subjects in the magnet, talking with them through headphones that connect the chambers. Large signage by doors and switch panels indicates emergency magnet stop equipment and other safety regulations.

In Zone Three, RAs wand the child, airport style, to ensure that no one carries so much as a penny's worth of metal on their person before they are transferred into the magnet. Small metal objects like earrings or pens can become dangerous projectiles when brought into the magnet room, and all magnetically coded objects like bank and credit cards must be stored outside, as they will be erased (see Joyce, Chapter 4, this volume, for the management of metal within clinical imaging settings). In Zone Three, bathroom checks and pregnancy tests for those young girls old enough to require them are also routinely discussed. Finally, two RAs walk the child into Zone Four, the scanning room, where the bed of the fMRI/magnet is already a familiar sight: potential subjects have taken a practice fMRI at the lab's uptown office, read the *Brain Pictures* booklet a moment ago and observed the empty room dominated by this large piece of equipment through the wall-length window as they tarried in Zone Three for final preparations.

Once inside Zone Four, two RAs fit the child into the magnet, reminding her of the loud noises, computer screens and various states and tasks the subject will be asked to perform during the scanning of her brain. Here, she is fitted with noise-abating earplugs and headphones for soundproofing/communication; a hand-held squeeze ball 'panic button'; and blankets to mitigate the room's low temperature. The child is then fitted into the coil helmet enabling the magnet to record her brain activity, and lying on her back, mechanically lifted up and into the magnet which will surround her head for the next 50–60 minutes.

The RAs double check the preparations and then leave Zone Four, talking continually to the child, finding out what video she might like to watch during 'down time' in the magnet, checking on comfort levels, and

offering continual words of encouragement and praise. Data that flow from the magnet are monitored on seven screens in Zone Three by researchers. One displays an overview of the subject's brain to check positioning; a second screen is divided into quadrants where movement can be monitored as the BOLD (blood oxygen level dependent) fMRI and diffusion tensor imaging (DTI) MRI programs capture both brain function and structure. There is a screen displaying the child's selected video of Sponge Bob, Planet Earth, or a Simpsons' episode (by far the most favoured); other monitors show breath/pulse monitoring; an eye tracker; and a screen on which files, forms and calendars can be accessed to check and revise subject availability. and schedule changes can be made. When the scans have been run, the child is taken out of the machine, praised and asked to sign a receipt for payment, which varies between \$55 and \$75 depending on the length of the study. In addition to her money, the child is given one or two printed 'pictures' of her brain, and often these are of the greatest interest. The child has completed the experiment, and information collected on the computers from her brain is sent to the lab's uptown offices, where it will be continually sorted and processed.

Later in lab meetings, some of these children's scans will be reported as failures while others will count as partial or full successes, depending on how still the subject was able to lie, and whether or not the entire length of the scanning protocol was achieved. This evaluation is linked to the continual activity that occurs in Zone Three while the scanning is in progress, where RAs and post-docs qualified to run the scanner talk the child through the noisy and disciplined process of lying still, eyes open, as resting state connectivity (RSC) signals from her brain are recorded. This work is occasionally interrupted as a subject is repositioned or asked to lie 'still as a mouse' so that a clearer image can be obtained.

On observation days, I sit with the RAs in Zone Three, having introduced myself to parents and kids in the waiting room, assuring them I'm only there to watch the scientists at work. Two preparation sessions have certified me as a safety-trained observer in the Institute, with entry privileges during business hours. But I would need to undergo an apprenticeship in scanning by the facility manager – completing supervised scans and considerable testing with annual recertification – before I would qualify as a machine operator, in which case I'd have my ID card coded for longer periods of entry. As many scans on children are conducted beyond business hours and over weekends when they can most easily be brought to the Institute, my low-coded status means I am frequently calling into the staff on the phone at the entrance to Zone Two, requesting entry through its locked doors.

Needless to say, members of the lab team have been more-than-gracious in welcoming my arrival, my questions, and my observations. It doesn't hurt that I am the mother of a college-aged son who has had the diagnosis of dyslexia since the age of six. Dyslexia is one of the conditions this lab is tracking, and many researchers are quite interested in hearing my 'real world' stories of interviewing other families that have a child with a diagnosis and an individual educational plan (IEP) – the federally mandated legal passport that is issued each year by the local school district entitling its student-bearer to specified forms of remediation and accommodation. Imagining my son's future also transformed my anthropological curiosity, opening a window on the human brain and the negotiations now ongoing in science, medicine, education, the law, media, and amongst families concerning the reality of what movement activists increasingly label as 'neurodiversity' to imply a form of human difference rather than simply deficit (cf. Ortega, 2009).

MAKING KNOWLEDGE

The data that are collected at NII must, of course, be constructed and interpreted by members of L-CAN, the Laboratory for Child and Adolescent Neuroscience, whose research I am tracking. L-CAN's director and his circulating pool of high-powered international post-docs, researchers, and doctoral students, as well as predominantly North American RAs and undergraduate interns, are well-organised to investigate a series of childhood psychiatric conditions. While most famous for its studies of attention deficit hyper-activity disorder (ADHD and its non-hyperactive variant, ADD), L-CAN is also pursuing funded research on childhood conditions as diverse as dyslexia, pervasive developmental disorder/autism, Tourette's, and epilepsy, recruiting children with such diagnoses and comparing their brain scans with those of healthy controls (HC, in the language of grants).

Scholarly outpouring of analyses using fMRI to collect 'real time' images of many forms of brain activity has rapidly accelerated in the last decade, as the expensive machines that enable its collection have become more widespread. The work of L-CAN should be viewed in the context of 'the rise of neuro-everything', in the words of historian of science Fernando Vidal (2011). Projects investigating the impact of advertising, truth and ethics in criminology, neuro-responses to varied kinds of music, and of course highly biomedicalised studies of language impairment, dementia, and pathologies of

personality as benign as 'shyness' and as potentially lethal as profound depression have all been subject to recent fMRI scrutiny. The eclipse of psychodynamic explanations of human variation and suffering in favour of brain-oriented hyper-materialist explorations has been the subject of much commentary, especially in the US case (e.g., Luhrmann, 2000; Choudhury, Nagel, & Slaby, 2009; Ortega, 2009; Weisberg, Keil, Goodstein, Rawson, & Gray, 2008).

Among the many biomedical research foci that have been boosted into high gear by the increasing availability of fMRI technology is ADHD – the most widely-diagnosed form of childhood neural impairment, estimated to affect 7-10% of school-aged children in the United States (Centers for Disease Control, 2011). Magnet research has predominantly focused on frontal regions of subjects' brains: the prefrontal cortex, the supplementary motor areas, and regions of the parietal cortex. Experimental conditions usually involve selected tasks presumed to represent 'real life' demands as these areas are imaged; for example, in game-playing or word and number recall. These regions are known to involve executive function, memory, and attentional focus – all initially localised in animal as well as human studies to frontal regions of the mammalian brain. Subjects with ADHD have been shown to have hypo-activity and lessened cortical brain volume in these areas when compared to healthy controls, and this is presumed to account for their slower reaction time and lapses in attention while performing tasks. Yet attempts to pinpoint the actual connective neural networks that account for focal lapses, slow response times, and other differences of ADHD are generally regarded as having yielded weak results, at best.

The director of L-CAN has made a substantial intervention into neuroscientific discourse about ADHD, arguing that other areas of the brain – especially the understudied precuneus region located in the back of the brain – are involved in neural networks that were not previously appreciated as being directly involved in regulating attention and related phenomena. He posits that the brains of children and adults with ADHD are less able to negotiate the complex interplay between default-mode network regions and frontal-parietal executive control regions. Failure to suppress such default mode networks is hypothesised to affect attentional focus, causing variable response time in tasks – a well-documented sign of ADHD. Such interference can best be shown, measured, and correlated by focusing on what is deemed resting state functional connectivity (RSFC), which is based on patterns of synchrony in spontaneous signals across brain regions. Subjects lie very still without task or video prompts, and scientists map and measure relationships that allow the identification of the brain's

default-mode network and other so-called resting state networks. RSFC across brain regions is presumed to represent a pre-social or a-social map of spontaneous connection, overlooked by the more obvious focus on task-oriented brain regions which have been the object of study in most prior research.

At the present time, virtually all brain imaging hours, data analysis, conference participation, and publications of the lab are devoted to analysing this more dispersed view of how children's brains actually function. We might interpret this emergent model as an instance of the 'neural democracy' described by Miguel Nicolelis in the opening quotation. To continue his metaphor, different brain regions 'vote' to produce various split-second differences in behaviour, achieving a kind of 'compromise consensus' across their sectoral diversity. Yet at present, the search for RSC involving networks across multiple brain regions is in its infancy, still linked to a set of contested indicators. "The one consistent thing about ADHD is that it's inconsistent", famously insists the MD/PhD associate laboratory director, quoting L-CAN's MD team head. "Folks used to think they could explain brain connections in the dorsal anterior cingulate cortex (frontal region, a locus of attentional control). But now we're showing that low-amplitude waves in the precuneus (back region) are anti-correlated with frontal action, they get in its way, and that's where the action is". In other words, L-CAN has shifted the focus of research across regions of the brain, looking at their relations in resting state in ADHD brains, when varied baseline connections are hypothesised to interfere with task-directed actions that occur in frontal, better-studied, parts of the brain. Laboratory publications characterise different neurological impairments in terms of this 'neural democracy' and its collaboration/competition amongst brain regions.

The presumed benefits of this research will include a more accurate description of childhood neurological differences in terms of subtle, dispersed network connectivity, and a future ability to pinpoint neural networks that may become targets of biobehavioural or pharmaceutical intervention at a future date. In the lab, the brain is thus about the future in a doubled sense. First, in those with the condition of interest, it is posited to be regionally interactive with split-second future consequences that disrupt and transform intentions in one area derailed by subtle connectivity to another. And second, it is widely hoped that knowledge about such connectivity may someday provide new future possibilities for intervention (cf. Moreira & Palladino, 2005). As the head of a major New York Psychiatry Department in a public hospital noted for its research capacity puts it, "Translational neuroscience of psychiatric illness is the future".

MAKING UP PEOPLE?

The future of such translational research is built through practical and highly disciplined activity: recruiting a research subject population is hard work. To amass adequate test subjects — both those affected with specific diagnoses and healthy controls to be matched against them — there is an intense choreography that links the scientists and their shifting army of assembled children. Youngsters are difficult subjects to recruit; my field notes at lab meetings are full of outreach strategies aimed at reaching potential subjects through clinics, educational programs, paid advertisements, and the ever-present Craigslist (an on-line swap and advertisement site very popular with young Americans). Financial incentives are offered, but these must be modest enough to pass Institutional Review Board (IRB; a federally mandated ethics committee) standards of non-coercion while alluring enough to interest members of the target audience.

Different studies require children with diverse diagnoses, and various ages ranging, for example, from toddlers with pervasive developmental disorder to middle schoolers (age 8–12 years) with dyslexia. Samples also must be matched for sex and handedness, two variables that have long been correlated with various cognitive diagnoses. Some children may be barred from one study, but eligible for another and a birthday or a slightly tweaked medical diagnosis may transform their situation: "That kid really wants to make money, too bad he's too old to use as a control for our epilepsy protocol", one scanner commented. Six months ago, before his latest birthday, the child would have qualified for that particular study.

Sometimes, data drawn from a specific research subject can be repurposed for use in a second study; at other times, successful subjects in one study are willing to return for additional scans in another. Different differences are continually being highlighted and engaged as the lab team recruits children with brains-of-interest: subjects' unique or overlapping diagnoses or control status in one or more studies, and the ages that may make them eligible for one study this season, and another one next, are all under continual negotiation.

The management of this ongoing and continuously recomposing subject population requires the work of a lab administrator and several RAs. It also involves cyber and geographical connections that criss-cross the greater metropolitan area; ADHD kids, for example, may be drawn from local clinics and other nearby after-school programs. So too may be controls: one woman I spoke with at the lab regularly accompanied her nine-year-old granddaughter who had served as a control on several studies. The child

earned 55 dollars that day – quite a bit of money for someone who appeared to be from a modest background, as she lived in a nearby low-income housing project. Her grandmother was particularly interested in teaching her grandchild to save:

She's so proud of her pictures, she takes her brain everywhere. She's making money, it's her own money. She can do anything, well, almost anything, she wants with it. But some of it has to get spent on going to college. She'll be allowed to treat herself to lunch, but really, the money has to go to some good purpose.

When I queried the staff about class differences in child enrolment, one said, "we recognise that all parents want to get the best for their children. Unfortunately, lower class parents don't pursue this option so much". Recruiters and scanners are quite sympathetic to the diversity of children and their families; but they do not seem to be aware of recent work in social psychology ACE (adverse childhood events) or epigenetics (Jablonka & Lamb, 2005) that suggest the profound social impact of stressful life factors to which kids growing up in poverty are much more likely to be exposed (see Tough, 2011, for popular interpretation). Such contemporary research might complicate researchers' understandings of which populations of children exhibit their diagnoses of interest, or how chronologies of early exposure to adversity might then affect multiple conditions and the severity of what are later diagnosed as neurological conditions.

The laboratory staff understand that children with a relevant diagnosis are often entered into studies because some parents can imagine future benefits of research on their child's condition. The mother of a four-year old in an epilepsy study, for example, told me that she was grateful for the many controls who served in that research since their participation bolstered her hope that someday soon there would be better medicines for her daughter's seizures. Parents in a dyslexia study uniformly expressed enthusiasm and support for research into brain differences involved with this condition: 'The bottom line is, we'll never get to the bottom of this without research.... They can't get funded for these studies unless folks like us volunteer', one said.

Another mother told me, "It's so interesting, why wouldn't we do this? The more you learn about the brain, what's going on with them, the brain is so interesting, it's always good to educate yourself, to know more about yourself". Despite her positive and universalising expressions, the same mother had said while looking at her daughter's brain scans a few moments earlier, "it's nothing special, it just looks like every other brain". It is hard to reconcile global expectations with the inconclusive specificity of the scans

their children take home. The real story lies elsewhere, from the scientists' point of view. Yet the highly experimental work of the laboratory and parent expectations in some groups with high scientific literacy and biomedical expectations may be contributing to the anticipation that studies like these will directly benefit their children and more general populations long before clinical implications are warranted.

This existential gap between parental expectations of science and the opacity of what their particular child's scans will be interpreted to illustrate presents an ongoing conundrum. The lab staff is particularly aware of this chasm: "You should hear our phone screens, 'can I take the scan to my doctor?' parents ask me. Really. Sure, you can take 'em but he knows less than we do". Another told me, "This is not diagnostic, but people think if you look at part of the brain you can say what's wrong with it. It's hard for them to understand that isn't what we're doing".

One mother of two dyslexics who were participating in the same study expressed her frustration to a scanner: "So what can you tell me from these pictures? Nothing! Unfortunately, I'm not a neuro-radiologist. OK, so I'll just get a textbook and interpret it myself". Another mother, looking at a side view scan of her child says, "You can tell it's him by the nose. But what's in his brain?" Again, the assumption of future abstract benefit is continually undercut by the disappointment of expectations when a scan is just a scan and does not reveal anything immediate about the child's diagnosis (cf. Pickersgill, Martin, & Cunningham-Burley, 2011).

At the same time, a shift across this existential gap also provides a valuable collaborative benefit for parents: a theory of neurodiversity takes the blame for a child's school or social failure off the parents (overwhelmingly, the mothers). The materiality of brain scans potentially demonstrates a difference which is far removed from Bruno Bettelheim's (1967) classic 'refrigerator mother' theory of autism, or popular blame of ADHD on 'too much television, sugar consumption, and other permissive parenting behaviours', as is widely believed in the United States. If the somatic truth of a child's school problems is lodged in specific brain regions and dysfunctional connections, the materiality of the condition can be dislodged from putative parental shortcomings, enabling a parent or teacher to accept childhood differences with potentially less frustration and more compassion. The future of brain studies may thus seem comforting to some parents.

Parents are not the only ones to project future efficacy into present imaging. Following L-CAN members to the American Association of Child and Adolescent Psychiatry meetings in 2010, I was struck by the frequency

of questions raised to poster-presenters: "How much will it cost to get my patient a scan, show her where in the brain her depression is?" asked one clinician. Another said, "I can see you're really zeroing in on ADHD, that's great. When will you start testing new meds?" Such questions imply that there was conclusive mapping of the widespread condition that could now be subject to what physicians imagined to be more efficacious pharmaceutical regimes. In my field notes taken at the meetings, I have scribbled down,

the clinicians only want to know when the fMRI machines will be ready for diagnosis; the researchers only want to know what comes next. There is no conceptual space between the tiny steps our lab describes toward using resting state connectivity to search carefully for areas of the brain linked by neural networks to other areas and specific diagnoses and healthy controls (both adult and kid) ... and what the audience wants. Everything is collapsed, they want the answers NOW.

Lab members were unfailingly polite in answering the questions posed. But in private conversations, they were also astonished at how little practicing clinicians – often from prestigious teaching institutions – seemed to understand about the difference between exploratory research and translational findings.

This same existential gap is regularly crossed by scan operators who interface with child subjects and their caretakers every day. Trying to understand the difference between expectation and data collection, I asked members of the lab whether they saw 'external' differences in children diagnosed with 'internal' differences, or controls. I was probing for these scientists' ideas about the relation of the structure of the brain to its behavioural functions. But no matter how I framed the question, not one member of the scanning staff ever pointed to significant direct brain-to-behaviour differences beyond those of age:

with the toddlers, we know they may not go to sleep and that's the end of our scan if they squirm. An older kid, even a kid with ADHD can be very nervous, you just calm them down, tell them to lie still. Eventually, they do. With the dyslexic ones, we know they may not be reading the social story [Getting Brain Pictures with an fMRI Scan, or the subtitles in the Simpsons]. But once you get 'em into the magnet, it's all the same. Knowing what they have, it doesn't bias our results, it just helps us better prepare them for the scan.

In fact, many scanners commented on how cute they found the kids to be, and one expressed amazement at their participation: "I think it's bizarre that parents let us scan their kids. I went into the fake scanner at the office and freaked out, it's so noisy. Now I have a little more sympathy for the little kids who wriggle out".

Yet specific diagnosis – a key element for recruitment – may be mediated through less obvious social factors that in turn may affect outcomes. A recent dyslexia study, for example, successfully recruited its subjects through the International Dyslexia Association; most of the families who signed up through the organisation were drawn from the wealthier suburbs of Westchester and Long Island. The scientist in charge of the investigation was quite specific in her description of this population:

These parents are different than lots of the parents I see from the New York City. These are very strict. Especially if they have dyslexia themselves, or have seen it in the family, they know the value of education. If the mother's brother has it, the mom limits sugar in her son's diet. [Parenthetically, all RAs comment on the lack of utility of dietary interventions, but still speak approvingly of the parental discipline it involves]. All these parents have given their children the best, they've all had remediation since they were diagnosed, a tutor, a remedial reading teacher. We know the left angular gyrus is deactivated in dyslexics, it can be reactivated after intensive remediation. So many of them have had this tutoring advantage. Maybe it has already changed their reading. But not their spelling. Even the good readers, they have trouble with spelling, so maybe that's another set of connections.

This researcher is aware of the conundrum this raises for resting state functional connectivity studies: one could easily posit that long-term interventions have already changed neural networks before the child is enrolled. Therefore, she is suggesting that if their reading is already far from a spontaneous 'baseline', having been socially remediated, other aspects of their dyslexia – notably, spelling – may still be amenable to differential analysis via fMRI data collection. In several conversations with me, the researcher underlined that the parents of these dyslexic students truly knew the value of research and really wanted to participate: she had never seen such quick and reliable enrolment in any prior study in which she had participated; this was thanks to the collaboration with the International Dyslexia Association. Yet, the IDA should be placed in its own specific historical and social context. The world in which dyslexia was first described, interventions developed, and families later organised around, involves an explicitly activist context (Sleeter, 1987, reprinted 2010; Ginsburg & Rapp, 2010). In other words, strategies for remediation linked to science-friendly research projects already place these specific families and their potential child dyslexic research subjects in a specific social context which may well have affected the brain patterns which are then being tested.

CONSTRUCTING DATA

Because fMRI research is both scientifically 'hot' and expensive to support, many labs collaborate in pooling and exchanging data. Subject populations are also made up through circulation and exchange. Current studies at L-CAN, for example, have relatively small sample sizes which range from 20 to 120, and recruitment may be open for several years before these numbers of volunteer subjects are achieved. The problem of sample size is widely recognised: many prior fMRI studies cited in the literature have been built through meta-analysis, combining data from multiple small studies. With collaborative exchanges, samples can be enlarged, although scientists are aware of methodological differences in data collection protocols that make additions and comparisons a highly technical matter: "data always needs to be massaged", fMRI scientists continually say, hence the status of the real is under construction through these exchanges that build databases which are at once collaborative and sometimes competitive.

Additionally, L-CAN's director has taken the lead in establishing an international consortium where brain images and the databases that accompany them can be uploaded and analysed across at least four continents. There may not, for example, be enough left-handed children of both sexes between the ages of 6 and 10 with an autism diagnosis who can be recruited to a specific study in lower Manhattan – but when compared to databases derived from similar subjects enrolled in Europe, Latin America, and Japan, findings may well become more statistically robust. Of course, neuroscientists are acutely aware of different diagnostic and research protocols that may affect results. Nonetheless, such collaborations aim to harmonise research strategies, building global brain libraries: the subject of a transnational and universal brain with potential variants of interest across multiple geographical, institutional, diversely funded sites is constantly being expanded in its make-up. Scientific collaborations have long constructed 'globally defined fields of possibility' (Appadurai, 1996, p. 31); now, such flows are attaching to brain data, smoothing out the differences across the lumpiness of laboratory life in its diverse national contexts.

When scientists speak of 'massaging data', they are referring to highly technical processes that abstract statistical patterns from images and measurements produced in the magnet. While the public – including physicians – is now accustomed to colourful images of the human brain in which various regions are dramatically pigmented to highlight working areas and connections, these bear little relation to 'snapshots' of an

individual brain in one particular moment in time. These images are brilliant-hued composites of data compiled to emphasise the direction and density of connections that researchers have painstakingly correlated in the human brain.

The magnet collects data using several programs: blood oxygen level dependence (BOLD) fMRI scans track direction and density of blood flow ('hemodynamism') through regions of interest (ROI) in the brain to identify potential functional networks of connectivity. The magnet picks up the ratio of cerebral blood flow to oxygen use in an ROI as it shifts upward and downward, suggesting which areas are relatively active in various states or tasks. Although the signals are small and only measured relative to one another, highly sophisticated statistical formulae can be applied to lift the data out of its background: signal to noise ratio is created by interpreting these electrical flows as signs of active, firing neurons whose direction and connections can then be mapped.

DTI MRI, a complementary and newer technology, uses water-diffusion to measure connectivity in the brain's white matter in ROIs. White matter is the name given to the nerve fibres or axons deep inside the brain which carry messages across regions: buried at the core of ROIs, white matter used to be hard to image, but DTI has recently made it accessible. In DTI, parameters are established for measuring the rate of water diffusion and its direction in each voxel (a three-dimensional pixel) into which the ROI is divided. Thus the convoluted asymmetrical three-dimensional space of the brain can be smoothed out and described as a map. The mathematics involved are highly abstract: the properties of each voxel are acquired by measuring many different gradients and orientations of water flow, then combined and weighed. Regions of the brain are 'seeded', which means that a computer program is set to take measurements at standardised distances from one another; the density of seeds is adjusted to sample size and the quantity/ quality of connections whose existence is being sought. Measurements reflecting the directions of water diffusion within each voxel are recorded. Using both BOLD and DTI, the function and structure (i.e., nerve fibres) of brain regions can be calculated.

By comparing the relative strength and direction of these signals (the 'signal to noise' ratio), neuroscientists search for associations between brain regions which are neurally networked. "Getting decent data, that's what it's all about ... we started an algorithm to get functional RSC reconstructed, it leads to better SNR [signal to noise ratio]", as one lab scientist told me. His data are highly abstract, provisional and negotiated, yet they are considered exciting, too. But they exist in an expert space far removed from the public

imagination of brain imaging: abstracted from standardised measurements that are intended to smooth out and make comparable very subtle differences in energy flows amongst brain regions which may correlate with aspects of diagnostic behaviour differences, such images are highly experimental. "Our data are made but they are not made up" as anthropologists might put it (Roseberry, 1982). Thus the status of what is real in brain imaging is constantly under statistically expert construction, and there is a profound existential gap, I would argue, between neuroscientists' daily experimental processes and what many other publics – including many clinicians, parents of affected children, and young adults living under these diagnostic categories – anticipate. Nonetheless, brain imaging has entered the collectively produced future imaginary.

DEVELOPING BRAINS

Brains regularly float out of the laboratory; they are tethered in the narratives parents tell about their child's diagnoses and struggles. When I asked parents of children who carried a school-related diagnosis to describe their child's brain, the hybrid notions they produced were quite complex. Often, their children's brains were metaphorised through other pieces of contemporary technology, as these interview excerpts demonstrate.

For example, a mother whose seven-year-old son has just been re-diagnosed, adding paediatric bipolar disorder to his prior category of Tourette's, described his brain this way:

It's all messed up, it's very complex. I imagine in like a crowded desk-top of a computer, you can't find any files in there, although they're all there. He's a mess. He's always in trouble in school, his brain doesn't work like the other kids. His brain is just different, it's like two giant things [Tourette's and paediatric bipolar] are operating independently, neither knows what the other is doing (they aren't connected, the MD tells me), but they both are getting in his way.

Likewise, an adult acquaintance who was only diagnosed with ADHD after his own children received this label and its medication regime said, "I'm also HDTV, just like the kids, I only discovered it as an adult, it explains a lot. There's attention stuff all over my family, years ago they didn't go for this. I just figured out what to do to get through school, I was always with the slow, dumb kids, my brain didn't work, it didn't help. Learning music saved my life". And contemporary electronics provided his humorous metaphor.

These individuals' use of high-tech metaphors also resonates with an ongoing public debate about whether early exposure to such platforms transforms the brain through multi-tasking and other behavioural adaptations that may encourage ADHD and what I here take to be 'neuronal democracy'.¹

The most self-reflexive interview I conducted took place with a medical student, Rajid, who grew up between India and the United States. He had recently been diagnosed with both learning disability (LD) and ADHD, having spent his life in a high-achieving educational/familial context figuring out ingenious, private strategies for his own accommodation in isolation, without support. As our interview began, he pointed to his Sony voice recorder saying, "This is pretty much my second brain". Rajid had taken a break from medical school to work at L-CAN, where he was warmly welcomed by the team. He viewed himself as the 'wave of the future' in medicine, struggling to make sense of neurodiversity among children and young adults. Becoming a brain scientist was a goal that enabled him to think more deeply about his own brain differences and deficits, searching for biomedical explanations and interventions on behalf of many others:

ADHD, you know, it's very controversial. Dyslexic, it's a little bit easier for people to swallow. There's a neurological, I use the word neurological instead of psychiatric, there's a neurological kind of difference ... We're in a kind of in [an] Adam Smith society where we specialise in, you know, this is how things work and I understand because that's how society functions as a whole, so if I had to pick one kind of facet it would definitely be medicine because I feel it is the most bang for the buck instead of fixing this and that ... I think we have a certain brain infrastructure and we figure out the best way to utilise that infrastructure. And you know, we can make little amendments. Can we completely change your brain, no probably not ... I find out what my weaknesses are and I make them my strengths. That is precisely what makes me, will make me great at this and what's gonna be the thing that gives me my confidence.

Many mothers likewise adopted the language of neurology and neuroscience to justify their own perceptions of a child's worth, despite school struggles and stigmas. As one mother put it in describing her daughter's school-based gaps:

Things go into her brain, it just happens in a completely different way. And she's got some really, really strong talents and abilities that a lot of people don't have because of the way that her brain is wired. But there's no question that ... she has trouble reading. She has that problem of coming up with the right word sometimes. You know, it's a processing thing. You know, it's the way her brain processes information is very different and she can come across as not very bright. And then when they see what she can do ... they're always saying, "Oh she's so smart."

Some parents were already brain-focused in their professional work before their child with a diagnosis reoriented and deepened it: Bridget Keene, a LD specialist, described her research and clinical work thus:

And as we know, most LD kids don't have one thing wrong with them. It's usually constellation misery ... So we don't know everything neurobiologically about why, but we do know that we can find common constellations that need treatment ... And we also know that certain symptoms go with different diagnoses, you know. Sometimes it could be ADHD related. Sometimes it could be addiction related. Sometimes it can be depression related ... It's really complicated. So let's just take these kids to school, that have these issues, right? So: I did this work for seventeen years, diagnosing, researching, providing tutoring and then I got pregnant, and I basically had a kid who looked like my research. And I don't know how this happens in the world ... Everybody has a personal connection.

These mothers are describing their children as 'cerebral subjects' whose 'Beliefs, desires, behavior and emotions are addressed in wholly cerebral, or rather neurochemical terms, and their social and cultural effects are also attributed to the brain' (Ortega, 2009, p. 426). Once again, such braincentred explanations that appropriate the concept of neurodiversity from social movements predominantly mounted by young adults diagnosed with autism may offer comfort to those who struggle with various forms of childhood difference (see also the chapter by Elizabeth N. Fein, this volume).

Some populations seem particularly open to brain-deficit explanations: parents of adopted children, especially if they were adopted internationally, widely believe that their kids are at considerable risk for disordered learning and disrupted social skills. Several adoptive parents I interviewed produced the number of '25% have learning issues', although there is no statistical base that I could locate to verify or contextualise this popular conception. But in six interviews with adoptive parents whose children hold diagnoses of ADHD and LD, two spoke of the young women they imagined the birth mothers to be: vulnerable to impulsive choices and mistaken social cues. perhaps bearers of ADHD themselves. Some spoke about poverty and poor maternal nutrition as contributing to brain differences in the children they bore and relinquished. One described a popular psychological theory in adoption circles known as 'the lost highway': maternal voices heard by the developing foetus in utero are thought to be abruptly replaced after birth by language in another tongue, and this was imagined to impair language learning in the infant's traumatised brain. One adoptive mother said, "Look, we tend to be more middle-class than the young girls who are giving up these babies. We're on the look-out for anything that could go wrong,

and when it does, we have them tested right away. If there's a brain problem, we pick it up". Indeed, one mother moved the discussion away from the brain and into the general environment, saying:

I have no idea why these kids have these things. I mean I could say it's the polluted environment ... Our food is toxic. It's all sprayed with chemicals. You know, I don't know. Why is it more? I have no idea. The way they think about education is different. The pressures around education are different ...

Of course, not all biological parents/adoptive parents think about their children's learning differences through this particular lens of the brain. One mother of an internationally adopted son who had an IEP and accommodations for part of his childhood described her son thus:

Look, Carlos is charming, very socially connected. And very lazy. It's just in his character not to work too hard in school. He doesn't want to be singled out with labels, and they never did him very much good, anyway. So I just have to stay on him to get the homework done.

An African-American professional mother rejected the diagnosis of ADHD given to her daughter who changed schools three times before she was eight in search of what her parents viewed as appropriate acceptance:

A child this ebullient who can't sit still is at grave risk of being labelled and medicated. The Black community is very conservative about children's behaviour, they just want her to suppress all those impulses. And in predominantly white schools, everyone is looking to her to be a role model. It's not a fair demand to make on a child who is a little slower to learn her social cues.

In this mother's view, a child under social pressure was being overmedicalised by what I might label as 'brain-blame'.

Some mothers remain agnostic when asked about their children's brains. Maureen MacNamara, for example, offered a mixed kinship/diagnostic narrative-a kind of 'blended inheritance' of the social and biological (Lock, Freeman, Sharples, & Lloyd, 2006). When asked about her son who was diagnosed with an autism spectrum disorder, she opined:

I do think the rise in autism is from the children being diagnosed better. Back in the day, I think that if you were high functioning like Asperger's, you were like Speech and Language Delayed or Language Delayed. I think if you were low functioning, you were mentally retarded. And now I think they're getting it better. Um, I don't know where it comes from. I don't know if it has anything to do with the brain ... According to my daughter, I will tell you what she told me when Gregory was diagnosed. She was 9. She informed me one night that it was her fault that her brother was autistic. I said, "Why is it your fault that your brother is autistic?" She says, "Because when I was in your belly, I took all the smarts. And I didn't leave anything for Greggy." I said, "Well, if you took

all the smarts and Greggy took all that was left." She said, "I know. I don't know what's gonna be left for Kevin (the youngest, also with a diagnosis)".

Similarly, a high school student who had had an IEP and special educational accommodations since being diagnosed on the autism spectrum at the age of five mixed a brain and a kinship explanation of his concrete differences:

I almost flunked chemistry and then I passed it. My teacher really helped me but mostly it was my mom, she went on the computer and figured out chemistry for me. My brain works different, I thought I got it but I didn't. And then I did. You ought to see my mom.

His mother, a strong advocate for her son's self-esteem and services, fits well into what we have elsewhere called 'Moxie Moms' (Ginsburg & Rapp, 2010). The powerful mix of brain language with 'the new kinship imaginary' linking advocate families with their diagnosed children, signals the rising comfort and acceptance of the heterogeneity of the brain as a metaphor for human difference.

EMERGENT EXPERTS

This hybrid usage of brain-as-diversity is particularly apparent in the words of young adults who succeeded in getting through their public school years with the benefits and burdens of IEP/special education labels. My fieldwork includes participant-observation with Project Eve to Eve (PE2E), the first national organisation by and for young adults who grew up with diagnoses of ADHD/LD and IEPs. Having gone to college against considerable odds, they now are organising chapters across the country, where members are trained to mentor kids in local middle schools near their campuses with the same diagnoses. College-age participants in PE2E provide a 'Beyond Normal Art Class' as an after-school activity; the art room is conceived of as an outreach towards self-acceptance and advocacy for the youngsters who participate. The curriculum uses art projects to build trust across LD/ADHD generations; young adult mentors use a theory of metacognition to hasten self-awareness and confidence amongst their mentees. The young adults who become cultural activists in the service of what they call a 'special ed revolution' are thus a very thoughtful group. Their language and classroom-based actions reveal neurodiversity as a user-friendly mainstay of their self-awareness and strategies.

My interview with NYU's chapter head began with her announcement that "My brain is raging today and I don't wanna take meds". She went on to tell me the history of her continual re-diagnosis as dyslexic and dysgraphic in a New England town, and the discouraging educational experiences that had circuitously brought her to leadership in PE2E. Now, after diagnosis of ADHD on top of her prior labels, she continues her story:

You can look at it and say that's a compensation, that's how my brain, its plasticity, works. And that's the science stuff ... Where do we take the information that we learn about people with different kinds of minds as all this science stuff comes out as, you know, well autism is a good thing and ADHD is a good thing and all of these sort of childhood disorders that end up being so well researched and have all this funding go into them ... At least [in] Eye To Eye we're trying to build these communities and we're looking at the attributes and the really great things about having a different kind of mind ... learning about ourselves as human beings and the kind of the world that we're in. ... [In] This very fast paced world where all of these different ideas are emerging together ... you have to be able to set yourself apart, you have to be able to think differently. And so what does that say for these people who have been able to think differently for their entire lives and haven't put themselves into this little box of being just like everyone else and doing it in the same time frame as everyone else does it? And in a globalised society how much is that going to make you be better than the next guy? What's gonna set you apart? Is it being different in a quirky better way that's gonna set you apart, or is it being the best of the normal people that's gonna make you who you are?

This young woman is raising activist aspirations and doubts about what I have here labelled 'neuronal democracy'. It is worth noting that her ideas about the importance of accepting the potential creativity of differently-abled brains are an instance of how scientific thinking diffuses far beyond the laboratory findings noted at research centers like L-CAN. In appropriating the idea of 'neuronal democracy', I point to the cultural distance between her social valorisation of putative brain differences, and how this concept was used to describe specific research findings by neuroscientists investigating momentary processes of brain action in Miguel Nicolelis' radio interview which opens this chapter. By underling the distance between popular and scientific usage, my argument suggests that the effects of laboratory research and the metaphors used to describe them may serve expansive purposes in the practices of those who see their subjectivity embedded in research findings.

Dave Flink and Marcus Soustras, respectively the Executive Director and National Program Director of PE2E, expressed similar sentiments in one of my earliest interviews with them:

We're forced into labels. We need to embrace them, say, 'I am dyslexic'. Cognitive diversity is just the same as saying, "I'm Black" or "I'm tall", it's just another physical thing ... When your label remains invisible, you're in the closet, you can't do your best.

Your brain works better when you've got the accommodations you need... Our weaknesses have a label but really good educators work with our strengths. Our disabilities can be healed when we're in an environment that accepts our neurodiversity, works with us to put it to work.

Coming out as 'being different, having a different brain' and using your accommodations to succeed is central to the mission of PE2E. In the NYU chapter to which I serve as mentor, three students with three different diagnoses expressed similarly the importance of understanding neurodiversity. As one said, "It's a way to get excited about being different, now I know that my brain just works differently, I pay attention to everything, that can be turned into a good thing". They, too, are embracing a theory of neuronal democracy.

The summer that I attended PE2E's Organizing Institute – a boot-camp/celebration and intensive leadership training workshop that the group holds annually on the campus of Brown University in Providence, Rhode Island – this sense of comfort with psychiatric diagnoses, and the creativity of brain differences presumed to underlie them, was quite visible. Below, I offer excerpts of the discourses revolving around Executive Director David Flink's opening speech at the OI. I wish to highlight the practical and ongoing embrace of diagnostic/neurodiversity paradigms that accompanied his inspirational talk. Insider humour was manifest as Dave was surrounded by activists cracking special ed brain jokes: "Pitch it quick I've got a short attention span", called out one; "Don't ramble off message, my brain can't follow" quipped another. After a workshop that participants were asked to evaluate, Marcus Soustras, National Program Director, said, "I promise this is the last survey all you dyslexics will have to fill out". And some wise-cracker immediately yelled out, "Do I get time-and-a-half for this one?"

As a participant-observer at the OI, I was struck by the materiality of difference: boxes of squeeze toys were distributed everywhere in recognition of the built-up physiological tensions that accompany long stretches of sitting for this crowd; public announcements include stair-running breaks and other highly physical suggestions for 'letting off steam' among ADHDers and Touretters at work. Once, I was asked to move to the back of a large gym; the clicking noise of my computer note-taking was distracting to some participants. The OI includes many informal but serious long discussions of 'meds', and their potential side effects. This population embraces neurodiversity and its biomedical and educational accommodations as a potent strategy for building their personal and political futures.

They are not alone. Paul Yellin, a neurodevelopmental paediatrician at NYU's Langone School of Medicine and founder of the Yellin Center for Mind, Brain and Education, pushes this idea of disability-as-diversity to its

logical limit: "I think everybody is potentially learning disabled. It depends on what you're trying to learn. I also think that nobody's learning disabled. I think that we have this huge false dichotomy – that we have typical learners and learning disabled, and I think it's really damaging". In these parental, professional and young adult discourses, the materiality of brain differences underlying diagnosis and remediation is embraced as the positive wave of the future.

In these excerpts from their annual Organizing Institute where new national chapters are formed and chapter leaders are trained, national leaders Dave Flink and Marcus Soustras articulate a theory of differently-abled brains and the role of neurodiversity in building a future without prejudice towards cognitive disabilities and the people who carry them. Such talk resonates with the 'social model' of dysfunction that disability activists, within and beyond the academy, have so long fought recognition for (Albrecht, Seelman, & Bury 2001). Here is a portion of Dave's opening speech at the conference:

I came here today from the future, I ripped through the space-time continuum to tell you something. I'm gonna tell you about the future, I saw some awesome things. Disabilities don't exist in the future. Why? Because LDs don't have the same meaning as they do for us. Because they don't affect us any more. Thirty years in the future, they've created an environment so inclusive ... that our spelling, our inability to pay attention doesn't matter. 20–30 years ago they called us mentally defective, retarded, lazy, 'you need to work harder, sit still', they'd say. About thirty years ago a bunch of people quit hiding their disability. They quit ... I get distracted easily. Those kids [you will be working with] are the future: you're holding the torch ... we're going to change the world ... Every time you come out of the closet you're changing LDs for someone else: ... The biggest piece is for these kids to have a role model, identify with someone who is highly successful ... Owning our disability, our different brains, doesn't mean we discount the struggle which is social, but we're committed to passing on our diversity to younger kids ... We're going to the future with this, we put the labels on, and people follow. We communicate metacognitive skills. We teach these kids that their brains are a resource, not a problem.

CODA

The neuroscientists whose research opens this essay share with PE2E this profound construct: the brain in all its neural diversity is about the future. As Miguel Nicolelis so appealingly put it, 'neuronal democracy' provides a contemporary metaphor for a future plus-que-parfait. Yet there is also a profound existential gap separating the quotidian extrapolations of small amplitude frequencies as abstractions on the part of paediatric

neuroscientists from the widely perceived public reception – and, indeed, constitution – of neurodiversity as a helpful context in medicine, disability activism, and family life. The various constituencies whose words and practices I have sketched in this essay do not necessarily see the burdens and benefits of putative brain differences from the same perspective. Nevertheless, collectively, the human brain is rapidly being hailed as a bridge to the future by neuroscientists, clinicians, families of diagnosed children, and activist young adults characterised with ADHD and LD themselves. In their company, we presently peer over an existential gap; there, neurodiversity is increasingly engaged as a polysemic metaphor for the acceptance of human difference lodged in the physiological brain.

Neurodiversity, as I have tried to show, is under intense negotiation not only in labs but also in households across America, where 15% of school-aged children are now diagnosed for special education services; some of them will grow up to be activists like members of PE2E. Whatever future is negotiated across this existential gap, we are all stakeholders in the status of its reality.

NOTE

1. I thank Alison Cool for this point, and for her insightful questions on an earlier draft of this chapter.

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