Are Your Thoughts Your Own?: "Neuroprivacy" and the Legal Implications of Brain Imaging

The Committee on Science and Law

INTRODUCTION

Scientists believe the ability to scan brain activity has the potential to yield knowledge about the inner workings of an individual's brain. Some researchers already claim to be able to discover certain unconscious preferences or to detect when someone is lying about being exposed to certain information based upon cerebral activity. Brain research is beginning to raise numerous legal and social policy questions including: What information is going to be discovered? Who will have access to it? How will the information be used? What privacy rights does a person have to his or her thoughts?

The study of the ethical, legal and social implications of neuroscience is being referred to "neuroethics."[1] Many types of brain research have, or will have, legal implications. However, this article will focus on the privacy concerns with respect to mental and cerebral functioning as delineated through brain imaging and other neurodiagnostic techniques—or what will be referred to here as "neuroprivacy."

Neuroprivacy issues clearly have hit a nerve among journalists and ethicists.[2] William Safire, the columnist and Chairman of the Dana Foundation, has commented,

> the specific ethics of brain science hits home as research on no other organ does. It deals with our consciousness—our sense of self—and as such is central to our being. What distinguishes us from each other beyond our looks? The answer: our personalities and behavior. And these are the characteristics that brain science will soon be able to change in significant ways. Let's face it: one person's liver is pretty much like another's. Our brains, by contrast, give us our intelligence, integrity, curiosity, compassion, and—here's the most mysterious one—conscience. The brain is the organ of individuality.[3]

However, until recently there has been little detailed discussion of the privacy implications of neuroimaging despite the fact that there are major information-gathering initiatives underway. With the development of "brain fingerprinting"[4] and other technologies, privacy concerns about advances in neuroscience are increasing.

The purpose of this report is to view potential legal questions within the context of existing brain imaging technology, applications and protections. The first section summarizes current technologies. The reliability of these technologies will be addressed in the second section. Potential applications of this technology and some of the legal implications will be discussed in the third section. The fourth section will review existing protections. Lastly, issues that have arisen in the area of genetic privacy will be reviewed and compared to similar concerns that might arise with respect to brain privacy concerns.

As would be expected in a pioneering field, there is little reported case law addressing neuroprivacy. Existing laws provide only a limited framework by which to protect the privacy of persons who are subjected to brain imaging to ascertain the veracity of their testimony or to determine their personal preferences and biases. Although the use of brain imaging for these purposes is not yet widespread, policy makers and legislators should address these issues prospectively.

I. CURRENT TECHNOLOGIES AND DEFINITIONS

"Neuroscience" is the science concerned with the development, structure, function, chemistry, pharmacology and pathology of the human nervous system.[5] It is directed at exploring the architecture and functions of the brain as well as the effects of stimuli on parts of the brain and cerebral performance. Currently, there are three primary areas of research: imaging of the brain and other neurodiagnostic techniques, exertion of

influence on the brain,[6] and design and construction of the brain.[7] Although there are legal concerns with the latter two areas, this article will focus on neuroimaging.

With respect to neuroimaging and adjunctive neurodiagnostic modalities, several advanced noninvasive techniques allow detailed monitoring of the brain and enable the scientist to observe cerebral neurochemical changes that occur as the brain processes information or responds to various stimuli.[8] The more basic techniques are discussed below. Very often two or more of them are combined to optimize results:

A. Positron emission tomography (PET): PET measures emissions from radioactively labeled chemicals that have been injected into the bloodstream and uses the data to produce two- or three-dimensional images of the distribution of the chemicals throughout the brain and the body. PET can be used to show blood flow, oxygen and glucose metabolism or drug concentrations within brain tissue. For example, PET scans are used in drug abuse research to identify the brain sites that are affected by drugs and to show how long drugs occupy these specific areas in the brain.

B. Single photon emission computed tomography (SPECT): SPECT also uses radioactive tracers and a scanner to record data that a computer uses to construct two- or three-dimensional images of metabolically active brain regions. SPECT is generally used for the same types of research as PET. While the technique is much less expensive than PET, it provides less detailed images.

C. Magnetic resonance imaging (MRI): MRI uses magnetic fields and radio waves to produce high quality two- or three-dimensional images of brain structures without injecting radioactive tracers. Functional MRI (fMRI) measures brain activity under resting and activated conditions. It can produce images of brain activity as fast as every second and enables scientists to make “movies” of changes in brain activity as patients perform different tasks or are exposed to various stimuli. Both MRI and fMRI are commonly used for identifying, investigating and/or monitoring brain tumors, congenital anatomical abnormalities, trauma or strokes or certain chronic disorders of the nervous system (e.g., multiple sclerosis).[9] Newer MRI technologies, including studies that are dependent upon blood oxygen levels (BOLD), recent advances in MRI spin techniques and structural MRIs, are primarily investigational in nature and not used commonly outside major academic centers conducting brain research.[10]

D. Electroencephalography (EEG). EEG is an adjunctive neuro-diagnostic modality, rather than a neuroimaging technique, that uses electrodes placed on the scalp to detect and measure patterns of electrical activity emanating from the brain. It is roughly comparable to electrocardiography (EKG), which uses electrodes on the chest to evaluate and monitor heart function. Other sophisticated techniques, such as event-related potentials (ERP) and near infrared spectroscopy (NIRS), are primarily investigational at this time.[11]

II. RELIABILITY ISSUES

One cannot presume that brain imaging as applied in this context uniformly provides meaningful information. While CT and MRI scanning has been utilized medically for over 20 years, fMRI and other neurodiagnostic techniques are still a subject of much research and some controversy. Possible applications of these newer techniques have been reported to the public through the lay press; however, there are variables that impact on the reliability of the results. Several questions that arise. What impact does the applied technique have on the results? Do the results differ when different MRI modalities are being used? Is the study conducted by a psychiatrist, a neurologist or a radiologist? Who is interpreting the study? How many subjects are enrolled in the studies? What particular machine (manufacturer, strength, construct) is being used? Are there any case controls? What standards are being developed or being used, if any? These are just some of the issues that would need to

be resolved before the use of brain imaging is accepted as a way to determine mental functioning and reasoning. Evidently, the legal ramifications of its widespread use are a primary concern.

Questions remain regarding the significance of the scans. Antonio Damasio, MD, the Director of Neurology at the University of Iowa and a noted researcher into the neurobiology of the mind, noted that,

> [t]he issue is what we can expect from functional imaging—namely, from PET or fMRI... For example, no one need have any doubt that we can now identify a lesion caused by a stroke, tumor, surgical incision, or head injury, and that we can localize it and intelligently combine that information with clinical data. This enables us to make very accurate diagnoses and even predictions about how the person is likely to evolve. And I don't have any problem with that being brought in court.... Most of the imaging issues that people are very worried about have to do with functional imaging in an experimental setting. Here the interpretation is tied to the hypothesis, to the design, and to the theory that are behind a given study and to analyses that vary from laboratory to laboratory. This is the kind of information that we have to be very cautious about and that I would not find appropriate to introduce in court at this point."[12]

III. USES OF BRAIN IMAGING AND POTENTIAL LEGAL IMPLICATIONS

Initially, brain imaging was used primarily to diagnose brain injuries or brain disorders; however, current projects are directed toward evaluating more complicated brain processes, including those neural pathways that subserve memory, language, emotion and decision-making. Although it is not yet possible for devices to read a person's mind or bring actual thoughts to a computer screen, a number of studies are focusing on exploring personality, thought processes and mindset by studying and analyzing individual "brain prints." The findings from these studies may reveal information regarding unconscious biases, and preferences of which the subjects had been unaware.

A. Non-medical Brain Research

Various non-medical research projects highlight the types of information that apparently can be determined. Some scientists maintain, for example, that socially relevant characteristics, such as racial group identity and unconscious racial attitudes, have neural correlates which can be measured.[13] In one small study, four black subjects and four white subjects viewed photographs of black and white faces. The investigators found that there were significant differences in the individual responses to the faces, which were attributable to whether the faces in the photographs were of the same race as the subject viewing them.[14] Another study of unconscious attitudes found that white subjects had greater activity in the amygdala (the area of the brain associated with the fear response) when viewing pictures of unfamiliar black faces as opposed to white faces.[15] An even more recent study indicates that fMRI may be used to show an individual's ability to deceive intentionally by having the test subject respond truthfully or falsely to a series of yes/no questions regarding autobiographical information.[16]

Other researchers now are now working in "neuromarketing," performing brain research for corporate clients. Neuroscientists at the Brighthouse Institute for Thought Sciences at Emory University Hospital in Atlanta believe that cerebral MRI scans which show increased activity in the medial prefrontal cortex of the subject's brain when shown a certain product are indicative of a preference for that product.[17] It is argued that such tests yield evidence of the subject's unbiased attitude toward an idea or an item, much like the person who claims not to like a product such as a potentially embarrassing pornographic magazine, but who in fact manifests a preference for it.[18]

Other neuroscientists remain skeptical of neuromarketing.[19] They maintain that increased activity in certain parts of the brain remains an enigma.[20] Critics have pointed out that "just because we can see neurons firing doesn't mean we always know what the mind is doing. For all their admirable successes, neuroscientists do not yet have an agreed-upon map of the brain."[21]

While some of this research may appear trivial, it would seem to have larger legal and policy implications than one might imagine at first. At the very least, one major concern or question is what will be done with these research and neuromarketing test results and who will have access to them.

B. "Brain Fingerprinting" and Evidence

"Brain Fingerprinting" technology is worth a close look as it has already been cited in two court cases. Brain Fingerprinting is a technique that purports to determine the truth by detecting information stored in the brain.[22] Using an EEG, it measures brainwave responses to words or pictures presented on a computer screen. A subject who has knowledge of the information being tested reportedly emits a specific, measurable response, a brain wave known as P300/MERMER (Memory and Encoding Related Multifaceted Electroencepholagraphic Response). A subject who lacks such knowledge would not manifest this response.

Testimony on brain fingerprinting first was introduced into evidence in Iowa in a convicted murderer's quest to have his conviction overturned and a new trial granted.[23] The trial court considered the admissibility of the test and stated,

> The test is based on a "P300 effect".… The P300 effect has been studied by psycho-physiologists…The P300 effect has been recognized for nearly twenty years. The P300 effect has been subject to testing and peer review in the scientific community. The consensus in the community of psycho-physiologists is that the P300 effect is valid….[24]

However, the trial court did not find the brain fingerprinting evidence persuasive and refused to vacate the conviction and grant a new trial.[25]

The Iowa Supreme Court subsequently reversed the trial court's decision on other grounds, granting post-conviction relief and a new trial.[26] Although the Iowa Supreme Court only briefly mentioned brain fingerprinting, it noted that the evidence

> was introduced through the testimony of Dr. Lawrence Farwell, who specializes in cognitive psychophysiology. Dr. Farwell measures certain patterns of brain activity (the P300 wave) to determine whether the person being tested recognizes or does not recognize offered information. This analysis basically 'provide[s] information about what the person has stored in his brain.' According to Dr. Farwell, his testing of Harrington established that Harrington's brain did not contain information about Schweer's murder. On the other hand, Dr. Farwell testified, testing did confirm that Harrington's brain contained information consistent with his alibi.[27]

The case is significant in that brain fingerprinting received the serious consideration by the court. It can be expected that as awareness of this case and the technology grows, it will become a more common topic.

There was also recently an unsuccessful attempt to introduce brain fingerprinting in *Slaughter v. State of Oklahoma*.[28] A convicted double murderer filed a second application for capital post-conviction relief on the ground that brain fingerprinting was "newly discovered scientific evidence," unavailable at the time of trial. The court was unswayed by the argument, questioning whether the science "would survive a Daubert analysis" and noting that the argument could have been raised much earlier on appeal.[29] Significantly, the court critically stated that "beyond Dr. Falwell's affidavit, we have no real evidence that Brain Fingerprinting has been extensively tested, has been presented and analyzed in numerous peer-review articles in recognized scientific publications, has a very low rate of error, has objective standards to control its operation, and/or is generally accepted within the 'relevant scientific community.' The failure to provide such evidence to support the claims raised can lead to no other conclusion, for post-conviction purposes, that such evidence does not exist."[30]

It remains to be seen how the courts in New York and other states will rule on the admissibility of a brain imaging test. It is possible that the results will be quite divergent. In New York, a Frye hearing—the type of hearing held to determine the admissibility of scientific evidence when a party seeks to submit innovative or "novel" scientific, medical or technical evidence—might be held to determine the admissibility of brain

fingerprinting.[31] For a novel scientific technique to be admissible under Frye, the court would need to be satisfied that such technique has gained "general acceptance," not that it would be unanimously endorsed in the field to which it belongs.[32]

Brain fingerprinting technology has the potential for other applications, including the detection of deception in the context of counter-terrorism. By using brain imaging, Brain Fingerprinting Laboratories claims to be able to answer questions such as "Who has participated in terrorist acts, directly or indirectly?" or "Who is a trained terrorist with the potential to commit future terrorist acts?"[33] If these technologies are perfected, it is possible that such brain scans might be done without the need to ask permission while persons are waiting to enter the country at U.S. Customs.[34]

C. Neuroimaging in the Context of Liberty Interests and Parental Rights

As this discussion suggests, the use of brain imaging test results as evidence in court proceedings has the potential to affect one's liberty interests. Sexually violent predators, persons civilly committed to psychiatric hospitals for lack of fitness to stand trial or by virtue of being found not guilty by reason of insanity, and those identified in criminal and national security investigations may be subject to continued hospitalization or incarceration if they fail to submit to certain tests or if the results of such tests show them to be a continued threat to society. On the other hand, test results may influence a parent's ability to retain custody of his or her child. It can be expected that brain fingerprinting and other brain imaging tests, as they become more reliable, could also be used as the basis for making decisions in such cases. These situations will now be considered in more detail.

1. Sexually Violent Predators

The evaluation of sexually violent predators shows the complexity that arises where neuroprivacy issues are involved. While the results of neuroimaging tests may increase the number of people who ultimately are released from confinement, some individuals may fear the tests will result in self-incrimination.

After the tragic murder of seven-year-old Megan Kanka in 1994, 16 states adopted legislation authorizing the involuntary civil commitment of sexually violent predators in a psychiatric hospital after the expiration of their prison terms.[35] Although, New York State has not yet passed such legislation, bills are pending in the state legislature.[36] In addition, a number of states have passed so-called Megan's Laws requiring the notification of neighbors when a sexually violent predator is released from prison to the community.

Under *Hendricks v Kansas*, in determining whether to commit a sexually violent predator involuntarily or to release a sexually violent predator from involuntary civil commitment, the state considered whether the individual (1) was convicted or charged with a sexually violent offense, (2) was suffering from a mental abnormality or personality disorder, and (3) if so, whether such a disorder made it difficult, if not impossible, for the person to control his/her dangerous behavior.[37] In making its determination, the state considered what thoughts and fantasies such a person was expressing, if the person was being truthful, and whether he or she could, in fact, control his/her behavior.

In practice, it appears that states rarely risk making the wrong decision. Under the New Jersey law permitting the involuntary commitment of sex offenders who were deemed "likely" to be dangerous after the expiration of their criminal sentences, none of the 300 persons committed under the law since 1999 have ever been recommended for release by the state.[38] Similarly, a 2000 draft study on the release of sexual predators upon the completion of their prison terms under Washington State's law found that they were unlikely to be released.[39] Of the 121 persons committed under the law since its enactment ten years before, only five had been conditionally released.[40]

There may be many reasons why few of these offenders were released. One explanation may be that it is considered impossible to determine people's thoughts or to predict how they will behave in the future. As the discussion of fMRI studies and the trends in neuroscience toward predicting behavior indicate, technology may soon help make some of these types of determinations possible. For example, fMRI studies of people with mental disorders meeting the criteria for involuntary civil confinement may eventually be able to provide an image of a "typical" brain affected by such disorders, a prototype of sorts, and brain fingerprinting may be able to assist in determining whether such persons are telling the "truth." Thus, it is possible that neuroimaging may help protect

people's liberty interests by permitting more accurate determinations about releasing certain individuals from involuntary confinement.

However, the possibility of additional tests and the information they can provide raises problems of its own. For example, convicted sex offenders can be required to complete an "Admission of Responsibility" form about crimes for which they have been sentenced, a sexual history form setting forth all prior sexual activities (regardless of whether these actions constituted a crime), and then to take a polygraph test about such history. If the inmate refuses to participate, he or she may lose privileges and be transferred to a maximum security prison. In addition, the information provided by the offender is not privileged and can be used against him or her in future criminal actions. These requirements have been upheld by the U.S. Supreme Court in *McKune v Lile*, as part of a treatment program and were found not to violate one's right against self-incrimination.[41]

As exemplified in *McKune*, convicted sexually violent predators face a Hobson's choice of participating in a program where anything they say about past events may lead to future criminal charges against them, of being subjected to a polygraph on such statements, or of being punished for failure to do so. In addition, the failure to submit to a polygraph may be viewed by the authorities as a failure to cooperate in treatment, resulting in their unwillingness to recommend discharge from detention. There is no reason to believe that an offender's unwillingness to agree to a form of brain imaging as may be required by the state would not result in his/her continued civil commitment or imprisonment. In this way, brain imaging presents a threat to personal liberty interests.

2. Discharge of Persons Who are Civilly Committed and Persons Who are Incompetent to Stand Trial or Have Been Found Not Guilty By Reason of Insanity

In New York State, psychiatric patients, both civilly and criminally committed, generally have the right to refuse medical treatment.[42] Nonetheless, as a practical matter, their refusal to undergo brain imaging tests to gauge whether or not they are dangerous might be used against them at a discharge hearing.[43] For example, appellate courts in both civil commitments and commitments arising from not guilty by reason of insanity verdicts have refused to order the discharge of patients who were no longer psychotic while incarcerated or hospitalized, but who failed to comply with treatment upon prior release and therefore experienced deterioration of their mental condition and resumed violent behavior.[44]

Although the results in these cases are based on the patients' noncompliance with psychotropic medication, which rendered them dangerous, it is arguable that refusing to have brain scans to determine their degree of dangerousness would be seen as posing a threat to self or others or as failing to comply with a treatment program. Thus, the liberty interest considerations would be similar to those raised in the context of sexually violent predators.

3. Child Custody and Child Protective Proceedings

In contested child custody proceedings, it is conceivable that brain imaging of a parent would be sought and ordered by the court in furtherance of the best interests of the child. Allegations arise on such issues as sexual abuse, domestic violence, substance and alcohol abuse and lack of parental interest. Under CPLR 3121, when the mental or physical condition of a party is in controversy, any party may request that the other be examined by a designated physician. The potential use of brain imaging in such a context is readily apparent.

Similarly, it is possible that such tests would be authorized in child protective proceedings (i.e., abuse and neglect) under Article 10 of the Family Court Act. Family Court Act Sec. 251 permits the court to order a psychiatric evaluation to determine if a parent suffers from a mental disorder that would impair one's parenting ability.[45]

IV. EXISTING PROTECTIONS

The use and abuse of an individual's medical information in an age of computerization and managed care has become a subject of increasing concern and regulation. In 1997, testimony to the Senate Committee on Labor and Human Resources, the U.S. Secretary of Health and Human Services testified that close to 75% of citizens

surveyed were concerned that computerized records will have a negative effect on their privacy. Despite the enormous ramifications of the potential use of brain scans, *however*, there has been little in the way of standards set specifically for privacy and confidentiality of neuroscience clinical information.[46]

This section will consider existing laws and regulations that may be used or interpreted to cover brain images, brain imaging technology and the privacy concerns raised by them. While potential protections are found in the laws regarding the use of lie detectors, medical research and HIPPA, they are piecemeal at best.

A. Lie Detectors/Polygraphs

It appears the use of brain imaging technologies such as Brain Fingerprinting might be governed by the rules relating to lie detectors and polygraphs. Although decisions are in conflict as to the admissibility of polygraph tests in court, the general rule is that they are inadmissible since there is no general scientific recognition that they are effective in determining the truth or that reasonable certainty can follow as a result of the test.[47] It has also been held that "a polygraph examination is essentially communicative, testimonial in nature, and within the guarantees of the Fifth Amendment" (though such guarantees could be waived).[48]

In spite of the conflicting decisions, in one case, a court admitted the test result, reasoning that a defendant cannot be compelled to take the test, but could do so voluntarily, which would constitute a waiver of his constitutional rights under the Fifth Amendment.[49] However, as a general rule, even though the polygraph may be helpful during the course of an investigation, the results of polygraphs continue to be inadmissible as evidence in criminal proceedings in New York.[50]

It is possible that a brain imaging device might fit within the definition of a lie detector under federal law if it is used as a technique to determine veracity. The federal Employee Polygraph Protection Act of 1988 (hereafter "EPPA" or the "Act"), prohibits employers in the private sector from directly or indirectly requiring or suggesting that employees or job applicants take a polygraph or other type of lie detector test. In addition, a private employer cannot use or refer to the results of a lie detector test, nor take any adverse employment action against an employee or job applicant who refuses to take such a test, or on the basis of the results of such a test, except as otherwise provided.[51]

Federal, state and local government employees are excluded from the protection of the Act.[52] Nevertheless, public employees are protected by the Fifth Amendment privilege against self-incrimination where the demand to take a lie detector does not relate narrowly and specifically to their official duties.[53] Moreover, other federal laws such as Title VII, the National Labor Relations Act, and the Railway Labor Act may protect private and public employees from the unfettered use of lie detectors.[54]

The EPPA defines the term "lie detector" to include "a polygraph, deceptograph, voice stress analyzer, psychological stress evaluator, or any other similar device (whether mechanical or electrical) that is used, or the results of which are used, for the purpose of rendering a diagnostic opinion regarding the honesty or dishonesty of an individual."[55] The definition has already been interpreted to include other types of technology. For example, in *Veazey v Communications & Cable of Chicago, Inc.*, a fired employee contended that his former employer violated the Act when it discharged him because he refused to provide a tape-recorded voice exemplar that his superiors had requested.[56] The employer made the demand after another employee had received a threatening voice mail message. In finding that a violation of the Act had occurred, the Court of Appeals stated that

> [w]e are of the opinion that the application of basic logic necessitates that a tape recorder might very well be considered as an adjunct to a 'lie detector' determination under the EPPA because the results of a tape recording (a voice exemplar) can be used to render a diagnostic opinion regarding the honesty or dishonesty of an individual when evaluated by a voice stress analyzer or similar device. Accordingly, a tape recorder, when used in conjunction with one of the devices enumerated in the statute or a similar device, may fit within the definition of a 'lie detector' under the EPPA.[57]

Importantly, the court also stated that "the EPPA's legislative history indicates that Congress intended the prohibition on the use of lie detectors to be interpreted broadly."[58] Thus, it is submitted that under such reasoning, various forms of brain imaging would likely constitute a lie detector as defined under the Act, and that employees in the private sector would be covered by its protections.

If a brain imaging device constituted a lie detector under the Act, the examiners also would be subject to limitations on disclosure. The Act expressly restricts limits who—other than the examinee—can disclose information obtained from a lie detector test.[59] Such information may be disclosed by an examiner only to the examinee or a person designated by him or her; the employer that requested the test; or any court, governmental agency, arbiter or mediator in accordance with a court order requiring the production of such information.[60] The employer who requested the test may disclose its results only to the employee or to a government agency, but only insofar that the information is an admission of criminal conduct.[61] Thus, if brain scans were interpreted as coming within the definition of lie detector in the Act, their disclosure would also be regulated.

B. Scientific Research

Given that neuroscience is a rapidly growing field of study and that research is moving toward investigating more complicated cognitive processes, one should consider whether the confidentiality of information obtained in research involving brain imaging needs to be strengthened. The federal regulatory protections afforded human subjects apply to research projects which are conducted by a federal agency, are federally funded, or, if not conducted or funded by the federal government, are subject to regulation by any federal agency.[62] However, the federal regulations do not include their own confidentiality privilege.[63]

Rather, confidentiality protection is required indirectly by the regulation of research by individual Institutional Review Boards ("IRBs") and by the informed consent requirements. For "research" (defined broadly under the regulations), a prerequisite to IRB approval is that "when appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data."[64] Confidentiality protections are one of the basic elements of informed consent under the HHS regulations in that the subjects must be provided with "[a] statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained."[65]

This is, in fact, the only mention of confidentiality in the HHS regulations and it allows room for the possibility that no protections will be taken to maintain the confidentiality of records.[66] In addition, the privacy protections are only required for IRB approval where "appropriate."[67] Thus, the protection afforded brain research subjects under federal regulations may prove illusory unless there is a separate, distinct confidentiality or privacy requirement built directly into the regulations.

Similarly, it is unclear to what extent New York state law would protect the privacy and confidentiality of a participant in a brain imaging study as there is also no explicit privacy requirement. For example, New York Public Health Law 2445 provides that state law is superseded when research is conducted in compliance with federal rules and regulations, so that federal regulations would apply in New York for federal projects. For non-federal projects, New York Public Health Law provides that "no human research may be performed in this state in the absence of the voluntary informed consent subscribed to in writing by the human subject."[68] In addition, the IRB is charged with ensuring that the rights and welfare of the subject are adequately protected.[69] Thus, outside of the employment and medical contexts, to the extent that brain scanning is conducted as part of a research project, there appears to be limited guidance for ensuring the protection of such information.

C. Brain Privacy under HIPAA

The Health Insurance Portability and Accountability Act of 1996 ("HIPAA"), implemented via the Privacy Rule issued by HHS, addresses some medical privacy concerns, but would be inapplicable to brain imaging that is not done by a covered entity in connection with a covered transaction. HIPAA protects all "individually identifiable health information" held or transmitted by a "covered entity" or its "business associates" in any form or media whether electronic, paper or oral.[70] Covered entities include health plans, health care clearinghouses, and health care providers that transmit health information in electronic form in connection with certain transactions (e.g., claims, benefit eligibility inquiries, coordination of benefits and referral authorization

requests).[71] Such information is called "protected health information" and is defined to include demographic data and information about:

- the individual's past, present or future physical or mental health or condition;
- the provision of health care to the individual;
- the past, present or future payment of health care;
- information that identifies the individual or for which there is a reasonable basis to believe it can be used to identify the individual.[72]

This definition is quite broad and it is likely that brain images, when generated for medical purposes by the appropriate entity, would fit within its scope.

HIPPA regulates disclosure and use of protected health information. A covered entity may not use or disclose protected health information except either (1) as the Privacy Rule permits or requires; or (2) as the individual who is the subject of the information (or the individual's personal representative) authorizes in writing.[73] The Privacy Rule permits a covered entity to disclose protected health information for research purposes, without the need for the individual's authorization for research purposes in certain instances.[74] If brain scanning was considered protected health information, it would benefit from HIPAA's protections against disclosure of such information.

While the HHS Privacy Rule is extensive in many respects, it is limited by the underlying statutory framework of HIPAA, which covers only three named categories of businesses: providers, payers, and information clearinghouses. However, the concept of a "business associate" of a covered entity within HIPAA permits the categories of regulated entities to be broadened somewhat as such an associated person must enter into a contract with the covered entity, promising that it will respect the privacy of information transmitted from the covered entity to the non-covered entity.[75] Nonetheless, medical information may be widely dispersed beyond these covered entities and the regulations do not directly affect employers or other non-covered entities. Thus, even if brain imaging were interpreted to come within HIPAA's provisions, its protections would be subject to the same limitations inherent in HIPAA.

At best, HIPAA sets a minimum standard of protection. States, however, may enact their own more stringent requirements. New York, for example, statutorily imposes an obligation on health care providers to keep patient information confidential and to only disclose it in accordance with the statute.[76] The restrictions on disclosure apply to a broad range of health care providers.[77] A health care provider may disclose patient information to someone other than the subject of the information pursuant to a patient authorization or when otherwise authorized by law by following the procedures set forth in the statute.[78] The party receiving the information must keep it confidential and is subject to the limitations on disclosure of N.Y. Public Health Law §18. If brain imaging were considered to come within these provisions of New York law, then the information would benefit from the additional protections afforded by such law.

In the justification for a bill[79] to establish a common law cause of action for invasion of privacy with regard to medical records in New York, it was noted that while health care practitioners are held to strict confidentiality standards, there is no way to hold others accountable when they improperly obtain or make improper use of medical records. Thus, improperly obtained information about brain scans could be made widely known.

As this brief discussion of legislation covering lie detectors, medical research and health information shows, it is possible that the privacy of brain images would benefit from some protection if interpreted to come with in the scope of these regulations. However, such coverage would be piecemeal, applying only in certain contexts. If existing legislation were expanded to cover brain images, then some of these concerns could be addressed. Alternatively, brain images and information may merit their own set of regulations to ensure the protection of neuroprivacy in a manner similar to genetic privacy, which will be discussed below.

V. BRAIN PRIVACY AND GENETIC PRIVACY

As the prior discussion indicates, there is little current legislation that appears capable of directly protecting neuroprivacy. There has not been a lot of detailed discussion of the privacy implications of neuroimaging technologies despite the fact that there are major information-gathering initiatives relating to brain data, such as the Human Brain Project ("HBP") whose purpose is similar to that of the Human Genome Project ("HGP").[80] In contrast to the HGP, which devotes 3-5% of its budget toward studying the ethical, legal, and social issues (ELSI) of the project, there appears to be little particular focus on, or funding for, the study of the social and ethical implications of gathering such information.[81]

Some individuals are, however, concerned about these issues. Arthur Caplan, the Director of the University of Pennsylvania Center for Ethics and a prominent bioethicist, has written "[i]t is very likely that advances in our ability to 'read' the brain will be exploited . . . for such purposes as screening job applicants, diagnosing and treating disease, determining who qualifies for disability benefits. . . ."[82] Others have expressed concern that one's brain will be used against them.[83] Reference even has been made to a "brainome," similar to a "genome": Donald Kennedy, neurobiologist and editor-in-chief of *Science*, has stated "I already don't want my employer or my insurance company to know my genome. As to my brainome, I don't want *anyone* to know it for any purpose whatsoever. It is . . . my most intimate identity."[84] With the development of "brain fingerprinting" and other technologies and the progression of research, privacy concerns about neuroscience will only increase.[85]

The fears expressed regarding the privacy of brain information echo in many ways the concerns expressed with respect to genetic information.[86] Such fears were not unfounded in the case of genetic information, as the experience with sickle cell anemia[87] and, much more recently, the Burlington Northern Santa Fe Railroad case[88] have demonstrated. There is no reason to believe that brain information could not or would not also be misused in similar ways. Brain information, just as genetic information, is viewed as having the potential to yield great benefits as well as great dangers.[89]

Given these similarities and the limited legal treatment of the privacy of brain information, it is worth reviewing genetic privacy concerns in more detail. As genetic privacy has received a great deal of attention in articles, books and legislation, it may provide a useful construct for framing neuroprivacy protections. To the extent that privacy concerns raised by information related to brain function (particularly regarding the results of neuroimaging and other neurodiagnostic techniques) are similar to the privacy concerns that arise with respect to genetic information, genetic privacy protections may be good models for developing neuroprivacy protections, as well as valuable sources of information as to what is most effective or ineffective. If the privacy concerns between the two areas are different, then genetic privacy protections may be a less useful source of guidance on developing neuroprivacy protections. This section will examine the parallels and differences between the privacy concerns that arise with respect to genetic and brain information.

A survey of the legal literature and legislation on genetic privacy[90] shows four main areas of concern: (1) the obtaining and collection of genetic information,[91] (2) the disclosure of such information,[92] (3) the use of such information, in particular the discriminatory use by employers and insurers but also by the government;[93] and (4) the right *not* to know genetic information.[94] The principal concern expressed is that genetic information, as an indicator of what medical conditions people have or may have in the future, will be used to deny employment and thereby restrict access to health care (as employment is the primary source of health care insurance).[95]

There are also privacy issues with respect to genetic information that are not related to the individual's health. For example, there is some concern about genetic information being used to predict behavior or ability (e.g., that employers will test potential employees to determine who is genetically wired to be diligent or honest or particularly creative).[96] The use of genetic information to identify an individual via DNA testing is also causing concern. The "national" DNA databases that are being created to store the genetic information of criminals as well as national health information also have significant privacy implications.[97]

However, most privacy concerns about genetic information appear to be related to accessing health care, not predicting behavior or identity. For example, in evaluating the degree to which genetic privacy is protected by existing legislation, it has been noted that it would be covered by HIPPA's protection of health information, which applies only in the context of health care insurance.[98] (*See* discussion *supra* Section IV.) The main themes in the Senate Report describing the proposed Genetic Information Non-Discrimination Act are genetic disease

and ways in which genetic information relates to health care access and medical practice. The Senate Report specifically rejects the idea of creating a different set of privacy rules for genetic information from the rules that apply to health information.[99]

Even in the employment context, genetic privacy concerns are significantly related to health care access. The main point is that people with genetic information showing susceptibility to a certain disease might simply not be hired or could be terminated as a way to reduce the employer's burden of health care costs in the form of employer sponsored insurance and lost work days.[100] The discussion in the Senate Report is representative of this view. It provides that an example of a prohibited practice under the proposed legislation would be for an "employer to refuse to hire an otherwise healthy applicant because of a fear that he may develop Parkinson's disease. . . ."[101]

Put more broadly, the privacy concerns raised about genetic information stem from its predictive quality, its uniqueness and stability and the fact that it provides information about more than one individual (i.e., its familial nature).[102] Some of these qualities are shared by the information gleaned from brain images. The main shared characteristic of genetic and brain data is that both types of information hold out the promise of prediction. By analyzing genes and brain scans, it is hoped that propensities for disease and behavior can be established. Just as one of the main outcomes of the HGP is the ability to test for genetic diseases and conditions,[103] so does brain imaging provide a way to see the structure and function of the brain.[104] It is expected that images of blood flow and neural activity can be used to show the future likelihood of developing certain diseases and mental abnormalities.[105] Eventually data from myriads of neuroscientific studies may be integrated in databases, similar to gene and protein sequence databases, to provide, among other things, functional models for how the brain operates—"brain atlases"—that will include a probability distribution for different cerebral characteristics and some indication of "normal" brain activity.[106]

Another shared quality of genetic and brain information is that both types of information expose unique and personal, and to a large extent, uncontrollable, aspects of a person that previously were unobservable.[107] Just as every person's genetic make-up is unique, so is the brain considered an "organ of individuality."[108] In both cases, the availability of this type of unique, personalized information is a very recent phenomenon. It is hoped that neuroscience techniques, such as brain scanning, will, in a manner analogous to DNA testing, provide reliable, objective information about an individual person.[109] Perhaps the pattern of blood flow and image of one's brain while engaged in a particular task will be as unique an identifier as a fingerprint or genome. The concerns that have been expressed about using genetic information as a means of identification of one individual would apply to brain imaging information as well. Just as a piece of hair can be obtained easily and used to conclusively identify an individual, so could a momentarily scanned brain be used to identify the subject and reveal detailed, personal information about him or her.

This discussion emphasizes the parallel concerns between the privacy of genetic and brain information, in particular, the predictive quality of both types of data.[110] Given that brain images are expected to be able to predict disease in a manner somewhat similar to genetic information and that there is a similar risk that brain images indicating a propensity for disease do not necessarily mean that the disease is present,[111] concerns arise about ensuring that such information remains private and is not used as a basis to deny health care or employment. In addition, if brain images could provide a source of an individual's identity and characteristics with the same ease and objectivity that genetic information does, then all the concerns about these features of genetic information would apply to neuroimaging as well. Given these similarities, legal protections developed to protect genetic privacy would be helpful toward protecting neuroprivacy.

However, there are significant differences in the privacy concerns that arise with respect to brain and genetic information. Although both types of information are predictive in nature, they differ in what they are considered predictive of. Genetic information is largely discussed in the literature as predictive of future disease;[112] brain information is potentially predictive not only of disease but also of behavior.[113] The idea that people's behavior in a range of areas could be predicted has privacy implications that are even greater than those that arise with genetic information.

Another unique aspect of brain imaging is that it may eventually permit seeing what people actually are thinking in real time. As technologies advance, these implications will receive more attention. As genetic privacy protections do not cover such concerns, they would be less useful models for protecting neuroprivacy and other protections will need to be developed.

Another set of concerns arises from the difference in the nature of genetic and brain information. The predictive aspect of brain and genetic information is made more complex by the fact that both genetic and mental processes are "multifactorial,"[114] but mental processes are arguably more so. Just as different genetic and environmental factors may coincide to give rise to the expression of genetic disease for which one has a predisposition, various factors, including learning and other external and internal stimuli, will influence how a brain functions. In addition, the factors present in the participant's providing information and in the recipient's interpretation of the information are very different in genetic and brain information: obtaining brain information and images currently requires the individual's conscious participation during the test, whereas in a genetic test, the subject's participation is relatively minimal.[115] In terms of interpretation, genetic information—especially with respect to the correlates between genome and disease—is more objective and, in large part, devoid of emotion and subjectivity. A sequence of DNA and amino acids is observed. However, the interpretation of brain images and behaviors is a much more subjective process, leaving more room for interpretation, bias, variation and error, as is discussed earlier. Thus, with brain imaging, the subjective factors are compounded, making interpretation and reliability of the information far more complicated.

Based on the discussion above, it appears that it would be worth considering genetic privacy protections as models for addressing privacy concerns raised by the ability of brain information to predict disease and its ability to identify an individual. However, the usefulness of genetic privacy protections will be limited due to the fact that brain information—with its potential ability to provide meaningful insight into complicated mental process such as predictions of behavior and views of real-time thoughts and mental functioning—raises privacy concerns and interpretive issues not present to the same degree with genetic information.

VI. CONCLUSION

With the potential to use neuroimaging techniques to predict behavior, display conscious or unconscious attitudes, or as a unique identifier or other purposes, there are many legal implications. Legal protection of neuroprivacy will be required as there is little existing law that seems capable of providing such safeguards. Existing law could be expanded to protect neuroprivacy, and genetic privacy legislation may serve as a useful model for shielding against some of the concerns that arise from neuroimaging. However, there are a range of factors that require careful consideration, since results are not yet standardized or uniform.

Moreover, future behavior based on brain function seems less predictable than future disease based on gene function (or even future disease based on brain function). While predicting future behavior is necessary in certain contexts—sexual abuse, parental rights—using it beyond a narrowly defined set of situations seems to cut against the exercise of free will, or even rehabilitation. In those instances where prediction of a person's future behavior is necessary to protect society from dangerous conduct, such as in civil and criminal commitment case involving mentally ill persons and sexual predators, and criminal investigations and counter terrorism, the legislature should weigh whether the state's exercise of its police power outweighs the individual's privacy interests. New laws may be necessary in these instances in order to protect society and the interests of children, as to the appropriateness of brain imaging in such contexts, the scope of its use, and the confidentiality of such data.

With regard to using brain imaging in the contexts of employment hiring decisions and the issuance of insurance, it is submitted that the individual's privacy interests outweigh the financial interests of the employer or insurance company. A person in these contexts should not be restricted in employment or in getting insurance on the basis of what he or she may be thinking now or at some future point, but should be given the opportunity to be judged by his or her actions.

Moreover, in the research field, new laws should be passed providing for the confidentiality of individually identifying information when brain imaging is used. While reviewing genetic privacy concerns is instructive and

there are many parallels to neuroprivacy concerns, it should be kept in mind that at the moment, genetic privacy concerns rarely involve liberty interests. When thinking about neuroprivacy, one should keep in mind the range of situations where brain scans could be at issue and the pace at which technology and research may advance in this field.

June 2005

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Footnotes

1. The term was used by the organizers of “Neuroethics: Mapping the Field,” a conference for neuroscientists, bioethicists, doctors of psychiatry and psychology, philosophers, and professors of law and public policy in San Francisco, CA, sponsored by the Dana Foundation on May 13-15, 2002 [hereinafter “Neuroethics”].

2. In the Philadelphia Inquirer, John Timpane wrote, “What if a brain-scan screener at the airport goes off, and I’m not allowed on the plane because I might be a troublemaker or a terrorist? ..previously private aspects of my personality have been rendered public. Which leads to a chilling question: What if my thoughts cease to be my property?” John Timpane, Philadelphia Inquirer, January 25, 2004 at. C1); See also Carey Goldberg, Some Fear Loss of Privacy as Science Pries into Brain, BOSTON GLOBE, May 1, 2003, at A1.

3. Proceedings, Caplan, Neuoroethics, p. 7.

4. *See* J. O’C. Hamilton, “If They Could Read Your Mind”, Stanford Magazine (January/February 2004) available at <http://www.stanfordalumni.org/news/magazine/2004/janfeb/features/neuroethics.html> [hereinafter *“Stanford”*]*; see also* R. Bailey, “The Battle For Your Brain” (February 2003) available at <http://www.reason.com/0302/fe.rb.the.shtml>; *see also* S.A.Falkenheimer, “Brain Monitoring: An Ethical Assessment”, Commentary: Center for Bioethics and Human Dignity (June 20, 2003), available at <http://www.cbhd.org/resources/ biotech/falkenheimer_2003-06-20_print.htm> [hereinafter “*Brain Monitoring”*].

5. Stedman’s Medical Dictionary, 24th Ed., p. 949 (1982).

6. “Non-invasive exertion of influence on the brain” usually refers to designing and applying drugs that affect brain performance. While the main focus used to be on improving mood, cognition or behavior, it appears to have shifted from the healing of brain disorders or malfunctions toward enhancing normal brain functioning. Enhancement of mood, cognition and vegetative functions is being studied. Pharmacological manipulations can alter cognitive abilities, including attention and memory. Attention, for example, is primarily modulated by dopamine and norepinephrine. Ritalin and Adderol affect both systems. In normal individuals, these drugs induce reliable changes in vigilance, response time and higher cognitive functions. Similarly, impulsive violence has been linked to certain abnormalities in the levels of the neurotransmitter seratonin and Fluoxetine was found to be helpful to reduce aggression in patients with personality disorders. For any person deemed a threat to self or others, including criminal offenders, judges routinely order compliance with medication. Court-ordered therapy is not limited to people who have a medically diagnosed illnesses, so as new drugs are developed, they will likely be prescribed for offenders.

7. The possibility of directly designing and constructing the brain through sophisticated technology is increasing. Although the outsourcing of certain brain functions to big computer networks or the use of the brain to intuitively control machines seems still to be far in the future, advances are already impressive. Researchers in California have presented the idea of building and implementing a brain prosthesis—an artificial hippocampus. Unlike devices such as cochlear implants, which merely stimulate brain activity, a silicon chip implant would perform the same processes as the damaged part of the brain it is replacing. This might be a way to help people who have suffered brain damage due to stroke, epilepsy or Alzheimer’s disease. Here too, the initial focus would probably be on healing brain disorders but might soon expand to computer augmented brain “enhancements.”

8. Robert Mathias, The Basics of Brain Imaging, NIDA Notes, Volume 11, Number 5, November/December 1996.

9. RSNA, Diagnostic Radiology, at: http://www.radiologyinfo.org/content/functional_mr.htm.

10. Martha J. Farah and Paul Root Wolpe. Monitoring and manipulating brain function: new neuroscience technologies and their ethical implications. The Hastings Center Report 34 (3): 35-47 (May 2004).

11. Id., p. 36.

12. Proceedings, Damasio, Neuoroethics, p. 122.

13. Farah, M.J. Emerging ethical issues in neuroscience. Nat. Neurosci.5, 1123-1129 (2002), at 1126.

14. Hart, A., Whalen P., McInerney S., Fischer H., Rauch S. Differential response in the human amygdala to racial outgroup vs ingroup face stimuli. Neuroreport 11, 2351-2355 (2000).

15. Phelps, EA., O’Connor KJ, Cunningham WA, Funayama ES, Gatenby JC, Gore JC, Banaji MR. Performances on indirect measures of race evaluation predicts amygdala activation. J. Cogn. Neurosci. 12, 729-38 (2000). Etkin A, Klemenhagen KC, Dudman JT, Rogan MT, Hen R, Kandel ER, Hirsch J. Individual differences in trait anxiety predict the response of the basolateral amygdala to unconsciously processed fearful faces. Neuron 44(6): 1043-55 (16 Dec 2004).”

16. Nunez JM, Casey BJ, Egner T, Hare T, Hirsh J. Intentional false responding share neural substrates with response conflict and cognitive control. *Neuroimage* 25(1):267-77 (Mar 2005).

17. C. Thompson, “There’s a Sucker Born in Every Medial Prefrontal Cortex”, NY Times, 10/26/03, Sec. 6, Col.1, Magazine Desk, p.54.

18. Id.

19. Id.

20. Id.

21. Id.

22. http://www.brainwavescience.com/ExecutiveSummary.php.

23. Harrington v. Iowa, 659 N.W.2d 509, (Iowa 2003), 2003 Iowa Sup. LEXIS 35 as cited in A. Moenssens, Brain Fingerprinting–Can it be Used to Detect the Innocence of Persons Charged With a Crime, 70 UMKC L. Rev. 891 (2002); Clive Thompson, The Year in Ideas: A to Z: The Lie Detector That Scans Your Brain, N.Y. TIMES, Dec. 9, 2001, §6, at 82; Jeffrey Kluger et al., How Science Solves Crimes From Ballistics to DNA, Forensic Scientists are Revolutionizing: Police Work–on TV and in Reality. And Just in Time, TIME MAGAZINE, Oct. 21, 2002, at 36.

24. http://brainwavescience.com/Ruled%20Admissable.php.

25. 659 NW2d 509, 2003 Iowa Sup. LEXIS 35 (S. Ct. of Iowa 2003).

26. Harrington v. Iowa., 659 N.W.2d 509, 516, footnote 6 (Iowa S. Ct. 2003).

27. Harrington v. Iowa., 659 N.W.2d 509, 516, footnote 6 (Iowa S. Ct. 2003).

28. 2005 Ok Cr 2, 105 P. 3d 832, 2005 Okla. Crim. App. LEXIS 1 (Ct. of Crim. App. Of Oklahoma 2005); K. Strutin, “Criminal Law: Lie Detection Tools; Advances in Technology May Help Defense Attorneys.” NEW YORK LAW JOURNAL, May 10, 2005, at p. 5.

29. 105 P. 3d 836.

30. 105 P. 3d 835.

31. Lambadarious v Kobren, 191 Misc2d 86, 89 (Sup. Ct. Nassau Co. 2002), citing with approval Frye v United States, 293 F 1013 (DC Cir 1923); People v Wernick, 89 NY2d 111 (1996).

32. Id.

33. http://www.brainwavescience.com/counterterrorism.php.

34. B. Evenson, The Guilty Mind: What if a Brain Scan Could Catch a Murderer? “Brain Fingerprinting” Measures Neural Response to Images from a Crime Scene. Ethicists Fear it as a Tool of Social Control, NATIONAL POST (Canada), Feb. 8, 2003, at A1.

35. Laura Mansnerus, Sex-Offender Release Policy Faces Change in New Jersey, N.Y. TIMES, Jan. 26, 2004, §B, at 5.

36. 2003 NY A.B. 3419; 2003 NY A.B. 6754; 2003 NY A.B. 7125; 2003 NY S.B. 5556.

37. Hendricks v. Kansas, 521 U.S. 346 (1999).

38. Laura Mansnerus, Sex-Offender Release Policy Faces Change in New Jersey, N.Y. TIMES, Jan. 26, 2004, §B, at 5; see also Laura Mansnerus, Unfinished Sentences: Keeping Prisoners as Patients: Questions Rise Over Imprisoning Sex Offenders Past Their Terms, N.Y. TIMES, Nov. 11, 2003, §A, at 1.

39. Carey Goldberg, Sex Offenders in Some States Serve More Than Their Time, N.Y. TIMES, Apr. 22, 2001, §1, at 1.

40. Laura Mansnerus, Sex-Offender Release Policy Faces Change in New Jersey, N.Y. TIMES, Jan. 26, 2004, §B, at 5; see also Laura Mansnerus, Unfinished Sentences: Keeping Prisoners as Patients: Questions Rise Over Imprisoning Sex Offenders Past Their Terms, N.Y. TIMES, Nov. 11, 2003, §A, at 1.

41. McKune v Lile, 536 U.S. 24 (2002).

42. Rivers v Katz, 67 NY2d 485 (1986); Mtr. of K.L., 2004 NY Lexis 182 (NY Ct. of Appeals, 2/17/04); 14 NYCRR 527.8; 14 NYCRR 541.13.

43. See Mental Hygiene Law Article 9; Criminal Procedure Law Sec. 330. 20; Criminal Procedure Law Article 730.

44. Matter of Francis S., 87 N.Y.2d 554, 556 (NY Ct. of App. 1995); Matter of Seltzer v Hogue, 187 A.D.2d 230, 230 (N.Y. App.. Div. 2d Dept 1993); In the Matter of Dwight J, 234 A.D.2d 116, 117 (N.Y. App. Div. 1st Department 1996) (In a civil commitment proceeding, the Appellate Division reversed a lower court's order directing the release of a psychiatric patient from the hospital because of his non-compliance with medical treatment. The appellate court stated that the "Supreme Court's finding that petitioner failed to demonstrate that respondent poses a substantial threat is not supported by the record, which reflects that respondent is schizophrenic, receives his medication by injection due to non-compliance, and is unlikely to take his medication after release.").

45. See Mtr. of Tyler S., 192 Misc.2d 728, 728 (N.Y. Fam. Ct. 2002).

46. This may have a negative effect on the willingness of potential research subjects as well. Proceedings, Caplan, Neuoroethics, p. 122.

47. 58 NY Jur 2d, Evidence & Witnesses § 444. See also People v Shedrick, 104 A.D.2d 263, 275 (4th Dept. 1984).

48. People v Daniels, 102 Misc.2d 540, 553 (N.Y. Sup. Ct. Westchester Co. 1979); see 31 NY Jur 2d Criminal Law § 707.

49. Id.

50. See People v Shedrick, 104 AD2d at 275; 58 NY Jur 2d § § 444, 445.

51. 29 U.S.C.S. 2002 (2003); Lexstat 2-12 Employment Screening § 12.03(1)(a) (Matthew Bender Co. 2003).

52. 29 U.S.C.S. 2006(a).

53. See Lexstat 2-12 Employment Screening Sec. 12.03(2).

54. Id. at Sec. 12.03(3).

55. 29 U.S.C. 2001(3).

56. 194 F.3d 850, 859 (7th Cir. 1999).

57. Id. at 859.

58. Id. See H.R. Conf. Rep. No. 100-659, at 11 (1988), reprinted in 1988 U.S.C.C.A.N. 749, 750 ("The conferees . . . intend that the prohibition on a lie detector test be construed broadly to include any use of a lie detector."

59. 29 USCS 2008 (a),(b); see Orr v Bank of America, 285 F.3d 764, 783 (9th Cir. 2002) (discharged employee's lawsuit under this provision was dismissed on the ground that the evidence submitted constituted inadmissible hearsay and was not authenticated).

60. 29 USCS 2008 (b); 29 C.F.R. § 801.35.

61. 29 USCS 2008 (c).

62. 45 C.F.R. § 46.101.

63. Id.

64. 45 C.F.R. § 46.111(a)(7).

65. 45 C.F.R. 46.116(a)(5); see also 14 NYCRR 372.12 (e)(2); 14 NYCRR 633.13 (a)(2)(i)(a).

66. See In re Jobe Concrete Prods., 101 S.W.3d 122, 128 (Tex. Ct. App. 2002); see also L. Gostin, Health Information Privacy, 80 Cornell L. Rev. 451, 504-505 (1995).

67. 45 CFR § 46.111(7)

68. Public Health Law 2444(2); see also 10 NYCRR 405.7 (a)(18) (right of hospital patients to refuse to participate in research); TD v. NY State Office of Mental Health, 650 N.Y.S.2d 173, 193-94 (N.Y. App. Div. 1st Dept. 1996) (regulations of state mental health agency were struck down which permitted greater than minimal risk non-therapeutic research on minor human subjects upon consent of legal guardian or in absence of such, an

adult family member, or waiver of a guardian's consent in certain instances, or overriding of a guardian's objection to such research by a psychiatrist, as violative of due process and in excess of statutory authority).

69. Id.

70. 45 C.F.R. § 160.103.

71. 45 C.F.R. §§ 160.102., 160.103.

72. 45 C.F.R. §160.103.

73. 45 C.F.R. §164.502(a).

74. 45 C.F.R. §164.512(i) (Covered entity may release information for research purposes without a release where this has been approved by an Institutional Review Board or privacy board; the researcher represents that s/he needs the information to prepare a research protocol, will not remove it from the facility and that it is necessary for the research; or the researcher represents that the information is solely for research on the health care information of decedents, is necessary for the research and at the request of the covered entity, documentation is provided on the death of the decedents about whom information is sought.).

75. 45 C.F.R §164.504.

76. N.Y. Pub. Health § 18((1)(e).

77. N.Y. Pub. Health § 18(1)(b), (c) and (d).

78. N.Y. Pub. Health § 18(1)(g), (2)(a), (2)(b), (2)(c) and (2)(d).

79. New York State Assembly A07197.

80. In fact the HBP was announced in 1993 only three years after the Human Genome Project ("HGP") was well underway in 1990 (though the HGP was officially announced two years earlier in 1988 by the National Research Council). See www.nimh.nih.gov/neuroinformatics/index.cfm. See also Final Report of the OECD Megascience Forum, Working Group on Biological Informatics, January 1999, available at <http://www.oecd.org/dataoecd /24/32/2105199.pdf> for a discussion of neuroinformatics. The HBP, like the HGP, is an international research project. It seeks, in part, to bring together information about the brain in a way that can be used by the research community and is related to the field of "neuroinformatics." See also W. Sententia, "Brain Fingerprinting: Databodies to Databrains," The Journal of Cognitive Liberties, vol. 2 issue 3, 31-46, available online at <http://www.cognitiveliberty.org/6jcl/6JCL31.htm.> [hereinafter "Databodies"] for additional discussion of the HBP.

81. Limited work has been done on these issues, and it has been done through private entities. The Dana Foundation and the American Association for the Advancement of Science (AAAS) cosponsored a 2003 conference for neuroscientists and law professionals to discuss emerging issues in neuroscience. The proceedings were recently published by the Dana Foundation in a compilation called *Neuroscience and the Law: Brain, Mind, and the Scales of Justice*, edited by Brent Garland. The articles do not discuss neuroprivacy at length.

82. As quoted in Stanford, supra note 4.

83. See Faye Flam, Your Brain May Soon Be Used Against You, Philadelphia Inquirer, Oct. 29, 2002, available at http://www.philly.com/mld/inquirer/4391614.htm; see also Databodies, supra note 80.

84. Stanford, supra note 4.

85. See The Future of Mind Control, Economist, May 25, 2002, at 11; see also Stanford, supra note 4; see also Ronald Bailey, The Battle For Your Brain, Reason, Feb. 2003, at 24, available at http://www.reason.com/0302/fe.rb.the.shtml; see "Brain Monitoring" *supra* Note 4.

86. Others have already addressed this level of similarity between neuroscience and genetic concerns. See, e.g., Henry Greely, Neuroethics and ELSI: Some Comparisons and Considerations, in Neuroethics, supra note 1, at 84 (listing the concerns arising over genetics and their similarity to neuroscience concerns) [hereinafter "Neuroethics Comparisons"].

87. When tests were developed in the 1970s that allowed for screening of the presence of sickle cell anemia, which tends to affect African-Americans, both employers and certain states required testing for the gene. The fact that the testing was sometimes done without the employee's knowledge, combined with the lack of adequate

measures to ensure privacy of the results, resulted in discrimination against carriers. Eventually the National Sickle Cell Anemia Control Act was passed in 1972.

88. Employees of the Burlington Northern Santa Fe Railroad were tested without their knowledge for the presence of a genetic mutation causing carpal tunnel syndrome and were deprived of health benefits on the basis of such genetic information. Burlington ultimately settled a lawsuit based on the Americans with Disabilities Act with the Equal Employment Opportunity Commission in 2001. For additional discussion of this case and the sickle cell anemia experience, see S. Rep. No. 108-122, at 7 (2003).

89. See Brain Monitoring, supra note 4.

90. It is beyond the scope of this section to discuss the definition of "privacy," which is a complicated area in itself. See Graeme T. Laurie, Genetic Privacy: A Challenge to Medico-Legal Norms (2002) [hereinafter "Genetic Challenge"] and Symposium, The Human Genome Project, DNA Science and the Law: the American Legal System's Response to Breakthroughs in Genetic Science, 51 Am. U. L. Rev. 451, for a discussion of these definitional issues. In New York, state law prohibits genetic tests on biological samples taken from an individual without that person's informed consent. N.Y. Civil Rights Law Sec. 79-I. In addition, New York law prohibits an insurance company from requesting or requiring a person seeking insurance to be the subject of a genetic test without that person's informed consent. Insurance Law Sec. 2612.

91. See, for example, section 105(c), "Prohibition on Collection of Genetic Information," of the proposed Genetic Information Nondiscrimination Act of 2003, which seeks to address this type of privacy concern. S. 1053, 108th Cong. § 105(c) (2003). Collection of genetic information is also protected under Exec. Order No. 13145, 65 C.F.R. § 6877 (2000). *See* N.Y. Civil Rights Law Sec 79-I, which in general treats genetic tests on biological samples taken from an individual to be confidential, and prohibits their disclosure without the person's informed consent.

92. This concern has been expressed in legislation such as the Health Insurance Portability and Accountability Act, 45 C.F.R. § 164.504(f)(1) (2004), which limits disclosure to employers, and in Exec. Order No. 13145, 65 C.F.R. § 6877 (2000). The question of disclosure to relatives is of particular concern. See Ellen Wright Clayton, What Should the Law Say About Disclosure of Genetic Information to Relatives?, 1 J. Health Care L. & Pol'y 373 (1998). Moreover, employers, employment agencies, licensing agencies and labor organizations are prohibited from requiring or obtaining genetic information as an incident to employment decisions, except where it is directly related to the occupational environment, where the particular generic anomaly might cause the employee to be at increased risk of disease in that environment. Exec Law 292.

93. See, for example, Title I and Title II of the proposed Genetic Information Nondiscrimination Act of 2003. S. 1053, 108th Cong. (2003).

94. See discussion in Genetic Challenge, supra note 90, where these concerns are also addressed using the concepts of "spatial" and "informational" privacy and where the right not to know is particularly emphasized.

95. See, e.g., Joanne L. Hustead & Janlori Goldman, The Genetics Revolution: Conflicts, Challenges and Conundra: Article: Genetics and Privacy, 28 Am. J.L. & Med. 285 (2002); Alexandra K. Glazier, Genetic Predispositions, Prophylactic Treatments and Private Health Insurance: Nothing Is Better Than a Good Pair of Genes, 23 Am. J.L. & Med. 45 (1997); Robyn B. Nicoll, Comment, Long-Term Care Insurance and Genetic Discrimination—Get It While You're Young and Ignorant: An Examination of Current Discriminatory Problems in Long-Term Care Insurance Through the Use of Genetic Information, 13 Alb. L.J. Sci. & Tech. 751(2003).

96. See Thomas F. Wieder, The Horse and Buggy Laws Meet Hyper-Speed Genetic Technology Symposium: Privacy Protection is Needed for DNA, 2002 L. Rev. M.S.U.-D.C.L. 927 (2002) [hereinafter "Horse and Buggy"]. See also Symposium, The Human Genome Project, DNA Science and the Law: the American Legal System's Response to Breakthroughs in Genetic Science, 51 Am. U. L. Rev. 451, 464.

97. In the United States "the DNA profiles of convicted felons . . . are routinely maintained in computer databases of the federal government and in all of the states." Jeffrey S. Grand, Note, The Blooding of America: Privacy and the DNA Dragnet, 23 Cardozo L. Rev. 2277, 2286 (August 2002). See also DNA Identification Act, 42 U.S.C. § 14132-14135; N.Y. Exec. Law § 995 (McKinney 2004). Also, the U.K. has a national forensic database of DNA samples taken from criminals, and there is significant cooperation and sharing of such forensic information within the E.U. In Iceland, a private company (aptly named "DeCode Genetics") maintains a national database of health records, including biological samples, for public health purposes, and other countries with uniquely genetically homogenous populations (such as Estonia) may follow suit. See Genetic Challenge, supra note 90, at 91, 172, 287. See also Horse and Buggy, supra note 96.

98. See S. Rep. No. 108-122, at 8 (2003) (stating that HIPAA "affords some protection against discriminatory practices in health insurance based on an individual's genetic information" and, later, that the medical privacy regulations promulgated under HIPAA "provide extensive regulatory direction on the permitted and impermissible uses of protected health information, including genetic information.").

99. See S. Rep. No. 108-122, at 16 (2003), under Section 105, Privacy and Confidentiality, referring to testimony by the Assistant Secretary of Planning and Evaluation urging the HELP Committee not to "craft" legislation that creates a "different set" of privacy regulations for genetic information from those that cover health information. The committee stated that it believes that "treating all health information" in a consistent and similar way will encourage insurance coverage of genetic tests and facilitate protection of the use and disclosure of genetic information and that "it is inherently difficult to separate genetic information from other medical information in the delivery of health care and medical research. . . ."

100. See Marisa Anne Pagnattaro, Genetic Discrimination and the Workplace: Employee's Right to Privacy v. Employer's Need to Know, 39 Am. Bus. L.J. 138, 176 (2001) (quoting Senator Louise Slaughter). See also Nathalie Smith, Note, The Right to Genetic Privacy? Are We Unlocking the Secrets of the Human Genome Only to Risk Insurance and Employment Discrimination?, 2000 Utah L. Rev. 705, 706 (2000).

101. See S. Rep. No. 108-122, at 18 (2003), under Section 202-205, Prohibited Practices.

102. See Genetic Challenge , supra note 90, at 104, for a discussion of the qualities of genetic information.

103. Genetic Challenge , supra note 90, at 87, 88.

104. See Barbara Koenig's presentation in Brain Science and Social Policy in Neuroethics, supra note 1, where she specifically discusses this predictive aspect.

105. For example, it is expected that it will be possible to predict when cognitive decline will begin for certain individuals. Neuroethics, supra note 1, at 61. See also Neuroethics Comparisons, supra note 86, at 84-86 (discussing the predictive aspect of the field of neuroscience); Rusinek H, De Santi S, Frid D, Tsui WH, Tarshish CY, Convit A, de Leon MJ. Regional brain atrophy rate predicts future cognitive decline: 6-year longitudinal MR imaging study of normal aging. Radiology 229(3):691-6 (Dec 2003).

106. See Databodies, supra note 80; see also Working Group on Biological Informatics, Org. for Econ. Co-operation and Dev., Final Report of the OECD Megascience Forum (Jan. 1999), at 47, available at http://www.oecd.org/dataoecd/24/32/2105199.pdf; see also Databasing the Brain, 406 Nature 822 (Aug. 24, 2000).

107. However, in the context of brain activity, patterns of activity showing in brain scans could most likely be modified by learning and response to environmental stimuli. For a discussion of the private nature of genetic information see George J. Annas, Privacy and Discrimination in the Age of Genetic Engineering: Genetic Privacy: There Ought to Be a Law, 4 Tex. Rev. L. & Pol. 7 (1999).

108. See Neuroethics, supra note 1, at 7. See also Deborah L. McLochlin, Comment, Whose Genetic Information Is It Anyway? A Legal Analysis of the Effects that Mapping the Human Genome Will Have on Privacy Rights and Genetic Discrimination, 19 J. Marshall J. Computer & Info. L. 609, 615 (2001) (discussing the very personal and private nature of genetic information).

109. William J. Winslade, Traumatic Brain Injury and Legal Responsibility, in Neuroethics, supra note 1, at 79.

110. See Neuroethics Comparisons, supra note 86, at 85, for a discussion of the predictive aspect of the field of neuroscience. "The same problems [as arise from genetic predictions] can arise from predictions obtained in neuroscience." Id. at 86.

111. In the same way that the presence of a certain gene does not necessarily result in the expression of a disorder, a certain pattern in a brain image does not necessarily mean that there is functional problem. For example, PET scans of individuals with Huntington's disease have been found to be indistinguishable from PET scans of people who were normal but at risk for the disease. See Neuroethics, supra note 1, at 116.

112. Although the search is on for genes predictive of violence, alcoholism, or homosexuality, there is general awareness that many factors intervene between having a gene for a trait and expressing that trait.

113. For example, see the scenario described in Stanford, supra note 4.

114. See Brain Monitoring, supra note 4.