PART II

The Ethics of Neuroscience

Four real-world contexts in which neuroethical issues arise and impact society are the focus in this section of the book: medical and clinical neuroethics, enhancement, legal and national security domains, and commercial enterprises and applications of neurotechnologies. The ethical concerns are complex when brain health and interventions on the brain are considered. Brain disorders impact not only our bodily health but also who we essentially think we are and, in some cases, who we might become.

Medical and Clinical Neuroethics

Clinical discussions in this section consider the ethical implications of rapidly evolving diagnostic technologies, as well as concerns about pathologizing difference and the value of neurodiversity. This section also discusses the blurring lines of diagnosis and treatment. Goering's chapter “Thinking Differently: Neurodiversity and Neural Engineering” endorses a mode of doing neural engineering in a way that takes neurodiversity seriously and is responsive to the perspectives of end users of neurotechnologies. In “The Ethics of Expanding Applications of Deep Brain Stimulation,” Christen and Müller consider unique ethical considerations in expanding clinical use of deep brain stimulation in patients with neurological disorders. “The Ethics of Prodromal and Preclinical Disease Stages” by Arias, Sarrett, Gonzalez, and Walker examines the potential and implications for early detection of disorders such as autism spectrum disorder, schizophrenia, and Alzheimer’s disease. In their chapter on disorders of consciousness, Friedrich and Jox explore novel technologies for diagnosing awareness in humans who appear otherwise nonresponsive. The final chapter in this section, “Placebo and Psychogenic Disorders” by Grubbs and Rommelfanger, explores how neuroscience information on both treatments and disorders of “mind” challenge our conceptualization of psychiatric phenomena such as placebo effects and so-called psychogenic disorders.

Enhancement

Human enhancement through genetic and pharmacological interventions has been a rich topic of debate in bioethics. Neuroethics has taken up the debate, with specific emphasis on brain interventions that might enhance cognition, memory, attention, and even human capacities.
The Ethics of Neuroscience

for moral reasoning. In his chapter “Cosmetic Neurology and the Ethics of Enhancement,” Chatterjee considers how advances in neuroscience and pharmacotherapeutics are opening up possibilities for manipulating cognitive and emotional systems in healthy people and the ethical concerns that arise with such practices. Mann and Sahakian consider technologies used in competitive education and professional/workplace environments and discuss the use of “smart drugs” in “Modafinil and the Increasing Lifestyle Use of Smart Drugs by Healthy People: Neuroethical and Societal Issues.” Tennison and Moreno consider possible dual-use applications of neurotechnology, including brain-interfacing technologies and cognitive enhancement for improving soldier performance. These uses raise fresh concerns about consent and coercion, while the therapeutic use of neurotechnologies like “forgetting pills” and deep brain stimulation to treat combat-related conditions like PTSD add urgency and currency to the long-standing debate about the distinction between treatment and enhancement. The potential weaponization of neurotechnologies for use in psychological warfare, torture, and interrogation are also discussed. This section concludes with “Moral Neuroenhancement” by Earp, Douglas, and Savulescu, an exploration of the promise and possible pitfalls of using neurotechnologies to facilitate moral enhancement.

Legal and National Security Domains

Legal discussions in this section will highlight the use of neurotechnologies for detecting mens rea (“guilty mind”) and criminal culpability, lies and guilty knowledge, and considerations about cognitive privacy and liberty. Brain-imaging data are finding their way into the courtroom as evidence and as potential testimony, and while many commentators take the view that neurotechnological “lie detection” and “mind reading,” while theoretically and philosophically compelling, are not ready for prime time, that skepticism does not reflect the enthusiasm for the use of technology in legal and judicial contexts. Some legal scholars and practitioners argue that, while these sources of information may not be perfected in the clinical or research domain, they are welcome improvements to current legal approaches, and they may be “good enough” for the legal context. Hardcastle’s chapter “My Brain Made Me Do It? Neuroscience and Criminal Responsibility” explores how the disconnect between theory and practice creates significant potential for abuse and misuse. On the other hand, a greater understanding of the neurological underpinnings of some criminal behavior might reshape the criminal justice system’s approach to responsibility, punishment, and rehabilitation. In “Your Brain on Lies: Deception Detection in Court,” Seaman surveys the current state of the science of lie detection and considers the evidentiary, constitutional, and ethical issues raised by its potential future use in legal contexts. Wolpe explores the concept of cognitive liberty, considering the possibilities for neurotechnologies to facilitate cognitive/affective coercion, and the privacy implications of brain monitoring. This section concludes with Johnson’s chapter “Chronic Traumatic Encephalopathy: Ethical, Legal, and Social Implications,” on the underexplored ramifications of prospective diagnosis of neurodegenerative brain disease in athletes.

Commercial

Commercial applications of neurotechnologies for cognitive enhancement have proliferated in recent years, even as evidence backing up claims about enhancement remains sparse. Public enthusiasm for neuroscience has been sparked, in part, by an ever-growing tendency toward neurohype and the proliferation of “neuro” neologisms and neurotechnology–oriented consumer products. Neuroscience is even being utilized for neuromarketing as a tool to identify
consumer preferences and decision-making practices. “Neurohype: A Field Guide to Exaggerated Brain-Based Claims,” by Lilienfeld, Aslinger, Marshall, and Satel is a useful resource for inoculation against “neurohype,” with a helpful checklist for the critical consumer of neuroscience. In “Neuroscience Online: Real Ethical Issues in Virtual Realms,” Purcell and Rommelfanger address the significant privacy and safety concerns and the lack of regulatory oversight for neuroscience in this growing commercial domain. In the absence of formal guidelines to protect the privacy of such data or to monitor the informed consent process in this kind of research, users risk their cognitive privacy and liberties, which, if violated, could ultimately lead to public distrust that undermines scientific progress. Wexler and Reiner shed light on the do-it-yourself (DIY) biohacker movement and transhumanism market in “Home Use of tDCS: From ‘Do-It-Yourself’ to ‘Direct-to-Consumer.’”
How we think is a fundamental part of who we are. We identify not just with our bodies or our roles and relationships but with how we think about our bodies, roles, and relationships. This sense of identity runs deeper than just what we think—the content of our thought—and into how we think—the way in which our minds work. In some cases (e.g., treatment for depression or obsessive-compulsive disorder), we assume that how we think is at least somewhat malleable—we enter into therapy, take medication, or adopt some combination of these measures under the presumption that we can alter our cognitive processing in desired and meaningful ways without really changing our identities. In other cases, our modes of thinking seem more entrenched. We may seek to alter them, but they persist. Or perhaps we simply identify with a mode of thinking that is not standard; we claim it as our own way of being. Others may recommend treatment, but we reject it. We think differently from the norm, and we’re okay with that.

In this chapter, I want to look at two different kinds of “thinking differently”—the neurodiversity movement and neural engineering, a field that seeks to create devices designed to engineer certain aspects of our thinking, in order to help us with neurological processing. The former typically seeks to preserve and value diverse functioning; the latter typically seeks to restore “normal” functioning. Here I argue that the two need not be at cross-purposes but could productively be brought into conversation. Their intersection recommends a mode of doing neural engineering that takes neurodiversity seriously and recognizes the wide range of acceptable neurological functioning. More importantly, it identifies a good way to ensure that recognition—by including the perspectives of potential “end users” of neural technology in the development and design process of neurally engineered devices.

The chapter will consist of three sections: (1) an overview of the neurodiversity movement and its claims regarding medical research and advocacy campaigns designed to treat and/or prevent the conditions (and modes of thinking) in question; (2) a look at how neural engineers are developing technologies that may affect how we think or perform neurological processing and that are designed to aid people with neurological disorders in order to improve their quality of life; and (3) an exploration of what neural engineers might productively learn from the neurodiversity movement.
Neurodiversity

Though many people have struggled throughout recent history for civil rights and respect for people whose modes of thinking are not standard, the label “neurodiversity movement” came into use only in the late 1990s (Silberman, 2015). And, although the label is most frequently associated with advocates for autism, other groups have found solidarity with the movement’s general aims. Thomas Armstrong, for instance, includes people who experience dyslexia, attention deficit hyperactivity disorder (ADHD), autism, bipolar disorder, and other psychiatric conditions (Armstrong, 2010), and other scholars and activists understand the neurodiversity movement to include people with epilepsy, Tourette syndrome, obsessive compulsive disorder, and even intellectual disabilities. As such, the neurodiversity movement represents a wide coalition of people whose neurological functioning is atypical. Often this group defines the contrast class as “neurotypical” (NT), or those who fall in the ranges of typical or normal neural and/or cognitive processing.

Broadly speaking, the neurodiversity movement “challenges widely held but inaccurate views of what constitutes functional human cognition—inaccurate views that pathologize some phenotypes that are properly regarded as non-maladaptive cognitive variations” for humans (Fenton and Krahn, 2007, 1). To better understand the neurodiversity movement, we must consider what the different modes of thinking or cognitive processing are and why they might be valuable, as well as how efforts to “fix” cognitive processing may be interpreted as devaluing individuals with the condition in question.

For more on the neurodiversity movement, see Chapter 26.

What Do We Mean By Neurodiverse Modes of Thinking, and Why Might They Be Valuable?

Members of the neurodiversity movement argue that they have a different way of being and thinking but not necessarily an inferior way of being and thinking (Saverese and Saverese, 2010). They argue that humans naturally have a wide variety of capacities and modes of processing—whether due to genetic, anatomical, hormonal, electrochemical, or developmental differences—and the “normal” mode of cognitive functioning should not be taken as the only acceptable form of functioning. Indeed, some disability scholars have suggested that diverse forms of embodiment and thinking may be integral to our species’s survival and flourishing (Garland-Thomson, 2012).

The neurodiversity literature calls attention to how differences in processing are framed, categorized, and valued. For instance, a common hypothesis in the autism literature relates to the capacity to form a “theory of mind”—to understand that another being has a distinct set of beliefs and to attribute beliefs to them relatively accurately. Many young children are what Victoria McGeer calls “co-minded”—they “don’t infer the moods, thoughts, feelings, or intentions of others, [but rather] simply see such subjective or mental phenomena—such ways of being minded—directly in their behavior” (2010, 283). She cites research on how quickly we anthropomorphize—for example, a 1944 experiment by Heider and Simmel involving a little animation of geometric figures that is typically “seen” as a big bully trying to keep a little guy in a box, even though the figures don’t have faces or body shapes that suggest any “minds” within.
It shows how primed typical children are for identifying mental states, given the scaffolding and implicit training provided by their parents. Their minds perceive the mental states of others as immediately as they perceive their own mental states; they are co-minded. Being able to do this provides an easy ground for social interaction and communication. Some experts suggest that autistic children, on the other hand, may have somewhat different processing “modules” for understanding others’ mental states and are not co-minded. They can learn to infer the mental states of others from their behavior and context, but it takes effort and is a learned skill (Frith and Happe, 1999). This framing seems to fit with Temple Grandin’s famous phrasing about feeling a bit like “an anthropologist on Mars,” trying to understand what other people mean by working to interpret their words and behaviors rather than having that meaning come relatively effortlessly.

The difference could be characterized as a deficit in theory of mind, as has been common in clinical discussions of autism, or, alternatively, as a mismatch in “forms of life” (Hacking, 2010; McGeer, 2010). On the deficit reading, the autistic individual lacks this cognitive machinery needed for normal processing; as a mismatch, the problem arises from different ways of processing, with “deficits” running in both directions. Autistic individuals may have difficulty reading neurotypicals (NTs), but likewise, NTs often experience difficulty understanding autistic people. So perhaps different neural “wiring”—and the sequelae of it—lead to different forms of life that appear impenetrable from the outside. The “forms of life” language is not intended to suggest radically different ways of being—such that we are inevitably alien to each other—but only some fundamental differences worth noticing. Hacking and McGeer are interested in how we might develop a shared form of life, how NTs might come to understand and appreciate autistic modes of thinking, and vice versa. Most autistic individuals are already given extensive therapy and strategies to learn to “decode” NT behavior. But relatively little attention is given to learning about autistic life; clinicians and parents tend to focus on deficits rather than capacities. Hacking argues that NTs should be attending closely to the narratives told in autobiographies from autistic individuals (Hacking, 2010). They give important clues about different ways of thinking and experiencing the world, and the narratives themselves—which offer language to describe experiences that are often not primarily verbal—help to shape what it is to experience the world as someone who is autistic. This is not just a point about understanding variety in the world but about recognizing valuable human modes of being in the world.

Is it worse not to be co-minded (or not to be co-minded in the typical way)? Not necessarily. It may make many social encounters difficult, given social expectations and norms, but again, that emphasizes what is lacking rather than what is present. Consider reports from members of the Autistic Self-Advocacy Network (ASAN) about their modes of cognitive processing. They call attention to their abilities rather than fixating on what they cannot do. So, for instance, autistic advocates have pointed to heightened abilities related to pattern recognition (Baggs, 2010), empathy with nonhuman animals (Grandin and Johnson, 2006), and sensory acuity and calculation capacity (Tammet, 2006) that may be more common in at least some autistic individuals. These heightened abilities coexist with seeming deficits in other areas (e.g., related to social interaction, communication, and repetitive behaviors).

Of course, whether the label of deficit even in those traditional areas is fair might depend on how we define well-being and good quality of life. Some things that an individual cannot do are not of interest to her and therefore are not perceived by the individual to be deficits (Reinders, 2014). Brownlow (2010), for instance, reports from online discussion groups of autistic individuals that many autistic people prefer not to be forced into face-to-face social interactions and have some modes of interacting that are nonstandard (e.g., arm flapping or other “stims”—repetitive self-stimulating behaviors that have calming effects on the individual) yet effective. As
such, they needn’t identify as having social or communicative deficits. Baggs (2010) reports that she is in “constant conversation with the world,” which might be understood as a surplus of communication rather than a deficit. Furthermore, she claims that her mode of experiencing the world is as rich as that of NTs. She says autistic people have

rich and varied forms of communication in their own right, not inadequate substitutes for the more standard forms of communication . . . those of us who are viewed purely as having had things taken away—as being essentially barren wastelands—are not shut out of the richness of life by being who we are. The richness we experience is not some cheap romanticized copy of the richness others experience. The richness of life is there for everyone, and whether one experiences it or not is not dependent on whether or not one is autistic.

(Baggs, 2010)

In Brownlow’s online discussion groups, autistic individuals sometimes view NTs as having somewhat unusual predilections and fascinations, even satirically defining an NT syndrome that “traps those affected in a lifelong struggle for social status and recognition. Neurotypical individuals almost invariably show a triad of impairments, consisting of inability to think independently of the social group, marked impairment in the ability to think logically or critically, and inability to form special interests (other than in social activity)” (Brownlow, 2010, 251). The point is that not being social or communicative in the “normal” ways may have certain advantages.

In sum, framing autistic and neurodiverse ways of thinking as differences opens up the possibility of recognizing strengths as well as limitations that accompany autism. As Robertson notes, “Under the deficit model, autistic people are portrayed as broken humans who are ill and require fixing to enable them to function normally in society. In contrast, nonautistic people are viewed as neurologically healthy and psychologically well. This deficit–focused view of autistic people has largely ignored their cognitive strengths, their diverse way of being, and their gifts and talents (2010, 28).” The neurodiversity movement seeks to highlight those often under-recognized attributes and explore their value.

Some critics of the neurodiversity movement argue that only the most high-functioning people are able to make such claims, and that for many other people with atypical modes of thinking, no such “gifts and talents” really exist. Valuing such atypical modes of thinking seems inconceivable to them. One response to such critics is that it is not always clear what capacities an individual has—too often when communication is difficult, we quickly presume that an individual’s cognitive capacities are impaired (Stubblefield, 2014; Biklen, 2005). The neurodiversity movement, though, includes many individuals who were once diagnosed as having very limited cognitive capacities but who became eloquent spokespersons for neurodiversity once they found modes of assistive communication that facilitated their verbal self-expression. (Even given widespread debunking of “facilitated communication,” other alternative communication options are available; Travers et al., 2014.) Consider autistic Sue Rubin’s claims: “[P]eople stare and marvel at my irregular behaviors which lead to poor assumptions that I am simply mentally disabled with little or no intellectual functioning. My appearance is very deceptive, and day after day, I am working, as an advocate for all autistic individuals, to let the world know that we are intelligent” (Rubin, 2005, 95). Intelligence and cognitive processing generally need not all look alike or develop in the same ways. This does not ignore the possibility that some individuals will not be able to advocate for themselves or may indeed have cognitive capacities that are limiting in important respects; it does, however, recommend against giving up on people who have not yet found a way to communicate (Saverese and Saverese, 2010). This is a view shared by Martha
Nussbaum (2007) in her work on disability. She argues for the need to work continuously to figure out ways to enhance the autonomy of individuals with cognitive disabilities to help them achieve the relevant capability.

Efforts to “Fix” Different Modes of Thinking and Implications for Devaluing Neurodiversity

Activism by people who experience atypical modes of thinking has been a powerful force in drawing attention to the need for respect and recognition across such differences (Silberman, 2015). But even as they accept those claims and perhaps even advocate for equal rights and respect, others may still believe that providing medical treatment for the conditions that lead to such different modes of thinking is justifiable (Kapp et al., 2012). Why? Because given the social and institutional norms we have, some modes of thinking will create real hardships for people. Even if the condition itself is not (always) on balance negative, having the condition within a certain system of norms can make life more difficult, and we ought to work to avoid that if possible. We could, of course, focus our attention on making the social and institutional norms more inclusive (as the social model of disability notably recommends; Oliver, 1996). Such change is difficult and slow-going but important and likely to benefit far more than a disabled or atypical minority. But others may well hold that treating an atypical mode of thinking is also a reasonable response—now, when the existing norms are still likely to create hardships for the individual, and in the future, when it may be more a matter of choosing what kind of cognitive processing one prefers. As Kapp et al. (2012) note, “even autistic people who support the ideals and long-term goals of the neurodiversity movement may view adapting to a ‘neurotypical’ world as a practical matter, given the slower pace of and less control over sociopolitical compared with personal change” (9).

Imagine a parent whose child is diagnosed with ADHD. She loves her rambunctious, free-thinking child and wants the child to be respected and recognized for her talents. But she also wants her to do well in school and her teachers recommend treatment for ADHD. Advocating for a more inclusive classroom, one that doesn’t demand that students sit for hours at a time or that allows for more individual attention to each child’s needs, is undoubtedly important. But the parent may also recognize that medicating the child could be more effective in the short term, allowing her to succeed in the existing classroom environment. So even with growing attention to the value of different modes of thinking, we find pressures to normalize functioning (Parens, 1998).

Of course, we would worry if the child in this scenario was gay and felt pressured to be heterosexual (or treated to ensure it) or if she felt uncomfortable with her assigned gender identity but was pressured to normalize and “act like a girl.” Why so? In part, because we tend to think of sexuality and gender (along with race) as integral to our identities. Changing those features of ourselves would mean changing who we are. Even recognizing heterosexist norms and the hardships they may create in the present for anyone with a nonconforming sexuality, we still aim to fix the world rather than treating the child to make her fit those norms. So why not the same with different modes of thinking (Barnes, 2009)? Why do we fund research to search for treatments for autism, ADHD, and any number of the other conditions associated with the neurodiversity movement rather than demanding that the world become more inclusive and such individuals be given space to develop as they are and to be accommodated when necessary?

A person’s neurobiology is but one feature of her identity, but—like gender or sexuality—our ways of thinking pervade our experience and so can feel quite central to who we are. Consider what autism self-advocate Jim Sinclair says: “Autism is a way of being. It is pervasive;
it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person—and if it were possible, the person you’d have left would not be the same person you started with” (Sinclair, 1993). His claim is echoed by many autistic self-advocates who argue that taking a cure for autism would be tantamount to making them different people. What they want is acceptance and accommodation, not a cure. “The object of autism advocacy should not be a world without autistic people—it should be a world in which autistic people can enjoy the same rights, opportunities, and quality of life as any of our neurotypical peers” (Ne’eman, 2010, 2). Saverese is a self-advocate who, when asked “Should autism be treated?” said “Yes, with respect” (quoted in Saverese and Saverese, 2010, 13).

Recognizing the connection between our modes of thinking and our identities and working for acceptance of a wider range of cognitive processing need not lead us to the conclusion that no medical or technological interventions are ever appropriate (Kapp et al., 2012). Acceptance might be accompanied by assistance. Sometimes the framing of an intervention is fundamental to how we view its aims. Is therapy intended to change the person or help her come to terms with herself, to do and be what she wants to do or be? Is a medication prescribed to “fix” a deficit or to aid an individual in achieving a desired outcome?

One might argue that this is too fine a line to draw—if an individual cannot achieve her desired outcome due to her mode of thinking (say she wants to be able to focus better, but her ADHD brain makes that difficult), then she has a deficit relative to that desired outcome, and that’s what the medication fixes. But note that the individual in this case is determining what counts as a deficit. If she prefers a different outcome, then others have no need to categorize her as deficient in some way. And if she asks for help in controlling her ability to focus, then a medication may be understood as enabling her autonomy rather than undermining her identity (Baylis, 2013; Parens, 2015). To be sure, the lines are not always distinct, and individuals can seek treatment only in order to conform to norms they reject without feeling fully able to exercise their autonomy in ways they would prefer (see for instance, the discussion of adults diagnosed with ADHD in Bolt and Schermer, 2009). But broadly, interventions that are developed and later offered in the interest of assisting individuals who face hardships (as opposed to changing them into people with new identities by “curing” or removing part of who they are) are less likely to be deemed threatening and more likely to be seen as helpful. Recognizing an individual’s strengths and making use of them can be part of helping the individual become who they want to be.

As Fenton and Krahn argue (2007), this might have some relatively radical implications for our medical categorizations. Should we get rid of the “disorder” part of autism spectrum disorder? Do autistic people need cognitive behavioral therapy to try to get rid of their tics and other behavioral oddities, or are those things part of their self-expression? Fenton and Krahn (2007) argue that it will be important to look at what is a “recognizable interest from their perspective—not from the perspective of the mainstream alone” (3). Understanding different modes of thinking will not be easy. To what extent can a NT person fully comprehend the claim that autistic thoughts are “more fluid with colors coming in and out and swirling into unique and beautiful patterns. (My thoughts are in pictures and sometimes moving colors)” (quoted in Donnellan et al., 2010). Trying to do so may help advance our shared capacities for imagining a much wider range of possibilities for engaging and understanding the world.

**Neural Engineering as a Means of Thinking/Acting Differently**

Given how closely we identify with our thinking—indeed, with the central organ of our thinking, the brain—the idea of neural engineering is, to many people, a little unnerving. While we may
appreciate and rely on engineering feats and devices outside of us (bridges, buildings, computers, cell phones, etc.) and even attached to us (prosthetics, insulin pumps, artificial hearts, etc.), many people balk at the idea of engineering the human brain. Why so? If we are asked to point to where we are, we typically point to our heads. We’re cognitive creatures; the brain is our “command center.” Engineering—which carries with it the connotation of invention and design, building and improving upon what we already have—seems risky, possibly arrogant, and likely to change something important about how we understand ourselves. If we can be engineered—if we can engineer our thinking or neurological processing by way of implanted devices, for example, deep brain stimulators or brain–computer interfaces—are we somehow more like machines? Or do we make ourselves into artifacts by turning our engineering skills on ourselves (President’s Council on Bioethics, 2003)?

One might counter that we already manipulate ourselves through various forms of pharmaceutical interventions (e.g., antidepressants for depression or stimulants for ADHD), and neural engineering may be merely a different means. Still, while the aim of the two interventions is often the same—we want to alter a brain process that is not to our liking—the mechanisms are somewhat different, and those differences may be significant. Several dimensions of possible differences may be noteworthy: (1) the level of precision (with pharmaceuticals, we flood our systems with a drug, even though we try to get the doses right to achieve the desired effect; with neural engineering, the specificity of the intervention can be at the level of a single neuron, though most current neural engineering techniques are much less precise); (2) the invasiveness of the intervention (taking a pill is relatively simple and requires little risk other than the effect of the medication; neural engineering involves the implantation of electrodes—or the external attachment of EEG recorders and external stimulating devices—and the associated risks of surgery (infection, placement error, etc.) as well as risks related to monitoring and hacking activities (e.g., risks of privacy or security; Farah and Wolpe, 2004); and (3) the long-term effects of the intervention (most pharmaceuticals have to be taken regularly but can also be discontinued in case of unwanted effects; neural engineering interventions, at least implantable ones, are much more difficult to take out, though they can be turned off, often requiring the help of a physician). These differences may not hold up over time—pharmaceuticals may become more precisely targeted, and neurally engineered devices may become less risky and more easily controlled by the individual. Still, the current prospect of neural engineering is, for many, somewhat more concerning than the use of pharmaceuticals to alter our brains and our thinking.

But how, exactly, might neural engineering alter our thinking? Some implantable devices aim to regulate areas of the brain that operate atypically (to be a “pacemaker” for the brain). A deep brain stimulator (DBS), for instance, involves electrodes implanted in relatively deep regions of the brain and set to deliver stimulation at a steady pace or in regular intervals. DBS has proven effective for treating tremors associated with Parkinson’s disease and essential tremors. Trials of DBS for movement disorders have in rare instances resulted in unusual side effects, such as increased impulsivity, gambling, and personality changes (Wang et al., 2016; Rossi, Gunduz, and Okun, 2015; Lipsman and Glannon, 2013; Parsons et al., 2006), but also sometimes had unintended beneficial effects, such as enhancing mood or control. Perhaps as a result, DBS is now also being tested for conditions such as OCD, Tourette syndrome, depression, epilepsy, and anorexia. Neural engineers are still not certain of the mechanism by which the stimulation achieves the desired effect, and some treat it as a relatively blunt tool for treatment, but that hasn’t dampened the optimism and the attention it receives as a new mode of treating conditions that have so far been relatively resistant to more traditional treatments.

Most such DBS devices are “open loop,” which means that they stimulate at a set level. New versions of these devices are designed to be “closed loop,” which means that they have
a feedback loop with both sensors and stimulators and can be triggered to stimulate only as needed. Such devices save on battery power and allow for a more selective use of stimulation. On the one hand, a closed-loop device is attractive in that it will be more responsive to the particular situation (turning on when needed and off when not without any need for intervention on the part of the user). On the other hand, the user may have difficulty locating herself in the loop. The device that runs autonomously in her brain may feel alien to her, almost like a “third-party” entity (Lipsman and Glannon, 2013) that exerts control over her cognitive and neurological processing. If she doesn’t identify with the device (and approve the alterations it imposes), then she may feel alienated from her own cognition and behavior (Kraemer, 2013). So neural engineering in the form of DBS devices may certainly help some people to live better, but it also may create changes in how we understand ourselves as agents (Klaming and Haselager, 2013); it can alter the underlying means of our thinking.

Another neural engineering device might attempt to wirelessly transfer electrical signaling across an area of damage—whether from the brain to spinal nerves, over an area of a spinal cord injury, or across cortical regions to induce neural plasticity following stroke or other brain injury. In the future, implantable brain–computer interfaces (BCIs), for instance, might translate a motor intention (e.g., “lift my finger”) into action (finger is lifted) despite a spinal cord injury that had previously made such movement impossible. The BCI would work by recognizing the motor intention, creating an algorithm for that movement, wirelessly transferring the data over an area of damage, and then stimulating the relevant spinal nerves or muscles. Or a BCI might help a person to communicate by translating motor intentions related to communication to a computer-driven voice output device. As our brains directly interface with computers to complete our intended actions, our modes of thinking may change somewhat. For instance, to use such a device, an individual would need to be trained so that the electrical activity associated with her intention to lift the finger can be isolated from other neural activity (“noise”) in the same area. Further, she might be given a code thought (say, “wiggle toes”) that is more easily isolated and identified, and that can then be used to trigger her desired finger movement. Then she would need to learn to think “wiggle toes”—presumably with some concentration, at least in the early stages of the implant—in order to achieve her intended action.

Would such neural engineering feats change how we think, giving us new and significantly different modes of thinking? They might not if they merely fill in for or replace a part of a mode of thinking that was already in effect. But as the latter example suggests, they might also complicate and alter our ways of thinking by adding steps, creating new associations, and at least relying on different mechanisms to implement our thinking (Clausen, 2008). At least in the early stages, users of the technology might need to be able to focus effectively on a code word or target activity (more so than is required in typical thinking) and might fail to effect a desired action if they lose focus or are interrupted (or if their medications create difficulties for focusing). If intended signals (via focused thought) are indecipherable, whether due to lack of training or difficulty in implementing the trained signal, the individual’s thinking may lead to a nonresponse or perhaps even an unintended response. How the individual thinks (and effectuates thinking) can then alter others’ understanding of who they are and what they take themselves to be doing. If my friend knocks over a cup of coffee on me when she’s angry, I may blame her, even if she insists that her BCI must have misfired in some way, because she didn’t intend to do that. In addition, the altered means of thinking and effecting our thinking may, through neural plasticity, also change our previous patterns of neurological processing. Over time, the user’s brain may become habituated to the association, so that the link between the thought and the action becomes relatively automatic and unconscious. Even if the processing becomes more fluid, we might still consider the mode of thinking to be somewhat different, given that other
kinds of interference (loss of battery power, device failure, hacking) are possible (Klaming and Haselager, 2013).

Consider what might be an even clearer case of neural technology affecting a mode of thinking. DBS devices have been tested in people who have treatment-resistant depression (Mayberg, et al. 2005). Such devices stimulate the brain in order to elevate a person’s mood and increase her motivational drive. A person with a DBS may report feeling happier and able to get on with her life. The treatment appears to be a success. But she may, at the same time, think of herself as less in control of her thinking, not sure about how to differentiate what she does and what her device does. If she yells at her daughter or fails to help her spouse, is she the angry or apathetic one, or is her device just not set appropriately (so that she’s doing what she can, but only within the bounds of her settings)? We often look at behavior to understand a person’s thinking, but when a device other than the individual may be influencing the behavior in a fairly direct way, what can we discern about her thinking? Her thinking may not even be fully transparent to her. Imagine, for instance, a DBS user who feels happy at a funeral—did she really not care about the one who died as much as she thought, or is her stimulation setting perhaps a bit too high and not responsive enough to her environment? She may not know herself and could find the experience confusing and unsettling. Neural engineering devices have the capacity to alter our ways of thinking and so, too, to shape how we think about ourselves.

The neural engineering efforts I have described—for BCI and DBS—emphasize creating new connections between thoughts and action (e.g., for people with spinal cord injury or stroke), and between mood and electrical stimulation (for people who have depression). As such, they aren’t strictly speaking focused on changing the thinking of people who identify with the neurodiversity movement. While some people who have been diagnosed as bipolar or who have dysthymia may take up the charge of the neurodiversity movement, typically people with treatment-resistant depression have no such affiliation. So why should the aims of the neurodiversity movement matter to the neural engineers? Because recognizing the diversity of valuable forms of neurological functioning is an important first step to ensuring that neural engineering efforts will be addressed to real needs and won’t unintentionally exacerbate the existing difficulties for people who function with atypical modes of thinking. Acknowledging neurodiversity in the early stages of neural engineering will help to secure a more capacious vision of neurological functioning and direct engineers to partner with disabled or differently abled people to help them achieve their own goals.

**Neurodiversity Meets Neural Engineering—Finding Common Ground**

Neurodiversity movement advocates argue that we should reconsider some atypical modes of thinking and recognize their value, even as they are admittedly outside “normal” modes of functioning. Neural engineering aims to create different modes of thinking, but in the service of restoring or improving function in the direction of what is “normal.” We might then think that these two movements are contradictory in their aims. But we should not ignore other striking similarities. Both groups seek to better understand neurological functioning and to find ways to allow individuals with atypical neurological functioning to improve their quality of life. Both want, at some level, for the broader public to accept a wider array of modes of thinking so that people who have atypical neurological function will not have to face stigma, whether due to their communicative or social interaction differences or because of the existence of an implanted device.

Those similarities, though, are at a level of generality that may not be very significant. If neural engineers dedicate their efforts to creating new ways to achieve “normal” functioning
(so different modes of thinking but toward the end of fitting a relatively constrained range of acceptable functioning), then the neurodiversity movement may have cause to be concerned. Neural engineers may well think that such “fixes” are exactly what autistic or disabled individuals most want or need. The neurodiversity movement suggests that may not be true. (I recognize that the neurodiversity movement does not include all autistic people or all people who live with conditions that sometimes fall under the neurodiversity banner.)

My recommendation here is for collaboration across the two movements. In particular, neural engineers should be aware of the neurodiversity movement and open to input from people who identify as part of that group. If improved neurological processing is the target of neural engineers, it makes sense to figure out what the intended end users view as their needs and priorities. Not every potential end user will identify as part of the neurodiversity movement or will value her atypical processing. But engineers would still benefit from hearing the range of views that their intended beneficiaries hold.

The best way to get such information about priorities and values is to engage potential end users early in the design process, even as the research priorities are being set. Too often, end user engagement comes quite late in the game, when a prototype is already available to be tested, and many decisions about function and design have already been determined. Engaging potential end users early in the work of neural engineering can help to ensure that product development aligns with needs and priorities of the intended group of beneficiaries.

What might change? In some cases, the focus or direction of the research may be affected. As an example, nondisabled people sometimes presume that not being able to walk is the greatest concern of most people who use wheelchairs. But that’s not usually the first priority of most people with spinal cord injury. Having nondisabled neural engineers talk with people with spinal cord injury about their experiences could alter that perspective. Neural engineering targeted to BCIs for motor disabilities, then, might focus on improved hand and arm function rather than walking and include attention to sexual or urological functioning, given stated priorities of people with spinal cord injuries (Anderson, 2004).

Other changes might involve shifting design features, such as altering the level of individual control a user has over the device. Early DBS systems had parameters set in a physician’s office and only changeable through office visits. Newer models offer the possibility for local control by the user so that the user can determine when stimulation needs to be changed, at least within a set range. Input from a focus group of people with spinal cord injuries suggests that most people would want this kind of control over any implantable neural device, and that recommendation then can alter the way the devices are designed. These focus group members were tentatively optimistic about the neural technologies under development but also expressed concerns that the typical nondisabled engineer might not really understand much about how their lives work or what they really value (Goering, unpublished focus group data).

Concerns about privacy or control over access to the data from the neural engineering device may be another factor that could be affected by input from likely end users. Engineers may see great value in having researchers get access to the data collected from a BCI, for instance, but users may prefer to have some control over what data is made accessible and how. The acceptable trade-offs between increased efficiency in movement or mood and privacy of data may not be the same in the target population versus within the group of designers. Input from likely end users is particularly important where end user groups may have values or perspectives (related to disability and neurodiversity) that are new to nondisabled engineers.

Other changes to the engineering process may be more subtle and involve different framing rather than designing technology differently. Cochlear implants are a good example here. Cochlear implants are a form of neural engineering—they allow information from sound waves
to be collected, processed, and delivered to the auditory cortex, bypassing regions of the ear or auditory nerves that would otherwise perform that function in nondeaf individuals. Cochlear implants do not “cure” deafness, but they do offer a way for deaf individuals to gain some access to the world of sound if they want it. In the early days of cochlear implant technologies, Deaf culturists viewed the technology as deeply threatening to their way of life (Crouch, 1997) and even expressed concern about cultural genocide (Lane and Grodin, 1997). The National Association for the Deaf (NAD) came out with a statement in opposition to their use. But over time, NAD softened its stance, in part because of increasing evidence that while cochlear implants have gotten better and more effective, they still do not make a person “hearing”—rather, they offer a deaf person a way of gaining some access to sound. Seen as an assistive device—one that can be chosen or not, depending on the values and desires of the parent or user—the cochlear implant is somewhat less threatening. The NAD site (http://nad.org/issues/technology/assistive-listening/cochlear-implants) now offers a more nuanced stance:

Cochlear implantation is a technology that represents a tool to be used in some forms of communication, and not a cure for deafness. Cochlear implants provide sensitive hearing, but do not, by themselves, impart the ability to understand spoken language through listening alone. . . . The NAD recognizes the rights of parents to make informed choices for their deaf and hard of hearing children, respects their choice to use cochlear implants and all other assistive devices, and strongly supports the development of the whole child and of language and literacy.

They go on to note, “Many within the medical profession continue to view deafness essentially as a disability and an abnormality and believe that deaf and hard of hearing individuals need to be ‘fixed’ by cochlear implants. This pathological view must be challenged and corrected by greater exposure to and interaction with well-adjusted and successful deaf and hard of hearing individuals.”

The similarities to the neurodiversity movement claims are striking here. People who have atypical neurological processing are working to raise awareness of their differences and their concerns about efforts to “cure” them. But if neural engineering devices are understood as assistive technologies that may help to address needs identified by individuals with atypical processing, then they are more likely to be accepted. Educating neural engineers about problems with having exclusively pathological views of the individuals they aim to help is imperative.

Community-based participatory research (CBPR) is gaining attention as a paradigm of research that insists on active collaboration and engagement with relevant communities of interest in order to ensure scientific results that are both ethical and likely to be effective (Hacker, 2013). CBPR has found uptake in work being done on autism. For example, the Academic and Autistic Spectrum Partnership in Research and Education (AASPIRE) “brings together the academic community and the autistic community to develop and perform research projects relevant to the needs of adults on the autism spectrum. . . . [A]cademics and community members serve as equal partners throughout the research process” (http://aaspire.org/). The partnership between the two groups helps to ensure that nondominant perspectives are heard and considered in research projects focusing on autism rather than presuming only the dominant “deficit” framing of autism.

The idea is fairly simple—if you want to know something about what autistic people want or need, get them involved in your project, and do it fairly early on, to help guide the direction and focus of your research project—but it still is not widely practiced. Partly this is due to engrained research practices and the institutional structures that support them (Israel et al., 2006). Expertise
is typically only identified as existing in the academic community and “need” outside of it rather than recognizing the relevant expertise of community members (Jordan et al., 2005). But community members have much to offer. Consider what Nicolaidis (the current AASPIRE codirector) says about her experience in learning about autism:

Interestingly, nowhere in my early foray as an “autism mom” (or in the years I had spent as a primary care physician) did anyone actually suggest learning from individuals on the autism spectrum. It was only by coincidence that I met a local autistic self-advocate who was active in the neurodiversity movement. Who could have guessed that she would change not only the way I looked at my autistic child, but also the way I practice medicine and focus my research?

(Nicolaidis, 2012)

The lived experience of people with the conditions in question is surely relevant to issues of research, treatment, and policy, yet decision makers too often fail to take it directly into account. As neural engineering continues to develop as a field, it is crucial to take into careful consideration the perspectives of potential end users, the people who are the intended beneficiaries of the technologies in development. They matter not just for the fine-tuning of existing technology prototypes but also early on in the research process, as priorities are being identified and research projects cultivated. Individuals who identify with the neurodiversity movement, whose neurological processing is atypical in some respects, have much to offer neural engineers in their quest to understand neurological processing and to develop devices that can provide wanted assistance and opportunities for enhanced well-being.

Acknowledgments

Thanks to Eran Klein and Laura Specker Sullivan for helpful comments on early drafts and to the CSNE faculty and students for their part in helping me understand neural engineering. Also thanks to the editors for their very helpful suggestions.

Further Reading


References

Sara Goering

Parenthetical notes:


