# 7

# THE LAME TO WALK AND THE DEAF FEAR

Why It Pays for Surveillance Capitalism to Exploit the Disabled

## **Brian Brock**

#### Thibault and His Exoskeleton

On the fourth of October, 2019, at Clinatec, a private biomedical research center in Grenoble, France, a man publicly known as "Thibault" stood up and walked. At the time a twenty-eight-year-old tetraplegic, Thibault had previously broken his neck in a fall from a fourth-floor balcony during a party.<sup>1</sup> Through an intense regime of experimental surgery, therapy, and technology, the sensors on the surface of his brain were now sufficiently sensitive to allow him to move all four of his paralyzed limbs by way of a mind-controlled exoskeleton suit. Awed by his experience, Thibault compared himself to the first man on the moon and expressed special appreciation for regaining his upright bodily stance: "I had forgotten that I used to be taller than a lot of people in the room. It was very impressive."<sup>2</sup>

The researchers in charge of the experimental procedure were not only technically cutting-edge but media savvy. On the day of the announcement that Thibault was walking again, the global media had all the glossy images and expert quotes they needed to broadcast the feat far and wide. The announcement of an event that had taken place behind the closed doors of a scientific lab was announced along with a series of photos of Thibault strapped into a remarkably glossy-looking exoskeleton in a suspiciously color-coordinated bioscience facility. A short and distinctly less impressive and aesthetically harmonious video of him in motion was also available. The articles that flooded the news-scape invariably invoked the scientific-progress-gives-us-hope narrative, and for many the media blitz clearly worked. As one person commented, "Always remember: For all the stories about stupidity and ones that make you feel like society is 'circling the drain,' advances like these are still being made by our most brilliant minds."<sup>3</sup>

As a public relations feat, Thibault's walking far surpassed previous unveilings such as the one that opened the 2014 World Cup in Brazil. There twenty–nine–year–old Juliano Pinto, a paraplegic man, used his neural interface to flex one leg to kick the first ball into play. His glitzy but primitive mechanical suit had been produced by researchers from Duke University's Center for Neuroengineering in cooperation with other private companies.<sup>4</sup> As of 2019, people in the United Kingdom were more aware of the various displays of the paraplegic American Paralympian Jennifer French standing up from her wheelchair by activating muscle–controlling neural implants.<sup>5</sup> All of these stories play to a well–entrenched cultural script that features the restoration of the power to stand and walk as self–evidently attractive.<sup>6</sup>

One of the watershed moments in the establishment of this public narrative came in the late 1990s when the Hollywood star Christopher Reeve very publicly announced his determination to walk again after having been paralyzed in a horse-riding accident. This narrative arguably reached a new cultural ascendency with the release of *Avatar*, the highest-grossing Hollywood film to that date. The main character in this story is a paraplegic man with a neural interface that allows him to inhabit a biological full-body prosthesis, into which his mind is eventually fully merged and his broken human body discarded.<sup>7</sup> The medical researchers who fitted Thibault in his exoskeleton transparently positioned their work within this cultural narrative, asserting, "The exoskeleton is a biometric anthropomorphic neuroprosthesis and is possibly the best solution to totally compensate for the impairment in a patient with tetraplegia."<sup>8</sup>

In this chapter, I approach familiar debates about the relation of therapeutic treatments to technological enhancements of the human from the point of view of disabled life as understood in Christian disability theology. In Christian theology, finitude and limitation are not a curse but welcomed. The majority of this paper is devoted to describing in detail exactly how we modern citizens of the developed West embody a repudiation of this claim. I will tell the story of one biomedical intervention in order to concretely display what I mean with this claim. The question "what does it mean to be human?" is one that we incrementally answer in the acts of everyday life. Being human is not a theory, a concept. Being human is a task, one we answer with every act, since, as Luther so often taught, there is no way of living or dying that is religiously neutral.<sup>9</sup>

The aim of this description is to show how the form of humanity we are currently living out is one in which we interact with one another as streams of information. The hopes of a capitalistic society to secure peace through material wealth converge to form a society-wide consensus that the future is best secured by developing better and more certain ways to mine and so control the information each person generates, just by living. What is well known is that we are increasingly becoming data shadows to be manipulated by business and government.<sup>10</sup> What this essay further explicates is how this cultural consensus, this belief in the importance of wealth and security, ends up exploiting people with disabilities.

This line of argument is in part a pushback against the consensus that has emerged among theologically oriented medical ethicists that the distinction between medical therapies and enhancements are no longer conceptually useful for distinguishing between research into new treatments and biotechnologies.<sup>11</sup> I will show that entirely abandoning the therapy-enhancement distinction abandons people with disabilities to the depredations of market economics. What are popularly called therapeutic medical interventions, in which the human body is altered in order to reduce suffering or restore lost functioning, are theologically and ethically uncontentious. In principle Christians can and in many cases should embrace medicine, surgery, and pharmaceutical treatments as a way of receiving their bodies from God with gratitude. But licit medical therapies can be misused, and those who are developing what are popularly called enhancements today are developing forms of medical procedure that aim to improve well-functioning bodies. The misuse of therapy and the desire to improve the well-functioning human body is the focus of this paper. The main part of my proposal is the suggestion that the therapy–enhancement distinction is a barrier to the designs of industry and political leaders to achieve the widespread use of human enhancements—enhancements of what we today think of as perfectly normally functioning bodies. The alteration of these bodies is unthinkable for most today, so powerful agents in developed societies today have good reason to introduce them as therapeutic techniques—a ploy in which disabled lives are used as pawns in an indefensible manner.

A brief final comment unveils how such desires must be understood as springing from a theological deformation. The dreams of transcending human finitude and vulnerability that have generated technologies like Thibault's exoskeleton express transhumanist desires to overcome the body that have no sense of what it means to live with mortal bodies in the power of the resurrecting Spirit. The transhumanist hopes to transcend the body are, fundamentally, the hope to master materiality. It is the modern hope to overcome and control nature writ large. Christian hope, in contrast, is one that embraces death as a constitutive reality for creaturely bodies and seeks a way of living in mutually upbuilding communion with one's own body and with other creatures. This affirmation of the goodness of the material world positions humans as hoping to be transformed into beings capable of living at peace—sustainably—in a material world that Christians confess is good and sufficient to fulfill the needs of every creature. The thoroughgoing commitment of transhumanists to imminent reality being all there is leads them to discount richer forms of hoping, making them unable to hope for genuine renewal of the individual's mind and social sensibility. Desiring to remake the body, transhumanists cannot imagine the more sweeping remaking of human self-understanding that is fundamental to Christian hope.

## A Closer Look at Public Attitudes to Ameliorating Disability

Most debates about the therapy-enhancement divide in the academic discourses of philosophical and theological ethics barely engage the moral landscape in which debates about human enhancement and the posthuman are taking place. A brief summary of a report compiled on behalf of the Royal Society on public attitudes helpfully illuminates attitudes of the general public in the United Kingdom to neural interfaces in the nation. This survey indicates how most people understand the relationship between enhancement technologies and disability, at least as they did in 2019.<sup>12</sup> This social scientific research relied on a large and representatively diverse group of respondents. Focus-group discussions began probing people's opinions about therapeutic use of neural interfaces by showing them examples of people in wheelchairs being able to stand up with help from cortical implants, or people with Parkinson's disease using a switch to halt their tremors by activating a wire that stimulated the affected region deep in their brain. The leading-edge example of a successful neural interface is the cochlear implant to treat hearing loss.<sup>13</sup> Yet those who described the benefits of this neural interface often did so in ways that indicated a desire to eliminate disability. "Anything to help the future generations overcome disability is a good thing," as one cochlear implant user group respondent put it.<sup>14</sup>

Perhaps one of the most ironic discoveries of the report is that the desire to create a more inclusive society is the most significant driver of the desire to eradicate disability. One group in Glasgow, for instance, remarked:

Your neutral interfaces essentially are taking away the disabilities. They're creating a more level playing field where everyone essentially becomes equal. When everyone's equal and you get rid of the marginalisation so that people aren't outsiders due to their disabilities, as perhaps they would have been otherwise.<sup>15</sup>

A group in Sheffield stated the eliminationist subtext of this remark more bluntly: "Everybody will now be created equal. . . . There will be no disabilities anymore. Everybody will be included. Everybody who now currently can't speak, will be able to engage fully in a full, productive life."<sup>16</sup>

Wide swaths of the British public seem to agree that the eradication of disability is a worthwhile scientific aim. One driver of this view is the belief that to remain socially connected in modern developed societies, people need to be independently mobile:

People affected by Parkinson's disease predicted in their discussions that in 20 years' time any neurological and neuro degenerative conditions, such as multiple sclerosis, Parkinson's and Alzheimer's disease could be fully treated by neural implants.

Others in the dialogue workshops spoke of their optimism for a future where there is no need for mobility assistance devices because of advances in Mollii suits and equivalent therapeutic devices. [In the words of one Glasgow respondent], "We believe that (by 2050) there will no longer be a use for wheelchairs or mobility assistance due to the suit being able to build muscle back into people's body and the spinal nerve connection. We could eradicate everyone's mobility issues in 30 years' time."<sup>17</sup>

Respondents felt that any technology that could increase independence was promising, because "current community structures very rarely allow for sufficient informal support for those who are relying on others for their basic care. [As one respondent in Glasgow remarked], 'Society has become so fragmented now. . . . This gives people a choice to potentially support themselves."<sup>18</sup> The dream of the eradication of disabilities rests on deeply interwoven and also contradictory desires for community and supportive relationships as well as the aspiration for mobility and financial independence.

Some cochlear implant users felt that improved neural link technologies promise to remove individuals altogether from the stigmatized category of the disabled. If this is achievable, it will be because the technology has succeeded in hiding itself. As authors of the report note, "Several participants in the Cochlear Implant User Group talked about the new development in cochlear implants which will be fully internal and controlled by a mobile phone. This was liked for taking away the stigma of an external hearing device."19 Even those with the most successful therapeutic types of neural interfaces, cochlear implants, felt keenly aware that the very devices that were eliminating their disability were not in fact curing, but only ameliorating, it. This cohort of technology users was no doubt aware that cochlear implants do not restore anything like "normal" hearing. They worried more about the cloaking of their prosthetic technologies in order to relieve them of being stigmatized as disabled<sup>20</sup> than they did about these prostheses seamlessly<sup>21</sup> restoring—let alone enhancing—their capacity to hear.

Intriguingly, the study also drew attention to the ways in which brain-computer interfaces might help disabled people and in so doing also burnish the reputation of technology itself: "Some participants saw the application of neural interfaces solving some of the world's most intractable medical problems as a hugely positive contribution to the narrative around technology in general. They thought that neural interfaces that could restore movement to those who are paralyzed or sight to those who are blind could help to rebalance the tech narrative that to date has been dominated by large social media companies and their use of data and artificial intelligence to influence our behavior."<sup>22</sup> Some might see the polyvalence about who benefits from these technologies as a win-win situation, for, in staving off widely shared dystopian worries about technology, the technological project itself was being rehabilitated and with it the tech companies bringing these technologies to the marketplace. In the words of one London participant, "It develops a positive narrative for technology. Not every tech gets a bad record but more from the media it gets quite negative."<sup>23</sup>

One widespread point of consensus across geography and demographic differences was a sense that a widespread use of neural implants is likely to cause a major shift in public understandings of injury, disability, and "normal" human performance:

The more conditions and disabilities that are treatable, the fewer disabled people there will be. Although that will mean that fewer people will be defined by their disability, many participants felt strongly that this can lead to a society in which people become more intolerant and less appreciative of diversity. This was seen as an undesirable future, as it may lead to a greater stigmatisation of those with untreatable disability or conditions. Participants said that this throws up ethical questions, e.g. who decides which disabilities will be prioritised for neural implant treatment and why. Conversations with cochlear implant users showed that some had encountered resistance in the deaf community against their decision to accept a cochlear implant. They said that in the deaf community, identity is shaped by communicating in other ways than is the societal norm. In a similar vein, discussions about the use of EEG for education led to a view in the dialogue that this type of non-medical neural implant can potentially contribute to the creation of a subset of an ever more uniform society that is stigmatised and at risk of being bullied.<sup>24</sup>

The Royal Society study also found that these negative impacts on disabled people's lives were coupled with further worries about nontherapeutic neural interfaces being implanted in otherwise healthy subjects. Suspicion abounds that nonmedical uses of neural implants are frivolous, worrying, or both. Many of these worries followed lines well-travelled in dystopian science fiction—that such technologies might lead to physical or mental laziness, or to big business controlling people's minds. Interestingly, these British respondents also considered it irresponsible to develop any of these technologies—even for therapeutic uses—if they were not to be widely available. The development of a two-tiered society of haves and have-nots lays behind this worry, as well as a firm commitment to equality in health care.

In this cultural context, it becomes clearer why the Clinatec media blitz around Thibault's walking is not an add-on to the "hard" science but intrinsic to the further success of the work going on in this biotech context. As long as public opinion is dominated by worries about neural technologies, the companies and governments who are funding them have little hope of recovering their investment and bringing them into widespread use.

## THE ADVENTUS OF NEURAL INTERFACES: WILL WE BE READY?

Insiders in industry and science generally assume public resistance to placing neural implants in healthy people will disappear. The question is not *whether* that will happen, but *when.*<sup>25</sup> The next three sections will indicate why we do not need to imagine that this certainty about the inevitability of widespread neural interface use is somehow being driven by a transhumanist avant-garde who know that the perfecting of such technologies is a necessary step to transcending the human as depicted in movies like *Avatar*. Tracing the technological evolution currently underway in developed societies indicates why the pressure to develop neural interfaces is more likely to grow than subside. Strong imperatives in this direction are already hardwired into our newly "wired" daily lives, economics, and political orders.

No consumer object in the history of the world has been so quickly and so universally adopted as the smartphone, and we have only begun to intuit what this change means for our societies, our psyches, and our ways of organizing the world.<sup>26</sup> Most of the human population has already become reliant on uninterrupted connection to the internet to accomplish daily goals. The smartphone was the first and most visible harbinger of a world called "the internet of things," which can be seen as the extension of the networked human into more and more active devices. Wearable biometric sensors like Fitbit and Apple Watch are already well known, as is their aim to offer more of the individual physical body and its functions as computationally available information. Having utilized biometric monitoring to optimize our own bodies, the utility of applying the same logic to make the many bodies that make up society more efficient appears self-evident. A "smart" home is a home where you do not have to think about adjusting the thermostat to stay comfortable, where a word can dim the lights or cue the music, and from which our every daily need becomes accessible to the corporations like Amazon designed to seamlessly meet them. The smart city is a citywide version of the same—where the traffic lights automatically adjust according to traffic levels, where police are always present when suspicious people congregate, where rental rates for shop space can be precisely calibrating according to pedestrian footfall, and where energy use and waste disposal can be anticipated and so Pareto-optimized. The humming hive that is human society is constantly generating information that can be captured and fed into the internet so that it can be continuously and algorithmically optimized. And this is a world in which we cannot participate without surrendering vast amounts of data.<sup>27</sup>

The information generated by all these wired devices about what we want, what we are doing, and how we communicate with each other is the raw material of our generation's new gold rush, which promises to remake our societies as fundamentally as did the discovery of fossil fuels. Shoshana Zuboff has recently documented this startling claim by asking what might be learned from the fact that the most spectacular wealth creators of the last decades have all been internet and technology companies. In the world in which everything is wired, information becomes the new currency. This is why we must understand Western developed nations to be entering a new era of capitalism she calls "surveillance capitalism." Once a critical mass of sensors and computing power are in place, prediction becomes the new and central economic and political imperative. This theme has been explored in fiction,<sup>28</sup> but contemporary sociological research has substantiated that the central driver of this evolution is an obvious development from previous understandings of marketing. Whereas once marketers promised to change behavior while not being able to prove that they had, in the new information economy the only change that matters is the change that produces tangible and testable real-time movements in human behavior. This is obviously a technique as suitable for moving consumers as for controlling national citizens.<sup>29</sup> This is the richest vein for which the new gold rush is aiming.<sup>30</sup>

The entire business model of companies like Facebook, Google, and Amazon is organized around generating ever deeper and broader information flows around consumer activity by harvesting and synchronizing information flows from across widely different platforms. Companies built on the techniques of data mining need to know what we talk about at breakfast, how much time we spend commuting to work, what we like in our refrigerators, and what we do for relaxation in our living rooms. The aim is to predict what we will do next. They need to understand the ebb and flow of our moods, what we lie about, and what we search for when no one is looking in order to effectively steer us toward the consumption that can be predicted and so capitalized. The gold of the new economy is knowledge of reality, the reality of our desires. "The aim of this undertaking is not to impose behavioral norms, such as conformity or obedience, but rather to produce behavior that reliably, definitively and certainly leads to desired commercial results. The research director of Gartner, the well-respected business advisory and research firm, makes the point . . . that mastery of the 'internet of things' will serve as 'a key enabler in the transformation of business models from "guaranteed levels of performance" to "guaranteed outcomes"."<sup>31</sup>

The holy grail of this new economy is to know the unconscious mind, and here again we meet a story in which the therapy of disability seems to be functioning as a Trojan horse for something very different. Professor Rosalind Picard, of the MIT Media Lab, is one of the pioneers of what has come to be called "affective computing," the automated sensing and processing of emotional states based on gauging a user's facial micro-expressions. The goal for such programs is to render both conscious and unconscious behavior as coded and calculable information streams. Picard's basic scientific work aimed to help autistic children develop skills in emotional communication and led to the development of computer games capable of fostering this emotional learning. Picard herself had some foreboding about what the tech giants and governments might do with this technology, understanding the strength of their incentives to sell us things in moments of emotional vulnerability or to seek to manipulate or control the emotions of a population. As it turns out, her fears were well placed, and only twenty years after the publication of Picard's research, a leading market research firm predicted that the "affective computing market" would grow from \$9.35 billion in 2015 to \$53.98 billion in 2021, a growth rate of nearly 35 percent driven almost exclusively by the marketing and advertising sector.<sup>32</sup>

Picard's story helps us to see how the aims of researchers to offer disabled people empowering therapies are vastly overshadowed by the interests of agents driven by commercial aims. Picard and her protégé at MIT, Rana el Kaliouby, used their research to build a machine system they called Mind-Reader, which they initially trained to recognize emotions by using paid actors to mimic specific emotional responses and characteristic facial gestures. Soon the pair were overwhelmed by inquiries from major corporations who wanted to use the technology to measure their customers' emotional responses. MIT encouraged Picard and Kaliouby to spin off a startup company around their technology, called Affectiva, of which Picard soon discovered herself elbowed out of control. The company boomed under the leadership of Kaliouby, who took it to venture capitalists and does business with thirty-two Fortune 100 companies and fourteen hundred global brands. Kaliouby now imagines that "pervasive 'emotional scanning' will come to be as taken for granted as a 'cookie' planted in your computer to track your online browsing. After all, those cookies once stirred outrage, and now they inundate every online move."33

It is not the therapeutic but the economic promise of these technologies that becomes most obvious to close observers such as Danielle Carr, a historian of these technologies: "Real-time information about neural activity is currently one of the hardest forms of data to acquire: everyone has a phone, but very few people have neural implants. This is why patients with Deep Brain Stimulation implants are treated as precious resources by scientific researchers; they often work simultaneously with multiple research teams running experiments in which the brain data gleaned by the device can be coupled with behavioral data. By combining different forms of data—the sort of information your phone collects, for example, and cortex activity—both sets become more meaningful."<sup>34</sup> In the midst of such a gold rush, however long it lasts, the culturally assessed stock price of those with the right disabilities will be soaring. The economic incentives here are so strong that it is hard to see how even the highest aspirations to serve those with disabilities will not be co-opted, as happened to Picard. The time may have come to relinguish our gualms and embrace the future of Western society as announced by the paralyzed American Adam Gorlitsky: "Either you adapt or you die."<sup>35</sup> Paralyzed from the waist down, Gorlitsky trained in his ReWalk exoskeleton to compete with a British man for the title of the fastest paralyzed man to complete a marathon. "In a weird way," he says, "it's a good time to be paralyzed."<sup>36</sup> The leaders of Silicon Valley's science and industry elites could not agree more, and from their perspective his message has the advantage of being culturally attractive. Gorlitsky's story proved the perfect leading episode in the tellingly titled video series Freethink Superhuman.

## PUBLIC OPINION AND THERAPEUTIC INTERVENTION

It is now becoming clearer that the role allocated to people with disabilities is positioned by the technological and economic imperative to develop neural interface technologies. As we have seen, significant sectors of the general public are worried about the ethical implications of neural interfaces but see therapeutic uses as defensible. Having surveyed a wide spectrum of British citizens, the independent (meaning not industry sponsored) authors of the Royal Society study project surveyed in the previous section concluded that the general public has "strong support for neural interfaces in situations where they enable patients to recover something that has been lost due to injury or a medical condition; but less support for the technology when it is used to enhance functions such as memory, concentration or physical skills among healthy people."37 We can be sure that Alim Louis Benabid understood that this was the crucial moral landscape in which his neural interface research that culminated in Thibault's exoskeleton would stand or fall. As one of the professors at Grenoble leading the project and the lead author of the study published in the *Lancet Neurology*, he no doubt has much riding on its success, also being the founder and executive board president of the biomedical firm Clinatec.<sup>38</sup> It is now evident why he was so insistent that his aim in this research is to develop a therapeutic technology, distancing himself from any insinuation that such technologies were about human enhancement: "This isn't about turning man into machine but about responding to a medical problem.... We're talking about 'repaired man,' not 'augmented man.<sup>379</sup>

One reason for Benabid to underline the therapeutic nature of Thibault's treatment was that the legal hurdles would have been much higher (and the PR benefit much lower) were such invasive surgery undertaken on an otherwise healthy person. In offering such treatments to a disabled person, Benabid continues a long tradition of building the edifice of modern medicine on the back of those with questionable capacity to consent to it.40 Even if the technology works and begins to be used more widely, such technologies will remain legally risky in undermining the functioning of a formerly healthy body. This remains the case even though almost all nontherapeutic medical treatments started off as therapeutic—cosmetic surgery was initially restorative, growth hormone developed for those who had a HGH deficiency, and so forth—but where these produce negative medical outcomes, the sense of patient outrage is understandable and risky for the doctor. On these grounds, both the level of biomedical research ethics and contemporary malpractice law, a working therapy-enhancement distinction remains an important part of the apparatus sustaining a just society. Once the technology is proved in the context of therapeutic uses, it fundamentally shifts the parameters of public debates about more widespread uses of neural interfaces. A chasm of cultural resistance and prejudice against these technologies must be crossed if the miniscule numbers of early adopters of these technologies in hightech settings is to be diffused more generally through society, so catalyzing entirely new ways of performing a host of traditional kinds of work. These are crucial issues for investors and industry leaders since neural interfaces are disruptive technologies.

The question of how to persuade the wider populace to accept these technologies is exercising many of the best minds in indus-

try, and the story always begins with the promise of medical treatments. Consider the roadmap proposed by Professor Tim Denison, professor of neurotechnology at the University of Oxford:

To help focus investment, neural interface technologies could benefit from an industry roadmap. Roadmaps can help guide the development of applications in a manner that meet [sic] the balanced requirements for successful translation, including economics. One historical example of successful application of platform deployment is provided by the innovator, Alfred E Mann. Mann's group developed a 16-channel cochlear implant for the hearing impaired. From this core stimulator, they expanded to a 16-channel spinal cord stimulator for chronic pain. Finally, they built a prototype of what would become the Argus retinal prosthesis using the same core building blocks. Common platforms can help to lower the marginal investment cost for exploring new ideas. . . . While the 16-channel retinal implant was useful as a prototype, it was upgraded to a 64-channel system before commercial translation as a humanitarian device exemption.41

Denison's three-step movement to "commercial translation" cannot get started without the development of medical applications. His proposed progression begins with the development of technologies capable of neuromodulation (treating Parkinson's disease, epilepsy, or chronic pain; assistive technologies; or mental health monitoring), followed by those that can be developed in consumer electronics (enhanced gaming, neurofeedback, and meditation assistance), and culminating in medicalized products offered to the consumer, which he labels as neuromarketed products for cognitive enhancement (memory, alertness, sleep quality, and academic performance enhancements).<sup>42</sup> The tension people feel between the hope for mastery and the hope for meaningful personal integrity is being met with the response: "But perhaps you could hope that these technologies might only enhance the 'real' you, since they will only augment those aspects of you that you already value?"

## THE PROSPECTORS IN THE NEURAL GOLD RUSH

Elon Musk is another keen investor in brain-machine interfacing, not wanting to be bypassed by the medical technologists at Clinatec,

Duke, and other biotech companies on a lucrative technological market. Musk has had some success with his robotic device for implanting brain-reading microfibers on the living brains of rats, monkeys, and pigs.<sup>43</sup> Perhaps unsurprisingly, Musk tends to find it harder than a full-time medical researcher like Benabid to present his project as a genuinely therapeutic intervention, his language falling into his native engineer-problem-solving idiom that sits at some distance from the hospital. At one live Neuralink event, for example, he emphasized that Neuralink technology would be able to treat a wide variety of spinal neurological conditions, including seizures, paralysis, brain damage, and depression. "These can all be solved with an implantable neural link," said Musk. "The neurons are like wiring, and you kind of need an electronic thing to solve an electronic problem." The company's aim is to "build an incredibly powerful brain-machine interface, a device with the power to handle lots of data, that can be inserted in a relatively simple surgery. Its short-term goal is to build a device that can help people with specific health conditions."44

What is important for our purposes is Neuralink's explicit admission that therapy is the "short-term goal" in the development of neural implant technology. Having worked with animals, Musk makes usefully explicit what I have suggested is only a tactical engagement in serving disabled people and people with "specific health conditions." Even if we grant Musk has noble desires to better the lives of disabled and mentally ill people,<sup>45</sup> we have already seen the reasons why those good intentions offer little protection against "long-term" market imperatives. Making quadriplegics walk will never be lucrative business, unless we see a radical reevaluation of the levels of investment in making this happen than we see today. (For instance, a friend in the Aberdeen rehabilitation and mobility service, which cares for some nine thousand patients in the region, told me that only a fraction are offered the "platinum" service of a powered wheelchair. Most are offered techniques of relational and practical empowerment to help them to live more peacefully with their new condition.) The distance between what these technologies are supposed to promise and what they actually can deliver in the ethico-political landscape of our present suggests that if Musk has made a contribution to the public discussion of neural implantations, it is not by making an advance in science but by performing a bit of science theater to legitimate the idea that the technology is capable of offering some sort of broad-based promise to those disenfranchised by their disabilities. As Danielle Carr observes:

Of all the wild speculations Elon Musk made during the Neuralink launch, the most accurate prediction was his quip that the device is "sort of like if your phone went in your brain." "Sort of like," indeed: Neuralink *is* like a phone in that it is yet another machine built for generating data. While the device does not represent a major advance in brain-machine interfaces, and the pipeline for applications beyond movement disorders is at best decades long, what Neuralink *does* offer is an opportunity to harvest data about the brain and couple it to the kinds of data about our choices and behaviors that are already being collected all the time. The device is best understood not as a rupture with the past, but as an intensification of the forms of surveillance and data accumulation that have come to define our everyday lives.<sup>46</sup>

One detail worth further examination is Musk's open avowal that some of the treatments he is imagining are ones that use neural links not in order for humans to control machines but so that machines can alter the mind, as in ameliorating depression (it should be noted that this aim is far more difficult and aspirational than physical movement, given that mental states are much less localized in one part of the brain).47 Many of the uses of these technologies that we might see in the next decade or less move in this computer-to-brain direction, at least if business strategists' predictions are accurate. Some relatively noninvasive brain-computer interfaces could, for instance, warn you when your attention is wandering, adjust the lighting in an office if the occupant is becoming stressed, or disable a company car if the driver is too drowsy. Some companies already have a dashboard that allows workers and managers to monitor the attention levels of their colleagues. Industry insiders predict that many of the more dangerous jobs in developed economies will eventually require brain-function monitoring of this type. More actively, these technologies can also enable people to control a PowerPoint presentation or Excel spreadsheet by a thought command. It is likely that "passthoughts" will be developed as a stronger biometric alternative to computer passwords.<sup>48</sup>

Western militaries have long dreamed of neuroenhancements, with neuroimplantation being a central focus of research. Military researchers hope to develop external suits to improve physical capacities of soldiers, not least because of the cultural legibility of superpower-granting exoskeletons like the comic book hero Iron Man. The need for exoskeletons to closely follow the movement of a soldier's body drives the quest of researchers to find new ways to more closely link the computer and the body, whether through central or peripheral nervous system interfaces.<sup>49</sup> Research is also ongoing on a range of other defense uses, such as to direct drones or other remotely operated vehicles, and it is here where we can see an obvious proximity of the therapeutic and military use of neuroimplants.<sup>50</sup> The most pressing reason why brain-computer interfaces are inevitable from the perspective of modern militaries is that the amount of information that needs to be immediately processed on the wired battlefield is overwhelming, which explains why the "Brain-Interface Project" is the most lavishly funded research program in the DARPA bioengineering program.<sup>51</sup>

Technology companies like Ekso Bionics (suppliers of paralyzed marathoner Adam Gorlitsky's exoskeleton) are also counting on the appeal of exoskeletons and other neuroprosthetics to people with limb paralysis and money to spend for high–end prosthetics. Even though the technologies of neuroimplantation and exoskel–eton prostheses are at highly variable levels of development, the promise of alleviation or the insinuation of a cure for paralysis remains a powerful marketing draw for those with able minds but bodies they cannot control.<sup>52</sup> Those with paraplegic and tetraple–gic family members tell me that they are astonished by the frequency that family members and friends send them stories of the miraculous power and promise of such healing technologies.

### THE POLITICAL UTILITY OF DISABILITY ANXIETY

Popular anxiety about disability is politically useful to governing elites. The crux of the story I have told thus far turns on the attempt to move popular attitudes regarding disability toward a greater acceptance of wider deployments of neural interfaces to healthy

people. We can now see that the particular problem in this specific case is that the general public is unsettled by precisely those uses that those developing neural interface technologies foresee them being used for. Because people are nervous about the suggestion that they need wires implanted in their brains in order to better control computers or to work more efficiently, those determined to profit from their development need to find a way to convince the public that it is ethically laudable to develop these technologies. We can go so far as to say that researchers and political strategists are vulnerably dependent on having a public that takes it as axiomatic truth that quadriplegics want to walk, just as those with other neurological conditions are desperate to be technologically healed. As long as there is widespread public support for the alleviation of illnesses and disabilities by any means, potential exists for breaking down people's fears about wider diffusion of the technology. Certainty about the rightness of eliminating disability is perfectly suited to bypass ethical qualms in the popular mind about a technology that pushes toward applications to extend beyond normal human capacity.

In fact, there have been recurrent deployments in modern developed nations of the fear of disability to produce political movement in populations. During the nineteenth century, for example, people with Down syndrome played this role. The doctor whose name was the source of the label "Down syndrome," John Langdon Down, based his theory of the condition on nineteenth-century racial classification systems. By classifying "idiots," Down was able to bolster his professional authority as an expert in the causes and development of the condition, and then shape public policy toward his preferred solution, institutional segregation. The power of anxiety was at the heart of his analysis. His theory was elegantly, even simplistically, focused on anxiety. Down syndrome was caused by maternal anxiety during pregnancy, and the presence of people with Down syndrome caused people anxiety. By regularly highlighting the anxiety of parents of children with Down syndrome, Down bolstered his case for his preferred political proposal: institutions in which people with disparate intellectual capacities could be kept away from the general populace. Thus, as Stacy Simplican has observed, "Down helped craft an anxiety of disability that arises between people due to incommensurate capacities. Down promised to ease this anxiety by first adding precision to the identification of idiots, then segregating them accordingly."<sup>53</sup> More recently, the high visibility of Down syndrome and public anxiety about the condition has again been harnessed to foster public acceptance of another technology initially viewed with popular skepticism: prenatal screening technologies—technologies designed from the outset with the aim in mind of eliminating people with Down syndrome, but also promising to eliminate other congenital conditions.<sup>54</sup>

The ground we have covered now makes it clear that there are substantial ethical questions at stake around neural implant technologies, and they are ones with direct links to the management of modern developed nation-states in the economic, policing, and medical domains. The COVID-19 pandemic has provided ample displays of the capacity of nation-states to deploy their legal power to confine populations to their homes, and their financial and industrial might to quickly develop new vaccines and deliver them to whole populations. As in previous eras, in such an emergency condition, governing authorities are often granted the power to rewrite laws and rules, without the usual safeguards. The more existentially threatening the emergency, the more obviously licit this rewriting of convention and law becomes, as Carl Schmitt so influentially argued. This happens differently, at once more subtly and invasively, in a bureaucratically managed surveillance state. Whereas infected citizens in previous eras could be walled off in a part of the city, essentially to die, our society need not physically segregate bodies but only to institute highly intricate track-andtrace systems, systems that are doubly useful in promising the constant goal of the wired society: hot-spot policing. In the process, laboriously constructed but tenuously balanced privacy protections are almost instantly swept away.

The basic political problem presented by the technologies of neuroimplantation is that the lowest-risk procedures, such as deep brain simulation, are minimally invasive and so not very risky but are effective at altering the brain, not using the brain to control a computer.<sup>55</sup> More contacts are needed with disparate parts of the brain if the flow of electrical information is to be reversed and to become rich enough to be usable for directing computers. Thibault's sensors

had to be large in order to allow more sensors to contact a greater number of points on the surface of the brain. Here we have the catch-22 for those who wish to see widespread neural interfaces, because very few of us would consent to have two five-centimeter holes drilled in our skulls. But for the elite who clearly see the great windfall that widespread use of neural interfaces promises, emergency cases such as Thibault's paralysis present themselves as an opportunity to dissolve the current legal and social resistance to such alterations of the human body. To achieve this end may occasionally demand that social anxiety about certain states of disabled life be increased through public messaging, as it has historically been in the past. What matters is that cases are found in which the unthinkable can be attempted. Once the technique has been safely accomplished, and its utility made publicly manifest through the usual media channels, an idea that had once been unthinkable can be presented in terms that the masses might find more acceptable. It soon will be forgotten that a technique first developed to serve a subpopulation that the public pities ought now be considered for its continuing profitability and usefulness.

So do techniques developed to "cure" a human condition that is widely feared become the occasion for the emergence of a new normal. We are used to the story of disabled lives being segregated, sequestered, and even remade for the good of the managed society.<sup>56</sup> What I am highlighting is the incorporation of disabled lives into a posthuman story about the good life for humans. Here disabled lives are not hidden away but rendered meaningful as a gateway to a new social order, and so meaningful, at least for a moment.

## **ON PARALYSIS AND EXOSKELETONS**

What popular feel-good articles and science-fiction films tend to hide away is the intense labor and great expense entailed in attempts at medical restoration of paralyzed limbs. Anyone who has spent any time around someone with a paralyzed limb or limbs will be aware that, relatively quickly after the loss of nerve control, a limb will contract and atrophy, to the extent that bending joints becomes difficult and painful. This is why putting a tetraplegic upright and forcing their limbs to move in a walking motion will never be the medically optimal or cost-efficient way to improve mobility.

The details provided in the official scientific report of Thibault's big walk make this point abundantly clear. We learn that his five meters of self-propelled locomotion while suspended by a ceiling track was the culmination of two years of preparation.<sup>57</sup> Thibault is paralyzed from his C5 vertebrae and had been only one of two who qualified for the research project, and the only one whose brain implants had worked as planned. The central technical innovation was a five-centimeter round disk with highly sensitive electric sensors on its surface. Only slightly thicker than the depth of the skull, this sensor was positioned outside the protective membrane around the brain, above the motor cortex in both of the brain's hemispheres. The innovation is this placement of the sensing apparatus on the membrane of the brain rather than inserting wires through that membrane, which tends to provoke immune responses. Two five-centimeter holes had to be cut into Thibault's skull in order for the sensors to be fitted, which are meant to remain there permanently. All previous approaches have attempted to avoid such large excisions of healthy skull bone, with the previous wire-implanting approaches requiring drilling only small holes in the skull. The first patient who had these new sensors implanted was left with two large holes in his skull when the malfunctioning units had to be removed, a not-insignificant negative outcome.

The academic article on the procedure Thibault underwent exposes what is artfully hidden in popular articles: this is a highly expensive research protocol and would only function in a resourceintensive environment. Surgeons are needed to implant the sensors, physiologists to stretch atrophying muscles, computer technicians to monitor and update software, and engineers to oversee the mechanical aspects of the exoskeleton. This is many orders of magnitude more expensive and complex than the implantation of a single wire into the brain of a patient suffering from Parkinson's disease, which this more complex sensor only superficially resembles. And even with these much more sensitive sensors implanted, the notion that they provided enough neural feedback to allow Thibault actually to walk remains a bit of a slight of hand: his exoskeleton is still tethered to a track on the ceiling of his lab, and it is clear from the videos released that very little weight rests on his feet. He is "walking" only in the sense that his limbs are making the basic motions of the walking gait, initiated if not controlled by his mind. He is in no sense standing on his own two feet, and we are a long way from the sensors having the bandwidth, for instance, to allow Thibault to catch himself should he trip or become imbalanced. Over the course of the entire research project, in thirty-nine sessions in the exoskeleton, Thibault covered only 145 meters in a cumulative total of 480 steps.

Exponentially more computing power will be needed if actual bipedal locomotion untethered from the supportive ceiling track is to be achieved, in addition to a more compact energy source. We are many iterations and vast financial expenditure away from this ungainly technology being anything that could be used to walk around a home or public place. As the authors of the published paper point out, however, the primary aim of the project was not to create a working exoskeleton or even facilitate Thibault's walking. His walking was essentially a visually arresting and culturally resonant deployment of the core focus of the study, a sensitive but long-lasting neural implant.<sup>58</sup> Having crossed this threshold, Thibault is now practicing using his brain implants to drive a motorized wheelchair, almost the identical wheelchair he was capable of steering before his neurotransmitter was implanted, using the remaining capacity in his right upper arm. Practically speaking, Thibault may have had a fun adventure in science, but it is unlikely to make any significant difference for his mobility or independence in years to come.

A disproportionate number of those who become paralyzed through a spinal injury already do not have adequate healthcare, leading them after paralysis to fall in disproportionate numbers even further below the poverty line.<sup>59</sup> Even if sufficient basic healthcare for the most needy was to be available, this particular technological route will never be a viable solution to their paralysis and the mobility limitations that attend it. It is a technology invented by the wealthy, which, if ever made functional, will be used only by those with access to substantial wealth. Even if neural implants were developed for Thibault, the remarkable imbalance between the cost and invasive nature of their installation and the limited benefit they give him makes it clear that they are intended to benefit others and have already benefitted Benabid and Clinatec. Given that research on ameliorating a

wide range of disabilities very often goes unfunded and given the relatively small numbers of patients who will use it, all indicators point to experiments of this type being directed not really at the good of the community of those with disabilities but at the investors who are rooting for it to look persuasive to the public.

We have now surveyed the economic, moral, and cultural landscape in which it makes perfect sense for popular articles discussing brain-machine interfaces to begin invariably by mentioning that these techniques were first developed to help people with brain or spinal cord injuries. It is precisely the rude primitivity to date of brain-computer link technologies sensitive enough to allow quadriplegics to walk that has allowed us to see that the therapyenhancement distinction might not be abstractly morally sustainable, but it nevertheless remains at the heart of the goal-masking demanded by modern economic and technological imperatives. Projects like Thibault's exoskeleton are the cultural mask for a more basic ethical gambit. Their essential function is to harness a widespread public desire to eliminate a specific disability as an occasion to create a technology that can be more widely deployed once it has been proved to work and to not have obvious downsides. A therapeutic usage is the gateway through which an economic hope—a survival hope widely shared by the politicians and citizens of developed nations—can be offered to citizens. Can we really afford to pass up the economic advantages that will inevitably accrue to those who master this new technology and deploy it more widely?

## MAKING THEMSELVES USEFUL: THEOLOGICAL THOUGHTS ON USING THE DISABLED

A nearly universal consensus has emerged among disability theologians on two basic points. First, disabled lives should not be instrumentalized to achieve the aims of others. It is this claim that energized secular movements like the emptying of the asylums, and that took form in Christian theology as an internal critique of the long-standing Christian presumption that the role of disabled people in God's economy was to be recipients of charity. That critique insisted that being vulnerable or different should never position anyone as an all-time recipient of charity for the exercise of the majority's need to "do good works to the needy." One of the early impulses funding the rise of the academic discourse of disability theology was the felt need to work out what follows in the wake of such an affirmation. Every human gaze that looks on a disabled person and sees the money that can be made from treating them (or from loudly broadcasting that they have been treated) falls foul of this first affirmation.

Second, the wide variations of human bodily and mental forms and capacities should be understood as a constitutive aspect of the vulnerability intrinsic to being creatures. The human race is more diverse than we imagine, and this diversity is good and should be affirmed. We should never seek to eliminate the differences of form and capacity that will always be present in the human community. This is often called the "normate assumption." To reject the assumption that all bodies should be judged against some universal norm is not to reject all therapeutic interventions that alter the body. It is to insist that all such interventions aim explicitly to ameliorate the sickness and suffering of individuals. There is no single norm for the functional human body to which every human ought to be made to conform. All hopes to eliminate disability entirely fall foul of this theological affirmation.

Might the first point prompt Christians to commit to refusing to use disabled lives to further their own agendas? Modern people have in fact very often refused to make any such commitment. The bodies of stillborn disabled fetuses and anomalously configured children's bodies have been a mainstay on which the imposing edifice of modern medical and genetic science has been built.<sup>60</sup> Modern philosophy in both its early and late modern varieties has almost invariably ignored physical and mental impairments except as useful illustrations of humans lacking supposedly universal human mental or physical traits.<sup>61</sup> Modern economics has systematically positioned those with disabilities alongside children and old people as nonproductive drags on the economy rather than productive contributors.<sup>62</sup>

It is this latter logic that almost certainly shaped the appeal made to Thibault to consider enrolling in a neural implant research protocol. Whether explicitly stated or not, as a young man of prime working age, Thibault could not but be aware of the widespread assumption that the technological elimination of disabilities is widely considered desirable among the late-modern public. Nor would it have been easy for him to ignore the assumption that by offering his body as a test bed for a socially useful technological innovation, he might transcend the class of nonproductive citizens to which disabled people are largely relegated in the developed world. One can also easily imagine the appeal to someone recently paralyzed at the beginning of the prime of life of being the center of a multimillion–euro research protocol at a world–class technology research lab. And under and through it all would no doubt filter the highly seductive call of the constantly present cultural narrative, that given powerful–enough technology, the lame can walk like the deaf have come to hear. It may even be that in agreeing to be the subject of this research, Thibault was trying to take control of his own treatment trajectory, which, remarkably, is often absent in the treatment regime to which most spinal cord patients are subjected.<sup>63</sup>

Having traced the widespread cultural anxieties about disability and disruptive technological change that percolate through developed societies helps us make sense of what is going on in the stepping out of Thibault onto the global stage wearing his mind-activated exoskeleton. Without the twinned anxiety about disability as well as the potentially ethically and socially problematic aspects of neural implants, we cannot make sense of his story with Clinatec and, through the global media, with us. His story forces us to examine our participation in culturally configured anxieties among modern humanity about how to relate to its limits, its finitude.

Here disability theology can help us understand the importance of making peace with our finitude.<sup>64</sup> But education alone cannot dispel the problem of modern anxiety about our finitude, suggests Stacy Simplican. "When we presume that we can dismantle our anxiety about disability with knowledge, we reassert the fantasyland of the cognitively ideal world: that we have control over our minds; that we can decide to choose the way we think; and that we can, on demand, recalibrate the way we feel. This fantasy disavows disability all over again, as it sustains the familiar and fantastic cognitively ideal self—always troublesome, always seductive."<sup>65</sup> I have drawn attention to a related but equally seductive dream, the dream of the ideal, upright, and mobile physical self, and the anxieties that typically attach to our fears of losing this state (at least for those of us who have never really contemplated life without bodily mobility).

#### 176 | Bioenhancement Technologies and the Vulnerable Body

Let me end where I might have begun. Anxiety about finitude is part of the human condition, one that ought not be waved away. There has been a tendency among modern Christian theology to overshadow this aspect of human existence by overemphasizing human anxiety about sin. But anxiety about sin and judgement for sin is intertwined with and rests on anxiety about finitude and bodily death. Thus, the case of Thibault brings us before the truth that the Christian life is a *manner* or *mode* of living out our finitude, of responding to our finitude. Sin is that form of life that lives out creaturely finitude as if it could be surmounted. Those people who believe in the resurrection of Jesus Christ from the dead, also called Christians, are people who live their mortal lives as those transformed, literally metamorphized by that hope. In 1 Corinthians 15, the apostle Paul presents a vision of the resurrected or spiritual body as definitional for all Christian hopes for transformation:

<sup>40</sup> There are both heavenly bodies and earthly bodies, but the glory of the heavenly is one thing, and that of the earthly is another. <sup>41</sup> There is one glory of the sun, and another glory of the moon, and another glory of the stars; indeed, star differs from star in glory. <sup>42</sup> So it is with the resurrection of the dead. What is sown is perishable, what is raised is imperishable. <sup>43</sup> It is sown in dishonor, it is raised in glory. It is sown in weakness, it is raised in power. <sup>44</sup> It is sown a physical body, it is raised a spiritual body. If there is a physical body, there is also a spiritual body. <sup>45</sup> Thus it is written, "The first man, Adam, became a living being"; the last Adam became a life-giving spirit.

Christian life is bodily, like everyone else's, yet is also animated by Christ as the "life-giving spirit" in a manner that changes the manner and mode of that body's activity. Paul does not deny but rather emphasizes that in the creaturely world the metamorphosis of the body that is death is a universal reality. All creaturely bodies come and go, changing form as they do so, metamorphizing. But Christ desires that these changeable bodies be transformed, by being animated by the Spirit.

Christians are left with the question of how to live this hope that transforms in a world without this hope. Without knowledge of eternal life, one can only hope to escape death and the limitations of finitude that can only appear as tragedies. Those who live only in the first Adam cannot but project the form of their current lives onto an undifferentiated span of future time to come. The only transformation possible for the first Adam is Nietzsche's recovery of the ancient idea of freedom as eternally accepting one's life and choices. From the viewpoint of the second Adam, however, this is an attempt at human self-transformation, the victory of our wills over death, finitude, and vulnerability.

A different way of living our fleshliness is held out in the resurrecting life of Christ, a life that can only be received through dying and vulnerability from the hand of the victor over death. The resurrecting power of God offers an alternative form of freedom to human lives than the dreams of the transhumanist, of which exoskeletons for the paraplegic are a telling icon. The exoskeleton may simulate lost mobility in some respects, and this may someday be a relatively good thing for people with mobility limitations. These are good things that might, perhaps accidentally,<sup>66</sup> emerge from transhumanist dreams. These dreams themselves are only another sad iteration of human resistance to the repentance and gratitude that leads to more wholesale transformation of not only our material bodies but our relationships to one another. Exoskeletons may simulate mobility, even if they spring from lives that have little inkling of genuinely new life.

There is more, much more, to say about disability from a theological perspective, but we will say none of this well if we have not made this crucial first move, of at least aspiring to learn what it means to come to terms with the implications of being finite creatures. To be freed from the sinful desire to be like gods takes not education but a savior who can show us the way through anxiety about illness and paralysis and physical suffering because he too has traversed it. By God's grace, Jesus Christ not only was resurrected with a glorified body but also showed us what it looks like to faithfully traverse the life of the finite creature, even through Gethsemane and Calvary.

#### Νοτές

 "Brain-Controlled Exoskeleton Helps Paralysed Man Learn to Walk Again in Technological Breakthrough," ABC News Australia, October 4, 2019, https://www.abc.net.au/news/2019-10-04/paralysed-man-learns -to-walk-again-brain-controlled-exoskeleton/11575882.

- 178 | Bioenhancement Technologies and the Vulnerable Body
  - 2 Clare Wilson, "A Mind-Controlled Exoskeleton Helped a Man with Paralysis Walk Again," New Scientist, October 3, 2019, https:// institutions.newscientist.com/article/2218863-a-mind-controlled -exoskeleton-helped-a-man-with-paralysis-walk-again/.
  - 3 Catherine Thorbecke, "Quadriplegic Man Walks with an Exoskeleton He Controls with His Brain," ABC News USA, October 4, 2019, https:// abcnews.go.com/Technology/quadriplegic-man-walks-exoskeleton -controls-brain/story?id=66060762.
  - 4 "World Cup 2014: First Kick Made by Paralyzed Man with the Help of Mind-Controlled Robot," YouTube video, 1:31, posted by Rajamanickam Antonimuthu, June 13, 2014, https://www.youtube.com/watch ?app=desktop&v=TcAvtglo9Jg&pli=1.
  - 5 Anita van Mil, Henrietta Hopkins, and Suzannah Kinsella, From Our Brain to the World: Views on the Future of Neural Interfaces; A Public Dialogue Research Programme Conducted on Behalf of the Royal Society (London: Creating Connections, Hopkins Van Mil, July 2019), 11.
  - 6 Kelly McCarthy, "After 7 Years in Wheelchair, Groom Walks Down Aisle on His Wedding Day," ABC News USA, April 27, 2018, https:// goodmorningamerica.com/family/story/years-wheelchair-groom -walks-aisle-wedding-day-54775343.
  - 7 Disability critiques of this story: Helena L. Martin, "Martyrs and Monsters of the Avengers: Christianity and Disability in the Marvel Cinematic Universe," Journal of Disability & Religion, 24, no. 4 (2020): 453–61.
  - 8 Alim Louis Benabid et al., "An Exoskeleton Controlled by an Epidural Wireless Brain–Machine Interface in a Tetraplegic Patient: A Proof–of– Concept Demonstration," *Lancet Neurology* 18, no. 12 (2019): 1120, https://doi.org/10.1016/S1474-4422(19)30321-7; "Watch Paralym– pian Jennifer French Stand Again Thanks to Bionic Implants," YouTube Video, 7:03, posted by World Science Festival, August 28, 2014, https:// www.youtube.com/watch?v=CZCLBiUAKgo.
  - 9 See Michael Banner, "A Doctrine of Human Being," in *The Doctrine* of God and Theological Ethics, ed. Alan Torrance and Michael Banner (London: T&T Clark International, 2006), 146. See also Tim Ingold, "'To Human' Is a Verb," in Verbs, Bones, and Brains: Interdisciplinary Perspectives on Human nature, ed. A. Fuentes and A. Visala (Notre Dame: University of Notre Dame Press, 2017), 71–87.
  - 10 Brian Brock, "Seeing Through the Data Shadow: Living the Communion of the Saints in a Surveillance Society," *Surveillance and Society* 16, no. 4 (2018): 533–45.
  - 11 The most sophisticated and up-to-date Christian argument for the unsustainability of the therapy-enhancement distinction is Gerald

P. McKenny, Biotechnology, Human Nature and Christian Ethics (Cambridge: Cambridge University Press, 2018).

- 12 Van Mil, Hopkins, and Kinsella, From Our Brain.
- 13 There is a long history of dispute about cochlear implants in the deaf community, which turns upon the advisability of such operations to partially restore hearing while fundamentally rejecting the culture deaf people have built up over many generations. Raylene Paludneviciene and Irene W. Leigh, eds., Cochlear Implants: Evolving Perspectives (Washington, D.C.: Gallaudet University Press, 2011). There is a fundamental incompatibility between the desire to be "proudly deaf" and implants. Discourses premised on the value of Deafness and Deaf culture typically have little positive to say about implants. H.-Dirksen L. Bauman and Joseph J. Murray, eds., Deaf Gain: Raising the Stakes for Human Diversity (Minneapolis: University of Minnesota Press, 2014). The feature film The Sound of Metal (Pacific Northwest Pictures, 2020) powerfully depicts the visceral experience of deaf communities to cochlear implants as a technology inflicting social and physical violence on deaf communities.
- 14 Van Mil, Hopkins, and Kinsella, From Our Brain, 12.
- 15 Van Mil, Hopkins, and Kinsella, From Our Brain, 37.
- 16 Van Mil, Hopkins, and Kinsella, From Our Brain, 37.
- 17 Van Mil, Hopkins, and Kinsella, From Our Brain, 40.
- 18 Van Mil, Hopkins, and Kinsella, From Our Brain, 25.
- 19 Van Mil, Hopkins, and Kinsella, From Our Brain, 22.
- 20 Van Mil, Hopkins, and Kinsella, From Our Brain, 38
- 21 Don Idhe, *Technology and the Lifeworld: From Garden to Earth* (Bloomington: Indiana University Press, 1990), 74–80.
- 22 Van Mil, Hopkins, and Kinsella, From Our Brain, 12–13.
- 23 Van Mil, Hopkins, and Kinsella, From Our Brain, 13.
- 24 Van Mil, Hopkins, and Kinsella, From Our Brain, 64. Note that throughout the document no awareness is shown of the difference between the labels "Deaf people" and "deaf people." The quotation here offers a popular restatement uncannily reminiscent of the main thesis of Hans Reinders' now twenty-year-old book, The Future of the Disabled in Liberal Society (Notre Dame: University of Notre Dame Press, 2000).
- 25 The title of a recent and influential Rand report is telling: Marissa Norris and Alyson Youngblood, "Brain–Computer Interfaces Are Coming: Will We Be Ready?" Rand Corporation, August 27, 2020, https:// www.rand.org/blog/articles/2020/08/brain–computer-interfaces-are -coming-will-we-be-ready.html.

- 180 | Bioenhancement Technologies and the Vulnerable Body
  - 26 Adam Greenfield, *Radical Technologies: The Design of Everyday Life* (London: Verso, 2018), chaps. 1–2.
  - 27 Shoshana Zuboff outlines why we cannot participate in the wired society without surrendering data, and why the ubiquitous "terms of agreement" that we sign on an almost daily basis do not, and cannot, function in the way pre-internet contracts once worked. In terms of the pre-internet definition of the contract, they are best labelled "uncontracts." There is no "opt out" of data sharing in the wired world, only cosmetic increments of how much data we share. In this respect, the sociological fact that vanishingly few of us read the contracts that we sign online is in fact a tacit recognition that if we choose to opt out of data sharing, we will lose the functionality of the device or app that we are using. Zuboff, *The Age of Surveillance Capitalism: The Fight for the Future at the New Frontier of Power* (London: Profile Books, 2019), chs. 5–7.
  - 28 The Hollywood blockbuster *Minority Report* (DreamWorks, 2002) first and most influentially announced the inevitability—but also the worrying implications—of the prediction–based politics of the "smart city."
  - 29 The much-criticized policing approaches going under the labels "broken windows," "stop and search," "zero-tolerance," and "quality of life policing" are all dependent on surveillance technologies that can predict hot spots where extra policing—or especially heavy-handed policing—is believed to be effectively deployed. The intent to track the real time location of the desire to menace or be antisocial is the policing analogue to the real-time location of consumer desire that is the engine of the click-and-buy economy. See Matt Taibbi, *I Can't Breathe: A Killing on Bay Street* (New York: Spiegel & Grau, 2017), 51–70.
  - 30 Zuboff, Age, ch. 5
  - 31 Zuboff, Age, 203 (emphasis original).
  - 32 Zuboff, Age, 287.
  - 33 Zuboff, Age, 289.
  - 34 Danielle Carr, "Shit for Brains," *Baffler*, September 29, 2020, https:// thebaffler.com/latest/shit-for-brains-carr.
  - 35 "Robotic Exoskeleton Helps Paralyzed Man Race Marathons," You-Tube video, 6:50, posted by "Freethink," August 7, 2019, https://www .youtube.com/watch?v=vBtXHGEezJA.
  - 36 "Robotic Exoskeleton," YouTube video posted by "Freethink."
  - 37 "iHuman Perspective: Neural Interfaces," Royal Society, September 10, 2019, https://royalsociety.org/topics-policy/projects/ihuman -perspective/.
  - 38 In 2014 Benabid won a big-tech-sponsored prize for other neural interfacing projects. In a press release on the Clinatec website, his links

to big tech are front and center as well as the role of the media in sustaining the narrative I have described in this chapter. "Clinatec Chairman Alim-Louis Benabid Wins Breakthrough Prize," Clinatec, November 12, 2014, https://www.clinatec.fr/en/breakthrough-prize-2/.

"Professor Benabid personifies the expertise and dedication that lead to new treatments for neurodegenerative diseases, disabilities, and cancer, which are at the center of Clinatec's research and development," said Jean Therme, director of technical research at CEA, the French alternative energies and atomic energy research institute that helped launch Clinatec. "The Breakthrough Prize and his many other awards offer encouragement to scientists and physicians at Clinatec and elsewhere who are dedicating their careers to improving the lives of patients."

The Breakthrough Prize in Life Sciences Foundation, which also recognizes exceptional work in fundamental physics and mathematics, is sponsored by some of the world's biggest high-tech names. Founders include Sergey Brin, co-founder of Google; Anne Wojcicki, co-founder of the genetics company 23andMe; Alibaba CEO Jack Ma and his wife, Cathy Zhang; the Russian venture capitalist Yuri Milner and his wife, Julia Milner, and Facebook CEO Mark Zuckerberg and his wife, Priscilla Chan.

The Breakthrough Prize in Life Sciences award was presented to Benabid and the other winners on Nov. 9 in Silicon Valley, Calif. The award ceremony will be televised in the U.S. as a simulcast on Discovery Channel and Science Channel on Nov. 15 and globally the weekend of Nov. 22 on BBC World News.

- 39 "Brain-Controlled Exoskeleton," ABC News Australia.
- 40 "Until medical experimentation is seen as an opportunity—and perhaps even an obligation—for everyone, I find it hard to justify the continued use of prisoners and the poor as experimental subjects." Stanley Hauerwas, Suffering Presence: Theological Reflections on Medicine the Mentally Handicapped and the Church (Edinburgh: T&T Clark, 1986), 120.
- 41 Tim Denison, "Neural Interface Technologies: Industrial Perspectives," iHuman Working Group Paper, Royal Society, 2019, 4, https://royalsociety .org/-/media/policy/projects/ihuman/7-industry-perspectives.pdf?la =en-GB&hash=496F7DD87D39C979293CC5A568120D8A.
- 42 Denison, "Neural," 5.
- 43 Musk's Neuralink project has, however, been dogged by accusations of animal cruelty. Theo Wayt, "Elon Musk's Neuralink Allegedly Subjected Monkeys to 'Extreme Suffering," New York Post, February 10, 2022.

- 182 | Bioenhancement Technologies and the Vulnerable Body
  - 44 Rebecca Heilweil, "Elon Musk Is One Step Closer to Connecting a Computer to Your Brain," Vox, August 28, 2020, https://www.vox.com/ recode/2020/8/28/21404802/elon-musk-neuralink-brain-machine -interface-research.
  - 45 On May 7, 2021, Musk publicly announced on Saturday Night Live that he has been diagnosed with Asperger's syndrome, positioning that announcement as an explanation for some of his more well-known social infractions. The announcement raises a host of questions, not least why Musk is using a diagnostic label that has been officially retired by the medical profession, and whether it is even possible to debate his right to identify as he would like. Adam McCrimmon, "What Happened to Asperger's Syndrome?" Conversation, March 8, 2018, http://theconversation.com/what-happened-to-aspergers -syndrome-89836; Victoria McGeer, "The Thought and Talk of Individuals with Autism: Reflections on Ian Hacking," Metaphilosophy 40, nos. 3–4 (2009): 517–30.
  - 46 Carr, "Shit for Brains" (emphasis original).
  - 47 Carr, "Shit for Brains."
  - 48 Alexandre Gonfalonieri, "What Brain-Computer Interfaces Could Mean for the Future of Work," *Harvard Business Review*, October 6, 2020, https://hbr.org/2020/10/what-brain-computer-interfaces -could-mean-for-the-future-of-work.
  - 49 Liam Stoker, "Military Exoskeletons Uncovered: Ironman Suits a Concrete Possibility," Army Technology, June 11, 2020, https://www.army -technology.com/features/featuremilitary-exoskeletons-uncovered -ironman-suits-a-concrete-possibility/ (accessed May 13, 2021).
  - 50 Gonfalonieri, "Brain-Computer."
  - 51 P. W. Singer, Wired for War: The Robotics Revolution and Conflict in the 21st Century (New York: Penguin, 2009), 71–74.
  - 52 "How Exoskeletons Can Help People With Paraplegia Walk Again," Spinal Cord Injury Zone, February 15, 2021, https://spinalcordinjuryzone .com/news/54908/how-exoskeletons-can-help-people-with -paraplegia-walk-again.
  - 53 Stacy Clifford Simplican, *The Capacity Contract: Intellectual Disability* and the Question of Citizenship (Minneapolis: University of Minnesota Press, 2015), 57.
  - 54 Gareth M. Thomas, Down Syndrome Screening and Reproductive Politics: Care, Choice, and Disability in the Prenatal Clinic (Abingdon, U.K.: Routledge, 2017); David Patterson and Alberto C. S. Costa, "History of Genetic Disease: Down Syndrome and Genetics—A Case of Linked Histories," Nature Reviews Genetics 6 (2005): 137–47.

- 55 "Deep Brain Stimulation," American Association of Neurological Surgeons, https://www.aans.org/en/Patients/Neurosurgical-Conditions -and-Treatments/Deep-Brain-Stimulation.
- 56 Martin Sullivan, "Subjected Bodies: Paraplegia, Rehabilitation, and the Politics of Movement," in *Foucault and the Government of Disability*, rev. ed., ed. Shelley Tremain (Ann Arbor: University of Michigan Press, 2015), 27–44.
- 57 Benabid et al., "Exoskeleton."
- <sup>58</sup> "This study describes the first successful long-term use of wireless epidural multi-channel recorders that were bilaterally implanted in a patient with tetraplegia. . . . All the technical elements that are required for long-term human clinical application (epidural recording, wireless power and emission, online decoding of many ECoG channels, and being totally embedded) have been combined for the first time." Benabid et al., "Exoskeleton," 1120.
- 59 Roni Caryn Rabin, "Study Raises Estimate of Paralyzed Americans," New York Times, April 20, 2009, https://www.nytimes.com/2009/04/ 21/health/21para.html.
- 60 Armand Marie Leroi, Mutants: On the Form, Varieties and Errors of the Human Body (London: Harper Perennial, 2005).
- 61 Licia Carlson, The Faces of Intellectual Disability: Philosophical Reflections (Bloomington: Indiana University Press, 2010); Angela Woods, The Sublime Object of Psychiatry: Schizophrenia in Clinical and Cultural Theory (Oxford: Oxford University Press, 2011).
- 62 David T. Mitchell with Sharon L. Snyder, *The Biopolitics of Disability:* Neoliberalism, Ablenationalism, and Peripheral Embodiment (Ann Arbor: University of Michigan Press, 2015); Michael Oliver and Colin Barnes, *The New Politics of Disablement*, rev. ed. (Basingstoke, U.K.: Palgrave Macmillan, 2012), ch. 3; Gary L. Albrecht, *The Disability Business: Rehabilitation in America* (Newbury Park, Calif.: Sage, 1992).
- 63 Sullivan, "Subjected Bodies," in Tremain, Foucault.
- 64 Deborah Beth Creamer, Disability and Christian Theology: Embodied Limits and Constructive Possibilities (Oxford: Oxford University Press, 2009).
- 65 Simplican, *Capacity Contract*, 92
- 66 Most effects of technology are unanticipated. Don Idhe, "The Designer Fallacy and Technological Imagination," in *Ironic Technics* (Copenhagen: Automatic Press / VIP, 2008), 19–30; Andrew Pickering, *The Mangle of Practice: Time Agency & Science* (Chicago: University of Chicago Press, 1995); Bruno Latour, *Aramis, or The Love of Technology*, trans. Catherine Porter (Cambridge, Mass.: Harvard University Press, 1996).