

Disability to Super-Ability:  
Issues Along The Human Enhancement Spectrum

by  
Ian R. Oakes

A THESIS

submitted to  
Oregon State University  
Honors College

in partial fulfillment of  
the requirements for the  
degree of

Honors Baccalaureate of Science in Bioengineering  
(Honors Scholar)

Presented June 3, 2020  
Commencement June 2020



## AN ABSTRACT OF THE THESIS OF

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Kenneth H. Funk II

Advancements in the field of medical and computer technology promise a new age of human enhancement technology (HET). These technologies may be aptly applied to existing Assistive Technology (AT), which was created to ameliorate disability, moving one up the spectrum of ability. This study aimed to determine how these technologies might act as a means or an impediment to living The Good Life, that is, a life of good health, purpose, fellowship, pleasure, and transcendence. Research was conducted in-person (prior to COVID-19) and remotely through Zoom. Research activities included guided interviews and open discussion with individuals living with physical disability. The interviews highlighted four primary issues with AT, representing barriers to achieving The Good Life: (1) cost, (2) distribution, (3) education, and (4) assessment, design, and customization. Corroboration with literature revealed a fundamental issue with AT: stigma leading to diminishment of humanity. These issues must be overcome for AT to improve one's opportunity to live The Good Life. Considerate policy decisions might address issues of cost, distribution, and assessment, yet, stigma represents an underlying issue that may become exacerbated by new forms of AT.

Key Words: Human enhancement technology, assistive technology, disability, The Good Life

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I understand that my project will become part of the permanent collection of Oregon State University, Honors College. My signature below authorizes release of my project to any reader upon request.

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## Foreword: COVID-19 Statement and Impact on Research

At the time of writing the United States and the world at large face an unprecedented public health emergency that has caused radical social and economic change over the course of several months. Currently (4 June 2020), there have been more than 108,000 deaths in the United States, and over 389,000 worldwide due to the novel coronavirus COVID-19.<sup>1</sup> To mitigate the rapid spread of the disease, stay-at-home orders were issued in most U.S. states. Here in Oregon, a stay-at-home order was issued by the governor on March 23, 2020. At Oregon State University all on-campus classes were canceled for the duration of spring term, and non-essential research has been halted.

As a direct result of these actions, in-person research was suspended for this thesis. Instead, remote interviews were approved by the IRB; however, the emotional, economic, and social stress resulting from the viral pandemic caused difficulty in recruitment activities. Insufficient numbers of participants were recruited, therefore, the thesis committee decided to shift the focus of this thesis from research-based to a theoretical/literature review format. As such, the research question was revised to focus on highlighting the existing issues with assistive and human enhancement technology.

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<sup>1</sup>COVID-19 Map. (2020, June 4). Retrieved June 4, 2020, from <https://coronavirus.jhu.edu/map.html>

## Introduction

Medicine, and by extension medical technology, seeks to promote wellbeing and uphold human health, a basic need that must be fulfilled before one can live The Good Life. While medicine has primarily aimed to bring individuals to a “normal state”, recent advances in the field of medical and computer technology promise the opportunity of human enhancement – that is, the use of technology to alter human traits beyond a natural ability level. For individuals living with a physical disability human enhancement might be an opportunity to improve quality of life, bringing one to a state of normal ability. Such technology may also allow individuals with normal ability to surpass normal ability to a state of “super-ability”, wherein abilities surpass the normal human range. It is necessary to consider the ethical dilemmas that could arise from this scenario and the impact of such technology on one’s ability to live The Good Life – a life of good health, purpose, fellowship with others, pleasure, and transcendence. Specifically, what does one give up (if anything), in terms of living The Good Life, to alter human ability and move up the continuum of human enhancement? Is it worth it?

Oscar Pistorius, a former South African professional sprinter and double-leg amputee, gained notoriety after fatally shooting his girlfriend in his home in Pretoria in 2013. It is acknowledged that this act likely brought him to the international spotlight, but Oscar’s story prior to the shooting is more relevant to the content of this thesis.

Pistorius was born with a congenital defect that caused incomplete development of parts of his feet and both fibula bones in his legs. At 11 months Pistorius’s parents decided to have his lower legs and feet amputated below the knee to ensure he could learn to walk in prosthetics. Even so, by primary school Pistorius was able to participate in numerous sports such as rugby, water polo, tennis, and wrestling. After a knee injury in 2003 forced Pistorius to end his rugby career, he began running while undergoing rehabilitation. With encouragement from his coach Ampie Louw, Pistorius began running full time. Needing a more robust prosthetic for running, Louw turned to prosthetist Francois van der Watt to fit Pistorius with his first racing prosthetics, later produced by the Icelandic company Össur.

Only one year later, in 2004, Pistorius competed in the Summer Paralympics in Athens, finishing third overall in the 100-meter dash T44. The T44 is a class for single below-knee amputees. Even though Pistorius classifies as a T43 (double below-knee), he chose to compete in the T44 because the competition in T44 was more aligned with his abilities (T44 athletes are

typically faster than T43). Soon after, Pistorius finished first with a world record time of 21.97 seconds in the T44 200-meter final (beating two American runners with single amputations). In 2005 Pistorius remained successful, finishing sixth in the non-disabled South African Championship 400-meter race, winning gold in the 100, 200 and 400 meters at the Paralympic World Cup, and smashing his own Paralympic records in the same events. After these successes, Pistorius looked to compete in the 2008 Summer Olympics in Beijing. As Pistorius continued to succeed in non-disabled events, controversy was sparked over the use of his advanced prosthetics.

Pistorius used J-shaped carbon fiber prosthetics developed by biomedical engineer Van Phillips. These prosthetics, named the “Flex-Foot Cheetah”, act as springs – storing the kinetic energy of each stride impact, to be released and propel the runner forward – replicating the action of the fibula, gastrocnemius (calf muscle), ankle, and foot.<sup>2</sup> After his successes during the 2006 season, Marion Shirley and Brian Frasure (competitors in the T44 200 meter dash) lodged complaints with the IAAF, claiming that Pistorius’s artificial limbs gave him an advantage over runners with normal ankles and feet. Shortly afterwards, the IAAF responded by amending the competition to rules to ban “any technical device that incorporates springs, wheels or any other element that provides a user with an advantage over another athlete not using such a device”.<sup>3</sup> Although the IAAF claimed the ruling was not specifically pointed to Pistorius, he was the only athlete directly impacted by the ruling. Several months later Pistorius was invited to participate in multiple scientific tests at the German Sports University Cologne under the guidance of the IAAF, to determine if his artificial limbs gave him a superhuman advantage. The findings reported that Pistorius’s used 25% less energy than runners with natural legs running at the same speed. Additionally, this equated to 30% less mechanical work for lifting the body.<sup>4</sup> Based on these results the IAAF banned Pistorius’s prostheses from all IAAF regulated events, which included the 2008 Summer Olympics.

In response, Pistorius and his team appealed the decision to the Court of Arbitration for Sport (CAS) in Switzerland. On May 16, 2008 CAS confirmed Pistorius’s appeal, and revoked the IAAF council ban. The CAS found that the German Sports University Cologne Study only

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<sup>2</sup> Oscar Pistorius, Össur, retrieved 20 January 2020

<sup>3</sup> IAAF Council introduces rule regarding "technical aids", IAAF, 26 March 2007, archived from the original on 17 June 2008, retrieved 25 January 2020; Competition Rules 2008 (PDF), Monaco: IAAF, 2008, p. rule 144.2(e)

<sup>4</sup> 'Blade Runner' handed Olympic ban, BBC Sport, 14 January 2008

tested Pistorius's biomechanics at full speed in a straight line, rather than considering the disadvantages Pistorius has during acceleration at the start of the race. They concluded that there was no evidence that Pistorius had a net advantage over non-disabled athletes.<sup>5</sup>

After the IAAF ruling was overturned, Pistorius attempted to qualify for the 400-meter race at the 2008 Summer Olympics in Beijing but failed to meet the 45.95 second qualifying time. Further controversy was sparked when IAAF secretary Pierre Weiss commented that IAAF preferred that the South African Olympic Committee not select Pistorius for its 4x400 meter relay team for "safety" reasons.<sup>6</sup> Yet, there was no recorded instance of physical safety issues regarding Pistorius's prosthetics. Motivated by yet another setback, Pistorius set his sights on the 2012 Olympics in London. On July 19<sup>th</sup>, 2011, Pistorius set a personal best in the 400-meter race with a time of 45.07 seconds, attaining the Olympic Games "A" standard qualification mark. Later that year, in August, the South Africa Olympic committee announced that Pistorius would compete in the 400-meter and 4x400 meter relay.

On August 4, 2012, Pistorius became the first amputee runner to compete in an Olympic Games event. He performed well but ended finishing eighth and last in the semi-final heats with a time of 46.54 seconds in the 400-meters. Regardless of the results, the race was a historic moment. It brought physical disability to the spotlight, challenging the status quo, and inspiring many to rethink notions of what "disability" really means. Pistorius's story highlights some of the ethical dilemmas associated with human enhancement technology, for instance - the fairness of increased ability, and the "humanity" in human enhancement technology. His story brings to light the controversy and misunderstanding that shroud policy decisions regarding human enhancement technology, and it highlights the prevalent stigma surrounding disability.

There is no doubt that Pistorius's ability enhancing prosthetics allowed him to achieve success in sports and the public eye. Still, fame, fortune, and success in sport are not indicators of The Good Life. This is even more evident now; Pistorius lives a troubled life, burdened with the guilt of murder and the prospect of a life behind bars. Was the human enhancement technology to blame? During his court hearing, Pistorius was ordered to walk before the jury on his stumps, an attempt by his lawyer, to prove his innocence. In doing so, the lawyer stripped him of his humanity. This mirrors the dehumanizing nature of Pistorius's nickname,

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<sup>5</sup> Arbitral award delivered by the Court of Arbitration for Sport ... in the arbitration between Mr. Oscar Pistorius ... v/ International Association of Athletics Federations (CAS 2008/A/1480 Pistorius v/ IAAF) (PDF)

<sup>6</sup> Relay safety fears over Pistorius, BBC Sport, 15 July 2008

“Bladerunner”, that emphasizes the machine over the man. At what point does technology like this remove the humanity from an individual? Might human enhancement be an impediment to The Good Life rather than a means? Alternatively, might the stigma and misunderstanding surrounding disability stand as a greater barrier to living The Good Life? It is necessary to consider these questions as human enhancement technology continues to advance, outpacing policy change and the capacity of culture to adapt intellectually and ethically.

## Research Questions

This honors thesis explores the issues introduced above, specifically regarding the relationship between disability, human enhancement technology, and living The Good Life. The research questions were informed by background research and literature review, in addition to research completed as a research assistant at Oregon State University.

### **Initial Research Question:**

What does one give up (if anything), in terms of living The Good Life, to alter human ability and move up the continuum of human enhancement, and is it worth it?

### **Revised Research Question (Mid COVID-19):**

How might assistive technologies created to move disabled individuals up the human enhancement continuum act as impediments as well as means to The Good Life?

## Background

### Brief History of Disability in the US

What is disability? This question has been debated throughout modern history, and it represents the fundamental principle which drives policy change, public education, and cultural attitudes towards disability. The purpose of this thesis is not to unpack this complex issue in depth, but it is necessary to understand the current and past definitions of disability in the United States in order to better inform and frame the research.

The current legal working definition of disability is from the 1990 American Disability Act (ADA). It states:

“The ADA defines a person with a disability as a person who has a physical or mental impairment that substantially limits one or more major life activity. This includes people who have a record of such an impairment, even if they do not currently have a disability. It also includes individuals who do not have a disability but are regarded as having a disability.”<sup>7</sup>

This definition emphasizes that disability is characterized by the limitations placed on a normal life activity – a broad classification that encompasses all different types of disability.

Additionally, this definition includes the paradoxical language: “[..] includes individuals who do not have a disability but are regarded as having a disability”. This language is telling: if the definition must extend to those who do not have a disability but are treated as such, there must be substantial discrimination against individuals with disability, warranting protection by law.

The definition from the Oxford English Dictionary shares common language with the ADA, albeit with slightly more emphasis on the individual’s abilities (movement and senses). It defines disability as:

“A physical or mental condition that limits a person's movements, senses, or activities.”<sup>8</sup>

These two current definitions were shaped by years of progress in the disability rights movement. While the story of disability began with the dawn of humankind, disability advocacy

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<sup>7</sup> ADA: Americans With Disabilities Act of 1990, Pub. L. No. 101-336, § 12102, 104 Stat. 328 (1990)

<sup>8</sup> “Disability.” Lexico Dictionaries | English, Lexico Dictionaries (Oxford), Jan. 2020, [www.lexico.com/en/definition/disability](http://www.lexico.com/en/definition/disability).

and the modern disability rights movement began in the 1950s. This coincided with the civil rights movement and followed the presidency of Franklin D. Roosevelt (the first president to appear physically disabled). This brief timeline gives an overview of the milestone events leading to the 1990 ADA, and modern-day amendments to it.

- 1961 ANSI accessibility standards – made buildings accessible to physically handicapped
- 1968 First International Special Olympics
- 1968 Architectural Barriers Act - required buildings be made accessible (through construction or alteration, federal funds available)
- 1975 Individuals with Disabilities Education Act (IDEA) – Free public education for all children with disabilities in the “least restrictive environment”
- 1978 National Council on Disability – advisory board within the Department of Education – guaranteeing equal opportunity for people with disabilities, inclusion and integration into society
- 1986 Air Carriers Access Act – prohibiting discrimination against individuals with physical or mental disabilities on flights (required boarding assistance, accessibility features to be built in aircraft)
- 1990 ADA – “civil rights law prohibiting discrimination against individuals with disabilities in all areas of public life”<sup>7</sup> ensuring equal rights and opportunity
- 1998 Assistive Technology Act – state provisions for assistive technology, federal funding<sup>9</sup>
- 2000 Genome Project – mapping of the entire human genome, promise of new cures and medical breakthroughs, disability advocates fear an “end of disability”
- 2008 ADAAA – amendments to the original ADA, revised the definition of disability to broaden the scope of coverage<sup>10,11</sup>

Disability policy in the United States has remained largely unchanged since the ADAAA in 2008. As with other civil rights issues, the disability rights movement remains active today.

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<sup>9</sup> Assistive Technology Act of 1998, Pub. L. No. 105-394, § 2432 (1998)

<sup>10</sup> “The ADA Amendments Act of 2008 .” U.S. Department of Labor, [www.dol.gov/agencies/ofccp/faqs/americans-with-disabilities-act-amendments](http://www.dol.gov/agencies/ofccp/faqs/americans-with-disabilities-act-amendments).

<sup>11</sup> “Timeline of Disability Policy.” Disability History: Timeline, National Consortium on Leadership and Disability for Youth, [www.ncl-d-youth.info/index.php?id=61](http://www.ncl-d-youth.info/index.php?id=61).

Ongoing activism to address issues of discrimination and unequal opportunity are central to the disability conversation today. This brief background of disability in the United States helps frame the discussion of human enhancement technology as a means to improving one's ability - bringing oneself from a state of disability to normal ability.

## Assistive Technology and Human Enhancement Technology

Recent developments in the fields of biomedical and computer technology have created the opportunity for human enhancement technology. While this is not a new concept – magnifying glasses, a primitive form of human enhancement technology, have existed since the 1020s<sup>12</sup> – recent advances promise a new era of technology that may radically improve one's ability in many dimensions. Such technology may be aptly applied to individuals living with disability. Traditional Assistive Technology has aimed to do this for decades – yet, the failings of assistive technology (discussed in Results) may be solved by new forms of human enhancement technology.

It is important to distinguish human enhancement technology from Assistive Technology. While the two terms may be used interchangeably, human enhancement technology is focused on improving ability beyond a natural level, while Assistive Technology (AT) is defined as:

any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.<sup>13</sup>

Common examples of AT include wheelchairs, scooters, walkers, canes, crutches, and prosthetic devices.<sup>14</sup> Hearing aids, computer assistive devices and software, ramps and grab bars, and specialized utensils are also considered AT.<sup>15</sup> AT is a broad classification for any technology that aims to ameliorate one's disability.

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<sup>12</sup> Ilardi, Vincent (2007), *Renaissance Vision from Spectacles to Telescopes*, Philadelphia, PA: American Philosophical Society, ISBN 9780871692597

<sup>13</sup> Assistive Technology Act of 1998, Pub. L. No. 105-394, § 2432 (1998)

<sup>14</sup> Medline Plus. (2016.) Mobility aids. Retrieved October 8, 2018, from <https://medlineplus.gov/mobilityaids.html>

<sup>15</sup> Center on Technology and Disability. (2018). Assistive technology 101. Retrieved September 28, 2018, from [https://www.ctdoinstitute.org/sites/default/files/file\\_attachments/CTD-AT101-V4.pdf](https://www.ctdoinstitute.org/sites/default/files/file_attachments/CTD-AT101-V4.pdf)

In contrast, human enhancement technology (HET) is not limited to disability applications. As it is used in this thesis, *human enhancement technology is a broad term for technologies that improve one's innate ability beyond a normal level*. This working definition was crafted from foundational literature, regarding “enhancement” in the term “human enhancement technology”.

Enhancement(s) – biomedical interventions that are used to improve human form or functioning beyond what is necessary to restore or sustain health.<sup>16</sup>

While foundational literature and ethical debate focus primarily on biomedical interventions, HET also includes those technologies that do not involve making biological modification (surgery, pharmaceutical, or genetic techniques). For instance, a robotic exoskeleton aimed at improving mobility or strength does not directly modify or enhance the biological body, yet, it effects the same outcome: improved ability. For the sake of this research, both types of technology (biomedical interventions and external devices) were included in the working definition of HET.

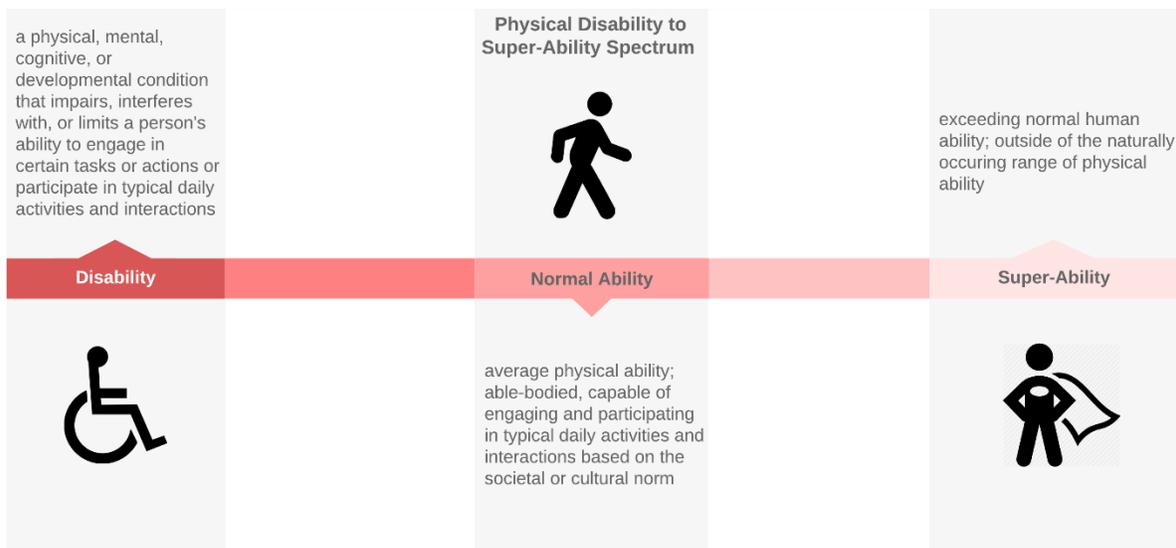
The line between AT and HET is difficult to draw. This is due in part to the particular use of such technology. For instance, a strengthening surgery (via composite materials, bone graft or other means) used to improve an athlete's competitive ability might be considered an HET. The same technique used to ameliorate one's disability would be considered AT. If this results in improved ability beyond a normal level, it might also be considered HET. Moreover, the same technique used to treat an injury of an able-bodied individual would likely be considered neither AT nor HET. These distinctions are not clear cut. Still, the significant overlap between AT and HET allow them to be considered together. Study of the current issues with AT will indicate potential issues in future HET, while AT's shortcomings might be improved or solved with HET.

### The Human Enhancement Spectrum

The Human Enhancement Spectrum is a theoretical framework the author created to help conceptualize/visualize the different entry and exit points based on ability, influenced by HET.

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<sup>16</sup> Parens, E., (ed.), (1998), *Enhancing Human Traits: Ethical and Social Implications*, Washington: Georgetown University Press.



**Figure 1. Spectrum of Ability** – Conceptual framework that demonstrates the spectrum of ability from disability to super-ability. Individuals may fall anywhere on the spectrum. HET moves individuals up the spectrum (right). Framework is useful in conceptualizing entry and exit points on the spectrum of ability, due to human enhancement tech.

To demonstrate this concept, think back to the story of Oscar Pistorius. Born with a physical disability, he entered the spectrum at the far left. Simple leg prostheses restored Pistorius to a state of normal ability. However, the advanced carbon-fiber prostheses he wore during racing improved his running ability arguably beyond a normal level. In this case Pistorius would land between the normal ability and super-ability section of the spectrum. Controversy ensued. Was this conferred advantage unfair? Did the prostheses provide a unique advantage, beyond what the human body is naturally capable of? It is hard to say. After all, he was neither the fastest, nor slowest competitor in his Olympic Games heats. All of this aside, did this HET improve Pistorius’s opportunity to live The Good Life?

### The Good Life

As stated in the introduction, The Good Life is a life of good health, purpose, fellowship with others, pleasure, and transcendence. In a broader sense “The Good Life” represents a philosophically ideal life – a concept originating among the ancient Greek philosophers that has

been debated for centuries. These philosophers helped shaped the working definition used in this thesis.

One of the earliest discussions of this concept is found in Plato's *Philebus*, which is a discussion between Philebus and Socrates about life's ultimate good. Philebus contends that enjoyment, pleasure, and delight are most important. Socrates instead contends wisdom, intelligence, memory, and right opinion are more important. Socrates believes there is no single key to The Good Life, instead it is composed of knowledge of good, evil, pleasure, opinion, independent thought, and wisdom.<sup>17</sup> Aristotle takes a slightly different approach in *Nicomachean Ethics*. He states that The Good Life is centered around understanding oneself, others, and the world – only attainable through education. Education brings wisdom which leads to additional virtue.<sup>18</sup> A third view, known now as hedonism, was proposed by Epicurus in *Letter to Menoeceus*. It contends that The Good Life can only be achieved through pleasure.<sup>19</sup> Pleasure should certainly not be the only element of The Good Life, because it often leads to lack of fulfillment and selfish desires. This is addressed in the fourth and final source, The Bible, which places more focus on the spiritual aspect. The book of Ecclesiastes is a testament to The Good Life from the perspective of King Solomon. Solomon concludes “Everything is meaningless” if you live “a life under the sun” (Ecclesiastes 1:2, 1:14). This is summed up in the book of Matthew when Jesus says, “What good will it be for a man if he gains the whole world yet forfeits his soul?” (Matthew 16:26). In other words, gaining material wealth and status are merely distractions from one's higher purpose, life's goal: transcendence. To break from this western-centric school of thought, exploration of the ancient Hindu Sanskrit reveals the term *puruṣārtha* which literally means “object of human pursuit” or aims of life; in other words, The Good Life. The four *puruṣārthas* are: Dharma (righteousness and moral values), Artha (prosperity and economic values), Kama (pleasure, love), Maksha (liberation, spiritual values, transcendence) which is the ultimate goal.<sup>20</sup> These elements of The Good Life mirror some of those proposed by the western philosophers.

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<sup>17</sup> Plato. *The Philebus Of Plato*. Cambridge [Eng.] :University Press, 1897. Print.

<sup>18</sup> Aristotle, W D. Ross, and Lesley Brown. *The Nicomachean Ethics*. Oxford: Oxford University Press, 2009. Print.

<sup>19</sup> Epicurus “Letter to Menoeceus.” Epicurus.Net, Dec. 1996, <http://www.epicurus.net/en/menoeceus.html>

<sup>20</sup> Hiriyanna (2000), *Philosophy of Values*, in *Indian Philosophy: Theory of value* (Editor: Roy Perrett), Routledge, ISBN 978-0-8153-3612-9

As a combination of all these influences, and for the purposes of this research, The Good Life was considered to be a life of good health, purpose, fellowship with others, pleasure, and transcendence. It is important to acknowledge that there are many opinions on what The Good Life is. Different perspectives, backgrounds, and cultures influence different interpretations; however, this working definition is intentionally broad to encompass different viewpoints, such that it may be considered a universal definition. For example, the Christian view of “transcendence” centers around communion with God through Christ, while the Buddhist view focuses on “divine oneness in Buddha nature... intrinsic to all sentient beings”.<sup>21</sup> Thus, the term transcendence encompasses both viewpoints. This working definition is similar to discussions of The Good Life in modern literature, in particular, that of the positive psychologists, like Seligman and Haidt. *The Happiness Hypothesis* by Haidt examines these ancient thinkers, and concurs that happiness, virtue, fulfillment, and meaning are central to The Good Life.<sup>22</sup>

Contemporary discussions of The Good Life are epitomized by Socrates’s famous quote “The unexamined life is not worth living”.<sup>23</sup> One such instance is found in a paper discussing biotechnology and The Good Life. Dr. Stuart Murray writes:

“To "examine" one's life today is to submit to medical knowledge and techniques, to evaluations, and to normalizing judgments. It is to be governed by so-called experts, and to be understood in and through recent genomic and molecular vocabularies of biomedicine. Indeed, these terms have come to constitute our norms, and it is by virtue of such terms that we can be said to be a "self" in any meaningful way...”<sup>24</sup>

According to Murray, examining oneself today is more about listening to medical experts and normalized judgments, than true self-examination. Dr. Murray goes on to discuss medicine as a “technology of the self”, that is, a set of practices and beliefs that provide one’s conceptual

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<sup>21</sup> Trammel, R. C. (2017). Tracing the roots of mindfulness: Transcendence in Buddhism and Christianity. *Journal of Religion & Spirituality in Social Work: Social Thought*, 36(3), 367-383.

<sup>22</sup> Haidt, J. (2006). *The happiness hypothesis: Finding modern truth in ancient wisdom*. Basic books.

<sup>23</sup> Plato . *Five dialogues: Euthyphro, Apology, Crito, Meno, Phaedo*. Indianapolis: Hackett; 1981. Apology; pp. 23–44.

<sup>24</sup> Murray, S. J. (2007). Care and the self: biotechnology, reproduction, and the good life. *Philosophy, Ethics, and Humanities in Medicine*, 2(1), 6.

understanding of self. Aristotle argued that understanding of self is central to The Good Life, yet if examination today is submission to medical knowledge and normalizing judgments, might disabled persons face an inherently biased assessment? How might one live The Good Life if modern assessments tell them they must be more “normal”?

In *Ethics: Subjectivity and Truth*, M. Foucault writes that technologies of the self “permit individuals to effect by their own means...operations on their own bodies and souls...to transform themselves in order to attain a certain state of happiness, purity, wisdom, or perfection”<sup>25</sup>, in other words to attain The Good Life. While Foucault is referencing metaphorical technologies of the self, this sentiment could also be applied to AT and HET. AT and HET present the opportunity of transforming oneself by increasing ability. Improved ability (physical ability) allows individuals with disability to function more effectively in a society designed for able-bodied individuals; therefore, these technologies may be one path to achieving The Good Life.

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<sup>25</sup> Foucault, M. (2019). *Ethics: Subjectivity and Truth: Essential Works of Michel Foucault 1954-1984*. Penguin UK.

## Methods

### In-Person Research

#### Overview

The study involved in-person interviews with individuals living with a physical disability. The author conducted face-to-face interviews with eligible participants that had been identified through recruitment procedures. Participants were deemed eligible if they satisfied the following: over 18 years of age, living with a physical disability, and not enrolled in classes taught by the PI or other research team members. Interviews lasted 15-30 minutes and were conducted in a reserved classroom at the Oregon State University campus in Corvallis, Oregon. Data was collected via handwritten notes or audio recording, at the preference of the participant.

#### Recruitment and Target Enrollment

Eligible individuals were recruited through physical and digital recruitment materials. Physical fliers were placed at various locations across the Oregon State University campus. Digital recruitment was conducted by sending recruitment materials to administrators of list-servs at Oregon State University - including student organizations and departments - asking that the email be included in newsletters and other mailings. Also, the email requested that recipients forward to other individuals who may be interested in participating.

Eligible participants had to be living with a physical disability (self-reported), over the age of 18, fluent in spoken English, and not part of the study team, not enrolled in courses taught by the principal investigator (the author's thesis adviser). Maximum enrollment was set at 30 participants. Target enrollment was set at 10-15 good interviews.

#### Interview Structure and Guide

Each interview began with obtainment of verbal informed consent. A consent form was provided, followed by a conversation with the participant to address any outstanding concerns. Audio recording and/or written notes were used to record responses. All data was kept confidential to the extent permitted by law. The interview was guided by the following written framework:

### ***Section 1 – Technology in Use Now***

1. What forms of technology, if any, are you using now related to living with [*Insert Disability*]?
  - a. Does X<sup>26</sup> technology make your life better?
  - b. Tell me about the three best and three worst aspects of living with X technology.
  - c. Are there any ways X technology could be improved to improve your quality of life?
  - d. How accessible is X technology to others like yourself?

### ***Section 2 – Technology Not in Use Now***

2. Is there any technology that exists now which is at least claimed to help with your kind of disability but that you choose not to use?
  - a. What are the reasons you choose not to use X technology?
  - b. How might X technology be improved or altered (if applicable) to improve your quality of life?

### ***Section 3 – Future Technology***

3. Relevant prototype/futuristic technology scenarios were presented relating to individual's disability – for instance, the ReWalk exoskeleton, a robotic prosthesis allowing individuals with spinal cord injury (SCI) to walk again.<sup>27</sup>
  - a. Based on your experience with technology in general and your disability, and on your understanding of X, what do you imagine would be the three best, and three worst aspects of X technology for people like you?
    - i. What are some ways this technology might disbenefit yourself or others?

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<sup>26</sup> Technology individual is currently using, identified in question 1. If individual is using more than 1, X represents each instance.

<sup>27</sup> Zeilig, G., Weingarden, H., Zwecker, M., Dudkiewicz, I., Bloch, A., & Esquenazi, A. (2012). Safety and tolerance of the ReWalk™ exoskeleton suit for ambulation by people with complete spinal cord injury: a pilot study. *The journal of spinal cord medicine*, 35(2), 96-101.

- b. Would you use this technology, if it were available to you today?
  - i. Why or why not?
  - ii. Assuming technology X allowed for improved ability, beyond the normal range, would you still want it?
- c. Should X technology (X that offers potential for superhuman ability) be limited to individuals living with a disability, or available to the public at large?
  - i. Do you think individuals should be allowed to increase their ability, beyond the “normal” human range? Why or why not?
- d. Do you have any other hopes or concerns with the technologies presented?

#### ***Section 4 – Open Ended Conversation***

- 4. Do you have any other input on any of the topics we have covered?
  - a. What is a problem (related to your disability) that you would like solved?
    - i. Do you have any ideas for solutions?

#### **End of Interview**

#### **Remote Research**

##### **Overview of Revisions**

Following the governor’s issuance of the statewide stay-at-home order, recruitment was conducted remotely through email. Remote interviews were conducted over Zoom voice chat. The original interview guide was used as a framework, although discussions focused more on examining issues with existing AT and HET. Specifically, interviews focused more on sections 1 and 2 in the above interview guide. Interview data was collected through field notes and audio recordings.

## Results

Due to the unforeseen circumstances of the COVID-19 outbreak, recruitment efforts were severely limited. A significant portion of the potential participant pool resided in sensitive locations including assisted living facilities, Oregon Health & Science University, and several orthotics clinics. Economic hardship, uncertainty, and anxiety also contributed to several participants backing out of the recruitment process. Thus, an insufficient number of participants – one in-person interview, and one remote interview – were recruited for data analysis. Due to the small sample size, it was not possible to perform formal statistical tests. Instead, a qualitative approach, identifying key terms and phrases from the participants' responses, was used to highlight issues with AT and HET and serve as a springboard for a deeper, focused literature review and discussion. For instance, in section 2 of the interview guide above, participants responded with “cost” as being the primary reason they do not use AT that is available now. A deeper look into the literature indeed revealed that AT cost often stands in the way of improved mobility that could lead a disabled person to a better life.

Participants identified the following issues with AT and HET and shared personal experience with one or more of these issues. Issues are ranked in order of occurrence in the interviews (most prevalent to least).

### Cost

Both participants expressed concern over the cost of current AT and future HET. One participant discussed how insurance often does not cover AT, especially if the AT is not deemed necessary by the provider. This forces families to pay for AT out-of-pocket, creating a barrier to access. The participant imagined that new advanced forms of AT (reaching into the realm of HET) would have a higher entry cost. Both participants chose cost as the primary reason they have not tried alternative forms of AT. Another participant was concerned that the existing socio-economic class gap would be widened by HET. They worried that distribution of ability-improving technology based on socio-economic class would disproportionately favor the wealthy; conferred ability leading to increased advantage in society.

## Distribution

Closely related to cost, participants highlighted the issue of distribution of AT and future HET. Specifically, ensuring technology reaches those in need first. Participants expressed concern that HET would be developed for groups other than the disabled first. For example, exoskeleton development, a current research area in military technology is usually designed for able bodied individuals first, then "trickles-down" to individuals with disabilities. Who deserves the technology most? Should persons with disability have preferential access?

## Education

Several participants expressed concern regarding the general population's lack of education regarding disability. They mentioned the stigma confronting them when using visibly obvious disability access technology and feared it would continue or worsen if technology becomes more visible or active – for example, a fully functioning robotic limb, or exoskeleton, compared to a conventional brace, cane, or walker. Perhaps most intriguing was the participants' concern over the perceived "humanity" of such technology. Participants discussed how conspicuous AT changes interactions with passersby – whether by drawing unwanted attention, or the common assumption that they are incapable and needing assistance. These combined lead to the diminishment of one's humanity.

## Assessment, design, and customization

Lastly, participants discussed the issue of assessment and design. Current AT lacks customization and patient-specific design. One participant expressed frustration with the fit of a hearing aid, choosing not to use it for this reason alone. Another participant discussed difficulty obtaining repair of an AT, instead being forced to purchase a new unit at full price.

Aside from these issues, participants were optimistic towards HET. Participants unanimously agreed that barring issues, AT did improve their quality of life by some degree. Each was optimistic that, if applied correctly, HET might further increase quality of life.

**Table 1.** Summary of interview results from 2 participants. Issues ranked by total number of mentions in interviews. Sample quotes from interview participants regarding issues.

<b>Rank</b>	<b>Times Cited</b>	<b>Issue</b>	<b>Quotes</b>
1	5	Cost	<p>“My soft braces are not covered by my insurance plan”</p> <p>“My insurance only covers one type and they don’t fit me”</p> <p>“I haven’t tried those [new hearing aid alternative] because they are too expensive”</p>
2	3	Distribution	<p>“They don’t make devices specifically for my condition”</p> <p>“I use soft braces made for sports injuries”</p>
3	2	Education	<p>“(peers) notice when I am wearing them, they act differently”</p> <p>“people ask if I need help”</p>
4	1	Assessment, Design, Customization	<p>“I stopped wearing them because they didn’t fit”</p> <p>“they are uncomfortable, so I only wear them when I have to”</p>

## Discussion and Corroboration with Literature

To recap, the purpose of this research was to answer the question: How might assistive technologies created to move disabled individuals up the human enhancement continuum act as impediments as well as means to the good life?

The story of Oscar Pistorius introduced several of the ethical issues regarding HET used to improve ability, while the results from the research study highlighted some of the issues with assistive technology in use today. Together, these sources have set-up a rich discussion to answer the research question. Namely, a discussion of the results, and their ties to existing literature; a look into what it means to be “human”, and the extent to which HET removes the humanity from an individual; and throughout, a discussion of the impact this has on one’s ability to live The Good Life.

As it stands, the issues with AT highlighted by the interviews represent potential impediments to living The Good Life. Since AT aims to ameliorate disability, it is assumed that “perfect” AT (if such existed) would allow an individual living with disability a better opportunity at living The Good Life. It must be made clear that AT is not required to live The Good Life. Notwithstanding one’s reduced ability, a person living with disability may live in perfectly good health (free from illness or injury).<sup>28</sup> They may also find purpose in life, experience fellowship with others, pleasure, and transcendence. Therefore, the neo-luddite living with an unassisted disability may just as well live The Good Life as an able-bodied one. Yet living in the 21<sup>st</sup> century does require some level of interaction with technology, and for the sake of addressing the research question, it is assumed that HET is inevitable. Inevitability does not imply this technology will be a requirement to live The Good Life, rather, it is a reminder that the choice to use HET will exist. Some individuals living with disability will decide that technology will be a means for them to live The Good Life, that which they are presently denied. Others will decide that any improvements gained by the technology will be offset by the impediments the technology places in the way of The Good Life.

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<sup>28</sup> “Health.” Lexico Dictionaries | English, Lexico Dictionaries (Oxford), Jan. 2020, [www.lexico.com/en/definition/health](http://www.lexico.com/en/definition/health).

Returning to the research question, let us focus on those technologies specifically aimed to move individuals up the human enhancement continuum. Are these technologies more of a means or impediment to achieving The Good Life? As the results discussed, participants identified four primary issues with AT that call to question its function as a means to The Good Life. First, cost represents a significant barrier to entry. According to a 1992 study by LaPlante, more than 2.5 million Americans did not have access to the AT they needed, with 70% citing cost as the primary reason they did not have it.<sup>29</sup> Device cost is high because markets for these devices are relatively small and sales volume is low. In addition, persons living with disability are often financially disadvantaged compared to the population as a whole.<sup>30</sup> In spite of this, the same 1992 study found that more than 75% of individuals living with AT purchased the devices themselves or with help from family. As mentioned by one of the study participants – a major reason for these out-of-pocket purchases is lack of insurance coverage. Several insurance carriers deny AT because they do not deem it a “medical necessity”.<sup>31</sup> Getting to the root of this problem is difficult because there are so many different funding sources for AT, including Medicare, Medicaid, private insurance, the Veterans Administration, Vocational and Special Rehabilitation, and loan subsidies.<sup>26</sup> This fragmented system of funding leads to financial problems for the consumer. As the most significant barrier to accessing AT, the issue of cost must be addressed. Cost represents an indirect impediment to The Good Life, because it limits one’s access to AT. Indeed, the AT itself is not the impediment here, rather, it is the *lack* of AT due to its high cost. This conclusion also assumes that AT benefits the user, which is supported by the 1992 LaPlante study which found, despite out-of-pocket purchase cost, most individuals experienced improved quality of life after receiving AT.<sup>26</sup> The best avenue to address this problem is likely policy change, specifically aiming to streamline the funding process.<sup>28</sup>

Perhaps a more fundamental issue related to cost arises when we consider the impact socio-economic class has on the distribution of AT and HET. If cost is a significant barrier, it follows that individuals of higher socio-economic class must have better access to the technology.

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<sup>29</sup> LaPlante MP, Hendershot GE, Moss AJ. (1992). Assistive technology devices and home accessibility features: prevalence, payment, need, and trends. *Advance Data* 217:1-11.

<sup>30</sup> O’Day, B. L., & Corcoran, P. J. (1994). Assistive technology: problems and policy alternatives. *Archives of physical medicine and rehabilitation*, 75(10), 1165-1169.

<sup>31</sup> Reeb KG Jr. (1987) Final report of the national task force on third party payment for rehabilitation equipment. Washington, DC: Electronic Industries Foundation

Considering that AT aims to improve one's ability, these advantages would be disproportionately conveyed to the wealthy. Since increased ability allows one to function more effectively in modern society, this conferred advantage would widen the gap between classes. This is encapsulated by the discussion of "haves and have nots", discussed at length in Noreena Hertz's book *The Silent Takeover: Global Capitalism and the Death of Democracy*. Hertz writes: "never before in modern times has the gap between the haves and have-nots been so wide, never have so many been excluded or so championless."<sup>32</sup> If this trend continues, HET will widen the gap because it has the potential to improve ability beyond a normal level. It is essential that policy measures consider these implications if we wish to guarantee equal opportunity. If we can solve the issue of cost, AT can reach those in need, potentially improving one's opportunity to live The Good Life.

After cost and distribution issues are addressed there remain several barriers with AT that reduce one's ability to live The Good Life: stigma, and assessment, design, and customization issues. Stigma, in this sense is defined as "an adverse reaction to the perception of a negatively evaluated difference".<sup>33</sup> Classic theoretical work in this area has shown that stigma can severely impact the quality of an individual's life.<sup>34</sup> Especially in a society that values health, normalcy, and independence, individuals living with disability are seen as bearers of negative traits.<sup>35</sup> This adverse reaction negatively impacts the stigmatized person's sense of self, which in turn impacts participation in daily life and amongst social circles.<sup>36</sup> Stigma might reduce one's ability to live The Good Life because it damages one's sense of purpose, and reduces opportunity to fellowship with others (both elements of The Good Life). For example, stigma experienced by a wheelchair user in a primarily able-bodied workplace limits one's ability to enjoy and partake in fellowship with coworkers. This in turn might reduce one's self esteem and sense of purpose, impeding one's ability to live The Good Life.

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<sup>32</sup> Hertz, N. (2001). *Divided We Fall*. In *The Silent Takeover: Global Capitalism and the Death of Democracy*. London: William Heinemann.

<sup>33</sup> Susman, J. (1994). Disability, stigma and deviance. *Social science & medicine*, 38(1), 15-22.

<sup>34</sup> Goffman, E. (2009). *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.

<sup>35</sup> Green, S. E. (2003). "What do you mean 'what's wrong with her?': Stigma and the lives of families of children with disabilities. *Social science & medicine*, 57(8), 1361-1374.

<sup>36</sup> Link, B. G., Cullen, F. T., Struening, E., Shrout, P. E., & Dohrenwend, B. P. (1989). A modified labeling theory approach to mental disorders: An empirical assessment. *American sociological review*, 400-423.

The effects of stigma might also be characterized as “dehumanizing”, that is, depriving a person of certain positive human qualities.<sup>37</sup> This phenomenon was described by both participants in this study. One participant experienced dehumanizing stigma most when using visibly obvious AT. This type of stigma was most severe when passersby noticed the AT because it was a physically obvious device deviating from the norm. The same participant mentioned feeling more comfortable using a discreet version of the AT. Besides deviation from the norm, AT may also be dehumanizing in design. For instance, a wheelchair is designed such that the user is placed at a height disadvantaged position. Whether intentional or not, this creates an unequal power dynamic with able-bodied peers. This power dynamic is evident when wheelchair users experience “patronizing help” – attempts by an able-bodied individual to offer help in a way that suggests the disabled person is inferior.<sup>38</sup> The effect of this dynamic was demonstrated by a recent 2018 social study that suggested disabled persons prefer to interact with disabled people, while able-bodied persons preferred to interact with able-bodied persons.<sup>39</sup> Interestingly, the research also suggested increasing the number of disabled persons in cooperation could revert the disadvantage imposed by their identity. These studies did not specifically consider the effects of AT, yet AT is one of the most common ways disabled persons are recognized; therefore, efforts to make AT more “human” (whether by education, design change, discreetness, or some combination of these), will likely minimize the harmful effects of stigma, improving one’s opportunity to live The Good Life. However, even if AT is designed to be more discreet, the use of such technology may be dehumanizing to one’s own self - for instance, the knowledge that underlying stigma still exists may be just as harmful, whether triggered by the visible AT or not. Participants did not mention anything relating to this, but it warrants exploration in a future study.

The last issue raised by the interviews regarded the assessment, design and customization of AT. Assessment of one’s AT needs has often been regarded as a process of trial and error, with few

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<sup>37</sup> “Dehumanizing.” Lexico Dictionaries | English, Lexico Dictionaries (Oxford), Jan. 2020, [www.lexico.com/en/definition/dehumanizing](http://www.lexico.com/en/definition/dehumanizing).

<sup>38</sup> Wang, K., Walker, K., Pietri, E., & Ashburn-Nardo, L. (2019). Consequences of confronting patronizing help for people with disabilities: Do target gender and disability type matter?. *Journal of Social Issues*, 75(3), 904-923.

<sup>39</sup> Liu, S., Xie, W., Han, S., Mou, Z., Zhang, X., & Zhang, L. (2018). Social interaction patterns of the disabled people in asymmetric social dilemmas. *Frontiers in psychology*, 9, 1683.

guidelines specifying the components necessary for an AT assessment.<sup>40</sup> AT is often developed for able-bodied stakeholders first, then adapted to individuals with disability. For instance, the first successful robotic exoskeleton, BLEEX, funded by DARPA, was designed to give able-bodied persons enhanced ability - namely, enhanced strength and reduced fatigue.<sup>41</sup> It was not until 2014 that the FDA approved the first consumer-available exoskeleton (ReWalk), specifically designed for disability.<sup>42</sup> Overall this is a positive development, since innovation, regardless of the origin, drives further innovation. Technologies like ReWalk are anomalies – flashy new solutions that garner press attention but exist well outside the reach of the end-user. If AT already lacks outside funding sources, how might a disabled person afford a \$77,000 exoskeleton? These examples detract from the underlying issue: most AT is outdated, “clunky,” and forgotten. Participants in the research study noted that obtaining repair, customization, and support was difficult for AT that they used. A 1994 study found that when AT breaks down, the user may be forced to live without it for months while it is returned to the manufacturer for repairs.<sup>43</sup> Some distributors have improved in the last 26 years, but many issues remain. This is due to a combination of low sales volume and a lack of funding. Clearly, there is significant opportunity for improvement. Addressing these needs will improve accessibility and function of AT, improving the integration with each user. If this barrier is overcome, AT will offer users a better opportunity at living The Good Life.

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<sup>40</sup> Copley, J., & Ziviani, J. (2004). Barriers to the use of assistive technology for children with multiple disabilities. *Occupational Therapy International*, 11(4), 229-243.

<sup>41</sup> Zoss, A. B., Kazerooni, H., & Chu, A. (2006). Biomechanical design of the Berkeley lower extremity exoskeleton (BLEEX). *IEEE/ASME Transactions on mechatronics*, 11(2), 128-138.

<sup>42</sup> He, Y., Eguren, D., Luu, T. P., & Contreras-Vidal, J. L. (2017). Risk management and regulations for lower limb medical exoskeletons: a review. *Medical devices (Auckland, NZ)*, 10, 89.

<sup>43</sup> Carey DM, Sale P (1994). Practical considerations in the use of technology to facilitate the inclusion of students with severe disabilities. *Technology and Disability* 3(2): 77–86.

## Conclusions and Recommendations

This research demonstrates the complexity surrounding AT and HET. It suggests that significant issues with current AT act as impediments to one's opportunity to live The Good Life. Most importantly, this research suggests that stigma is a fundamental issue with AT use. Stigma contributes to reduction of one's humanity, which impedes one's ability to live The Good Life. These findings demonstrate the need for a wholistic solution incorporating significant government policy change and a collaboration between researchers, manufacturers, users, and the general public. Policy change might involve amendments and laws that ensure equal access and opportunity to AT, distribute funds more adequately or mandates funding sources, streamline the assessment process for AT needs, and provide better public/social education regarding disability. From a manufacturer, research, and user perspective, the findings demonstrate a need for thoughtful design of AT. Thoughtful design in this sense means utilizing user feedback to provide discreet, durable, customizable, and repairable solutions. These goals will contribute to minimizing the dehumanizing effects of stigma regarding visible AT, while improving quality and access to AT. Lastly, the findings demonstrate a need for better public education surrounding issues of disability ethics, and social justice. One solution might be a joint effort between public education and disability advocacy groups to raise public awareness.

These findings have demonstrated that AT and HET should not be assumed to be beneficial in all regards. Moving one up the spectrum of ability will not improve one's opportunity to live The Good Life if the same action increases stigma and its dehumanizing effects. It has been shown that AT can be both a means and an impediment to living The Good Life. More often than not, the issues with AT stand as impediments to living The Good Life, and they must be addressed before AT and HET can be considered a viable means to living The Good Life.

This study demonstrated the need to further explore the extent to which HET removes the humanity from an individual. Could AT and HET move one to becoming a cybernetic organism (cyborg)? What would the consequences be, and how might this change society? Could such a development cause stigma, like that experienced by disabled persons? These dilemmas must be considered as this technology rapidly advances, pushing us closer to the age of human enhancement.

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**Recruitment Flyer for Research Study:  
The Human Enhancement Spectrum**

**SEEKING VOLUNTEERS FOR A RESEARCH STUDY**

The purpose of this study is to characterize the ethical dilemmas associated with human enhancement technology to mitigate or overcome disability.

To participate in this research, you must:

- Live with a physical disability
- Be 18 years old or older
- Be fluent in English

Participation in this study involves:

- A one-time, one-on-one interview of no more than 30 minutes
- \$10 cash compensation

**For more information about this study,  
please contact Ian Oakes at:**

- Phone: (503)-989-1510
- Email: [oakesi@oregonstate.edu](mailto:oakesi@oregonstate.edu)

**Study Title:** The Human Enhancement Spectrum

**Principal Investigator:** Dr. Kenneth Funk

<p><b>Research Study:</b> The Human Enhancement Spectrum <b>Contact:</b> Ian Oakes <b>Email:</b> <a href="mailto:oakesi@oregonstate.edu">oakesi@oregonstate.edu</a></p>	<p><b>Research Study:</b> The Human Enhancement Spectrum <b>Contact:</b> Ian Oakes <b>Email:</b> <a href="mailto:oakesi@oregonstate.edu">oakesi@oregonstate.edu</a></p>	<p><b>Research Study:</b> The Human Enhancement Spectrum <b>Contact:</b> Ian Oakes <b>Email:</b> <a href="mailto:oakesi@oregonstate.edu">oakesi@oregonstate.edu</a></p>	<p><b>Research Study:</b> The Human Enhancement Spectrum <b>Contact:</b> Ian Oakes <b>Email:</b> <a href="mailto:oakesi@oregonstate.edu">oakesi@oregonstate.edu</a></p>	<p><b>Research Study:</b> The Human Enhancement Spectrum <b>Contact:</b> Ian Oakes <b>Email:</b> <a href="mailto:oakesi@oregonstate.edu">oakesi@oregonstate.edu</a></p>	<p><b>Research Study:</b> The Human Enhancement Spectrum <b>Contact:</b> Ian Oakes <b>Email:</b> <a href="mailto:oakesi@oregonstate.edu">oakesi@oregonstate.edu</a></p>	<p><b>Research Study:</b> The Human Enhancement Spectrum <b>Contact:</b> Ian Oakes <b>Email:</b> <a href="mailto:oakesi@oregonstate.edu">oakesi@oregonstate.edu</a></p>	<p><b>Research Study:</b> The Human Enhancement Spectrum <b>Contact:</b> Ian Oakes <b>Email:</b> <a href="mailto:oakesi@oregonstate.edu">oakesi@oregonstate.edu</a></p>	<p><b>Research Study:</b> The Human Enhancement Spectrum <b>Contact:</b> Ian Oakes <b>Email:</b> <a href="mailto:oakesi@oregonstate.edu">oakesi@oregonstate.edu</a></p>
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## Appendix B



### Recruitment Email for Research Study

Greetings,

The Oregon State University Department of Mechanical, Industrial and Manufacturing Engineering is seeking current OSU students who are at least 18 years old and live with a physical disability to participate in a research study. The purpose of this study is to characterize the ethical dilemmas associated with human enhancement technology to mitigate or overcome disability.

Participation in this study involves:

- Meeting with a student researcher for a one-on-one interview of no more than 30 minutes, at a location of your convenience
- \$10 cash compensation

For more information about this study, please contact the student researcher, Ian Oakes, by phone at 503-989-1510 or email at [oakesi@oregonstate.edu](mailto:oakesi@oregonstate.edu).

Thank you,

Ian Oakes  
Student Researcher

Study Title: The Human Enhancement Spectrum  
Principal Investigator: Kenneth Funk II, PhD

## Appendix C



### Interview Consent Form

**Study Title:** The Human Enhancement Spectrum  
**Principal Investigator:** Kenneth H. Funk II, PhD  
**Student Researcher:** Ian Oakes  
**Version Date:** February 8, 2020

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**Purpose:** We are inviting you to take part in a research study. The purpose of this research is to characterize and discuss the ethical dilemmas associated with human enhancement technology to mitigate or overcome disability, specifically applied to individuals with physical disabilities. The result will also be used as part of the student researcher's undergraduate honors thesis.

You must be fluent in spoken English.

You should not be in this study if you are under the age of 18, do not live with a physical disability; or if you are employed, advised, or taught by Dr. Kenneth Funk.

**Voluntary:** Participation in this study is voluntary, and you can choose to withdraw at any time. Refusal to participate or withdrawal will not affect your grades, academic standing, or employment at OSU.

**Activities:** The study activities include participating in a one-on-one interview with the student researcher to understand your experiences with assistive technologies related to your disability, and your opinions about future assistive and enhancement technologies. This conversation will be between you and the student researcher only and can be ended by you at any time. The researcher will take notes, or audio record (depending on your preference).

**Time:** Your participation in this study interview will last no longer than 30 minutes.

**Risks:** The possible risks or discomforts associated with the being in the study include potential for mental/emotional stress (such as embarrassment) or discomfort upon discussing one's disability. Even though proper safeguards are in place, there is a risk of breach of confidentiality. Aside from the contact information you provide, no other identifying information will be stored, nor will any link exist between you and the responses you give.

**Benefit:** We do not know if you will benefit from being in this study. However, this study will help increase awareness of ethical dilemmas related to human enhancement and disability, which may help inform other scholars and policy makers, in addition to the public at large.

**Confidentiality:** The information you provide will be kept confidential to the extent permitted by law. No personal identifiers will be collected, and all data will be de-identified. Information that is collected as part of the research will not be used or distributed for future research studies.

**Payment:** You will be given a \$10 bill for participating in an interview.

**Study contacts:** We would like you to ask us questions if there is anything about the study that you do not understand. Please contact: Ian Oakes at [oakesi@oregonstate.edu](mailto:oakesi@oregonstate.edu) or Dr. Kenneth Funk at [funkk@engr.orst.edu](mailto:funkk@engr.orst.edu). You can also contact the Human Research Protection Program with any concerns that you have about your rights or welfare as a study participant. This office can be reached at (541) 737-8008 or by email at [IRB@oregonstate.edu](mailto:IRB@oregonstate.edu)