

Our Posthuman Present: Thinking Through Ableism, Disability, and Untethered Norms

By

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Abstract

This dissertation aims to show, through the example of disability studies, how changes in the modes of normalization in our contemporary society have affected how abnormality is perceived and controlled. The purpose is to explore, promote, and contribute in some way to the more critical currents of Disability Studies, but also to use these more nuanced critical currents as roadmaps to how we may destabilize dominant narratives that affect, or are slated to affect, an increasing number of people in the near future. I argue that to understand the situation of disability today is to understand our shared *posthuman condition*. In Part 1, I describe the ways in which biomedicine and neoliberalism as technologies of control have mutated beyond the historical limits of modernist thinking. Practically speaking, it is argued that we can think of optimization and maximization as fundamental orienting norms in a *de facto* posthuman world. In Part 2, I describe transhumanism as the dominant framework through which we develop our ideas about the future, and oppose it to a disability informed critical posthumanist perspective. I conclude the work with some preliminary political and ethical considerations about our relationship to technology, the value we place on alternative embodiments, and the need to include alternative voices in choosing an acceptable future. These remain preliminary because the purpose is not to offer a definitive vision of the future but offer some enabling conditions for those marginal and minoritarian voices to contribute to our shared project of world-making.

Key words: Disability Studies, Transhumanism, Posthumanism, Critical Posthumanism, Optimization, Maximization, Normalization

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Introduction—Why and for Whom?

Those who have talked down the social model while failing to replace it with something more meaningful or useful must bear a heavy burden of responsibility for [the current] state of affairs. Disabled people urgently need a reinvigorated social model - or something new to replace it.

Mike Oliver

Any theory that would inhibit the struggle for autonomy, self-direction, participation, and integration for people living with disabilities would be useless at best, and wholly immoral at worst—as advocating this is clearly unacceptable and damaging. Alternatively, not exploring the dangers of these demands and the results of these struggles (and the paradoxical foundations on which they rest) would itself be naïve at best, and disastrous (for some) at worst. One can understand Oliver’s frustration, highlighted in the epigraph above. Theory for the sake of theory, and tokenistic thinking are real challenges to the Disability movement and can be damaging to the practical daily struggles of those who simply need better tools for social action. Therefore, the perspective, the recommendations for a posthuman ethics, and preliminary suggestions for political resistance contained herein should be read either in parallel with traditional social model activism, or must at some later point be better

integrated. A Disability Studies informed understanding of the challenges, dangers, and pressures inherent in contemporary discourses about the human, health, and technology have universal implications; though, people living with disabilities risk being the most affected. In one sense, the social model demands equal participation in a social system that we will identify as inherently problematic, and people with disabilities are among the first to feel its pressures. As we will see, what underlays the Social Model *is* a Marxist critique of the capitalist system; though in practice capitalism has a way of immunizing itself and integrating these critiques into forms of neoliberal power and control. I would argue that as a historical fact, it has largely been co-opted. However, in the absence of large-scale change, Marxist or post-Marxist, one has to use the tools at their disposal to eliminate immanent oppression, stigma, discrimination, and barriers to a fulfilling life. Following Braidotti, what I will propose in the closing chapters of this dissertation is a strategic, co-operative, and successive dismantling of problematic aspects of our current system—not an outright call for revolution. The goal here, then, is not to enter into a polemic with the social model and its adherents, but to nurture a strategic co-existence. In fact, in practice, *out there in the world*, I encounter and use the social model and its tools quite often—strategically. To use a pointed metaphor, a well-equipped soldier still keeps a side-arm and a bayonet. Philosophical friction be damned; though I propose an alternative to the social model, I do not entirely reject it.

Wholly outside of this friction between theory and practice, is another concern: that Disability produced knowledge may be used or mined to improve the situation of more privileged people, leaving the producers of this knowledge in the wake. One must ensure that it is a symbiotic relationship and not a parasitic one, to use an apt metaphor. Learning from experience, crossing disciplinary boundaries, and adapting knowledge to increasingly diverse

problems are important parts of developing a more complete understanding of complex phenomena. Our current human condition certainly qualifies as a complex phenomenon. Of interest to us here is the increasingly specific and manifold pathologizations of human behaviour, increased pressures of performance and self-regulation placed on individuals, and the expanding role of technology into our environment, way of life, bodies and worldview. As I will argue, these are developing features of our contemporary world, but its distribution is not uniform or homogenous. The experience of those at the margins, here people with disabilities, can show us the historical trajectory and current problems with these contemporary developments. Not only does this beckon us to act in the name of justice for those already experiencing the negative effects of the current dominant discourse, but give those who still hold some privilege a window into how their existence is likewise threatened by this discourse.

Marxism, postmodernism, critical theory and posthumanism are critical currents in the history of ideas that cross the boundaries of many different movement or academic disciplines. The ways of understanding and forms of resistance that come out of them can be adapted to many different social positions, especially when they share the same object of critique—here modernity and a certain developing form of ‘hyper-modernity.’ What we get in Disability Studies is an engagement with these currents from the perspective of individuals who are, in some significant ways, negatively affected by modernity and its current mutations. As Wolbring put it, “Disability Studies-based research, especially the work around the concept of ableism, has strong utility outside Disability Studies, but so far,

it is rarely applied outside of the Disability Studies realm.”¹ Though I believe there is mutual benefit in the upcoming exercise, certainly the bulk of the utility is one sided. Following Wolbring here, I think the work done by disability studies scholars is absolutely essential in describing the posthuman world we live in, and has been insufficiently broadened to more general problematics in the current academic landscape. Out of necessity, disability scholars engage with the broad social, political, and historical trends that define our posthuman present. Braidotti, in her foundational text of critical posthumanism, writes that disability studies is “emblematic of posthumanism,”² but her overall project is aimed at pinning critical posthumanism against the tradition of the humanities and not exploring the practical lines of resonance between disability scholars’ analyses and the posthuman world we are living in. She remains, as Goodley, Runswick-Cole, and Liddard³ recognize, very relevant within disability studies. I believe the flow outward from disability studies is under explored. This is what Wolbring suggests, and what I will try to develop here. More specifically, to show that a) we have organically moved into a posthuman world; b) how the experience of disability lays bare a posthuman value system that tends towards the optimization of capacity and maximization of output in many areas of our individual and social lives; c) that the feedback loop between biotechnology and the self does not inherently lead to a better society, but that

¹ Gregor Wolbring, “Expanding Ableism: Taking Down the Ghettoization of Impact of Disability Studies Scholars,” *Societies* 2, No. 3 (2012): 78.

² Rosi Braidotti, *The Posthuman*, (Cambridge: Polity Press, 2013), 145.

³ Dan Goodley, Rebecca Lawthom, Katherine Runswick-Cole, “Posthuman Disability Studies,” *Subjectivity* 7, no. 4 (2014): 342-361; Kristy Liddiard, Sally Whitney, Katy Evans, Lucy Watts, Emma Vogelmann, Ruth Spurr, Carrie Aimes, Katherine Runswick-Cole, and Dan Goodley, “Working the Edges of Posthuman Disability Studies: Theorising with Disabled Young People with Life-Limiting Impairments,” *Sociology of Health and Illness* 41, no. 8 (2019): 1473-1487.

it has the potential to; and finally, d) that we can only access those possibilities by learning from those already placed in opposition to the worst tendencies of the world-in-transition that we find ourselves in. It is these under-developed areas of the literature that I will explore here to contribute to this very important and evolving scholarship.

The title of this dissertation points to an ambiguity. To think through something can mean to get to the bottom of it. To solve a problem. Alternatively, however, thinking through something can also mean thinking through a lens or a screen. To have what is on the other side coloured by the thing we look through. This is what is meant here. However, as Disability Studies grows as a social-academic enterprise, Dan Goodley *et. al.* have recently offered up what he calls “provocations” for thinkers in this and related fields. One of these provocations is most relevant here; specifically, the intention behind using disability as an object of inquiry. As they write, “[w]e do wonder, however, about who is doing theory and for what reasons. When disability becomes merely the object of intellectual inquiry, then there is a real danger that the politics of disability are domesticated.”⁴ As Disability Studies grows, who gets to ‘do’ this kind of thinking and for what purpose? My own experience with mental health and learning challenges is not a member card that authorizes me to speak with authority on the subject. No group is a monolith, nobody speaks for everyone, and most importantly, one must consciously and explicitly treat the knowledge that comes out of the experience of others with a certain respect for their intention and expectation. My interpretations and strategic uses ought not benefit privilege and further silence those at the margins.

⁴ Dan Goodley, Rebecca Lawthom, Kirsty Liddiard and Katherine Runswick-Cole, “Provocations for Critical Disability Studies,” *Disability & Society* 34, No. 6 (2019): 972-997.

For this reason, this Dissertation has two interrelated purposes: to explore, promote, and contribute in some way to the more critical currents of Disability Studies under development, but also to use these more nuanced critical currents as roadmaps to how we may destabilize dominant narratives that affect, or are slated to affect, everyone in various interrelated ways. At the root of how populations are governed and how people regulate their thoughts and behaviours is a regime of truth about who we are and what a worthy life is. Though we do not want to homogenize all people, and deny the uniqueness of the experience of disability, much can be learned from seeing how and why certain forms of power are applied. The advantage from the perspective of disability activism and resistance is that as more like forms of control are identified and the more widely they are resisted the more reasonable the general argument becomes. I consider this a reasonable aspiration. Additionally, this opens up avenues for cooperation and unity among people affected and concerned about problematic aspects of our current order of things. People living with disabilities are not monoliths; there are many forms of difference that can intersect. Additionally, as I will argue, people who have traditionally not been seen as marginal do not escape the grips of hyper-modernity and its fantasies for the future. A more varied understanding of the myriad ways people experience the dominant discourses of health, norms of behaviour, acceptable ways of being, and historical progress may help us find and create possible connections, collaborations, and opportunities for co-resistance. As stated above, however, it must be accompanied by acknowledgement and respect for the source of the knowledge, and cannot be done in spite or instead of disability specific resistance and activist movements. What cannot be ignored is that many contemporary problematics are left

unattended by the social model. These problematics extend well beyond that field of study, even though they are well positioned to comment on it and resist them practically.

In the first two chapters of Part 1, I orient the reader to the prerequisite framework that will make visible the foundational ideas that are important to our counter-narrative; namely, rational man, scientific naturalism, and the belief in linear progress. In Chapters three to five, I discuss how health has come to play an important role in the normalization of bodies and population, follow some relevant mutations to its discourse, and discuss the ways in which it today manifests in self-regulation towards flexible norms. I conclude Part 1 by synthesizing two important normalization mechanisms into a useful dichotomy; namely that of optimization and maximization. It is my contention that this represents a current or directional line that underlays a great deal of what is problematic about the changing norms of our contemporary society. This is relevant for various forms of practical social resistance, as well as a frame to critique our current historical course being spearheaded by transhumanist fantasies. The latter leading us into Part 2.

Those places where maximization/optimization norms are most relevant is in our relationship to technomedicine and technological progress more generally. In Part 2 I explore several themes of interest in this vein. In Chapter one, I introduce different perspectives on posthumanism and the ways in which critical posthumanism and critical disability resonate with each other to suggest radically different ways to think about ourselves and technology. In Chapter two, I look at the distinction between therapy and enhancement and its shaky foundation on fixed norms. This distinction and its grounding in naturalism is fundamental to the most problematic forms of posthumanism and transhumanism. In Chapter three I discuss an alternative to the idea of fixed and limited norms of human functioning. I present what I

consider to be more adequate models that include the inherent adaptability of human life and the contingent nature of normality in a changing environment. Finally, in Chapter four I synthesize the entirety of what has been discussed to that point into actionable and practical directions for the future.

Contained herein is what could only be described as a narrative. One that walks through the history of ideas, passes through common experience, and lands on an aspirational, but somewhat optimistic note for the future of our society. It focuses on problematics: the history of social control and current modes of normalization; modernist understandings of the body and its abilities; scientific progress in the social sciences attached to a technoscientific worldview; the encroachment of economic-type value systems into general decision making; established systems of value with regard to who matters and who gets to participate in history making. As discussed in the very next chapter, the glue that holds such a narrative together is a foucauldian approach to critical exploration; a thinker who resisted being defined by any discipline and whose influence has touched practically all forms of academic thought in the late 20th century.

At its core, this dissertation makes a small number of claims. That understanding our current situation *as* already posthuman and interpreting its problematics through disability experience is the best way to describe the world as it is today. That the dissolution of the modernist human subject as a practical and conceptual fact, and the positioning of critical disability directly against the orthodox Western liberal-technoscientific optimism of our time, helps us identify the inherent dangers in the future we are currently manifesting. And finally, that where we find established resistance and problematizations from disability scholars and activists, we also have signposts of the more generalized problems of our

society. I argue that to understand the situation of disability today is to understand our shared *posthuman condition*.

The current dissertation does not start from a set method or collection of traditionally disciplinary concerns. It is by definition an interdisciplinary endeavour. This complicates the question of who the audience may be for such a work and who might find something useful within it. The simple answer is that it may be useful to thinkers in critical posthumanism or critical Disability Studies. Though this may be the most reasonable answer on the surface, the hope—optimistic as it may be—is that it serves as a rich source to be mined by anyone who finds resonance in the themes explored. It is my hope that it leads thinkers and doers in a great many contexts to be more critical about the dominant ideas of our time and the dangers they may entail. Far from presenting solutions, it ought to be read as more of a statement on our current state and some directions for those who share a sense of unease about where we are heading.

**PART 1—Theoretical Prelude and
Reflections on Power**

Introduction—A Roadmap

It is the purpose of this introduction to give an initial sketch to the reader for what is about to follow. A preliminary remark, however, is that this section will not serve as a complete history of the ideas contained within--Disability Studies, Critical Medicine Studies, Governmentality, Posthumanism--but will serve as a conceptual narrative that will bring the reader to the conclusions and important concepts to be used in Part 2. It is a historical narrative explicitly vectored on a contemporary problematic (*à la* Foucault),⁵ aimed at creating--to use Deleuzian terminology--a certain resonance in the reader. Or, more specifically for our purpose, to put forth a way of seeing that may elucidate some dangers in our present situation.

In Chapter one I explore two major threads in the emergence and practice of the interdisciplinary field of Disability Studies. I look at the idea common to both, namely, the dichotomy between impairment and disability, and show how it took on two different functions in the geopolitical and historical context within which it was applied. Summarily,

⁵ As Dreyfus and Rabinow put it while discussing the concept of “the history of the present” in Foucault, “This approach explicitly and self-reflectively begins with a diagnosis of the current situation. There is an unabashed contemporary orientation. The historian locates the acute manifestations of a particular ‘meticulous ritual of power’ or ‘political technology of the body’ to see where it arose, took shape, gained importance, and so on” (Hubert L. Dreyfus, Paul Rabinow, and Michel Foucault, *Michel Foucault: beyond Structuralism and Hermeneutics*: 2. Ed. (New York: Harvester Wheatsheaf, 2006), 119). While Foucault’s analyses focused on the archive and on creating new tools, my method here is to use those tools and develop a few poignant mutations away from their original applications. It remains, however, that my purpose in turning back toward history is not to create an alternate reading, but to show how aspects of our present that seem spontaneous and inevitable have roots in contingent historical conceptualizations that, by virtue of their contingent nature, could be otherwise today. It is this destabilization, because of Foucault and going beyond Foucault, which can allow us to attempt to reconfigure and change the present.

in America it represents a focus on rights and legal protection, while in the UK it was more concerned with social change and removing barriers to participation--both taken together represent the contemporary Social Model orthodoxy. I then engage with a few issues with this perspective, not to negate the work that has been done in its name, but to show how a critical disability perspective might avoid some of the theoretical pitfalls present in this earlier conception, without for all that denying its past and present successes in political engagement and in collectivizing activism and academia.

Chapter two serves a dual purpose. I briefly describe the foundational discourse of modernity in order to set up the framework that will define itself in opposition to its major currents: rational man, naturalism, and the belief in linear progress. It will also afford me the opportunity to discuss some methodological considerations and define the purpose of critique as I use it. Essential here is that when I point out dangers and problems with certain social trends, discourses, or disciplinary practices I do not intend to reject them outright. One of the benefits of a critical attitude in the Foucauldian tradition is that nothing is all Good or all Bad. The intention is not to engage with universals, but to look at the contingency of actual practices in order to open the door to alternatives. The point of critique is not to do away with the object of analysis; describing mutations in medicine and their negative results is not a call to do away with medicine entirely--like for e.g., the anti-psychiatry and anti-medicine of some activist currents in the 1970s and 1980s in the US; a critique of modernity's victims is not to deny that it did lead to some good in general--the spirit of social change and the possibilities inherent in modernity's forward looking flexibility were certainly present in feminism's first wave; and to critique technological progress is not to advocate for a luddite revolution or a return to a romantic pre-industrial past--these moves

themselves have inherent dangers and follies; likewise, to critique Disability Studies is not to deny its gains and contributions. The hyper-pessimistic search for dangers is a pre-condition of finding points of contact for resistance and change. It counters the optimism of unrestricted progress and paves the way for thinking differently.

In Chapter three I introduce an important switch point where medicine came to be inserted in the normalization of bodies and populations; a view that will be complicated by mutations in normalization (a shift towards normalism) in Chapter four, and its implications within the emergence of technomedicine and vital politics in Chapter five. It is in these chapters that I point to the move from self-regulatory forms of power based on fixed clinical norms to a more flexible ‘ground-up’ form of normalization based on real-time performance monitoring and decision-making. I also explore the modes of subjection that correlate with these mutations; namely, a more involved *homo oeconomicus* and the somatic self. It is in Chapter six that all this is baked together into an analytical framework that incorporates the flexibility of normalism and the commitment to unrestricted progress, resulting in the dual self-governing frameworks of maximization and optimization for the subjects themselves and the resulting posthumanism that incorporates the visible and coming effects on our present. It is on these two tendencies that the energies of the historical sketch outlined in all previous chapters come to their apex. By maximization I understand the tendency for individuals to take personal responsibility over the development of their capacities using an economic model of risk and collective good. And by optimization I mean the tendency to self-manage and discipline the malleable body into its optimal form in line with contemporary neuro-chemical and technomedical understandings of life. Taken together, I argue, we have a model of contemporary biopower that allows us to understand and criticise

the image of man that is currently leading the cutting edge of contemporary political and technological practices.

The latter will be discussed in Part 2 of this dissertation. In this first Part, we will land at the intersection of what Dan Goodley aspirationally calls “dis/ability studies” and “critical ableist studies.”⁶ I say at the intersection because it is my contention that the results of the analysis apply equally to impaired and non-impaired persons, and that the line itself between ability and disability are being blurred by flexible normalism and the undertow of posthumanism. Understanding of, and resistance to, the dangers present in the coming order of things is first felt by the margins, but it does not terminate there. In this case, I considered the situation of disability--physical, developmental, and psychiatric--but similar analysis could and should be done for other forms of marginality. We ought to, without denying the specificity of other’s experiences, come together in order to understand what is at stake in the present situation. By way of conclusion, if I am allowed to make Foucault talk for me, it is politically necessary to collectively conduct an “analysis of power relation in a given society, their historical formation, the source of their strength or fragility, the conditions which are necessary to transform some or to abolish others”⁷ for “[a]fter all, we are all members of the community of the governed, and thereby obliged to show mutual solidarity.”⁸

⁶ Goodley, Dan, *Dis/Ability Studies* (NY: Routledge, 2014), 21-34.

⁷ Michel Foucault, “Afterword: The Subject and Power,” in *Michel Foucault; Beyond Structuralism and Hermeneutics* (Chicago: Chicago UP, 1983), 223

⁸ Michel Foucault, “Confronting Governments: Human Rights,” in *The Chomsky-Foucault Debate on Human Nature* (New York: The New Press, 2006), 212.

Chapter 1—Perspectives on the Disabling Society

In this chapter I will not be providing a detailed history of Disability Studies or systematically dismantling its underlying theoretical foundations. The purpose is much more pointed. I will indeed look at some of the history and major themes of this movement because it does represent the beginning of the present field of inquiry; however, I will quickly move on, in the proceeding chapters, to concerns that are not necessarily present in the orthodoxy or tradition of this field. I will follow an alternative critical stream, but it will be useful to start with a sketch of where it all began. It has to be acknowledged that the purpose in showing some of the weaknesses in the established view is to, as others in the field have done, carve out lines that connect with broader philosophical and sociological currents that are making an impact in many other interdisciplinary academic-activist areas. Namely, for this current work, critical theory, postmodernism, and posthumanism. In spite of this overall goal, the social model of disability, as a tool for resistance and *in-the-field* criticism of certain practices, remains relevant and useful.

1.1 The Social Model; Disability Studies' 'Big Idea'

The view of illness and disability as reflecting immorality, lack of piety or any other fabricated cause has changed to the point where the medicalized body makes immediate sense to us today. To its credit, the medical model revolutionized the ways in which we think about life and the body, which has, throughout the 19th and 20th centuries, helped develop a large number of technical interventions that improved and lengthened the life of individuals.

However, as a result of medicalization, the *cause* of disability, stripped of its previous metaphysical or moral dimension, remains centered on the body. In the past, one of the most damaging aspects of disability was its identification with the whole of one's body, identity, and being. Once diagnosed with a disability, the whole person *was* something different; and in many cases; the person was to blame.

This led Oliver to argue that, in spite of all its value and progress, the Medical Model is in fact still an individualistic model. Its explanatory model may be different, but it continues to center itself on the individual as the root cause of the deficit. He states: “for me, there is no such thing as the medical model of disability, there is instead, an individual model of disability of which medicalization is one component.”⁹ In terms of the entire history of disability, and of abnormality altogether, no model has ever placed the cause of disability anywhere but the body. This is the originality of Oliver's novel formulation.

The Social Model of disability, a model that was first developed in a significant way by sociologist Michel Oliver in the landmark publication *The Politics of Disablement*,¹⁰ has had tremendous influence on disability theory—to the extent that it helped establish Disability Studies as a field of research. In many ways, Oliver can be seen as one of the first ‘disability theorists’ in a classical sense of the word. His basic argument is, at the foundational level, quite similar to other arguments that have been made in anti-discrimination/liberation movements of the 20th century. It is not so different than Beauvoir's

⁹ Mike Oliver, “The Social Model in Context,” in *Understanding Disability* (London: Palgrave, 1996): 31.

¹⁰ Mike Oliver, *The Politics of Disablement* (New York: St Martin's Press, 1990).

observation that one is not born woman but becomes woman, or Fanon’s dual insight that the “black subject” is an identity constructed in relation to normal/superior “whites” and that the resulting oppression under colonialism *causes* mental pathology. In other words, the social model of disability is built on the assertion that human beings have constructed identities that are not determined by biology (at least not exclusively) but rather, by a myriad of interacting social factors (scientific, literary, polemic, role based, political, social, cultural, etc.).

Although Oliver is credited with the development of this model—and before I begin to explain what it is—it must be acknowledged, as he has, that it is based on earlier work by a group called the Union of Physically Impaired Against Segregation (UPIAS). Oliver saw himself not as a founder but rather as a mouthpiece for, and promoter of, their conception of disablement. It is from this group that we get the fundamental division between disability and impairment. UPIAS defined the two terms in this way:

Impairment: lacking part or all of a limb, or having a defective limb, organism or mechanism of the body;

Disability: the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities.¹¹

¹¹ Union of the Physically Impaired Against Segregation (UPIAS), “Fundamental Principles of Disability,” (London; Leeds, 1994), 20. <http://disability-studies.leeds.ac.uk/files/library/UPIAS-fundamental-principles.pdf> Quoted in Oliver, *The Politics of Disablement*, 11; and Dan Goodley, *Disability Studies: an Interdisciplinary Introduction* (Los Angeles: SAGE, 2017), 8.

The group Disabled People's International (DPI) then reiterated this definition in almost the same terms:

Impairment: is the functional limitation within the individual caused by physical, mental or sensory impairment;

Disability: is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.¹²

Although the terminology used by both organizations (UPIAS & DPI) is similar, their ideologies diverge in one important respect. UPIAS is an organization explicitly focused on physical disability—limiting membership to this group—while DPI is open to all forms of disability including mental health challenges and even considering medical issues such as heart conditions or diabetes as disabilities. Though the idea comes first from the UPIAS, it is on the more inclusive versions that Oliver builds his social model.¹³

Interestingly, by following the dichotomy between impairment and disability, Oliver and those who adhered to the social model were able to acknowledge the physical aspect of living with impairment while postulating a definition of disability that was wholly social: “What is at stake here is causation [...] the above definition locates the causes of disability squarely within society and social organization.”¹⁴ Or, put another way by the UPIAS, “in

¹² Disabled People International, *Proceedings of the First International Congress* (Singapore: DPI, 1982), quoted in Goodley, *Disability Studies*, 8.

¹³ Cf. Oliver, *The Politics of Disablement*; Michael Oliver, *Understanding Disability: From Theory to Practice*, (New York: Palgrave, 1996); Oliver, *Understanding Disability*.

¹⁴ Oliver, *The Politics of Disablement*, 11.

our view *it is society which disables* physically impaired people.”¹⁵ This is a radical claim to say the least. They—UPIAS, IDP and Oliver—claimed that what we would colloquially identify as a disability, say being ‘*deaf*’, is in fact a hearing impairment and that disability, i.e., the problems that arise from *impaired* hearing, are socially constituted. For Oliver it is only by looking at social organization as *cause* that we may understand the sources of the oppression that individuals with impairments face. He maintained that it is through this general and inclusive perspective—as opposed to looking for specific instances of oppression—that we ought to frame the problem. As he wrote,

it is the same society which disables people whatever their type, or degree of physical impairment, and therefore there is a single cause within the organization of society that is responsible for the creation of the disability of physically impaired people.

Understanding the cause of disability will enable us to understand the situation of those less affected, as well as helping us to prevent getting lost in the details of the degrees of oppression at the expense of focusing on the essence of the problem.¹⁶

The attribution of *cause* to society has been quite fruitful for disability theory; however, the task does not end there. In large part because of Oliver’s work, the Social Model has been hailed as the “big idea” in Disability Studies. This brief synopsis by no means concludes Michel Oliver’s contribution to the field, but summarizes the basic foundation that was taken up by a generation of activists, academics, and organizations.

¹⁵ UPIAS, “Fundamental Principles,” 20.

¹⁶ Oliver, *Politics of Disablement*, 23.

Oliver points out in a presentation to the research unit of the Royal College of Physicians that the “real issues” of disability and society are “oppression, discrimination, inequality, and poverty.”¹⁷ By “real issues” he means those issues that his model addressed—issues of oppression, inequality, and dehumanization. However, the Social Model cannot be seen as an inherently anti-medical endeavour (like the anti-psychiatric movement would for example). The dichotomy between impairment and disability allows some leeway for medicine to legitimately act in the realm of impairment (i.e., that its legitimate realm of intervention is clearly limited to the impairment itself); however, in practice, this is still challenging because medicine does not typically dichotomise disability and impairment. Medicine’s discourse acts on both, for example, by medicalizing psychological and social impacts, as well as engineered equipment or adaptive environments. The discourse of medicine, and the myriad mutations it will undergo, plays a practical (here seen as legitimate) role, but it will also impact both social and individual conceptions of life. In doing so, it will go beyond both the medical and social models.

1.2 Different Geographical Contexts

As argued by Goodley, various models of disability, taking the impairment/disability dichotomy as their point of departure, have been developed within different national/geographical contexts.¹⁸ For the purpose of this chapter, I will limit this discussion

¹⁷ Michael Oliver, “The Individual and Social Models of Disability: On People with Established Locomotor Disabilities in Hospitals” (London; Leeds, 1990). <http://disability-studies.leeds.ac.uk/files/library/Oliver-in-soc-dis.pdf>

¹⁸ Goodley, *Disability Studies*, 1-21.

to the British and the North American models. I will do this because my goal is not to mount a detailed rejection of the social model, and these two versions are the most representative. Disability Studies, as I will borrow from it, has taken two alternative routes: one mostly concerned with applied sociological analysis and policy change, and the other with critical understandings of disability and social critique in general. These two models, the barriers approach and the rights perspective respectively, are of utmost importance in disability study's mainstream (the first route). They underlie much of the activist work that has been done, and that continues to be done. Not explored here are two other significant variations of this model, which are the relational model (a product of Nordic countries) and the Cultural Model (primarily North American). These are interesting models, but their exploration would ground us further in the literature than the sketch I am drawing here requires.

Arguably, the Social Model remains a strong conceptual tool in some situations, but as we will see when it is incorporated into the discourses of global NGOs like the WHO, or in other professional settings like the hospital, it falls short from reaching its initial goal of fighting oppression. The theoretical move of reframing society as disabling remains important. The social barriers approach and the rights/identity approach are great in isolation; however, my goal is to go beyond these historically important approaches to address some more contemporary problems that these approaches are not equipped to face. I will only draw simple sketches here because the idea is to pull from this discussion a few problematizations to be explored. The goal is not to offer a complete criticism of the models themselves, but to position ourselves critically in relation to them. Both these models have been great catalysts for social change, and they *will continue* despite my problematizations—

as they should. What I will suggest, however, is that there are certain issues and ideas, arising in contemporary critical theory that may allow us to think differently.

1.2.1 The Social Barriers Approach (UK) or Oliver continued...

The social model of disability was primarily developed in the UK—both the UPIAS and Oliver are British. We can call the specific approach the “social barriers” approach because, though the term social model has been expanded upon in different contexts, the defining feature of the UK approach was its focus on social barriers for those who live with impairments. However, in the above section I discussed what was common to all “social models”; that is, the dichotomy between impairment and disability and the placing of *cause* of disability in society (external cause) as opposed to inside the person (individual cause). In other words, the above section was the *genus* (social model) and the following sections will be the *differentia* (UK barriers approach).

Focusing on the fact that it is society that disables opened the discussion up about *how it is* that society disables, that is, the mechanism of this complex form of oppression. For the British model, the answer is that people are disabled through constructed *barriers* that result from an ableist¹⁹ social organization. As Goodley summarized, “Social model scholars turned attention away from preoccupation with people’s impairments to a focus on the causes of exclusion through social, economic, political, cultural, relational and psychological

¹⁹ Generally Speaking, Ableism is a form of discrimination like any other ‘ism.’ It can represent direct discrimination, systematic, or institutional discrimination. It can also describe attitudes, practices, and policies that lead to discrimination, stigma, injustice or other negative consequences for the person based on the fact that they have a disability or that they are in an environment or situation that assumes ablebodiedness.

barriers.”²⁰ These scholars—and the various organizations that inspired them—noticed that the barriers faced by people with disabilities go much further than physical barriers (i.e., the question of accessible environments) and access to assistive technologies (interpreters, brail text, prosthetics, medication etc.), but include barriers to equal education, employment, stigma, and all forms of civic/social participation. In general, the social model sought to understand all the material forms of discrimination and oppression in society—often bringing attention to the barriers resulting from poverty.

It is through these concerns (social organization, poverty, equality etc.) that the disability movement organized some very successful forms of resistance. A framework of power struggle, of underclasses, collective consciousness, and liberation is ubiquitous to early disability activism well into the early 2000s. In fact, Oliver himself tied the emergence of the concept of disabled bodies with industrialization and urbanization, crediting the oppression of disabled individuals to the demands placed on them by advanced industrialized society and capitalism.²¹ In his landmark book *The Politics of Disablement* (and later *The New Politics of Disablement*) he argues that in small rural communities, people with impairment found a place for participation, but that it is with the industrialization of Britain that the concept of an able-bodied worker became the antithesis to the “disabled” individual.

At the core of Oliver’s work is not only the Marxist theory of power (possessed/dispossessed power and domination/oppression) but of Marxist historiography.

²⁰ Goodley, *Disability Studies*, 11.

²¹ E.g., Michael Oliver and Colin Barnes, “The Rise of Disabling Capitalism,” in *The New Politics of Disablement* (London: Palgrave, 2012), 52-72.

That is to say, he follows the “evolutionary perspective” of human history (present in Marx but also in Comte and Weber) as well as Marx’s formulation of the progression through pre-established stages of human history; the “transitions from feudal through capitalist to socialist society.”²² “No attempt has been made,” he stated, “to apply this (or indeed any other social theory) to the history of disability.”²³ That is not to say that there were no attempts to link the history of disability to social change—he mentioned the work of activist Vic Finkelstein—but that there were no properly concrete histories of disability from the perspective of historical materialism.

This later point will be important to my discussion of critical models, as they will directly problematize the idea that power can be held by a person or one group over another, the evolutionary perspective of social development, and the idea of a linear historical progress. However, for all of its theoretical weaknesses, at the time Oliver was writing this work (three decades ago) there was indeed a great practical advantage in organizing around Marxism. At the conclusion of this chapter I will look at some reasons why we may want to find an alternative framework.

In summation, the origins of the social model can be traced to disabled people’s organizations like the DIP and the UPIAS discussed above, and was developed by academic activists such as Michel Oliver and his long-time collaborator—and influential author in his own right—Colin Barnes. It has been called the “big idea” in Disability Studies, and shows no signs of slowing down. Inspired by Marxist theories and the general leftist social

²² *Ibid.*, 25-32.

²³ *Ibid.*, 26

movements of the 1970s-1980s, the Social Model has made quite an impact in both Britain and the global disability movement. In the next section of this chapter, I will briefly explore how the social model was re-conceptualized in North America through a ‘civil rights’ type movement that also accepted the impairment-disability dichotomy, and similarly sought to address the real issues of “oppression, discrimination, inequality, and poverty.” The resulting model remains essentially the same but takes on a different focus for historical reasons.

1.2.2 Minority Group Model and the Law (USA)

The history of the disability movement and its theories in the USA was less connected to NGOs than in the UK, but rather took on the model of the various civil rights movements of the 1960s and 1970s. In other words, they learned from the now well-known anti-racist and gender equality movements—the powerful ideas of generations of resistance. During this time, political action was concentrated on questions of civic rights, equity in law, and an end to institutionalization (institutions in the physical sense of asylums, clinics, and special boarding schools).

In fact, though the release of individuals from institutions was the hallmark of all disability movements in the decades ranging from the 1970s to the 1990s, deinstitutionalization took on a special significance in the USA. For many Americans, Robert Kennedy’s speech after his visit to Willowbrook State School in 1965 legitimized the disability movement’s claim to be part of the civil rights movements. One year prior, people living with disabilities were not given protection under the Civil Rights Act of 1964, and therefore were not included in what Americans considered landmark legislation. In the original speech Kennedy gave at Willowbrook, he likened the overcrowded and decrepit

institution to a “snake pit.” This is most probably a reference to the movie *The Snake Pit* (1948), which is about a woman who finds herself in a state institution.²⁴ In this particular speech by Robert Kennedy, we see the use of language of civil rights and a call to action of all New Yorkers:

We hear a great deal, these days, about civil rights, and civil liberties, and equality of opportunity, and justice. But there are no civil rights for young retarded adults—then they are denied the protection of the state education law which commands that all other children must receive an education. There are no civil liberties for those put in the *cells* of Willowbrook—living amidst brutality and human excrement and intestinal disease. [...] The burden is ours. In the year 1965, that the conditions such as those I saw should exist in this great state is a reproach to us all.²⁵

The torrent of articles, documentaries, and on-air reporting in the decades following Kennedy’s visit to Willowbrook, and the momentum of the civil rights movement, enhanced the effort of the Disability Movement. It found its form in a unique political situation. If we

²⁴ This film uses the Ward numbers as a sort of hierarchical system for the stratification of patients; Ward 1 likened to heaven and ward 35-35b in the basement as the “snake pit,” overcrowded with patients who will never be ‘cured.’ Also interesting in this movie—possibly alluding to the works of Antonin Artaud who was arrested in Ireland before being sent to an asylum in France—Virginia, in her confusion, does not remember being admitted to a hospital and believes she has been sent to prison. This ‘delusion’ repeats once again prior to her first electroshock treatment, as she asks the nurse “You’re going to electrocute me. Was my crime so great?” In fact, there have been several films made portraying life in the institution in the latter half of the 20th century. Notable examples include *Shock Corridor* (1963), *One Flew Over the Cuckoo’s Nest* (1975), *Rain Man* (1988), *Awakenings* (1990), *Girl Interrupted* (1999), *A Beautiful Mind* (2001) etc. Without getting into the details of the actual quality or authenticity of the representation (which will interest proponents of the *Cultural Model* of disability), I mention this here just to show that the issue of institutionalization found itself all the way to Hollywood and occupied a significant cultural space in the America imagination following this period.

²⁵ Robert F. Kennedy, “Excerpts from Statement by Kennedy,” *NY Times* (September 10th, 1965).

can envy the British model for its influential conceptual models and the effective formation of self-governed disability organizations, there is also reason to envy the US disability movement's ability to mobilize a broad range of individuals within the framework of the civil rights movement. In the 1960s and 1970s the American environment was ripe for social movements, and activists with disabilities and their allies seized the opportunity.

The narrative of the American disability movements is very much told in terms of a struggle for protection under the law and, once acquired, of successive battles for the recognition of these rights. There is a progression of legislated rights starting with section 504 of the Rehabilitation Act of 1973,²⁶ then the Education for All Handicapped Children Act of 1975,²⁷ and finally, a broad civil rights legislation in the form of the American with Disabilities Act of 1990.²⁸ In the first case (section 504, 1973) there was, for the first time, a legal standard for inclusion in any federally funded programs and the first legal definition of disability. The act reads:

No otherwise qualified individual with a disability in the United States, as defined in section 705 (20) of this title, shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination

²⁶ It is in this section of the *Rehabilitation Act* (1973) that for the first time discrimination laws are extended to the category of disability. It would serve as the foundation for the *Americans with Disabilities Act* of 1990.

²⁷ Renamed to *Individuals with Disabilities Education Act* (IDEA) in 1990.

²⁸ This is the final large-scale federal law that expands on the original 1973 stipulation.

under any program or activity receiving Federal financial assistance [...]”²⁹ where section 705 (20) defines someone with a disability as an individual who “has a physical or mental impairment which for such individual constitutes or results in a substantial impediment to employment.”³⁰

This piece of legislation, in what Longmore calls one of America’s great ironies, was signed into law in 1973 by none other than President Nixon. But it also went almost unnoticed until some work had to be done to keep it tabled and to get it implemented. In the first case, Nixon rejected the section of the rehabilitation act on two grounds: (1) It would direct the state level priorities of vocational programs, which he considered an overstepping of federal government on state decision making, and (2) that it would be too costly to incorporate the demands of independent living centers and jeopardize the intended goals of the act.³¹ Two versions of the Act, which secured funding for Independent Living Centers were vetoed by Nixon, but by 1973, a third version of the Rehabilitation Act was signed into law, which included the aforementioned sections.³²

²⁹ United States Department of Health, Education, and Welfare, Office for Civil Rights, *Section 504 of the Rehabilitation Act of 1973, Handicapped Persons Rights under Federal Law*, (Washington: Dept. of Health, Education, and Welfare, Office of the Secretary, Office for Civil Rights, 1978):

<https://www.dol.gov/agencies/oasam/centers-offices/civil-rights-center/statutes/section-504-rehabilitation-act-of-1973>

³⁰ Legal Information Institute, “United States Code, Title 29-Labor, Chapter 16: Vocational Rehabilitation And Other Rehabilitation Services, General Provisions, Section 705, Definitions, Paragraph 20,” (Cornell Law School): <http://www.gpo.gov/fdsys/pkg/USCODE-2011-title29/pdf/USCODE-2011-title29-chap16-other-sec705.pdf>

³¹ Paul K. Longmore, “The Disability Rights Movement; Activism in the 1970s and Beyond,” in *Why I Burned my Book, and Other Essays* (Temple UP, 2003), 103-104.

³² *Ibid.*, 104.

There are two very important aspects to this ‘event’ in the history of disability in the US. Firstly, it had been recognized by legislators that people living with significant disabilities had to be included in the Rehabilitation Act, but none of them had any real knowledge of disability issues or activism.³³ As Longmore puts it, “Nixon and his advisors overlooked 504. Indeed, it escaped the notice of virtually everyone”³⁴; this became a foot in the door for legal representation of people living with disabilities. Secondly, disability activism groups prior to the protests surrounding the passing of the Rehabilitation Act had been quite isolated because of competition for funding, and perceived difference of issues faced.³⁵ Nixon’s vetoing of the first two version of the Act provided activists with a common enemy around which to organize, sparking the budding of a coming common identity for disability activists and politically engaged people living with disabilities. To reiterate, this event produced a foot in the door for disability movement’s battle for legal recognition and protection, and began to solidify the co-operation among groups of activists and different categories of disability.

Interestingly, the passing of section 504 did not, however, lead to immediate change. As Longmore reminded us, three years of activism was required to pass regulations that would force institutions (civic, educational, commercial, etc.) to comply with section 504. Notably, hospitals and higher education institutions could in effect delay the implementation of structural change by delaying regulations—saving face by not being perceived as

³³ Ibid.

³⁴ Ibid.

³⁵ Ibid.

opposing civil rights issues.³⁶ The Department of Health, Education, and Welfare (HEW) were tasked with the development of regulations but three years had passed and no change was implemented. The political victory had been great—the actual signing of legislation—, but the delay in implementation showed that there was still quite a bit of resistance to change. In 1976 and 1977 disability activists had secured court orders for the HEW to release regulations, but were met with more delay tactics. A committee was formed and 22 proposed changes to the regulations were introduced—some being as serious as introducing segregated schools to avoid making regular schools accessible. By April 4th, 1977 the American Coalition of Citizens with Disabilities (ACCD) delivered an ultimatum; that the regulations should immediately pass unaltered or they would stage a nationwide protest. When it did finally get to that point, protesters occupied nine HEW offices. The most successful by far was the protest in San Francisco that lasted three and a half weeks. In the end, the regulations were signed virtually unchanged.³⁷ As the historian Longmore reminds us, the intersections of the civil rights movements represented more than a plainly intellectual or theoretical kinship. At the aforementioned San Francisco HEW office sit-in, vital supplies were brought in—under risk of arrest—by the local Black Panther group and the Delancy Street Foundation (a peer-run non-profit addictions and homelessness organization in San Francisco).³⁸ Where the struggle of 1973 helped to consolidate the disability movement from internal division, this 1977 sit in showed that the disability movement had earned its place in the constellation of civil rights movements.

³⁶ *Ibid.*, 105.

³⁷ *Ibid.*, 105-109.

³⁸ *Ibid.*, 106-107ff.

Another significant event that came more than a decade later was the passing of the flagship disability legislation—though it has always been the target of some criticism—of the Americans with Disabilities Act (ADA) of 1990. As Linda Hamilton Kriegert noted, in an article from 2000, it was surprising for some civil rights activist groups that the ADA passed with such wide acceptance (e.g., 377 to 28 in the House of Representatives, and 91 to 6 in the Senate).³⁹ Be it President Bush’s likening of the breaking of barriers for disabled Americans with the tearing down of the Berlin wall, Senator Tom Harkin delivering floor remarks in sign language, or the large scale signing party on the Whitehouse lawn, it seemed that indeed American government and legislators were open to a new era of disability rights.

This did not go as smoothly as the disability movement might have hoped, however, as there were many negative media representations that showed that the issue of discrimination and stigma were still very present. Two examples from popular television shows would be an episode of the Simpsons entitled “King Size Homer” and a King of the Hill episode entitled “Junky Business”; the first where Homer Simpson, the father of the Simpsons family, goes on an eating binge with the help of a quack doctor in order to seek protection under the ADA not to participate in a mandatory exercise program at his workplace, and the second, where Hank, father and business owner, is prevented in firing a ‘lazy’ employee with unrealistic expectations for accommodation—demands to come in late, dim all the lights in the office and spend most of his day in a foetal position doing little work—on the grounds that he would be violating the ADA. I was much too young to

³⁹ Linda Hamilton Kriegert, “Foreword-Backlash Against the ADA: Interdisciplinary Perspectives and Implications for Social Justice Strategies,” *Berkeley Journal of Employment & Labor Law* 21, No. 1 (2000).

understand the politics behind these representations and the greater social commentary; I remember these episodes in detail to this day. I mention it here in passing, as I did with the films portraying institutionalization previously, to highlight the importance of media and culture in the resistance to the disability movement in the USA.

Summing up the events of 1973 and 1977, Longmore identified four features that marked this moment as a turning point in the making of an American disability movement. Firstly, it reframed, in a politically charged way, the fact that the problems faced by people living with disabilities were not medical, but were predominantly social. Secondly, it effectively created lines of cooperation with other political groups (such as race or poverty activists). This again reinforced the social and political nature of marginalization and opened the door for forms of allyship and intersectional thinking that would come later. Thirdly, it broke down barriers between disability groups that previously believed they were fighting for different things or perceived that they were fighting in isolation. As he stated, “the demonstrators for the moment set aside disability parochialism. They proclaimed an ecumenical ideology of disability: all people with disabilities, whatever their particular conditions, confronted a common set of stigmatizing values and social hazards.”⁴⁰ I highlight this fact because it shows that it is at this time that we can say a disability *movement* existed. No less important is the fourth and final aspect, that a disability identity was born out of the 1970s: “Their activism enabled many of the protestors to assume the authority to define themselves, not *despite* their disabilities, but, in a positive way, *as* people with disabilities.

⁴⁰ Longmore, *Burned my Book*, 110.

That was at least as radical as their claim that disability was a civil rights issue.”⁴¹ All four aspects will survive as parts of the North American approach to disability, and in many ways will also be inherited by the World Health Organization and their approach to disability.

Additionally, the issue of perception and discrimination will likewise continue to affect people living with disabilities as financial assistance and workplace accommodations are often still viewed negatively by people who resist these initiatives. Evidence of this can be found in the fact that in 2020 cases of discrimination accepted by the Human Rights Commission of Canada were overwhelmingly based on disability (54%)—outpacing the number based on race (29%).⁴² We also see some trends related to austerity and challenges to social assistance that threaten equitable access to the necessities of life and social existence. These latter aspects will be discussed at various points in this work. But there is a subtlety to this fourth aspect that needs to be explored further, i.e., the idea that disability is an identity category that can be at once a source of pride and solidarity as well as a source of stigma, discrimination and marginalization.

1.3 Discrimination, Identity, and a Return to the Social

By and large, disabled activists in America adopted the discourse of *minority* in order to seek special protections under the law because it became apparent that what they were facing was *discrimination* and *stigma*. These were the justifications for denying rights to people who

⁴¹ *Ibid.*, 111.

⁴²“By the Numbers,” *Canadian Human Rights Commission* (2020) <https://chrcreport.ca/by-the-numbers.html>. Note, as they did, that 29% of complaints were related to psychiatric disability; and that 47% were intersectional, in that they had more than one ground for the discrimination.

deserved them. Like other movements, they organized around an identity concept (like ‘black’, ‘gay’ or ‘woman’) and linked it with the particular inequalities that affected that population. By claiming disability’s minority status they could fight for protection under one banner. Remnants of this long fought battle are still present outside the US today where, for example, people with disabilities are included as a minority in United Nation discourse—literally called ‘the world’s largest minority’.⁴³ It is important to dwell on this fact because it shows the development of disability activism in America and ties it to a larger historical context outside of American political history.

The “minority model” is not automatically a Social Model in the same sense as the British model. It does not *automatically* subscribe to the dichotomy between disability and impairment—though it would eventually do this—but it does organize around a *social* movement, which effectively de-individualizes the struggle of disability. Though I’ve separated the British and American models in the previous section in order to focus on their differences, it is here that we can see how and why they have come together so easily. Whether the strategy was to define the ways in which rights were denied to people on the basis of their disability or to explore the means by which society was creating barriers for people with impairments there was a common need to tie these struggles to a larger historical and social theory.

Speaking of section 504 (1973) and the ADA (1990), Harlan Hahn reminds us that “the aim of these statutes *and* the sociopolitical perspective is to foster conditions in which disabled

⁴³ United Nations, “Some Facts about People With disabilities” in *Enable! International Convention on the Rights of People with Disabilities* (New York: United Nations, 2006).
<http://www.un.org/disabilities/convention/pdfs/factsheet.pdf>

and nondisabled persons can occupy positions in society on the basis of genuine equality. As a result, the sociopolitical definition has become *a major source of support* for the minority group model of disability.”⁴⁴ The goal of equality under the law is supported here by the “sociopolitical” definition, which, when explored, is precisely the ‘big idea’ imported from UK theorists: “From this perspective, the effects of disability can be attributed primarily to a disabling environment rather than to personal defects or deficiencies. Thus, the principal solutions to the problems confronting disabled citizens are centred on programs to change the environment instead of the individual”⁴⁵ If the American model did not initially go far enough with their identification of discrimination as the source for the denial of rights, the British model’s focus on imposed barriers as the cause of disability goes a bit further in informing a sustainable social movement. Furthermore, Oliver had already, in his seminal book of 1990, connected the source of social barriers to a historical-material shift in the organization of labour after industrialization. This position was very much in vogue in many social movements of the 1990s and played a large role in the development of Disability Theory in academic and activist circles. But the analysis is meant to contextualize the emergence of barriers, and a proposed plan to liberate individuals *from them*.

1.4 General Problems

It is argued that the individual with impairment became “oppressed” during the rise of industrial capitalism and urbanization because the able-worker became the category of ideal

⁴⁴ Harlan Hahn, “Antidiscrimination Laws and Social Research on Disability: The Minority Group Perspective,” *Behavioral Sciences & the Law* 14, No.1 (1996): 46; *emphasis added*.

⁴⁵ *Ibid.*

social value. Certainly, capitalism can be criticized from many angles. Among them on the basis of its limiting impacts on various marginalized people. Even with this firmly acknowledged however, when the purpose of critique is simply the removal of barriers, it often only impacts the least marginalized (e.g., well classed, western, un-racialized etc.). Those who have intersecting oppressions have multitudes of material and institutional barriers that must be dismantled as well. All of the successive victories do not culminate in the completion of an overall political project. They are piecemeal and insufficiently broad. As Oliver himself recognized, the problem with social normalization approaches (or simple inclusion as I would call it) is that it does not contribute to a reshaping of social structures,⁴⁶ but only demands that people participate in what is already a detrimental system for them. For example, one can criticize capitalism for putting human value uniquely on the ability to produce some kind of economic wealth. If we demand that barriers be removed so that individuals with disabilities can participate in the creation of wealth, we at the same time validate those individuals solely on their ability to create wealth. In other words, they become complicit in the system that defined them as valueless in the first place. When an isolated social victory is achieved or a specific barrier removed—hard fought and legitimate as it may have been—there is no fundamental challenge to the system itself, and those left behind are no better off. Marginalized individuals find creative means to value all kinds of

⁴⁶ Mike Oliver, "Capitalism, disability and ideology: A materialist critique of the Normalization principle," in Robert Flynn, and Raymond Lemay (eds.), *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact* (Ottawa: Ottawa UP, 1999). I would argue the same to be true of contemporary rehabilitation models, see for e.g.: World Health Organization, "How to use the ICF: A Practical Manual for Using the International Classification of Functioning, Disability and Health (ICF), Exposure draft for comment," (Geneva: WHO, October 2013), e.g 5; World Health Organization, "Towards a Common Language for Functioning, Disability and Health," (Geneva: WHO, 2002), 9.

different ways of living. This is certainly true of those who have had some experiences with disability as well as other historically marginalized groups. The fact that such a re-valuation naturally happens from experience illustrates the issue. The removal of social barriers does not take the extra step of re-evaluating how we value certain forms of life or redefine it outright. It fails to do this because it inscribes itself within the worldview that supported those barriers in the first place. I will argue, that outside the materialist critique of capitalism in Oliver is a more adequate source of sociopolitical change. Namely, in the critique of normalizing discourses rooted in modernity and its contemporary mutations.

Oliver's materialism reiterates the Foucauldian idea that the institutions of the state create the "disabled individual," but it seems to do so in a way that is more consistent with a social constructionism that maintains the ontological idea that impairment is real and separate from disability.⁴⁷ This dichotomy has been most famously criticized by Tom Shakespeare in his *Disability Rights and Wrongs*⁴⁸ on the basis that it is too reductive. For him, the dichotomy between impairment and disability denies the lived reality of impairment and the effects that might have on people's experiences, irrespective of social barriers or social relations. His contention is that a social theory of the interplay between impairments and social relations would be a more useful endeavour. The result is essentially a psychosocial model of disability, common to much of the disability discourse in mainstream

⁴⁷ Mike Oliver, "Capitalism, Disability and Ideology: A Materialist Critique of the Normalization Principle" in Robert Flynn and Raymond Lemay, *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact* (Ottawa: Ottawa UP, 1999): 163-73.

⁴⁸ Tom Shakespeare, *disability Rights and Wrongs* (London: Routledge, 2006); Tom Shakespeare and Nicholas Watson, "The Social Model of Disability: An Outdated Ideology," *Research in Social Science and Disability* 2 (2002): 9-28.

social medicine today. It denies that the dichotomy between disability and impairment is based in reality in any way. Likewise, Anastasiou and Kauffman identify this as Disability Study's Achilles heel: "[u]nfortunately, we do not think that it would be possible to eradicate disabilities by changing only the sociopolitical context. Why? Because the dichotomy between impairment and disability is methodological; it is not ontological."⁴⁹ However, there is another way to criticize the impairment-disability dichotomy that does not rely on reducing it to a methodological choice. This would be the perspective taken by Shelly Tremain in her oft-cited work "On the Government of Disability."⁵⁰ Here she explicitly takes a nominalist approach to social phenomenon, which will underlay the entire project I am undertaking here. We can talk of her contribution by analogy with the work of Judith Butler, who thought that the dichotomy between sex and gender was problematic because there is never a "sex" that is defined outside of an already existing "gender" and no "gender" that is not already affected by what is considered "sex." They are both aspects of the same subject formation. They are constituted in, and performed with relation to, the power relations and dividing practices of a specific discourse. As she describes it:

As effects of a historically specific political discourse (namely, bio-power), impairments are materialized as universal attributes (properties) of subjects through the

⁴⁹ Dimitris Anastasiou, and James M. Kauffman, "The Social Model of Disability: Dichotomy between Impairment and Disability," *Journal of Medicine and Philosophy* 38 (2013): 447.

⁵⁰ Shelly Tremain, "On the Government of Disability," *Social Theory and Practice* 27, no. 4 (2001).

iteration and reiteration of rather culturally specific regulatory norms and ideals about (for example) human function and structure, competency, intelligence, and ability.⁵¹

This rejects both the idea that impairments are neutral descriptions of a body that is then limited by society in a one sided manner (Oliver) or a co-limitation model of complex relations (Shakespeare). Tremain's application of Foucault shows how they are functionally dependent and co-constituted in the same discourse. Using this lens, later I will explore what happens when both the political discourse and individual properties change.

As I will argue, changes in medical understandings of human life and a rapid global change in the life sciences have introduced a great deal of dangers in leaving impairment vulnerable to bio-medical reduction, even in the presence of collective political action *vis-à-vis* social barriers. Moreover, from the critical disability perspective, the strategy of separating the body from social existence has shown itself to be incongruent with an understanding of how individuals (and their bodies) are shaped by society and how they shape themselves to participate in it. Without this, the social model cannot continue to redefine disability in the coming biological age where bodies are reduced to information that can be manipulated in their most minute building blocks. The latter may evoke images of science fiction, but advancements in science and technology are quickly changing the ways in which all individuals exist in society, how they see themselves in relation to others, and what kinds of possibilities are opened up for their bodies. The neuro-biological perspectives that come to the fore leave individuals with impairments vulnerable, and political struggle for inclusion limited to the state apparatus precludes a useful critique of those perspectives.

⁵¹ Tremain, "Government of Disability," 632.

Going further, if inclusion means broadening the borders that contain concepts like normality, ability, or humanity then there will always be another class of individual that fall outside that definition. The very function of those categories prevents their destruction by expansion. As new types of individuals become accepted in the realm of normality, or are accepted as fully ‘unqualified’ human, it is simultaneous with the exclusion of another. In the case of humanity, there are a growing number of authors who find it more useful to completely do away with the concept of the human altogether (i.e., critical posthumanists or anti-humanists). It is precisely these kinds of critical perspectives that go far beyond inclusion, and Disability Studies must engage with them.

Before we engage with what we can refer to as a post-human turn, we must look at general movements in the history of thought and how they have shaped both the idea of the human, and the practices of normalization that we face today. More specifically, we must track this more broad question of “who and what we are?” from its modernist conception through to the counterpoints of the dichotomy of impairment/disability, minority and identity models, and the accompanying political strategies of inclusion. It will be the primary goal of this dissertation that the first two issues be explored in order to inform this third goal: the development of a Posthuman Critical Disability perspective.

A posthuman perspective will not be without its own challenges. The real strength of the social, cultural, and rights-based approaches was that they were immediately practical. Challenging as it may be, critical perspectives must likewise lead to actionable avenues of resistance. What is plainly visible, however, is that the posthuman turn will necessitate a large scale theoretical and historical reframing that is not so obviously practical at the outset. It is much better at problematizing discourses and challenging intellectual traditions than

interacting with real world problems. This is not a reason to reject it outright, but a cautionary note to come back, at the end of this work, to some practical directions for disability movements, activists, and those affected by the structures under critical analysis.

1.5 Summary

In this chapter I began with an exploration of the Social Model of Disability. I focused on two key versions of this theory, the British and American ones, because they show us two dimensions that have come to dominate the practical landscape of disability following its formalization into a discipline and movement. The UK approach has been very good at identifying barriers and removing them through political action, while the American version was very good at organizing collective action around rights and demanding legal protections. In practice, both continue to be mobilized globally as strategies for resistance and continues to maintain a healthy activist network. Though it leads to immediate gains for some, it is not the basis for a historically rooted critique of our present. As discussed, successive removal of barriers does not change the socio-political worldview that supports the entire gamut, so Oliver suggests institutional critiques. This does not go far enough, as I would argue, because institutions have a limited role in what is a dispersed normalizing power that includes both population based measures and substantial self-regulation outside the walls of public institutions. Many of these come from our understanding of who we are, constructed in the evolving discourse of medicine. It is at the level of these discourses that I will develop my critique.

In Chapter four and five, I will show how the constitutive discourses of medicine and civic personhood interact with disability in ways that go beyond rights or barrier based approaches. In Chapter six I will begin to formulate this idea into a more concrete perspective that ties together normalization and posthumanism in order to inform my work in Part 2 of this dissertation. What is important to remember in the context of this current chapter is that whatever theoretical focus I take, I must be able to integrate into my framework the idea of political resistance in a way that explains why the social model has been so successful and how we can capture its beneficial features without repeating its dangers. The interest here was not to do a comprehensive critique of these models, but to acknowledge them as the foundational theoretical frameworks that launched the Disability Studies endeavour, acknowledge some of their strengths, but also to introduce a few reasons why I will be trying to think outside of these in this dissertation. It is not a polemical motive, but more a productive one—a means to orient towards a different way of doing things.

Chapter 2—The Frame of Reference; Why Critique and How?

Before I enter into more pointed discussions about the topic at hand, it would be useful here to reflect a bit on the general frame of reference I will be using and the general intention of critique as I see it. In an interdisciplinary work such as this one, it is useful to make explicit some of the theoretical and historical assumptions that will be present throughout in lieu of a received point of reference that would be present in a more concrete disciplinary project. Summarily, I would consider this project inspired by the French critico-historical school of thought, and following a subset of critical theorists who attempted to translate this way of thinking into concrete sociological or anthropological critiques of contemporary practices.

2.1 Modernity and Beyond

The 'age of enlightenment' or age of reason is a period in history where knowledge was greatly reformed. Value began to be placed on scientific knowledge gained through experimentation and observation, while at the same time focusing on reason and rational argumentation. Building on the earlier scientific method initiated by Bacon, authors like Locke, and Hume, developed their empiricism, which laid the foundations for experimental science. On the other hand, authors like Descartes, Spinoza, and Leibniz developed their modern rationalism paving the way for modern mathematics and the manifold discussions around logic, objectivity and the limits of science that will follow. Consequently, this explosion of new knowledge unleashed a cultural revolution.

I would argue that this is best illustrated by reflecting on 18th century France where the fashionable ideas of the times turned their attention to issues of social organization and

political power. This period can be summed up by the well-known axiom 'knowledge is power', where established religious beliefs and engrained political structures were being challenged on the grounds of reason, innate human freedom, and individual freedom of thought. The culmination of these challenges came in the form of the French revolution where the established tiered system that dominated the previous centuries was overthrown and where society began to be redefined in the image of the rational man. The French revolution is the most poignant of these examples because the result was not a gradual change, but a complete and sudden rupture with the 'old regime.'⁵² Nonetheless, this Cultural Revolution played a significant role in world history from North America to the farthest reaches of Europe as well as many colonies unhappy with the authoritarian and oppressive systems established around them.

Because of the depth and breadth of this revolution, we consider it an entirely new period in intellectual and social history—Modernity. *Modernity* can be said to begin with the French revolution because it is the most visible moment in this cultural shift. However, the Cultural Revolution itself is made up of thousands of examples of rationality being applied to all forms of human understanding and actions. This sketch served simply to introduce the frame of reference, but modernity has to be operationalized.

For the purpose of this current work, modernity is defined as the mobilization of meta-narratives about historical progress of the enlightenment (e.g., progress of medicine,

⁵² The attempt was made to rid every aspect of the old system of power based on class or religion. A new de-Christianised calendar was created, everyone referred to each other as citizen (highlighting their equal status but also their duty), the universal rights of man were developed, followed by Napoleon's coup d'état and the era of centralized education and social medicine in France.

progress of law, progress of liberty and freedom, etc.), and the idea that current sociopolitical landscape is the result of greater applications of reason and rationality in the realm of civilization. From the perspective of modernity, the development of Western political and military superiority, liberal economics and capitalism, and social medicine are unquestionable evidence of progress. Adorno, an early critic of this idea, criticized the Hegelian concept of total history and the development towards perfect freedom, stating that “[m]illions of Jews have been murdered, and this is supposed to be only the intermission and not the catastrophe itself. What exactly is this culture waiting for anyway?”⁵³ Some historical moments are hard to reconcile with this idea of progress, such as the suffering brought on by industrialization, the industrial revolution, the great depression, the first and second world wars, the cold war, etc., but these are seen as necessary moments on the road to progress—something like growing pains. The industrial revolution led to better standards of living, the world wars marked much advancement in technology, but also in clinical and social medicine, the cold war established the superiority of capitalism and opened the world up to commerce etc. Possibly the most naïve formulation is found in Fukuyama, whose reading of Hegel is more positive, claims that with the French revolution the ideas of liberal democracy were introduced into history, launching its final phase i.e., the end of history.⁵⁴ But there is one glaring moment of cognitive dissonance within this idea of progress; the multiple global threats to our species brought on by recent human activity.

⁵³ Theodor Adorno, *Minima Moralia; Reflections on a Damaged Life* (New York: Verso, 2005).

⁵⁴ Fukuyama, *The End of History and the Last Man* (New York: Free Press, 2006); *The Origins of Political Order: From Prehuman Times to the French Revolution* (London: Profile Books, 2011); *Political Order and Political Decay: From the Industrial Revolution to the Globalization of Democracy* (London: Profile Books, 2014).

In a perfect example from popular culture, we can look at an article by Dylan Matthews “23 Charts and Maps that Show the World is Getting Much, Much Better.”⁵⁵ This article includes a collection of infographical—this will be important later—representations of all the good in the world over time. Granted, they represent achievements in the sense that some show a decline in morally troubling facts about the world—child labour, extreme poverty, world hunger, homicide rates and nuclear armament—but individually they only give us a very limited picture of complex problems. This is not, however, the point of bringing this article up. It is its abrupt end, on a less optimistic note, that gives one pause. “Climate change is one big area where we’re not making progress, and things are getting considerably worse. There’s no sugar-coating that. One bright spot is the declining price of solar power, which is fuelling [sic] a rapid increase in adoption.”⁵⁶ One analogy that comes to mind is that of a football team scoring a touchdown in the closing minutes of a losing game, but being happy to have at least avoided a shutout.

This brings us to the issue of what anthropologist Ronald Wright calls “the progress trap.” It is the idea that with advancements in technological progress we certainly see improvements in the short term, but fail to see longer-term predicaments where we may lack the resources, technologies, or political will to turn back.⁵⁷ Many civilizations have collapsed under the weight of this trap. Certainly, the critique of modernity and the progress trap take

⁵⁵ Dylan Matthews, “23 Charts and Maps That Show the World Is Getting Much, Much Better,” Vox (Vox, November 24, 2014), <https://www.vox.com/2014/11/24/7272929/global-poverty-health-crime-literacy-good-news>.

⁵⁶ Ibid., no pagination.

⁵⁷ Wright, Ronald, *A Short History of Progress* (Toronto: House of Anansi Press, 2004).

on its most obvious manifestation in the ecological crisis, which in itself is a larger problem than this dissertation can integrate, but it remains true for other forms of technological advancements in genetics, informatics, AI, and the neoliberal/biopolitical forms of valuation inherent in our contemporary society. It may be that the short-term gains have unintended consequences or hidden dangers that must be brought to light. The purpose is not to present a fatalistic or nihilistic view of the future, but to counter the overwhelmingly optimistic progressivist discourses of modernity with some sobering pessimism.

2.2 Why Critique and How?

There are dangers inherent in any application of reason, there are unintended results that go beyond the initial event, moments of discontinuity and dead ends. These complicate the received idea of modernity that downturns or crises are temporary events leading to a permanently better state. If we are too reductive, we miss the fact that in every state of affairs and every discourse of truth there are inherent dangers. Some of these dangers disproportionately affect those at the margins of society, and at its extreme, they threaten our very survival.

As Foucault put it:

I think that the central issue of philosophy and critical thought since the eighteenth century has always been, still is, and will, I hope, remain the question: *What* is this Reason that we use? What are its historical effects? What are its limits, and what are its dangers? How can we exist as rational beings

fortunately committed to practicing rationality that is unfortunately crisscrossed by intrinsic dangers?⁵⁸

One problem with modernist metanarratives is the focus on positive linear histories that they are *ad hoc* representations of a successful application of reason, and not proof of the rule. The same Reason that we use in one instance can have devastating effects in the other. This does not deny that some improvement may have taken place, but it ought to make us a bit more careful about being too optimistic about the power of our reason. Of course the eradication of smallpox is a great human achievement, but most would argue that the same eradication approach (carried out globally) on specific forms of impairment is quite a bit more problematic and complex. The example that Foucault gives at the end of the above statement is the fact that Darwinism is quite rational, but its reason can be used to legitimize racism and serve a destructive purpose for the Nazis.⁵⁹ The exercise of Reason is problematic in that it is intrinsically dangerous, but this is not a reason to fall into irrationality. It simply sets out the task of critical thought. It beacons us to continue working. Foucault reiterated this in a later interview when he explained:

My point is not that everything is bad, but that everything is dangerous, which is not exactly the same as bad. If everything is dangerous, then we always have something to do. So my position leads not to apathy but to a hyper- and

⁵⁸ Michel Foucault, "Space, Knowledge, and Power" in *The Foucault Reader* (NY: Pantheon, 1984): 248-49.

⁵⁹ *Ibid.*,

pessimistic activism. I think the ethico-political choice we have to make each day is to determine which is the main danger.⁶⁰

It is important to keep in mind that the criticisms of modernity, of medicine, and of technology—among others—contained in this dissertation are not universal criticisms. An expansion of human rights, new treatments, novel prosthetics and engineered environments are not intrinsically bad because they may originate in modernity. They are positive developments and are experienced as such by those who benefit. The aspect that is put under scrutiny here is that they originate in the same reason that has perpetuated certain forms of ableism and discrimination (and risk doing so well into the future). What I will aim to do is to critique, following Foucault's caution, the tangential results of universal modernist Reason being applied to abnormality in general, and disability in particular. By way of orientation my stance on modernism is consistent with Corker and Shakespeare when they wrote:

At the heart of modernity is the culture of the enlightenment. This is founded on assumptions about the unity of humanity, the individual as the creative force of society and history, the superiority of the West, the idea of science as Truth and the belief in social progress, and this is what we mean when we refer to modernism. [...] The individual and medical models of disability, which perceive and classify disability in terms of a meta-narrative of deviance, lack and tragedy, and assume it to be logically separate from and inferior to 'normalcy', are

⁶⁰ Michel Foucault, "On the Genealogy of Ethics: An Overview of Work in Progress" in *Michel Foucault: Beyond Structuralism and Hermeneutics* (Chicago: University of Massachusetts Press, 1983), 231-32.

characteristic of the kinds of epistemologies or knowledge systems generated by modernism.⁶¹

What we will see is that the modernist conception of society, and its focus on a scientifically defined normality—especially neurological and biological normality—will set the stage for the control and manipulation of abnormality (disability is only one facet). It is by looking at the life sciences through this lens, and looking at the actual and potential changes underway, that we come to recognize the dangers inherent for individuals with disabilities. As posited by Corker and Shakespeare, because of the “public celebration of a culture of self-redemption and emancipatory hope, large numbers of people remain oppressed within modernism, particularly those who are perceived not to meet the modernist ideal of the rational, independent subject.”⁶² Images of disability throughout modernity have been multifaceted and complex, but none of its incarnations reached the level of a subject who can participate in norm making and who can teach us something about how we ought to perceive a life worth living—they have been the antithesis to these very definitions throughout. They are among, as Braidotti would put it, the “structural-Others” of modernity.⁶³

But already, in the postmodernist rejection of meta-narratives and the emergence of counter-subjectivities there is a weakening of the foundational idea of the modernist man. Speaking here of various movements of the second half of the 20th century (e.g., woman’s

⁶¹ Mairian Corker and Tom Shakespeare, “Mapping the Terrain,” in *Disability/Postmodernity; Embodying Disability Theory* (NY: Continuum, 2006), 2.

⁶² *Ibid.*,

⁶³ Rosi Braidotti, *The Posthuman*, 37; Rosi Braidotti, “Feminist Epistemology After Postmodernism: Critiquing Science, Technology And Globalization,” *Interdisciplinary Science Reviews* 32, No. 1 (2007): 67.

rights or anti-colonial movements) and the challenge they bring to the modernist subject she writes, “[t]hey are simultaneously the symptom of the crisis of the subject, and for conservatives even its ‘cause’, but they also express positive, i.e., non-reactive, alternatives. [...] They also inevitably mark the crisis of the former ‘centre’ or dominant subject-position.”⁶⁴ Their ‘otherness’ expressed through resistance and social change is disruptive, but there is always the danger, as we have seen happen before, that the current order transforms or reduces that potential into simple marketability. For Braidotti these emerging voices of difference, and the proliferation of giving voice to difference in postmodernism, gives rise to the potential that bodies may be caught up as both “disposable commodities to be vampirised” as well as “agents for political and ethical transformation”—where being able to tell the difference is a matter of critical analysis.⁶⁵ She reminds us, “with Foucault, that power is a multilayered concept, which covers both negative or confining methods (potestas) as well as empowering or affirmative technologies (potentia).”⁶⁶ How transformation is confronted by established power-relations and discursive networks is an important and sobering reality that resistance is not as easy as *doing*, one must also be constantly *evaluative*. As Dreyfus and Rabinow recall Foucault saying, “people know what they do; frequently they know why they do what they do; but what they don’t know is what what they do does.”⁶⁷ Even insofar as Disability Studies has great transformative potential, it necessitates this hyper-pessimistic activism that Foucault was advocating—a constant and

⁶⁴ Ibid, 67.

⁶⁵ Ibid.

⁶⁶ Ibid.

⁶⁷ Dreyfus and Rabinow, *Michel Foucault*, 187.

critical look at the dangers inherent in every practice of engagement and resistance. I likewise acknowledge, following Braidotti, that engagement with disability inscribes itself in a much broader critical project. It is through this limited lens of disability that I might tease out some more general dangers and problematizations in relation to our current situation.

2.3 Summary

In this brief chapter I have set out my general frame of reference for the current undertaking. Looking forward, we can see that many of the current problematizations will cleave the modernist category of man and the rising voices of its structural others. In this current work, it is disability in its various forms—physical, developmental, and psychiatric—that will be mobilized for their transformative potential with respect to the redefinition of man and the human condition. As we have seen, our definitions of man used disability as the categorical other from which we could derive a theory of nature and of man in his natural condition.

The critical attitude that Foucault espoused, and how I will put it into practice here, is to attempt to point to some of the dangers and pitfalls of the changing discourse on the body in contemporary society. As we shall see, these come in direct confrontation with how we define ourselves, and how we regulate behaviour. At least on questions of normalization and social progress, we will see why we need to go beyond critiques based in identity, social barriers, or institutions. In Part 1 of this dissertation I will be looking primarily at some issues inherent in normalization today, while in Part 2 I aim to contribute to a perspective that may better suit the transformative power of disability in mitigating some of these issues.

In summation, the multiple discourses of modernity have created a certain category of human as the ideal *contra* a multitude of ‘structural others’ whose resistance has been destabilizing this center since the mid-20th century. For modernity, postmodernity, and even what I will discuss as our posthumanity, we need to remain constantly and pessimistically critical of the current impact of established norms, and the potential consequences of proposed futures based on modifications of these norms. This will necessarily be an exploratory work, not seeking to establish the final authoritative framework. What is transformative and revolutionary today, may be degenerative and destructive tomorrow. It beckons us, to be both hyper-critical about what we evaluate and critically modest about the prescriptions we derive from them.

Chapter 3—Normalization and Medicine; From La Mettrie to Biopolitics

In this chapter, I will track a critical history of how medical discourse has become central to the idea of normality generally, and has become a normalizing force in society. Not only will it serve as the foundation for the coming mutations to this discourse, it will show a critique of medical discourse goes further than pointing out and rejecting its individualizing and essentializing character, as the Social Model does. Medicalization, understood more broadly, is the historical emergence of a form of power that relies on clinical norms to fix developmental trajectory, typical and acceptable abilities and behaviours, and acceptable and unacceptable deviations within populations. By setting what can be said and what counts as true on these matters, it establishes a network of dispossessed power that results in the justification of sanctions and limitations placed on individuals as well as gives rise to forms of self-regulation and disenfranchisement more broadly. This does not invalidate the central ideas of ableism and social barriers that many activists attempt to resist, but displaces the source and its scope; i.e., not as the power of one group over the other resulting from a specific material cause, but a dispersed regime of truth from which we govern ourselves and others.

3.1 Descartes, La Mettrie, and the Emergence of Normalization

Canguilhem wrote extensively on the history behind the development of the concepts of life, health and pathology during the 17th to 19th century. Although he wrote of specific issues in ancient medicine (e.g., Hippocrates and *medicatrix naturae*), the bulk of his work focussed on the emergence of medicine as an experimental and practical science. In the development

of medicine as a discipline, he found two major trends in the objectification of the human body: (1) reduction to a body-machine or the anatomical-clinical model of health/illness, and (2) the quantification of health related environmental factors and charting the propagation of illness and disease (epidemics, venereal infections, etc.). In the first case, he traces the objectification of the body from Descartes in the 17th century to clinical medicine.⁶⁸ In this second case, which I will get back to shortly, we can see the beginning of social medicine and population health.

Descartes likened the human body to automatons, the moving statues that were popular at the time, where movement and reflexive action were not necessarily evidence of mind or will but could simply be the result of design and mechanism. As Canguilhem described it, “[s]uch an attitude justified the construction of a mechanical model of the living body, including the human body—for Descartes, the human body, if not man himself, was a machine. Descartes found the mechanical model he was looking for in automata, or moving machines.”⁶⁹ Using the analogy of the clock Descartes explains his mechanical philosophy:

And as a clock composed of wheels and counter-weights no less exactly observes the laws of nature when it is badly made, and does not show the time properly, then when it entirely satisfies the wishes of its maker, and as, if I consider the body of a man as

⁶⁸ I begin here with Canguilhem because his discussion of Descartes centers more specifically on the objectification of the body as machine, while Foucault would discuss at length how Descartes’ reflections are more important in relation to the emergence of madness and unreason (*History of Madness* (NY: Routledge, 2006)). There is no question, however, that Foucault followed this line of interpretation that understood Descartes’ dualism as foundational for medicine’s use of the body; though he would also complicate this understanding in relation to representation on the one hand, and discourse on the other in subsequent works discussed later in this thesis (*The Birth of the Clinic* (NY: Routledge, 1989)).

⁶⁹ Georges Canguilhem, *A Vital Rationalist; Selected Writings* (NY: Zone Books, 2000), 228.

being a sort of machine so built up and composed of nerves, muscles, veins, blood and skin, that though there were no mind in it at all, it would not cease to have the same motions as at present, exception being made of those movements which are due to the direction of the will, and in consequence depend upon the mind [as opposed to those which operate by the disposition of its organs], I easily recognise that it would be as natural to this body, supposing it to be, for example, dropsical, to suffer the parchedness of the throat which usually signifies to the mind the feeling of thirst, and to be disposed by this parched feeling to move the nerves and other parts in the way requisite for drinking, and thus to augment its malady and do harm to itself, as it is natural to do, when it has no indisposition, to be impelled to drink for its good by a similar cause.⁷⁰

For Descartes, the body has its own functional set of motions and reflexes that arise exclusively from the mechanical functioning of “nerves, muscles, veins, blood and skin”; when something goes wrong, as in thirst caused by dropsy, the body follows the instinctual course of drinking. This self-destructive behaviour shows that there is no *reason* in the animal/mechanical body; there is no mind involved. As Canguilhem noted “Descartes does for animals what Aristotle did for slaves: he devalues them in order to justify using them as instruments.”⁷¹ The devaluation of animals is the foundation for Descartes’ devaluation of the body, for after all, without mind we are simply automatons. This absolute dichotomy between the mechanical body and the human mind will be foundational in the elaboration of

⁷⁰ Descartes, René. *Discourse on Method and Meditations*, in Elizabeth S. Haldane and G.R.T. Ross Trans. (New York: Dover Philosophical Classics, 2003), 117. *Brackets in original*.

⁷¹ Canguilhem, *Vital Rationalist*, 227.

scientific understandings of the body and of medical interventions well into modern day. The connection between a modern philosopher and the science of medicine may not be immediately clear. But for Canguilhem it is absolutely relevant. For him it is by looking critically at central concepts in the history of the sciences that we can uncover issues in contemporary practices. It is from this perspective that Foucault further developed his own method of analysis.

In his seminal work *Discipline and Punish*, Foucault would split the effects of Descartes' discourse in two ways, the intelligible body and the useful body. In this first instance he described the intelligible body as “the anatomico-metaphysical register, of which Descartes wrote the first pages and which the physicians and philosophers continued”—i.e., “the intelligible body.”⁷² This is the body understood through mechanical and functional classification of organs and structures as in Harvey's work on circulation or Willis' connection between neuroanatomy and behaviour. Certainly there were earlier and contemporary anatomists, of which Descartes was aware, but it is Descartes who made the body-machine intelligible in the modern episteme—he gave it a position in the realm of the knowable, which was a prior condition for the elaboration of discourses of truth based on both the rational and empirical demands of the 17th and 18th centuries. This mechanical body would, in its later developments, mature into clinical medicine where mechanical deviations from the norm (lesions, blockages, or malformations) were invitations for physicians to engage in discourses of truth about the essence of the disease unique to their

⁷² Michel Foucault, *Discipline and Punish* (New York: Vintage, 1995), 136.

art.⁷³ A field of clinical judgements predated the idea of the mechanical body, but this specialized way of seeing became the basis on which physicians could make statements about the truth of the body and of disease at this period of development in anatomical medicine. It established what the body *was* (i.e. a knowable scientific object).

In defining the useful body, the second aspect of this discourse, Foucault would turn to La Mettrie's development of a technico-political register. Foucault defines the "useful body" as "constituted by a whole set of regulations and by empirical and calculated methods [...] for controlling or correcting the operations of the body."⁷⁴ If Descartes gave us the framework for understanding the body, La Mettrie suggested it could be manipulated and changed by external pressure. As Foucault recounts, "La Mettrie's *L'Homme machine*, is both a materialist reduction of the soul and a general theory of *dressage*, at the center of which reigns the notion of 'docility', which joins the analysable body to the manipulatable body. A body is docile that may be subjected, used, transformed and improved."⁷⁵ For Foucault, it is this manipulatable body that became the basis around which institutions were developed in the 17th and 18th century. The school, the barracks, the workshop; these represented institutions that 'mould' the body in its minute functions so that they would become useful entities—e.g., a disciplined soldier.

La Mettrie, like Descartes, wanted to espouse a version of the body as a machine, but he collapsed the hard division between mind and body, and also endowed animals with

⁷³ Foucault, *The Birth of the Clinic*, 3-21.

⁷⁴ Foucault, *Discipline*, 136.

⁷⁵ *Ibid.*

minds that were much like our own. In his argument for the ‘materialisation’ of the mind, La Mettrie takes up many arguments that will often be repeated in the history of disability; the idea of one’s physiognomy reflecting the quality of one’s character or aptitude (e.g., phrenology), or the heredity of moral constitution (e.g., that vice can be passed on, even when the child is separated by his/her mother). These are all general ideas consistent with La Mettrie’s novel argument; however, they were not uniquely his own, they were borrowed from the science of the times to support his argument.⁷⁶

What is interesting in La Mettrie’s writings, and what possibly exerted more influence in medical discourse was the extent to which ‘discipline’ could change biology. For La Mettrie animals had the ability to express complex emotions like remorse, which shows that they do have mind. Moreover, using period beliefs about the abilities of animals to learn to speak or communicate, La Mettrie went so far as to state that those well-established beliefs about the exceptionality of man in relation to animals were a matter of learning. Man had *learned* those things we consider points of separation such as the use of tools and language. He believed that these differences were the sum of, and result of, the human animal’s situation in nature. As he stated, “Words, languages, laws, sciences, and the fine arts have come, and by them finally the rough diamond of our mind has been polished. Man has been trained in the same way as animals. He has become an author, as they became beasts of burden.”⁷⁷ Moreover, he maintained that “the imbecile and the fool are animals

⁷⁶ Julien Offray de la Mettrie, *Man a Machine* (Chicago: The Open Court Publishing Co., 1912).

⁷⁷ *Ibid.*, 103

with human faces, as the intelligent ape is a little man in another shape”⁷⁸ and added “let us then conclude boldly that man is a machine, and that in the whole universe there is but a single substance differently modified.”⁷⁹ We see here the extreme of what Foucault identified as the “docile” or “useful” body, and this specifically in ways that would develop into the practices that managed and treated all forms of deviance and deficiency in the following centuries.

3.2 From Useful Body to Correcting the Defective Body

Speaking of horrific legal cases of his time, La Mettrie makes an interesting statement that illustrates this moment where sovereign power, which Foucault would roughly equate with ritualistic laws, begin to be replaced by “techniques of discipline and discourses born of discipline.”⁸⁰ La Mettrie claims that certain crimes can be traced to physical states that cause an individual to commit dreadful acts of violence. He connects punishment in these cases to internal suffering in the form of remorse but makes a sharp distinction between these “excusable” crimes and the inexcusable crimes of the true criminal. This is quite important because it shows that the idea of culpability takes on a biological or clinical register as opposed to a legal one. He goes so far as to say: “it is much to be wished that excellent

⁷⁸ Ibid., 146

⁷⁹ Ibid., 148

⁸⁰ Foucault, *“Society Must be Defended”*: *Lectures at the Collège de France, 1975-1976* (London: Picador, 2003), 38.

physicians might be the only judges. They alone could tell the innocent criminal from the guilty.”⁸¹ This echoes the words of Foucault in *Society Must Be Defended* when he stated:

The discourse of disciplines is about the rule: not a juridical rule derived from sovereignty, but discourse about a natural rule, or in other words a norm. Disciplines will define not a code of law, but a code of normalization, and they will necessarily refer to a theoretical horizon that is not the edifice of law, but the field of the human sciences. And the jurisprudence of these disciplines will be that of clinical knowledge.⁸²

This is a turning point moment for Foucault. It is the moment where disciplinary power (a normalizing power) emerges along side sovereign forms of power (which Foucault identifies with concrete legal norms) toward a normalizing society. Sovereign forms of power do not disappear, but the primary discourse of truth about subjects will be of a clinical nature as opposed to a civic-legal relationship to authoritative political power. The idea of a docile body, in conjunction with a social reorganization based on the modernist idea of human nature and the state makes possible—and even make use of—discourses of hygiene, health, and medicine. Certainly in La Mettrie there is precedence for thinking of society through the idea of a docile body as evidenced in this passage aimed at explaining that difference is *learned* in a fluid developmental process from lower forms to greater forms:

⁸¹ La Mettrie, *Man a Machine*, 119.

⁸² Foucault, “*Society Must be Defended*,” 38.

One nation is of heavy and stupid wit, and another quick, light and penetrating. Whence comes this difference, if not in part from the difference in foods, and difference in inheritance,⁸³ and in part from the elements which float around in the immensity of the void?⁸⁴

If we take this passage in conjunction with La Mettrie's idea that man's intellect has been differentiated from animals through a long process of change, we can see how he thought of the difference between nations in the same terms—at least in terms of the same process. There is here a precedent for trying to control illness, disability, and deviance as both lower forms of life, and a failed historical process that impacts the present health of the population. La Mettrie does not explicitly go this far, but certainly Foucault has seen in it evidence of such a shift in understanding. The idea that one's environment has a direct effect on the body, and thus that manipulating the environment has an effect on collections of bodies is a condition for the possibility of a discourse about the hygiene or health of a population. The idea of the malleable body is the basis on which disciplinary institutions are developed, but it is also relevant to the concerns with the health and productivity of a nation. This change from sovereign forms of power (i.e. legal and religious authority) towards clinical understandings is clear in the history of disability.

The budding scientification of normality marks a rupture with the idea of the world order of the classical period where deviations are no longer seen as 'unnatural' or

⁸³ Footnote from original: "The history of animals and of men proved how the mind and the body of children are dominated by their inheritance from their fathers."

⁸⁴ La Mettrie, *Man a Machine*, 97.

‘monstrous’ but are seen as statistically abnormal and interesting. In his introduction to *Histories of the Normal and the Abnormal* Ernst cautions us against interpreting the shift from unnatural to abnormal in a progressivist historical perspective where it shows only a change in terminology consistent with the secularization of modern society.⁸⁵ She argued that a stark difference in *kind* truly exists between a “religiously ordained natural order” that gives rise to the natural/unnatural binary, and “a scientifically grounded theory of normal/abnormal.”⁸⁶

This is evident in Mitchell’s article discussing conjoined twins in this same volume.⁸⁷ Where in the 19th century conjoined twins were assimilated in a whole discipline of typifying and systematizing monstrous bodies that showed the liminal bounds of the possibilities of nature the condition was seen as something to be interpreted and learned from. However, as the possibility of separation turned to the stated goal of “normalizing” conjoined twins through surgical separation, the very condition of conjoined twins changed from a monstrosity or curiosity to an example of pathology proper.⁸⁸ The case of conjoined twins showed how medical science changed from a means of understanding the world of diseases, to the manipulation of the world of disease aimed at correcting and normalizing bodies—the medical goal of *cure*. Where nineteenth century treatises’ focused on what monstrous bodies could do, by the late twentieth century there was a “shift from ‘normal’ within their own

⁸⁵ Waltraud Ernst (eds.), *Histories of the Normal and the Abnormal: Social and Cultural Histories of Norms and Normativity* (New York: Routledge, 2012), 4.

⁸⁶ *Ibid.*

⁸⁷ Sarah Mitchell, “From ‘Monstrous’ to ‘Abnormal’: The Case of Conjoined Twins in the Nineteenth Century,” in Ernst, *Histories*, 66.

⁸⁸ *ibid.*, 68

context, to ‘abnormal’ within a larger societal context in which difference was less acceptable.”⁸⁹ The development of clinical norms as they came to be applied to the individual within the multiplicity or species body, and where deviance from the norm becomes a pathological state in need of correction emerges at this historical switch point.

We see this change in more general terms, as Striker shows, through Diderot’s “*Letter on the Blind for the Use of Those Who Can See.*”⁹⁰ In this lengthy letter practically all of the central themes of modernity are present: the value of education, empiricism and scientific enquiry, and progress marked by advancements in the sciences, secular and free thought among others; unsurprisingly, given that Diderot was one of its central figures and main author of the *Encyclopédie*. It is important to note, biographically, that after the publication of this letter Diderot was arrested and imprisoned in Paris for its clear commitment to secular empiricism.⁹¹ This is important because prevailing debates about disability at the time were centered, as mentioned above, on monstrosity and the creator’s infallibility. There was a struggle to explain how such defects could be reconciled with a religiously ordered world, children, after all, were innocent—what worldly being could be responsible? The prevailing theory was Duverney’s idea of the accident or “crushed-germ” leading to deformity or monstrosity (teratism), introducing something that was not there

⁸⁹ Ibid., 67.

⁹⁰ Diderot, “Letter on the Blind for the Use of Those Who Can See,” in Margaret Jourdain trans., *Diderot’s Early Philosophical Works* (Chicago: Open Court Publishing Company, 1916), 68-141.

⁹¹ Margo, Curtis, Lynn E. Harman, Don B. Smith, “Blindness and the Age of Enlightenment; Diderot’s Letter on the Blind,” *Journal of the American Medical Association Ophthalmology* 131, No. 1 (2013): 98.

prior to entry into the world.⁹² A few years after Duverney's death, this was rejected by Winslow using problematic cases uncovered by the science of the day, but he was careful not to engage in philosophical or religious discourse. It is for this reason that we can say, following Striker, that "'letter on the blind,' abandoning the debates of the preceding century, established the lines of inquiry of the biological sciences [...] Diderot's text inaugurates the period when aberrancy, monstrosity, diminished faculties, and deformity will be addressed as simple impairments."⁹³ It marks disability's proper insertion into the realm of the social sciences.

Discussing these authors is useful in exploring polarizing ideas that have changed the ways in which we conceptualize life. However, it is not the goal of such an exploration to credit these authors with the great honour of having revolutionized the present. Their ideas are at most symptomatic of the concerns of their time, showing the limits of what can be taken to be true, and representing the conditions of possibility for ideas that follow. Their discourses are not 'True' in the scientific sense; nevertheless, they had truth effects in the development of our contemporary discourses. Consequently, they serve a genealogical function. Beyond their influence within medicine and without, both La Mettrie and Descartes must be read within the greater frame of the rupture between sovereign forms of power (the divine right/law), and modernist forms of power (discipline/regulation).

⁹² Jacques Roger, *The Life Sciences in Eighteenth-Century French Thought* (Stanford: Stanford UP, 1997), 325-330.

⁹³ Striker, *A History of Disability* (Ann Arbor: University of Michigan Press, 2000), 103.

3.3 Normalizing Society; Discipline and Biopolitics

The rupture mentioned at the end of the previous section alludes to a wholly different relationship between a society and its people. To simplify, sovereign power is based on the imposition of rules—decisions from a sovereign, a religious code, a legal code justified by a right to rule. This power is absolute (i.e., it has the authority to punish or kill), but limited to the licit and illicit acts that individuals can enact. As I will show later, the normalizing society—marked by the predominance of flexible norms—is unlimited in its scope. It applies itself to the entirety of the human being; its body, its behaviour and the soundness of its inner decision-making.

Foucault’s normalizing society is defined by two intersecting modes of power that center on the body. The first is disciplinary power, which is the result of “the classical age discover[ing] the body as object and target of power,”⁹⁴ and in controlling the details that make up the whole of a subject-machine. Disciplinary power is “centered on the body as machine: its disciplining, the optimization of its capabilities, the extortion of its forces, the parallel increase of its usefulness and its docility,” in other words, “an *anatomo-politics of the human body*.”⁹⁵ Suggesting the old French understanding of the word politics—i.e., not entirely removed from its connection with policing—and anatomo-politics of the body suggest the ability to police the very minutiae of bodily motions and functions towards a goal. E.g., speaking of an ordinance for training soldiers from 1764 Foucault suggested that

⁹⁴ Foucault, *Discipline and Punish*, 136.

⁹⁵ Michel Foucault, *The History of Sexuality; and Introduction Volume 1* (New York: Vintage, 1990), 139.

to make a soldier stand up straight, they would be made to stand against a wall in order to acquire the habit. Once removed, even in the absence of the wall, the body keeps its shape. As Foucault described the utility of disciplinary power, again in the mechanical terms observed above, “out of a formless clay [...] the machine required can be constructed.”⁹⁶

For Foucault, there does not need to be physical apparatuses such a wall to keep the posture straight. In perhaps the most notable concept from *Discipline and Punish*—that of the panopticon and panoptic power—Foucault shows that disciplinary power also functions in the case of observation or mere suggestion of observation—it is self-regulating. The panoptic prison is a prison design where cells are organized in a circle with a lone tower in the middle. A single guard manning the tower can *control* through observation the entirety of the prison population because at any time he could see any of the prisoners. Consequently, with the *possibility* of being observed each individual acts *as if* they were the ones under observation. Therefore, even in the absence of confirmed observation, individual’s self-discipline such as being conditioned to maintain a soldier’s posture remains true in the absence of the supporting wall. It is this form of power that makes us internalize social norms, and makes us self-regulate our behaviours even in the absence of actual social judgment.

The second aspect is what Foucault would call biopower or biopolitics. This particular form of power is centered not on the individual body but on the multitude of bodies that constitute a population, a state or a species. As he continues from the above quote:

⁹⁶ Foucault, *Discipline and Punish*, 135.

The second, formed somewhat later, focused on the species body, the body imbued with the mechanics of life and serving as the basis of the biological processes: propagation, births and mortality, the level of health, life expectancy and longevity, with all the conditions that cause these to vary. [...] The disciplines of the body and the regulation of the population constituted the two poles around which the organization of power over life was deployed.⁹⁷

This second form is what La Mettrie's clinical focus really opened up. It gave rise to a *regulatory* power aimed at limiting naturally occurring negative phenomenon and promoting healthy ones in order to maintain the fitness of the whole. At first, these were the natural processes that we can observe in a society such as the births, the deaths, and the level of illness. Though there was a concern for scientific explanations of epidemics, a striving to understand the course and causes of the great plagues, and of rampant diseases and such: what is more symptomatic of biopolitics is the attempt to understand those natural processes within a population and to regulate them (i.e., those things that bubble up from within).

At the end of the eighteenth century, it was not epidemics that were the issue, but something else—what might broadly be called endemics, or in other words, the forms, nature, extension, duration, and intensity of the illnesses prevalent in a population.⁹⁸

⁹⁷ Ibid.

⁹⁸ Foucault, "*Society must be Defended*," 243.

Understanding these things necessitated the use of new tools and techniques of observation. It required a great amount of statistical techniques to observe and account for deviance and deviation. Again this takes on a dual form: in terms of the individual body we came to norm the life course and identify deviant patterns. As McWhorter would put it, “Newton and Leibniz invented calculus in the late seventeenth century. Before the end of the nineteenth, that invention had made it possible to study various developmental trajectories and ‘norm’ them.”⁹⁹ It is this mechanism that will serve the function of establishing ‘clinical norms’ of the body. They will help differentiate between normal and pathological bodily or mental states.

It would be impossible, according to Canguilhem, for an objective science of life based on statistical trends to exist without the supporting assumption that pathological states, or concepts such as illness, disease, deficit, are value neutral and objectively known.¹⁰⁰ He argued, however, that these norms, based on averages and trends, had two distinct problems. The first being that physicians must use some discretion based on professional conventions to determine what counts as pathological as individuals deviate from the average, and the second problem being that statistical averages are applied either to single aspects of the individual—opening itself up to “partial normality” and the problem of interaction—or, the average is extrapolated from classes and populations who are interpreted to have common markers to produce more accurate and actionable averages. In the latter case, convention and

⁹⁹ Ladelle McWhorter, “Sex, Race, Biopower: A Foucauldian Genealogy,” *Hypatia* 19, No. 3 (2004): 38.

¹⁰⁰ Canguilhem, *A Vital Rationalist*, 350.

value creeps in where the lines are drawn and “all objectivity vanishes in the determination of a universal normality.”¹⁰¹

Throughout history, attempts to discover concrete norms of pathology and normal functioning, as they relate to health and illness as species norms, follow the pursuits of reifying body. The issue is that, though individual bodies are participating in the extrapolation of species norms, those norms are only assumed to be universal and therefore, it may be dangerous when reversed and used to ‘objectively’ measure things like disability or prognosis in the individual body. To use scientific terms, the actual objective measurement (in the individual body) is aggregated with other individual measurements, and statistically plotted in a trend (which becomes the norm), and is then used to interpret the individual measurement. The factuality of the original measurement has no relation to pathology. Nor does the statistical variation itself explain the content of pathology or deviancy without qualitative clinical judgements. Pathology is the convention that emerges in relation to the plotted norm, whose interpretation is subjective and evidence is inductive. As such, pathology has no legitimate claim to objectivity or universality; it is always value-laden and susceptible to external needs and pressures.

Social medicine, for example, first represented the need to monitor endemic phenomena that could jeopardise the health of the workforce¹⁰² but quickly turned to other problematic phenomenon such as deformity, deficit, deviancy, and madness. It is in the late

¹⁰¹ Ibid.

¹⁰² Michel Foucault, "The Birth of Social Medicine," in James D. Faubion, Robert Hurley and Paul Rabinow (eds.), *Power; Essential Works of Foucault* (New York: New Press, 2001); Georges Canguilhem, *Écrits sur la médecine*, (Paris: Seuil, 2002), 36-38.

18th century that these concerns materialize in the development of analyses regarding the biological in general (hygiene, epidemics, births and deaths...), in problematic social patterns specifically (such as child rearing, breastfeeding and family planning...), and later in the development of institutions, professions, and policies for their regulation.¹⁰³ In this context biometrics and statistical monitoring of chosen population metrics established a whole system of practices aimed at defining deviations to be corrected. As Hacking writes, “one name for statistics, especially in France, has been ‘moral science’: the science of deviancy, of criminals, court convictions, suicides, prostitution, divorce,” and other such phenomenon.¹⁰⁴ This “moral science,” said Hacking, is one that “studied, empirically and *en masse*, immoral behaviour.”¹⁰⁵ Consequently, what began as a simple concern over biological processes within the population and the possibilities for maximizing health also came to be applied to all pathological states of society. Hacking discusses Durkheim, the father of sociology, as one such (important) instance of this trend. For Durkheim the objectivity of patterns of behaviour were established in their consistency as Hacking points out:

Durkheim’s innovation was to found his argument on the sheer regularity and stability of quantitative social facts about statistics and crime. [...] It is no accident that

¹⁰³ Michel Foucault, “Confessions of the Flesh,” in Colin Gordon (eds.), *Power/Knowledge* (New York: Random House, 1980), 226.

¹⁰⁴ Ian Hacking, “How Should we do the History of Statistics?,” in Graham Burchell, Colin Gordon, and Peter Miller (eds.), *The Foucault Effect: Studies in Governmentality* (Chicago: Chicago UP, 1991), 182.

¹⁰⁵ Ibid.

Durkheim conceived that he was providing a general theory to distinguish normal from pathological states of society.”¹⁰⁶

The method of statistical averages concretizes itself in a form recognizable today as the bell curve. The bell curve being the very foundation of how the norm is visualized and the statistical significance of a deviation calculated. Hacking further points out that, “[i]n the same final decade of the nineteenth century, Karl Pearson, a founding father of biometrics, eugenics and Anglo-American statistical theory, called the Gaussian distribution the normal curve.”¹⁰⁷ In social sciences, the normal curve is the means by which measures are visualized and it is used as a tool for the justification of the validity and statistical significance of an inquiry. Ergo, it constitutes the foundation of a fundamental truth. Statistics come to apply themselves to the entirety of measurable aspects of human society, and not just ‘health’ as we would usually interpret it—it also defines the field of political intervention. We see here the importance Foucault has placed on the political administration of health through the social sciences and the use of statistics within the social sciences themselves. As Hacking put it, “Statistics has helped determine the form of laws about society and the character of social facts. [...] It may think of itself as providing only information, but it is itself part of the technology of power in a modern state.”¹⁰⁸

¹⁰⁶ *Ibid.*, 182-83.

¹⁰⁷ *Ibid.*, 183. This statistical tool is the foundation of all inferential statistics in the form of the Confidence Interval (the interval on a curve that contains the object of analysis in the population) and the P-value, which calculates the probability that whatever analysis was run, if it were run a 100 times, would uphold the null hypothesis less than 5% of the time.

¹⁰⁸ *Ibid.*, 181.

In a later section of this dissertation I will explain how medical norms and economic norms come together to form a policy landscape that guides social medicine guidelines directed at reintegrating “disabled bodies” into the productive workforce and responsible citizenry. This perspective lets us see how statistical norms become part of a technology of power and which will be centrally important to a critical perspective on disability.

3.4 Summary

In summation, Descartes can be seen as one of the primary thinkers who applied the general modernist idea of the mechanisation of nature onto the human body. Though this has been hugely influential and important, it is in the lesser-known case of La Mettrie that Foucault finds the anatomico-political foundation of a political power centered on the body. Without imposing a dualism between body and mind, La Mettrie describes a body whose trainability is not limited to motion but to ability in the broadest sense. The body as machine, operationalized as the docile body, serves as a condition of possibility for a whole discourse of clinical intervention on the body and biopolitical intervention on populations. These discourses are based on clinical and statistical observations that constitute the bounds of *normality* in the social sciences; themselves mobilized as discourses of *truth about bodies and behaviours*.

What has been presented in this chapter will serve only as a foundation for the layers of complexity that I will be adding throughout Part 1. In the next chapter, I will correlate and highlight a dichotomy that has been put to use by disability philosopher and activist Anne Waldschmidt and fellow German thinker Jürgen Link. Her dichotomy between Normative

norms and Normalistic norms (or Link's "normalities") will help guide the discussion of self-regulation and the flexibility of norms.¹⁰⁹ Many of the applications of this form of power will deviate from disciplinary forms of power, but the foundational centering of clinical norms on the body and the population share this common historical emergence.

¹⁰⁹ There are only a limited number of translations for either thinker, so they will be discussed in conjunction with each other. It is important to note that Link is the originator of this dichotomy and Waldschmidt's aim is to apply it within Disability Studies.

Chapter 4—Flexible Norms and Neoliberal Responsibilities

In her article “Who is Normal? Who is Deviant?” Anne Waldschmidt gives us a useful way to conceptualize norms that helps us understand the ways in which norms function in the normalizing society. As we have seen, in the normalizing society, the body is conceived as both a dividual unit that is malleable and changeable, and a species body that is predictably risky and deviant that can be regulated to maximize potential. As Foucault stated, “there is one element that will circulate between the disciplinary and the regulatory, which will also be applied to body and population alike [... .] The element that circulates between the two is the norm.”¹¹⁰ So the question remains, what kinds of norms “can be applied to both the body one wishes to discipline and a population one wishes to regularize”¹¹¹ and how do these norms regulate behaviour today.

4.1 Kinds of Norms

For Waldschmidt, the normalizing society is defined by “flexible normalism.” She claimed that in flexible normalism, there are “two types of norms that guide human action: *normative norms* and *normalistic norms*.”¹¹² Normative norms are those norms that are linked to *normativity* in the traditional sense. They are prescriptive norms that impose a course of

¹¹⁰ Foucault, “*Society Must be Defended*,” 253.

¹¹¹ Ibid.

¹¹² Waldschmidt, “Who is Normal? Who is Deviant?,” in Shelly Tremain, *Foucault and the Government of Disability* (Ann Arbor: University of Michigan Press, 2005), 192.

action on individuals and dispense sanctions and punishments (or the threat thereof) when norms are transgressed. The purpose of normative norms is “to generate conformity, prevent deviation, and protect society from upheaval and chaos.”¹¹³ In this sense they correlate with sovereign modes of power. These can be laws, policies, rules, or conventions to name a few, that can lead to actual sanctions (such as community treatment orders, forced hospitalization, denial of service or denial of benefit) or fear of sanctions that lead to a modification of behaviour. Normative norms are static, concrete, and external. Though as I have stated earlier, even though sovereign forms of power no longer predominate, they do not entirely disappear.

Norms of pathology and abnormality still compartmentalize people in order to administer systems of assistance, service, or treatment and manage access to these. One recent example is how the provincial government changed the definition of long-term disability in a way that disqualifies future applicants with mental health issues that are episodic (as opposed to chronic) from receiving disability income on the grounds that it is not a substantial disability.¹¹⁴ Often austerity measures and the loosening of governmental responsibility means that programs that already only give the bare minimum for survival become increasingly difficult to access or disappear entirely. In the community where this dissertation is being written, the legal aid clinic states that 60% of their cases are appeals for individuals who were denied Ontario Disability Support Program assistance, and that in 80%

¹¹³ Ibid., 193.

¹¹⁴ Raymond Cheng, “Why the Definition of ‘Disability’ in Social Assistance Matters to PWLE in Ontario.” *Ontario Peer Development Initiative* (January 9, 2019). <https://www.opdi.org/blog/why-the-definition-of-disability-in-social-assistance-matters-to-pwle-in-ontario/>.

of these cases, the decisions are overturned (i.e., these are not frivolous appeals).¹¹⁵ These same clinics, province wide, have had their budgets cut by 30% this year, making it likely that individuals will have a more difficult time fighting wrongful denials.¹¹⁶ One must fight to fit into certain definitions and subject positions in order to have their bare necessities met. It is a black and white compartmentalization—and one’s need to define oneself in those terms—that requires someone to conform to a rigid set of predetermined rules and regulations.

What the focus on disability shows us is that though we are heading in the direction of normalistic norms in general—i.e., flexible and orienting norms—, normative norms (or protonormalism to use Link’s terms) continue to describe an important aspect of navigating the world with an abnormal body or mind. I would also note here that disability activism and traditional models of disability discussed in the introductory chapters play an important role in normative normalization. As Lilja and Vinthagen claimed, more direct forms of power are resisted by defiance or open collective resistance to prohibitive or law-like systems of power—i.e., those strategies already present in social movements or revolutionary movements.¹¹⁷ Though the focus of this chapter is to develop an idea of normalistic norms that will be connected to somaticism and vital politics in the next chapter, it must be

¹¹⁵ “Fighting for ODSP with Provincial Dollars-It Does Suggest That the System Is in Some Way Broken’ | CBC News,” CBCnews (CBC/Radio Canada, February 25, 2019), <https://www.cbc.ca/news/canada/sudbury/ontario-disability-support-appeals-sudbury-1.5029428>.

¹¹⁶ “Legal Aid Funding Cut Nearly 30% in Ontario Budget | CBC News,” CBCnews (CBC/Radio Canada, April 12, 2019), <https://www.cbc.ca/news/canada/ottawa/ontario-legal-aid-funding-cut-1.5095058>.

¹¹⁷ Mona Lilja and Stellan Vinthagen, “Sovereign Power, Disciplinary Power, and Biopower: Resisting what Power with what Resistance?” *Journal of Political Power* 7, No 1 (2014): 114.

acknowledged that normative norms are an important part of the Disability Studies project and of disability activism generally. Both types of norms co-exist, but normalistic norms play a much greater role than what is typically acknowledged, and there is a great danger in not engaging with them.

Normalistic norms, for their part, are flexible, changing, and not oriented towards a concrete rule. They refer to customary behaviours “whose statistical documentation can become the basis of guidelines and standards.”¹¹⁸ These norms are established through statistical averages that are dynamic and on-going through the “symbolic or factual production of normal curves.”¹¹⁹ These can be factual in the sense that they are passed down by the social sciences in actual empirical studies, or they can be symbolic, in the sense that they are *perceived* averages that orient behaviour (general observations or assumed trends such as blaming immigrants for “taking our jobs” or calling millennials “lazy and incompetent” for living with their parents). In this sense, they are also susceptible to ideological spin or political discourses outside of empirical social science, because the interpretation of statistical curves has a narrative basis. In its general manifestation, this is precisely the kind of norm that emerges in bio-power; but what Link aims to show is that there is a change in how statistics are being integrated into the system of regulation. Self-regulation is no longer only done in relation to a fixed normal category—whose graphical representation is the normal curve—but through the *infograph*. The image of normal is also different in this optic. One *is* not normal, one *returns* to a normal—not normality as a state,

¹¹⁸ Ibid., 194.

¹¹⁹ Ibid., 195.

but normalcy as a state of affairs.¹²⁰ The best analogy for this is the use of denormalization and normalization in the political context. Link recalls George W. Bush’s speech following 9/11 where, 9 days after the attack, he tells the nation that it is his hope that they may in the coming months and years return to ‘almost’ normal, or W.G. Hardings presidential campaign slogan following the conclusion of WWI—on which he won the presidency—‘Back to Normalcy.’¹²¹ So in the realm of normalization that I am interested in here—disability—flexible normalism will be less concerned with normed trajectories and clinical prognoses with their socio-political reactions (policies, laws, service provisions, etc.), but individual relationships to the myriad personal, social, or financial crises that come up over time. This ‘infographic’ relationship to denormalization and normalization has specific subjective effects.

As Link put it:

...the normalistic structures of data are subjectivized through infographs in many respects. On the one hand, the curves are completed through symbolic figures, that is, subjects with positive and negative appeals of identification. On the other hand, the curves themselves send out positive and negative appeals to the subject in which they mark and offer for "application" zones of supernormal chance, subnormal risks (hence,

¹²⁰ In fact, Link claims that the translation of the French “normalization” has led to some misreadings of Foucault (in his case in German) where he was interpreted to mean it in the sense of standardization, while in reality, he meant something much closer to normalcy in the sense of a return to a state before a certain perturbation. See Jürgen Link, “Crisis between ‘Denormalization’ and the ‘New Normal’: Reflections on the Theory of Normalism Today,” in *Norms, Normality and Normalization* (Nottingham: Nottingham UP eprints, 2014), http://eprints.nottingham.ac.uk/3611/1/Norms_Normality_and_Normalization.pdf

¹²¹ Ibid.

positive and negative abnormalities) and in-suring normality. To the extent that the figures of the infographs connote both actions and conflicts, and to the extent that the curves connote processes in themselves, both fragments and building blocks of modern myths automatically connect themselves to the collective symbolism.¹²²

Seeing ourselves in infographic terms has accepted negative and positive effects. It beckons us to act (and when) to curb downswings or return to normalcy following some calamity; however, it also signals us to act when we may maximize a certain return or in situations of mitigated risks—like market traders watching the ticker and acting when the time is right. Link offers the analogy of the market analyst playing the role of the soothsayers studying the flight of birds in order to extract from it some future course. There are subjective interpretive tropes that pre-determine the meaning of statistical curves; “the meaning of individual fates of curves is placed in the perspective of the central modern myth of the *endless growing snake* (of *progress*).”¹²³ There are a number of interpretive heuristics that, though they are applied to the analysis of curves on graphs, have clear narrative connotations: the “*vertical start, upswing, turning point, tug, downhill run, hard or soft landing, roller coaster, downward spiral, crash, normalization* and so on.”¹²⁴ An injury, for example, may cause a *downward spiral* in productivity and a denormalization of the person’s life, but the subject recognizing that this is an undesirable effect, seeks to find ways to *bounce back* and normalize their level of productivity in order to get *back on course*. A more

¹²² Jürgen Link, “The Normalistic Subject and its Curves: On the Symbolic Visualization of Orienteering Data,” *Cultural Critique* 57, (2004): 56.

¹²³ Ibid.

¹²⁴ Ibid., 59.

mundane, but potentially more relatable example because it is part of our cultural narrative is the idea of weight and personal attractiveness in today's society. It is not based on BMI but value is certainly intersubjectively created, and the fabled "crisis" of beach season orients the individual to the idea of a downswing (usually the result of seasonal affective disorder or the laxity of personal control around winter holidays) and need to bounce back through dieting. For Link an individual can see him/herself within a statistical average framed within the limits of a delineated subject position, but they also, importantly, see themselves in fractured, temporal, and real-time performance measures.

The subject's *will* (or collection of choices) plot onto and affect the course of these *curves* and serve to normalize or denormalize their trajectory. This demonstrable *relationship to a trend* carries with it a certain expectation to engage; one can see what is a good and bad trend, and one is responsible to act in a way to sustain or correct its course. Link states, "[a]ll of these occurrences or fates can be related interdiscursively not merely to economics, but also, in a like manner, to sociocultural and especially psychological normal-fields (i.e., *personal growth*)."¹²⁵ In a crisis, as in the case of a life altering negative event leading to decline or crash, one can analogically look at what happens in a case of market collapse: the only course of action is to do some damage control, and to funnel all energies towards re-normalization.

Link uses the term 'orienting' data to describe this because the curve-landscapes do not simply impose or engineer subject positions, but orients subjects to participate in their own subject-making—(explicitly following Foucault here, as I have in this current work). As

¹²⁵ Ibid., 59.

he states, “the curve-landscape now serves not as an imperative, but rather as an orienteering help for self-normalization.”¹²⁶ Infographs are not foreign to us today, individuals freely measure and modify their habits using blood-pressure monitors, blood glucose meters, fit-bits, heart rate monitors, sleep tracking apps etc. Whether these measures result in actual infographs or not, the point is that these behaviours are of a different kind than the normed trajectories of old—they are personalized and self-regulating. The former may have been something like an IQ score, while the other is a leaderboard or friends group on a brain-training mobile app. It is precisely what one would expect of the technologies of power marked by biopower and neoliberalism. This leaves open a lot of room for self-directed action, norm challenging, and personal development; however, the problem, as Degener and Köbsell put it in a discussion of prenatal diagnostics, “*the concept of self-determination [...] is increasingly being instrumentalized as a social weapon.*”¹²⁷ This is true in general. Responsibilizing the individual to participate in their own ongoing self-regulation changes the dimensions of control once associated with social deviance or undesirability. This has a myriad of effects on how disability is experienced and what people are able to attain any level of valuation and acceptance. This is consistent with Foucault’s understanding of biopower, but represents a contemporary flavour of that mechanism.

To summarize, the normalizing power appropriate for flexible normalism is one of orienteering data that resists fixing an individual on a statistical *course*, but asks the subject

¹²⁶ Ibid., 63, 65.

¹²⁷ Theresia Degener, and Swantje Köbsell, “*Hauptsache, es ist gesund!*” quoted in Anne Waldschmidt, “Normalcy, Bio-Politics and Disability: Some Remarks on the German Disability Discourse,” *Disability Studies Quarterly* 26, No. 2 (2006).

orient themselves based on what is currently happening in order to act in ways that are consistent with a narrative of personal growth or improvement. The infograph *narrates* a certain relationship to a benchmark; either positive or negative, in relatively short timeframes. Subjects see themselves in real-time through *trends* as opposed to being a fixed point on a bell-curve or pre-determined developmental trajectory (clinical or sociological). What is important is how individual trajectories change with setbacks and challenges, as well as successes and overachievements, and how each micro-deviation carries with a certain significance and opportunity for engagement. Importantly, as Waldschmidt discussed, this form of normalization emerged concurrently with the loosening of freedom on previously ‘problematic’ social phenomenon like deinstitutionalization, control over non-traditional sexualities, the establishment of systems for rehabilitation/recovery from addictions.¹²⁸ But when the self-regulating aspects of normalism threaten the stability (normalcy) of the system, normative norms come to the rescue—authoritative political action is taken.

I will conclude this chapter with a discussion of neoliberalism and what its consequences might be as it both plots itself well on the dimension of self-regulation in flexible normalism, and it is one of the two important axes of self-regulation I will be mobilizing in this dissertation.

¹²⁸ Waldschmidt, “Who is Normal? Who is Deviant?,” 196.

4.2 Neoliberalism and Self-regulation

Neoliberalism is one of those terms that is difficult to define because it denotes a change that has significantly affected a great deal of discourses and research areas in the humanities and social sciences. To operationalize it here, Foucault defined the neoliberal subject as a “*homo oeconomicus*” an “entrepreneur of himself, being for himself his own capital, being for himself his own producer, being for himself the source of [his] earnings.”¹²⁹ For him it is a type of individual that is created within an economic movement of the 18th century that held that the wealth of the nation is contingent on the entrepreneurial character of its citizens to create wealth. It creates the type of individual that exists in a society—a responsible and reasonable agent whose efforts are guided by the principle maximising personal capital.

Brown summarised these changes quite succinctly in her article *Neoliberalism and the End of Liberal Democracy*.¹³⁰ She claimed that the neoliberal political sphere is marked by a complete consolidation of all dimensions of human life in economic terms; it reduces all action to entrepreneurial action that submits to a “calculus of utility, benefit, or satisfaction against a microeconomic grid of scarcity, supply and demand, and moral value-neutrality.”¹³¹ The rationality and moral character of action is guided not by justice, legitimacy, or rights but on what a government can do to maximise possible benefit with the least cost—it is deeply consequentialist and utilitarian. This neoliberal situation “erases the discrepancy

¹²⁹ Ibid., 226.

¹³⁰ Wendy Brown, *Edgework: Critical Essays on Knowledge and Politics* (Princeton: Princeton UP, 2006), 41-2.

¹³¹ Ibid., 41.

between economic and moral behaviour by configuring morality as entirely a matter of rational deliberation.”¹³²

Such a system ‘prescribes’ and creates a certain citizen-subject that is rational and radically self-regulating. In a dual way it (1) defines individuals as “calculating creatures whose moral autonomy is measured by their capacity for ‘self-care’—the ability to provide for their own needs and service their own ambition” (i.e., what an individual subject *is*), and (2) “the rationally calculating individual carries full responsibility for the consequences of his or her actions no matter how severe the constraints on this action—for example, lack of skills, education, and childcare in a period of high unemployment and limited welfare benefits.”¹³³ Unlike the traditional liberal subject, whose basic needs were provisioned by the state or demanded of the state, the neoliberal subject is one who provisions for his/her own needs even in times of general economic hardship, and the responsibility for the fulfilment of—or failure to fulfil—those needs reflects a mismanagement of One’s own personal capital. The political and moral implications of this are wide ranging.

The political struggle for inclusion becomes a battle to show that one can *produce* in spite of one’s disability if legal, political, or social barriers are removed. This risks reducing the political struggle of disability activism to that of ensuring that everyone is allowed to be neoliberal subjects. This would impart value *only* on those who can successfully harvest their human capital. The more assistance one needs to participate, the farther they are from the

¹³² Ibid.

¹³³ Ibid., 42.

expanded middle range, and the more precarious their situation becomes. As Fritsch put it in a recent article:

Regardless of how politically useful the distinction between impairment and disability has been to assertions of rights and demands for access to work, transportation, and community life, this strategy of political sameness is caught up in the neoliberal hegemonic social imagination that organises bodies to make them productive within a neoliberal economy; that is, the disabled body of the disability rights movement is rendered intelligible and valued as a body that matters in order to claim its status as a body that can work and produce.¹³⁴

In flexible normalism¹³⁵ there is always a trade off, where flexing the norm comes at the cost of a reinvention that allows the norm to continue to do its work of dividing subjects.

Neoliberal discourse is no longer tethered to a single ideal but rather takes its aim at a more general commitment to upward movement and growth, and to a flexible inclusion and wider acceptance of people at the margins *so as to bring them into the system of competition*. This level of flexibility and inclusion has led a great many social gains. Nevertheless, it remains that neoliberalism and its reliance on precarity, volatility, and radical personal-responsibility, is equally destructive for those at the margins. It does not eliminate oppression, but only sets a looser limit on those who are let in, at the cost of those who are still left behind.

¹³⁴ Kelly Fritsch, “Desiring Disability Differently: Neoliberalism, Heterotopic Imagination and Intra-corporeal Reconfigurations,” *Foucault Studies* 19 (2015): 49.

¹³⁵ Waldschmidt, “Who is Normal? Who is Deviant?”

For example, we can legislate that someone may require a chair with different weight requirements, receive job training and coaching, or require assistive software/hardware; we may even accept that individuals may need to go on health leave from time to time. With these, individuals may have what they need to enable them to enter the workforce. This is an example of how beneficial flexible normalization can be for some. However, in cases where an individual may be experiencing episodic bouts of psychosis, we may be more ready to accept that that individual is *less employable* and we might accept the fact that that individual may *need* to live a life of constant poverty and precarity. In reality, like any well-treated condition the tools to accommodate are not unreasonable, but people lack the understanding of what life with these conditions looks like and assume that they are incompatible with workplace performance and desire to work.¹³⁶ These are due to a lack of first hand knowledge, media representations, and archaic clinical judgements.

The political struggle to make the job market accessible and accepting does open it up to more individuals, but it does nothing for those whose participation is not enabled. To illustrate, in one survey (2021), unemployment rates for individuals living with disabilities in the U.S. was 12.6%.¹³⁷ This is certainly not an acceptable state of affairs for disability advocates, and people do engage in legitimate political struggle to enable more individuals with disabilities to find meaningful work. On the other hand, the unemployment rate for

¹³⁶ See for e.g. Margaret E Hampson, Hicks, Richard and Watt, Bruce, "Beliefs about Employment of People Living with Psychosis," *Australian Journal of Psychology* 70, No. 2 (2018): 103-112; Cassandra Westcott, Waghorn, Geoffrey, Mclean, Duncan, Statham, Dixie, and Mowry, Bryan, "Interest in Employment Among People With Schizophrenia," *American Journal of Psychiatric Rehabilitation* 18, vol. 2 (2015): 187-207.

¹³⁷ U.S. Bureau of Labor Statistics, "News Release: Person With a Disability: Labor Force Characteristics 2020," (Massachusetts: U.S. Bureau of Labor Statistics, 2021): <https://www.bls.gov/news.release/pdf/disabl.pdf>

individuals living with psychosis in 2007 was between 85.5 to 82.8%--18 times greater than the rate of the general population at the time (4.6% vs 82.8%).¹³⁸ There are many complex reasons why individuals may not move from benefit systems to employment, but what these numbers illustrate is that the neoliberal struggle for participation does not apply itself universally to the heterogeneous group of individuals who identify as having a disability. Though flexible normalism does expand the “normal range” to be more inclusive, the wings of the distribution remain mostly untouched. Employment being one of the major ways that people find meaning and purpose, the unequal distribution is illustrative of the general situation. I will argue later that there are other ways to find meaning and purpose which need to be valued as well. For now, it suffices to say that proceeding by mere inclusion by flexing the norm does not reach the level of a general critique of the status of disability in our contemporary society.

The slackening of control over individuals with disabilities does not preclude the fact that there is still an undertow of default and unspecified undesirability attached to the category of disability in general. As Fritsch put it, “although some disabled people both have and produce value within neoliberal economies, and despite the fact that many people enthusiastically support the rights of disabled people to access education, work, and have meaningful social lives, disability remains stubbornly undesirable.”¹³⁹ It is at the level of

¹³⁸ Viviana Carmona, Juana Gomez-Benito, Tania Huedo-Medina, and Emilio Rojo, “Employment Outcomes For People With Schizophrenia Spectrum Disorder: A Meta-Analysis Of Randomized Controlled Trials,” *International Journal of Occupational Medicine and Environmental Health* 30, No. 3 (2017): 346; U.S. Bureau of Labor Statistics, “Household Data, Annual Averages, Employment Status of the Civilian Noninstitutional Population, 1947 to Date” (Massachusetts: U.S. Bureau of Labor Statistics, 2017): <https://www.bls.gov/cps/aa2017/cpsaat01.pdf>

¹³⁹ Fritsch, “Desiring Disability Differently,” 44.

how we value disabled lives that the resistance has to be applied. The individuation that takes place through neoliberalism and the kind of real-time and self-regulation described by Link fail to re-value disability, because individual energies—politicised or not—are funnelled into a practice that does not challenge the ableist foundations of valuation. Fritsch continues, “challenging the undesirability of disability requires more than individualised access to education, employment, or vibrant social lives [...] Challenging the undesirability of disability requires that disability be imagined differently, that is, imagined in ways that ensure that disability can be collectively practised and experienced differently.”¹⁴⁰. Despite the negative aspects of having or acquiring a disability, it is not a totalizing experience. It does not negate the wholeness of the individual or their existence. Disabilities are integrated and established as normal aspects of that person’s experience. As I will argue in Part 2, it becomes *normative*. To simplify here, people living with disabilities have to find new or innovative ways of living outside established default trajectories. This process has a lot to teach us about the human condition, and our collective practices around difference or loss. However, the general undesirability of disability, and accepted truth behind those default trajectories, limits the range of possibilities available to individuals. If the only acceptable social goal of disability activism is inclusion, then only those who can approximate normality within the flexible norm can escape dependence, poverty, or social death. This is not to demonise individuals living with disabilities that have found traditional or innovative ways to reach economic or other successes. The point is that the social struggle to access and participate is not a complete political project in itself.

¹⁴⁰ Ibid., 45.

As it relates to the inducement towards productivity, individuals with disabilities are subject to the same modes of power and have no more responsibility to challenge them in general than their able-bodied counterparts (who participate equally in confirming the value system inherent in neoliberal capitalism). However, it is precisely in this fracturing that makes re-valuation so difficult. Reflecting on Canguilhem, Waldschmidt states, “[w]hen we define ourselves as normal, we also simultaneously define who should be considered as abnormal in comparison to us. In other words, both freedom and normality have their drawbacks, their social ‘costs,’ and their victims.”¹⁴¹ Though there is nothing morally or inherently wrong about wanting to be included and participate in society, those successes do not invalidate the more general critique about the status of disability in neoliberalism or modernist conceptions of man. In equating these with evidence of social progress with respect to disability, we ignore the continued devaluation of those still unable to participate.

4.3 Results

I have traced how statistical methods emerged in 19th century social science as a means to track and objectify politically useful social phenomenon. These remain in effect for both Waldschmidt and Link through what they call normative norms or protonormalism. These norms are derived from statistical landscapes but in the traditional sense of a normal distribution. These normative distributions inform policies and practices that are imposed to control problematic types of individuals. Government will provide for the very limited survival of these individuals, but only to the extent that it is framed in a narrative of

¹⁴¹ Waldschmidt, “Who is Normal? Who is Deviant?” 192.

suffering, undesirability, or charity and only to the extent that they submit to predetermined policies, rules, and regulations.

In flexible normalism, these strategies are limited and only come into play to add stability to the system. In general, strategies that dominate today are much softer, more inclusive, and attempt to open up the idea of what is acceptable. It has become much more acceptable to have conversations about accessibility, workplace accommodations, employment training programs, educational equality, individual and caregiver support etc. all with the aim of allowing individuals who were once ostracised to participate in society. Individuals may choose to voluntarily participate in programs and benefits in order to bring themselves within the bounds of normality, and to maximise their personal growth. Since normalizing power is a participatory power that works through self-regulation and choice; resistance to specific norms and guidelines does not get at the root of the matter, it only sets new limits in the ongoing and ever changing network of regulatory norms. Loosening the responsibility of governments and placing that responsibility onto individuals does lead to two changes (a) individuals are made to self-regulate as much as possible towards an orienting norm, so one's value is equal to the decisions one makes to maximizing their productivity in whatever respect, and (b) those who cannot attain a given level of productivity are left at the margins with a far weaker political position. In other words, the self-regulation that comes from the individualization of responsibility fractures the collective resistance to negative conceptions of disability that have a far greater potential for change. The hope of inclusion is that as more people integrate in society and enter the bounds of normality that their example will show the reductive tendencies of those grand narratives of suffering and undesirability; however, the reality is, it only challenges a very narrow field of

devaluation. Some forms of impairment still remain irreconcilable with the bounds of acceptable normality and certainly even those individuals who did attain some success are only partially accepted for who they are. There are other aspects of themselves and the way they experience the world that has not led to a direct challenge as a result of their participation.

Neoliberalism and the economic nature of social valuation is an important aspect of normalization today. But it is not the only aspect that needs to be discussed. The question of what lives are considered in the canon of normality is accompanied by the question of what lives are worth living or allowing. This is a question that will bring us to the discourse on the biological nature of our existence. In the following chapter, I will explore changes in the discourse of medicine that will help us understand how life is perceived and lived today. What I aim to show is that they follow very much the same idea of self-regulation and orienteering norms to control problematic bodies. Because of the precarious nature of existence today, and the ability of medicine to manipulate the very building blocks of life our relationship to our bodies has changed. Ideas of precarity, risk, and neuromolecularity will be inscribed into the normalizing practices discussed, above and connected to the system of valuation inherent in neoliberalism. Both together will be important in informing the critical posthumanist perspective to be developed in Part 2.

4.4 Summary

In this chapter I have introduced two different types of norms with two distinct functions. The first, normative norms, are represented by established or fixed boundary that are not to

be crossed. They function like rules that ensure a certain course of action, or entail sanctions against disobedience. These are the forms of power that Foucault would have placed within the realm of sovereign power. Secondly, we have normalistic norms, that represent flexible norms that are tied to advanced-statistical societies and whose politically significant uses emerged in the 18th century through concerns about births rates, mortality and later epidemics and ‘endemic’ phenomena including incapacity and abnormality (discussed in Chapter three). This kind of power is what Foucault described as biopower—the mechanisms of regulation applied to bodies and population. What Waldschmidt and Link develop is one of those mechanisms through which power attaches itself to normalcy and how it guides action *in-real-time*. Normalistic norms represent the landscape of understanding that individuals use in their attempts to regain normalcy, maintain normalcy, or maximize outputs at times of maximum potential or minimal risk. They connect to a constant evaluative decision making process about what we are and what we ought to do.

Given biopower’s emergence in social medicine and the sociology of deviancy it is not immediately clear why we conclude with neoliberal and economic forms of self-regulation. If we dig a bit, as Foucault did, we see that one of the main concerns of social medicine in its infancy was a labour medicine and the need to maintain and insure a healthy workforce.¹⁴² In fact, Foucault tells us that capitalism itself would not be possible without this folding of the population into economic processes.¹⁴³ The subject that was created in this

¹⁴² Foucault, Michel. "The Birth of Social Medicine," in James D. Faubion, Robert Hurley and Paul Rabinow (eds.), *Power; Essential Works of Foucault* (New York: New Press, 2001), 134-156.

¹⁴³ Foucault, *History of Sexuality*, 140ff.

node of biopower and economic rationality was the *homo œconomicus*.¹⁴⁴ In the absence of a sovereign will or a social order determining ones position or purpose, some rationality must be applied to self-understanding and decision-making. This important dimension of subjectification and self-regulation maps onto normalism and normalcy. I will continue to develop and add layers of complexity to this perspective in the following two chapters.

¹⁴⁴ Michel Foucault, *The Birth of Biopolitics, Lectures at the Collège de France 1978-79* (New York: Palgrave, 2008), 215-237.

Chapter 5— Regulating the Self in the Age of Vital Politics

In Chapter three I discussed the emergence of the docile body, and the role that biological understandings had in creating this particular functional description of the body, as well as the role of medicine in the development of population statistics as a regulatory political mechanism. These remain relevant as historical and contextualizing realities. In this chapter I will be addressing a mutation in that very discourse and the resulting effects on our contemporary understandings of the human. In conjunction with Chapter four where I have shown the neoliberal dimensions of self-regulation, I will discuss self-regulatory behaviours tied directly to the functions of the body. I will conclude that we can operationalize self-regulation on two axes—maximization and optimization. This dichotomy, which I will develop in Chapter six, will serve as the impetus for the analysis of a few contemporary problematics that are closely tied to it.

5.1 Neuromolecular Gaze and Technomedicine

There are several events that shape the medicine of today, some of which happened in Foucault’ and Canguilhem’s lifetimes; namely, the development of psychopharmaceuticals (1950s), the first heart transplant (1967), or the eradication of smallpox (1980). Since the death of both philosophers, we have seen the cloning of Dolly the sheep (1996), the mapping of the human genome (2003), the first genetically modified human embryo (2015),¹⁴⁵ the

¹⁴⁵ For genetically modified embryo implanted in vitro, see David Cyranoski and Sara Reardon, “Chinese Scientists Genetically Modify Human Embryos,” *Nature News* (Nature Publishing Group, April 22, 2015), <https://www.nature.com/articles/nature.2015.17378>

reverse engineering of a pluripotent stem cell from a skin cell (2018);¹⁴⁶ even a plausible attempt to reconstruct a dinosaur through genetic reversal,¹⁴⁷ among other such planned or ongoing attempts to find the limits of our current capacity. Working with the concepts of biopolitics, Rose essentially ‘updates’—if one agrees with his premises—Foucault’s framework to incorporate such events, as well as the important epistemico-historical shifts (or “mutations”) implicated in them.¹⁴⁸ The shift from molar to molecular will signal both a change in scale of biomedical gaze and introduce the element of transferable and manipulatable components of genetic information.¹⁴⁹

Essentially, due to the tremendous advancement in medical and scientific screening technologies our understanding of life or our gaze upon life no longer takes place at the molar level, meaning at “the scale of limbs, organs, tissues, flows of blood, hormones, and so forth [...] [which] was the focus of clinical medicine, as it took shape over the nineteenth

¹⁴⁶ Jere Weltner, Diego Balboa, Shintaro Katayama, Maxim Bernal, Kaarel Krjutškov, Eeva-Mari Jouhilahti, Ras Trokovic, Juha Kere, and Timo Otonkoski, “Human pluripotent reprogramming with CRISPR activators,” *Nature Communications* 9, No. 1 (2018).

¹⁴⁷ Jack Horner and James Gorman, *How to Build a Dinosaur, Extinction Doesn’t Have to be Forever* (New York: Dutton, 2009). The original idea was posited in this book and Horner has been working on the idea since.

¹⁴⁸ Nikolas Rose and Peter Miller, *Governing the Present, Administering Economic, Social and Personal Life* (Cambridge: Polity Press, 2008); Rose, *The Politics of Life Itself*; Nikolas Rose, “The Human Sciences in a Biological Age,” *Theory, Culture and Society* 30, No. 1 (2013): 3-34; Nikolas Rose, “The Birth of the Neuromolecular Gaze,” *History of the Human Sciences* 23, No.1 (2010): 11-36; Nikolas Rose, “Screen and Intervene: Governing Risky Brains” *History of the Human Sciences* 23, No.1 (2010): 79-105.

¹⁴⁹ See also Tamar Sharon, *Human Nature in an Age of Biotechnology; The case for Mediated Posthumanism* (New York: Springer Dordrecht Heidelberg, 2004), 117; Carlos Novas and Nikolas Rose, “Genetic Risk and The Birth of The Somatic Individual,” *Economy and Society* 29, no. 4 (2000).

century.”¹⁵⁰ Currently, “biomedicine visualizes life at another level—the molecular level [...] ion channels, enzyme activity, transporter genes, membrane potentials.”¹⁵¹ Where the ‘anatomico-clinical’ revolution of the 19th century had a “molar” gaze, the medicine of today has a “molecular” gaze that directs both research and therapeutics (genetic screening, primacy of pharmaceutical therapeutics, genetic mapping of epidemics, ethnicity specific treatments, stem cell research, gene editing etc.). For this new medicine an abnormality can be found in an individual before any symptom is experienced and before any sign can be found.¹⁵² It is *pre-symptom and pre-signal* and it is best represented in the form of the statistical risk of a future danger. Medicine can now project a certain pattern of problems that can then be judged long before it materializes, and the landscape of responsibility—(to which I will return shortly)—is on the scale of familial (genetic) history and individual choice.

In the past, the fracturing of the body into its parts (limbs and systems) was still *essentialist* in that the parts were very practically tied to the whole and not thought of as separable elements. However, the fracturing that takes place at the neuromolecular level is of a different kind. Reading Rose, Sharon writes, they “acquire a new flexibility and

¹⁵⁰ Rose, *The Politics of Life Itself*, 11.

¹⁵¹ *Ibid.*, 12.

¹⁵² *Ibid.*, 107; the “risk society” has been analyzed by a number of sociologists with their own idiosyncrasies, but Rose and Castel were primarily used here because of their affinity to and development from the Canguilhem-Foucault line of thought. For alternative and generally compatible analyses see the work of Anthony Giddens, Ulrich Bech and Scott Lash on the risk society and reflexive modernization: Beck, Giddens, Ande Lash, *Reflexive Modernization; Politics, Tradition and Aesthetics in the Modern Social Order* (Staford: Stanford University Press, 1994); Beck, and Ulrich, *Risk Society: Towards a New Modernity* (New Delhi: Sage, 1992); Anthony Giddens, *Consequences of Modernity* (Cambridge: Polity Press, 1990); Giddens, “Risk and Responsibility” *Modern Law Review* 62, no. 1 (1999): 1-10.

mobility, since they can be distinguished from the biological substrate, the organisms, in which they are located [...] vital elements can be re-engineered by molecular manipulation, customized and cloned.”¹⁵³ Even the tools that doctors use are not tied to the essence of a disease. This is evidenced by the fact that in the US as much as one in five prescriptions for outpatients are given for “off label”—i.e., unapproved—uses according to one source,¹⁵⁴ and 11% in one Canadian study.¹⁵⁵ Medications are tied to a certain functional unit within the body (a neuro-transmitter systems, RNA replications, specific cellular functions, etc.) and not the disease or condition itself. Though a medication can be developed for one use, the doctor may prescribe it for another completely unrelated use, if they judge that the effect of that medication on the vital processes of the body will also benefit the patient with whatever issue they are experiencing. This is a very common practice in fighting side effects in psychiatry, e.g., using a stimulant like Lisdexamfetamine (Vyvanse) to fight the sedating effects of an anti-psychotic medication like Clozapine (Clozaril). The development of technology facilitated a fracturing of the body by changing its *way of seeing*. It opened up the possibility of manipulation outside the bounds of the organism as a whole, and it also decoupled its use of technology from the essential connection to the disease.

¹⁵³ Tamar Sharon, *Human Nature*, 117.

¹⁵⁴ David Radley, Stan Finkelstein, Randall Stafford, “Off-Label Prescribing Among Office-Based Physicians,” *Journal of the American Medical Association Internal Medicine* 166, No. 9 (2006), 1021-1026.

¹⁵⁵ Tewodros Eguale, David Buckeridge, Nancy Winslade, Andrea Benedetti, James Hanley, Robyn Tamblyn, “Drug, Patient, and Physician Characteristics Associated with Off-Label Prescribing in Primary Care,” *Journal of the American Medical Association Internal Medicine* 172, No. 10 (2012), 781-88.

This is not an isolated event in the history of medicine, this *way of seeing life*, or the adoption of the neuro-molecular gaze, has related socio-political effects. New strategies of regulation and control that follow this same line, according to Castel, “dissolve the notion of a *subject* or a concrete individual, and put in its place a combinatory of *factors*,” contact with individuals is replaced by the collection of data centered on establishing “*flows of populations* based on the collation of a range of abstract factors deemed liable to produce risk in general.”¹⁵⁶ Much like medical understandings of the body-machine and the docile body (see Chapter three) were two sides of the same coin, the molecular gaze and the fractured/risky body will equally co-exist in technomedicine. Deleuze was quite forward looking when, in thinking through what he calls a society of control, he described a medicine “‘without doctor or patient’ that singles out potential sick people and subjects at risk”¹⁵⁷, not in terms of problematic *individuals* within a population, but in a way that “substitutes for the individual or numerical body the code of a ‘dividual’ material to be controlled.”¹⁵⁸ He likens the code to a password in the sense that it opens access to networks of regulation and control. One does not become problematized as an individual, but the problematic “dividual material” (something to be controlled like high blood pressure, Alzheimer’s, or psychosis) ‘grants access’ to networks built around those categories.¹⁵⁹ In this context, exchange does not happen in a traditional clinic, with doctor and patient exchanging information, but in a

¹⁵⁶ Robert Castel, “From Dangerousness to Risk,” in *The Foucault Effect*, 281.

¹⁵⁷ Gilles Deleuze, “Postscript on the Societies of Control,” *October* 59 (1992), 7.

¹⁵⁸ *Ibid.*

¹⁵⁹ The term ‘granting access’ may be a bit awkward—though sometimes it best captures the metaphor of ‘membership’, one could think here of an support group or advocacy group with their specific definitions and perspectives—but to put it another way, it *occasions* certain networked (i.e., interrelated) relationships that will play a role in self-regulation.

techno-laboratory setting where risk is identified and the individual is thrown into a network of information and technological manipulation. Patient groups, specialized clinics, research hospitals, university or industry research programs, medical information websites, pharmaceutical websites and commercials, as well as online forums are things that become pertinent once a combination of risk factors or a coded material is discovered. Of course, most individuals realize that there is a problem when the disease or issue manifests itself symptomatically—this is when they initiate contact with technomedicine through a doctor. Nevertheless, that is not a counter-argument against the idea that power is distributed outside the clinic. When and by whom the issue is found is of little consequence; once confirmed individuals are placed in relation to a whole interpretive network outside its walls, whose access is simply occasioned by the coded individual problematization (e.g., diagnosis or predictive identification in the case of fitness, lifestyle, or risk-identified behaviours).

The role of the doctor becomes one of identification (of the issue) and gatekeeper of access to reasonable technologies and therapies. To foreshadow a bit, the new screening technologies and frames of reference for disease (through neuromolecularity and individual flows¹⁶⁰) in conjunction with regulatory mechanisms that are initiated outside the walls of the clinic will depend on ever evolving technologies to manipulate the body in novel ways. As Lewis reminds us, “[n]ot only has technomedicine become a staple of medical diagnosis and treatment, technoscience has catapulted medicine into an era of physical and mental

¹⁶⁰ I.e., any problematic bodily process or patterns of actions that have some identified prevalence in a population.

enhancement.”¹⁶¹ I will take a closer look at enhancement later in this dissertation, however, it remains that it is one aspect of this technomedicine equally present in implanted devices, complex pharmaceutical medications, and the coming intelligent prosthetics. Medical knowledge itself is shared with, and developed by, industry and academia. It is developed within universities and engineering laboratories outside of the clinic and works its way down the chain of commerce, social networks, and mass media. At the frontier of medical science is a seismic shift away from the doctor’s role as expert and interpreter towards that of a technician. At the limit, “clinicians are in danger of becoming glorified distributors of the new technologies for the giant transnational biotech corporations—sort of like new car dealers with a medical certificate.”¹⁶² It would be going too far to say that this is already entirely the case, but it points to where we are going. It points to how the entanglements of society’s technoscientific practices, and the commercial realities of advanced capitalist societies are fundamentally changing the institution of medicine; an institution that we acknowledge plays an important role in our own self-understanding and normative judgements about acceptable life. What, then, can we say about the consumer-patient of this new regime?

5.2 Geneticization, the Somatic Self, and the New Patient

The ever-evolving discourse of technomedicine has brought sharp criticism from bioethicists

¹⁶¹ Bradley E. Lewis, “Prozac and the Post-Human Politics of Cyborgs,” *Journal of Medical Humanities* 24 (2003), 52.

¹⁶² *Ibid.*

(among other sociologists and activists), especially those who deal with the issues of genetic screening and genetic counselling. One such critique is that of Abby Lippman who coined the term *Geneticization* to describe the encroachment of genetic thinking in the cultural differentiation of subjects.¹⁶³ In an argument that is quite consistent with much of the disability discourse, Lippman argues that *geneticization* turns all our attention to a limited part of the human being (genetics), ignoring other aspects of their being. In this sense, geneticization leads to policies and practices that are consistent with deterministic—even though empirically unverified—claims about the genetic cause of ‘everything.’ So for these authors¹⁶⁴ the discourse becomes oppressive and over-deterministic and is something that needs to be resisted on the basis of rights, equality, and social justice.¹⁶⁵ Certainly, the practices that come out of geneticization, as I will argue later, *do* require direct political resistance. However, the mechanism through which they affect people needs to be better understood.

What is true, is that even as an aspect of somaticization in general, genetic-

¹⁶³ Abby Lippman, “Led (Astray) by Genetic Maps: The Cartography of the Human Genome And Health Care,” *Social Science & Medicine* 35, no. 12 (1992): 1469-1476. Also, Fiona Miller and Abby Lipman, “Geneticization: An Interview with Abby Lippman on New Genetics,” *Canadian Women's Health Network* 2, no. 2 (1999), <http://www.cwhn.ca/en/node/39708>.

¹⁶⁴ e.g., Abby Lippman, “Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities” *American Journal of Law & Medicine* 17, no. 1–2 (1991): 15-50; Abby Lippman “The Genetic Construction of Prenatal Testing: Choice, Consent or Conformity For Women?” in Karen Rothenberg, Elizabeth Jean Thomson (Eds.), *Women and Prenatal Testing: Facing the Challenges of Genetic Testing* (Columbus: Ohio State University, 1994), 9-34; Joseph Alpers, Jon Beckwith, “Genetic Fatalism and Social Policy: The Implications of Behavior Genetics Research,” *Yale Journal of Biological Medicine* 66 (1993): 511-524; Michael J. Montoya, *Making the Mexican Diabetic: Race, Science, and the Genetics of Inequality* (Berkeley: University of California Press, 2011); Ruth Hubbard, and Elijah Wald, *Exploding the Gene Myth* (Boston: Beacon Press, 1993).

¹⁶⁵ Rose, *Politics of Life Itself*, 110. Re. Lippman, “Prenatal Genetic Testing and Screening.”

determinism *does* play a socio-political role in the experience of disability. In her Foucauldian-influenced analysis, critical feminist disability theorist Melinda Hall traces a genealogy of eugenics and enhancement debates that both responsabilizes and problematizes the individual with a disability.¹⁶⁶ Though genetic determinism is a gross over-simplification it operates as an essential reduction of a cause and effect consistent with the overall biomedical framework, without which complex issues about disability could not be framed as a medical issue. In today's intellectual and ethical climate disability would not have a solid and actionable biological foundation without a simple connection to genetic determinism, and so would not be a justifiable target of prevention or elimination in the first place. But this drive to prevent and eliminate disability maps onto a much earlier discourse on increasing the genetic fitness of the population through personal health practices, one that equally problematized disability without the "one gene one disease" oversimplification of today. The veil of greater scientific understanding is simply a new form of the same essentialist reduction which obscures the socio-political factors that themselves contribute to the construction of disease and deviance categories. The same ethico-political practices present in the long history of biopolitical modes of power are implicated here. The responsibility to control deviance is either placed onto the individual (i.e., they must work to eliminate the disability in themselves) or onto decision makers who ought to prevent disability in order to prevent suffering (with the goal, implicit in bioethical discourses and explicit in transhumanist discourses, of enhanced fitness for humanity in general¹⁶⁷).

¹⁶⁶ Malinda Hall, *The Bioethics of Enhancement; Transhumanism, Disability, and Biopolitics*, (New York: Lexington Books, 2017), 75.

¹⁶⁷ Hall, "Rethinking Enhancement: A Genealogical Approach," in *The Bioethics of Enhancement*, 57-84.

As Novas and Rose argue, the critiques of geneticization from the purely bioethical point of view is not *false*, but partial and misleading or incomplete.¹⁶⁸ For example, as Lippman argues, the development of instrumentation for the screening of genetic risk—first through Ultrasound (1970s) and more recently by maternal blood analysis—has problematized pregnancy and reproduction by projecting social expectations and ethical responsibility onto the mother. In doing so, it disproportionately affects marginalized populations by imposing a very western-middle class set of concerns and expectations about valuable or healthy life.¹⁶⁹ For all its practical value, and there is much there, it relies on the assumption that pregnancy before genetic testing was somehow less problematic from a biomedical point of view and claims to show the isolated effects new technologies in cultural context. What is misleading is that it takes the historical moment for granted and fails to connect the critique to a larger framework about subject formation. It ignores the deeply entrenched discourses of truth that make such technologies part and parcel of the mirror through which we create our self-image and make demands of biomedicine. In other words, it substitutes the active process of subjectification and somaticization as it developed over a few centuries of clinical discourses for an isolated technological and cultural transgression on the integrity of the maternal body.

In her more pointed analysis of genetics and enhancement, Hall did provide a situated critique of these practices and how they come to construct the category of disability through

¹⁶⁸ Carlos Novas and Nikolas Rose, “Genetic Risk and The Birth of The Somatic Individual,” *Economy and Society* 29, no. 4 (2000); Rose, *Politics of life itself*, 110.

¹⁶⁹ E.g. Lippman, “Prenatal Genetic Testing and Screening,” 26-33.

which individuals are created as subjects of deviance and unfitness.¹⁷⁰ It is precisely this kind of analysis that Novas and Rose are advocating (though their more macro-level term somaticism is meant to encompass a wide array of subject formations). Let us discuss this mechanism a bit further in order to inform our analytical framework.

We can agree that genetic information is presented as overly deterministic—both in their assumption that we *are* our genes, and in the assumption that the presence of a defective gene *will* lead to a specific condition—but Rose and Novas do not identify such a discourse as inherently oppressive. There is nothing to be directly oppressed or suppressed, no un-geneticized maternal body bearing the onslaught of genetic risk factors and diagnostic technologies. To see it as a form of oppression is to accept some form of essentialized human body that can be transgressed by this new understanding. However, we have already argued that such a thing is itself constituted through a discourse of modernity and biomedicine. The introduction of geneticization is just part of a greater shift in the constitutive discourse of medicine, not the introduction of new invasive practices and tools. It is here the crucial difference between Lippman, and Novas and Rose.

The geneticization argument implies that to ascribe genetic identity to individuals or groups is to objectify them, hence denying something essential to human subjectivity. But to make human individuality the object of positive knowledge is not ‘subjection’ in the sense of domination and the suppression of freedom – it is the creation of subjects

¹⁷⁰ Hall, *Loc. Cit.*; We will return to Hall’s analysis when we discuss more specifically about posthuman ethics in Part 2.

that is at stake here.¹⁷¹

In fact, individuals actively adopt these discourses as constitutive of themselves, and seek out genetic information in order to guide their own choices.¹⁷² It is not a dominating power, because it does not rely on force or oppression, it is not a hegemonic power because it is not a matter of simply consenting to genetic understandings because of the futility of resistance or the potential for self-empowerment, it is an *acceptance* of genetic (and other) biomedical explanations *as truth* about the self. If it is a discourse about *who we are*, and we accept its methods as valid and conclusions as true, then it would be unreasonable not to accept them as saying something about the self. Even in cases where it lacks full empirical justification (ex. over-determination, one gene one disease, environmental and epigenetic factors, etc.) the general mode of understanding becomes the primary framework through which a subject can see or say something valid about the self.

By looking at it from this perspective, we see that geneticization is not a new weapon of the oppressive ‘powers-that-be,’ but a logical continuation of the discourses of medicine that include a plethora of other problematizations linked to reproduction, psychopharmacology, advanced functional imaging and modeling, ethnic heredity and genetic disease markers (including personalized medicine), all of which lead to a general “somaticization” of the individual.¹⁷³ The somatic frame of reference comes to dominate

¹⁷¹ Novas and Rose, “Genetic Risk and the Birth,” 485-513.

¹⁷² Rose, *Politics of Life itself*, 106-16; Nikolas Rose, “Normality and Pathology in a Biomedical Age,” *The Sociological Review* 57, (2009): 66-83.

¹⁷³ Novas and Rose, “Genetic Risk”; Rose, “Neuromolecular Selves,” in *Politics of Life Itself*. We also have to acknowledge that there are other identity discourses apart from somaticization that are important in the making of an individual’s self-concept. Somaticization will be most relevant to the

self-understandings whether one is ill or not, impaired or not; it is the framework of *life itself* that changes.

In this view we can say that somaticism, or the focus on a piece of molecular information—be it in the body or in the foetus—acts as coded ‘dividual’ material to be controlled (to use Deleuze’s terms above). And this puts the subject in relational network that are not at the scale of “society” but of “communities” such as “groups, associations, communities of those similarly at risk; groups of patients at particular hospitals or clinics; participants in trials of new therapies; subjects of documentaries and dramas on radio, television and the movies.”¹⁷⁴ There can include traditional support networks or alternative care networks. One relevant example of the latter front of mind in our current times, we can mention the most recent iteration of the “anti-vax” movement. The origins of this movement are found in the now debunked research by Dr. Wakefield that claimed a link between the MMR vaccine and autism. Even decades after the original study has been retracted and no link found by subsequent research, a growing community of parents and citizens—facilitated by social media—are now interested in the functions and risks of vaccines. Not only are they modifying their personal choices, but encouraging others to do so as well based on a range of concerns from parental responsibility over the health of their children to a belief in a government conspiracy to genetically modify its population. The latter connected to a slew of public health communication about vaccine safety, anti-misinformation campaigns, and as

analysis here, but for the others, I would venture to say that they represent coded dividual pieces of information, and function much like the discourse of somaticization here—even if they are not directly related or relatable to biology (e.g., sexual identity, racialization, geo-political factors etc.).

¹⁷⁴ Novas and Rose, “Genetic Risk and the Birth,” 490.

well as media, workplace, and family level communications.¹⁷⁵

Generally speaking, genetic problematizations, new diagnoses, states of impairment of varying degrees etc., are not only understood through some passive internal self-identification, but put the individual in relation to a network or landscape through which they come to understand their role going forward. They work *with (or against)* medicine and *with (or against)* the doctor as *protoexperts*. They are seeking out information about themselves (e.g., mail order medical lab tests for everything from food sensitivity, to gut biome, to medical genetic testing), information on the condition in the free and dispersed web of knowledge about medicine on the Internet or other media (self-help books, magazines, television etc.), and organize themselves around conditions in the form of special interests groups, support groups (individual or family), and Internet discussion forums and activist networks. Somaticization does not lead to individuation, but place individuals in “networks of relatedness and obligation” while simultaneously placing in the individual the task of being “free yet responsible, enterprising yet prudent, conducting life in a calculative manner by making choices with an eye to the future and with the aspiration of maintaining and increasing his or he own well-being and that of their family.”¹⁷⁶ The self-understanding of somaticism within a society of flexible norms leads to self-regulation in the same way that

¹⁷⁵ One must note, however, that even for those who accept the vaccine neoliberal responsibility is ever-present. Those that espouse its benefits, though standing on more valid science, claim personal expertise, see themselves as responsible for their’s and other’s safety, and try to regulate other’s behaviours by convincing them or subjecting them to ridicule, ostracization, or anger. On the governmental side, the ways in which ‘anti-vaxxers’ are dealt with likewise illustrates the mechanisms of biopower and control—education campaigns, restrictions on access, imposing sanctions, in some cases fines or exclusion from certain financial relief benefits, etc. Whether we think these are proportional or ethical does not matter, the mechanism with which it is enforced is very illustrative. This could itself be the subject of a lengthy analysis.

¹⁷⁶ Rose, *Politics of Life Itself*, 111.

neoliberal understandings of the self do.

Operationally, I will use two interrelated terms to denote these phenomenon: (1) optimization being the calculation of risk and self-regulation related to the somatic self—i.e., the optimization of outcomes or capacities, and (2) maximization to denote the calculation of output and self-regulation of personal capital related to the *homo æconomicus*—i.e., maximization of performance and productivity within society.

5.3 Preliminary Example

To conclude with an example relevant to Lippman’s discussion of geneticization, we can look at the technology of prenatal diagnostics. This preliminary example will tease out some of the elements that will be connected with a more general framework in the next chapter.

Whether in the clinic or outside of it, there is a general understanding of risk in relation to pregnancy in general, and increased risk calculated based on family history of genetic conditions and age. Understanding these risks pre-pregnancy can include things such as personal DNA tests bought online, informal discussions about diseases or abnormalities taking place in one’s social group, genetic counsellors that can discuss family history or offer testing themselves, and fertility clinics that can offer information and options to women at risk. Additionally, there are pre-natal networks that include the latter as well as routine screenings and additional out-of-pocket testing.¹⁷⁷ Further, to this we can now add umbilical

¹⁷⁷ E.g., newly developed “Panorama” test, a non-invasive prenatal test that can be purchased in Canada at medical testing labs. (<https://www.lifelabsgenetics.com/product/non-invasive-prenatal-testing/>).

cord blood bio-banks and the extensive expectations around diet, sleep, and stress management for pregnant women that further responsabilize the mother for the baby's health later in life. Such interactions reinforce and develop further the idea that the foetus as well as the mother are made of biomolecular material prone to risk (i.e., reinforced a *way of seeing*) and in responsabilizing the woman to make risk aversion choices within a social context (i.e., social fitness and overall reduction in suffering). Again, the idea is not to look at these technologies and techniques as part of an oppressive system of control, in most cases they are welcomed and sought after. The idea is to show how the techniques, practices and technologies themselves provide a framework through which we define the maternal body and the future life to be created. Certainly it has its practical benefits and drawbacks in relation to the experience of pregnancy and the process of reproduction. Nevertheless, it has, just as any other subjectivising discourses, its own specific dangers. One such danger, for the purpose of this dissertation, is how it might relate to disability, understood as a neuro-biological (genetic) deficit. The prospective or future mother is responsabilized to provide for herself, her family, and the future baby in a way that ensures health and fiscal viability.

In a society that has an explicitly deficit view of disability and values able-bodied and productive neoliberal subjects, it is no wonder what choice is expected of the mother if an abnormality is found,¹⁷⁸ and no big surprise that termination rates for prenatal diagnostics of

¹⁷⁸ One must clarify here that this is not an anti-abortion argument. A woman's right to choose what happens to her body was a long fought (and still unfinished) project that itself is an important political move for one of modernity's largest marginalized populations—mothers of reproductive age. My discussion here focuses solely on abortion as a medical technique and the effects of discourse on what choices are being made and what that shows us about the regulatory powers that surround the question of disability today. It is not a condemnation of women who have had abortions, whatever the reason. I want to make it clear that it is not an argument about individual choices, but about how society deals with disability, the expectations that are placed on women and families in

Down's Syndrome range from 60-93%.¹⁷⁹ As Goodley put it, “[i]t is not the case that disabled people are hated . . . , it’s just that *they* don’t fit the world’s (ableist) demands.”¹⁸⁰

The point here is not to make these individual women culpable of what Waldschmidt (among others) describe as a new form of eugenics,¹⁸¹ even less to make them feel like they are complicit in enacting one. A human genetic practice informed by statistical measures of risk that are seen as objective and consistent with the somatic understandings that prevail in society *result* in these reasonable individual choices. When I say that the person is responsiblized, they are so in a very limited sense of being responsible for their immediate networks.

We can point to the issues inherent in the elimination of babies based on disability, but they are systemic. The entire biomedical research enterprise organized around prenatal diagnosis, current research in genetic therapies, and the bioethical debates about what lives are worth living attach themselves to centuries old ideas about population health and the

advanced western capitalism, and how we collectively think about what makes up a valuable and desirable life. For more on the discussion of reproduction and disability, see Anne Waldschmidt, “Who is Normal? Who is Deviant?,” Anne Waldschmidt, “Normalcy, Bio-Politics and Disability;” and my discussion of these texts in Martin Boucher, “The Normalizing Society and Disabilities,” in Moira Ferguson and Alain Beaulieu, *Studies in Disability* (Sudbury: Laurentian University, 2012). See also Shelley Tremain, “Reproductive Freedom, Self-Regulation, and the Government of Impairment In Utero,” *Maternal Bodies 21*, no. 1 (2006): 35-53.

¹⁷⁹ One meta-analysis of data between 1980 and 1998, 92% of prenatal Down Syndrome diagnoses led to termination (Caroline Mansfield, Suellen Hopfer, and Theresa M. Marteau, “Termination Rates After Prenatal Diagnosis of Down Syndrome, Spina Bifida, Anencephaly, and Turner And Klinefelter Syndromes: A Systematic Literature Review,” *Prenatal Diagnosis 19*, no. 9 (1999): 808-812) and in a more recent meta-study a range between 60% and 93% was found in different settings (Jaime Natoli, Deborah Ackerman, Suzanne McDermott, and Janice Edwards, “Prenatal Diagnosis of Down Syndrome: A Systematic Review Of Termination Rates (1995-2011),” *Prenatal Diagnosis 32*, no.2 (2012), 142-53.

¹⁸⁰ Ibid.

¹⁸¹ Waldshmidt, “Who is Normal who is Deviant,” 205.

genetic enhancement of the human species.¹⁸² Eliminating genetic diseases means that we will limit the number of supports for those that do proceed to live birth and that we are limiting the ability of those individuals and their difference to inform what lives have value (for their own condition or disability in general). Neither of these are within the scope of a woman's choice to terminate a pregnancy. Making them personally responsible is as silly as the idea, by analogy, that the solution to our climate crisis is for you to recycle, or stop driving your car, or for you to only use glass bottles—a real solution necessitates large scale change and practicality for the people involved. Making individuals in difficult situations responsible for the solution through extremely limited action is exactly how self-regulating power prevents macro-level change and obscures the source of the problem. In fact, it is the very mechanism that makes people with disabilities responsible for the mitigation of their own lack of output and lack of flourishing, while obscuring the fact that society is inequitable in its access to and provision for the means through which someone can produce and flourish. I will talk more specifically about resistance and its difficulties in Part 2.

In any case, this short example is meant to introduce the idea that the woman's normal or abnormal pregnancy are coded into networks in and out of the clinic, leading to all sorts of self-regulating behaviours aimed at optimizing health and considerations for the maximization of their family and future children's financial viability. We also see that the same mechanism (optimization/maximization) is applied whether genetics are problematized or not. Umbilical cord blood has nothing to do with predictive genetics but is framed as a means to minimize risk if a future condition develops where the baby might need stem cells

¹⁸² Hall, "Rethinking Enhancement: A Genealogical Approach," in *The Bioethics of Enhancement*, 57-84.

(something only made available recently by advanced technomedicine). This too contributes to the creation of the human body as a somatic entity liable to produce risk and suitable for intervention at the vital level; while additionally, it creates a new ethical responsibility to mitigate future risk. We can go further and look at the even more mundane health discourses about the woman's health behaviours at its effect on the foetus such as abstaining from alcohol or tobacco, the need for extra iron and amino-acids, the neuro-chemical effects of inadequate sleep and stress. All of these help constitute the body, they are not *challenges* to it (contra to how Lippman conceptualized geneticization). The example of the reproductive-mother's body is quite specific, but it is instructive because most of the regulatory mechanisms associated with it are common knowledge and immediately identifiable for a large number of readers. In the next chapter I will look more closely at the connection point between optimization and maximization and how this regulatory power problematizes an increasingly large number of individuals with a much wider effect.

5.4 Summary

Just like the *homo oeconomicus* was the form of subjectification that resulted from neoliberal discourses, the somatic body emerged from the discourse of neuro-molecular technomedicine. Where ancient medicine, once mostly limited to the study of symptoms, underwent a profound change following the scientific revolution in light of advancements in anatomy, germ theory, and early instrumentalization like the stethoscope and chemical testing techniques; resulting in what we call molar medicine or biomedicine. It is a medicine of limbs, organs and symptoms understood through their signs. The primary setting for this medicine is the clinic and the laboratory.

In the second half of the 20th century, technical developments opened up the possibility of seeing the body in increasingly smaller scales and led to the focus away from the molar level of structure/function towards the vital processes of life itself. This opened up a whole new avenue for both manipulation and temporality. Abnormalities and deficits can be identified before any sign or symptom is discovered or experienced. The primary characteristics of this medicine are that life itself is knowable through highly technical diagnostic technologies, it lends itself to manipulation and engineering, and it is compartmentalizable through probabilistic thinking and the reduction to risk factors that flow throughout the population. These culminate in a dispersed medicine not limited to the clinic or the laboratory but to research networks, private industry, advocacy groups and patient networks. These networks, and the discourses that support them, constitute the landscape of subjectification through which the individual comes to understand him/her/themselves.

Rose described somaticization as the molecular understanding of the self most obvious in genetic understandings, but equally present in neurological understandings of the mind and the molecular functions of the body (through nutrition and pharmacology). It is easy for bioethicists to see the ‘oppressive’ potential in geneticization because it represents an incredibly reductive vision of the human being and, in its most dangerous manifestations, overdetermines—as fact—what is only based in probability. However, for those who follow Foucauldian frameworks, these discourses are not oppressive, and their accuracy is of little importance because they have *truth effects*. They represent what is seen and what can be said, and in doing so *create* the type of subject relevant to that discourse. When we look at the origins and the function of that discourse, it goes beyond geneticization. The subjects that come out of this discourse are responsibilized to manage their own health and decisions, and

to think beyond the self in order to minimize risk to implicated parties (family, offspring, social group, etc.). The subject is understood through factors related to risk, probability, or through diagnosis, the latter representing a failure to prevent or predict their own situation. In doing so, they are coded (i.e., ‘reasonably’ implicated) in networks of clinical practice, cutting edge medical knowledge, private industry and research, as well as other knowledge sources, knowledge holders, and quasi-professionals coded into that network (individuals, their families, practitioner-educators, alternative practitioner-educators, research dissemination networks, media, cultural and artistic representations, etc.). All these presuppose an active and self-regulating individual intent on optimizing their health in light of whatever possible or real pathology is present, for which we see evidence of in the patient as proto-expert, the oft. ridiculed ‘Dr. Google’, and the proliferation of health monitoring devices and ‘body hacking’ or enhancing technologies.

The following chapter will explore how this somaticism and its tendency towards optimization coalesces with neoliberalism and its tendency towards maximization. Preliminarily, and what is the main purpose of this first part of the dissertation, is the idea that flexible normalism and the self-regulation inherent in contemporary biopower and neoliberalism result in a tendency towards unfettered optimization of capacity and maximization of performance that functions, analogically, like the individualized mechanism of the myth of progress. That is to say, as a drive towards unchecked quantitative increase guided by mere fantasy.

Chapter 6—Optimization/Maximization Towards Posthumanism

In the entirety of this Dissertation so far, I have been tracing a historical phenomenon and evolving mode of power that originated in modernity. I have discussed two types of self-regulation and their accompanying discourses that themselves have relied on an image of man passed down from this era. However, as we have seen, the limits of this reliance are challenged by evolving biotechnologies and flexible social norms. In this chapter I will do two things: 1) synthesize the two pressures explored so far—namely, optimization and maximization,—and 2) argue that these forms of power, and their accompanying discourses of what it means to be human, are no longer fully tethered to earlier modernist ideas. I will argue that they are guided by the imperatives to self-optimize/maximize itself without reference to a natural or fixed limit. I will call this a runaway norm, and the resulting images of man as organically posthuman.

6.1 Optimizing Health and Maximizing Personal Capital; Bringing Together Biopower, Self-Regulation, and our Frame of Reference

It is here that I can start to synthesize our discussion so far. As suggested in previous chapters, the predominant way that power functions today is through flexible normalization that is constant and self-directed. One way in which this is the case is through neoliberal understandings of the self, which impel individuals to act in ways that maximize their personal capital. In other words, One is responsible to behave in ways that make them marketable and productive in society. Expected to seek out opportunities for personal development or seek to remove barriers in order to maximize gains. Important socio-political

questions become dominated by ideas of independence, productivity, and utility above all else. Certainly, this is an abstraction, but what I claim is that it accurately represents the idealized orienting norm of maximization in our society. This does not mean that every person always follows the norm faithfully, but it represents the context within which we judge reasonable action. It is a mutation of the *homo economicus* that takes into account the ways in which highly technologically advanced societies measure and monitor change. This form of self-regulation is not guided by old norms that take for granted some natural given or category (i.e. something to attain once and for all), but are personalized and fluid. They start where one is at in that point in time and induces one to maximize gains or correct unproductive trends, as one would manage one's stock portfolio. This not in purely economic terms, but for what we might term the quantifiable aspects of personal development.

When it comes to somaticization, power functions in much the same way. Individuals are impelled to optimize health or capacity through a calculation that minimizes risk or harm. Individuals have a responsibility to others and to the future that goes beyond the immediate self. In being coded with some future risk (as in genetic screening or family history) or some emerging condition (chronic or acute health issues); individuals are placed in a network of relations that are either familial (i.e., linked to familial past or the future of offsprings and dependents) or communal (i.e., research or practice communities, support communities, activist communities or simply communities of shared lived experience). Engagements with these communities have the quality of orienteering data; they show us what other's do and orient us towards a specific norm (i.e., what to expect and how we ought to act in relation to the normal course of events). Concurrently, it leads to a responsabilization to participate

actively to changing conditions and participate in ways to maximize health outcomes both in the clinic and in personal life. At its extreme, one sees the evidence of this in the practices of the patient “seeking multiple forms of expert and nonexpert advice in devising their life strategies, and expecting medics to act as servants and not masters of this process.”¹⁸³ More mundane examples are the prevalence of home blood pressure monitors and personal glucose meters—which brought the medical laboratory into the home and in the hands of patients—or unspecified biomedical devices such as pedometers (fit bits) and sleep monitoring apps that have become a staple of contemporary Western society. A quick Google search for “personal biomedical devices” brings up an array of product reviews and ‘best of’ lists that include diagnostic/monitoring devices such as personal EKG, smartphone ultrasound device, bra inserts that alert to the detection of tumour formation, baby monitoring devices that track heart rate and body temperature, to air quality sensors and water purifiers. All of these represent an evolution in technomedicine coupled with the somaticization and responsabilization of the self. They point to the active role of self-regulation outside of the clinic, and normalizing strategies that do not necessarily rely on long-term normed trajectories but constant and real-time optimization.

What this shows is that in the current normalization landscape, individuals are not typically oppressed or acted upon as passive, but are constituted by and participate in the discourses of social valuation and body-life. A condition like an illness or impairment may be coded and place an individual in relation to a whole slew of informational decision networks and they may be responsabilized to act in ways that are reasonable within these

¹⁸³ Rose, *Politics of Life itself*, 111.

communities and networks; however, they are not forced to do so in the traditional understanding of power. What we have described here is what Waldschmidt and Link termed normalistic norms: a more inclusive form of normalization where people participate in norm making, and where norms are collectively shaped within—following Deleuze and Rose—specific communities and networks of coded individuals that emerge in technomedicine. But what happens if we refuse to participate or cannot participate?

6.2 What happens when we do not self-regulate; An Interlude

If we recall the analysis put forth in Chapter four, normalistic norms are norms that are more fluid and flexible, but they can only be stretched so far before they swing back into normative norms.

When normalistic norms do not do the job of normalization and there is some issue that needs to be controlled there is a return to normative norms. In cases where individuals are unable to self-regulate in sufficiently productive and optimal ways we encounter all sorts of punitive and corrective mechanisms. Examples are most striking in cases of forced confinement or community treatment orders in psychiatric disabilities, but also the myriad of policies and requirements individuals must go through to qualify for basic necessities and life-enabling assistance. Some individuals must fight for a basic economic existence that most would qualify as perpetual ‘hard-times,’ which is itself justified by self-fulfilling discourses of disability as suffering and governmental assistance as charity. The political motivation of the management of disability is straightforward when policies are in direct conflict with medical opinion. The very existence and qualification for disability assistance, at least in Canada, is intrinsically linked to an inability to work. This must also be *proven by*

a doctor and is still often rejected. The disconnection between medical opinion and assistance criteria is quite important. In the UK austerity linked “fit-for-work” assessments were championed in 2008 as a means to better evaluate claimants based on their ability—as opposed to disability—and to better connect them with appropriate benefits and services. However, between 2010 and 2017, over 2300 people died within two weeks of being found “fit-for-work.”¹⁸⁴ Certainly we cannot attribute their deaths to the assessment themselves,¹⁸⁵ but it may be safe to assume that individuals who were in reality weeks away from death and seeking disability assistance were in fact not *fit-to-work*. Comparable to the local figures mentioned in Chapter four, 56% of denied claims in the UK are overturned on appeal. Most importantly, in this example the disconnect between medical assessment of capacity and governmental assessment of fitness to work is an example of what Castel describes as a process of “administrative assignation”¹⁸⁶ where medical expertise only plays a role in a larger process of administration. The process is bound by medical opinion and the expertise is meant only to define a certain characteristic or factor in the assessment. We can understand the plight of individuals with disabilities as part of a “two-speed” society where

¹⁸⁴ Department for Work and Pensions, “Mortality Statistics: Employment and Support Allowance, Incapacity Benefit or Severe Disablement Allowance; Additional Information On Those Who Have Died After Claiming Employment And Support Allowance (ESA), Incapacity Benefit (IB) Or Severe Disablement Allowance (SDA),” (Sheffield: Department for Work and Pensions, 2015), 8: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/459106/mortality-statistics-esa-ib-sda.pdf

¹⁸⁵ Though, not immaterially, the reassessment process itself has been linked to 560 suicides in one study and 279 000 cases of self-reported mental health problems in three years (B. Barr, D. Taylor Robinson, D. Struckler, R. Loopstra, A. Reeves, M. Whitehead, “First, Do no Harm: Are Disability Assessments Associated with Adverse Trends in Mental Health? A Longitudinal Ecological Study,” *Journal of Epidemiology and Community Mental Health* 70, (2016): 339-345). In fact, the situation got so bad in 2016 that the UN condemned the UK for their contravention of the rights of individuals with disabilities.

¹⁸⁶ Castel, “Dangerousness to Risk,” 290.

there are those “hyper-competitive sectors obedient to the harshest requirements of economic rationality, and marginal activities that provide refuge (or a dump) for those unable to take part in the circuits of intensive exchange.”¹⁸⁷ Those that cannot perform fall into this secondary society of exchange. They can fall in this category by default (diagnosis), as matter of administrative sorting (political desire), or in confrontation with systematic barriers to fair assessment—the former two being forms of coding, and the latter a confrontation with social organization within the process.

The Work Capability Assessment under the fit-to-work program shows very well how such assessments can be used to manage the flow of populations. First, an individual is assessed on their capacities at home, those capacities are extrapolated onto a list of work related tasks (in the background) and second, they receive three possible judgments, fit-for-work, unfit-for-work but fit for work related activities, and fit for neither work nor work related activities. If one is found fit for work, benefits are immediately terminated. The ones found fit for work related activities are put into a “work-related activities group” and given programs and services to improve their ability to work in the future. The last group is for those who are not expected to ever return to work, and so, are not put in the network of retraining and skill development of the previous group. Certainly there is an element of normativity here, as individuals must *show* that they legitimately fail to attain a certain established norm of behaviour (or attain a norm of impairment consistent with the inability to work); moreover, if they qualify for a given benefit, they may still fall into a category of individuals who are expected to take part in work related activities and skills development—

¹⁸⁷ Ibid., 294.

not necessarily by choice. Although the primary focus of this chapter is on the self-directed nature of normalistic norms, we must acknowledge that normative norms do exist alongside it. As Waldshmidt pointed out, “any threat that the entire normal field could dissolve would spark a backlash, a return to strategies that emphasize narrow normality zones and fixed boundaries.”¹⁸⁸ The inability to participate in the free market of competition and exchange justifies a return to imposed restrictions on self-regulation (e.g., expectations to engage in retraining and skills building regardless of one’s volition). Though people are expected to self-regulate, and if they do not they are typically left to suffer the consequences of falling behind, in the case of social assistance we find that sanctioning and disciplinary forms of power remain in operation at several crucial points.

Those in this ‘secondary’ society are more closely monitored and controlled by normative norms than the others to ensure the stability of the system. Individuals are expected to temper their expectations and aspirations both as a function of disability and fiscal reality. They are expected to manage their health conditions and impairments like any other good citizen. Likewise, they are expected to manage their finances in accordance with the responsibility of using *other people’s money*, as evidenced by the various attempts—some successful and some not—to introduce universal drug testing for people receiving benefits.¹⁸⁹ Additionally, the failure to attain self-reliance opens the door to various forms of devaluation. People are seen as receiving a “free ride” even though they are given at

¹⁸⁸ Waldshmidt, “Who is Normal who is Deviant?” 196.

¹⁸⁹ Emma Wincup, “Thoroughfares, Crossroads and Cul-de-sacs: Drug Testing of Welfare Recipients,” *International Journal of Drug Policy* 25, no. 5 (2014) 1031-37.

maximum an income well under poverty line—a difficult concept to reconcile.¹⁹⁰ On the other hand, there are individuals whose condition is so debilitating that it precludes an expectation of work even in the most ardent fiscal conservative,¹⁹¹ in which case they become nothing more than a ‘human interest story’ whose suffering defines and reinforces the idea that disabled lives are not worth living. Worst still, you have the opposite image of a ‘freeloader’ who has found a way to live off benefits in some attempt to professionalize laziness. All of these are attempts to reconcile the ableist imaginary of self-reliance with the reality of a system of dependence.¹⁹² More than simply ‘negative attitudes’ they play the role of justification for the establishment of normative norms (limiting self-regulation). To justify certain sanctioning policies, one must establish a demonized figure (the freeloader) or appeal to the person’s failure to appropriately exercise their freedom for the good of society (e.g., unwillingness to participate in assessment processes or retraining/modified work efforts). For the latter, ensuring that assessment processes are accessible and fair is certainly important, but it does not exhaust the issue of what justifies the onerousness of the process or the rates of rejection above and beyond medical recommendation.

¹⁹⁰ E.g., Maximum shelter amount for single person in a single residence is \$497 and maximum basic needs allowance is \$673 (Ministry of Children, Community, and Social Services, “Ontario Disability Support Program-Income Support,” (Toronto: Queen’s Printer, 2018) https://www.mcsc.gov.on.ca/en/mcsc/programs/social/directives/odsp/is/6_1_ODSP_ISDirectives.aspx)

¹⁹¹ e.g., the life of David Vetter, the “boy in the bubble” that was the inspiration for at least two movies and an episode of Seinfeld E47. As an entire class, we see this in children with life-limiting and life threatening disabilities (see Dan Goodley, Rebecca Lawthom, Katherine Runswick-Cole, “Posthuman Disability Studies,” *Subjectivity* 7, no. 4 (2014): 342-361).

¹⁹² We can add to this those individuals receiving unemployment benefits and other forms of social assistance. In fact, a recent proposed merger of unemployment benefits and disability benefits was proposed in Ontario (2014-15), but disability activists and those in the disability services sector successfully resisted it. The suggestion itself shows that from the perspective of governance, separating the *reason* for an inability to work is at least not *necessary*.

In fact, the ableist understandings are foundational to the whole system of governance—normative and normalistic. For Goodley *et al.*, neoliberal-ableism can be defined as “a consideration of the centrality of ability (and its counter disability) to the theorisation of late capitalist neoliberal societies.”¹⁹³ In fact, they argue, one cannot be separated from the other. When we say that neoliberal-ableism favours individuals who are independent, rational, productive and autonomous, we are implicitly assuming that this individual is of sound mind and able body. Ableism is rarely discussed explicitly because it so clearly implied, but individuals with disability, who most often fall outside of the norms of neoliberalism, are keenly aware of its ableist elements and the need to challenge them. Ableism assumes that individuals ought to be independent and productive, when that is not attained, fixed norms to control behaviour are established and the beliefs that support them become visible. We see in the increasingly supported idea of austerity the belief that one that cannot provide for themselves ought to get the *minimum* required for survival, and that one ought to minimize their dependence as much as possible. This ignoring the fact that aid rarely reaches the level of bare necessity, and that barriers and disincentives to participation are established under the same guise. These are not simply attitudes, they are normative and ethical requirements bred out of ableism that materialise in policies and regulations aimed at minimizing the financial impact of disability. From this example, we likewise may be able to understand what is ahead for those who are unable to be full actors in the ‘primary’ society of exchange as runaway norms and performance enhancement technologies widen their scope. I discuss this below, as well as in the second part of this dissertation in our discussion

¹⁹³ Dan Goodley, Rebecca Hawthorn, “Critical Disability Studies, Brexit and Trump: a Time of Neoliberal–Ableism,” *The Journal of Theory and Practice* 23, No. 2 (2019): 237.

of the posthuman re-imagining of our society.

6.3 What Kind of Person is Created and Transformed?

What I would like to complicate in Goodley’s account is the idea that tethering ableism to neoliberalism, which is absolutely valid, also unties it from its earlier source in modernity and biomedical understandings. Doing so uncovers a more flexible foundation in the normalistic landscape, as opposed to being definitionally tied to a natural conception of human capacity—(though it still functions in normativity). This allows for inflation in the number of people who can be considered neoliberal-*unable* and how we might understand what is to be done with them in the current landscape. Wolbring has in many ways begun to make this shift in his exploration of hyper-ableism tied to transhumanism, and has looked at this important nexus of thought outside the bounds of Disability Studies.¹⁹⁴ What I want to emphasize in this chapter, is that this change is not based on a cognitive or cultural understanding of transhumanism and its re-interpretation of ability—though this lens is very useful. I want to show that it is the result of the forms of power that are already untethered from the idea of the human and its relationship with technology that began long before transhumanism.¹⁹⁵ Evidently, it is a future already playing itself out. The language of species-typical/sub-typical/beyond-typical will be useful here, but it will also be relativized in Part 2 of this dissertation. I want to show here the resonance between an evolving ableism and the category of subjects unable to reach the level of ability required for participation in

¹⁹⁴ Gregory Wolbring, “The Politics of Ableism,” *Development* 51, no. 2 (2008): 252-58.

¹⁹⁵ This later aspect will be explored in Part 2.

the primary neoliberal market. I argue that it may be broadening in scope, and that the regulatory mechanisms that are applied to disability may be quickly expanding to others.

Speaking of vital politics, Rose writes quite provocatively, “[b]ut what has become of the notion of normality – the healthy, the average, the absence of pathology? At the genomic level, the answer may seem surprising – none of us – none of you – are ‘normal’ [...] We are all asymptotically, presymptomatically ill – and perhaps all suitable cases for treatment.”¹⁹⁶ We all have risks in our genes, making the absence of pathology a temporary state and an illusion. As he states “we are all at risk [...] all of us harbour, in those three billion base pairs that make up our 23 chromosomes, multiple minor variations that are potentially knowable, and which appear (although I would like to stress that word) to render our future risks of everything, from Alzheimer’s disease to obesity, knowable and calculable.”¹⁹⁷ At the genetic level, there is no norm from which we may judge the pathological, since the norm is to be (pre)pathological or susceptible. Somatic individuality makes us think in terms of risk, and increasingly in terms of our vulnerabilities. The somatic self does not end at the level of genetics either, there are other somatic concerns like the vulnerability inherent in aging, in physically and psychologically dangerous work, in our food systems, environmental contamination, natural disasters and ‘acts of god’, etc. We can see how the pathological life is not tied to a specific class or type of individual, but one where we problematize possible or yet unrealized individuals (e.g., obesity, cancer, Alzheimer’s disease, injury, burn-out, addiction, etc.). These things are present in the

¹⁹⁶ Nikolas Rose, “Normality and Pathology in a Biomedical Age,” *Sociological Review* 57, (2009): 73.

¹⁹⁷ *Ibid.*

population, and individuals must take care of their health so as to not fall prey to them—we are all susceptible and vulnerable to pathology. When they do manifest, or the risks are identified through testing, individuals are coded into the networks that have been built around those conditions and are given more opportunity to actively participate in prevention, management, or re-establishment towards the norm (of ability). On the other hand, the demands of neoliberalism often have somatic consequences too. The demands of productivity can create whole new categories of sub-optimal and vulnerable under-performers—outside of pathology itself. To illustrate this point, we can look specifically at our most elite athletes.

Already the athlete's body can be seen in somatic terms and reduced to its vital processes. Personalized diets that calculate precise amounts of nutrients calibrated to the exertion and depletion of energy through physical exercise, and supplements that go beyond the possibilities of normal food intake. Everything from maintaining one's immunity, to building muscle capacity, or recovering from workouts, all become essential parts of the *business* of being a world class athlete. When the demands become too great, it is of little surprise that individuals choose to take illicit substances that can enhance further. As performance levels increase, individuals orient towards this new norm, and continue to *chase* the demand to improve through biotechnology. Those who do not continue to actively seek ways to optimize their bodies do not perform to a level that affords them the ability to participate/work in the most competitive leagues and competitions. The demands of the job are performance based, but there are no external requirements for the use of supplements, expert training regimes, or certainly not illicit substances—they do however, become part of the “culture.” The merger of the somatic self and market performance in a normalistic

landscape are beautifully illustrated here. The difference is that individuals are not coded externally, but enter themselves into a whole network of marketed products, health research, risk and safety information, specialized networks of knowledge and peers not easily understood by outsiders—all of which are aimed at better performance and management of risk or injury. One's desire to participate in competitive sport does code an individual in an entire network of commerce, research and development, experiential sharing and shared knowledge about body optimization, ethical and policy standards for sport, but it does not attach itself to a pathology or somatic abnormality. The effects are the same, but its importance for our purpose may be a bit hidden. What I would aim to show is that pathology ceases to be the defining characteristic of this system of problematizing bodies, and that falling short of performance norms serves the same function. Let us look at some more pertinent examples before I return to this.

Without suggesting that ADHD—and any other condition discussed here—does not lead to actual negative experiences for people, we can comfortably make the claim that it is not an objective and value-neutral category. Clinical considerations *are* performance based and are inscribed in the matrix of responsibility and expectation characteristic of our society. Concerns over ADHD are intimately tied to one's ability to perform as expected in social, work, and education settings. A look at the DSM-5's criteria make this clear, six of the criteria explicitly mention school or work, and the qualification of clinically significant distress is absent.¹⁹⁸ This category, linked to a deficiency in performance is coded into an entire network of ADHD specific information, support and treatment in order to engage the

¹⁹⁸ The criteria of significant distress is often used as a justification for clinical intervention in psychological disorders.

individual in optimization techniques to maximize productivity *for them*.

But what happens when one cannot perform, even when they do not attain the DSM-5 threshold? In an era where we see ourselves in somatic terms—as processes, neurochemical systems, informational/computational apparatuses, etc.—the fact that therapeutic stimulants are being used by undiagnosed individuals as biotechnology should not surprise us. These technologies exist, they have an effect on the somatic processes that make up the self, and a person may have a perceived lack or active desire to surpass the typical limits of those processes. As in the case of the athlete previously mentioned, there are no explicit external requirements to do so; one does it from personal choice and a calculation of optimization and maximization.

For a decade now we have known that university students are using prescription stimulants in order to maximize their ability to perform on academic tasks (in the absence of any diagnosis).¹⁹⁹ The Canadian Center on Substance Use and Addiction reports the annual prevalence of non-medical use of prescription stimulants at 4-6% and a lifetime prevalence at 17% for Canadian college students.²⁰⁰ A recent qualitative analysis of the trends in non-medical substance use have discussed the rise in use of stimulants within the context of

¹⁹⁹ e.g., Timothy Wilens, Lenard Adler, Jill Adams, Stephanie Sgambati, John Rotrosen, Robert Sawtelle, Linsey Utzinger, and Steven Fusillo, “Misuse and Diversion Of Stimulants Prescribed For ADHD: A Systematic Review of The Literature,” *Journal of the American Academy of Child Adolescent Psychiatry* 47, no. 1 (2008): 21-31.

²⁰⁰ “Non-Medical Prescription Stimulant Use among Post-Secondary Students,” *Canadian Centre on Substance Use and Addiction*, (2008): <https://www.ccsa.ca/sites/default/files/2019-04/CCSA-Non-Medical-Prescription-Stimulant-Use-Students-Summary-2018-en.pdf>.

strategic use of pharmaceuticals as biotechnologies and an ethic of performance.²⁰¹ A recent documentary entitled *Take Your Pills* has made such claims, attaching stimulant use to the gaming and programming industry as well as the university.²⁰² The phenomenon of amphetamine based pharmaceuticals use in industry and education remains under-studied. However another stimulant (unrelated to amphetamines) sold under the brand name Provigil (US) and Alerte (Canada), is believed to be in wide use within several contexts where long hours and focus are required. These environments are as varied as universities, militaries and government bureaucracies, the Canadian astronauts on the ISS, as well as those working in Silicon Valley and Wall Street.²⁰³ Using pharmaceutical stimulants to perform at work is not new—one could mention The Beatles and their beloved Dr. Roberts²⁰⁴—but it is becoming part of the typical toolkit for individuals seeking to meet the demands of neoliberal

²⁰¹ Caroline Robitaille and Johanne Collin, “Prescription Psychostimulant Use Among Young Adults: A Narrative Review of Qualitative Studies,” *Substance Use & Misuse* 51, No. 3 (2016): 357-369.

²⁰² Maria Shriver, Christina Schwarzenegger (Ex. Prod.), and Alison Klayman (Dir.), *Take your Pills*, Netflix Productions, 2018.

²⁰³ Arthur Estrada, Amanda Kelley, Catherine Webb, Jeremy Athy, and John Crowley, “Modafinil as a Replacement for Dextroamphetamine for Sustaining Alertness in Military Helicopter Pilots,” *Aviation, Space, and Environmental Medicine* 83, No. 6 (2012): 556-64; Robert Thirsk, Andre Kuipers, Chiaki Mukai, and David Williams, “The Space-Flight Environment: The International Space Station and Beyond,” *Canadian Medical Association Journal* 180, No. 12 (2009): Figure 1; Martin, Richard, “It’s Wake-up Time,” *Wired*, Conde Nast, November 1, 2003: <https://www.wired.com/2003/11/sleep/>; Malcolm Farr, “Public Servants Used Drug Modafinil to Stay Awake to Complete the Federal Budget on Time,” *NewsComAu* (news.com.au, May 27, 2014); <https://www.news.com.au/national/public-servants-used-drug-modafinil-to-stay-awake-to-complete-the-federal-budget-on-time/news-story/8bc517ef259fbfb882ca68b3bd405a4>; Robert Kolker, “Modafinil Is Wall Street’s New Drug of Choice,” *New York Magazine* (New York Magazine, March 29, 2013), <https://nymag.com/news/intelligencer/modafinil-2013-4/>; Carl Caderstrom, “Like It or Not, ‘Smart Drugs’ Are Coming to the Office,” *Harvard Business Review* (May 19, 2016): <https://hbr.org/2016/05/like-it-or-not-smart-drugs-are-coming-to-the-office>.

²⁰⁴ The link between the demanding performance schedule of the Beatles and their use of the stimulant phenmetrazine is well documented, see Hunter Davies, *The Beatles: The Authorized Biography*, (London: Ebury Press, 2009), 246.

productivity by optimizing their somatic stock—with or without being implicated in some discourse of pathology.

Taking Lewis' discussion of fluoxetine (Prozac) into consideration, we have a further example of a psychopharmaceutical being used; however, not for stimulation but for mood. Like amphetamines well known in our society (e.g., Adderall or Vivance) and Provigil, Prozac can sometimes be anchored within the discourse of pathology, and other times not. In many ways, it paved the way for the wide use and acceptance of prescription stimulants in our culture. As Lewis reminds us, Prozac was approved for sale in the United States in 1987, by 1994 it had been prescribed to 10 million Americans and took off as a cultural symbol of the 1990s.²⁰⁵ For some it presented itself as a legitimate improvement over other forms of therapy for an existing diagnosis of depression. For others, it enhanced their abilities to deal with the world, and for some it represented an evil encroachment of pharmaceutical companies into the nature of the self. Regardless of the variety of individual perspectives, it opened up a whole new world of medicine outside the walls of the clinic. It is in this context that Dr. Peter Kramer coined the term cosmetic pharmacology.²⁰⁶ The lines of therapeutics and enhancement/cosmetic uses of these technologies (and they are *technologies*) is so blurred as to prevent one from finding a concrete delineator. The following illustrative example is as humorous as it is telling,

²⁰⁵ Lewis, "Prozac and the Post-Human,"; Clyde Haberman, "Retro Report: Selling Prozac as the Life-Enhancing Cure for Mental Woes," *The New York Times* (The New York Times, September 21, 2014): <https://www.nytimes.com/2014/09/22/us/selling-prozac-as-the-life-enhancing-cure-for-mental-woes.html>

²⁰⁶ Peter Kramer, *Listening to Prozac: A Psychiatrist Explores Antidepressant Drugs and the Remaking of the Self*, (New York: Penguin Books, 1994), x-xvi.

Recently a woman friend of mine in her early fifties went for a routine check-up to her gynaecologist, also a woman. After the examination was over, the gynaecologist asked her, “Well, do you want me to write you a prescription for Prozac?” “Why should I want to take Prozac?” my friend replied. “I’m not depressed.” “How do you know?” asked the doctor.²⁰⁷ (Weil, 1995, p. 201)

The line between being depressed and being well is made so fine in the era that follows the cultural explosion of Prozac that one does not know if they *need* or ought to *desire* Prozac until they have tried it. Following Haraway, Lewis writes that we are in a time where, “[i]t is of little use to decry the impurity or artificiality of Prozac-induced mental states. From Haraway’s perspective, post-humanity in the New World Order, Inc. is too intertwined with technoscience for these distinctions to be of much use.”²⁰⁸ The idea of a natural mental state, which would be altered by the medication, becomes a signification within a discourse that still makes use of concrete categories of what is natural. The issue is that we have become so intertwined with technologies that the lines themselves no longer make sense.

As Haraway put it, “by the late twentieth century, our time, a mythic time, we are all chimeras, theorized and fabricated hybrids of machine and organism; in short, we are cyborgs.”²⁰⁹ Three basic distinctions undermine the unity of the self for Haraway, and the grand narratives that kept all this together. The distinction between animal and man,

²⁰⁷ Andrew Weil, *Spontaneous Healing*, quoted in Lewis, “Prozac and the Post-Human,” 51.

²⁰⁸ *Ibid.*, 55.

²⁰⁹ Donna Haraway, *Simian, Cyborgs, and Women: The Reinvention of Nature*, (New York: Routledge, 1991), 150.

man/animal and machine, and organic and inorganic. All are dividual pieces that exist in loosely coherent networks. The fall of modernity, and with it the exceptionality of the human animal, undermines the privileged place we had made for ourselves. Our continued interaction and development of machines that mimic, enable, or enhance our capabilities are increasingly essential to our way of life. Moreover, we can couple this with the fact that our somatic self is always pre-symptomatically ill and vulnerable to destruction, loss of functionality or injury. And further, add that the demands of hyper-capitalism necessitate the use of technologies to increase productivity and optimize our bodily output. All these contribute to a situation where the norm is flexed beyond any recognizable “natural” limit.

The propensity to push the limits and establish new norms does not come from the outside, it is the result of the collection of self-propelled individual quests to push the limits of the possible towards new and changing norms of performance and optimization. Helped along by technomedicine and evolving technological apparatuses we are seeing the emergence of an unrecognizable future. What I will highlight is that the discourse that drives the development of norms, performance, and optimization today no longer essentially depends on the modern category of human as a frame of reference. I want to show the ways in which self-regulation towards untethered norms already push us beyond the bounds of ‘modern man’.

As runaway normalistic norms are established, they become less and less attainable and the category of neoliberal-able bodies diminishes. More and more people as neoliberal-*unable* in the absence of mediating technologies, and the ableism that underpins ideas of normality is no longer the discourses of natural capabilities. It becomes an ableism that is informed by the transhumanist ideal of un-restricted progress and improvement. Speaking of

Wolbring's work, Goodley calls this emerging imbrication of ableism and transhumanism as *hyper-ableism*.²¹⁰ For Wolbring there are two aspects to ableism: (1) one that sets species-typical abilities as standard vs. deficient sub-species-typical abilities, and (2) the other being the value-laden practice of valuing as superior one set of abilities over and above ones from other species or segments within a given species.²¹¹ As he concludes, in the short work quoted here, “[w]ith the fall of the species-typical barrier it is unlikely that there will be an endpoint to the race for abilities and the sentiment of out-able-ing others (on an individual or collective level).”²¹² Taking this line of thinking to its end, Wolbring uses the example of the hyper-able Olympics, where they will host only “beyond-species-typical” enhanced athletes, with Paralympics hosting species-typical and sub-typical athletes.²¹³ If what we imagine is an opening day parade of half-robotic cyborgs, we can be forgiven for thinking it is not the time to think of such things yet. Biotech is evolving fast, but it is not so visibly or openly challenging to our sensibilities. However, without focusing on shiny and impressive new technologies, we find that the future that Wolbring mentions is not so unimaginable or far into the future. Performance enhancing drugs are a problem from college to elite level sporting leagues. This is above and beyond issues of stimulant use, pharmacological substance misuse (e.g. insulin or the transfusion of synthetic oxygen carriers), and the completely licit extremely regimented training/nutrition programs, hyperbaric oxygen

²¹⁰ Dan Goodley, *Dis/ability Theory: Theorising Disablism and Ableism*, (New York: Routledge, 2014), 23.

²¹¹ Gregory Wolbring, “Is There an End to Out-Able? Is There an End to the Rat Race for Abilities?” *M/C Journal* 11, no. 3 (2008): no pagination. <https://doi.org/10.5204/mcj.57>

²¹² *Ibid*,

²¹³ *Ibid*.

therapy, and cryotherapy that allows athletes to push the limits of what is typically possible. At what point do we accept that the norms of that sport go beyond the “species-typical”? Taken as a whole, the possibilities for enhancement are already widely available, so Wolbring’s extreme example may not be so extreme after all.

In any case, there is here an essential task placed in front of those interested in thinking through disability critically. We are beckoned on two fronts to engage with what will be called “critical posthumanism”:

- (1) On the one hand, People living with disabilities, as well as other marginalized individuals represent the ‘structural others’ of modernity in that they have never been considered fully human, and that their purported natural deficiency played a central role in differentiating—in relation to their lack—what being fully human was.
- (2) On the other hand, we have this great mutation, that I have been tracing here, which consists in the flexibility of normalization, the runaway norm, technomedicine and vital politics, and the removal of the “species-typical barrier,” all of which in themselves collapse the fundamental category of human.

We are in a post-human world, whether it is because the category of human no longer accurately describes—if it ever did—our relationship to our bodies and each other or, in the second instance, that normalization and control no longer require it to function. In other

words, we have a historic-political and practical reason to develop a coherent posthuman perspective on disability and neoliberal-ableism. That being the case, the lines of reasoning and the types of arguments that are made will be different in either case. It is this second form of engagement that I will be exploring further here. It is my contention that this will not invalidate—in fact I rely upon—the analysis of Wolbring and Goodley, but will entail a reframing of that discourse.

To return to our examples, the treatment of depression, narcolepsy, or ADHD are not value-neutral medical practices; they are inscribed in discourses of somatic inefficiency and under-performance. In fact, the somatic technologies developed as treatments of these conditions can just as well be used as cosmetic or functional enhancements. In both cases, though, the category of neoliberal-unable individuals grows.

In the case of ADHD, performance is itself medicalized; first through school children, and then in adulthood. This is one form of expansion, i.e, the creation of a category based on performance. I am not claiming that the pattern of behaviour or the experience of ADHD is not real, just that its scientific-neutrality is clearly brought into question by the fact that it was first described by a failure of moral regulation and then a failure in productivity.²¹⁴ The flexible norm of productivity justifies the expansion of the category, wholly independently from its medical pathology. Further, the technologies developed as therapies for this condition become part of the toolkit for individuals that are non-pathologized and who use them for the same reason—fixing *under*-performance. As the

²¹⁴ Klaus W. Lange, Susanne Reichl, Katharina M. Lange, Lara Tucha, Oliver Tucha, “The History of Attention Deficit Hyperactivity Disorder,” *Attention Deficit and Hyperactivity Disorders* 2, No.4 (2010): 241-255.

norms of performance in our society continue to move, more and more bodies are under-performing and sub-optimal, leading to the use of the same therapeutic technologies in the absence of clinical indications. We could make the argument that the use is different in these cases—one is therapy and one is enhancement—but as we see in our discussion of Prozac, the categories of natural/artificial and species-typical ability (and the sliding performance norms) blur these categories beyond any usefulness. So what are these ‘non-clinically indicated’ users coded into? In the case of psycho-pharmaceuticals, individuals are coded into public health and addictions discourses that try and warn of the dangers, and transhumanist discourses of brain-hacking that glorify the use of technologies to surpass oneself. In both cases, without access to these technologies, they risk falling into the secondary market as neoliberal-unable subject.

The goal of Part 2 of this dissertation is to explain this change in great detail. It must be mentioned however, that the reinterpretation of Goodley’s neoliberal-able, and my reliance on the experience and examples of disability so far are not diminished by the expansion of the category to those being provisionally called neoliberal-unable. The goal is not to monopolize the term neoliberal-able and take it from the disability movement, but to create more allied positions in order to show how the mechanism works. Moreover, the category of disability remains a politically potent site of resistance and is explanatorily necessary to understand how the transhumanist project works. It has a leading role to play in the political significance of resistance for posthumanism in general and will inform my model of posthumanism throughout. What is common is that more and more forms of life are struggling to attain the new norms of performance—whether through new medicalized categories, or through normalized and ubiquitous improvement technologies. It will be my

contention that it does this without any recourse to the idea of the human; and rather, that it relies on depersonalized combinations of capacities and a flexible expansion of benchmark norms.

6.4 Summary of Essential Characteristics

Modernity represented certain concepts of man and society that had negative consequences for individuals who failed to attain the ideals developed at this period. We have called these individuals, following Braidotti, the ‘structural Others of modernity.’ They served the dual function of marking out the boundaries of normality and were invalidated by the very concept by virtue of their inability to live within those boundaries. But modernity is also accentuated by another idea, the idea of scientific and technological progress as always being linear with no foreseeable end. This myth, with its traps and follies, attaches itself to more contemporary concepts such as hyper-ableism, transhumanism, and what I have termed the runaway norm.

It is my contention that the self-regulatory and flexible nature of normalization today, in conjunction with the continued belief in technological progress and improvement, has led to a situation of untethered commitment to forward movement—untethered in the larger sense of modernist naturalism, and more specifically to the fixed nature of clinical norms. The expansion of pathology within psychiatry, off-label prescribing, the proliferation of psychotherapeutics for medical or non-medically indicated uses, the emergence of ‘smart’ drugs and enhancement drugs, body hacking, personal health devices to name a few, are all symptomatic of this changing landscape.

Furthermore, the decoupling of norms from their long-standing and fixed limitations inevitably leads to *post-humanism*. We can approach posthumanism in many interrelated ways, if we follow Braidotti we recognize the fact that what was once a naturalized view of man was exclusionary and depended on this exclusion to function--it did not capture the reality of the diversity of lives and bodies it attempted to describe. With the collapse of the category we must deconstruct the accumulation of knowledge that depended on it, and therefore must think in terms of *post-humanism* (i.e., after and as result of the collapse of the concept).²¹⁵

There are changes in biology--computational models of mind and artificial intelligence, informatics and the reduction of vital processes to information--which already, though we have not seen the full breadth of the result, announce the coming posthuman. The use of smart devices, of genetic therapies, and prosthetics that can bridge the organic and inorganic shows us that the practical applications of bodily technologies implicates a large number of practices that can equally be said to emerge from computing and engineering than from medicine or biology proper. In light of these interconnections, the claim that there is something in the human that differs in kind from other forms of information and other forms of materiality is fast becoming untenable—e.g., inorganic biotech or bionics. Even though in practice many of these emerging areas only offer possibilities and a hint at a future to come, it has profoundly changed how we see life. As Hayles suggests:

Whether or not interventions have been made on the body, new models of subjectivity emerging from such fields as cognitive science and artificial life imply that even a

²¹⁵ Braidotti, *The Posthuman*, 13-54.

biologically unaltered Homo-sapiens counts as posthuman. The defining characteristics involve the construction of subjectivity, not the presence of nonbiological components.²¹⁶

In fact, the vital importance of technology for contemporary life--on which we depend for our very survival²¹⁷--already foreshadow the true imbrication of inorganic and organic that will need to be sussed out further. It was already apparent to Haraway in the 1980s that this hard division between the organic and inorganic, and all of its political implications for Others, had become untenable²¹⁸--long before the introduction of more elaborate and ever complexifying technological invention and molecular reductions of the components of subjectivity.

My purpose going forward will be to add to this cluster of thought the idea of flexible normalism, which I believe goes beyond what the authors intended, and shows us how norms function in the process of this decoupling with the collapsing categories of human/non-human, natural/unnatural, organic/inorganic, prosthetic/therapeutic, ability/disability, etc. I will try to show, in Part 2, that this represents an emerging form of *posthuman* normalization--a focus on optimization and maximization that constantly pushes boundary norms. To apply it to our current problematic, which will tip-toe the line between critical ableism and critical dis/ableism--to use Goodley's terms--I will build on the emerging

²¹⁶ Kathrine Hayles, *How we became Post-Human; Virtual Bodies in Cybernetics, Literature, and Informatics*, (Chicago: Chicago UP, 2008), 4.

²¹⁷ I.e., the technological dependence of our food systems, sanitation and health, communications, commerce and workforce etc.

²¹⁸ Haraway, "Cyborg Manifesto: Science, Technology, and Socialist-Feminism in the Late Twentieth Century," in *Simians and Cyborgs*, 149-182.

posthuman current in Disability Studies represented primarily by the research cluster of Goodley, Runswick-Cole, and Lawthom in the UK, and Wolbring here in Canada.

Conclusion—Into the Future Without a Guard Rail

In this section I have laid down the narrative trajectory and conceptual framework that will inform Part 2 of this dissertation. Most importantly we explored and presented how modernism has set the foundations for a discourse about the human and about the nature of abnormality that is quickly eroding. Moreover, I elucidated the complexities of biomedicine and the mutation that has integrated into it neuro-molecularity and technomedicine, leaving us with a much more complex object than the one treated as simply “individualizing” that was the foundation of the Social Model. In fact, medicine is not individualizing and oppressive but constitutive and productive--what we can see, what we can say, and what we ought to do within the bounds of this discourse creates the kinds of subjects that we are.

What I have also tried to show is that the co-mutation of neuro-molecular/technomedicine that has opened up the possibilities for the monitoring and manipulation of life in its most minute manifestations on the one hand, and how changes in normalization strategies resulting from neuro-molecularity and flexible normalism has itself led to a posthuman situation on the other. This is not to say that there is a qualitative difference regarding what the human *is*. What I describe is very different than the received view, but we had never attained that ideal anyhow. What we do find is that there is a qualitative difference in the discourse of power, and the forms of self-regulation that emerge from them, since our frames of reference no longer essentially depend on the categorical differences between established binaries such as human/non-human, natural/unnatural, organic/inorganic, prosthetic/therapeutic, or ability/disability. I describe this as a

‘decoupling’ of the norm from its fixed boundaries, as those limiting boundaries are being consistently transgressed on an ongoing basis in our society.

In Part 2 I will apply this framework to wide-ranging themes that will constitute the intersection of posthumanism and disability: the idea of hyper-ableism and prostheticity, the question of our relationship to technology, the idea of vulnerability and interdependence, the creative potential of alternative embodiments, and the political/ethical frameworks that are possible for our emerging posthumanism.

Part 2—Learning to be Posthuman; Lessons from the Experience of Disability

Introduction—What is Posthumanism, and why is it not a Transhumanism?

At the end of the previous section I began talking about posthumanism. I tried to show how the changes in normalization and technological advancements have themselves led to a posthuman situation. At this point, I have not situated this in a more concrete description of what posthumanism is, and what kind of posthumanism I am envisioning. Therefore, this section will begin with a more detailed exploration of where this dissertation fits in the variety of positions that identify with posthumanism.

To begin, I have to explain what posthumanism is not. By way of analogy the ‘post-’ in postmodernism can denote a few different things, two of interest to us here. It can denote both a period of time we find ourselves in and/or it can represent a counter-discourse and critique of modernism’s central concepts. Certainly, in the case of postmodernism, both may appear within the same work, but there is a division between arguments against the ideas of modernism, and postmodernism as a historical period or cultural movement. The same occurs with posthumanism. Though I will follow Braidotti in her critique of posthumanism as concept or discourse—the post- here representing thought after the idea of the human—part of that critique also describes our current situation itself as something challenging to the ideas of modernist humanism. An example of this is Haraway’s contention that we are already cyborgs, that we do not have to chose to be or try to bring such a reality to fruition. I explored this in the final chapter of Part 1, focusing on the disappearing limits of modernist norms of natural ability and human productivity. We can identify this as a historical period or shift, but not in qualitative terms. The subject did not become fundamentally different with the new moniker. In both of the latter cases, the ‘posthuman’ is not quantitatively

different than the human, we simply recognize in them new ways of being in the world and our lack of imagination about what was possible in modernism.

Outside these critical discourses, however, we see emerging another idea; that technology has allowed us to move so far passed what the human is, that a new being is created. The tendency to enhance the human body beyond its natural limits towards a new being is more accurately labelled as transhumanism. The “trans-” in transhumanism can be seen in much the same way as it is used in transdisciplinarity; it is the idea of transcending a series of established boundaries. Adding to the confusion, however, is the fact that the ‘transhuman subject’ is an intermediary, and that the subject that will emerge at the horizon of the transhuman project is called *the posthuman*.²¹⁹ Attaching the latter to posthumanism leads to a misunderstanding, as they represent diametrically opposed intellectual, political, social, and ethical positions.

Lastly, and more confusing still, is the idea of cyborgism introduced to the debate, which claims that technology has *distributed* the self outside the boundaries of the body— with or without a claim about the validity of the original idea (i.e. the undistributed embodied self); the latter being more consistent with posthumanism than transhumanism. For this reason, many authors, including myself, have taken to using the term “critical posthumanism” to designate those positions that do not rely on an established category of the human (i.e. represent a conceptual form of anti-humanism). I will disentangle some of this in the introduction here.

²¹⁹ Nick Bostrom, “In Defense of Posthuman Dignity,” *Bioethics* 18, No. 3 (2005): 202-214.

In the conclusion of the previous chapter, I made the claim that transhumanism was not an entirely new way of thinking but a continuation of modernism, albeit modified by technological advancements opening up new physical possibilities. Likewise, following the link drawn between ableism and modernism, Wolbring identifies hyper-ableism with transhumanism.²²⁰ He attempts to demonstrate a qualitative shift in the application of modernism, but in doing so already applies a critical attitude not present in transhumanism itself. In fact, the foundations described by transhumanists themselves are explicitly modernist, most notably in Bostrom.

Nick Bostrom in his *“A History of Transhumanist Thought”* traces the history of transhumanism from the ancient desire to acquire new capabilities—the herb of immortality, the fountain of youth, the alchemical elixir of life, etc.—which was only decoupled from mythological thought in the Age of Enlightenment and scientific revolutions.

“Transhumanism has its roots in rational humanism,”²²¹ he plainly states. For Bostrom, the human quest for enhancement is an inherent part of our nature. He adds that the tools of the scientific revolution give us the means to manipulate this nature, and our status as man-machines (he credits La Mettrie for this “bold idea”), and our place in the natural order of

²²⁰ Goodley uses the term hyper-ableism in reference to Wolbring’s work. This is a term that I have adopted as well, but I cannot find a direct source for it. Wolbring rather speaks of a “transhumanization of ableism” as an intensification of modernist norms of capacity and performance through transhumanist discourses and practices. This is what is captured under the term “hyper-ableism.” See Gregor Wolbring, “Expanding Ableism: Taking Down the Ghettoization of Impact of Disability Studies Scholars,” *Societies* 2, No. 3 (2012): 75-83; Gregor Wolbring, “Human Enhancement Through the Ableism Lens,” *Dilemata*, Vol. 2 (2010), 1-13; Gregor Wolbring, “The Politics of Ableism,” *Development* 51 (2008): 252-58; Gregor Wolbring, “Is there an End to Out-Able? Is There an End to the Rat Race for Abilities?” *Journal of Media and Culture* 11, No. 3 (2008): <https://journal.media-culture.org.au/index.php/mcjournal/article/view/57>

²²¹ Nick Bostrom, “A History of Transhumanist Thought,” *Journal of Evolution and Technology* 14, no. 1 (2005), 3: <https://jetpress.org/volume14/bostrom.pdf>

life (through Darwin’s great discovery) we are finally able to manipulate our very nature (for the better)²²²—in fact, it is our responsibility to do so.²²³ In general, this *instrumentalization* of knowledge has imbricated general historical progress—with all its ethical and social implications—with scientific progress.²²⁴ In this, transhumanists see opportunity and responsibility to push the limits of knowledge in order to overcome our inherent human frailty as well as our socio-political failings. I made the claim, in Part 1 of this dissertation, that modernist ideas of man continued to pervade the social and intellectual climate of the social sciences today; however, nowhere is it more direct and dogmatic than in the transhumanist line of thought. In fact it serves as a foundational assumption to the entire enterprise. In speaking about modernity and techno-science specifically, Michael Burdett calls this tendency the ‘myth of progress,’ not because it is opposed to truth or rests on a supernatural narrative (it does not), but because it serves the function of a myth—a foundational narrative that glues together the scientific worldview.²²⁵ According to Burdett, “Transhumanism radicalizes this myth of progress. It asserts that not only does technology

²²² e.g. “*Transhumanist Declaration*,” Humanity+, February 22, 2021, <https://humanityplus.org/transhumanism/transhumanist-declaration/>; Nick Bostrom and Anders Sandberg, “The Wisdom of Nature: An Evolutionary Heuristic for Human Enhancement,” in *Human Enhancement* (Oxford: Oxford UP, 2008), 375-416; Ray Kurzweil, *The Singularity is Near; When Humans Transcend Biology*, (New York: Viking Press, 2005).

²²³ E.g. Julian Savulescu, “Procreative Beneficence: Why we Should Select the Best Children,” *Bioethics* 15, no. 5 (2001): 413–426; Julian Savulescu, “New Breeds of Humans: The Moral Obligation to Enhance,” *Ethics Law and Moral Philosophy of Reproductive Biomedicine* 1, no. 1 (2005): 36–39; John Harris, *Enhancing Evolution; The Ethical Case for Making Better People* (Princeton: Princeton University Press, 2007).

²²⁴ Henryk Skolimowski, “The Scientific World View and the Illusions Progress,” *Social Research* 41, No. 1 (1974): 54ff.

²²⁵ Michael Burdett, “The Religion of Technology: Transhumanism and the Myth of Progress,” in Calvin Mercer and Tracy Trothen (eds.), *Religion and Transhumanism: The Unknown Future of Human Enhancement*, (Connecticut: Praeger, 2014).

transform society and the economy for the better, but also individual human experience can be affected directly through bodily enhancement.”²²⁶ Transhumanism takes the Cartesian idea of being “master and possessor” of the world and turns it inward to the human being itself. They formalize the tendency to want to master the laws of nature into a guiding principle to modify and create man in the image of unrestricted possibility.

This radicalization can be traced in the work of authors like Ray Kurzweil who identify the progression of technological advancement with a natural process (with which we participate) on par with evolution—both on a human and cosmic scale.²²⁷ In the technology and industry sectors, the myth of progress is illustrated more concretely in the overall tendency to express trends in technological advancements in the form of scientific Laws, e.g. Moore’s Law (i.e. that transistor density doubles every two years); Eroom’s Law (that pharmaceutical discoveries double in cost every 9 years); Gilder’s Law (that bandwidth grows three times faster than improvements in computing power); Koomey’s Law (that the amount of battery power needed for the computation of a fixed operation decreases by a factor of two every 1.5 years); to name only a few. The same tendency existed in economic discourses that sought to naturalize market forces and global finance in the 19th and 20th centuries. To simplify, there is a certain dynamic at play here, one that unquestionably believes that we are gaining *better* truths about the world, that they do and will continue to lead to technological advancements, that these advancements inevitably lead to social/human

²²⁶ Ibid., 142.

²²⁷ Re. Ray Kurzweil, *The Singularity is Near*. In this work, Kurzweil maps the history of science onto the history of our species in a series of 6 phases. The first being our discovery of chemistry and physics, and the last being the spread of artificially intelligent matter all over the universe.

progress, and that the progression of our species towards something greater (the transhuman horizon or the singularity) this is wholly natural or self-propelled. Many aspects of this are problematic, but most relevant is that the re-imagined (and imaginary) posthuman that is created brings with it the assumption of what is desirable and what will—naturally—have to disappear from our species.

To bring it back to what Wolbring calls hyper-ableism, we see pronouncements from transhumanists such as “Fifty years out, I think we will have largely eliminated disability”²²⁸ and Kurzweil’s wide-ranging predictions in 2003 that,

By 2010, computers will disappear. They will be so tiny that they will be embedded in our environment, in clothing, and so on. [...] For people who are hearing impaired, we will have systems that provide subtitles around the world [...] For people who are blind, we will have reading machines [...] you will be able to wear them on your lapel and scan in all directions [...] The Food and Drug Administration just approved a neural implant for Parkinson’s disease that replaces the portion of the brain destroyed by that disease [...] by 2029, we will be able to send these intelligent devices through the bloodstream. [...] With the full flowering of the biotechnology revolution, within 10 years, we will be adding more than a year to the live expectancy every year. So if we can hang in there for another 10 years, we may actually get to experience the full

²²⁸ Hugh Herr, quoted in Eliza Strickland, “We Will End Disability by Becoming Cyborgs: Neural Interfaces and Prosthetics will do away with Biology’s Failings,” *IEEE Spectrum* (May 27th 2014): <https://spectrum.ieee.org/biomedical/bionics/we-will-end-disability-by-becoming-cyborgs>

measure of the profound century ahead.²²⁹

This type of reasoning illustrates quite a few assumptions: (1) that progress is linear and rapid, (2) that disability will be eliminated by the course of technological development as a matter of course, and (3) that human life itself will be profoundly changed by technological progress. Making an assumption based on the history of how technologies are rolled out, however, we can see that thinkers like Kurzweil live in a warped reality where possibility is reality. Given the rate and breadth of technological advancement, it seems to be simply ‘a matter of time.’ The profound issue with this is that these technologies, even the ones that do exist, are by no means widely distributed. They represent what can be done at the limit, within resource rich context with privileged stakeholders. What is important, from our perspective, is the skeleton of such an argument: 1) disability is a problem, 2) technology solves problems, evidenced in all of these examples of solved problems, 3) technology will solve the problem of disability. Even if we accept #2, we can object to the characterization in #1 on the grounds that it is simplistic and founded on shaky socio-historical grounds, and #3 on the grounds that a possibility does not ensure practical success; humane solutions, wanted interventions, equitable distribution, etc. Moreover, it is dominated by the idea that we can generalize the successes of the past to any future issue that presents itself, i.e., that progress is linear and without limit.

The myth of progress is illustrated most plainly, is the conclusion of the introductory section of his paper, where while discussing the eventual collapse of Moore’s law (because

²²⁹ Ray Kurzweil, “The Future of Intelligent Technology and Its Impacts on Disabilities,” *Journal of Visual Impairments & Blindness* 97, No. 10 (2003): 583-84.

of physical constraints) he says, “will it be the end of Moore’s law? Perhaps—but other paradigms *will* emerge that hold even *greater* potential.”²³⁰ There is no room for ambiguity, progress *will* continue, and it will continue to grow in its benefit to mankind. Even more uncritical is this instance, in an interview, where he states that in the merging of man and machine—which he thinks will inevitably happen and without much problem—that there is consensus that scientific progress in this direction is desirable: “People focus on our differences and talk about culture wars, and yes, there are certain issues that divide us. But what we all agree on is actually much more pervasive than what we disagree on. This includes a belief in progress.”²³¹ This is certainly true in the transhumanist circles, and arguably in the general scientific community, but it is not universally true in academia (which includes post-modernist, deconstructionists, and posthumanists who directly oppose this idea) and even less so in Disability Studies and other disciplines that necessarily need a more critical attitude toward technology and technological progress. This does not mean that Disability Studies or posthuman Disability Studies is necessarily Luddite or bio-conservative. Much to the contrary, thinking through disability means engaging with current and potential developments in bodily and sensory technologies, however, it must do so from a critical, anti-ableist, and politically useful way. If we want to explore body modifications—therapeutic or enhancing—we ought not proceed without taking into account the experience and historical applications of techno-medicine to disability.

²³⁰ Ibid., emphasis added.

²³¹ Ray Kurzweil and Aaron M. Cohen, “Merging With the Machines: Information Technology, Artificial Intelligence, and the Law of Exponential Growth; An interview with Ray Kurzweil,” *World Future Review* 2, No. 2 (2010): 59.

Critical engagement in Disability Studies and technology has come in many forms, but it remains under-developed and much too narrowly read outside the discipline itself. For some time now authors have engaged in thinking around cyborgs and cyborgism²³² and posthumanism proper,²³³ as well as significant controversies involving Christopher Reeves' transhumanist activism (and the use of disability narratives in transhumanism in general)²³⁴ and the controversy surrounding Oscar Pistorius' inadmissibility into the Olympics for "techno-doping."²³⁵ The most significant contribution to this literature is the work of

²³² See for e.g. Margaret Quinlan, and Benjamin R. Bates, "Unsmoothing the Cyborg: Technology and the Body in Integrated Dance," *Disability Studies Quarterly* 34, no. 4 (2014): no pagination; Alison Kafer, "The Cyborg and the Crip," in *Feminist, Queer, Crip* (Indiana UP, 2013), 103-128; Donna Reeve, "Cyborgs, Cripples and iCrip: Reflections on the Contribution of Haraway to Disability Studies," in Dan Goodley, Bill Hughes, and Leonard Davis (eds.), *Disability and Social Theory*, (Palgrave Macmillan, 2012), 91-111; Dan Goodley, "Developments: Critical Disability Studies," in *Disability Studies and Interdisciplinary Introduction*, 157-175; Ingunn Moser, "Against Normalisation: Subverting Norms of Ability and Disability," *Science as Culture* 9, no. 2 (2000): 201-240; Ingunn Moser, "On Becoming Disabled and Articulating Alternatives: The Multiple Modes of Ordering Disability and their Interferences," *Cultural Studies* 19, no. 6 (2005): 667-700.

²³³ Griets Roets, and Rosi Braidotti, "Nomadology and Subjectivity: Deleuze, Guattari and Critical Disability Studies" in Dan Goodley, Bill Hughes, and Leonard Davis (eds.), *Disability and Social Theory*, (Palgrave Macmillan, 2012), 161-178; Dan Goodley, *Dis/ability Theory: Theorising Disablism and Ableism* (New York: Routledge, 2014); Dan Goodley, Rebecca Lawthom, and Katherine Runswick-Cole, "Posthuman Disability Studies," *Subjectivity* 7, no. 4 (2014): 342-361; Dan Goodley, and Katherine Runswick-Cole, "Becoming Dishuman: Thinking about the Human Through Dis/ability," *Discourse: Studies in the Cultural Politics of Education* 37, no. 1 (2016): 1-15; Dan Goodley, Kirsty Liddiard, and Katherine Runswick-Cole. "Feeling Disability: Theories of Affect and Critical Disability Studies," *Disability & Society* 33, no. 2 (2018): pp.197-217; Kristy Liddiard, Sally Whitney, Katy Evans, Lucy Watts, Emma Vogelmann, Ruth Spurr, Carrie Aimes, Katherine Runswick-Cole, and Dan Goodley, "Working the Edges of Posthuman Disability Studies: Theorising with Disabled Young People with Life-Limiting Impairments," *Sociology of Health and Illness* 41, no. 8 (2019): 1473-1487; Wolbring, "Expanding Ableism,"; Wolbring, "Human Enhancement Through the Ableism Lens"; Wolbring, "The Politics of Ableism."

²³⁴ See for e.g., Dan Goodley, *Dis/Ability Studies*, 23-26; Elisabeth Scherman, "The Speech that Didn't Fly: Polysemic Readings of Christopher Reeve's Speech to the 1996 Democratic National Convention," *Disability Studies Quarterly* 29, No. 2 (2009): no pagination; Gerard Goggin, and Christopher Newell, "Fame and Disability: Christopher Reeve, Super Crips, and Infamous Celebrity," *Media and Culture Journal* 7, No. 5 (2004).

²³⁵ E.g., Jeré Longman, "An Amputee Sprinter: Is He Disabled or Too-Abled?," *NY Times*, (May 15th 2007); Silvia Camporesi, "Oscar Pistorius, Enhancement and Post-humans," *Journal of Medical*

Goodley and his colleagues who do attempt to connect their insights to a general posthumanist framework (primarily Braidotti and contemporary uses of Deleuze) as well as Wolbring and colleagues who approach the challenges of disability and technology as a bioethical and empirical phenomenon. I will be using these insights and understandings and applying them to specific posthuman problematics. The goal is to ground them in the model of posthuman responsibility developed in Part 1, and ground these critical dis/ability insights in an explicitly critical posthuman framework.

0.1 Situating Critical Posthumanism

Before I move on, it may be useful to engage with a taxonomy of posthumanism proposed by Tamar Sharon in order to situate the general landscape of the perspective to be explored here. In her book *Human Nature in the Age of Biotechnology*, Sharon classifies posthuman philosophies on three general axes: The first being pessimistic v. optimistic, the second being historical materialist v. philosophical-ontological, and the third being humanist v. non-humanist.

With respect to Sharon's first axes, I focus on the general disposition of different posthuman perspectives, mainly on two points: the possibilities or dangers inherent in the disappearance or elimination of the 'human' and on the person-technology relationship. In other words, is the posthuman turn a good thing, does it open up possibilities, or does it

Ethics 34, No. 9 (2008): 639; Thomas Corrigan, Jamie Paton, Erin Holt, and Marie Hardin, "Discourses of the "Too Abled": Contested Body Hierarchies and the Oscar Pistorius Case," *Human Kinetics Journal* 3, No. 3 (2010): 288-307; Gregor Wolbring, "Paralympians Outperforming Olympians: An Increasing Challenge for Olympism and the Paralympic and Olympic Movement," *Sport, Ethics and Philosophy* 6, No. 2 (2012): 251-266; Gregor Wolbring and Jeremy Tynedal, "Pistorius and the Media: Missed Story Angles," *Sports Technology* 6, No. 3 (2013): 177-183.

negate the value of the individual? More concretely, it is where I can start to evaluate the relationship to technology. On one end of the spectrum we have the bioconservatives who see in biotechnology a real danger of eclipsing human dignity and moral right.²³⁶ On the other end, we have those perspectives that do see in technological advancement some possibilities for positive change (ethical, political or material). We have already discussed the transhumanists Bostrom and Kurzweil here, but we can add Haraway and Braidotti too. Though on the side of the transhumanists (which Sharon calls ‘liberal posthumanism’) we see arguments that favour the ethical responsibility to enhance and improve ourselves using technology, while on the side of critical posthumanism we find radical potential in the ability of technology to deconstruct modernist dichotomies in favour of more fluid political alliances and human ontologies (i.e., a non-humanist statement of ‘what we are’). While these two positions are incompatible, they do share a general sense of optimism. It is on this pole, the optimistic pole, that I argue we ought to place critical dis/ability.

It may seem like there might be a possible convergence between transhumanism and critical posthumanism on the question of technology, given that they are both on the optimistic side of the spectrum. However, where they become quite different is in their position on the second and third axes. On the second axes, Sharon places historical-materialist perspectives on one end, and philosophical-ontological perspectives on the other. On the far end of the spectrum we find radical posthumanism (roughly what I have termed

²³⁶ Francis Fukuyama, *Our Posthuman Future: Consequences of the Biotechnology Revolution* (New York: Farrar, Straus and Giroux, 2002); Francis Fukuyama, “The World’s Most Dangerous Idea,” *Foreign Policy* 144, (2004); Leon Kass, “Ageless Bodies, Happy Souls: Biotechnology and the Pursuit of Perfection,” *The New Atlantis* 1, (2003): 9-28; Michael Sandel, *The Case Against Perfection* (Cambridge: Harvard University Press, 2009).

critical posthumanism), and on the other liberal (transhuman) and methodological posthumanism. As mentioned above, posthumanism can be seen as a historical period (by transhumanists and methodological posthumanists alike) or as a critical reaction to a historical way of thinking (as we see in the radical posthumanism of the Braidottians). To place the current work on this axis is a bit difficult. The primary purpose of Sharon’s book is to show how “mediated posthumanism” may be a better perspective than either methodological or radical posthumanism as separate entities. We can already point out a particularity in the current perspective that I have been developing in Part 1 that places us in the middle of this axis. As I have argued, the mutation of normalizing strategies towards two radical forms of self-regulation untethered to natural/human limiting categories have already pushed us towards posthumanism in socio-political terms. We have also seen how in historical and philosophical terms the “Others” of modernity never participated in the category of human anyways—women, racialized populations, colonized populations, the mad and the disabled. They were always excluded and so, their ways of being and living shows us, in ethical and political terms, some possibilities for living a posthuman life. Further still, they show us something about what *being* posthuman is; there is an ontological dimension that is revealed in what some have called the “new materialisms” or the materialist turn.²³⁷ I will not engage in the latter at great length, but what I will show in

²³⁷ See for e.g., Karen Barad, “Posthumanist Performativity: Toward and Understanding of How Matter Comes to Matter,” *Journal of Woman in Culture and Society* 28, No. 3 (2003): 801-831; Rick Dolphij, and Iris van der Tuin (eds.), *New Materialism: Interviews and Cartographies* (Ann Arbor: Open Humanities, 2012). In Disability Studies proper: Sarah Reddington, and Deborah Price, “Pedagogy of New Materialism: Advancing the Educational Inclusion Agenda for Children and Youth with Disabilities,” *Disability Studies Quarterly* 38, No. 1 (2018): no pagination; Susan Flynn, “Engaging with Materialism and Material Reality: Critical Disability Studies and Economic Recession,” *Disability & Society* 32, No. 2, (2007): 143–59; Michael Feely, “Disability Studies after

Chapter one of Part 2 is that technology does not *change* us in the sense that we become (or are becoming) something different, but that an aspect of our ontology is *revealed* through a disability informed posthuman reflection on technology. The most obvious point of convergence in both, and its greatest distance from transhumanism, is reflected in the third axis; namely, humanist and non-humanist perspectives.

Even though transhumanists want to surpass the limits of the human, they are not anti-humanist in the conceptual sense. The category of the thing that needs to be surpassed, the human remains important and foundational. In fact, it is more properly seen as a continuation or an intensification of these; *ultra*-modernism, *hyper*-ableism, and a post-*human*. I think we can, without much difficulty, expand this axis to include the related dichotomies of modernist and anti-modernist as well as ableist and anti-(or critical)-ableism perspectives. Where transhumanism redoubles the efforts, critical posthumanism is inherently grounded in these three great rejections—the human, modernity, and ableism. It will be the goal of the following set of chapters to develop and ground the insights of critical disability and ability research into a farther-reaching posthuman framework. Before we move onto that, however, we will engage with transhumanism a bit more to show why it cannot simply be circumvented, but has to be taken on by critical disability and posthumanist positions.

the Ontological Turn: A Return to the Material World and Material Bodies without a Return to Essentialism,” *Disability & Society* 31, No. 7, (2016): 863–83.

0.2 Grounding Ourselves in Disability Insights

The connection between genetic treatment, genetic enhancement, and transhumanism is a very important but contentious one. The clinical applications of genetic technologies have become one of the central issues of our time. Often, these technologies are criticised as introducing a slippery slope towards eugenics and likened to a new form of Nazism by bioconservative thinkers. These critiques often fail to be convincing because they are bogged down by polemics and dystopian sci-fi fantasy. They appeal only to other bioconservatives and contribute almost nothing to our understanding. On the other side of the spectrum, many bioethicists contend that preventing disease and suffering are not a eugenic goal. By limiting themselves to therapeutic (not enhancing) applications they claim to not risk going down the slippery slope towards eugenics. As I will argue in the upcoming chapter, though it is more sophisticated than the bioconservative argument, in the absence of a clear delineation between therapy and enhancement it fails to set a reasonable limit. Going a bit further, transhumanists generally do promote the idea that we ought to enhance humanity beyond therapeutic limits, but they never—at least I have not encountered one—promote the idea of large-scale elimination of undesirables and forced enhancement of the masses. None of them are wrong in distancing themselves from traditional eugenics; however, when one looks below the surface, one finds many eugenic undercurrents conceptually and practically. I find bioconservative arguments unsatisfying, because they do not go below the surface and only argue against very obviously problematic practices or imagine a danger that is at most not inherent. I will return to issues specific to traditional bioethics in coming chapters, but will see that in application, many practitioners and thinkers in this sub-discipline are influenced by transhumanist thought and vice-versa. Of primary importance, and what I will turn to now, is the discourse from transhumanism.

Transhumanism is a deeply individualistic endeavour that promotes personal choice and liberty. In a neoliberal western society, this serves as a kind of magic prophylactic against the ethical and political dangers of advanced biotechnologies. Large scale implications for society, and diffuse coercive mechanisms, are systematically ignored because the moral status of free choice and the social good (future of humanity) serve as satisfactory foundations for arguments for or against a given novel intervention. Moreover, what makes transhumanism so dangerous is the optimism with which they project their sci-fi visions into the future, not the act itself. This more general projected goal of transhumanism (a better future) places ethical justification and/or self-righteousness in the realm of quasi-plausible imagination as opposed to a reasonable extrapolation of the current state; but it functions in many discourses because it resonates quite deeply with the stated goals of science that came out of modernity.

In fact, as critical and grounded as bioethics may appear in practice, the influence of transhumanism in its most general sense holds a great deal of power. The word technoscience, which has become quite common in its usage, was coined by a bioethicist in 1976 where it appeared alongside transhumanism. For Hottois, the possibilities that technology opened up pushed both science and bioethics into a new frontier not adequately covered by the established philosophical and theological currents of the time.²³⁸ From Christianity to Marxism, man was to find some terminal point at the end of a historical journey. Technoscience was a disruptive force in this neat trajectory. As he put it, “modern science, the technosciences are ‘science fiction’ if we consider the etymology of the word

²³⁸ Gilbert Hottois, “Defining Bioethics; Back to the Sources,” in Darian Meacham (eds.), *Medicine and Society, New Perspectives in Continental Philosophy* (New York: Springer, 2015), 29.

‘fiction.’ The Latin word *ingere* originally signifies ‘to fashion, to physically shape, to fabricate.’ It is in a secondary sense that it means ‘to represent,’ ‘to imagine.’”²³⁹ In this sense, we do live in a world of science fiction, “a world fashioned by science turned technoscience.”²⁴⁰ This idea of technology as a means of opening up possibilities and as a tool for *world-making* will be central to the posthumanism I will discuss here.

Transhumanism, posthumanism, bioethics, and technoscience (technomedicine included) all take place in their own little corner of this common clearing. They all attempt to think through the possibilities of novel technological development, but with very different forward looking aims. Certainly, bioethical discussions or practical questions about what a novel technology can do have value. However, the question we need to ask is, in what discourse do we ground our vision of the future? Do we simply trust in the infallibility of linear progress and let the cards fall where they may, as the transhumanists do? Do we speculate on the possibilities emerging from technoscience for achieving greater and greater degrees of ‘the good’ and of ‘the right’ at the cost of more mundane but immanent socio-political solutions and visions? Or, do we ground the vision of technoscience in the empirical reality of marginalised populations such as people living with disabilities among others?²⁴¹ I would argue the latter, especially in the biogenetic sciences, where the idea of acceptable

²³⁹ Gilbert Hottois, “Bioéthique, technosciences et transhumanisme,” in Emmanuel Hirsch, François Hirsch (eds.), *Traité de bioéthique* (Toulouse: Éditions Érès, 2018), 464.

²⁴⁰ Ibid.

²⁴¹ See here the clear ethical vision, to be discussed later, of Aimi Hamraie and Kelly Fritsch in “Crip Technoscience Manifesto” *Catalyst: Feminism, Theory, Technoscience* 5, No. 1 (2019): 1-34.

life—which so often has dismissed the voices of disability—is precisely the battle ground for future-making imaginaries.

If we take the technology itself as the starting point, we are cultivating visions that do not correspond to the lived reality and needs of people who would benefit. That is, the technology is not the means through which we may expand the possibilities of life given the challenges of our current situation, but the means to envision an ideal life and correct the issues we encounter to fit that ideal. Though the vision comes from us, what drives that vision is a belief in an external telos of scientific progress. Especially obvious in transhumanist visions, our task with relation to technology is to clear the way, or actively bring about, a version of society that is given in the nature of science and progress itself. Much like one would try to bring about a religious vision expressed in some scripture, there is a sense of detachment from practical concerns with a self-righteousness that comes from participating in some truth bigger than ourselves. In its less extreme version common in technoscientific optimism, all identified problems are seen as primary candidates for technological intervention. It imposes a limitation in the field of vision for many, even those whose intentions are without reproach. The core issue with this is that technology is developed, applied, or proposed from a top down and detached re-imagining of society, one that idealises the optimization of bodies and the maximization of their capacity. Alternatively, finding our ground in the immanent concerns of people, especially those at the margins, can give us a more adequate view of technoscience. It can justify a legitimate optimism for its impact on our future, but a sober appraisal of its failures as a singular approach, as well as its role in maintaining inequities.

When one uses technologies to overcome disability in a general vision of the future, there is a reductive tendency to simply match impairment in certain categories of function (e.g. mobility, perceptive, cognitive, etc.) with types of potential technologies. In the implementation, however, there are always practical issues that need to be overcome. One might need to modify the living or working environment to accommodate the technology, likely medical (or technician) follow-ups are needed and regular maintenance required, there might be a learning curve for those using the technologies, the given technology may only address part of the disability or condition; moreover, they might not address issues of discrimination, they may not address one's most pressing needs, and there are questions about affordability and access. Medical engineers and technicians certainly grapple with some of these considerations, and consultation with end users is typically part of the process. The argument I am advancing here is broader. What I perceive in the writings of transhumanists and technophiles is that certain high level of biotechnology is unproblematically part of the imagination of the future, and it is assumed that all other related issues are secondary and solvable (later). What I argue here is that this ought to be reversed. Prioritization of biotechnologies based on needs, consultation about how biotechnologies might be implemented or further developed, provisions for access and affordability of the technology and its associated maintenance, a revision of how these would impact governmental responsibility and the administration of social benefits, among other arising concerns. Potential biotechnologies are exciting, and rightfully so, but they have to be supplemented by a general strategy that would avoid the pitfalls and deficits of our current systems. I do not take issue with the optimism, and I do not suggest that advanced biotechnologies ought not be part of our future; I have a positive view of advanced technology, and I think their

substantial impact on the future is inevitable. I make the assertion that a singular focus on the latter nearly guarantees that it will not succeed in improving the general or global approach to disability.

In what is a very insightful and practical statement, Tom Shakespeare recently wrote, “when it comes to envisioning futures, fantasies are not a reliable guide. We need grounded, balanced, and immediate understandings. Disability research can offer us this corrective.”²⁴² One such corrective to the scale of transhumanist imagination is the idea of reach and access. If we find a way to enhance humanity through genetics to offer everything from disease resistance to enhanced cognition, it would be foolish to think that these technologies would be equitably distributed globally. Having worked on the WHO’s World Report on Disability and having been in the field almost a quarter decade, Shakespeare is well acquainted with the disparities in access to assistive devices and care. As he states, “in the context of low and middle-income countries, the solution is not the iBot, the futuristic power chair which lifts the owner to make eye contact, and enables them to negotiate stairs and other obstacles (cost \$25,000). The solution is the Motivation basic wheelchair (cost \$200).”²⁴³ Technology gets cheaper, one could argue: As the market corrects, the high tech devices will become more affordable and widely distributed. This argument is weakened, however, by the practical fact that “only 5-15 percent of disabled people worldwide have access to the assistive devices they need—and this refers to simple gadgets such as hearing aids, wheelchairs, crutches, and

²⁴² Tom Shakespeare, “Foreward: Five Thoughts About Enhancement,” in Miriam Eilers, Katrin Grüber, and Christoph Rehmann-Sutter (eds.), *The Human Enhancement Debate and Disability; New Bodies for a Better Life* (New York: Palgrave Macmillan, 2014).

²⁴³ *Ibid.*, Location 134. No pagination.

prosthetic limbs.”²⁴⁴ This directly goes against the belief that developments in biotechnologies are the solution to large-scale social problems. In fact, this seems to only be the case when people with privilege concerns are able to capitalize on a given technology, or when a direct and measurable economic value can be derived from the intervention. This is by no means surprising, but it ought to legitimately give us pause to think that any vision of the future that claims a desire to eliminate suffering or enhance quality of life through technology (its ethical pretext) has the means to singularly do so without being accompanied by a radically different value system than our own. We are reminded here, that no such radical re-imagining is taking place, and that in transhumanist discourses we see an explicit re-affirmation of individualistic liberal values passed down from modernity. Given that the general value framework of transhumanism is the same as modernism, its ableist dimensions and what they identify as problematic is not likely to promote the idea that genetic technologies ought to be equitably distributed any more than current low-tech prosthetics are equally distributed based on need.

Emblematic of concerns over ‘top-down’ applications of technology is the fast-evolving field of human genetic intervention. In this technology, we see the historical result of being at once an afterthought in the reimagining of human society, and a targeted problem of the technology under development. This field of research is the source of many idealised future visions of man, but are also the source of counter horror-fantasies that likewise need to be grounded if we are to salvage anything from genetics. Thinking through the often

²⁴⁴ Ibid.; “Assistive Technologies,” *World Health Organization*, “Section: Unmet Global Need for Assistive Technologies,” no pagination: <https://www.who.int/news-room/fact-sheets/detail/assistive-technology>

dystopian idea of a two-speed society, one where the unenhanced would be subhuman and the enhanced the masters of the world, we can begin to disentangle actual dangers from alarmist overreactions. The two-speed society exists in actual terms, and further technological advancement in the area of human genetic enhancement is likely to widen these disparities—within our own national borders and globally as well. However, genetic technologies are not inherently bad, they are a tool like any other that may have the potential to improve or enhance us in desirable ways. The issue is the context within which they are developed. Who has a say in what is needed or what is to be prioritized, and what kind of society would allow for just application/distribution of a given genetic intervention. Sadly, in both cases, on its current course a society such as ours all but guarantees suppression and inequity at best. Being grounded in the margins makes it clear that any discussion of the value or appropriateness of technology—genetics in this case—is full of related discussions and challenges to peripheral norms that are already established. As a result, any discussion of the future is going to be much more complex and involve much more change than what is limited to the ethical concerns of a given technology. For some up stream concerns over what would facilitate different kinds of lives falls out of scope, while for others they are the only concern and genetic technologies are to be rejected outright.

Chief among things that need to change is the value we place on the lives of people with disabilities. This goes beyond ‘awareness’ raising (often tied to fundraising), but of a real deconstruction of what we have considered a valuable person for millennia (from the Greek ideal of rational man to the liberal citizen of the European enlightenment). As we have seen in Part 1 of this current work, disability, madness, and illness are all counter-examples to what is considered desirable and so are undesirable by default. Fears around a developing

eugenics are most often coming from this point of view; i.e., not who will have access to enhancement, but what kinds of lives do we want to prevent? Again, these fears are often grounded in sci-fi fantasy about designer babies who will surpass our abilities beyond what is fathomable, making the idea of a ‘natural’ child squarely unethical.²⁴⁵ In fact, some authors suggest that there may even come a time where natural birth may be outlawed on the grounds that it is a crime against the child-to-be.²⁴⁶ I could add to this, all those dystopian fears about failed enhancements that would cause all sorts of monstrosities and destruction often seen in our fictional works around this issue. What we know, though, about the current state of genetic screening is that there is already an established tendency towards termination,²⁴⁷ and the explicit opinion by some ethicists that this *ought* to be the case.²⁴⁸ In the latter, disability is unequivocally and objectively something to be avoided. I do not wish to engage the entire abortion debate here, as this would require a lengthy discussion that would detract from the main point. What I do want to point to is that a) some aspects of disability *do* cause suffering, and b) parents are well within their rights, and are acting in a morally defensible way, if they proceed to an abortion to avoid said suffering. What I would add, as a consideration, is that the perception of suffering in many cases is amplified by

²⁴⁵ Eg. Carl Shulman and Nick Bostrom, “Embryo Selection For Cognitive Enhancement: Curiosity or Game-Changer” *Global Policy* 5, No. 1 (2014): 85-92.

²⁴⁶ E.g., Laurent Alexandre, *La guerre des intelligences: Intelligence artificielle vs intelligence humaine* (Paris: Lattès, 2017), 194ff.

²⁴⁷ As discussed in a previous chapter, the identification of a genetic mutation causing Down’s Syndrome leads to termination of pregnancy in 60-93% of cases.

²⁴⁸ Eg. Peter Singer, *Practical Ethics* (Cambridge, Cambridge UP, 2011), 160-67. In a more limited case, “procreative beneficence” justifies this as long as the socio-political as well as biological conditions would lead to a sub-optimal existence: see, Savulescu, “Procreative Beneficence,”; Julian Savulescu, and Guy Kahane, “The Moral Obligation to Create Children With The Best Chance Of The Best Life,” *Bioethics* 23, No. 9 (2009): 274–90.

uncertainty or ignorance, and the source of this suffering is not always objectively discernable. In a society where the positive aspects of disabled lives, and robust social systems that support them are in place, the decision is not always so one sided. In many cases, what is perceived as comprehensive suffering from the outside is experienced as isolated aspects of discomfort, frustration, or pain in an otherwise normal life. We will return to the subjective aspects of normativity in Chapter 2.

Outside of the limited discussion of genetic disability, I posit that a life free of suffering is not the norm. Acquired disability, disease, trauma, and aging are part of the human condition. In order to move forward in showing how disability can ground our vision of the future, we cannot begin from an assumption that the alternative is the absence of pain and suffering. From this perspective, one can ask what will happen when a) screening technologies allow us to identify many more ‘sources of suffering’ (e.g. predisposition to cancer, heart disease, diabetes, dementia, autism, addictions, etc.), and if b) the benchmark for unacceptable forms of suffering changes as current ‘norms’ are substantially surpassed. The former problematizes a great deal of us now, and the latter, likely a great deal more into the future. The former, I suggest, is a reflection that all lives have the potential for suffering, and the latter that social support structures and privilege substantially contextualizes this suffering. This is so far very abstracted, but it is the same mechanism we see in the real case of genetic screening for disabilities and IVF practices.

This is not an alarmist slippery slope, but the reasonable extension of what may result from a changing principle of fitness within a framework of parental responsibility for risk avoidance. The principle of a responsibility to parents to select children likely to have the best life is intuitive, as the empirical evidence of the termination rates from prenatal

screening shows. Understandably so, wanting to avoid causing (or allowing) suffering is minimally altruistic. However, this is only so intuitive if the alternative is no suffering at all. If we put aside the cases of disability, I argue that many forms of pain, discomfort, and suffering are ubiquitous in human life. If we have the ability to screen for some sources of these, do we not have the responsibility to avoid those births as well? We recall the earlier discussion of Rose where he reminds us that we are all potentially pre-symptomatically ill, all harbouring in our genetic code a myriad of mutations associated with countless potential diseases and disabilities.

As I have argued here, these will go beyond the limited cases that are typically discussed. As technology improved, the category of avoidable suffering is poised to expand. The category easily accommodates already problematic lives (e.g. predisposition to madness or addictions), and potentially to other undesirable conditions (e.g. predisposition to cancer or cardiovascular disease). Even further we can imagine a society where perfectly acceptable levels of performance are problematic. For example, a society of enhanced intelligence where today's norm would itself be considered inadequate and debilitating. Without engaging in the latter, which is an unlikely projection, I claim that the problem already exists today. The technology to screen *in vitro* and *in vivo* is increasing alongside our understanding of genetic diseases and predispositions. This creates an ethical responsibility and choice.

We have various ways of addressing this. The slippery slope towards eugenics is a common argument in bioconservative critiques of transhumanism,²⁴⁹ but it typically rests on some form of moral decay or transgression of some natural (or religious) characteristic inherent to human life. I do not find this perspective convincing for many reasons implied in our discussion throughout this dissertation. What we are left with, then, is some moral calculation about what is acceptable and desirable when evaluating the results of screening technologies. I think this level of reflection and deliberation *is* what is required. I likewise acknowledge that transhumanists and bioethicists engage with this question at this level. The argument from the perspective I have been developing here, however, is that this deliberation is skewed, and that there are a certain number of social changes that have to occur for it to be accurate. It has to take place within the framework of suffering being part of the human condition (i.e. that there is no mythical zero); that the baseline variation of human embodiment cannot be measured by a fixed idealized standard; that our understanding of the sources and level of suffering are informed by actual situated experience (to be discussed in Chapter 2); and that that non-biological factors that give rise to suffering are given precedence for intervention (because their impact is greater and they are a prerequisite for a just deliberation).

On the latter, optimism for biotechnical problem solving only works in conjunction with social, political, and economic problem solving. If it narrowly engages only scientific optimism, it ignores more effective and practical means to reduce suffering that will still need to be addressed in that imagined future. Genetic technologies will not be the focus of

²⁴⁹ Fukuyama, *Our Posthuman Future*; Sandel Michael, “The Case Against Perfection: Ethics in the Age of Genetic Engineering,” (Cambridge: Harvard University Press, 2007).

our broader discussion about technology and embodiment; however, it plays an important role in framing the overdetermination of disability in the transhumanist and liberal biotechnophilic imagination more broadly. My argument is that a singular focus on technology leads one to extrapolate general solutions from narrowly beneficial technologies, and that the idealised human abstraction that transhumanists are working with does not reflect the reality of the human condition *in its milieu*.

To its credit, transhumanism's commitment to freedom of choice shields it from the worst dystopic predictions of state-enforced eugenics like we saw in the 1940s. The foundational individualism inherent in transhumanism is a problem in some cases, but it is a guardrail against broadly enforced eugenics. It is not compatible with Nazism in this respect, and it should not be suggested that it is. The kind of eugenics I am describing is something wholly new, one that rests on personal choice and a biopolitics of desirability. Some form of deliberation about intervening on life is unavoidable, and we can call this eugenics. We have to be careful, though, to not present this as a straw man. We will see below how it might share some problematic aspects with the 'old' eugenics, but it is in many respects qualitatively different.

As Snyder and Mitchell argue, Nazism did not have an exceptional view of the fit subject; it was a political application of the desirable subject presupposed in modernist discourses.²⁵⁰ Transhumanism is an "outgrowth" of the enlightenment and humanism,²⁵¹ but

²⁵⁰ Sharon Snyder, and David Mitchell, *Cultural Locations of Disability*, (Chicago: Chicago UP, 2006) quoted in Hall, *Bioethics of Enhancement*. See Snyder and Mitchell, *Cultural Locations*, "Introduction" and "Part I. Dis-locations of Culture."

²⁵¹ Bostrom, "In Defense of Posthuman Dignity," and Bostrom, "History of Posthumanism."

it seeks to push this subject and society beyond its natural limits. It stands to reason that an increasing number of tolerated deviances from the modernist norm would become incompatible with the perfected human, and that many of these would be seen as undesirable with respect to this new standard. It is here that transhumanism has more teeth than the garden-variety biomedical optimist. Both share the weakness of being too reductive, but transhumanism attaches their vision of the future to a responsibility toward the greater good of the species. This aspect is a mutation of another earlier eugenic discourse.

For this, Hall's genealogy of eugenics is quite informative.²⁵² Schematically, she argues that the eugenics discourse of the past, grounded in the idea of individual fitness giving health to the whole of society, is not an archaic discourse of yesteryear. Eugenics has always been grounded in an idea of the "natural" and the optimizability of the fitness of the entire population. At the turn of the century the concern was centered on inherited traits and family planning, with the goal of minimizing the burden of dependence and increasing the number of citizens who were fit, productive, and happy. Representative of such a social movement for Hall is the concept of 'physical culture' "inherited from the Victorians, [which] emphasized exercise, body-building, and hygiene."²⁵³ This focused on self-discipline and the responsibility over one's health—culminating on the 1947 motto printed on the cover of *Physical Culture* magazine "'Sickness is a sin: Don't be a sinner' and 'Weakness is a crime: Don't be a criminal'."²⁵⁴ Not only were individuals expected to discipline their bodies

²⁵² Hall, "Rethinking Enhancement; A Genealogical Approach," in *The Bioethics of Enhancement; Transhumanism, Disability, and Biopolitics*, 57-84.

²⁵³ *Ibid.*, 61.

²⁵⁴ *Ibid.*, 62.

out of dysfunction, using vitamins, exercise, and letting go of the crutch of prosthetics, parents were seen as irresponsible if they were to pass on any undesirable traits to their children.²⁵⁵ For Hall, these are not artefacts of history; these very same arguments are reversed, but unchanged, in current enhancement debates. As science evolved, so to did these same arguments about individual responsibilities and the social good. First, they were rooted in the idea of hormone issues, and later squarely in genetic determinism. There has been an attempt throughout recent history, even where solid empirical evidence was lacking, to naturalise and essentialise the desirable body in relation to the dangerous or expendable remainder. In doing so, ‘enhancement’ is cast in a network, where individuals are responsible for their own desirability, and their choices moralized through the idea of the social good, i.e., the overall health of the population. The latter is done through both an ableist lens of what counts as valuable, as well as the drive to bring about the future we consider possible in the near future.

One striking example is the paper “Embryo Selection for Cognitive Enhancement: Curiosity or Game-Changer?”²⁵⁶ In this work, Shulman and Bostrom propose the use of “iterated embryo selection”—an admittedly quite ingenious way to use IVF technologies—to produce what is essentially a group of super-geniuses. In iterated embryo selection, one selects embryos that have the desired trait (here, intelligence), convert that genetic material into sperm and ova, cross those sperm and ova and allow them to mature (about 6 weeks) and repeat the process until the desired enhancement is achieved, after which one implants

²⁵⁵ Ibid., 62-66.

²⁵⁶ Carl Shulman and Nick Bostrom, “Embryo Selection for Cognitive Enhancement: Curiosity or Game-Changer?” *Global Policy* 5, No. 1 (2014): 85-92.

the embryo for live birth. What this achieves is genetic selection over multiple generations in a fraction of the time it would take in *normal* human reproduction. In fact, they propose that in conjunction with investments in education and nutrition, iterative embryo selection could increase IQ by as much as 300 points (intelligence and cognitive ability equated here with IQ).

The goal is not to create post-humans for their own sake, but for its social good; as they claim, “human genetic selection may significantly influence national competitiveness and global economic and scientific productivity in the second half of the century.”²⁵⁷ But if economic benefits were the only advantage, we could imagine that resistance to this kind of thinking might be quite strong. However, what we recognize as fear-based calls to action in historical discourses of eugenics—for e.g., the dangerousness of unfit people and their criminality, or the progressive degradation of the genetic fitness of the population²⁵⁸—are echoed in this paper in some modified form. It is said that human cognitive enhancement should be seriously considered along side large scale social issues such as sustainability, overpopulation, climate change, inequality etc. because “in addition to [cognitive enhancement] being an important issue in its own right, [it] would interact quite strongly with all of these other long-term issues, since human problem-solving ability is a factor in every challenge we face.”²⁵⁹ So, for the sake of all our social ills, the radical programme of

²⁵⁷ Ibid., 85. The technologies are 10 to 15 years away, and it would take a generation or two for those augmented individuals to make an impact on society—hence the benefits only coming to fruition in the second half of the century.

²⁵⁸ Re. discussion of Hall above.

²⁵⁹ Shulman and Bostrom, “Embryo Selection,” 90.

human cognitive enhancement proposed here *ought* to be followed. In several places in this short work, it is also claimed that this technology would decrease the prevalence of intellectual disability—as a side benefit. Though it does not advocate for an active eugenics,²⁶⁰ it very readily implies that people with intellectual disabilities will play no role in the making of an improved human future. They are not worthy of consideration as actors in imagining this future because they have no ability to participate in the high-level problem solving required (we are in a crisis after all), and cognitive enhancements themselves will make their *condition* disappear.

In these discourses, disability is individualised and the social issues that contribute to their negative life experiences are eclipsed by the identified ‘cause’. These causes identified in genetic determinism, failure of the parent to choose health, inability of the individual *by definition* to provision for their own health and flourishing etc. Within such a view, there is no chance that disability may contribute to a profound redefinition of what lives may substantially contribute to our vision of the future, and there is no reason to apply intellectual, social, and political labour in improving the lives of people with disability because the solution is uniquely bio-technical.

So, given that technologies themselves have no innate ethical substance (they are not themselves good or bad), one can separate the technology (genetic enhancement) from the history of its uses (or imagined uses). We can see in this short example that, what transhumanists argue, and its result in the established value systems of our society, is

²⁶⁰ Though some do entertain the idea, see for e.g., Julian Savulescu, “Procreative Beneficence”; Julian Savulescu, *New Breeds of Humans*; John Harris, *Enhancing Evolution*.

certainly not *the same thing* as state sponsored eugenics, but we find points of historical continuity in their vision of desirability, and moments of functional convergence (suggested or actual elimination of the undesirable trait) through the mechanism of individual choice and ethical responsibility. Even reframed by the apparent neutrality of contemporary genetics, disability as a “kind” of deviance whose solution is found in bio-technical/technomedical intervention depends on the earlier constructions of personal health choices and improvement (enhancement) of society through the maximization of fitness. This is intensified when the social (or species) fitness is (perceived to be) threatened. What is different in our contemporary situation is that in general, it lacks the immanence of previous eugenic discourses because the risk calculation is individualized, and the threat is to a utopian future. It is presented clearly, however, in the above example from Shulman and Bostrom where the enhancement of intelligence is a necessity for survival. In this example, though, it is the enhancement that will save us. The elimination of intellectual disability is just a side effect of the technology, and is something that will naturally disappear from the imagined future.

Transhumanists do not argue for a return of the old eugenics, i.e., state enforced elimination of undesirability. This would clash with their deeply individualist ethics. The arguments that do surface have to do with prevention or promotion as opposed to termination. In the clearest case is the argument that parents are morally obliged to abort, treat, or enhance on the grounds of future suffering. More broadly, biotechnical researchers, developers and engineers are responsible for the future survival/fitness of the species. Given the mechanisms of truth-power we have been tracking so far, this is precisely the kind of argument that would gain traction in contemporary discourses. Whether we call it eugenics

or not, we can recognize the same historical process of society wide improvement of species body. That it looks different should not surprise us; it looks precisely as we should expect given the analysis in Part 1 of this dissertation.

The real tragedy of all this is that though technological advancements in general do bring with them some positive changes to society, they never attain the level of deep, universal, and equitably distributed change that makes up their intended vision (and justification). What we see time and time again, is the promise of a utopian future weighed against temporary suffering, but what is delivered is almost always a shell of the change promised and only for the privileged few. This makes it difficult for disability informed posthumanism to contribute positively to the future of genetic biotechnology. There is such a thick shell of problematic arguments that it is difficult to move past them to propose an acceptable future. It is the most difficult case, and I provide no answer here. The question of genetics in posthumanism and critical disability is a difficult one that goes beyond the bounds of the current work. For my purposes, what this difficult case shows us is how intricately the history of disability is tied to historical attempts to deal with socially undesirable traits.

Here we traced how the mechanisms of control are individualized through responsibility for health (or avoidance of suffering), and how the general direction or development of genetic technologies are led not by the needs of people ‘in the trenches’ but in the name of an imagined (utopian) future humanity. The latter is an expected strategy given the trajectory of biopower and the guiding narrative of the unlimited benefits of biotechnological progress. These insights, made obvious by this short exploration of genetic

technologies and transhumanism, will likewise function in the more general discussion of biotechnology that follows.

Disability grounded insights about transhumanist technoscience help us separate the wheat of real implications from the chaff of what is likely a future fantasy unlikely to materialize—whether we are talking about genetic manipulations, prosthetics, or our built environments. I will return to these general concerns when I discuss enhancement and hyper-normalization; however, for now I will return to the topic of our relationship to technology and what possibilities that can open up for a critical posthuman disability perspective.

Chapter 1—Our Intimate Relationship to Technology

In situating ourselves in posthumanism we have located ourselves in relation to transhumanism and their idea of ‘the posthuman’ which represents a type of individual separate in kind from the human (and an evolution from it). In the absence of a concrete category of ‘human’ and with the highly relational nature of posthuman thinking there seems to be an implicit connection between the body and technology. In this chapter I will return to the work of Tamar Sharon to explore the ideas of technological mediation and originary prostheticity as such a site for this connection. I will further develop these in relation to runaway norms and hyper-ableism.

Our focus will be on the development of technologies that mediate between us and the world; however, I did detour at the end of the introduction into the territory of genetic screening, selection, and manipulation as these do not represent prostheticity per se, but are intricately linked to the discourse of optimization/maximization, our historical present, and our posthuman subjecthood. What is apparent in the discourse on genetics is the hyper-ableism of transhumanism and the inescapable problems of current genetic technologies for the question of disability. The sketch above has shown us how current discourses are continuous with historical attempts to increase the fitness of the population by managing undesirable traits, how the manner in which we do that follows the trajectory of biopower I have outlined in Part 1 (maximization/optimization through personal responsibility), and the driving function of transhumanist imagination for the development and application of novel technologies. These will likewise function in our discussion of our relationship to technology in everyday life that will be the topic of this current chapter.

1.1 Reflexivity in our Relationship to Technology

For Sharon, reflexivity exists between technology and the context within which it emerges (including ourselves). Technology itself is not following a fatalistic sprint towards destruction or liberation—as the technophilic or technophobic pundits would have it—and we do not get to control exactly how we are affected or changed by technology. The latter bringing into question the idea that we can (at least entirely or effectively) control or mitigate the effects of new technologies through policy, research ethics, or governance itself. Thinking here of academics on both sides of the spectrum who either believe that policy can limit the excesses of technological advancement or the utopists on the other side who believe that scientists and engineers can self-govern technological development. I do not want to introduce a false dilemma here; these are the extremes that signify only a ‘type’ of position. The important thing is what assumptions justify these perspectives. Sharon attempts to identify two basic relationship-concepts to technology; namely, substantivism and instrumentalism.²⁶¹

Substantivism is the idea that once developed, technologies take on ‘a life of their own,’ to use a common phrase, in that their effects are pre-destined (i.e., are destructive or constructive independent of human subjects) and technologies are value-laden (i.e., are essentially or intrinsically good or bad independent of subjectivity). Instrumentalism, as a model for our relationship to technology, denotes the idea that technology itself is value-neutral and inert, and that they are mere tools to be used; their effects are wholly dependent

²⁶¹ Sharon, *Human Nature*, 83-7.

on human subjects and serve only an ‘additive’ function. In liberal posthumanism or transhumanism technology is simply instrumental. It has use value and we control its use (by force of will) as we would any other object in the world. This relationship is supported by traditional modernist philosophies that separate the subject from the world of objects; the old Cartesian idea of man as master and possessor of nature. On the other hand, dystopic posthumanisms have a substantive view of technology. They imbue technology with some kind of inherent value (negative) or alternatively some independent self-propulsion that usually challenges the essential characteristics or values of the human (e.g., dignity or autonomy). Sharon proposes that we ought to fall somewhere in the middle of these extremes, “[t]he reflexive view shares traits with both instrumentalism and substantivism: it agrees with instrumentalism that technology is in some sense controllable, and it agrees with substantivism that technology is value-laden”; however, it differentiates itself because it does not believe that technologies have essential destructive or liberating properties, and the social and political values that technologies embody are not inherent and predetermined—both of these can always be shaped and ‘negotiated.’²⁶² That is to say, technologies have some *use* value, in that we can *do* things with them, but we also recognize that our relationship to the world is mediated through technology and so, they have meaningful effects on how we interact and exist in the world. This sets before us a much more critical and complex set of issues. For those with substantivist perspectives, there is but one task, to judge a technology on its inherent properties—positive or negative—on whatever value one’s perspective dictates (ex. human dignity, justice, nature, religious permissibility, etc.). On the

²⁶² Ibid., 89.

instrumentalist side, the issue is rather with the consequences of such technologies, i.e., do they open up useful possibilities or introduce practical problems that are difficult to resolve.

In the context of a posthuman disability perspective on technology, like in Sharon's mediated posthumanism, both play a role and interact in complex ways. Certainly technology can do things to change the capacity of the human body like in assistive technologies, prosthetics, or pharmacological interventions, and these can range in complexity from a grab bar or eyeglasses to computer software, intelligent prosthetics, or even genetic editing. The idea is that the technology is a means to an end. This comes with a number of practical issues, including those of access and technology as a means to attain changing hyper-ableist norms. On the other hand, we also understand that these very technologies are not simply *additive* or *extrinsic* in any real sense. Technology, as any number and kind of tools, are integrated both into one's conscious experience of the world and one's sense of self and embodiment.

1.2 Technological Mediation and the intersection of embodiment and ableism

Don Ihde has offered a very useful analysis of how our relationship to technology is substantive through his 'post-phenomenological' analysis of technology. In his seminal book *Technology and the Lifeworld*,²⁶³ he offers us four types of world-technology-person relations that are useful to a posthuman exploration of the role of technology.²⁶⁴ Two of these

²⁶³ Don Ihde, *Technology and the Lifeworld, From Garden to Earth* (Bloomington: Indiana UP, 1990).

²⁶⁴ Sharon, *Human Nature*, 90-96. Recognition of this, find other references to his use in posthumanism and disability

will not be explored, not because they are unimportant but because they are less relevant to the discussion framed here. These are hermeneutic relations, and alterity relations.

Background relations constitute those relations that are so integrated in our everyday experience that we are no longer conscious of them. They are represented schematically as I (-technology-world). The classic example of this would be the thermostat. When we are in a controlled environment, we are not conscious (unless the mechanism is rather noisy) of the heat running on and off and maintaining, in the background, an adequate temperature in the room. A universal human experience sheds light on the invisibility of background relations—the power outage. We do not realize how many artefacts function in the background until they all turn off at once (lighting, heat, Wi-Fi or internet connectivity in our devices etc.). This is important to note, because individuals who use assistive devices tied to their environment have different occasions to have those relations break down. As technology becomes more and more integrated in our environments we come to depend on them more and more. For those early adopters of smart-home technology, a breakdown at this level may be frustrating or inconvenient but for many, it can bring on a real crisis. The little known area of assistive domotics—the use of technology in the home to enable older adults or individuals with disabilities to live at home—is sure to become an increasingly important enterprise as western populations age and technologies open up new possibilities for living at home longer (as opposed to staffed or assisted living facilities). The trend towards the merging of environment and technology, though, is tied to commercialization and the issues of justice and access remain present here; the formation of a “two-speed” or secondary society as discussed in Chapter six of Part 1 is particularly relevant.

Of primary interest here are *Embodiment* relations. This type of relation denotes the ways in which we come to ‘embody’ or *incorporate* our technologies within the capacities of our body. These can include traditional prosthetics or assistive technologies, but also things like cars, keyboards, and cellphones. Ihde relies here on some very traditional analyses, e.g., Heidegger’s idea of *ready-to-hand* or, more importantly, Merleau-Ponty’s idea that from the perspective of our experience in the world, technologies are “incorporated.” The blind man’s cane, which extends the sense of touch to the pavement that it encounters, the feather on the lady’s hat that extends her sense of space when she ducks to avoid a door frame, or the driver of a car that ‘knows’ it can go through a narrow opening.²⁶⁵ In doing so, one’s body goes beyond the bounds of the skin, beyond *humanist* corporeality. The mechanism that Ihde points to is precisely the one described by Merleau-Ponty, as stated most clearly in the *Phenomenology of Perception*. As he writes, “[t]o get used to a hat, a car or a stick is to be transplanted into them, or conversely, to incorporate them into the bulk of our body. Habit expresses our power of dilating our being-in-the-world, or *changing our existence* by appropriating fresh instruments.”²⁶⁶ The ‘incorporation’ of technology and the ‘dilation’ of our bodies beyond the bounds of the flesh are central to the idea of embodiment relations.

To go a bit further, our mediated contact with the world is in a reflexive relationship with more general ways of knowing, being, and the self—especially as it relates to science. In a discussion of Price and Galileo, Ihde points out that the use of the telescope was not simply a perceptual shift in distance and space facilitated by technology, it also allowed

²⁶⁵ Maurice Merleau-Ponty, *Phenomenology of Perception*, Colin Smith (trans.) (New York: Routledge, 2002), 165-66; Ihde, *Technology and the Lifeworld*, 38-41.

²⁶⁶ Merleau-Ponty, *Phenomenology of Perception*, 166.

Galileo to use the old tools of Greek geometry to expand the world we inhabit.²⁶⁷ Looking at the peaks and valleys, noticing the shadows of the craters of the moon as it moved, allowed Galileo to make the calculations and show that they were *in reality* of the same stuff as earth. The mathematization of the cosmos so common in the development of modernity is not simply an intellectual paradigm shift brought on by the development of knowledge, but it is the result of the ‘embodied scientific vision’—an (I [Galileo]-instrument [telescope])→world relationship. This is important when we consider the discussion of technomedicine and the neuro-molecular gaze discussed in Part 1 of this dissertation. Genetic screening and editing technologies, functional imaging, and pharmacological innovations all facilitated by advanced computing (including AI) have led to new *ways of seeing* which in turn have led to a mutation in the medical gaze and in individual’s self-perceptions/self-image. What results, though, is much more than an understanding (e.g., geneticization or neuromolecularity) but a plethora of related expectations, responsibilities and self-regulatory practices. These in turn effect the individual’s relationship to technologies that goes a bit beyond a strictly “embodiment” relationship, but shows how the phenomenological insight fits into the constellation of problematizations around the posthuman subject explored so far. These macro-mutations (at the level of knowledge-power/normalization) multiply the desirability, acceptability and direct contact with technological artefacts that make up contemporary embodiment.

²⁶⁷ Ibid., 53-5

Additionally, we can bring to the forefront a few more aspects of embodiment that come out of Reynolds's critique of Merleau-Ponty's analysis of the blind man's cane.²⁶⁸ He does not offer a critique of Ihde's phenomenology, but does point to a very relevant aspect of embodiment for our purposes. For Reynolds, the assertion that the blind man's cane is embodied in the same way as the woman's hat does not account for socio-historical factors that effect real-world experience. The visibility and social meaning of the white cane colours perception and disrupts the seamless integration of the technology for the user. Ableist perceptions of suffering or lack, people's discomfort or pity, forms of discrimination, etc., all lead, for lack of a better word, to a *reminder* of the artifactual nature of the bodily extension. When the user is spoken down to, treated with pity, are not asked about actual needs and are taken charge of etc., there is a disruption in the integration of the technology and consciousness is turned back towards the device—it ceases to be integrated for a moment. The white cane, unlike the lady's feathered cap, is a loaded social symbol. Certainly, this is not always the case, but there is a certain vulnerability to disintegration not present in the lady's hat, which makes the integration of the cane a more complex form of incorporation. The disruption caused by ableism, and the reason Ihde's phenomenology is strengthened by such nuanced disability informed critiques, will be quite important in the evaluation of background relations. We can acknowledge that though I equated technological use in both the case of disability and that of typically-abled individuals—i.e., that they were attempts to attain neoliberal and biopolitical norms of performance and optimization—that there remains

²⁶⁸ Joel Michael Reynolds, "Merleau-Ponty, World-Creating Blindness, and the Phenomenology of Non-Normate Bodies," *Chiasmi International* 19 (2017): 419-436.

significant social and political challenge related to ableism.²⁶⁹ Ableist social perceptions of how a normal body navigates the world and the aesthetics of idealised/normal bodies (i.e., what is *added* or *subtracted* from it) do have a reflexive effect on the embodiment of technologies. There are legitimate lived experiences tied to those embodiments that are unique to those who are recognizably abnormal. Making space in the analysis of technological embodiment for these socio-political dimensions makes for a richer understanding of how they are actually embodied in the real world.

The second critique that Reynolds makes of Merleau-Ponty's equivocation of the cane and the hat is that in the case of the cane, the embodiment of the technology is *transformative* where in the case of the lady with the hat; this does not seem to be the case. The critique being that Merleau-Ponty's example conflates habit with true incorporation of the technology. I would argue that the experiential mechanism is the same, but that there is some relevance to exploring the degree of transformation as it relates to the role the technology plays. So to say, as he does, that a sighted person using a white cane would never go through the transformation that someone who depends on the cane to experience the world is not the Achilles heel of embodiment relations as discussed here. It does, however, highlight an important aspect of technological incorporation; it must have a substantial effect on what someone can do or how he or she does it in order to be transformative. It cannot be an artificial *addition* or simply a curiosity of experience as in the lady's hat. It is interesting

²⁶⁹ Reynolds goes a bit further in his critique of Merleau-Ponty than we do here. He argues that Merleau-Ponty and those who use his arguments around embodiment conflate habit with legitimate incorporation. I argue that technological mediation as a form of embodiment includes even the most mundane technological artefacts, though it may lack some relational qualities that ableism bring to light.

and informative that the lady ducks to avoid a doorframe, it shows us how the body extends beyond itself, but it does not introduce a substantial change in the world of perception for that person. The white cane as an extension of the body for the person with a visual impairment is *the* means of access to that sense, so it becomes part of that person's world of perception. We will look a bit deeper at this when I discuss Andy Clark in the next section, but the insight, which Reynolds highlights, is that a technology that has become transparent becomes part of the self when it is integrated into the perception of capability and whose use is required on a regular basis. It is not simply habit—which would represent a certain mastery over the technology—but a dependence on the technological extension to the same degree we would depend on other means of access to or navigation of the world.

Reynolds' argument is that in the case of acquired disability there is a cognitive transformation that happens that goes beyond other, more superficial, uses of technology.²⁷⁰ I would argue, that novel technologies do bring with them transformative change, even if they do not always do so at the degree of an acquired disability. The idea that one cannot simulate with technology alone the experience of being blind—i.e., that one cannot know what it is like to have a disability without having a disability—is undeniably true. But the fact that incorporating a technology like an automobile into one's extended body-in-the-world is not earth-shatteringly transformative (i.e., to give one a new subject-position un-inhabitable prior to the experience) does not invalidate the premise—nor does it reject Reynolds's observations about the embodiment of disability. Not only does the operation of the vehicle

²⁷⁰ See Reynolds, "Merleau-Ponty," as well as Helena Preester, and Manos Tsakiris, "Body-Extension Versus Body-Incorporation: Is There a Need for a Body-Model?" *Phenomenology and the Cognitive Sciences* 8, no. 3 (2009): 307-19.

become a transparent part of everyday experience, it expands the circle of one's milieu, it factors into what one believes they are capable of and what projects they take on. Consider the deeply personal and shattering affront to the self-perception of the aging individual whose license must be taken away. The technology has been integrated into a sense of who they are and how they navigate the world, of how they perceive themselves and are perceived by others—their sense of autonomy and capacity. Again, this may be of a different magnitude as a body-extending technology that taps into a core sense-experience, but it is transformative to a significant extent even though it is obscured by the fact that the experience is unexceptional. The full world transforming experience, we can cede, may only be extended to technologies—'therapeutic' or 'enhancing'—that tap into a core sense or function whose operation is necessary and so becomes inseparable from the individual world of perception. I see this not as a critique from Reynolds extended on my arguments here, but an important insight about how we might consider the experience of embodiment relations from the perspective of people living with disabilities. It is true that technologies on which we fundamentally *depend* for the experience or navigation of our world will inevitably lead to a more deeply transformative embodiment relation, and that these types of technologies are usually the ones implicated in the lives of people living with disabilities. This fact highlights the importance of looking at the case of disability, and learning from it, when considering broader questions of the role of technology in our contemporary world.

I have been dealing, so far, mostly with technologies that are not necessarily representative of transhumanist aspirations. And though the argument will be that the mechanisms are the same, it is important here to look at more deeply integrated "cyborg" technologies in order to show how their exceptionality is only illusory.

1.3 Cyborg Relations and Integrated/Implanted Technologies; Can we Justify a New Relation Type?

One might reasonably argue that this idea of embodiment and the ableist disruption only applies to physical tool-like technologies (e.g., the white cane or an obvious prosthetic). This is precisely one of the argument that Verbeek makes in a paper entitled “Cyborg Intentionality: Rethinking the Phenomenology of Human–Technology Relations.” Here Verbeek attempts to update or expand the analysis provided by his mentor Ihde.²⁷¹ His intention in this work and others²⁷² is to show how technologies themselves have ‘intentionality’ and share ‘intentionality’ with human subjects, and so they play a role in human ethics. I will not engage with this broader argument here, but highlight his suggestion of creating a second embodiment category for those more integrated biotechnologies that we find in our environment. In recognizing that not all technologies seem to have the potential opacity as those mediating technologies that are “removable,” for lack of a better word, Verbeek proposes the term cyborg embodiment when technologies are physically integrated into the body. He differentiates them as follows,

When microchips are implanted to enhance the vision of visually impaired people, when antidepressants help to change people’s mood, or when artificial valves and pacemakers help to make people’s heart beat, there is no embodiment relation anymore – at least, not a relation

²⁷¹ Paul Verbeek, “Cyborg Intentionality: Rethinking the Phenomenology of Human–Technology Relations” *Phenomenology and the Cognitive Sciences* 7 (2008): 387-395.

²⁷² Peter-Paul Verbeek, *Moralizing Technology, Understanding and Designing the Morality of Things* (Chicago: Chicago University Press, 2011); Peter-Paul Verbeek, “Materializing Morality: Design Ethics and Technological Mediation,” *Science, Technology and Human Values* 31, No. 3 (2006).

which could compare to wearing eyeglasses or using a telephone.²⁷³

The difference between embodiment and cyborg relations for Verbeek is that once the technology merges with the body, it ceases to be a mediating experience and becomes inseparably and essentially part of the perceiving entity. Quite explicitly, he attaches embodiment relations discussed above in the same terms that I (following Sharon) favour in this dissertation. He states that the recognition of the myriad forms of mediation between human and technology, and their power to co-constitute what it means to be human, represents a significant challenge to traditional humanism.²⁷⁴ On the other hand, he likens those integrated technologies to transhumanism and the transhumanist movement, pointing to a more literal definition of cyborgism (more literal than Haraway for example). This is antithetical to what I have been discussing so far, which has largely equated both types of technologies insofar as they represent the same quest for ever complexifying means to attain a moving standard and the co-evolving sense of self that accompanies these attempts. This argument has rested on the fact that without a concrete category of ‘human,’ the transgressive or artificial character of new biotechnologies depends on a historical construction (human/nature) rather than an ontological reality. How, then, can we support or reject the ontological difference between ‘wearable’ prosthetics and ‘integrated’ ones?

1.3.1 Can Originary Prostheticity Link Embodiment Relations and Cyborg Embodiment?

Originary prostheticity is the idea proposed by Bernard Stiegler that the human is not the

²⁷³ Verbeek, “Cyborg Intentionality,” 391.

²⁷⁴ Ibid.

subject of a history of technology, but is co-extensive with this history.²⁷⁵ In other words, man is not a being apart from the artefacts that they make use of, but are constituted through time by the integration of these technologies into their Being.

Stiegler recognizes in Rousseau the modernist search for an origin of Man. This is an important step in establishing the whole project of the enlightenment and the naturalization of the human condition. For Rousseau, the human emerges at the moment they get up and walk on two feet and makes use of their hands.²⁷⁶ Though this origin already betrays what is to follow, Stiegler points out, as hands manipulate tools, and standing on two feet, free the hands to carry this labour. Nonetheless, it is this simplified moment where Man begins his climb away from the lower world of animals. The original condition, where nature provides food and shelter immediately at hand, is devoid of a need for external tools. The gap, between the animality of original man and the specificity of what we consider the human today, comes from the successive and accidental discoveries and use of prostheses that take us farther and farther from original necessity.

Making a dwelling and fashioning clothing were hardly necessary, assumes Rousseau, because man had been satisfied without them before—their immediate needs were met. The mastery of the environment, by exceptional—read divine—intelligence gave rise to the cultured man we see today. As Stiegler summarised, “the first man to have indulged in the apparent power of prostheses, obliged to do so by an accident in nature, took the road

²⁷⁵ Bernard Seigler, *Technics and Time I: The Fault of Epimetheus* (Stanford: Stanford UP, 1998).

²⁷⁶ *Ibid.*, 113.

down to his fall, and led his descendants down the same.”²⁷⁷ Even the development of man’s intellectual and emotional faculties—though not, for Rousseau, possible without divine intervention—follows a similar denaturalization where we move successively from a natural compassion to reason, living in immediacy to projecting ourselves towards future wants and needs, and the development of language and cooperation, all of which are unnecessary for original man. In setting such an origin, modernist thinkers like Rousseau or Descartes (discussed earlier), one could construct an image of man as exceptional and above nature, capable of mastery. However, this corrupted origin has a paradoxical result: man, as we see him today, with all that modernist and folk understandings identify as being part of what makes him specifically human—from imagination and language to using tools and technical mastery over the world—are *the result* of all the ancillary prosthetics that make up their co-evolution.²⁷⁸ To us contemporary secular thinkers, all matters of exceptionality not grounded in biology disappear from the narrative. No divine intervention or supernatural precondition is needed to explain the divergence from other forms of humanoid life. Once removed, however, we can see one of the aspects of this story come out of obscurity, i.e. the role that technological artefacts (tools) may have played. Stiegler states,

“Rousseau’s narrative of the origin shows us through antithesis how everything of the order of what is usually considered specifically human is immediately and irremediably linked to an absence of property [*impropriété*]²⁷⁹, to a process of

²⁷⁷ Ibid., 118.

²⁷⁸ Ibid., 133.

²⁷⁹ Note: “absence of property” here seems to be an awkward translation. In this context, I would interpret it more as meaning something that does not belong, being out of place, or simply foreign to

‘supplementation,’ of prosthetization or exteriorization, in which nothing is any longer immediately at hand, where everything is found mediated and instrumentalized, technicized, unbalanced.”²⁸⁰

At the end of the search for a human “origin,” we find that there is no naked humanness, nothing to be protected from the encroachment of technology. As Sharon would put it in her reading of Stiegler, “[i]nstead of remaining committed to the essential distinction and even opposition between the human and the technical, a position which ‘forgets’ the originary prosthetic nature of humans, we should understand that technologies are the enabling condition, not obstruction, of human experience.”²⁸¹ Our being is *always already* a technological one; there is no human ‘core’ to which we simply add or subtract technologies, and there is no essential ‘humanness’ that the artificiality of technology may threaten. If we accept the originary prostheticity argument, we must reject a number of positions on the technology-human relationship: the view that technologies are simple tools wholly separate from the self (supplemental view), or the substantive view where the technologies themselves have inherent qualities that threaten (dystopic) or augment (transhuman) some essentially human characteristics. Either view assumes a prior origin that we reject here, i.e., a human that *exists* independently from technology, and has a core threshold (typically the skin) that is transgressed by these. This human core is the “thing” that Fukuyama wants to protect, it is the “thing” that transhumanists such as Kurzweil want to overcome, and it is

it’s object. It is always inextricably linked, as in the following phrase, something external or supplementary; in other words, something wholly different than the human itself.

²⁸⁰ Ibid., 133.

²⁸¹ Sharon, *Human Nature*, 101.

precisely the view that justifies the distinction between embodiment relations and cyborg relations for Verbeek.²⁸²

The fact that integrated technologies are “more intimate”²⁸³ does not necessarily mean that they have disappeared into the subject any more than eyeglasses or phones.²⁸⁴ Much like eyeglasses need to be wiped clean of fingerprints, cochlear implants and deep brain stimulators need batteries, and those batteries need to be changed; they are just as susceptible to opacity as wearable technologies. They seem more integrated because they cross the barrier of the skin, but no matter how hidden from view they require upkeep-interactions. Likewise, prosthetic knees or hips have lifespans, and if some are designed to easily outlive our experience, the experience of seeing an other’s pain can bring one’s own prosthetic to mind. Moreover, in the same way that the social perceptions—i.e., ableism—of the white cane has an effect on how it is experienced (Reynolds argument above), an individual taking psychotropic medications is still subject to having their embodiment of that technology disrupted when they need to fill their prescriptions, take their medications in public, disclose the medications they take to medical professionals, or at times personally question if they need them at all. On the latter, the term anosognosia is often used to describe the state where someone using psychiatric medications successfully come to think that they do not need them, because they do not have the feedback from the symptoms to remind them

²⁸² Note that for the two previous authors the discussion of the human is the primary object, while for Verbeek it is a methodological necessity. The very basis of a phenomenological analysis is the experiencing subject and his/her/their role in the interplay of human-nonhuman relations.

²⁸³ Verbeek, “Beyond Interaction; A Short Introduction to Mediation Theory,” *Interactions* 22 (2015): 29.

²⁸⁴ Verbeek, “Cyborg Intentionality,” 391.

of the reason for taking them. Often, these individuals stop taking their medications, sometimes with negative effect. The memory of what happens—guilt or trauma associated with social judgements—sometimes introduces opacity to even in the deeply personal act of taking one’s medications at home. Even the most intimate technologies, from brain implants to psychoactive medications, have the potential to break down or become opaque and become disintegrated at least momentarily. That alone does not distinguish them.

Additionally, for Verbeek, cyborg relations can be distinguished from embodiment relations because in the latter one can discern the human and technological “share” in the mediated experience (i.e., the ‘role’ of the phone is easily distinguished from that of the speaker).²⁸⁵ One example he uses to illustrate this is the hearing aid vs. cochlear implant. Whereas the hearing aid is a digital amplifier, a cochlear implant connects directly to the user’s biological apparatus by way of electrodes in the cochlea. Its close association means that the user does not experience the world *through* the technology, they experience it as an integrated “I.” As he states, “True, in both cases it is an association of a human being and a technological artefact that experiences reality, but in the “bionic” or “cyborg” association there actually is no association of a human and a technology anymore. Rather, a new entity comes about. Instead of organizing an interplay between a human and a nonhuman entity, this association physically alters the human.”²⁸⁶ For Verbeek, a *new being* is created because the quality of the intentionality is changed.

In their interactions with the world, how can one separate the “hearing” that is no

²⁸⁵ Ibid.,

²⁸⁶ Ibid.,

longer a wave entering the cochlea? The case is more obviously complicated when we talk about ‘consumable’ technology, i.e., how much time did the anabolic steroid shave off of Lance Armstrong’s lap-time? If a person with clinical depression enjoys planting a garden, how do we distinguish the role of the anti-depressant in that person’s mood? The argument from Verbeek is that the inseparability makes the technology part of the individual’s intentionality, whereas in embodiment relations the intentionality of the individual remains intact. To put it another way, the cyborg relation is transformative. From our perspective, however, this is already a potential for embodiment relations. Starting from the point of view of originary prostheticity, the reflexive relationship between technologies and the self, and a rejection of the impermeability of the physical body threshold, cyborg relations are not a differentiated type for mediated posthumanism. The two perspectives may share experiential insights, but they operate on a different ontological perspective of the human body (i.e., a permeable extended body *always already* mediated by technological artefacts). In other words, from the perspective I have been discussing here, embodiment relations and cyborg relations are just different experiences of the same relationship. Every embodied technology has the potential to be integrated into a subject’s intentionality, and even ‘cyborg’ technologies can become disintegrated from them in experience. In other words, as we will see below, the distinction makes sense within the context of an isolated phenomenological exploration, but in the reality of lived experience the distinction does not hold. So, what mechanism explains away the apparent difference between wearable and implanted or mechanical and neurochemical technologies?

For this purpose, it is useful to look at the work of cognitive scientist Andy Clark²⁸⁷ who successfully collapses the distinction between apparent supplemental technology and more integrated (“cyborg”) technology. For Clark, there is no distinction between human capabilities and the rest of the natural world; our sense of self emerges from the interaction between the biological body and the technologies that we take into our control.²⁸⁸ More radical than the idea that our human characteristics emerge as a reaction to tool use (through selection for efficiency i.e., advantage)—the technical intelligence hypothesis—Clark’s claim is that tool use is the very origin of the sense of self.²⁸⁹ It is precisely the ontological claim that justifies the perspective I have been piecing together so far (and the one assumed by originary prostheticity). The technical intelligence hypothesis answers the question of *what we are* with the idea that tool use gave us an evolutionary advantage. The pressures for which the use of tools gave our ancestors increased fitness selected for beings with the cognitive capacity for things like self-awareness and language (i.e., the successive generations of tool-using survivors). The technology is *secondary*, and external to these capacities. What originary prostheticity claims, and what Clark tries to show in his analysis is that tool use itself is inextricably linked to these capabilities themselves, not simply external or additive. *We are* technological beings, or we *are* cyborgs. Technologies are not an assault on our humanness, they are a fundamental characteristic of it.

²⁸⁷ Sharon offers a quite complete sketch of several theorists that incorporate, implicitly or explicitly, the idea of originary prostheticity and the extended self in her book *Human Nature in an Age of Biotechnology* (97-105). Most relevant to our analysis is the work of Andy Clark who dissolves the illusion of a bodily threshold present in most understandings of prosthetic embodiment.

²⁸⁸ Andy Clark, *Natural-Born Cyborgs; Minds, Technologies, and the Future of Human Intelligence* (Oxford: Oxford UP, 2003). Ebook.

²⁸⁹ Sharon, *Human Nature*, 103.

We may accept this when speaking about embodied technologies that approximate, in some sense, to the tool use that our ancestors engaged in. The cognitive leap that needs to be made is to understand how more ‘cyborg’ technologies fit into this narrative. One striking example is the work, reported on by Clark, of a team led by Roy Bakay in the United States. Scientists at this laboratory have successfully surgically introduced two micro glass cones in a patient with paralysis in order to enable them to control a computer cursor.²⁹⁰ On the face of it, nothing could be more unnatural than such a technology. What is important for Clark, however, is the process of learning that takes place as the technology becomes integrated. Patients with these implants have to “experiment” by trying to move the immobile limbs. ,When the implant software recognizes a signal it buzzes, giving the patient feedback that they have found a neural pathway that can be used for a specific action. The patient must then learn to will that action on demand, which is then paired to a function by computer software (e.g., move cursor left, left-click, or double-tap). The action is *learned*, clumsily at first, as we all did when we learned to type on a keyboard with fingers meant for grasping.

One must admit that there is, at least apparently, something quite novel happening here. Both in the sense that there is something “foreign” about communicating directly through software, and that in learning to do so, we must essentially “hijack” a more natural neuronal network (the one controlling the motions of the leg for example).²⁹¹ For Clark, neither of these are sufficiently novel to necessitate a difference in type of interaction. He proposes that as children we must learn to navigate our environment and that things like the

²⁹⁰ Clark, *Natural-Born Cyborgs*, Location 1472.

²⁹¹ *Ibid.*, Location 1475, 1503.

control of our limbs does not happen without the same kind of learning/feedback (from our environment) than what is provided by the computer software (beeps from the sensors and intentional focus from the participant) in the case of the implant. As he states,

[...] despite initial appearances, I claim that the kind of thought control, which cortical implants make available, is thought control in *precisely the same sense* as is implied when we say that our thoughts can make our fingers move, and so on.²⁹²

One might still argue that certain networks have specific meaning (i.e., a network signal “means” in some essential way that the leg should move, not a cursor). But this would ring true in all cases of tool use, whether integrated or not, and rest on the idea that there is some pre-determined meaning to the signals that make up bodily motions and senses that are in every case corrupted by tool use—i.e., the hand is meant for grasping not throwing, pointing, or writing. We fall right back into the absurdity of Rousseau’s paradoxical origin discussed at the beginning of this section. And, I would argue we would fall into an ableist or folk understanding of ability, because we are left having to pick and choose what specific motions correspond enough to what we consider natural by consensus, and not some objective measure. The latter is essentially the point at which people’s adaptations are seen as secondary to natural (i.e., species typical) abilities. It is also the basis from which we can collapse the distinction between assistive devices and enhancing technologies, i.e., the therapy/enhancement dichotomy.

Though it may be thought provoking, it is easier for us to accept the fact that our

²⁹² Ibid., Location 1506.

bodies may be *extended* and even our senses may be extended beyond the barrier of the given limits of the body (limbs and the skin) as we have been exploring. Though I could end our discussion here, it would leave out one of the most challenging ideas to emerge from this line of reasoning—i.e., the ways in which cognition and mind may be extended outward into embodied technologies.

For Clark, not only do we integrate technologies into the self in terms of an actual body-image or extension of our senses (we do do this), but our ‘minds,’ our cognition itself is extended in the world through technologies (or “offloaded” to use his term).²⁹³ An often-quoted example comes from his collaborative work with David Chalmers²⁹⁴: Otto, a person experiencing dementia, constantly navigates the world with a notebook where he keeps important information he may need to recall at any moment. Without ascribing some essential difference to the task of recording and retrieving the information based on the material (pen and paper vs. neurons) we find that the cognitive activity is much the same—Otto has offloaded some of the functions of memory to the notebook. Taking his notebook away would be, for him, tantamount to performing a targeted lobotomy. But this example is not exceptional, the aptly named smart-phone that 85% of us possess²⁹⁵ does a huge amount of cognitive work. If I am asked to speak at an out of town conference, I may think about what I will present on, I may have some anxiety about timeframes, I may ask myself if I can

²⁹³ Ibid., 1704.

²⁹⁴ Andy Clark and David Chalmers, “The Extended Mind,” in Richard Menary (ed.) *The Extended Mind* (Cambridge: MIT press, 2010).

²⁹⁵ “Demographics of Mobile Device Ownership and Adoption in the United States,” *Pew Research Center: Internet, Science & Tech* (Pew Research Center, April 26, 2021): <https://www.pewresearch.org/internet/fact-sheet/mobile/>.

afford to go out of town, or if my spouse can accommodate taking-on childcare duties, etc. However, in accepting to present, there are a great number of tasks which are performed by my cell phone which I unconsciously expect will be performed when I make the decision. An electronic ticket means I do not have to remember from the moment of booking when my flight will leave, that I will not have other engagements while I am away because my calendar alerts me of scheduling conflicts, that I will wake up at the appropriate time because I have an electronic alarm set on my phone (maybe even multiple alarms, expecting some resistance to the first one), that once I arrive I can use my GPS to find the campus, and that once there I can Google a site-map to find the appropriate building in which the conference will take place. I must also remember to bring the phone and for this, my wife knowing me and my failings, may put a post-it note on the door or leave a reminder on top of my shoes. Yes, we offload cognition onto others too, not just technology.

One can make the argument that this is simply an explanation of supplemental technology that has not been integrated in the same way that the white cane or the cochlear implant has. And though it is true that in *setting* an alarm, in *entering* the dates in my calendar, and in navigating with the GPS I enter into an alterity-relation with the technology; however, in accepting the speaking engagement, I had fully integrated the fact that these tasks were well within my capabilities. They had been unconsciously implied in the “I” that saw speaking in a novel environment possible. As Clark puts it,

Easy access to specific bodies of information, as and when such access is normally required, is all it takes for us to begin to factor such knowledge as part of the bundle of skills and abilities that we take for granted in our day to day life. It is this bundle of ‘taken-for-granted’ skills, knowledge, and abilities that structures and inform our

sense of who we are and what we know.²⁹⁶

There is a sort of expansion of the embodiment relation, where unconscious processes of the mind are mediated by information technologies and are seamlessly integrated into our general experience of the world.²⁹⁷ He is speaking here in general, but elsewhere the argument is expanded to assistive devices, and helpers as well; “[t]echnological aids can be both external to and part of the mind, and other people’s cognitive capacities can be deeply intertwined with our own.”²⁹⁸ The self as a thinking, feeling, and doing being, is a “biotechnological hybrid” through and through. Who “I” am is not only a matter of my body, it is also a cumulative story of my goals, commitments and projects through which I identify myself and others define me.²⁹⁹ All of these are affected by the possibilities that lead to the ability to take things on, to choose one path over another, or to give up on certain dreams and aspirations.

²⁹⁶ Clark, *Natural-Born Cyborgs*, Location 1629.

²⁹⁷ Note that there is a big difference between saying on the one hand that an accountant may offload some cognitive labour to a calculator and the he/she has embedded this function into a conception of his/her own abilities, and on the other hand saying that the calculator thinks or shares in the conscious experience of bookkeeping. Without entering into a long standing debate about the philosophy of mind and consciousness, Clark is not a reductive functionalist about consciousness—he does attribute consciousness (as we experience it) to our biological “wetware,” but he does remain a functionalist in the softer sense of equating *cognition* to its functional equivalents and so the performance of aspects usually equated with the *mind* are also extended and offloaded outwardly. When these cognitive tasks become transparent (i.e., they are embodied in the mediated sense described above) they integrate into our sense of self and in our sense of who we are (the “I”).

²⁹⁸ Zoe Drayson, and Andy Clark, “Cognitive Disability and Embodied, Extended Mind,” in David Wasserman and Adam Cureton (eds.), *The Oxford Handbook of Philosophy and Disability*, Oxford Handbooks Online (2019). In this Chapter, they discuss Silvers’ idea of memory prosthetics and distinguish it from their version of extended mind. Though it is not technically extended mind, it is still significant and falls under the embodiment of technology as we discussed it in relation to Ihde and Verbeek and does represent an ‘offloading’ of ability.

²⁹⁹ Clark, *Natural-Born Cyborgs*, Location 1612.

Consider this notion of embodiment and self in the relationship of a man and his guide dog. Speaking of the now famous book *The Two-in-one; Walking with Smokie, Walking with Blindness*,³⁰⁰ sociologist Rod Michalko likewise describes the need to complicate both the experience of alternative ways of sensing the world and one's relationship with aids like guide dogs. Michalko describes first taking blindness at face value, then understanding it through its social constructions and ramifications (i.e. a constructed form of "social deviance").³⁰¹ He states, however, that his experience with his dog Smokie taught him that our experience of the world is part of an interdependent interpretive chain. He states,

The links in this interpretive chain are ontologically interdependent; they rely upon one another not only for their sense and meaning but for their very being. As an animal, Smokie symbolically represents nature while I, as a person, do the same in relation to society. The bond between Smokie and me may be understood as the bond between nature and society. Smokie and I do not merely inhabit a common natural and social world; we depend upon one another for our existence, and together we construct and re-construct the world. Smokie and I are, almost literally, extensions of each other, and the interpretive chain that we inhabit takes the form of a circle rather than a straight line.³⁰²

Although he uses different language, what I argue he does here is describe his realization of an embodiment relation, and one that acknowledges how we can be deeply interdependent

³⁰⁰ Rod Michalko, *The Two-in-One, Walking with Smokie, Walking with Blindness* (Philadelphia: Temple University Press, 1999).

³⁰¹ *Ibid.*, Location 60.

³⁰² *Ibid.*, Location 73-6.

with, in this case, another living being.³⁰³ It challenges entrenched and default humanist assumptions about dependence and selfhood—assumptions that Michalko, a trained sociologist, held himself. In a participatory action research project that involved other human-guide dog assemblages, Liddard *et al.* recognized that, “[o]ur co-researchers understand this blurring of human-animal bodies and they talk in very posthuman ways,” which the researchers interpret “not just as a technology enabling (humanist) desires but as a posthuman intimacy that offers expansive ways for living.”³⁰⁴ This is not only a perceptual curiosity to be described and forgotten about. It enables us to see how we all integrate technologies and human/non-human others into our lives and the affirmative posthuman possibilities inherent in these relationships.

A person that I think illustrates all of these points quite well is Jason Becker, guitar virtuoso who developed ALS at the age of 20, at the height of his meteoric rise. It was certainly a shock to the guitar community, and many still today speak of his story as one of lost potential. However, there is another narrative about Jason Becker, the fact that he continues to compose and record music. How he achieves this challenges what we typically think of when we think of a composer—he represents an assemblage that we can call a posthuman-composer. To compose his music, he depends on an eye-movement communication interface to communicate to his father about which notes to play on the guitar. Once recorded, Becker directs an assistant to arrange the song electronically, note-by-

³⁰³ Note that though he describes an embodiment relation, and does point to an inherent interdependent relationship, he does not himself go as far as integrating the technology in the self. See chapter 7 “The Two-in-One” *Ibid.*, Location 1729-1879.

³⁰⁴ Liddiard, *et al.*, “Working the Edges,” 1479.

note, on music editing software (LogicPro). After this initial composition is complete, he seeks out other musicians and producers to polish the composition into a final mix. Using this complex network of intermediaries—eye movements, “Vocal Eye Becker Communication System” (see Figure 1 below),³⁰⁵ his father, fellow musicians, producers and sound engineers etc.—Becker enacts the role of composer. It is important to note that because we are turning our gaze to his process, we see a myriad of interconnections that come together to produce the final product. However, it must be noted that nearly all distributed music similarly involves a great deal of interconnection between people, technologies, and artefacts. Ghost writers, producers, session musicians, guest musicians, sound engineers, studios, audio-tech companies etc. all make up the final product that we attribute to an artist—and they all *add* something that goes beyond mere automatism. What we consider an artist is never just an independent unitary individual that exists in a vacuum. The final product is not an unadulterated carbon copy of the author’s pure idea; it is mediated by technology, people, and practices.

If we focus here on the role of technology itself, we can see how they can be harnessed for their affirmative potential and as instruments of resistance. To begin, if we look more closely at the relationship between Jason and Gary Becker we can focus on two things: the “Vocal Eyes Becker Communication System” as a moment of creative adaptation, and the role of his father (or “reader”) as an example of a “mental prosthetic.” When Jason was losing his ability to communicate, his father developed a system where a glass plate

³⁰⁵ You can see how it works in action here as well as an explanation from Gary: <https://www.youtube.com/watch?v=AYSXh5sfLtY>, As well as the written guide made public for all to use here: <http://jasonbeckerarchive.com/VocalEyesCommunicate.pdf>

would be divided into six squares, each containing 4 letters arrange like the cardinal directions of a compass (with two extra letters in one of the squares). Each letter selection takes two eye movements, one selecting the square, and one selecting the letter with a predetermined yes or no signal to communicate agreement or errors in interpretation. As the reader becomes familiar with the system, it becomes unnecessary for Jason to spell out each word as following a few letters prompts what we would call an autocomplete by the reader (if compared with many text based computer programs today). So, if Jason were to receive a guest, pointing to “h,” “e,” “l,” would reasonably prompt the reader to complete the word “hello,” to which Jason would communicate agreement with the sign for yes (eyebrow raise in his case), or no (mouth twitch). With enough time, as in Jason and Gary’s case, the communicator and reader can become proficient enough to communicate without the help of the glass panel.

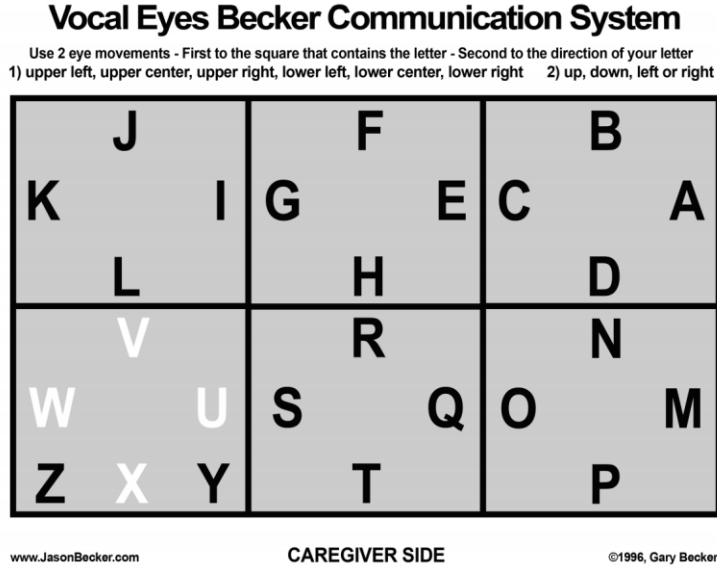


Figure 1: Vocal Eyes Communication System

The role that the reader is fulfilling here is precisely that of a mental prosthetic, or a human assistive device. The reader does not interpret the meaning of the communication, but

simply converts it to speech serving as a vocal prosthetic. If this reduction is difficult to reconcile with the fact of the reader’s agency, we can easily imagine an eye-to-text technology replacing this actor without any change in the function. In fact, such technologies exist. One example is the “Eye Gaze Edge[®],”³⁰⁶ an eye-to-text tablet interface precisely for patients in Jason’s situation. It tracks eye movements using a QWERTY keyboard and even allows the user to browse the internet, control smart devices in the home, control any app or program supported on the tablet, and comes fully email integrated. This more readily satisfies our imagination of a prosthetic device and of a posthuman technology, but it ought not to. The moment of creative adaptation between Jason and Gary enabled Jason-as-assemblage to remain a composer. This was something inconceivable from the standpoint of his medical prognosis and the state of assistive technologies at the time. A shared will to communicate and, what appears to me as, simply acrylic paint on a pane of glass challenged both the objective limits of what was possible for Jason’s body, and the received idea of what a composer is.

In elevating these stories we have to be careful to do it in order to be descriptive and to tease from it some insights that may challenge received ideas. We ought not imbue them with mythical heroism. This artificially overlays their lives with the idea of the “super cripple”: a person who is so exceptional that they have overcome the deepest and most devastating disabilities against all odds.³⁰⁷ These are the tropes that organizations use to raise

³⁰⁶ “Eyegaze Edge,” Eyegaze (2021): <https://eyegaze.com/products/eyegaze-edge/>.

³⁰⁷ Colin Barnes, *Disabling Imagery and the Media: An Exploration of the Principles for Media Representations of Disabled People*, (Halifax: Ryburn Publishing, 1992), 12-3: <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-disabling-imagery.pdf>

money for research, sell products, or benefit their charities. They perpetuate the idea of disability as suffering and elevate the exceptional individual at the cost of the collective.

The individuals discussed here are exceptional because of their achievements (full stop), and politically/philosophically important for their manner of challenging the norms and expectations of society. The forms of embodiment and independence they display does not make them any more valuable from an ethical point of view than someone who harnesses these technologies to enable them to enact their own versions of independence or meaningful living. Using the Eye Gaze Edge[®] to order a movie on Netflix to discuss it with a friend on Facebook is still a valuable and meaningful expression of posthuman embodiment *if it satisfies the individual's idea of meaningful action*. In other words, the experiences described here are meant to illustrate the nature of our relationship to technology, one that we could apply to our own daily experiences—even the most mundane. Naturally, the examples that are rich enough to discuss in detail are those of exceptional people. What we ought to focus on here is not *what* they do with these technologies, but *how* they live with them.

1.4 Conclusion: The White Cane, Variations on the Theme

Technological mediation goes much deeper than the experience of the subject, and so, though it is useful, a purely phenomenological approach misses a certain reality of interconnectedness that is both socially and politically important. Unlike Rousseau, or evolutionary perspectives, Stiegler shows us that the history the human and the history of technology are co-extensive, and through Clark we reinforce the fact that all technologies are integrated into the self no matter how simple or complex (contra the distinction apparent to the bracketed “I” of post-phenomenologists). It reinforces the idea that *we have always been*

technological beings, and shows us that socially, politically, and scientifically the role of technology cannot be thought of as a secondary question for posthumanists. It is a central concern. This not because they can solve the problem of disability or compensate for an impairment—as transhumanists or liberal technoscience would have it—but because they are a fundamental part of who we are, no matter how simple or complex the artefact. If we have no sharp distinctions on which to either defend or criticise certain technologies, we must engage in the much more difficult task of deciphering what to support and what to resist on other less established grounds (i.e., the experiences of people at the margins, the conceptual frameworks that guide development and their political implications, the ethical ramifications of prohibiting, limiting, or permitting development/use/access to novel technologies).

Relevant here, the task rests on four important dimensions: a) the transparency and opacity in experience of embodied technologies, b) the constitutive role of technologies in the making of the self and life course of the individual, c) the social implications of the visibility of technological integration, and d) how these technologies align with problematic norms of performance and optimization.

To return to a low-tech example of technological integration, we can apply the insights discussed here to the example of the white cane.

I began with Merleau-Ponty and Ihde, who contend that as experiencing subjects we integrate into our very bodies the technologies that extend it outward beyond the bounds of the skin. For the individual using the cane, it represents more than just a means of navigation, it expands their world of experience and it becomes part of their cohesive being-in-the-world. This technological mediation is *world creating* in the sense that what it opens up changes our sense of who we are. The cane-user must reconcile this new world of

experience with a sense of what he/she is, and his/her place in the world. This is more obvious in Ihde's discussion of Galileo's observation of the moon. Seeing the craters and their shadows confirmed that the world "out there" was of the same "stuff," and radically shaped our understanding of the universe and ourselves. The same goes for the successive discoveries and mutations of medical science that have led not only to the development of biotechnologies, but the understanding of human life and the perceptions of the self attached to it—i.e., pathological forms of life (clinical medicine), social deviancy and population health (social medicine), the geneticization and the somatic self (genetics and technomedical diagnostics), and treatment vs. enhancement (technomedical interventions and artefacts).

These collective understandings passed down from the sciences are not the only social dimensions of technological integration. As Reynolds points out, the perceptions of others can challenge the integration of the technology with the self and break down the transparency of the embodiment relation. These can often come in the form of discrimination or stigmatization resulting from ableism, or quite simply the changes in how people interact or avoid interacting with people living with disabilities. The technology may enable some capacity or ability, but social perception reinforces the fact of exceptionality and deficit. Moreover, the embodiment of technology from the standpoint of the person with disability brings with it a whole world transformation that includes the shedding of inherited and internalised ideas of what life is and ought to be. Quoting Hull,

First I believed that blindness was when you couldn't see because something had gone wrong with your eyes. Then I understood that blindness was a deprivation of knowledge for which alternative sources and kinds of knowledge would compensate. Gradually I came to see that blindness is a whole-body condition. It is not simply that

your eyes have ceased to function; your whole body undergoes a profound transformation in its relationship to the world. Finally, I came to believe that blindness is a world-creating condition.³⁰⁸

For Reynolds, the transformation from blindness understood within an ableist framework of lack and suffering to a positive life affirming experience is instructive. One would not want to assume that all conditions would lead to such an all encompassing perspectival change, but certainly all conditions are transformative to varying degrees. They tie experience to a privileged position from which insights may be gained and shared. A responsible perspective on technological embodiment listens to and incorporates those marginal or limit experiences.

Throughout this chapter I have discussed the embodiment relation and the incorporation of technologies from the mundane everyday, to clinical applications, to enhancement. The idea of originary prostheticity and the extended mind goes a long way in flattening the divisions between these three forms of embodiment. Clark shows us how the mind and self are not the standpoint through which technology is experienced but represent a reflexive and co-constitutive interaction where one and the other cannot be separated. This does not invalidate either Ihde's or Verbeek's insights but flattens the exceptionality of how the technology may 'connect' to the body. Moreover, though it opens up the idea of embodiment to a greater field of low-tech and highly technological artefacts, it does not invalidate Reynolds' observations either. I would argue that it confirms and supports the idea that a greater dependence on technological mediation leads to a much greater transformation

³⁰⁸ John Hull, *On Sight and Insight: A Journey Into the World of Blindness* (London: Oneworld press, 1997), xii, Quoted with author's added emphasis in Reynolds, "Merleau-Ponty," 425.

of perception and the self. The white cane does not represent something inherently different than a limb, through haptic feedback the cane-user *feels and incorporates* the texture and structure of the world they navigate in the same way any other sense would hardwire itself to experience; however, the nature and possibilities opened up by the cane also lead to a recalibration of the sense of self and the self among others. As he states, “The narrative self is a self built out of our own and others’ conceptions of our projects, capacities, possibilities and potentials.”³⁰⁹ Reynolds simply reminds us that this transformation of the self is not always so deeply consequential, and that its political dimensions are not homogenous. The fact of disability and the collective understanding of it have to factor into the analysis.

It is important to recognize the everyday embodiment of technology because their transparency also leads to their disappearance in the overall understanding of how deeply we are already cyborgs. But, at least at the surface, the political and social implications of technology are more relevant in the case of clinical applications and enhancement, because they are not outwardly transparent. With the idea of an originary imbrication of technology and the self we can expand the insight substantially. We do this not in order to disregard or degrade the importance of the experience of disability, but to acknowledge the great diversity and potential diversity in life affirming technological embodiments. And *with it*, i.e., the experience of disability, some of the potential pitfalls and political dangers associated with it. As Braidotti put it, it is time for “pragmatic experimentation” with novel technologies, with the caveat that it is not accompanied by a nostalgic humanism but truly does imply experimentation with new forms of subjectivity, while remaining careful not to have them

³⁰⁹ Clark, *Natural-Born Cyborgs*,132.

co-opted by neoliberal normalizing mechanisms.³¹⁰ This implies a much more nuanced and complex view of the role of technology in relation to disability and the political situation we currently find ourselves in.

In the following chapter I will look a bit deeper at this division between enhancement and therapy. If, as I have claimed, they do not represent substantially different uses of technology, then one can presume that everything is permitted or that I am promoting a certain form of transhumanism; this is not the case. What I will try to show is how the collapse of this dichotomy brings with it some new challenges that ought to make us rethink the ways in which we think of human-technology relationships. We are technological beings, full stop. Participating in the development and envisioning of future technologies, as well as access and control over the ones already developed, *is* a struggle over the making of the self and potential future selves.

³¹⁰ Braidotti, *The Posthuman*, 45.

Chapter 2—Placing Limits on Variation and Fixing the Point of Bifurcation; the Need to Broaden our View of Enhancement and Therapy

In this chapter I will discuss the enhancement/therapy dichotomy in light of the posthumanism I have been discussing so far. Preliminarily, we might say that therapy has the aim of returning someone to normal functioning (making up for a lack) while on the other hand we might say that enhancement is anything that brings a person beyond normal functioning in one sense or the other. This folk, but widely held, distinction will be problematized on two basic fronts. Firstly, I reject the received idea of a purely objective concept of normality itself. It is on the basis of such a notion that one intervention is said to bring a return to normality (therapy) and the other an overcoming of it (enhancement), as if it was a fixed benchmark. Once destabilized, maintaining a strict division between the two becomes much less tenable and valid. Secondly, I argue that naturalizing the range of human abilities does not solve the issue of what is normal, as it does not account for the variability inherent in the coevolution of humans and technology discussed in the previous chapter. I will add to this the Canguilhemian understanding of life's adaptive quality. All together, this will make the therapy and enhancement dichotomy a matter of convention and historical interpretation as opposed to the objective basis on which matter of fact ethical statements can be made about this or that use of technology. The issue we need to overcome is the privilege position given to an idealized and fictional *natural man*, and the not so neutral or objective judgements that are made on that basis. In a society such as our own, dominated by the latter, the point of view of individuals with disabilities does not factor into normative judgements about what lives have value and what technological improvements ought to be pursued. Disability represents lack, and therapy is the default solution. They are always one step

behind the cutting edge of expanding human capacity, and their concerns are of a different type. As I will argue, understanding the therapy-enhancement dichotomy in more relative and contingent terms forces us to reconsider the reductive medical classification of assistive devices, and allow those forms of technoscientific development to contribute more fully to our vision of a posthuman future. In transhumanist discourses they are sharply distinguished, and have different aims. One is meant to correct nature's mistakes, while the other is the means of attaining a new reality. Alternatively, if equated, the experience of disability has a much greater role to play in the latter.

2.1 Enhancement and Disability in the Contemporary Social Context

For transhumanists the definition of enhancement is quite clear, it is any use of technology that significantly improves the outcome or functioning of the individual. Certainly, transhumanists do speak of more general social benefits of technologies, from improved health to survival of the species itself,³¹¹ but these in terms of the cumulative benefits of individual liberty to research and develop technologies, and the wide availability and personal liberty to choose to enhance.³¹² With such a view on enhancement, it is natural that transhumanists would individualise the concept of ability and health, which we have already

³¹¹ E.g., Igmarr Persson and Julian Savulescu, "Moral Transhumanism," *Journal of Medicine and Philosophy* 35, No. 2 (2010); Nick Bostrom, "The Future of Humanity," in Jan-Kyrre Berg Olsen, Evan Selinger, and Soren Riis eds., *New Waves in Philosophy of Technology* (New York: Palgrave MacMillan, 2009).

³¹² See point 8 in "Transhumanist Declaration," Humanity+ (World Transhumanist Association, 2009): <https://humanityplus.org/transhumanism/transhumanist-declaration/>; "Derivative Values" section in Nick Bostrom, "Transhumanist Values," *Review of Contemporary Philosophy* 4 (2005): <https://www.nickbostrom.com/ethics/values.pdf>

established is the very fundamental problem that Disability Studies has been resisting since its inception. From the standpoint of traditional Disability Studies, disability is inextricably tied to material social factors for which *cure* is not the solution, and it would be no leap to say, consequently, that the race to enhancement is similarly problematic. The focus on wearable or implantable biotechnology as well as psychopharmaceutical and genetic manipulation technologies are very individualizing, and this is not without reason.

Transhumanism is also individualistic in its ethical commitment to personal choice, where one of the primary bioethical arguments for this perspective is the right to morphological liberty. This has the dual effect of disregarding other ways in which we enhance our lives, and of obscuring the potential already available in more distributed and general adaptations.

To a great extent, having a healthy social service system in an equitable society would substantially improve the lives of individuals with disabilities to the same extent that a prosthetic or assistive device could. They are not *technologies*, but they add a dimension of another order to the debilitating aspects of disability; they serve the function of removing barriers and opening up possibilities. Undeniably, they take aim at very different causes, though they are all *improvements*.[√] It is worth mentioning because social improvements are neither considered enhancements nor therapies, but they are a top priority for disability activism and in modified form for a posthuman disability position.

Related to the idea of social change (improvements), are those ways we might potentially enhance ourselves through others. Though they are not easily classified as enhancements, they lead to quantifiably similar improvements. Functionally speaking, a guide animal, an interpreter, or a support person can serve as an external therapeutic technology. The improvement these can represent in the life of an individual is palpable,

even though they are not as neat and tidy as a consumer product or freestanding artefact. They are relational enhancements.³¹³ Quite radically, despite the lack of silicon, titanium and shiny steal of our posthuman imagination, human and animal support-workers can serve a prosthetic function. Taking the arguments of Clark from the previous chapter to their limit, these are integrated into the self as any other technology would. To reiterate Goodley's quote from the introduction, "be careful not to be seduced by shiny technology when, on a more mundane level, we are already potentially enhancing our humanity through a myriad of inter-relationships."³¹⁴ We return here to the issue of the instrumental view of technology. Seeing technologies as individualised artefacts outside of its incorporation by the user simplifies the argument, but ignores the networked nature of their existence. In doing so, it is easier to value one kind of improvement over the other. This is not a curiosity, more mundane ways of enhancing are fundamental and much more important in general than specific technological developments individually. A focus on the latter is more in line with engineering and scientific problem solving, but it further limits a more robust understanding of enhancement and how it relates to the general social purpose of disability activism and posthumanism. The ways in which people with disabilities enhance their lives, or potentially could, through the adaptation of simple technologies, environments, or human and non-human others is often more cost effective and accessible than shiny new technologies being developed in the lab. This is not to say that what we traditionally think of as biotechnologies or enhancements do not have a place; it is just not always the best or most appropriate intervention. In fact, the point of a critical technological perspective is to show that they have their place *among*

³¹³ We return to this in our discussion of interdependence and mental prosthetics in the next chapter.

³¹⁴ Goodley, Lawthom, Runswick-Cole, "Posthuman Disability Studies," 352.

others.

This first step in broadening the definition is to answer the question of ‘what makes an improvement either a therapy or an enhancement?’ Traditionally, for therapy it is a diagnosable dysfunction and for enhancement it is the observed limitation of the human body. Both assume that there is an objective basis onto which a deficit or shortcoming can be identified and that the intervention represents a measurable improvement that can be easily quantified. This objective basis gives these forms of improvements the apex position when it comes to the investment of financial and intellectual labour. I will give a more fulsome account of how difficult it is to quantify human norms in the next chapter. What is important here is that the predominance of the biomedical interpretation of average man is fundamental to the distinction between therapy and enhancement and resonates with other forms of social investments today.

Concurrently, when we speak of the things that disability activists have traditionally been fighting for, immediate changes are largely qualitative because they are social and political in nature, and the measureable improvements (for e.g., in wellness/health measurements, employment numbers, or income disparities) happen downstream. A direct causal link is either ignored or hard to measure. Moreover, these improvements are not necessarily tied to the biological realities of impairment (i.e., the clinical condition itself) but are often aimed at social or environmental factors. All of this takes it away from those most valued aspects of decision making and planning today: evidence based decisions (i.e., quantifiable and measurable changes), somatic view of individuals, economic reasoning, and public health level planning. I am not arguing that these are bad decision making or planning frameworks, or that the things disability activists are fighting for—even the deeply

philosophical re-valuation of human life argued for in this dissertation—would not lead to quantifiable benefits. What is clear, is that quantifying those qualitative improvements is just either less valued (social science research vs. medical research) or harder to study (indirect measurement vs. direct measurement) than more robust scientific interventions. This is important because it means that the voices that bubble to the surface are those of traditional biomedical research compounding the issue of fighting the narrowly biomedical definition of disability and the accompanying narrative of suffering and perpetual unwellness. Clinical trials of medications and new technologies or epidemiological type studies with their well-defined parameters are the low hanging fruit of such a framework—and are much more likely to receive significant funding. The confirmation bias of the biomedical understanding of human experience reinforces these narratives and points to the very individualizing solutions that have been so problematic for the disability movement. More innovative and ‘rooted’ understandings lack the empirical backing to play at this game. This has the result of perpetuating off-the-shelf solutions to quasi-problems based on a dichotomy that does not reflect experience.

A critical posthuman disability perspective on technology places a whole series of demands that result in a seismic shift in perspective—i.e., our foundational cyborgism, the distributed and relational self, the political and ontological weaknesses of modernity—all of which are diametrically opposed to transhumanist value systems (that are themselves quite at home with therapeutic frameworks). What Goodley points to in his discussion of interconnectedness³¹⁵ is a challenge that must be brought to the idea of individualism; an idea

³¹⁵ Ibid., 353ff; to be discussed in next chapter.

central to biomedicine, neoliberal economics, and transhumanism. The idea of a distributed self—through technology as well as through others (helpers, service providers, and guide-animals)—is incompatible with either an individualizing pathology or individualizing ethico-political lens. So, as Goodley recognizes (using Braidotti), what we need is a total reorientation of our perspective towards a collective ethical lens, which in the latter (Braidotti) goes as far as an eco-philosophy of interconnected living and non-living entities.³¹⁶ I will not go so far out of scope here, but it does put in perspective how much of a shift is needed and how large the task is. The practical challenges of a disability informed politics, of research tied to disabled experiences and ways of being, of sociological reorientations of policy and governmental practices are all tied to our historical understandings whose supporting ontological premises are constructed in the discourses themselves.

Schües is quite instructive here. As discussed, it is an important aspect of modernist thought that human beings are malleable and changeable,³¹⁷ but at every stage in history there has been an ethical discussion on what ought to be improved about the human being supported by anthropological notions of who we are.³¹⁸ Improvement of any kind, and this includes the forms I am discussing here, are dependent on some identification of a deficiency. Historically, it has been chaos for the Greeks, a disconnectedness with God for

³¹⁶ Braidotti, *The Posthuman*, 48ff

³¹⁷ This fundamentally Foucauldian argument (see *Discipline and Punish*) has been repeated innumerable times in Disability Studies, including Schües' conceptual history discussed here.

³¹⁸ Christina Schües, "Improving Deficiencies? Historical, Anthropological, and Ethical Aspects of the Human Condition," in *The Human Enhancement Debate and Disability*, 38-62.

Middle Age Europeans, maladaptation for the European evolutionary modernists, degeneration of the population for the Westerners at the turn of the 20th century, all have had their problematizations.³¹⁹ Today's technomedicine takes issue with the deficiencies in the vital processes of the body and seeks to optimize functions at this micro-level, as well as the social issues of individual economic viability and national competitiveness against which we measure improvements in savings, growth, and productivity. Transhumanist fantasies of enhancement take these to the extreme, where *improvement* of any kind, even beyond established normal boundaries, is desirable. Both depend on the "normal" category, but they have a different relationship to it. In the case of enhancement, the relationship adds complexity when trying to make value/ethical judgements. Chief among them, from our perspective here, is the individualizing of decision-making that forms the foundation of transhumanist ethical thinking. An improvement for one individual does not necessarily represent an improvement for an other, and the unequal burden of implementation (or even ethical disagreement) means that there might be differences in how one thinks an improvement ought to be achieved.³²⁰ One cannot, solely on the basis of a measurable increase or decrease, judge the status or desirability of a given technology; not all technologies that represent measurable quantitative improvements can be considered enhancements. New technologies have networked effects; they are not limited to the choices of specific individuals or limited groups of individuals.

For Shües enhancements also have a qualitative nature to them. Enhancements do not

³¹⁹ Ibid, 40-47.

³²⁰ Ibid., 48.

have limited local effects but have substantial dispersed effects on the world around us—they change the human condition itself. How we live it, how we see it, and how we define ourselves through it. Without oversimplifying the insight, we can plainly see that things like the steam engine, motorized farming equipment, immunization/antibiotics, electricity, or the internet have qualitatively changed the human condition in profound ways—materially, culturally, politically, socially and *experientially* (for e.g., our abilities, vulnerabilities, and concerns). As she writes,

since the human condition and features are either contingent, pre-given, and created, they can be brought out or suppressed in different ways and can lead to different social structures and relationships. [...] the application of enhancement technologies in a strong sense changes the order of the world, culture, society, and generations, and each person's life, decision-making, and responsibilities in more or less drastic ways.³²¹

This realization of the contingency of the human condition and the *world-making* nature of enhancement highlights the importance of taking a more relational view of the societal integration of technology and the inherent dangers of privileging the dominant discourse of normality over the collective challenges of people at the margins—disability here, but others marginal groups suffer a similar fate. Moreover, I agree with Schües only if we include therapeutic advancements in this scheme, as they too have this quality to them. This is clearly exemplified in our discussion of how changes in medical practices and technologies have led to completely different subject formations. For Schües, enhancement discourses do untether themselves from the *telos* of the human in a way that is not seen in medical

³²¹ Ibid., 53-54.

discourses. Certainly, the imaginative nature of transhumanism and the explicit goal to create a new world/transhuman render this qualitative change more obvious, but I do not think that it represents an adequate demarcation criteria, as the lines are not so easily drawn in advanced technomedicine. Technomedicine (as a technoscience) is equally *world-making*, as I have discussed in relation to Hottos and transhumanism in the previous chapter—it is, and will continue to be, a guiding narrative that is already reshaping our contemporary world. The possibilities opened up by contemporary technomedicine not only open up a virtual future, but also qualitatively change the ways in which we experience the present.

The important take-aways here are threefold: 1) though it challenges our received definition of enhancement, we must consider how more mundane technologies, environmental structures, as well as Others (human and non-human) are integrated into the self and how essential functions are offloaded to them in our navigation of the world; 2) that a broader view of enhancement acknowledges how networked and integrated we are in the socio-political world more generally, and highlights how the question of technology might go beyond the judgement of individual artefacts; 3) that the individuation of technology and the obsession with *cure* and *elimination* through biotechnology is an insufficient foundation for a social change and world-making. It is with these in mind that we are able to carve out a critical perspective on technology (enhancing or therapeutic) that fits between a pessimistic bioconservatism on the one hand, and an idealistic transhumanism on the other. Though I have discussed enhancement here in terms of its function, the issue of the norm as the central demarcation criteria is further problematized when we consider how it is fixed. Though it is considered a matter of objective fact, how *normality* is defined is influenced by received assumptions about ability and one's experiential point of view. In the next chapter I will

criticize the narrow sense in which we have defined human ability and adaptation; however, in the following section I will discuss the related idea of how the restrictive definition of normality in the normal function view emerges. Taken together, these further destabilize the enhancement/therapy dichotomy and opens up avenues through which we may have a more appropriately complex relationship to biotechnology.

2.2 Normality is not a Solid Foundation

It is no question that the definition of therapy vs. enhancement has an important *raison d'être* in both medical practice and medical research. It is important in setting the limits of legitimate or permissible practices within the medical profession and plays a role in the ethical discussions around medical research, medical intervention, and public health funding. In trying to differentiate therapy and enhancement, the two most common perspectives are normal function accounts and therapeutic necessity accounts. These are the most used because they are the most practical; purportedly, they rely on objective measures and so have a solid foundation from which to set a fixed boundary. In the case of normal functioning there is an explicit or presumed natural *species-typical* range of capacities, and on the therapeutic necessity account there is an idea that disease can be identified and described in such a way that intervention is necessarily justified. Both rely on naturalised and objective definitions of their object—function or disease. The critique of this perspective can be found

in the work of Jackie Leach Scully,³²² and Anita Silvers³²³ who have been trying to navigate the waters of bioethics, enhancement, and disability for several decades.

Both authors acknowledge the fact that the process of defining norms is always influenced by implicit assumptions about what is natural and species-typical in line with biomedical understandings, but also that those assumptions are *normative* in the sense that they create ethical relations from responsibility and justice, value judgements about quality of life, and ethico-political judgements about permissibility, investment, and legitimate access. In other words, as Scully argues, there are two levels to bioethical norm setting, the actual intervention being debated—resulting in a number of deontic judgements about what is allowed or forbidden for e.g.,—and the underlying and implicit ontological judgements about what is good and bad, normal and pathological in the variety of human embodiments.³²⁴ In trying to dichotomize enhancement and therapy, two things have to happen. One must create an axis onto which human embodiments can be organized from worse to better, and one has to fix the point of reference at which something crosses over from therapy to enhancement. The solution for the normal functioning account is to fix the point of reference at what is “species-typical,” i.e., what is considered to be the normal (statistically average or physiological descriptions) of the specific function. The problem with these definitions is that they are not neutrally reflective of a biological reality, but

³²² Jackie Leach Scully, “When Norms Normalize: The Case of Genetic Enhancement,” *Human Gene Therapy* 12 (2001): 87-95.

³²³ Anita Silvers, “A Fatal Attraction to Normalizing: Treating Disabilities as Deviations from ‘Species Typical’ Functioning,” in Erik Parens (ed.), *Enhancing Human Traits, Ethical and Social Implications* (Washington, DC: Georgetown University Press, 1998), 95-123

³²⁴ Scully, “When Norms Normalize,” 88.

representative of a personal optic situated in a social, historical, and professional practice.

If we take the perspective of the person with a disability, their particular embodiment (whether they accept it or want to change it) is *experienced* as a natural given. Moreover, this variation is seen as within the *natural* variation of human embodiment insofar as they represent a point on the scale of possible human capacity. As Scully writes, “[i]f a cut off point is to be set that will exclude some degrees of variation but not others from the category of species-typical, it must therefore be chosen rather than deduced from self-evident biological criteria [...] It is essentially a value judgement that cannot be grounded in descriptive statements about nature or statistics.”³²⁵ There seems to be a self-evident and common sense understanding of what is normal, but this only seems to be the case from our geo-political and historical frame of reference. What we measure, and what we deem acceptable is based on the social demands of performance and are tied to liberal civic participation and market demands for certain types of capacities. One’s position on the IQ spectrum was not very relevant for serfs working under a feudal state, but today one can look in any university psychology textbook and see what level of achievement they should typically strive for based solely on their performance on this measure—neatly organized in a table with corresponding professions. In fact, these charts also show, by correlation only of course, what I should assume my reader’s IQ to be. Less tongue-and-cheek, this has socio-political importance because the factors that influence IQ become valuable as our Western society turns away from manufacturing and towards a more technologically advanced workforce. To the extreme, I can bring back the example of Bostrom discussed above where

³²⁵ Ibid., 92ff.

average intelligence is itself inadequate and we ought to look at ways to create individuals with enhanced intelligence *for the social good*. The important insight here is that the “norm” as statistical average does not necessarily set the limit of what is an acceptable variation.

Assuming the accuracy of IQ-performance correlations for sake of argument only: a society made up of mostly illiterate labourers does not have a need to medicalize IQs under 85 (e.g., feudal societies), but in one possible near future a society that *requires* significant numbers of high IQ individuals, smart drugs may be equally therapeutic for an individual with significantly low IQ as for someone with average IQ who find themselves unable to get work or perform in the job market. If we take the slightly different disease view—i.e., that something is a therapy if there is an identifiable pathology or impairment for which it is mobilized—the result is not much different. As discussed in the final chapters of Part 1, there is an abundance of examples where medicine is used to pathologize either an undesirable social phenomenon or an individual’s inability to attain a social standard.

Going beyond Scully’s paper discussed here, because it did not take transhumanism/posthumanism as its subject, we can say that there are two confounding insights to the normal function view.

- 1) As technological means of individual improvement coming from technomedicine and biotechnologies increase, and neoliberal demands of individual responsibility over performance intensifies, the range of acceptable variation diminishes and the point of reference justified by a normal function view means that more and more technologies fall under the therapeutic rather than the enhancement side of the dichotomy. Again this does not harken to a distant

future, its effects are already evident in the proliferation of smart drugs or stimulants in our universities, athletes, and advanced technoscientific workforces.

- 2) If we accept the fact of originary prostheticity and mediated posthumanism we can argue that what is species-typical is not legitimately a biological phenomenon. What *is* species typical is the wide range of variation and perpetual change that emerges from our interaction and ongoing relationship to technology-environment and the collective adaptive problem solving that emerges from these pressures. One could argue that this is quite similar to the transhumanist idea that we have *always sought to enhance our humanity*, but this only makes sense if we set a natural and normative limit. A critical posthuman perspective does acknowledge that we do seek improvements through tools and technologies, but not as a means of overcoming some natural limit. A cane, crutches, wheelchairs, etc. are all as adaptive and “human” as the pursuit of bionic legs. Given the lack of demarcating criteria, the ‘what’ that is being overcome is not a simple ability, but a more complex integrated phenomenon that requires social, historical, and political reflection from a situated point of view.

What Scully argues is that the normal limit is relativized by one’s point of view, which represents quite the reversal from the natural limit perspective.³²⁶ One’s experience is normative, not the other way around. For example, a person who reaches 4 feet tall at

³²⁶ Ibid., 93. We will return to this shortly.

maturity, this will become the normal height with which they have learned to navigate the world. However, if there was some biomedical intervention that could bring them up to 5 feet 6 inches (the current average) we would see a divergence of interpretation: to the recipient, it would be an enhancement but for the medical professional it would be treatment. Conversely, if someone born with exceptional hearing—say in the 99th percentile—acquires hearing loss that brings them down to the average range, an intervention to bring them back to where they were would be, for them, a form of treatment. This would be, from the perspective of average function, an enhancement by definition. Certainly, since there is measurable loss, it would still be clinically justified. But this further weakens the idea of fixed norms, as one can only justify intervention because the exceptionality was normal *for them*. This is precisely the point that Scully is making. These examples show that statistical averages are not adequate markers because they do not account for the normative nature of personal experience. In *standardizing* typical experience, a choice is made that is neither neutral nor biologically grounded. In fact, we can make the same criticism as we did of modernity itself; namely, that idealized *normal* man is not a biological or natural entity but a fantasy that serves a normative function.

In a widely influential paper, *A Fatal Attraction to Normalizing: Treating Disabilities as Deviations from “Species-Typical” Functioning*, Anita Silvers shows how public health perspectives around justice and access to medical services can be shown to rest on problematic footing and lead to the normalizing practices I have discussed throughout this section. For her, the primary problem is that the normal functioning view identifies what is *normal* as what is typically expected of a person in society, and therefore, justice in healthcare is using biomedical intervention to bring people with disabilities to this norm of

expectation and performance. For Daniels *et al.*³²⁷ what differentiates just treatment (and treatment by definition) and unjustified intervention (enhancement) is that treatment explicitly seeks to bring the individual to normal capacity so that participation in society remains unaffected. Though this might be a noble goal, what ends up happening is that the norm becomes the social expectation and medical treatment a means of normalization. The only differentiator is that of a diagnostic category,³²⁸ which we have already seen expands quickly—especially in psychiatry and school psychology—based on social norms of performance. Though at face value it appears to be a good distinction, this makes Daniels’ dichotomy an ineffective alternative, because it is contingent on the same categories that are elsewhere essentialized. Like other clinical settings, the individual is not meant to decide what they deem normal or acceptable, but must choose whether or not they want to take the option offered to them by the biomedical establishment and be responsible for the consequences of their choice. Once something is identified as an acceptable treatment, it does not become simply an option, it becomes a responsibility for the individual over their defective body—rejected at their own peril. Leaving the normalizing aspect aside, for a moment, we can look specifically at the relative nature of the norm with respect to the socio-historical context.

To show how the simple view of ‘treatment as return to normal’ is inadequate, Silvers uses the example of breast reduction procedures.³²⁹ In many Western countries today,

³²⁷ Norman Daniels, *Just Health, Meeting Health Needs Fairly*, (Cambridge, Cambridge UP, 2007), 149-155.

³²⁸ *Ibid.*, 153-54.

³²⁹ Silvers, “A Fatal Attraction,” 98.

breast reductions are considered therapeutic because the disadvantages of having large breasts are acknowledged: back pain, issues with exercise or sport, difficulty in finding clothes that fit their body types, it makes them the target of unwanted attention or disadvantage in the workplace, etc. In another context, where a woman would not be expected to work outside the home, where clothes were made to custom fit, where exercise and sport were not ‘lady-like’, it would be impossible to consider breast reduction a treatment. It would increase comfort, but it would not remove a disadvantage. Now suppose a woman in the latter society would argue that maintaining the normal functioning of women *is itself* a disadvantage because it limits the roles a woman can assume, does it then become treatment? Having moved from the society where the expectations of women were not to work and perform sport to one where it does include these things, we are struck (or ought to be struck) by two things: 1) the contingent nature of expected functioning, and 2) the tenuous foundation of the enhancement-treatment distinction.

In fact, from my perspective, it is precisely this function that will become problematic as the runaway norms of maximization/optimization continue to change the level of expected performance of individuals in the workforce, in education, and in sport. As we expect more and more out of individuals, the less we consider performance-*enhancers* as such, and the more these technologies will become equalizing technologies. My goal is not to pass judgement on whether or not someone should use a stimulant or an anabolic steroid, but simply to point out that the weakness of these distinctions are not only theoretical. Who we pathologize and who we seek to normalize, as well as the question of justice relative to who has access to what intervention has real life implications. In the examples I have discussed in Chapter six, in order to keep up with social expectations we may medicalize certain people

so that stimulant use becomes therapeutic, but for those whose use falls outside the medical profession, they are criminalized and face sanctions—this is as true in education as in athletic settings.³³⁰

To reiterate one of our earlier examples, the use of Provigil has become quite publicised recently because of its use in Silicon Valley. The technology (Provigil) was developed to treat various sleep disorders. It is used in Silicon Valley as a cognitive enhancer and as a means to remain competitive in a cutting edge techno-scientific area of practice. Certainly, there is a cultural dimension of the acceptability of enhancement in this area, and the privileged position of highly valued multi-millionaires gives them some protection to publicly discuss the off-label and non-therapeutic uses of these technologies. It is technically *criminal* behaviour, but with some ethical gray area given the transhumanist insistence on personal freedom, the limited involvement in black markets, and the general social attitudes towards drug addiction and drug use (i.e., it *appears* different and the intention is not recreation). Though it is veiled by big personalities and the quest for personal perfection and glory, there is a dimension of being pulled by an unattainable performance standard. We expect *more* from them, so we accept some overstepping. As one family doctor in the heart of Silicon Valley stated in the Washington Post, “People want to find an edge over their competitor — that’s how they got their position in the first place. I’m trying to give them a little more wiggle room — but in a safe way.”³³¹ Most examples, though, are not usually

³³⁰ Keeping in mind that I am not advocating for any use of pharmaceuticals to enhance performance. This is a dangerous and irresponsible practice. However, for all that, we cannot ignore that it happens and why.

³³¹ Sara Solovitch, “Tweaking Brains with 'Smart Drugs' to Get Ahead in Silicon Valley,” The Washington Post (WP Company, June 11, 2017): <https://www.washingtonpost.com/national/health->

limited to such privileged people and the goal of enhancement is not so openly stated.

One area related to work where Provigil has a legitimate therapeutic use is the diagnostic category of Shift Work Sleep Disorder.³³² The body's inability to regulate circadian rhythms in some individuals is seen as a legitimate medical disorder because it represents a variation that is not universal *in those people who do shift work*. In other words, it represents a variation in response to a specific social practice. As we have seen, even though this variation is *natural*³³³ in the sense that it is observed in the population, it is not *normal* in the sense that it creates a disadvantage in a desired function that is attainable in average people within that class. Again, evidenced in the breast reduction example, such variations would not be recognized as sites of intervention and just access in a different common social practice. As was apparent in that example too, from the perspective of the individual doing shiftwork—who is disproportionately less educated and of lower socioeconomic status—Provigil is *treatment*. However, from the perspective of a pre-industrial and pre-globalized society where 24hr work cycles are not typical (or even essential to national competitiveness) such interventions would be regarded as enhancement. The related issue being that the *variation* is pathologized while the expectation placed on these more economically precarious workers are not themselves problematized—the norm or expectation is not the issue, it is the worker's body that is the issue. It does not represent an objective biological limit, nor does the use of Provigil in one situation differ in *kind* from the

science/tweaking-brains-with-smart-drugs-to-get-ahead-in-silicon-valley/2017/06/09/5bc9c064-0b35-11e7-93dc-00f9bdd74ed1_story.html.

³³² International Classification of Disease 10th edition, “Sleep Disorders” ICD-10-CM, G47.26.

³³³ Using it here in the same sense that normal functioning perspectives use it, though I will argue this is itself problematic.

other—in both cases Provigil is meant to improve function so that individuals can perform to an established social standard. The example of Shift Work Sleep Disorder makes the contingent nature of pathologizing human variations based on social standards quite clear, but in the case of the Silicon Valley CEO the argument needs an extra step. This step goes beyond Both Scully’s and Silver’s arguments because they are not discussing transhumanism specifically.

Legitimately, one could argue that in the first example—the CEO—Provigil use *does* differ in *kind* with the shift worker because the level of performance is outside the observed variation within the population. But again, this standard is established as a snapshot of today’s individual outside of the technoscientific context, historical period, and political environment within which that person is placed. We could arbitrarily choose a moment in the history of our species and decide to set the limits of observable variation of every possible human capacity, but this variation would not be fixed. As we integrate technologies in our modes of living and as these co-develop and change what abilities we would find important and the level of performance that is *normal* on those measures. For example, past societies that use only oral traditions place certain needs on long term memory that are not as important for people with written histories—esp. those that have access to things like Google and searchable books.³³⁴ While showing the subjective nature of fixing a point within the range of human variability as a scientific norm is fallacious may be an effective critique of

³³⁴ I am not making an anthropological cross-cultural argument here because I do not have the empirical data to support such an argument. So even taking Anglo-American history as the standard for this argument, our ancestors did not always have the written word or the need for widespread literacy; moreover, in just a few generations digital literacy introduces even new expectations that were not present before (and other’s become less important). This, to me, seems to be an uncontroversial truism.

the normal function view—as Scully and Silvers have done—we can go further and say that even the measured variability, if all variations are deemed acceptable modes of human life, still does not give us all acceptable variations. Arguing from a posthumanist position, informed by originary prostheticity, we can say that the range of variability is itself variable because of the unpredictability of the co-development of human-technology relations over time. In practical terms, predicting how individuals will use technology to adapt to new challenges is speculative, and any fixed limit on the variation of human abilities is a dangerous prediction of their potential. Fixing a limit of acceptability may be useful in avoiding negative consequences, but it also limits the creative and affirmative potential of technological adaptation. We can see here that there is a danger in collapsing the distinction between therapy and enhancement, because it seems to lend some credence to some of the claims that transhumanists make (e.g., the need to develop technologies and increase human potential etc.). However, given the parallel critique of naturalization and a fixed human constitution, it does much the opposite. It dethrones them as the primary discourse on the future of technology-human relations, and opens up the possibility of learning from those at the margins about the potentials and dangers of contemporary practices.

Most importantly, for Scully and Silvers, is that failing to see how normality is dependent on one's position and perspective not only influences the ways in which ethical decisions are made, but goes much further in creating a scientific basis for dichotomizing between two types of people: species-typical and abnormal.³³⁵ Such practices must be resisted because it invites reductive value judgements placed on individuals that fall on either

³³⁵ *Ibid.*, 93.

side of the dichotomy. To bring it back to this dissertation, it creates the supposed objective distinctions (and subject positions) between under-performing populations, the “disabled,” transhumans, and posthumans and places value judgements on these categories. Sketchily the value statements would follow these lines, from the perspective of disability, variations in functioning may be a wholly acceptable (or even desired) normal, though sometimes it does lead to negative experiences for which treatment may be sought and ought to be made available; from the perspective of the standard normal function view, people with disabilities represent a problematic population whose impairments are inevitably a source of suffering that ought to be avoided and treated as a matter of course; from the perspective of the transhuman both disability and natural (normal) limits are part of the poisoned gift of nature and ought to be overcome. Without doing away with the fixed standard of normality, disability cannot be seen as *acceptable* variation, and the perspective of their experience is not seen as a valid position from which to make normative judgements on acceptable forms of human life or acceptable uses of technology. We recognize that there is a common kinship among the normal function view and the transhumanist view, insofar as they both accept that the *norm* is a natural limit, though they disagree on what to do with it. Does it set an ethical limit of intervention on the human body, or does it represent a launching pad for the technological exploration of human potential? The best thing that a disability informed critical posthumanism can do is undermine this foundational assumption so as to destabilize the monopoly of these perspectives on normative judgements and lay bare the socio-political undertow of their resulting policies and practices.

2.3 Whose Voices?

It is quite understandable that in both folk understandings and in professional circles that therapy and enhancement seems like a fairly obvious distinction. This is because the normal function view is based on the *typical* point of reference experienced by the majority of people,³³⁶ and it is consistent with the contemporary objective value attributed to biological norms. As we have seen, however, this perspective fails in a few key ways. We are left, then, with quite far-reaching and still unresolved problems about how to understand the place for technology and its limits of acceptability. What is clear, however, is that given the lack of objective standard, we have to include the perspectives of individuals with disabilities and all others at the margins. Not only in terms of their wishes and concerns, but in the actual practice of defining things like normalcy, disability, enhancement, justice, etc. In fact, all judgements of technology are relative to the situated normativity of individual experience, and the normalizing power or social expectation. This is true for everyone, just more obvious in the case of disability because their experience has been systematically suppressed as expressions of normal life, and their bodies and behaviours been the perennial example of failure that social norms (expectations) are built on.

In looking quite generally at Schües' historical analysis here, we understand that there is an entanglement between what a society identifies as its epoch defining ills, what it considers worthy of sustained political improvement projects, and the understanding of who and what we are. The infinitely malleable body at the level of its vital processes and the ideal of the free and responsible neoliberal individual represents the anthropological notion of who

³³⁶ Ibid.,

we are, and improvement projects related to cure, prevention, and elimination of biological barriers to attaining these aforementioned norms are numerous; though not always without controversy (e.g., germ-line manipulations). Whatever we identify as the defining impetus at terminus of these myriad projects—a utopian society of perfect health, justice, and liberty representing an idealized bioconservative perspective, the overcoming of all human and environmental limitations towards a technoscientific society hitherto only possible in our wildest imagination, or everything in between—people living with disabilities remain overdetermined by these discourses.

Even non-transhumanist bioethicists and industry influencers seem, more and more, to participate in this game of fantasy and imagination, treating hypothetical problems as if they were a few years away from reality. This is a dangerous place to be, because it creates a reality based on the same concepts and discourses that have already been shown to be disastrous for people with disabilities; creating new forms of discrimination and perpetuating old ones, all the while shutting out their voices (adaptive/normative experiences and alternative embodiments). As the structural Others of modernity, marginalized people never really had a strong voice in creating our current world. Casting the transhumanist-like future as an already present reality leaves untouched the ontological distinction between desirable normality and undesirable forms of life.³³⁷ Transhumanists discourses, and the biotechnical trends that dominate today, perpetuate this structural otherness at all levels of technological development and acceptability of intervention. The therapy/enhancement dichotomy serves an important discursive purpose, but its justification in neutral scientific fact is

³³⁷ See Chapter 2 and 3 of Part 1.

unsubstantiated. It is the product of a political worldview that is situated in a privileged position. The reason for this is not so much some nefarious want to disenfranchise a whole population, but the result of how we access the world through situated experience. As Scully argues, the reliance on species-typicality and functional normality has less to do with science, and more to do with the role and effectiveness of the socio-political arguments being made, as well as the experiential bias of common (average) experience.³³⁸ This makes correcting the issue difficult. The problem cannot be *seen* by everyone, least of which the people who typically do the research and policy work related to social difficulties. The situatedness of experience makes understanding a challenge. Scully explores this with respect to hearing difficulties and deafness.

Though the definition of what is species-typical seems easy to decipher from a biological point of view, in reality we can plainly see that instead of naturalizing the variety of typically occurring human experiences and capacities (including impairments and exceptionalities) what is considered normal represents a conventional view.³³⁹ It relies on a certain narrowing of variations so that the argument can be effective. One's normality is extrapolated from the population average or clinically acceptable range, the identification of a cause and actual or potential solutions, the needs of performance in a given form of social organization (economic participation and civic responsibility), and the image of man (as an anthropological and philosophical concept)—all of which *necessarily* separate themselves

³³⁸ Scully, *When Norms Normalize*; for a similar issue in ethics see also, Jackie Leach Scully, "Drawing Lines, Crossing Lines, Ethics and the Challenged of Disabled Embodiment," *Feminist Theory* 11, No. 3 (2003) 265-280.

³³⁹ Scully, *When Norms Normalize*, 91-93; Silvers, "Fatal Attraction," 99-100.

from subjective experience. It is an epistemological necessity for the claims to objectivity that underlies the authoritative truth of these discursive devices, which in turn are needed to establish technoscientific or social development projects.

The problem of perspective troubles this foundation, and ought to lead to a total collapse of the strict distinction between therapeutic (read “acceptable”) and enhancement (read “contentious”) technologies. For example, if being born with limited or no hearing were acknowledged as part of *normal* human variation, it would be much more difficult to argue that a cochlear implant is essentially therapeutic. The argument is not that it is *not* therapeutic, but that it is not so in some self-evident or necessary way. If we want to use this distinction, it must be drawn *with regard to the perspective and wishes of the person with a hearing impairment*.

On the one hand, if a person with a hearing impairment desires some medical intervention in order to bring back a function that *they consider* a loss then it can certainly be perceived as a therapeutic use. On the other hand, in a previous historical period, it was believed with much scientific zeal that people born deaf *also* had reduced cognitive ability—typically called the “deaf and dumb.” Certainly, society has changed, but individuals in the Deaf community still face discrimination and high levels of unemployment or under-employment. A person might seek medical intervention to escape discrimination or modify their bodies to attain an established norm of performance (in a mis-fitting system³⁴⁰). This use of technology to better fit socio-political expectations, i.e., to normalize oneself, is not so

³⁴⁰ The *level* of functioning is not the problem, but the *mode* of functioning that does not fit with current social organization. We will come back to this in the next chapter.

easily placed on the therapy-enhancement dichotomy. The argument is not that a distinction cannot be made, but that it is more complex than relying on a biological standard. Moreover, it takes the focus away from pathological embodiments to problematic social structures. Destabilizing normal functioning view makes arguments for social change more visible and much stronger. It is true that it can simply lead to willing self-normalization—which is something we all do in some form or another—, but it also opens up avenues for political action and resistance.

Conversely, individuals might see no issue arising from their deafness at all and consider it a completely normal, or desired, part of their embodied experience.

The scientists and clinicians who believed that they were providing a cure for the loss of hearing by purely technical means did not realize that not all Deaf people actually experience deafness as a loss of function of the ear, as something that needs to be cured. There are many Deaf people, especially those who were born deaf, who do not see themselves as disabled but rather as a member of a minority group with a rich culture (‘Deaf culture’) and its own language.³⁴¹

The automatic assumption that disability=bad is *perspectival*, it represents the fear of loss in those whose experience has normalized a certain function and the inability to imagine a life without them. There have been many challenges to the personal tragedy view beyond the fairly strong Deaf and Blind person movements, for example neuro-atypicals, aspies, crip culture, and mad pride. But these affirmative social currents fail to change the received view

³⁴¹ Christopher Rehmman-Sutter, Miriam Eilers, and Katrin Grüber, “Refocusing the Enhancement Debate,” *The Human Enhancement Debate*.

of disability. And one can certainly understand why this is.

To use myself as an example, having been born as a hearing person I have accessed education, work, and leisure in the manner in which society is currently set up to deliver these things. So it has appeared, for lack of a better word, seamless. Even in the most mundane ways, I play musical instruments, I enjoy watching documentaries and sitcoms, I talk to my family on the phone, I do not consider asking for accommodation before I go to a job interview, I go to conferences without checking if there will be an interpreter, etc. It all seems very natural to *me*. This is by no means exceptional; the way we receive, navigate, and interact with the world over time becomes entrenched in our every day experience. We create what is normal to us, and people with hearing impairments find their way. Whether this process of creating our personal worlds through experience happens from birth, or whether we establish new norms following some calamity, the process remains the same.

It is understandable, from my experiential point of view, situated in this historical and cultural moment, that I would interpret deafness—seemingly objectively—as a deficit and as undesirable for all. But this is *not* the case, and it is the same mistake the “scientists and clinicians” in the above quote were making. It is a generalization of my subjective experience and related fears presented under the guise of scientific objectivity. We can argue that it is bad science, but the reality is that it is a nearly automatic cognitive assumption that serves as one of the root cause of ableism itself. If taken seriously, however, what it highlights is the need to include the voices of people living with disability in order to fill in the richness of normative life-worlds and embodiments that represents the actual variation of human experience. This task is not limited to people born with variations in functioning. Insights can be gained from universal experiences such as aging, illness, mental health and

substance use challenges, as well as acquired disabilities. We often ignore the fact that what we consider normal is a precarious thing, and the need to adapt one's life to a myriad of changes. In the best of scenarios, those experiences would contribute to and change the way we organize our societies instead of ending at the level of personal tragedy or reactive accommodation. Instead of looking at biotechnology and environmental technologies as either means to treat backwards medical conditions on the one hand, and means with which we move forward in creating a new and improved world, we ought to mindfully acknowledge the actual reality we exist in. We already live in a posthuman world, this for me is a given. This I have argued in the previous chapter. The question for me is, can we make a series of minor course corrections—e.g. in our definitions of enhancement and therapy, upstream investments in social inequities, our understanding of acceptable human variation, etc.—in order to ground the future of technological progress in reality as opposed to a fantastical world that will never be.

2.4 Summary

In this chapter I have extracted a few important insights from what appeared to be a fairly straightforward distinction between treatment and enhancement.

We understand that there is a political dimension to what, in a given period, we mark out as suitable for improvement on a large scale. Pathology in all forms is an important site of problematization since the birth of biomedicine, and since the turn of the century this has been tied to the hereditary (today genetic) health of the population and its productive capacities. The discussion of what counts as therapeutic and what counts as enhancement

does not happen outside of this general scheme. As I have established in the first part of this dissertation, clinical norms come to dominate the discourse of truth, and it is this discourse of truth about medicine, of individuals and populations, that animates normalization in our society. We see that working itself out here. What counts as therapeutic is what brings the individual back to the norm. This norm is both biological (i.e., average or typical functions), and population based (i.e., typical variations on expected performance measures). However, the decision to normalize certain typically occurring human variations and problematize others is a matter of professional convention and not objective science, and the identification of what counts as a functional impairment is contingent on the expectations of performance in a given historical period. Certainly, some human variations lead to difficulties, but the extrapolation from that to an objective and fixed limit is an overstatement that bolsters a myriad of problematic normalization strategies and diverts attention away from the actual needs of people living with disabilities. It supports the idea that disability is an objective class of conditions whose solution can be found in the development of ever-more-complex technoscientific interventions. From the perspective of disability, however, there are several problems with the scenario discussed here. Not all human variations are experienced as pathological embodiments, the scale of investment in biotechnology ought to be balanced with social change and access to even very basic assistive devices. Moreover, the dominant perspective in biotechnological development perpetuates the idea that disability is an objectively negative class of embodiments that necessarily represents suffering and limited social value. Certainly, it would be valid to point out that some aspects of various disabilities are objectively negative. However, once corrected for the peripheral causes of difficulties (social, political, and economic), those aspects of the disability join ranks with other more

typical forms of human suffering. This is the point. Not that disability, disease, trauma or injury are to be considered as inherently positive, but that they are part of the human condition. A being with all of these removed is nothing but an idealized fantasy. It is this being that forms the ideal of modernist man, and which is further surpassed by transhumanism. The critical posthuman, by contrast, is simply the more accurate description of man in confrontation with natural adversity finding ways to adapt and affirm life—suffering and all. We will discuss this in more detail in the next chapter.

The idealized human figure can be traced to the codification of the situated average experience into a science of human capacity and its potentials. This is a problem generally, but it is most acute when we look at the increasingly biotechnological-performance obsessed society currently being developed. It gives us a narrow field of intervention when thinking about the future of our technologically advanced society. It is key, then, that the true variety of human experience and its changing milieu contributes to the rolling trajectory of technological development and regulation. And central to allowing for such a contribution is to do away with the idea of a purely objective metric for normal functioning and the enhancement/therapy dichotomy it supports. Such a distinction cannot be extrapolated from the understanding of bodily functions or the rationalizations derived from diagnostic categories. With respect to disability, without this more nuanced view the contribution risks being reduced to a description of a medicalized (impairment) experience, speaking only on matters of therapeutics, and only from the position of a consumer or research subject.

In the following chapter I will build on some of these ideas in order to suggest some deeper insights that come from the experience of disability; insights that challenge received ideas about our relationship to technology, our relationship to each other, and the adaptive

nature of life itself.

Chapter 3—Two Insights from a Disability Perspective

In both previous chapters I have brought up some important points of friction that come about from a person's 'situatedness.' In this chapter I will explore two moments, grounded in these experiences, where disability can open up alternative ways of seeing. First, we will talk about what I will term modal adaptations, discussed in Silvers³⁴² as traditionally devalued alternative ways of performing bodily tasks. A wheelchair, for example, is typically seen as acceptable, but less desirable than bipedal walking. This simple move of placing it *under* typical has important implications when framed in the general discourse of health and ability. Secondly, I will discuss the concept of interdependence and precarity as it will frame more generally all of the insights present in this and two previous chapters. More specifically, how a call to be more grounded in reality about our posthuman world is not an argument only for those at the margins, but one that affects everybody. It will also serve as the turning point towards the final consideration for this dissertation, i.e., the questions of what can we do with all of this?

3.1 Modal Adaptations and the Lived-Body

From the standpoint of the multiplicity of valid points of view, we have seen that the attempt to set a universal limit between therapy and enhancement is deeply problematic. There is however, a parallel challenge when trying to quantify disability more generally. For Silvers, there is a clear bias for typical *modes* of functioning above and beyond actual levels of

³⁴² Silvers, "A Fatal Attraction to Normalizing"

functioning. She argues that there is a certain ‘tribalism’ in our way of thinking about ability, a “partiality for interacting with those most like us, undoubtedly influenc[ing] us to assign pre-eminence to (the appearance of) normalcy” even when the personal costs do not outweigh the apparent social benefits.³⁴³ She gives us a few historical examples like the early resistance to the development of sign language, or the painful and inadequate prostheses developed for children born with malformations following the use of thalidomide. In Canada, and elsewhere, children with inherited malformations due to maternal exposure to thalidomide were “forbidden to roll or crawl”; an adaptation that increased their ability to navigate the world but accentuated their malformations and differences. As the children grew up, the therapeutic focus would turn to “artificial limb design and manufacture rather than wheelchair design” which she claims “was influenced by the supposition that walking makes people more socially acceptable than wheeling does.”³⁴⁴ She notes that, as these children developed into adults, they mostly returned to wheelchair use as their preferred adaptation—contra the attempts to normalize their bodies to conform to the bipedal ideal. Similarly, in the case of deafness, there was significant debate in how to educate deaf children in the mid-19th century; one camp the ‘oralists,’ focused on lip reading and mimicking mouth movements as a means to acquire typical speech, while some argued for a position termed ‘manualism’ which represents the origins of today’s sign languages. The argument from the oralists, which happened to prevail for some time, was that sign language would make deaf people part of an underclass unable to approximate proper participation in society, which would represent, for them, a source of unimaginable dehumanization and suffering. This argument

³⁴³ Ibid., 113.

³⁴⁴ Ibid., 114.

was quite effective in justifying a focus on lip reading and oral speech while suppressing efforts to develop sign language. We see here the same ‘tribalist’ idea than the example of bipedal walking. Silvers generalizes this tendency where the appearance of normality and the social acceptability of an adaptation is more important than the ability and capacity benefits of a modally different way of doing. In other words, approximating modal normality with diminished capacity has a higher value than better capacity with obvious differences, *because of the psychosocial costs of being different.*³⁴⁵ In other words, we value sameness above all, and shroud the suppression of alternatives in a benevolent veil of inclusion. These movements certainly saw their work as benevolent, and their goal was a noble one; the integration in, and access to, society for people living with disabilities. In many ways, current biomedical perspectives on disability follow this exact structure. Bring the individual as close as possible to the norm through intervention and declare access to that intervention a fundamental right. Certainly, on the face of it, it seems perfectly acceptable to say that minimizing the negative psychosocial effects of disability and acknowledging the right to equity is a worthwhile and morally acceptable goal. In many ways it is. However, the problem is that we continue to do it by focusing on the individual body, naturalising and valuing the typical-function norm, and failing to challenge any aspect of society or the environment. This is a significant ethical and political problem. As Silvers puts it,

Far from being the natural way of conducting ourselves, the modes of functioning that typify our species may merely be ways of doing things that are preferred by the dominant classes and to which we have therefore become accustomed. To the extent that this preference is the

³⁴⁵ See Silvers’ critique of Brock in “A Fatal Attraction to Normalization,” 115-18.

case, policies of normalizing, however well-intentioned, threaten not to equalize but to preserve existing patterns of functional dominance and privilege.³⁴⁶

In other words, benevolence does not automatically lead to justice, in fact history shows that such an idea is quite damaging when people claim to speak for universal humanity or speak for the needs of others. As was the case for those citizens who, once they reached maturity organically moved towards wheelchair use as opposed to the array of prosthetics benevolently imposed on them, we find that individuals adapt to their environment in ways that they find acceptable given the available means. This is not a comment on how people deal with disability, but a fundamental truth about our (post)human condition.

I am thinking here of the importance of Canguilhem's vitalism and what it can teach us about *de-pathologizing* modes of functioning. For Canguilhem, the very possibility of calamity, falling ill, or being challenged is what gives life its specificity. As he sees it, there is no such thing as health or pathology in and of itself; they are the mere descriptions of 'fit' between person and environment given a certain change in either. As such,

[a] sick individual is an individual locked in a struggle with its environment to establish a new order or stability. Recovery establishes a new norm, different from the old. [...] A healthy person is a person capable of confronting risks. Health is creative—call it normative—in that it is capable of surviving catastrophe and establishing a new order.³⁴⁷

³⁴⁶ Ibid., 108, 117.

³⁴⁷ Canguilhem, *A Vital Rationalist; Selected Writings*, 355.

There is no mention here of fixed norms or quantifiable markers of health. It is the practical expression of Canguilhem's vital principle; that is to say, of the immanent and dynamic establishment of life norms in confrontation with the environment, illness, or impairment. Health, illness, and disability are first and foremost a description of either a failed or successful process of creative adaptation to an environment or pressure.³⁴⁸ So health is not 'in the body' it happens in the space 'in-between' a relational self and his/hers/their environment. There is no fixed healthy body or way of being. Likewise, no environment is 'normal' in the sense that it is a natural given.³⁴⁹ One ought to be able to challenge either. Not only is this a better description of what we see people living with disability *actually doing*, it confirms the importance of the political mission to change society to be more amenable difference. To use Silvers' language, we need to counter the 'tribalism' that problematizes and resists perfectly feasible adaptive strategies to the benefit of "custom" and the "preferences of the dominant classes." Neither custom nor preference is healthier or more 'natural' by definition which, challenges the dominance and privilege attributed to the established modes of functioning. Relying on Canguilhem again,

the normal is that which is normative under given conditions, but not everything that is normal under given conditions is normative. It must always be permissible to test the normal by varying the ambient conditions. It is in this sense that *the*

³⁴⁸ 'Creative' in the dual sense that it represents something novel but also that it is productive—it brings about something new. It creates new forms of embodiment and new relationships between the self, human and non-human others, and technologies/artefacts.

³⁴⁹ *Ibid.*, 354.

*history of the world is the judgement of the world.*³⁵⁰

To put it simply, we cannot look at how things are and extrapolate from that what forms of life ought to be pursued. This establishes what is normative by excluding adaptations that may be perfectly normal in a given situation. It is a politically damaging exclusion that reverberates through history and into the future. The insights we have explored in the last few chapters converge on this point. If we are inherently cyborg beings, with no fixed natural benchmark from which we can extrapolate universal species-typical norms, and we engage by default in a process of creative adaptation to, and successive creation of, our environment then we ought to resist attempts to *limit* alternative forms of life.

Modal adaptations, i.e., ways of doing things that are atypical and different, have potential far beyond the individual. We see this historically with the formation of an affirmative deaf culture around sign language that ended the detrimental effects of limiting language acquisition of deaf children. Unfortunately, it would have been impossible, at that moment in time, to predict the impact that sign language would really have on our society so many years later. It needed the space to make its mark on our social history. This highlights the need to broaden the range of acceptable contribution, because norms of performance, human morphology, the social acceptability of biotechnology or wearable technology, the genetic malleability of future generations, etc., all have the paradoxical effect of opening up difference *for some* privileged people, and of imposing more and more normalizing limits, regardless of negative effects, *for others*. It is imperative that the actual practices of people with disabilities that challenge the norms are valued and included in those important currents

³⁵⁰ Ibid., 370.

of change. Those modes of adaptation and models of embodiment are important because the discourses through which disability is recognized and created, and through which people recognize themselves as subjects are completely void of a whole subset of valid models of living and the *qualia* of individual experience as *normative* experience. For most people ‘on the ground,’ life does not typically involve hours (months, years) of contemplation about historical movements, philosophical concepts, and social action. The challenge for activists, engineers and academics is in harnessing useful form of resistance from that which is organically occurring for and with those who are currently left behind. The burden of making society listen cannot be placed on the individuals engaged in basic survival. This will bring us to the insight in the next section, i.e., our inherent interdependence. This is very apparent for people with disabilities, but only because in the current order of things, individuals within the accepted—tribal—range of normality have the illusion of independence and individual achievement. Dispelling this is paramount to resisting the exclusionary tendencies of established norms and dethroning transhumanists in their monopoly over imagining our future societies. It represents one of the most important challenges that disability theory can engage in for establishing a more equitable and ethical future for all. As Braidotti would put it, “[a]t this particular point in our collective history, we simply do not know what our enflashed selves, minds and bodies as one, can actually do. [...] A sustainable ethics for non-unitary subjects rests on an enlarged sense of inter-connection between self and others [...] by removing the obstacle of self-centered individualism on the one hand and the barriers of negativity on the other.”³⁵¹ The insights of interdependence beyond the illusions that are enforced by neoliberal normalization and the ideas of natural man come, for Braidotti, from

³⁵¹ Braidotti, *The Posthuman*, 189.

the varied fields of gender studies, animal studies, and eco-criticism. Interestingly she also does make special mention of Disability Studies as “emblematic of the posthuman” because it marries this critique of the normative body and advocates for “creative models of embodiment.”³⁵² Today we are faced with a great number of issues from the ecological crisis to the potential dangers of the manipulation of life’s building blocks, to the runaway norms that problematize more and more modes of life, to the social issues that flow from austerity and inequity. The position of posthumanism and posthumanist Disability Studies is that the answer to these issues will at least in part come from a reevaluation of human life and a dismantling of the radical individualism that give rise to the worst results of these trends.

3.2 Independence is not a Binary Variable

As discussed in the previous section, we must find ways to integrate the experience of disability in our more general frameworks of understanding. We must do this not only because it is politically useful for disability, but also because it is a more accurate representation of our human condition. One of the areas where this is most obvious is that of independence. Not only is independence the cornerstone of modern man, it is also the goal of many services for people with disability (i.e., to help people live *independently*). For the purpose of this section, we have to be specific about what we are referring to when we use the term independence. We can talk about independence in the folk sense of being able to accomplish certain things *on one’s own*. Modifying someone’s environment or offering prosthetics, engaging in treatment or rehabilitation, education and training, or giving

³⁵² Ibid., 145.

someone the means to have access to various levels of assisted living in order to maximize the individual's ability to do things on their own can be described as *increasing independence*. Certainly, it would not be my intention to argue that such things ought not to be pursued, much to the contrary. The idea is that we challenge what we *mean* by independence in this context, and that we do not forgo or suppress creative and liberating forms of adaptation for more established medical and socio-typical ones. We have to be careful not to fall into the trap of advocating for technologies and interventions that aim only at simple inclusion as discussed elsewhere.³⁵³ Aiming only at inclusion leaves people at the mercy of established normalization strategies and contributes nothing to the shaping of society or a reevaluation of what lives are worth living. Keeping these issues in mind, it remains that much of disability activism does make use of modernist concepts like independence, dignity, and human rights. The goal should not be to discourage such action, but to purposefully modify these terms to encompass a much broader spectrum of possibilities.

One such relevant attempt to broaden these concepts in order to make them more useful for critical disability perspectives has been the work of Goodley and Runswick-Cole around 'dis/ability' and 'dis/humanism'. As they put it, to "dis" something is a slang term for showing contempt for something or disrespecting it; "to *dis* is to trouble."³⁵⁴ When people with disabilities claim concepts that have historically been denied to them like independence and dignity counter to the definitions and images we have of them, they are troubling the

³⁵³ On this last point, see Chapters 1, 4 and 6 of Part 1.

³⁵⁴ Goodley *et al.*, "Becoming Dishuman," 5.

foundations of what those concepts are. They are not iterations of independence, but purposeful modifications of it and (potentially) are a form of active resistance. The ways in which they claim these in practice often substitutes for the fixed and ahistorical foundation of such terms the contingent and fluid character of actual lived experience. Goodley and Runswick-Cole use the metaphor of the *fallacy of equivocation* to illustrate the point. They posited that when people with disabilities claim these terms, their meaning is not equivocal to the ones claimed by humanism, and it is the differences that have potential to destabilize the definitions we make of them. If a person living in an assisted living facility attends treatment planning meetings and make decisions about their treatments and needs or if a person attends a protest or votes with the help of an assistant can we legitimately deny them the labels of independence or citizenship? It is not until the 1990s in Canada that full civic participation and patient-centered care started to officially take hold. And if we see these as examples of progress as our society becomes more inclusive and tolerant, then we are missing the point. There is one assumed default of independence, and the closer we get to that unattainable ideal the easier it is to ignore our own forms of dependence; however, as people with disabilities chip away at this illusion we see that everyone is dependent on things, environments, and others in very significant ways. There ought not to be one class of independent human beings and one class of dependent beings that have only a potential for partial, assisted, or qualified independence. What is default, we learn, is interdependence and mediated independence in all cases.

If the argument is successful, the challenge to traditional thinking is profound, Man in his natural and desired state is a rational and autonomous actor it has been argued. This version of man is considered a precondition for the political system of liberal democracy and

of neoliberal society writ large. As such, it attaches itself to other related concepts like typical-functioning, civic expectations, and economic viability. Deviance or abnormality in the form of disability are defined against these and so are placed categorically in the camp of problematic dependence. Surely, we can plainly see that people living with disabilities are dependent on technologies, people, and things in their environment to complete any number of tasks ranging from daily living activities to employment and education. To deny this would be to wilfully ignore their lived reality. The problem is, we do the opposite when we look at typical experience. Non-impaired people are equally dependent on environments adapted to their needs, on tools and technologies, on trusted others and official agents. We explored this in depth as it relates to embodied technology in chapter 2, but the argument here is much more general.

All contemporary beings are cyborg beings and the integration of technologies in our lived environments have made us dependent on both artifacts and others for everything from basic nutrition, to security, to education and any individual pursuits. Even further, as Braidotti argues, “bio-genic capitalism” and the ecological crisis, both emerging out of modernity, leads to a “reactive mutual inter-dependence” between all beings, human and non-human.³⁵⁵ This description of the *way things are* comes with certain responsibilities. We have here a point of contact between transhumanists and critical posthumanists. Both have to grapple with the existential threats emerging from biogenetic manipulation, the environmental impacts of industrialization/late-stage capitalism and population growth, as well as the destruction of our environment the ensues. They do, however, have diametrically

³⁵⁵ Braidotti, *The Posthuman*, 48ff.

opposite conclusions. In the case of the transhumanists, individual freedom and the further development of technological interventions in conjunction with traditional bioethical forms of regulation are seen as sufficient. Conversely, for critical posthumanism, these forms of entanglement require us to bring to the foreground our interdependence and completely rethink our own place in the world.

The problem is quite far-reaching, and too complex to discuss within the parameters of the present dissertation, but it can be summarized in the following terms. In rejecting the unitary and independent subject we lose the foundation of contemporary ethical and political discourses. By putting in place the relational (i.e., cyborg/contingent) subject ethics transforms itself into a critical praxis of managing power-relations and one's responsibilities to the Other.³⁵⁶ Practically, for our purposes here, it means looking at the micro-politics of disability as it transverses the material and discursive reality of our historical present with the view of increasing the affective³⁵⁷ capacity of people living with disability on the world. It begins by challenging the “default” dichotomies of abnormal/dependent and normal/independent, as well as letting the experience of disability teach us something about who we all are—living with an impairment or not. Following Goodley, it is a form of neoliberal-ableism³⁵⁸ that people with disabilities are defined as dependent because of their need for social assistance or assistive devices, while normal independent people are not

³⁵⁶ Rosi Braidotti, *Transpositions: On Nomadic Ethics* (Cambridge: Polity Press, 2006), 11-15; see also Margrit Shildrick, “Beyond the Body of Bioethics: Challenging the Conventions,” in *Ethics of the Body: Postconventional Challenges* (Cambridge: MIT Press, 2005), 1-26.

³⁵⁷ Meant in Spinozist terms here, i.e., in their ability to affect the world and others. Not affect in the limited sense of an emotional reaction.

³⁵⁸ Dan Goodley, “Ableism,” in *Dis/ability Studies*; Goodley and Runswick-Cole, “Becoming Dis/human.”

despite being no less dependent on a myriad of social/governmental services and technologies in order to perform at “typical” levels. Certainly, enlightenment thinkers did not conceive of independence in a vacuum. What is challenged is the extent of how much this independence is qualified by forms of dependence, especially in its socio-political application—i.e. in practice.

From a critical posthuman position, disability is not a *problem* or form of deviance, but an organically occurring form of (relational/mediated) embodiment. These embodiments, like their non-pathologized counterparts, have the potential to create affirmative ethical relations with other human and non-human subjects. In all their complexity and vulnerability, they have something to teach us about adaptability and our human condition. In connecting with the previous section of this chapter, acknowledging the universal nature of interdependence and learning from the types of relations that enable and empower the lives of marginalized people can teach us something about how we ought to live with each other more generally. In other words, it means initiating a feedback loop so that the politically useful concepts such as quality of life, independence, and civil rights remain grounded in the reality of lived-experience. As some authors have recognized within disability theory, this idea of affirmative ethics and interdependence will have to serve as the foundation of the future of disability politics.³⁵⁹ Without a tectonic shift in how we perceive the relational qualities of human life generally, disability is doomed to remain at the

³⁵⁹ Goodley, *et al.* “Posthuman Disability Studies”; Goodley, *Dis/ability*; Dan Goodley, “Towards Socially Just Pedagogies, Deleuzoguattaria Critical Disability Studies,” *International Journal of Inclusive Education* 11, No. 3 (2007): 317-334; Mia Mingus, “Changing the Framework, Disability Justice,” *Leaving Evidence Blog* (February 2011): <https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice/>

margins—silenced and politically ineffectual. The final chapter of this dissertation will deal with a more practical reflection on posthuman ethics and politics, but the description of what we can learn from disability here is a prerequisite for such a reflection.

3.3 Seeing Through the Lens of Disaster

One might argue that all I have shown here is that people with disabilities have some capacity to adapt to challenges and that *they* are interdependent and vulnerable, but that I have not sufficiently generalized this to most people. The examples I used, for the most part, are far removed from many people's typical experience. This is a difficult task because certain default modes of interdependence are so common in our society that they fail to challenge one's sense of independence. As discussed in the previous chapter, someone's idea of normal is relativized by their situated point of view, and stepping outside of that as an intellectual exercise is difficult to do. Without an event that would fundamentally and sharply disrupt multiple aspects of our current way of life, it would be difficult for the average person to become cognisant of the sheer contingency of what they consider a normal and independent existence. Consider again Hull's experience with acquired blindness. What he thought about blindness—the simple lack of function—was transformed into the acknowledgement of a wholly different mode of life. In writing this dissertation, I struggled to find examples that had the amplitude necessary to illuminate the shaky foundations of our sense of independence, and then my life, like most people, was completely turned upside-down by the global COVID-19 pandemic.

Seemingly overnight, society has had to completely overhaul its social behaviours:

the ways in which work is done; manage access to medical supplies, household supplies, and food; manage childcare responsibilities and various forms of co-habitation; rethink our responsibility towards vulnerable others; to grapple with the value placed on the economy vs. public health; to re-evaluate the role of political leaders and the intricacies of global politics... the moment is so potent that the possibilities for critical reflection can overwhelm. I will not do a complete analysis of what COVID-19 does or can mean for posthumanism or disability, but I do wish to offer a sketch of a few observations that may bring to light ways in which we should all take stock, as a society, of the possibilities of modal adaptation—technological and otherwise—as well as our interdependence and interconnectedness. Notably absent, and important in its own right, is an analysis of the disproportionately negative effect this pandemic has and continues to have on marginalized population (including those with disabilities) and people with various health vulnerabilities.³⁶⁰ I do not mean to minimize the ways in which this pandemic has been devastating for many, but only wish to discuss the limited ways in which it may give us a few insights on the issues discussed in this and preceding chapters.

³⁶⁰ Certainly, when this is all over a retrospective look at what happened for those living with disabilities will be needed. There is ongoing research, but like any disaster of this scale, it will take years to untangle. What we already know is that this pandemic has exacerbated inequalities in healthcare access and that people with disabilities have experienced disproportionately negative health outcomes. Understanding what happened, and what happens from this point on to recover from the pandemic will be an important academic and social exercise. For some preliminary research see Tom Shakespeare, Florence Ndagire, Queen E. Seketi, “Triple Jeopardy: Disabled People and the COVID-19 Pandemic,” *The Lancet* 397, (2021): 1331-33; Gerald Goggin and Katie Ellis, “Disability, Communication, and Life Itself in the COVID-19 Pandemic,” *Health Sociology Review* 29, No.2 (2020): 168-176; Maya Sabatello, Scott Landes, Katherine McDonald, “People With Disabilities in COVID-19, Fixing our Priorities,” *The American Journal of Bioethics* 20, No. 7 (2020): 187-190; Hannah Kuper, Tess Bright, Calum Davey, and Tom Shakespeare, “Disability-Inclusive COVID-19 response: What It Is, Why It Is Important And What We Can Learn From The United Kingdom’s Response,” *Wellcome Open Research* 5, no. 79 (2020): 1–7.

To begin with, we can point out how the current crisis may make us a bit more cognisant of why people with disabilities may make some of the socio-political demands that they do. As a society we have decided to pay out enormous sums of money so that people who are unemployed would not suffer because of an illness outside their control. We have put evictions on hold and in countries where health systems are privatized, a great deal of political will was mobilized to ensure that people could access the care they needed. We have started a conversation about the mental health costs of isolation and grief, the difficulties of living in poverty, and the need for society to be more empathetic and open.

We can summarize this as people reacting appropriately to the fact of entire cohorts of the population being thrust into the second speed society.³⁶¹ In other words, we have collectively gotten a taste of what it is like to acquire a disability. As Nancy Boyle put it in a recent *Forbes* article,

One statistic that people are often shocked by is that 83% of all disabilities are acquired [...] A few months ago, the world was suddenly plunged into a situation where physical proximity to others became a no go. In one swoop, a whole group of people were placed at an immediate disadvantage without having done anything to deserve it.³⁶²

³⁶¹ Remember that white-collar individuals are less affected by this crisis, and that the very rich are actually profiting. To say that society has collapsed for everyone would be an overstatement.

³⁶² Nancy Doyle, “We Have Been Disabled: How The Pandemic Has Proven The Social Model Of Disability,” *Forbes* (April 29th, 2020):

<https://www.forbes.com/sites/drnancydoyle/2020/04/29/we-have-been-disabled-how-the-pandemic-has-proven-the-social-model-of-disability/#3e60084f2b1d>

The elusion here is clear, the moment of sudden change and need to adapt is an experience that people living with disabilities have similarly already had to go through. She quotes a number of functional limitations that people now have to adapt to that roughly correspond to actual challenges that some people face in the best of times. The difficulties of telecommunications in important work matters mirrors the difficulties some have in communicating because of their impairments in critical health matters; she draws the parallel of people who have physical or verbal tics with the negative reactions and embarrassment that people with allergies or ‘smoker’s cough’ now feel coughing or sneezing in public; the fact that many people express their discomfort wearing masks (or unwillingness to) because it causes them anxiety or something akin to claustrophobia and how this mirrors the expectations we place on people that experience sensory processing issues in school and work environments; and finally the fact that people complain about the difficulties of isolation and the mental health toll it is taking on them, while people with disabilities often face high rates of social isolation over long periods of time in normal circumstances. We can learn, as she concludes, to be much more open to offering accommodations or changing some of our social practices when we realize that people with disabilities are not just being difficult or needy, but legitimate in their demands.

One area where I think our reaction to this event may have a lasting impact is on facilitating affirmative uses of telecommunications technologies; from socializing, to religious services, to work and education people with disabilities have benefited from a turn

to the virtual.³⁶³ It has opened up the possibility, for those already in isolation, to participate in aspects of society that had been cut off from them. Though, it may be bittersweet for some that it took such a calamity to make certain adaptations acceptable. As one person being interviewed said in relation to finally being able to access university classes from home, “I am so torn between being so grateful that I can get my education and [...] feeling a bit betrayed that it was possible the whole time;” and another in relation to what this may represent for accessibility in the future “my overriding suspicion is it will be a massive missed opportunity.”³⁶⁴ Much like the role Gary Becker played in Jason’s becoming-composer, if we focus just on the possibilities opened up by video-conferencing technologies we are struck by a great deal of potential. However, the exercise, because it is temporary, is not wholly transformative for society. There is no guarantee that it will lead to lasting change, but it does give us a rare opportunity to find moments of politically potent kinship.

Practically overnight we were all made to presume we were infectious or vulnerable to infection. In effect, we all began to live the life of a person with a compromised immune system. We connect with family and friends on Facebook video chat, we watch our favourite talk show hosts on YouTube without audience laughter or applause, our favourite musicians offer virtual concerts, etc. These may be trivial or mundane because they are temporary, but they are modal adaptations. Now, sadly, it’s not all socialising and entertainment. Some of us put off seeking medical care for all sorts of ailments; some have had to access care through

³⁶³ Frances Ryan, “Covid Lockdown Opening up World for People with Disabilities,” *The Guardian* (April 20th, 2020): https://www.theguardian.com/world/2020/apr/20/covid-lockdown-opening-up-world-for-people-with-disabilities?CMP=Share_iOSApp_Other

³⁶⁴ *Ibid.*, no pagination.

teleconference instead of going to a clinic, having to deal with what is for many a new experience of anxiety when told to present to a lab for a test or a pharmacy for a prescription; some, including myself, have had to say goodbye to loved ones virtually because they could not go into the hospital to visit or travel to attend funeral services; some had to watch the numbers from home as outbreaks hit older adult assisted living facilities where loved ones were living—comforted temporarily by their voice on the other side of a telephone. In other words, we have had to adapt the ways in which we maintain our wellness or meet our most important personal needs.

The pandemic has also sharply brought to light our interdependence in obvious ways. Collectively we quickly realised that the health of people around the globe has an impact on our own. That other countries' ability to care for their people and contain the virus, as well as the behaviour of people in general has a direct impact on us. We also see that sharing information and collaborating on scientific matters is an incredibly important (and powerful) tool. We have recognized that we are not wholly independent and self-sufficient in making our own decision in a globalized world where medical supplies and equipment are unequally produced and distributed. Though for some this is a wakeup call for more isolationist and xenophobic policies, it can equally signal a need for cooperation beyond the purely economic bonds that seem to make for such a precarious foundation. It has also brought home that individual actions have collective consequences in our own communities. The very premise of self-isolation (following a possible contact with the virus) is to sacrifice one's own freedom of movement for the benefit of others.

Examples abound of these novel altruistic expectations: to stay home to limit spread even if we are not currently sick or at high risk; to wear a mask so that if we are pre- or a-

symptomatic that we may not spread the disease to others when we are out in community; to vilify hoarders and profiteers for taking more than they need and exploiting those who are without; to allow for special hours of operation at some stores so that high risk individuals may do essential shopping with lowered risk; etc. Though the solutions are not perfect, we have banded together as a society and put a lot of effort into establishing them because we recognize that we must find a way to meet our collective needs. But that is the point, because in many cases these are not new kinds of challenges for people living with disabilities. It brings to light the fact that, on a regular day, we choose not to solve them for others because we take for granted that they are *individual* problems.

In another, more general sense, there have also been very significant outward expressions of support for health and hospital workers at every level, as we have all recognized the great personal risk, they have put themselves in to ensure that people have the care they need in this time of crisis. But more surprisingly, in many Western countries we have adopted the language of calling many traditionally taken-for-granted and undervalued workers as “essential workers.” Grocery store clerks, cleaners, cab drivers, public transit workers, factory workers, postal workers, and food chain workers; many of which are low-wage or working-poor people that we typically pay little attention to. The danger here is that this feel-good terminology does not translate into the realization that, even in the best of times, *our way of life depends on their work*. We ought to recognize that they are essential, regardless of the added risk that they take on in this particular moment. It remains to be seen, as with the gains in acceptance for communication technology alternatives, if we will continue to support liveable wages, safer workplaces, and flexibility with regard to mental health and family responsibility after the pandemic.

Generally speaking, like the background relations I discussed in terms of technology, our dependence on others is obscured by the structures of our society, giving most the seemingly natural feeling that we navigate the world as independent individuals. One could say that the virus *made us interdependent* as people, but that would be a mistake. The virus *showed us that we are dependent on others*, and it ought to beckon us to recognize how dependence can stay hidden for some, while being painfully obvious for others. This is the part that has the most potential to cause frustration. We have been shown that many issues that we considered to be individual are deeply rooted in collective interdependence, and we have been shown that the seemingly natural and smooth expression of our daily lives is dependent on the performance of undervalued members of our society—but it is framed by the expectation that it is temporary. There is no guarantee that it will be transformative and that we will not confirm the cynicism of the individual quoted above and make this a “massive missed opportunity.” Doyle frames her article as the coronavirus crisis confirming the social model of disability.³⁶⁵ And though this is useful as an illustration, I think it oversimplifies the description of what is occurring.

If we take the example of the student above who finally had access to the education she so desperately wanted, we learn that she had previously been told that she could not attend remotely because her accommodation would be difficult and cost prohibitive. Frustrating when you consider how rapidly it was implemented with existing software when more students needed that accommodation. But we fail to see the issue, from this posthuman perspective, if we frame it simply as an issue of *right to access*. We can share frustration at

³⁶⁵ Doyle, “We Have Been Disabled,” no pagination.

the decision of the institution, criticize its economic reasoning or lack of motivation to find equitable solutions, but we have to recognize that their reasoning and actions are completely rational and understandable within the context of our historical moment. The demand to allow one to be educated from home is transversal, in the sense that it cuts through a number of practical issues like an institution's social responsibility for equity and fair business practices, the purpose of higher education and pedagogical considerations (readiness, quality, and lack of metrics); and rooted more deeply in discourses of ability and ableism, of rights and neoliberalism, and the value of the disadvantaged few in relation to the masses. On such questions, one cannot expect an institution to act otherwise than within the discourses through which they were created and continue to be constituted—i.e., the demands of maximization/optimization. In other words, it is not simply a matter of challenging certain practices, but the underlying discourse that makes these challenges necessary and guides the institutional responses to them.

It is illustrative that we have tanked the global economy to save lives; that the discourse of health took precedence over that of economics. Though, likely fuelled by a collective sense of self-preservation, at least we have shown that large-scale change is possible and that the structures that enable alternative forms of relationality can be implemented at awe-inspiring scales. What we need to consider is how much political will it would take to solve the much smaller issue of enabling people with disabilities to fully express the potential of their different embodiments. We should think more broadly such an attitude justified the construction of a mechanical model of the living body, including the human body broadly about what we are capable of. Thinking here of that often quoted Spinozist idea that 'we do not yet know what the body can do,' because we have not yet

harnessed the potential of affectability in the Nature of which we are part.³⁶⁶ To simplify it, Spinoza’s monism allowed for the idea that we find new ways of being not in the form of transcendence over others and the natural world, but within it through novel configurations that enable new powers of action. This might all seem very esoteric and quasi-spiritual, but it is not meant to be. We have already discussed at length how our subjectivities and life projects are the result of complex assemblages between people, animals, technologies, and aspects of the environment—these already presuppose, in some sense, this Spinozist realization. Allowing life to do what it does, to open up possibilities and allowing for creative alternative entanglements is a way of participating in world-creation and social change. As Braidotti reformulates it, “[a]t this particular point in our collective history, we simply do not know what our enfolded selves, minds and bodies as one, can actually do.”³⁶⁷ People living with disabilities explore this in real terms on a daily basis, as we have seen in the myriad examples in this chapter. Building an enabling society goes beyond inclusion and tolerance, or rights and access. It would mean harnessing the potential of new person—technology, person—person, person—non-human-other entanglements that increase modal or creative adaptation (*potentia*) while engaging in resistance to or a revaluation of the discourses, institutions, and practices that disable the expression of alternatives/differences (*potestas*). Focusing on the things that make us the same (life as adaptation to challenges and

³⁶⁶ This is from *The Ethics*, Book 3, Prop 2, Schol. This is a reference to Spinoza interpreted by Deleuze and often used by Braidotti and other posthuman thinkers. It is a productive one, but as it is used it goes beyond the meaning of the original passage—though the interpretation fits the Deleuzian/Braidottian reading of Spinoza’s overall project. Note however, that it is not the orthodox reading of Spinoza and has been criticized elsewhere for being an empty reference with little connection to its source (Abrams, Thomas, “Braidotti, Spinoza and Disability Studies After the Human,” *History of the Human Sciences* 30, no. 5 (2017): 89-94.

³⁶⁷ Braidotti, *The Posthuman*, 189; also quoted in the first section of this chapter.

interdependence) and seeing our differences as untapped alternative *powers of activity* requires us to change the nature of our ethical relationship to life itself. If we let it, this moment of mutual recognition brought on by the coronavirus has the potential to be transformative beyond just creating temporary moments of allyship on a few limited issues. What a critical posthuman disability position does is offer resistance to the discourses that create restrictive forms of power and limit the ability for alternative forms of embodiment and flourishing. Much like we could not predict the result of supporting manualism in deaf education—the creation of a thriving human sub-culture, and the positive effects for a great many people born without the *normal* means of communication—we do not know what such deep changes in our way of thinking can bring to our society. If we are to let disability speak to us, as I have advocated throughout this chapter, we need a new form of openness to difference that gets at the core of what we are, and what our relationships to each other ought to be.

3.4 Summary

Modal adaptation, or creative adaptation, is just a description of the universal process of life confronting its environment. Using the term “modal,” as Silvers does, points to the fact that they represent alternatives to the established norms of doing things. These adaptations or alternatives have historically, and continue to be, artificially devalued out of a certain form of tribalism that seeks to remove difference. As she has shown, this often comes at a cost for those living with disabilities regardless of the intentions behind particular intervention aimed

at improving their lives. This is largely because we value sameness and ignore the needs and wishes of the actual individuals involved.

In accepting the relative nature of modal adaptations—in the sense that they represent a challenge to the dominant norms, and are no less natural—I rely on Canguilhem’s vitalism to describe a universal process of creative adaptation. What people with disabilities do to adapt to their environment is no different than what all living things do. It does not differ in *kind*. One does not represent nature or health and the other deviance and pathology; they both, at least potentially, have equal claim to normativity. This realization brings to the foreground the contingent nature of the exclusion of people with disabilities in the process of historical change, and the importance of their voice here. This is made more urgent given the increasing level of technological integration in our environments and the ubiquity of the devaluation of disability in the dominant visions of the future.

What the above amounts to is a demand to dispel some illusions about what we consider natural and normal in relation to man, and how we may dismantle some of the ways in which this has excluded some from participation, in a very deep sense, in the making of our world. This cannot be accomplished without a rejection of inherent independence, and an acknowledgement of the myriad ways in which we are all interdependent and vulnerable. We have to acknowledge that we exist in relation to human and non-human others, technologies, social and material structures, and that we depend on these networks no matter what subject position we inhabit. We see the artificiality of these privileged positions in the example of how crisis can remove the veil of accepted normalcy to reveal our practical dependence on technologies and our ethical and political relationships to each other.

Chapter 4—Post-conventionalist Toolbox for a Posthuman Resistance

As mentioned in the summary of the previous section, the intention here is not to give an alternative model of disability. The purpose here is to think through what it means to be in a posthuman world, and to learn from thinkers at the edges that are grappling with increasingly relevant aspects of such a world. Neoliberalism, biopolitics, and posthumanism are already being discussed within and outside the disability literature, and I have offered here a few modest contributions to those reflections while taking much from them. What I tried to do is to immerse myself in this perspective with the intention, in the present chapter, to propose a few heuristics, well grounded in our current situation, that might aid those inside and outside of these movements to resist or act more critically in our current environment. Following Braidotti, looking at the ways in which we may better live together and develop our collective potential is neither strictly an ethical or political vision; it is the proposition of a different relationship to the world we inhabit that may disrupt problematic social, ethical, or political practices.

The reason we have pitted posthumanism against transhumanism throughout this work is relevant precisely at this moment. They are the two archetypical perspectives that acknowledge the rupture between our modernist world and where we are today, but they draw from it two different visions of the future. The transhumanists we have been discussing here are typically technological innovators (e.g. Kurzweil or Musk) and bioethicists (e.g. Bostrom, Sanders or Savulescue) or their followers. These individuals understand the potential of technology to change our world, but in the first instance are adept at problem solving very narrow sets of technical problems (and extrapolating a utopian future from them), and for the latter of exploring innovation and possibility within the confines of an

established disciplinary framework. To simplify what is a very well developed critique here, having not first passed through a critique of the modernist foundations of our current understandings, these thinkers are limited in their scope by out-dated conventions and consensus about what is normal, valuable, right, and acceptable. What we need in this moment is a reasonable recalibration of our ethical frameworks in light of the crumbling foundations of humanism and the resulting inability to find universally valid guidelines for emerging problems.³⁶⁸ As Shildrick writes in “*Beyond the Body of Bioethics*”:

[i]f nothing can be taken as a given, then there is always an intrinsic undecidability at work. [...] The ethical task is very different from that of ‘proper’ moral procedure. It involves the risk of thinking beyond the boundaries of the familiar [...] What a postmodernist bioethics demands is an openness to the risk of the unknown, a commitment to self-reflection, and a willingness to be unsettled.³⁶⁹

I lean heavily on this unsettled, loose footing that Braidotti and Shildrick point to. Not because it is favourable. In fact, it would be much stronger to claim a solid foundation or set of acceptable assumptions about the world and claim from there what we ought to do politically and ethically. This would, however, be inauthentic and disingenuous, because no such foundation exists. We are in the process as a species of coming to terms with the fluidity of what it means to be posthuman, and what we want that world to look like. We do not start from zero, and I caution against total rejection, binary “us versus them” thinking, or

³⁶⁸ Shildrick, “Beyond the Body of Bioethics”; for an earlier formulation re. women’s bodies, see Margrit Shildrick, *Leaky Bodies and Boundaries: Feminism, Postmodernism and (Bio)ethics* (New York: Routledge, 1997).

³⁶⁹ Shildrick, “Beyond the Body of Bioethics,” 11, 12, 13.

the anti-intellectual populist position that is common in today's social climate. These are disastrous for academia as well as society. We have seen throughout this dissertation that the stakes are high, and that many are being left behind, but the solution is not simple or foolproof. This is not cynical or defeatist, but realistic. In this chapter, I will revisit those challenges and convert them—for lack of a better word—into heuristics or tools that can encourage or enable a postconventionalist approach to posthuman resistance.

4.1 What Ought we to do? The Difficult Ethical and Political Question

What I present here is not sufficient, in the sense that it does not in itself change the entire field of ethical thinking and/or replaces the structures of the dominant position. What it attempts to do is give some tools for action in our present situation that are consistent with the critical and posthuman vision that was explored throughout this work. The work itself must be done alongside those most affected and led by those most easily ignored or sidelined. In this context, third world, BIPOC, Trans, and queer people with disabilities is a good starting point.³⁷⁰ Consistent with the undecidability and lack of fixed foundation I cannot propose a complete framework or position, but it does not mean that it is completely relative. The resistance movements that are emerging ground themselves in experience, the politics of relationality, and the reality of our interconnectedness and shared needs and responsibilities. So we can ask, what does social and political action look like in the vacuum left by the dismantling of modernity?

³⁷⁰ Sins Invalid, *Skin, Tooth, and Bone: The Basis of Movement is Our People* (Berkeley, Sins Invalid, 2019), 17-18; also, 2nd principle, page 23.

In recognizing the disastrous results of neoliberalism on marginalized people one completely legitimate reaction would be to advocate or actively seek to dismantle the entire system, i.e., to seek to replace capitalist forms of relation with socialist alternatives. These arguments are legitimate because they represent alternative forms of valuation that could be consistent with what I have been discussing here. Moreover, they have some historical precedent as counter narrative of some impact, though they have never been practically realised in any way that would directly address the issues of ableism and technomedicine. The extent of borrowing varies, but one can see how it would be an attractive option to inform social action. As discussed in Chapter one, the roots of the social model's historiography are linked to Marxist-materialist thinking dominant in the 1960s and its social ambitions tied to the upswing in political action by marginalized people. Many activists and movements continue to identify with and employ the strategies of this period, but I believe, with some modification. In the post-war period there was a surge in anti-capitalist and pro-Marxist movements in Europe culminating, in France, with the labour and student actions of 1968. What began as a student protest quickly developed into a general strike that implicated almost 25% of the French population and brought the French economy to a halt. Its message made its way around the globe and seemed to be the perfect example of a socialist revolution and the proletariat power of self-expression and resistance. Famously, writing a decade after the event, Deleuze laments that the event failed to establish large scale social change, and, more concerning for him, translate this event into a new subjectivity.³⁷¹ Not only did these

³⁷¹ Deleuze "May 68 did not take place" in *Two Regimes of Madness*, (Cambridge: Semiotexte, 2007), 133-136.

kinds of revolutionary actions fail to create large-scale change, they seem to have changed in quality in the last half-century—our own attempts have to adapt.

In fact, the general feeling that I have is that the organized forms of resistance we see today are not the same *kind* that I grew up learning about and claiming for myself. Whether they ever were could be the subject of a much larger reflection, but there is a point here. There is an entire field of research in sociology that attempts to understand, categorize and analyse social movements. Within this field, Buechler recognized a shift in the 1980s towards “new social movement theories,” where our attempts to understand and explain social movements moved away from class based frames of reference to everything from episteme and culture, to identity.³⁷² Historical-material or class struggle seems to be too broad to capture, and even less predict, recent movements like Occupy Wall street, Silent No More, #MeToo, and Black Lives Matter as well as many examples of ecological/climate actions, and actions aimed at legislative reform (e.g., gun control, marijuana legislation, prison reform, etc.). Much like our frames of reference for ethical thinking are becoming more fluid and experimental, it seems the same trend should be followed in our socio-political action. In fact, the issues I have been pointing to here, around maximization-optimization and the dangers of transhumanist history making for people at the margins is one such issue that escapes traditional categories of oppression and political resistance.

Though the posthuman authors mentioned in the entirety of part 2 are all firmly on the left, their social consciousness is not necessarily of the traditional Marxist type. In fact,

³⁷² Steven Buechler, “New social movement theories” *Sociological Quarterly* 36, no. 3 (1995); Steven Buechler, *Social Movements in Advanced Capitalism* (Oxford: Oxford University Press, 1999).

though Braidotti's rhetoric speaks of large-scale changes in social consciousness and collective practices, it does not, at least recently, take the form of a call to revolution usually attached to Marxist-Leninist critiques. This may be subtle for new readers as she often uses the term "radical" in various contexts (e.g., "radical epistemology," "radical transformation," "radical immanence," etc.); 61 times in her landmark book *The Posthuman* in fact.³⁷³ Within the context of her work, her focus on creative revaluations and fundamental challenges to how we create and use knowledge, I would argue, rather points to a call for novel, critical, and far-reaching alternative ways of thinking and acting—such as I have discussed, with her spirit in mind, in relation to disability in the previous chapter. She discusses this specifically in a recent interview:

if we are part of the problem, we must become part of the solution. We have to work together to find the margins for action. [...] I believe that revolution today is a fascist concept. I believe that the people calling for revolution are from the extreme right: they are Steve Bannon, they are conservatives who believe in a neo-revolution to recover the values and notions of God, nation and family. I believe that at present a more preferable option is active activism, a collective commitment to creating affirmative values, rather than joining what seems to me to be a fascist restoration of the notion of revolution that merely aims to open the doors to violence and abuse and to turn the clock back again to pre-1968. [...]. We have to realise that, contrary to the Marxist-Leninist idea of a global revolution, the changes that we can achieve are

³⁷³ In fact, we can recognize this rhetorical tendency as early as her 1991 book *Patterns of Dissonance: A Study of Women and Contemporary Philosophy* (Cambridge: Polity Press, 2013) where, among other thing, she argues for the potential of "radical feminism" to go beyond the scope of Marxist analysis.

collective, but step by step, by distancing ourselves. Look at how feminism has shown us how to distance ourselves from male violence. Or how anti-racism has shown us how to distance ourselves from white supremacy. The point is to distance ourselves. It is like an exercise in detoxification. We have to detoxify our bad habits, in our way of consuming, of thinking, and of relating with others.³⁷⁴

There is something very important in this. Many academic movements and activist traditions yearn for outright revolution, but these seldom succeed. In the recent history of philosophy, we can point to the challenge that the USSR's Gulags brought to hardline Marxists in France once they came to light, or the initial optimism Foucault had for Iran's Islamist revolution until the violence and repression that resulted became utterly problematic. Authors that I admire, that have shaped me as a thinker and a human being, have fallen for this trap. This does not mean that we have to 'throw the baby out with the bath water' so to speak. In a larger sense, revolution as the ultimate aim of social and political philosophy on the left has had a great influence on the history of thought. I mean here specifically the history of post-war continental philosophy, critical theory, and the "new left" in the US. These intellectual movements have had an impact on practically all the interdisciplinary area studies that emerged from postmodernity (gender and sexuality studies, race studies, education studies, Disability Studies, etc.), on sociology and the practice of social work, and on activism generally. The theoretical basis for many of these movements and their fiery rhetoric is often revolutionary, and it is engaging. But its real gift has been to push many generations to

³⁷⁴ Iu Andrés and Rosi Braidotti, "What Is Necessary Is a Radical Transformation, Following the Bases of Feminism, Anti-Racism and Anti-Fascism," (CCCB Lab, May 6, 2019): <https://lab.cccb.org/en/rosi-braidotti-what-is-necessary-is-a-radical-transformation-following-the-bases-of-feminism-anti-racism-and-anti-fascism/>

reflect on how we turn theory into practice, and to entrench the idea that intellectuals must engage with the world around them to affect positive change. Conversely, however, the polemic it has set up gave rise to a situation where the ability to effectively critique and affect change has been hampered by its association with what is often referred to as a ‘culture war’ in North American and some European nations. It is telling that Braidotti, a self-proclaimed continental philosopher, who was educated and worked primarily in continental Europe and Australia would recall Steve Bannon as emblematic of far-right claims to revolution. There is a far-right problem globally, but none is more obvious than the movement in the United States. It is well documented that the American public has been consistently polarizing over time since at least the 1990s.³⁷⁵ The rise of the “alt-right” or far-right in the USA, galvanized by the election of a political newcomer rallying around a backward-looking revolution “Make America Great Again,” is emblematic of the fact that revolution does not only go *in one direction*. ‘Progress’ is not inherently pointed towards socialist revolution, perfect freedom, universal liberation, or whatever teleology was historically attached to the various incarnations of Marxism. Even though many leftists have long rejected that traditional Marxist-Leninist/Hegelian idea, their strategies and their rhetoric does not always reflect that fact; at least in the US, they typically call themselves *progressives*. Though, from an outside (Canadian) standpoint, the polemic from the American right that identifies some of their progressive politicians as “radical socialists” is

³⁷⁵ For a good visualization of the trend over three decades see: Pew Research Center, “Political Polarization in the American Public” (Pew, June, 2014): www.pewresearch.org/politics/wp-content/uploads/sites/4/2014/06/6-12-2014-Political-Polarization-Release.pdf; for more recent data, see Pew Research Center, “In a Politically Polarized Era, Sharp Divides in Both Partisan Coalitions,” (Pew, December, 2019): https://www.pewresearch.org/politics/wp-content/uploads/sites/4/2019/12/PP_2019.12.17_Political-Values_FINAL.pdf

often laughable. But the reality is, this rhetoric is used to justify authoritarian and violent acts, from government and domestic terrorists—and this language is spreading beyond American borders.³⁷⁶

What Braidotti is saying in the above excerpt, and in her critical writings about affirmative ethics,³⁷⁷ is that what we need today is political and social movements based on collective action and an ethical regard for each other, as well as a distancing from violent and ‘toxic’ discourses. For disability, this would mean detoxing ourselves from authoritarianism, ableism (austerity, disposability, perfectibility, etc.), dependence and individuality; that is to say, it would mean creating a distance between our collective demands and these discourses, while actively resisting their detrimental effects on the affirmative potential of people with disabilities. This is *radical*, but it is not *revolutionary*. It is the implementation of strategic, incremental change that pushes the effects of marginalizing discourses to the margins themselves.

³⁷⁶ I point here to the violent reaction to recent anti-racism protests, but one must note that “domestic terrorism” as a problem is very much tied to the right today, but many left-aligned groups have also been identified as terrorist organizations in both Canada and the US. Many of these designations are contested, but they point to the fact that neither side is immune from an association with violence. Certainly, in recent years there had been a far-right violence problem, and many events such as the Chicago Synagogue shooting of 2018 and the Quebec City Mosque shooting of 2019 come immediately to mind, but left-wing terrorism, though it may be less common today, has been a problem historically (e.g. the Front de liberation du Quebec, or Weather Underground Organization in the USA)—and there is no indication that such a thing could not happen again. Replacing violence and revolution with collective action and affirmative possibility is an everyone-problem, not an inherently right or left problem.

³⁷⁷ Rosi Braidotti, “Affirmation Versus Vulnerability: On Contemporary Ethical Debates,” *Symposium: Canadian Journal of Continental Philosophy* 10, No. 1, (2006): 235-254; Rosi Braidotti, “A Theoretical Framework for the Critical Posthumanities,” *Theory, Culture & Society* 36, No. 6 (2018): 31-61.

Braidotti often uses the term “experimentation” when describing what is happening around us, and how we attempt to deal with it. This maps very well onto what Shildrick was pointing to above in her discussion of post-conventional ethics. We are in a moment where concrete and well-defined ethical questions and its related procedural ethical frameworks have been shown to be untenable. In such a situation, our posthuman condition, all we have to rely on, is a set of tools or guides with which to critically engage with emerging issues, and with which to distance ourselves from damaging practices. This is the ‘action’ counterpart to the Foucaudian critical framework we have been tracking since the beginning of this work. Where Foucault gives us a critical framework for understanding and beckons us to be hyper-pessimistic and politically active, he does not give us a normative framework. This is where Braidotti comes in. What we ought to do is focus on the affirmative potential of a given practice or technology, demonstrate an openness to creative alternatives, and take a collective—as opposed to individualistic—frame of reference for judgement. We must do this with an understanding of the turbulent political times we currently live in. We have to avoid polemics and learn to advocate with/for marginal people and build bridges where bridges can be built. It means not demonizing people who have competing positions or competing needs. We need to put some stock in our understanding of intellectual history, the reality of our experience and our ability to affect change with them. This conviction is certain to make me unpopular among otherwise like-minded *progressives* because the response does not seem to match the gravity of the issue. It may even be surprising given the ferventness with which I have argued in this dissertation so far. However, I truly believe the alternative on two extremes are a failed utopian dream with little practical benefit on the one hand, or a descent into political violence and parallel authoritarian thinking on the other.

Neither give us a better world. It is not a call for complacency, but for strategic detoxification of the worst aspects of our world and a willingness to think and act in the unsettled and murky historical moment we are currently in.

4.2 Maximization

With respect to disability theory, new critiques had to be developed because resistance movements based solely on the removal of barriers and the right to accommodation did not challenge the dominant forms of normalization. Though it does improve life for some, it did not represent a solution for those who do not, or cannot, attain the idealised level of productivity required in our society. Its practical goal of creating a truly inclusive society remains unachieved, so there is practical work to be done there. However, as a model through which to understand our posthuman condition and disability's position within it, it fails from the outset. As I have discussed in relation to Rose and Waldschmidt, and as explored within disability theory by Fritsch,³⁷⁸ neoliberalism has reduced social value and personal choice to economic types of reasoning and activist participation in this form of valuation helps to maintain the status quo. In addition to this critique I have argued that what defines our world as posthuman is the disappearance of limiting parameters on normed performance standard. The resulting perceived expectation of performance aided by increasingly integrated technological, environmental, and biochemical artefacts means that

³⁷⁸ Fritsch, "Desiring Disability Differently"; Kelly Fritsch, "Gradations of Debility and Capacity, Biocapitalism and the Neoliberalization of Disability Relations," *Canadian Journal of Disability Studies* 4, No. 2 (2005): 12-48; Kelly Michelle Fritsch, "The Neoliberal Biopolitics of Disability, Towards Emergent Intracorporeal Practices" (dissertation, York University, 2015), 283.

the number of individuals who fail the standard grows—within and outside the disability community. At the individual level, it multiplies situations of perceived personal failure, and at the macro level accelerates a transhumanist transformation of society. This realization is important because it allows us to learn a more general truth about our contemporary society from the critical work being done on the history of disability. What it suggests to us, I believe, is the need to engage in some basic re-valuations about human life and what we find important.

The challenge is, as I discussed in Braidotti above, to enter a time of “experimentation” around what forms of life we can choose, and how we can distance ourselves from the demands of constant and perpetual calculation of personal economic productivity and the collective devaluation of ‘underperforming’ bodies *today*. What kinds of lives we should value, and what form of life ought to be acceptable is not something I have an answer to. Neoliberal-ableist ways of thinking are so entrenched that it is nearly impossible to think of other forms of value—social/interpersonal, aesthetic, ethical, religious, etc.—and for those living with disabilities the same difficulties apply. In the latter case, we sometimes see the establishment of alternatives that, if formalized, may offer viable challenges to maximization; however, people are largely preoccupied with basic survival and the need to not fall behind. In biopolitical terms, choosing not to participate is to choose to be left for dead (to use Foucault’s metaphor in *The History of Sexuality*). A critical posthuman worldview invites new forms of value based on purpose, meaning, and fulfillment beyond economic type, but it runs into this practical challenge of existing in the already established treadmill of maximization. There is a need for larger segments of society to recognize more broadly the insufficiency of the neoliberal system of values.

4.2.1 Despair, Meaning, and Non-Economic Values

The above is not just armchair academic reverie. In the age of austerity, the significant challenges of the 2008 economic crisis, and the recent economic crash due to the global pandemic, we ought to recognize the inadequacy of economics as a form of value. We have seen, in these two contexts, a rise in what has been termed “diseases of despair” and “deaths of despair” even for those considered most privileged globally (young white males in G7 countries). For example, Anne Case and Angus Deaton have published a paper that has had a huge impact on how economists interpret the situation of the current American workforce.³⁷⁹ In their analysis they showed that for White non-Hispanic Americans without college education there has been a sharp increase in deaths of despair—i.e., deaths due to alcohol-related liver mortality, overdose, and suicide—between 1998 and 2015 because of the worsening labour economy for those without advanced skills. For them, there were “cumulative” disadvantages for this generation where not only did real wages and professional opportunities decrease, but the structures of religion, marriage, and family became increasingly less determined and fixed. This effectively removed the traditional ways in which this segment of the population found meaning in their lives. As they state:

These changes left people with less structure when they came to choose their careers, their religion, and the nature of their family lives. When such choices succeed, they are liberating;

³⁷⁹ Anne Case and Angus Deaton, “Mortality and Morbidity in the 21st Century” *Bookings Papers on Economic Activity* (Spring, 2017): 397-443; see also, Anne Case and Angus Deaton, *Deaths of Despair and the Future of Capitalism* (Princeton: Princeton UP, 2020); Emily A Knapp, Usama Bilal, Loraine T Dean, Mariana Lazo, David Celentano, “Economic Insecurity and Deaths of Despair in US Counties,” *American Journal of Epidemiology* 188, No. 12 (2019), 2131-2139.

when they fail, the individual can only hold himself or herself responsible. In the worst cases of failure, this is a Durkheim-like recipe for suicide. We can see this as a failure to meet early expectations or, more fundamentally, as a loss of the structures that give life a meaning.³⁸⁰

In conjunction with the recent decrease in economic opportunity, we have seen a parallel destabilization of established customary values around occupation, marriage, and family largely due to progressive political changes that the great majority of us would consider very positive. One can understand why certain segments of the American population may be mad at “liberals” as generation over generation they have seen the dominance of their sense of structure and tradition disintegrate in tandem with their quality of life. In this context, it is easy to reconcile the strong correlation between whites without a college degree’s voting trends toward Trump in 2016 and 2020. The campaign rhetoric was very much about a “return” to the great past, one where opportunity was only incidentally linked to a set of conservative values. No surprise either that those considered to be linked to the decline of traditional American values—progressives, intellectuals, newcomers, etc.,—became the target of vitriol or ridicule.³⁸¹ Disregarding political polemics, we need to understand the

³⁸⁰ Case and Deaton, “Mortality and Morbidity,” 430.

³⁸¹ In broad strokes, we can compare Trump’s rhetoric to the British National Party in the early 2000s. “Make America Great Again” seems like a direct throwback to “Put the Great Back in Great Britain.” Though this party was more explicitly dominated by white nationalist, many of the isolationist, anti-intellectual, anti-immigration and anti-leftist rhetoric crosses over. Though in Trump’s case there is a minority of his voter base that can be identified as far-right extremist, this segment has been linked to violent and anti-social actions. The intensity of individual actions is proportionate to the perceived transgression and the need for meaning, and certainly does not define the whole. I do not wish here to reinforce the idea that any Trump voter is a racist, uneducated, or extremist, this is precisely the tendency that prevents bridge building—and it is patently false. Despite its resonance with some of the vilest currents of our culture, and its potential as catalyst for violence for this segment, for most what it represents is an answer to the decline in standard of living and the disintegration of the system of value and meaning attached to that standard of living in the past half century. The majority are precisely those that have seen their quality of life decline, and in not wanting to blame themselves or the system as a whole, seek to hold the Other responsible.

effects on a whole segment of once privileged individuals who are made ‘underproductive’ by socio-economic changes,³⁸² without a recognized form of meaning or purpose to fall back on, nor a society that could provision for their needs. The result is the incursion of hate, violence, and exclusion—which do impart meaning and purpose—or disease, despair, and death, as opposed to new forms of affirmative collective meaning and purpose. It is here that we see, in the inadequacy of economic productivity as chief ordering value, the rise of the fascist concept of revolution that Braidotti warns against. It is the idea that a revolutionary return to an idyllic past is the answer to current problems—ignoring the gains and affirmative possibilities of our current time. This example from the United States is illustrative because it shows how precarious the investment in economics as the sole marker of value can be, and the disastrous consequences of having no affirmative systems of meaning to fall back on.

Certainly, one may object and say that it has nothing to do with value systems, and that material changes that lead to basic insecurity is the likely cause. I would not argue against that proposition. That assessment is likely correct given that at least one metric of diseases of despair—suicide rates—has been shown to increase during economic contraction and decrease during economic expansion.³⁸³ One study showed this effect in 30 different

³⁸² The shift from manufacturing to service based economies, increasing share of low wage jobs, and the increasing use of technology in every sector has changed the workforce landscape, which is projected to be further affected by automation in most labour intensive jobs in the near future. A more specific example would be the growing problem of rising student debt, high rates of underemployment and market challenges, especially for graduates shortly after the 2008 recession and, as we can assume, those graduating during the pandemic. What used to be a ticket to the middle class—and largely for moderately privileged families—now in many cases leads to debt and dissatisfaction.

³⁸³ Luo Feijun, Curtis S. Florence, Myriam Quispe-Agnoli, Lijing Ouyang, and Alexander E. Crosby, “Impact of Business Cycles on US Suicide Rates, 1928–2007” *American Journal of Public Health*

countries, but importantly, they found that the effect was smaller in countries with robust protections and benefits.³⁸⁴ In fact, one study in the European Union found that for every \$10 USD invested in workforce protections per worker, there is a measurable decrease of .038% (per 1% rise in unemployment) on suicide rates.³⁸⁵ So the objection that diseases of despair are due to economic policy as opposed to a lack of alternative value systems is valid to an extent; however, this is important for us for two reasons.

Firstly, economic policy does not happen in a vacuum. Countries with more robust social safety nets, at least in practice, have a more solid sense of collective responsibility and broader acceptance of certain forms of dependence. This is not to glorify these countries, as we have seen in the example of the United Kingdom, the policies are still largely problematic as a whole.³⁸⁶ When we advocate for new systems of human value that would—in our case here—better serve people living with disabilities in the posthuman future that awaits us, we are asking for more significant change than a few dollars in benefits. The context of global ecological crisis, automation, and artificial intelligence, as well as globalization and labour

101, No. 6 (2011): 1139-1146; José A. Tapia Granados, Ana V. Diez Roux, “Life and death during the Great Depression,” *Proceedings of the National Academy of Science* 106, No. 41 (2009): 17290-17295.

³⁸⁴ Thor Norström, and Hans Grönqvist, “The Great Recession, Unemployment and Suicide,” *Journal of Epidemiology and Public Health* 69 (2015): 110-116.

³⁸⁵ David Stuckler, Sanjay Basu, Marc Suhrcke, Adam Coutts, Martin McKee, “The Public Health Effect of Economic Crises and Alternative Policy Responses in Europe: an Empirical Analysis,” *The Lancet* 374, No. 9686 (2009): 315-323.

³⁸⁶ A reminder that the UK, once considered a prime example of a healthy welfare state, has been thoroughly gripped by austerity politics. The result has been disastrous for people who depend on benefits to survive, to the point where it even attracted condemnation by the United Nations. See United Nations, Convention on the Rights of Persons with Disabilities, “Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention; Report of the Committee,” (United Nations, October 2016): <http://www.ohchr.org/Documents/HRBodies/CRPD/CRPD.C.15.R.2.Rev.1-ENG.doc>

market trends generally happen at a much larger scale than the case of recessions explored here. It is meant to be illustrative.

With that in mind, we get to the second point. Knowing how vulnerable all people are to changes in the economy and how important protective policies are, highlights the need to advocate and resist the broad-brush austerity that has been so popular in the West for the past few decades. The obsession with debt, tax rates, monetary and lending policies, and labour market trends, which used to be the concern of economists behind closed doors, have become the subject of popular politics. Being stewards of our own personal capital in turbulent times has turned us into prospectors increasingly looking for ways to understand the context within which we maximize the output of our personal decisions—i.e. career, education, family, and recreation. In essence, this has individualized the impact of economic policy, and led many people to see collective investments as unacceptable limits to personal choice and freedom, even when the result is a measurable decline in overall quality of life. People overestimate the individual impact of their choices, find themselves responsible to protect the gains they have achieved, and underestimate their own vulnerability. Globally, as well as in the United States and Canada, income and wealth inequality is a growing problem, and economic mobility is declining.³⁸⁷ In other words, the number of people who are well-off is declining and the opportunity to increase ones social position is also declining. In fact, there is a growing income inequality in 70% of the global population, and this trend is likely

³⁸⁷ Marie Connolly, Catherine Haeck and David Lapierre, “Trends in Intergenerational Income Mobility and Income Inequality in Canada,” *Statistics Canada, Minister of Industry, Cat. 11F0019M, No. 458* (2021). Web: <https://www150.statcan.gc.ca/n1/pub/11f0019m/11f0019m2021001-eng.pdf>

to continue into the future due to technological innovation, climate change, urbanization, and international migration.³⁸⁸

In this game, people with disabilities are sure to fall victim once again. Given the perception of dependence for people living with disabilities, it is typical to expect those individuals to do with the bare minimum and just accept their lot. If they have basic food and shelter (in many cases even these are quite insecure), it is assumed, they have no other claims to make. In many ways, this is similar to the idea that the only valuable investments in one's personal or social development are those that increase our output; though, in this case it is more based on a fiscal responsibility to the collective. There is a more pronounced normative social expectation placed on people living with disabilities because of the perception of their exceptional dependence. The result is that while economic policies drive those individuals towards a struggle for survival (literally), we also see a rise in hate crime and discrimination. As Ryan put it in the UK austerity context, “[t]he increase in disability hate crime in recent years – from which even disabled children have not been exempt – shows, at its most extreme, the toxic attitudes bolstering such unprecedented cuts. The people on the very bottom rung of society have been shrewdly dehumanized by those at the top.”³⁸⁹ The political struggle for people living with disability can no longer just be a politics of inclusion or the demands for accommodation; it has to be accompanied by a new socio-political vision.

³⁸⁸ United Nations, “World Social Report 2020; Inequality in a Rapidly Changing World,” *Department of Economic and Social Affairs, No. E.20.IV.1* (2020). Web: <https://www.un-ilibrary.org/content/books/9789210043670/read>

³⁸⁹ Frances Ryan, *Crippled: Austerity and the Demonization of Disabled People* (London: Verso, 2019), ebook, Location 2676.

The current system harms more than those with disabilities. As we saw in the example above of working-class Americans, life in our neoliberal times is precarious for all but the most privileged. As noted again by Ryan:

it is no real surprise at a time of squeezed wages, unaffordable homes, diminishing life chances and growing uncertainty that the average voter has had little desire to think of their disabled neighbour. Or, worse, that they are ripe for duplicitous voices to tell them that the cause of their woes is not, say, insecure jobs or a lack of social housing but the costly ‘welfare’ bill. It is difficult to focus your energy on what is happening in a care home to a disabled stranger when you’re struggling to pay the bills, or your children can’t find affordable housing. **The challenge in the coming years is to bridge this gap, to show not only that disabled people are not an economic threat, but also that the struggles facing each of us are not so different after all.**

Certainly, I do not mean to be equivocal here. The challenges that most people face are not at the same scale as those already at the margins. But we have to recognize how the system impacts most people, and how that impact leads, on the one hand, to despair, disease and death, and on the other hand, a doubling down on further violence to those at the margins. This is where a collective solution has to begin. We have to move beyond polemics based on identity or politics and find allyship in those aspects of normalization that places pressure on all of us. This is not a complete solution, there is still a need to put on the political pressure beyond our commonalities, have uncomfortable conversations, challenge problematic ideas like ableism, hate and discrimination, etc. However, understanding common sources of despair and inadequacy as opposed to finding comfort in the ‘us’ (identity politics) side of an ‘us and them’ political worldview is a precondition to incremental change towards a better

society. Though there will be insurmountable differences in some cases, I believe there are more opportunities for allyship than there are inevitable confrontations.

One common denominator in our predicament can be described as ‘slow death,’ a term that Goodley *et al.* borrows from Berlant.³⁹⁰ The concept of slow death is that essentially, we do not only surrender our time to labour and production, but we sacrifice our bodies as well. We wear out, we get hurt, we sacrifice time spent on exercise and nutrition to the detriment of our health—all effects that are more pronounced the lower your economic status is. For Berlant, the deterioration he observed at the level of population represents a historical condition of capitalism.³⁹¹ Though the effects are amplified at the margins, as Goodley puts it,

Alliances can be made. Interconnections should be sought. Disabled activists and union workers have much in common. But, dis/ability might also offer a challenge to those caught up in slow death who seek recognition and identity through neoliberal projects of work, spend, improve, work, die. Could care rather than work, be a place to find identity and recognition?³⁹²

In other words, we all wear ourselves out. Could wearing ourselves out for the benefit of others as opposed to the demands of capital be a viable alternative?

³⁹⁰ Goodley, Dan, Rebecca Lawthom, Kathrine Runswick-Cole, “Dis/ability and Austerity: Beyond Work and Slow Death,” *Disability and Society* 6 (2014): 980-984; Goodley, *Dis/ability*, 96-98.

³⁹¹ *Ibid.*

³⁹² *Ibid.*, 96.

I do not mean here to say that the care for disabled people is an alternative source of value—i.e. some self-righteous form of charity—I mean the care of *all* people rooted in interdependence. Goodley is speaking here about care as an orienting value. It means finding value in interconnection and reframing non-economic commitments as a form of resistance-labour. What I term volunteer work, charity, or other forms of unpaid social, cultural, and community-based activity is often seen as a form of self-sacrifice for the greater good—in many cases it is. But this is because its function is to make up for, by the surplus energy and self-sacrifice of otherwise productive individuals, the failures, and gaps of late-stage capitalism, i.e., to make up for the things that are not provisioned for by economic productivity, but that are necessary to a resilient and fulfilling human society. This is why the target of these initiatives are typically the marginalized and less fortunate, but we all depend on the non-economic care of others. In this idea of care is an alternative and radical counter-value; that not all-purposeful action needs to be monetized, and that we can find meaning in collective action outside of work. I am not claiming that we can replace work or occupation as a primary source of meaningful action; this would be inconceivable. What I am saying is that non-monetized purposeful action is systematically undervalued under capitalism even though it is entirely necessary. We ignore interpersonal care in the same way we have historically, and in some ways still do, ignore and undervalue the necessity of non-economic domestic labour. We see this issue raised in contemporary feminist rhetoric, given the historically unequal distribution of this labour. Much like the issue of domestic labour was largely ignored until women entered the workforce in the 1960s and 1970s and their non-economic value became obvious, the issue of our interdependence for care will become more and more obvious as austerity measures erode social safety nets and increasing

numbers of people fail to participate in the over competitive and technologically complex primary economy. In fact, the latter is a great analogy for the expansion of what we choose to value argued more broadly for in this section. Healthy children and adults cannot be manufactured or bought; the same is true of a healthy community or society. A recognition of the necessity of non-economic contributions to society in tandem with a recognition of our precarity, frailty, interdependence, and interconnectedness is essential to the acceptance of alternative ways of being. Activism, advocacy, volunteering, community development and improvement, culture, and art are all avenues of purpose that have the potential to enrich life and bolster interconnection. They are also avenues, among many others, through which people with different abilities and ways-of-being contribute to our society. Unfortunately, our current system has monetized what it could, and has offloaded the responsibility of the rest to the few with the excess energy, resources, and the will to engage in care—despite it literally being irrational vis-à-vis the logic of neoliberalism. This is why the solution is not as simple as telling people to *do more* or *participate*. This individualizes responsibility for a structural flaw of advanced capitalism.

The reality is, these are the avenues where many people, those unable to participate in the workforce included, find meaning. However, when austerity pushes people further towards bare survival and inadequate care, their individual value is diminished along with their valuable contribution to the community, while at the same time their need for support becomes amplified. The idea that people should suffer because they are unable to contribute to the primary economy is one of the most dangerous ideas of neoliberal capitalism, whether it is due to the mismatch between one's body/ability and the structures of the workforce, and the myriad disincentives and barriers to participation that exist in one instance, or the

growing demands of performance, ups and downs of the economy or workforce, and the automation of manual labour in the other. Though the effects are easily ignored in the short term by those who are currently favoured in the market economy, it is an unsustainable idea that will lead to the erosion of many intangible things that make life meaningful for all.

Broadly, people are inadequately cared for in neoliberal capitalism because needs go beyond what can be monetized or are not provided for by the excess wealth created by society as a collective.

The affirmative possibility here is that we may advocate for and develop forms of social value and meaning tied to care for all people in our society, where disability theory and activism may contribute a deep understanding of what is needed. The alternative, I would argue, leads to neoliberal slow death, despair, increased discrimination, violence and hate as a certain segment of society grasps at an idealistic past and the other holds on to an old revolution without substance. Though I have drifted towards more general comments here, at the close of this section we do need to acknowledge the unevenness of who suffers in our current system. Though I believe that at the core of disability activism is an issue of importance to all, to take the specificity away would dilute the potency of this movement. There are forms of activism that need to be targeted to disability specific issues.

In this vein there is an interesting emerging perspective in the disability movement called “disability justice” which is gaining momentum in the activist community. Though it does not emerge from an explicitly posthuman perspective it shares many of the concerns, especially as it relates to neoliberalism and maximization. This movement, largely spearheaded by an arts collective called ‘Sins Invalid,’ shares many of the concerns discussed throughout this dissertation; resistance to economic valuation, the transversality of

disability and any number of social, political, and material challenges of our time, the intersectionality and default diversity of people, and the poverty of a purely rights based/social model approach.³⁹³ For *Sins Invalid*, the only viable option is a broad allyship between people of all abilities, social and political position, of intersecting identities. Previous activism focusing on disability as a singular issue and from a rights based approach privileges those already easily integrated and whose rights are already largely respected—i.e. disability that intersects with other forms of privilege.³⁹⁴ For this reason, they advocate for an escalation of leadership of those most affected, and promote cross-movement solidarity and intersectionality.³⁹⁵ Though their rhetoric is not entirely compatible with the perspective advocated here—e.g., their focus on oppression and liberation—the spirit and active piece of it is the manifestation of precisely what is needed. Political and social action that does not reduce to a single people or issue, but one that creates space for diverse voices and creates bridges between transversal issues and their resistance movements.

Generally speaking, resistance to neoliberal-ableism transverses aspects of social existence (family structures, hardship, responsibility, personal failures, discrimination) social organization (class, privilege and marginalization, interpersonal relations), national politics (austerity, workforce and productivity, investments and strategic development), and our attempts to maintain competitiveness in light of global economic, techno-scientific, and environmental trends. In this complex web of overlapping pressures we need to promote

³⁹³ *Sins Invalid*, *Skin, Tooth, and Bone*, 11-20.

³⁹⁴ *Ibid.*, 15.

³⁹⁵ *Ibid.*, 18, 24-5.

alternative values that do not descend so easily into despair, discrimination, and political violence, and support more pointed cross-movement activism led by those most affected. In doing so, we may create a bit of distance from the worst manifestations of a singular focus on self-directed maximization and the overarching value of independence. This is a structural aspect of our society, and as such, what is proposed here is not likely to be a tectonic cultural shift—as observed in the civil rights movement, for example—but a multi-generational process of change. Let us move on, then, to the second aspect that occupied the analysis so far, optimization.

4.3 Optimization

If Foucault found in the factory the model for disciplinary power, i.e., a malleable body whose actions are strictly controlled until learned, the model for the kind of self-regulatory normalization we see today finds its analogy in practices of piecework.³⁹⁶ In piecework one's work is compensated and measured against standard targets. One attempts to complete X amount of units, performance is measured closely and determined to be under or over performing. Under performance is understood as a personal failure, and any structural or individual intervention (e.g. new machine or piece of software) that lead to consistent over performance changes the target to be reached (becomes the new norm). This is precisely how the body, and its many abilities (and deficits), are viewed in flexible normalization (see discussion of Link and Waldschmidt in Chapter four of Part 1). Clearly, the analogy is

³⁹⁶ Piecework is a practice where workers are paid “by the piece” and/or given standard production targets that they have to meet. It essentially began in the industrial revolution where instrumentation and assembly line work made repetitive productive tasks the norm.

reductive because there are any number of measurable outputs to be optimized *in the real world*, but the mechanism is very illustrative. With respect to optimization people are brought to view their bodies and abilities in line with perceived averages or collective expectations where they are responsible not to fall into underperformance, and where opportunities for over performance are to be sought out. As we have discussed, this is closely tied to technoscientific innovation as a great number of apparatuses, tools, and biochemical aids become commonplace and the expected standard of performance permanently increases. This tendency incidentally comes to dominate the direction of technological development, as these are the ‘problems’ that scientists and engineers encounter. From the perspective of disability, and for those who are looking to establish different forms of acceptable life, this represents a far too narrow application of technology’s ability to completely change our lifeworld (Part 2 Chapter 2) and to facilitate modally distinct ways of life (Part 2 Chapter 3).

4.3.1 Technology and Affirmation

A first step in harnessing the affirmative potential of technology is to become critical of how technology is developed. Counter to contemporary practices, disability must be respected and not commercialized or exploited for funding—i.e., that it is developed based on the needs of people instead of the needs of science and technology to develop new applications and new markets. People living with disabilities in their entirety are not the beneficiaries of technological advancements, and in many cases, are simply seen as a depoliticised and depersonalised problem to be solved. In a world where a bio-somatic understanding of the body and an incapacity/suffering narrative of disability intersect, the apolitical nature of

disability and its solution is confirmed in the popular imagination. As Goggin and Newell explain in their study of medicalization and disability:

The tragic life of an individual or several devalued individuals is portrayed in a way designed to elicit maximum effect; A technology is portrayed as delivering a person from disability, provided society legalizes, funds, or embraces such a solution; securing the technology means that disability has been “dealt with;” after deploying such rhetoric there is to be no more appeal to emotion and the solution lies in the rational pursuit of the technology identified in step 2; disability as a political issue goes away, until the next time it is needed in the powerful politics of media representation.³⁹⁷

Disability as suffering is confirmed, and social or political change unjustified; real benevolence is to be found in its elimination.³⁹⁸ Where medicine’s goal of *cure* was the target of social model critiques, current biotechnological medicine has the much more ambitious target of *elimination*. This can take on the form of a soft-eugenics (i.e. screen and intervene on the unborn in order to circumvent the problem of disability), or creating technologies that ‘level the playing field’ and reinforcing the expectation of self-regulated adoption of the solution provided. Any effort that falls outside the search for better biomedical interventions are likely to be met with significant resistance. Activism is reduced to fundraising, access to benefits or treatments, or individual parent/patient rights—all things

³⁹⁷ Gerard Goggin and Christopher Newell, *Disability in Australia; Exposing a Social Apartheid*, 108, quoted in Dan Goodley, *Dis/ability*, 5.

³⁹⁸ Certainly, scientists by and large have benevolent intentions, but as we have seen in the examples of modal adaptations in the previous chapter (section 3.1), as well as the general commercialization of medicine discussed throughout the current work, that in practice the people for whom the technologies are developed seldom participate in the process and rarely receive the benefits of the development.

that have been shown to be problematic throughout this dissertation.³⁹⁹ These demands still have a place in disability activism, but none represent a collective political vision, especially not one that can organize against transhumanist narratives and its socio-political influence. What we need is the ability to affirm that technology can open up possibilities for people with disabilities—as it has the potential to do for all people—without it negating essential aspects of disability politics, activism, and experience.

One such vision, that must be mentioned here, is so called *Crip Technoscience*. Aimi Hamraie, leading theorist on critical design and Kelly Fritsch, critic of neoliberalism and the normalization of disabled experience discussed in many places throughout this work, have recently proposed four “commitments” for a critical engagement with technoscience. These map very well onto, and respond to, the challenges I have been discussing in Part 2 of this work. They are: a commitment to (1) affirming the centrality of disabled people as “knowers and makers,” (2) to “access as friction,” (3) to “interdependence as a political technology,” (4) and to “disability justice.”⁴⁰⁰ Let’s explore these here.

³⁹⁹ I.e., that the received understanding that disability is synonymous with suffering, deficit, and inadequacy are not challenged but exploited by the current grand narrative, and that this significantly weakens the ability of people with disabilities to contribute to the making of their world; that personal choice can be used as a mechanism of control that responsabilizes the individual to act in accordance with accepted norms; that individualizing the issues undermines the possibility for collective change and resistance, and that simply fighting for access and inclusion often only ensures that some can participate in a problematic—albeit more comfortable—system of production while others who do not have the requisite forms of adaptation remain in a weakened and marginalized social position.

⁴⁰⁰ Aimi Hamraie and Kelly Fritsch, “Crip Technoscience Manifesto,” *Catalyst: Feminism, Theory, Technoscience* 5, No. 1 (2019): 1-34.

(1) In affirming the central role that people with disabilities must play we avoid many of the issues of inadequate technologies and ableist assumptions about use and purpose. User-driven design ought to be a given when we talk about body interfacing technologies, but as history shows us, more often than not, technological innovation is bio-medically driven and based on the expected mechanics of the normal body. Hamraie and Fritsch give us a multitude of examples of people with disabilities having to engage in *ad hoc* tinkering to make assistive devices and everyday technologies fit their ways of interacting with the world.⁴⁰¹ This leads to important moments of hacktivism, community building, and political action; these are all things that naturally occur and ought to be supported; from the disabled veterans of WWII adapting their homes to their changed bodies, to Hotchkiss' snow ploughing wheelchair in the 1960s which resulted in the creation of a social enterprise, to contemporary examples of disabled parenting websites, blogs, and online communities that share both experience and practical modifications to available products.

The Hotchkiss example is quite important because it shows what experience-led design can, or is likely, to do. When we say that the users of the products should be genuinely involved in the process of design, there is still a risk that the output is just a better consumer product. Certainly, inclusion in the process and a reversal of the ultimate status of biomedical knowledge as the driver in the process is itself a moment of letting disability speak for itself. It is a political victory, but it is a minor one if the product itself is simply inserted in a system of consumption where access is limited and inequitably distributed. Hotchkiss' innovation did not end with his own wheelchair, he sought out better designs to engineer more suitable

⁴⁰¹ Ibid., 7-10.

chairs and found what he was looking for in the innovative practices of four Nicaraguan users-tinkerers.⁴⁰² These four individuals were sharing one wheelchair and had re-welded and redesigned it over time to fit both their individual needs and the wear and tear of heavy daily use. Hotchkiss worked with them to start Whirlwind Wheelchair International whose mission is to build and distribute the RoughRider, an affordable and serviceable wheelchair with the potential to fill some of the global accessibility gap. This would have been an unlikely mission for an able-bodied engineer in a commercial biomedical laboratory. Though disability is not a disqualifier for greed or complacency, it is a fact that the more involved and the more control users have over the development process and the design, the more politicised the purpose of that technology becomes. Engagement and control at all levels is a political necessity if technology is to play an affirmative role in the future of disability activism and action.

Likewise, the Internet has been one of the biggest barrier busting technologies of our time because it is so easily co-opted for accessibility. It is by design an inter-connecting and a malleable technology that can be adapted to the needs of its users. Certainly, it has and continues to be a vehicle of bullying, discriminatory attitudes, body shaming, monitoring and surveillance, etc., but it also serves as a platform for collective sharing such as in the example of the Disabled Parenting Project,⁴⁰³ and Engineering At Home,⁴⁰⁴ discussed by

⁴⁰² Ralf Hotchkiss, “Extended Interview” *PBS Frontline*, web: <http://www.pbs.org/frontlineworld/stories/vietnam804/interview/extended.html>, quoted in Hamraie and Fritsch, “Crip Technoscience,” 8-9.

⁴⁰³ *Ibid.*, 10.

⁴⁰⁴ “Engineering at Home,” Engineering at Home, accessed August 7, 2021, <http://engineeringathome.org/>, discussed in Hamraie and Fritsch, “Crip Technoscience,” 9.

Hamraie and Fritsch, as well as other practices like open source software,⁴⁰⁵ open source development and affordable prosthetic initiatives,⁴⁰⁶ and new trends such as crowd-sourcing, and 3D printing. All of these hold some promise of both valuing people as knowers and doers, while simultaneously allowing for individual and community control over the innovation. This intersection of the virtual and physical disability community will serve as an important site of resistance for posthuman disability.

We have to look at alternative routes of development, distribution, and cooperation in biotechnological innovation, while continuing to support the resistance of people whose potential embodiments are most problematically tied to these technologies. Without this, we risk: a) perpetuating the development of technologies based on biomedical concepts as opposed to acknowledging the normative nature of actual lived-experience, b) callously marketing novel prosthetics as solutions to the ‘problem’ of disability while in actuality only resting on the trope of *disability-as-suffering* to develop limited products for a privileged few, and c) ignoring the important insights of people with alternative adaptive embodiments on the potentials and dangers of biotechnological prosthetics and interventions.

(2) The discussion of access as friction brings up an issue already discussed that is central to our need to move beyond the social model. The issue is that simple inclusion is too

⁴⁰⁵ E.g., “Fullmeasure.co.uk. Open Source Assistive Technology Software.” Fullmeasure, accessed August 7, 2021, <http://fullmeasure.co.uk/>.

⁴⁰⁶ E.g., OPENBIONICS. Accessed August 7, 2021. <http://www.openbionics.org/>; Waag, “Low Cost Prosthesis,” accessed August 7, 2021, <https://waag.org/en/project/low-cost-prosthesis>.

easily co-opted by neoliberal economic considerations and severs political action from any political or social change more generally. Access in the way that Hamrie and Fritsch discuss is tied to a certain politics of action. It shares much in common with the social model and claims much of its actions (e.g., early activism in the US, the independent living movement, Luke Anderson’s “stopgap.ca” ramp making charity, and Collin Kennedy’s attack on hospital parking meters).⁴⁰⁷ Whether or not the justifications or intentions of these actors aligns with a posthuman ‘crip technoscience’ is not the question, what is important is that they can be compatible, and that we can adopt a more mindful and politicised fight for access going forward. The issue we have discussed so far around simple inclusion does not invalidate the point here. In the kind of activism that Anderson or Kennedy are engaging in, the intervention is not meant to be a solution in itself, but is a critique and a moment of friction that brings awareness to the lived inequities in our society.

In typical fights for access, those barriers that eliminate the most difference with the least social/physical change, and those that cost least or open up the largest markets are broadly validated or pursued. They do not follow the needs or political demands of a social movement. Fritsch particularly has discussed the ease with which fights for access can be co-opted by neoliberalism. We can add to this the transhumanist/biotechnical idea that technology will make disability disappear and we find that disability activism’s *raison d’être* is severely weakened. There is much more to be done than to fight for access, and to continue to consume technology as a means to optimize performance in order to neutralize impairments. The fight for access cannot be separated from the critique of society, as it is apt

⁴⁰⁷ Hamraie and Fritsch, “Crip Technoscience,” 11-12.

to do to be successful within official channels. Access as friction is a response to these challenges.

(3) The idea of interdependence as a political technology is a very interesting one. Hamrae and Fritsch quote Kafer as saying that people living with disabilities are not cyborgs “because of [their] bodies (e.g., [their] use of prosthetics, ventilators, or attendants), but because of our political practices.”⁴⁰⁸ In a general sense, this is how I have been discussing interdependence in this dissertation, but it is accessed from a different point, which highlights a very different set of practices. As discussed previously, interdependence is not an aspect of disabled experience but a universal aspect of the human condition that is ignored in the latter context and exceptionalized and brought to the forefront in the former. Bringing the inherent contradiction of this formulation into focus destabilizes the idea of independence as the mark of normality and value. Though the discussion so far is compatible (as I see it)⁴⁰⁹ it has been much more general. I am trying to bridge disabled and non-disabled uses of technology and resistance to the dangers of technophilic hyper-modernity. In the Crip Technoscience Manifesto they are speaking quite specifically about how technoscientific interdependence can and is used as a political technology. That is to say, the ways in which

⁴⁰⁸ Kafer, *Feminist, Queer, Crip*, 120, Quoted in Hamraie and Fritsch, “Crip Technoscience,” 13.

⁴⁰⁹ It could be argued that I do discuss the community of people living with disabilities in a way that may be perceived as making them the “paragon” of posthumanism, but I believe I do this in a sufficiently critical sense (i.e., outside the bounds of transhumanist imagination and modernist normalization). They are only, from this perspective, the paragon in the sense that their experience has something to reveal to us, not that they represent the pinnacle of some technoscientific aspiration.

technoscientific interdependence can be harnessed for social action in the disability movement.

Two insights can be gleaned from the examples they use, first that technology ought to be used to facilitate collective resistance to limiting practices, and second that as a matter of course, those who are meant to be users of the technology ought to be centrally involved or collaborate on equal footing in the deployment of the technology itself. As we have seen in our historical explorations, this is sound advice for any type of intervention, but is of utmost importance at this critical time when the powers of technological advancement are guiding major scientific and political trends that have direct negative impacts on people living with disabilities. Though posthumanism is primarily a reaction to the failures of modernism and humanism, because of the moment in time where we find ourselves the question of technology and biotechnical modification play a central part in any cohesive political or social programme. It is in this context that Hamraie and Fritsch call on the disability movement to find uses of technology that can facilitate collective action while at the same time seeing all use of technology as an interconnected and collective experience. Veiled in this third commitment of Crip technoscience is the old and central insight of second wave feminist that the personal is political. Though technologies are typically seen as individual interventions—e.g., a medical device—and are aimed at making a difference in that person’s life—e.g., rehabilitation or treatment—, they are also intricately tied to social and political frictions of the perception of disability, the ability of people with disabilities to resist or re-write what an able-body is, and of what the purpose and acceptable use of a technology is. Examples of the latter abound in the use of technology for political, leisure, sexual, and cultural purposes as non-productive (in the capitalist sense) demands that are at odds with

established norms. But the idea of the political nature of personal action (and technological integration) is also evident in the discourses of access, privilege, and justice. Which brings us to the fourth commitment of Crip technoscience: disability justice.

(4) As mentioned in the previous section, disability justice is a perspective that sees the struggles of people living with disabilities as both an issue of justice, in the limited sense of ableism being a form of injustice, while at the same time the recognition that injustice in all forms are intertwined in complex ways. A person living with a disability is not a univocal category but incorporates many personal, social, and geopolitical factors that significantly complicate political action. If by “person living with a disability” we imagine anything other than a default middle class white western male with a physical impairment we can say that there are *typically* more than one intersecting forms of oppression involved in any discussion of justice. Moreover, we also recognize that disability is not an isolatable issue, and that it transverses many major social problems from poverty to religious extremism to global climate change and everything in-between. In response to this more generally, it means that disability activism *must* engage in formative allyship with other movements and harness the experience of intersectional voices within its own movement. As a first step, it means recognizing that traditional technoscientific and transhumanist discourses coming from disability sources are often rooted in privilege and are artificially made to speak for all.

More specifically, as it relates to technology, a useful term that Hamraie and Fritsch use is “wholeness.”⁴¹⁰ A term borrowed from Eli Clare, it essentially means that there is a formative tension between accepting that there are parts of ourselves that we would like to

⁴¹⁰ Hamraie and Fritsch, “Crip Technoscience,” 19.

change while maintaining that those parts do not make a person broken or less valuable. In other words, if the disability movement is to fight to make disability acceptable, there is a possible contradiction with the idea that they may also fight for innovative and body-modifying technologies. However, the search for body modification and the fight to be recognized as whole and valuable people are not independent from each other. On the one hand, we can acknowledge that a disabled body has an innate and immutable value, while on the other hand we can accept that there are things about those bodies that one may legitimately wish to change or improve outside the value laden medical discourse on impairment. Moreover, as I would argue, it is a natural tension that is within all of us in a world where there are so many possibilities for technology-body mediation, though for marginalized groups the stakes are much higher.

The major lines of the debate follow biomedical or bioconservative perspectives and the only important question is ‘what ought to be allowed or disallowed and on what principle?’ What ought to be done, what limits ought to be placed, what we should permit or disallow are not questions with concrete answers. We must, following Braidotti, formulate an ethical relationship with others that respects interdependence and vulnerability and, following Shildrick, be ok with the uncertainty and uneasiness of exploring the questions of technology-body mediation outside the once secure boundaries of the rational, white, able-bodied, and entrepreneurial self. A disability informed critical posthumanism demands that we act on collective needs, and to incorporate as many diverse and intersecting situated points of view as possible in our political movements. Disability justice presents itself as an example of this push for an experimental form of techno-mediated ethical relation based on

collective needs and diverse points of view; an example that ought to serve as a prototype for many forms of posthuman movements.

4.4 Conclusion

If we started from a speculative point in time where an ideal situation could be manufactured that would counter the negative aspects of modernity, neoliberal capitalism, and biomedical understandings of all human variations; our situation would be fairly simple. We know that this is not our situation, so there is friction between the ideal solutions and our current opportunities. For the most part, people with disabilities and the transversal forms of marginalization that often intersect with these bodies have been the target of various forms of discrimination and violence for several hundred years as tracked in some form throughout this dissertation. By no means are they captured in their entirety; it is a history that could be told in many volumes. What I have found, and what I argue here, is that the solution is not to fight fire with fire, but to remove its fuel by destabilizing the foundations of their broken ideas, by offering alternatives, and by distancing ourselves by invalidating entrenched norms through social action (e.g., feminist resistance, anti-racism, decolonisation and anti-ableist action to name a few).

What is important to note is that the many forms of normalization that have traditionally taken aim at the disabled body are in a moment of significant transition. Challenging fundamental assumptions and replacing them with more inclusive and radically different alternatives is an effective form of resistance, especially when we consider that in the face of these changes we have on the one side a hyper-conservative revolutionary

movement towards traditional values, less government (i.e., less services) and anti-intellectualism, and on the other we have a progressive and future-projected utopia that intensifies the promises of modernity. Both extremes fail to grapple with the reality and experience of disability in its uniqueness, as well as the similitude of its challenges with a great majority of the population going forward. In other words, showing how our current order of things has been disastrous for people living with disabilities ought to serve as a warning (or illustration) of what most people can expect in the age of advanced technocapitalism. Whether we resist its march or try to find ways to navigate it towards more friendly waters, we have to find ways to promote collaboration and allyship.

As recognized by many critics of capitalism and neoliberalism alike, a singular focus on economic forms of social valuation leads to an existence that is increasingly devoid of meaning and purpose. This is something that could historically be ignored because it affected those voiceless people first, but it is becoming clear that grievances were legitimate and ought to have been addressed. The past decade has seen a rise in political division and a rise in political violence in North America and Europe that increases the need for collective, practical, and targeted resistance that destabilizes old master narratives. This is a difficult task, and an all at once reversal may represent a utopian reverie—at least it does for me. What is required is incremental change in key areas. These include the idealised bodies and functions passed down from modernity and intensified through transhumanist discourses, as well as extrinsic performance and productivity needs manufactured by the demands of our technoscientific present.

A significant contemporary issue where both of these come to a head are at the intersection of technology and the body. Our ability to modify, increase, decrease, enhance,

add and subtract aspects of our bodies and our performance of these bodies is being harnessed by the same forces that have historically problematized abnormal bodies and reflects their purpose of elimination—an ideal that is unattainable but whose exercise has many victims. Wholesale rejection on those grounds would be understandable, but would, from one perspective which I share, be out of touch with the times. We are and always have been technologically mediated beings, and we are in this moment of experimentation whether we want to or not. Moreover, it is undeniable that biotechnology has the potential to open up a myriad of opportunity and new forms of life worthy of exploration. The danger in this is that these possibilities cannot be explored without first pushing back on the dominant view that social problems are technoscientific problems. What we need to do is work to ensure that it is not writing a sequel to the history of exclusion and domination of the past, but fulfils its theoretical promise of creating a new and better world. This necessitates that the voices of those that formed the structuring and structural otherness of modernity are not reduced to a function and justification for modes of normalization that deny them participation in world-making once again.

As laid out in the posthuman manifesto, Goodley et al.'s recent work on posthumanism in disability, and the works of Braidotti what we need is a period of posthuman experimentation where experience is central to directing the development and use of technology. Especially when the target is a specific group likely to be significantly impacted, such as in prenatal diagnostics or the development of smart prosthetics. We need a politicized agenda for access to innovation and a justice based ethico-political framework for action. This is critical in posthuman disability because of the imminent risks of repeating historical mistakes, but it also applies to a growing number of people who fall outside the

bounds of the ‘cutting edge’ of the developing transhumanist society. Bringing politics into the mix and relying on justice frameworks as opposed to more established ethico-political thinking does bring with it several challenges. There is a great deal of potential for lateral violence between those that seek to conform to contemporary demands and values (i.e. those who accept a de-politicised view of their own bodies/social position) and those that seek to rewrite priorities and disassociate from certain practices or initiatives. In fact, any contemporary issue we identify will have people on either side, the idea is not to enter into a polemic or demonizing the “other side.” There has to be room for both. Haste, fervour, and idealism leads to a fundamentalism with the expectation of widespread adherence. This is antithetical to collaborative change, and too often drifts into a form of utopianism and authoritarianism with which I am uncomfortable. Collective and sustained resistance towards incremental change is most likely to create a world congruent with the wishes of people living with disabilities, those unable to perform to the standards of neoliberal capitalism, and others likely to fall prey to the dangers of hypermodernity. Key to this is finding moments of shared understanding and struggle, across movements, class, and social position that give glimpses into the injustice already firmly established for those at the margins. People living with disabilities have much in common with those experiencing workplace burnout, accessing food banks for the first time throughout the pandemic, those who cannot find adequate housing for their families because they have been priced out of the market, those that cannot find adequate employment because of shifting demands, those that reflect on the fact that the life enjoyed by the previous generation is not available to them no matter how hard they work. These moments of looking outward at the structural failures of our society are moments of bridge building. Individually, there are also many opportunities to identify

with people using assistive technologies, prosthetics, or pharmaceuticals in an age where universal technological mediation is becoming more and more obvious (especially through work and aging), and technological aids to productivity and everyday life more commonplace. The exceptionality of taking a daily medication, for example, is not what it was just a half century ago.

All this requires a robust collective push towards inclusive justice and widespread buy-in from those that currently have influence in politics, science, and academia. This need is not well suited to our current era of oppositional personal politics. Radical thinking should be encouraged and harnessed; this is a great source of innovation and novelty. The place at which they transform into action ought not be a battlefield, but a firm, affirmative and strategic deployment of action for the benefit of the collectivity and their diverse needs. The result is not passivity or complacency, but the acknowledgment that change will not come tomorrow from a large-scale revolution. It will come from a correction in trajectory brought on by collaboration and persistent pushback. As alluded to by Braidotti in the introduction to this chapter, it is through this kind of activism that leads to a detoxification of our ways of thinking and acting evidenced by feminist and anti-racism movements. At a time when technoscientific interventions on the body and the demands of performance outweigh the resources of an increasing number of individuals, there is room for optimism about the possibility of finding a receptive audience to the resistance of posthumanism and disability activism to the most undesirable aspects of our contemporary situation.

This optimism may run counter to the acknowledgement that disability discrimination and hate crimes remain frequent, as well as the common social approval for austerity as it relates to social services. It is my belief, possibly somewhat contentiously, that this is the

evidence of the widespread failure of our contemporary society to fulfil the needs of its people, and that it does represent a certain form of lateral violence understood more broadly; i.e., that people whose needs are not met in the current order of things displace that anger and frustration towards others who are equally underserved (though they do not identify them as peers in this struggle). I tend to believe, or hope, that concerted efforts to destabilize the discourses that prop up maximization/optimization norms as well as a more developed sense of interdependence in the need to resist these will yield a more receptive society. It is precisely for this reason that I try to bridge, throughout this work, the currents of posthumanism and critical Disability Studies. Success depends on these, and many more, instances of bridge-building.

Conclusion—Reflection on an Alternative

Transhumanism can seem on the face of things as an optimistic worldview that results from the application of scientific advancement to the human condition. This would not be a misinterpretation, but it is a defanged oversimplification. It ignores its roots in modernity and the direction this gives to a particularly dangerous utopian imagination. It attached itself to a society already obsessed with a certain type of improvement and development, old concerns for the perfection of the human animal and its social organization are intensified to an extent that can only be possible for an imagined new species. Norms of performance and bodily mastery develop outside the limits of an interpretation of nature itself. What I termed hyper-modernity I could also have called unhinged modernity. One way to resist this would be to reject the influence of technoscience and its possibilities for improving the human condition wholesale. However, from our perspective, this move is both naïve and impractical. Naïve because we are already in a technoscientific posthuman situation, and impractical because as a tool technoscience has a lot of potential for good. It is the singular focus of the transhumanist imagination, and the authority with which it can speak to humanity's concerns that is problematic. It is entirely uncritical in the sense that it ignores legitimate and continuous challenges to the foundations of the modernity from which it sprouts, and the conclusions it draws about the nature of man that it purports to overcome. This uneasy similitude is not new, it was already recognized by Haraway in her landmark book *Simeans, Cyborgs, and Women* where she writes:

From one perspective, a cyborg world is about the final imposition of a grid of control on the planet, about the final abstraction embodied in a Star Wars apocalypse

waged in the name of defense, about the final appropriation of women's bodies in a masculinist orgy of war (Sofa 1984). From another perspective, a cyborg world might be about lived social and bodily realities in which people are not afraid of their joint kinship with animals and machines, not afraid of permanently partial identities and contradictory standpoints. The political struggle is to see from both perspectives at once because each reveals both dominations and possibilities unimaginable from the other vantage point.⁴¹¹

Extrapolating what she is saying here about feminism to our broader object, in the first instance is the idea that our advanced technological present projects a detached cosmic imagination that justifies an intensification of a grid of control on women's—for us, disabled or marginalized—bodies. It gives rise to actual practices in the name of a potential future. For example, the source she cites here is a paper criticizing the equivocation of a life lost to abortion with the potential generations lost to nuclear extinction, i.e., that being anti-nuclear weapon is only congruent with a pro-life position on abortion, an argument used at the time to criticize pro-life feminism and bodily autonomy.⁴¹² In the 30 years since she cited this, the strategy itself lives on in transhumanist and technophilic discourses. Note the particularly striking example of iterative embryo selection discussed in Chapter three of Part 2; where the need to create superhuman intelligence was a necessity for survival (from various existential threats), and its effects on disability politics put aside as a non-issue. Speaking more broadly, it represents this idea that the imagined future, where humanity might harness new

⁴¹¹ Haraway, "Cyborg Manifesto," 154.

⁴¹² Zoe Sofia, "Exterminating Fetuses: Abortion, Disarmament, and the Sexo-Semiotics of Extraterrestrialism" *Diacritics* 14, No. 2 (1984), 47-59.

possibilities for itself, has no place for either the defective Other or the original human (the one to be surpassed).

The second perspective that she describes represents, from my perspective, the anti-humanist and anti-modernist reflections of posthuman and disability thinkers discussed throughout Part 2 that seek to create new forms of acceptable life and new forms of relationality, technological or otherwise. The political struggle, as I read it, is to understand and find ways to harness the power and potential to remake our world—what singularly dominates the imagination of the first perspective—while maintaining the politics and experimental nature of the second.

A successful resistance movement to the advancement of hyper-modernistic/technophilic discourses would have to first destabilize its claims to objectivity and neutrality and second, show its practical cost in the lived experience of mankind as a whole. It would also have to propose an alternative view of technological development itself. It would have to challenge the dominant worldview that currently ascribes all successful technologies to its own progressive historical movement and legitimizes its imagined future by claiming it as an inevitability. For these, both critical posthumanism and critical Disability Studies offer effective counter-narratives. It is here that I find the purpose of the current work, i.e., to destabilize the limited and destructive narratives that both rely on and contribute to the devaluation and suppression of disability. Though the mechanisms are far reaching, disability serves as a historical and philosophical case study of resistance to modernity and a guide to the hyper-modernity currently in development. Though the issue is not with technology itself, given our current situation, it is the driver of the acceleration of normalization for people at the margins. This is the case materially, in that it directly mutates

our bodies, behaviours, and environments, but also at the level of world-making and normative social relationships, insofar as it dictates what we value and what we want to develop for the future of humanity. It is a constitutive discourse in every way.

Though technology is substantive, it has no inherent value or direction. The technology has no telos, it is something *through* which we interact with ourselves and our world. What gives it direction, and what makes it possible for transhumanists to speak of the inevitability of its future vision, is the nearly 500-year history of instrumentalist interpretations of technology coupled with three centuries of idealized images of man and nature. Statements congruent with these foundations, even if they claim to go beyond them, have truth-value. The typical debate, then, primarily cleaves between either relatively technophobic perspectives, on the grounds that biotechnologies are an overreach or an affront to established natural norms, or a technophilic perspective of optimism for the positive potential of technology informed by a progressivist view of history. Our perspective has much more in common with the technophilic worldview, but challenges foundational aspects of its philosophy. This puts us in direct confrontation and leads to wildly opposite conclusions. Because of its outgrowth from modernism and adherence to a linear historiography of scientific progress, the dominant technophilic worldview leads one down the road of techno-optimization and continued exclusion for some, and a privileged existence for others. A critique could be mounted simply on the latter; on the practical grounds that the fruits of technological progress are unjustly distributed. However, once one explores the source of exclusion and marginalization, of the practical inequities that exist, fissures in the foundations become apparent.

Discussed here were a number of these ‘destabilizing fissures’:

We can challenge the idea that we can find an objective/quantitative metric of what the ‘normal’ human is. What we find is that throughout the history of modernity ‘normal’ has meant both average and idealized Man. We realize that what we consider desirable is contingent on the values and needs of a certain historical period, and that ‘objective’ and ‘neutral’ statistical measures likewise depend on what we choose to measure and naturalize through them. Taking a broader view, we find that variation itself is natural and that a wider set of human experiences ought to be considered normal and normative. It is society that problematizes these ways of being, not some objective science of the human animal. In fact, if we follow Canguilhem’s general line of reasoning, creative adaptation to internal and external pressures *is* what gives life its specificity, not a collection of static attributes and abilities. This is a much more inclusive and fluid interpretation of life and its potential, which buttresses quite nicely the creative ways that technology is used by those living with and without disabilities.

A related challenge is to the consideration of technology as something novel that is leading mankind towards a new kind of world, and even towards a qualitatively different species (i.e., the transhuman or H+). However, a broader view of what technology is and how it is integrated into our world of experience casts doubt on the claim that anything novel is happening at all. Following the thread of ordinary prostheticity and technological mediation through the lens of Canguilhemian biology we can understand the current biotechnological expansion as congruent and familiar. It beckons us to rethink our role in shaping and directing the type of world where these technologies play a role and to be more critical of those discourses that use the potential of technology to perpetuate and reinforce marginalization, exclusion, and inequity. Technology itself does not lead the way, people do.

Though even this is an oversimplification that may obscure the scope of the task. The power to shape the direction of technological intervention—and all world-making for that matter—is tied to a problematic historical discourse about truth within which well-meaning people participate (academics, scientists, doctors, politicians, activists, etc.). From many vantage points, reinforcing the mechanisms I have been criticizing here appears like the *right thing to do*. It seems humane, compassionate, and *progressive*; but it is paternalistic, exclusionary, and perpetuates damaging norms. This is why traditional inclusion or barriers approaches, for all the good they do bring to the world, are not an all inclusive answer to the problems that people on the margins face.

One must, at the end of it all, learn from and find alternatives to the current order of things. Turn back towards practical concerns that affect a broader range of individuals and their actual lived reality in a substantial way. Politically, this means creating partnership and collaborations, alternative values, productive uses of technology and asymmetrical resistance with respect to the course of optimization and maximization. Closely related to this is a caution to me and those interested in this current work. The stated goal of learning from the history and experience of disability in order to better understand the broader implications of the current order of things has one potential pitfall—and a significant one. Once the potential dangers of hyper-modernity, and effective alternative ways of seeing our relationship to technology, our world, and others are co-developed, they ought not be used to further protect people of privilege. It becomes a moral issue to follow it up with a robust critical posthuman foundation that does not prioritize traditionally dominant classes of people. One must not mine their experience to further protect people not yet fully at the margins of society. This means that when philosophy is turned into political action, that it does not speak for others,

whitewash the differences and unique experiences of people, and that it acknowledges the uneven distribution of burden already borne by those at the margins. This ‘thing’ that we ought to resist is not a thing at all, it is a pervasive and dispersed set of concepts and practices that have to be resisted where they are encountered, by those who are affected, with support by all who recognize the danger.

General Conclusion—Some Direction for Future Action

While most modernist and Judaeo-Christian intellectual movements until now have set their terminal point at the culmination of some human or divine journey, new ways of thinking terminate at the point of a new species. The future for which they strive is beyond the horizon of knowability. Faced with the horizon of technical ability that would allow for a nearly total manipulation of biological, chemical, and physical mechanisms, we encounter idealized and utopian ideas of remaking our world that have an air of attainability. The resonance of these ideas with the dominant discourse of technological progress gives it power. Though technoscience has profoundly changed our world, and will continue to do so, the imaginary future that emboldens its adherence—transhumanism—is both fantasy and fiction. If it were not damaging, their half victories would justify the whole, but this fantasy has a cost.

Very practically, on its current course, we are establishing what can only be described as a two speed society, one with a privileged few in control of the trajectory of technoscience, and likewise very few capable of participating in a self-regulating performance based society whose moving target pathologizes the masses left in its wake. Equally troubling is the marshalling of biotechnology to eliminate undesirable human differences while idealizing the development (and creation) of those judged to be desirable.

Though it may seem like what we need is a full-blown revolution, much like one cannot overcome the trajectory of a tanker-ship by making a wild course correction at once,

the dangers have to be recognized early, and corrected by incremental and persistent change. This in itself is likely to be a contentious idea in a world that is increasingly polarized and, at least in the West, where people seek comfort in radical and isolated bubbles of like individuals. I have no answer to this, but only hope that laying out the issue as I have in this dissertation, and building a bridge between critical disability and critical posthumanism, that the insights generated can serve as a modular toolkit to support more general resistance.

The manner of normalization operating today is based on extrinsic metrics of productivity that stem from economic reasoning on the one hand, and idealised bodies that reduces human existence to optimizable capacities on the other. This affects first those populations that are easily targeted for historical and political reasons, but gradually seeps into aspects of the general population. This means that we have a lot to learn from the experience of people living at the margins, but also that we have all likely experienced or willingly participated in aspects of these forms of normalization. By focusing in this dissertation on disability, we gain understanding not by tokenising the experience, but by integrating their experience in our critical frameworks. The analysis could, and should be repeated with all its idiosyncrasies from the perspective of other marginalized subject positions. Such analyses offer an opportunity for shared experience of the failures of our present, and the potential to correct some of its most harmful tendencies. It is in this kind of ongoing practice that we might find a posthuman future, one that is not projected or imagined, but realistic and practical. Beyond a general consciousness raising and awareness, there are a few intellectual and political tracks that can be followed. These are what I would consider the low hanging fruit of practical action in the right direction.

Academically, we need to promote interdisciplinary understandings that accept some flexibility in basic assumptions about human norms in order to broaden the scope of what experiences are considered valid and admissible. Certainly, the posthumanism outlined here is only effective if it is convincing, and there is no guarantee that such a broadening would always be compatible with this perspective. However, these are practices that, by virtue of the clearing they create, allow varied approaches to contribute to the same goals even without complete consensus. By their very nature, the issues that we face intersect many different kinds of knowledges and group practices. Disciplinary knowledges have the advantage of focus and depth, and they play an important role in producing great descriptions and understandings of specific phenomena. However, when knowledge production has a social or political purpose and aims to be prescriptive or inform action, those disciplinary lines can be problematic. This is why I think focusing on introducing some reflexivity and openness as an aspect of interdisciplinarity is one of those adaptations to the fundamental uncertainty of posthumanity. The idea is not to take down the entire academic edifice. We depend on healthy disciplinary knowledges and enlightened researchers in all fields of study. Evidently, there are empirical and scientific questions that are not good candidates for interdisciplinary projects or entire fields of study that, whatever their shared worldview, do not lead to problematic practices. This brings us to a particularity of our current political moment, where we tend to think in black and white, us against them. The role of critical thought is to critique, dialogue, and advocate not police, cancel, or demonize.

In the social sciences the critique is more pressing and the stakes much higher, but I believe that challenging at least the primacy of the default point of view strengthens the field as opposed to impose restrictions on it. Generally speaking, academics in the social sciences

need to take the old protest cliché “nothing about us without us” seriously. The people who are the subjects of research or are most likely to be affected ought to be included in the production of knowledge itself. Not only does this avoid the problem of situated knowledge, it opens up the research to applications and avenues hidden to the research team. It really ought to be seen as a positive contribution, not a limitation on research. Here in Canada, with our history of research and intervention within First Nations, Inuit and Metis communities, we have recognized the need to collaborate with and include subject and affected communities in our research. An entire chapter of our guidelines for ethical research involving humans⁴¹³ outlines the steps that must be taken when conducting research with First Nations communities. Without minimizing the history of settler research practices we ought to also recognize the problematic history of research for other marginalized populations, and develop like practices for consultation, cooperation, and inclusion. We would hope that it can be practically integrated into academic practices, but in some future cases—e.g. germ-line genetic editing, intelligent prosthetics, artificial intelligence etc., —it may be that these kinds of regulated consultations ought to be introduced as well.

Politically, we need to recognize what is happening to people living with disabilities and other intersecting marginalizations, and ought to develop an anti-austerity, anti-ableist politics that informs what we advocate for in terms of investment in technological development, social research, and social services/benefits. Transhumanist ways of thinking

⁴¹³ Interagency Panel on Research Ethics, “Chapter 9 – Research Involving the First Nations, Inuit and Métis Peoples of Canada,” in “Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 (2018),” *Interagency Advisory Panel on Research Ethics* (Ottawa: Government of Canada, Government of Canada, 2020): https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2018.html.

about technology and the problems of our time—i.e., as the solution to all of our problems—has a trickle-down effect when mixed with the general optimism of those working in the science and technology fields. Moreover, this optimism is taken up by decision makers and politicians who see in the promises of technology both ready-made solutions to expensive social problems and competitive developments for advanced industry. The inertia of this is difficult to resist from those involved in Disability Studies and those on the ground living their reality. However, they are most often down-stream solutions predicated on ‘disability-as-suffering’ and other ableist understandings that obscure the needs of the people most affected by these investments. What people at the margins, and those increasingly unable to perform in society, need most often are up-stream social interventions or supports. This is a universal problem of our short-cycle politics, problem/solution ways of thinking, and the unchallenged belief in the linear trajectory of progress. It impacts where cuts are made in times of financial difficulty, and where investment and research funds are allocated in affluent times. It has the effect of delaying or foregoing known effective general solutions for the potential of novel and limited interventions that *look* like progress. Moreover, maintaining a strict delineation between enhancement and therapy means that a technological advancement that has the aim of improving the lives of those with disabilities are likely to be targeted on the body, and defined by pathology, as opposed to the environment or social milieu.

The rate of technological advancement and the possibilities opened up by new technologies ought to make us optimistic for the future. Unfortunately, this is not always evident for people with disabilities, or others who experience new technologies not as liberating potential, but as introducing new mechanisms of control or elimination. We have

seen that for many globally, what is needed is access to already developed and now commonplace examples of biotechnologies/assistive devices. We can rightly understand the apprehension of bio conservatives, or the alarms being raised by disability advocates and activists about new technologies and technomedical practices when centuries old technology remains inaccessible. The fact remains that unfortunately or fortunately, we are already technological beings, we live in a posthuman world, and novel technologies *will* continue to profoundly change our future. The legitimate problem is not if, but how can we all participate and create a world that is acceptable for all, and not just those with privileged voices and positions.

It seems to me that politically, there are two related areas of direct political action implied in the analysis we have undergone here:

- 1) that we continue to fight for more adequate systems of support and care for those at the margins in our society. The somewhat recent intensification of austerity and disinvestments in social support systems in the West have amplified the survival needs of those living with disabilities (and many others). And, the general economic and self-responsibilizing economic discourses of our times have multiplied discrimination and stigma attached to those needing those social supports. Whether this is in the form of traditional struggles for access, removal of barriers and rights, to more critical resistance, to the social and economic systems that lead to austerity and hardship, to the general call for more inclusive narratives of acceptable life, there is work to be done on the ‘current state.’ Exemplary in this regard, with respect to the problematizations outlined in this dissertation, is the work of *Sins Invalid* discussed in Part 2.

- 2) That within the context of a more supportive society, i.e., the resistance described above, that we think more broadly and inclusively about what role technology can play in our lives, what investments need to be made and where, and what kind of future we want to create. A future, of course, that includes people living with disabilities using, developing, and creating relationships with and through technology. The alternative is that people with disabilities remain the target of technological development, within a narrative that sees their bodies as fractured and deficient, and their experience as devoid of insight and creative potential. In fact, examples to the contrary show that when people with disabilities take control of technological development, they give rise to creative and useful practices. Whether we are talking about Becker as composer, or Hotchkiss as social entrepreneur, a diversity in voices promotes creative technological innovation and useful technological development. Exemplary in this regard, with respect to the problematizations outlined in this dissertation, is the *Crip Technoscience Manifesto* discussed in Part 2.

In both these areas, what is needed is an open movement that harnesses the potential of all who are negatively impacted by the current state or the future-in-development that is slated to leave many people suffering in its wake. There is a need to promote coalition building at all levels between social and political movements big and small. It has to recognize normalization in its many applications and contexts (from traditional ‘others’ to once privileged and dominant classes), as well as the many ways that those normalization strategies and value narratives intersect in the real world where people are rarely only affected by one type of discourse. In recognizing this, we do not devalue any identified form

of suffering, but we also recognize that smaller segments of our society are targeted much more than others. All voices are valid, but we do need to allow for, promote, and empower the leadership of the most affected.

None of this is earth-shattering or surprising, but the way we got there is informative. I have shown that the world we live in today can be considered *posthuman* already. That our intertwining with technology and human perfectionism (maximizing outputs, and optimizing capacity) are not novel aspects of a new humanity but are part of our human origins. That we are inherently technologically mediated beings, and that our default way of life is to adapt to external and internal pressures by rewriting what is normative in each case and establishing new norms of embodiment and performance. This is a fundamental aspect of the world we live, which is why I dedicated an entire chapter to showing how, though it is more obvious when we speak of disability experience, it is a universal part of our common experience of contemporary life. Understanding the extent to which we are extended into technological artefacts and our sense of self-efficacy imbricated in them is to recognize our inherently posthuman existence. For all the potential that this brings, the dominant narrative in our politics and social interpretations continue to hold onto assumptions about human improvement that narrowly defines one version of adaptation as meaningful while pushing all others to the margins. What is most challenging is not that these tendencies are irrational or evil, but that their conviction in a limited number of truths about humanity leads many well-meaning people to established social structures that are limiting and marginalizing. As high-level philosophical ideas, this interpretation resonates with contemporary critical posthumanists, but it is not very convincing or useful for those outside this field of study or those interested in these philosophical ideas. It is for this reason that in addition to exploring

these concepts in their complexity, I also attempted to bring it down to the experience of actual people and their potential practices. Disability Studies, being a very well developed field of study with these philosophical perspectives already seeping in seemed a perfect guide. What I have modestly proposed in action compared to the weight of what I have shown in the analysis seems inadequate in its scope; however, my analysis finds no magic bullet to exploit, no easy thread to pull on that would unravel hypermodernity. I believe this is an inevitable part of engaging both in critique and in social action. Change happens over time. When resistance is successful it creates fault lines that need to be pressed and followed. This cannot always be planned. Examples of this are the mental health and human resource pressures emerging in hyper-competitive industries (big tech, athletics, etc), the COVID-19 pandemic, or the increasing gap in Western nations between those who see themselves as part of a great society and those who find themselves falling into a secondary and impotent social position. In all cases, as discussed, there is potential for the emergence of a new way of thinking that we see already in critical disability and posthumanism, but to think that these will come about organically is foolish. There is potential for allyship and cooperation for those falling behind, but at least as much potential for them to double down on their assumptions, turn to lateral violence, or turn to misery and despair.

More generally, every generation has a feeling that they are at a precipice; that they are at the horizon of some great new world or of a great cataclysm. Our current time could realistically give rise to either, and both perspectives circulate in popular consciousness. Technological advancement and the material gains of industrial capitalism can give us the conceptual tools to imagine a perfect future; while the realities of inequity, political violence and the multifaceted threats of extinction (from environmental degradation to technological

misuse) give credence to more pessimistic or cynical projections. The reality is that either realization has the potential to cloud judgement and/or stunt reasonable action. One ought to see them not as mutually exclusive, but bring them back to earth to deal with them as they exist in the present. Technological and material advancement are not the answer to all of our problems, but they certainly are not the singular source of them either. And though the challenges we face as a society are great, one cannot conjure an alternative from nowhere and simply wish it into existence—we start from here. What we find in the exploration throughout this dissertation is both a microcosm of the general issues of our time, and an example of a population whose struggle transverses all of the major issues in our society. Therefore, whether the reader is an optimist or a pessimist; an activist, person with lived or living experience, or academic in the social sciences; I hope that through this work they understand a bit more about their current state, about where they and their decision lay in relation to the dominant discourses of abnormality and responsibility, and about who and what kind of future we may be uncritically projecting and supporting. I also hope that if the reader finds resonance with the problematizations and conclusions outlined throughout, that they may take away a few strategies or gain a few critical insights for their own political and social resistance, or professional practices.

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